

# Disability 2.0: Student dis/Connections.

A study of student experiences of disability and social networks on campus in Higher Education.

Sarah Lewthwaite, MA, BA (Hons).

Thesis submitted to the University of Nottingham  
for the degree of Doctor of Philosophy

July 2011

## Abstract

---

For many young people, social networks are an essential part of their student experience. Using a Foucauldian perspective, this qualitative study explores the networked experiences of disabled students to examine how dis/ability difference is ascribed and negotiated within social networks. Data comprises 34 internet-enabled interviews with 18 participants from three English universities. Accessible field methods recognise participant preferences and circumstances. Data is analysed using discourse analysis, with an attention to context framed by activity theory.

Disabled students' networked experiences are found to be complex and diverse. For a proportion, the network shifts the boundaries of disability, creating non-disabled subjectivities. For these students, the network represents the opportunity to mobilise new ways of being, building social capital and mitigating impairment.

Other participants experience the network as punitive and disabling. Disability is socio-technically ascribed by the social networking site and the networked public. Each inducts norms that constitute disability as a visible, deviant and deficit identity. In the highly normative conditions of the network, where every action is open to scrutiny, impairment is subjected to an unequal gaze that produces disabled subjectivities. For some students with unseen impairments, a social experience of disability is inducted for the first time.

As a result, students deploy diverse strategies to retain control and resist deviant status. Self-surveillance, self-discipline and self-advocacy are evoked, each involving numerous social, cognitive and technological tactics for self-determination, including disconnection. I conclude that networks function both as Technologies of the Self and as Technologies of Power. For some disabled students, the network supports 'normal' status. For others, it must be resisted as a form of social domination.

Importantly, in each instance, the network propels students towards disciplinary techniques that mask diversity, rendering disability and the possibility of disability invisible. Consequently, disability is both produced and suppressed by the network.

## Acknowledgements

---

In completing this thesis, I would like to offer my sincere thanks to my supervisors, Dr Charles Crook and Dr Gordon Joyes for their critical insights, perseverance and determined 'scaffolding'. Without their expertise, support and guidance, this thesis would not have been possible.

I am greatly indebted to the participants of this study, the students who offered me an education in their networked activities and gave their time and expertise so generously, over and above what I had originally envisaged.

Furthermore, I could not have undertaken this research without the support of my funders, the Economic and Social Research Council.

My husband, Paul Lewthwaite, has been a tireless supporter of my work. He has repeatedly shown me how to continue. *Quocunque Jeceris Stabit*. I'd also like to thank my friends and family for their unwavering support, my parents, John Moore, Jacqui Moore and my good friends Nicola Underdown and Abi Diamond.

Over the course of this project I have relied upon strong and weak ties across many institutions and organisations. I highlight these to express a debt of gratitude, but also to give visibility to the tools and communities I have accessed in case this information is of value to researchers entering the field.

This research has been instigated from within the School of Education at the University of Nottingham. I've been proud to be part of the research community. In particular I thank Dr Munir Ahmed, Dr Paola Signorini, Irina Hawker, Dr Nadeem Khan, LeRoy Hill and Dr Carole Mallia, from whom I have stolen post-its, literature and no small amount of inspiration.

As a Graduate Associate of the Learning Sciences Research Institute, I have benefitted from the expertise and insight of fellows from other disciplines including Computer Science and Psychology. I would like to thank Prof. Mike Sharples and everyone else at the LSRI for letting me participate in their vibrant research community and for being so generous with their time and expertise.

In the UK, I have also benefitted from numerous conversations and consultations, drawing on the expertise of research groups, disability advocates and others involved in the shared project of accessibility. I am grateful to Carole East and

others at Academic Support and Rebecca Robinson from Information Services at the University of Nottingham; Rebecca Mallett and the Sheffield Hallam Disability Research Forum; Also Jackie Goode, Bridget Leadbeater and David Brown.

During my research I benefitted from a Universitas 21 visiting scholarship to advance my knowledge of international intersects between higher education, technology and disability at the Centre for the Study of Higher Education at the University of Melbourne. In Australia I benefitted greatly from the insights of Matt Brett, Jenny Shaw, Liddy Nevile, Richard James and David Clarke amongst others.

I have relied on personal and professional networks established via the Disability Studies Association, the Nordic Network on Disability Research and AbilityNet. All have instigated events and subsequent research dialogue that has helped to inform my work.

My research training has advanced thanks to the ESRC's LiveSociology research training in new media at Goldsmith's, London. The 'Researching the use of Assistive Technologies: Interdisciplinary perspectives' seminar series organized by Chris Abbott and the 'New Perspectives in Disability Research' PhD workshop at the Stein Rokkan Centre, University of Bergen. In particular, I thank Nick Watson, Bodil Ravneberg and Les Back for their insight.

Virtual networks have also played a part in the completion of this research. I have benefitted from membership and online interaction with the Society for Disability Studies [sds\_listserv@listserv.uic.edu], the Association for Learning Technology, disability-research@jiscmail.ac.uk, Dis-Forum [dis-forum@jiscmail.ac.uk] and the ICT Research Network [research@lists.becta.org.uk]. In the later stages of my PhD, when unable to dedicate much time to keeping up with new research, I have benefitted strongly from #accessibility, #a11y and education technology networks on Twitter.com. In particular I'd like to thank @BrianKelly (Brian Kelly) @Sloandr (David Sloan) for their generosity in the sharing of expertise, amongst others too numerous to mention.

Thank you.

This thesis is dedicated to the memories of Anne Kirkham, Margaret and Peter Bull.

# Table of Contents

---

<b>Abstract</b> .....	<b>ii</b>
<b>Acknowledgements</b> .....	<b>iii</b>
<b>Table of Contents</b> .....	<b>v</b>
<b>List of Figures</b> .....	<b>x</b>
<b>Glossary of Abbreviations</b> .....	<b>xiii</b>
<b>Chapter 1. Introduction to the Research</b> .....	<b>1</b>
1.1 My Project .....	2
1.1.1 Organization of the Thesis .....	4
1.2 Terms of Reference .....	6
1.2.1 Disability and Impairment .....	7
1.2.2 Social Networks .....	8
1.3 Research Motivations .....	9
1.3.1 Prioritising Social Experiences of Disability .....	10
1.3.2 Breaking a Cycle of Inaccessibility .....	11
1.3.3 Expanding Notions of ‘Ordinary’ Experience .....	13
1.3.4 Researching ‘In the Wild’ .....	15
<b>Chapter 2. The Research Context</b> .....	<b>17</b>
2.1 Social and Political Changes in Higher Education.....	18
2.2 Technological Advances: the Advent of Web 2.0.....	21
2.3 Social Networking Sites in Higher Education.....	23
2.4 Researching Social Experiences of Disability in Higher Education .....	25
2.5 Researching Social Experiences of Disability Online.....	28
2.5.1 Social Networking Sites and Accessibility .....	29
2.5.2 Social Networking Sites in Higher Education .....	30
2.5.3 Seeking Disabled Perspectives on Beyond Higher Education.....	31
2.6 Research Questions .....	34
2.7 Summary .....	35
<b>Chapter 3. Conceptual Framework</b> .....	<b>36</b>
3.1 Representations of Disability .....	37
3.1.1 The Medical and Social Models of Disability .....	38
3.1.2 Postmodern and Poststructuralist approaches .....	39
3.1.3 Difference, Knowledge and Power .....	42
3.1.4 Critiques of Foucauldian Poststructuralism .....	46
3.2 Categorising Disability in Higher Education .....	49
3.2.1 Counting Disability .....	51
3.2.2 A Medical Base-Line .....	52
3.2.3 HESA and UCAS Definitions of Disability.....	53
3.2.4 Shifting Conceptions of Disability.....	57
3.2.5 Fossilisation and Looping Effects.....	60
3.3 Expanding the Taxonomic Practices of Disability .....	61
3.3.1 Relational Taxonomies.....	62
3.3.2 Faceting Approaches to Disability.....	64

3.4	Faceting Disability in My Research Project.....	65
3.5	Summary .....	68
<b>Chapter 4.</b>	<b>Methodology .....</b>	<b>70</b>
4.1	Defining My Study .....	71
4.2	Methodology .....	72
4.2.1	Activity Theory .....	74
4.2.2	Phenomenography.....	77
4.2.3	Activity Theory and Power .....	79
4.2.4	A Discursive Intervention .....	80
4.3	Developing Field Methods .....	83
4.3.1	Ethical Considerations .....	83
4.3.2	Accountability .....	84
4.3.3	Piloting and Technical Methods.....	85
4.3.4	Evaluation of Technical Approaches .....	93
4.3.5	Recruitment.....	95
4.4	In the Interview .....	98
4.4.1	Participation .....	99
4.4.2	The Structure of the Interview .....	103
4.4.3	Repeat Interviews.....	106
4.4.4	Sensitive Issues .....	107
4.4.5	Informed Consent.....	109
4.4.6	Privacy.....	110
4.4.7	Inconvenience Allowance .....	111
4.4.8	Debriefing and Ongoing Contact .....	112
4.5	Sample Demographics.....	113
4.6	Managing Data .....	120
4.7	Thematic Analysis and Presentation .....	122
4.7.1	Discourse Analysis and Case Study.....	122
4.7.2	Onscreen Phenomena .....	125
4.7.3	Confidentiality and Representation.....	127
4.8	Summary .....	128
<b>Chapter 5.</b>	<b>Case studies.....</b>	<b>129</b>
5.1.1	Selection of Case Studies .....	129
5.1.2	Order and Structure of Case Studies .....	130
5.2	Network Context .....	132
5.2.1	Ownership of Technology.....	132
5.2.2	General Internet Use .....	135
5.2.3	Participant Use of Social Networking Sites.....	136
5.3	Enabled Perspectives .....	141
5.3.1	Freya.....	141
5.3.2	Adele .....	145
5.3.3	Ben .....	149
5.3.4	Howie .....	153
5.4	Dis/Abled Perspectives.....	157
5.4.1	Roy .....	157
5.4.2	Edward .....	164
5.4.3	Sally .....	170
5.4.4	Liam .....	176

5.4.5	Jack.....	183
5.4.6	David.....	188
5.4.7	Pierce.....	193
5.4.8	Gemma.....	200
5.4.9	Naomi.....	205
5.4.10	James.....	211
5.4.11	Ana.....	216
5.4.12	Elizabeth.....	220
5.4.13	Dennis.....	226
5.4.14	Claire.....	232
5.5	Summary.....	239
<b>Chapter 6. Experience of Disability in the Network .....</b>		<b>240</b>
6.1	Experiencing Fit and Misfit.....	242
6.1.1	Functional Fit Between the System and the Individual .....	243
6.1.2	Life-Fit between the System, the Individual and Socio-Cultural Practices .....	244
6.1.3	Misfit Produces Dis/Ability .....	244
6.2	Ordinary and Extra-Ordinary Experiences.....	245
6.3	Didactic Experiences of Dis/Ability: The Social Networking Site .....	246
6.3.1	Receiving Ability: Positive Experiences of the Network .....	246
6.3.2	Receiving Disability: Negative Experiences of the Network .....	250
6.3.3	The Social Networking Site Ascribes Dis/Ability .....	261
6.4	Dialogic Experiences of Dis/Ability: The Networked Public .....	262
6.4.1	Participant Conceptions of the Networked Public .....	264
6.4.2	Notions of Visibility.....	265
6.4.3	Networks of Necessity .....	266
6.4.4	Consolidated Identity .....	268
6.5	Extra Visibility: David's Experiences of Dyslexia and the Networked Public .....	270
6.5.1	Dyslexia and the Unequal Gaze .....	271
6.5.2	Social Constructions of Dyslexia.....	272
6.6	Extra Visibility: Gemma's Experience of Life-Misfit in the Networked Public .....	275
6.6.1	Unseen Impairments and the Unequal Gaze .....	275
6.6.2	Risk and the Extent of the Network .....	276
6.6.3	Misfit, Prejudice and Stigma.....	277
6.6.4	Normative Pressure and Peer Intervention.....	279
6.6.5	Network Creep .....	280
6.6.6	Unseen Experiences .....	281
6.7	Extra Visibility: Naomi's Experiences of Depression in the Networked Public .....	281
6.7.1	Depression as Deviance .....	281
6.7.2	Social Surveillance and Peer Intervention .....	282
6.7.3	Network Affirmation.....	283
6.8	Conclusion.....	284
<b>Chapter 7. Managing Disability in the Network .....</b>		<b>287</b>
7.1	Self-Surveillance .....	289
7.1.1	Managing Direct Disclosure .....	291

7.1.2	Managing Indirect Disclosure .....	294
7.2	Self-Discipline .....	299
7.2.1	Managing Time Resource .....	299
7.2.2	Managing Reflexivity.....	303
7.2.3	Managing Privacy .....	306
7.3	Self-Advocacy .....	308
7.3.1	Digital Agility .....	309
7.3.2	Building Digital Capital .....	312
7.3.3	Research Participation.....	313
7.4	Self-Affect .....	314
7.4.1	Creating a Safe Space.....	314
7.4.2	Affirming the Self .....	315
7.5	Summary .....	316
<b>Chapter 8.</b>	<b>Discussion.....</b>	<b>318</b>
8.1	Technologies of the Self, Technologies of Power.....	319
8.2	The Network as a Technology of the Self .....	321
8.2.1	Building Social Capital .....	322
8.2.2	Writing Identity .....	323
8.2.3	Assimilating into Student Culture.....	324
8.3	Social Networks as Technologies of Power .....	325
8.3.1	Morphing Ablism .....	326
8.3.2	Resistance.....	327
8.3.3	Participant Perspectives on Disability.....	328
8.4	Self-Surveillance .....	330
8.4.1	Passing .....	331
8.4.2	Self Care.....	332
8.5	Self-Discipline .....	334
8.5.1	Governance .....	334
8.6	Self-Advocacy .....	337
8.6.1	Empowered Disconnections?.....	340
8.7	Summary .....	342
<b>Chapter 9.</b>	<b>Concluding Remarks .....</b>	<b>343</b>
9.1	Research Overview.....	343
9.2	Implications for Research and Practice .....	346
9.2.1	Re-Envisioning Disability .....	351
9.2.2	Deconstructing Normalcy .....	356
9.3	Lasting Impressions.....	357
<b>References .....</b>	<b>.....</b>	<b>359</b>
<b>Appendix 1: Glossary of Terms .....</b>	<b>.....</b>	<b>376</b>
Assistive Technologies.....	.....	376
Web 2.0 and Related Technologies.....	.....	377
Social Networking Sites .....	.....	378
<b>Appendix 2: Participant Profiles .....</b>	<b>.....</b>	<b>384</b>
<b>Appendix 3: Timeline of Facebook Developments.....</b>	<b>.....</b>	<b>386</b>

<b>Appendix 4: Research Materials .....</b>	<b>391</b>
Example of Recruitment Materials .....	391
Example of Participant Consent Form .....	392
Example of Interview Schedule .....	393
<b>Appendix 5: Sample Data.....</b>	<b>395</b>
Example of Participant Transcript .....	395
Sample Extract of Coding Process .....	410
Sample of Coding Output .....	411
Surveillance (Negative) / Child Code: Exposure .....	411
Surveillance (Negative) / Child Code: 'No Escape' .....	414
Dis/ability Coding Structures .....	416
Coding Framework [RQ1] Locating disability in disabled students'	
networks .....	416
Coding Framework [RQ2] How do disabled students experience disability	
in the network? .....	417
Coding Framework [RQ3] How do disabled students manage disability in	
the network? .....	419

## List of Figures

---

Figure 3-1: UCAS and HESA Coding by Disability .....	56
Figure 4-1: Vygotsky’s Model of Mediated Act; its common reformulation (Engeström, 1987:134).....	74
Figure 4-2: The Structure of a Human Activity System .....	75
Figure 4-3: First-Order and Second-Order Perspectives (Uljens, 1991). .....	77
Figure 4-4: Technologies Used to Capture Onscreen Data.....	88
Figure 4-5: Arrangement of Technologies Used for Telephone Interviews. ....	88
Figure 4-6: Arrangement of Technologies Used for Face-to-Face Interviews.....	88
Figure 4-7: Techinline Client ID window .....	90
Figure 4-8: Stitched view of 32” desktop, with white line indicating point of screenshot overlap .....	92
Figure 4-9: Degrees of Participant Involvement. Adapted from Fajerman and Treseder, in (Radermacher 2006).....	100
Figure 4-10: Students by disability 2007-2008 (HESA, 2008b).....	114
Figure 4-11: Participants by disability (according to UCAS/HESA categories) .....	115
Figure 4-12: Proportion of students in receipt of DSA .....	117
Figure 4-13: Number of Disabled Students at Research Site University A by Discipline .....	118
Figure 4-14: Participants by subject group .....	119
Figure 5-1: Ownership of Technology. N = 18.....	132
Figure 5-2: Assistive Technology Use by Type. N = 18. ....	133
Figure 5-3: Ownership of Generalised Assistive Technology. N = 9.....	134
Figure 5-4: Ownership of Specialised Assistive Technology. N = 8.....	134
Figure 5-5: Participant Online Activity. N = 18. ....	135
Figure 5-6: Participant Use of Social Networking Sites. N = 17.....	136

Figure 5-7: Average Frequency of Access to Facebook by Year Group. N = 18...	137
Figure 5-8: Size of Facebook Network by Participant and Year Group .....	138
Figure 5-9: Facebook Activities. N = 16.....	139
Figure 5-10: Adele's workspace (08.12.08). .....	146
Figure 5-11: Roy's workspace (01.10.08). .....	159
Figure 5-12: Roy's workspace (09.12.08). .....	160
Figure 5-13: Edward's workspace (11.12.08). .....	166
Figure 5-14: Edward's network (29.09.08).....	170
Figure 5-15: Edward's network (11.12.08).....	170
Figure 5-16: Sally's workspace (23.10.08).....	172
Figure 5-17: Liam's workspace (12.12.08). .....	178
Figure 5-18: Jack's workspace (30.10.08).....	184
Figure 5-19: Pierce gestures to an error in his Status Update (05.11.08). .....	197
Figure 5-20: Naomi's 'Go Pokey' App (11.11.08).....	209
Figure 5-21: Naomi's 'Go Pokey' App (11.11.08).....	209
Figure 5-22: Ana's workspace at home (09.10.08) .....	218
Figure 5-23: Claire's Facebook homepage (23.02.09).....	236
Figure 6-1: Claire's Facebook homepage: detail (02.02.09).....	257
Figure 6-2: Claire's Facebook Wall (23.02.09).....	259
Figure 6-3: Claire's News Feed (23.02.09).....	260
Figure 6-4: Ad-hoc door label from Roy's Hall of Residence (09.12.08) .....	267
Figure 7-1: Sally's browser homepage (03.10.08). .....	310
Figure 7-2: Jacks' desktop (12.12.08). .....	311
Figure 7-3: Two of Naomi's 'bumper stickers' (11.11.08). .....	315
Appendix 3 Figure 1: Timeline of Facebook Developments and Research Period	387

Appendix 3 Figure 2: Visualisation of Default Privacy Settings: 2006 (McKeon, 2010) .....	388
Appendix 3 Figure 3: Visualisation of Default Privacy Settings: 2007 (McKeon, 2010) .....	389
Appendix 3 Figure 4: Visualisation of Default Privacy Settings: Nov 2009 (McKeon, 2010) .....	390
Appendix 5 Figure 1: Example of Student Activity System.....	416
Appendix 5 Figure 2: Positive Experiences at the level of the technology .....	417
Appendix 5 Figure 3: Negative Experiences at the level of the technology.....	417
Appendix 5 Figure 4: Positive and Negative Experiences in the Networked Public.....	418
Appendix 5 Figure 5: Management Strategies: Self Surveillance .....	419
Appendix 5 Figure 6: Management Strategies: Self-Discipline. ....	420
Appendix 5 Figure 7: Management Strategies: Self-Advocacy.....	420
Appendix 5 Figure 8: Management Strategies: Self-Affect.....	421

## Glossary of Abbreviations

---

3G	Third Generation
ADHD	Attention Deficit Hyperactivity Disorder
AFB	American Foundation for the Blind
AT	Assistive Technology
BBC	British Broadcasting Corporation
CMC	Computer Mediated Communication
CSS	Cascading Style Sheets
DDA	Disability Discrimination Act
DIUS	Department for Innovation Universities and Skills
DRC	Disability Rights Commission
DSA	Disabled Students' Allowance
EHRC	Equality and Human Rights Commission
HE	Higher Education
HEFCE	Higher Education Funding Council for England
HESA	Higher Education Statistics Agency
HTML	HyperText Markup Language
HIV	Human Immunodeficiency Virus
ICT	Information and Communication Technology
JCR	Junior Common Room
MSN	MicroSoft Network
SENDA	Special Educational Needs and Disabilities Act
SKILL	National Bureau for Students with Disabilities
SNSs	Social Networking Sites
SMS	Short Messaging Service
TEL	Technology Enhanced Learning
UCAS	Universities and Colleges Admissions Service
UN	United Nations
UPIAS	Union of the Physically Impaired Against Segregation
URL	Uniform Resource Locator
VOIP	Voice Over Internet Protocol
W3C	World Wide Web Consortium
WAI	Web Accessibility Initiative

# Chapter 1. Introduction to the Research

---

In the UK and elsewhere, the number of students in higher education has been steadily increasing over the past 10 years. The decade ended with record student numbers (UCAS, 2010). This increase, in conjunction with policy moves towards social justice, has led to a more diverse student population. As student cohorts increase and diversify, beyond the lecture hall and seminar room the social landscape of the university campus has been radically transformed. Students are now digitally networked as never before.

For many young people social networks such as Facebook have become an essential part of their student experience (Selwyn, 2009). In the academic year 2008-9 it was estimated 95% of the 744, 000 undergraduate students in the UK regularly used social networking sites (SNSs) (Mage et al., 2009). Other web-based services like Wikipedia and YouTube are also an important facet of everyday student life. These social web-based services tacitly promote collaboration and sharing, dependent on user contributed content and interaction. Since 2004 this platform has been broadly conceived as a second generation of internet services, nominally 'Web 2.0' (O'Reilly, 2005) or the 'participatory web'.

New technologies have always been scrutinized for their capacity to support education and, as social technologies become more pervasive, universities are increasingly seeking to appropriate them for teaching, learning and student engagement (Minocha, 2009). However, the social impact of Web 2.0 technologies is at present uncertain, and unproven in education (Selwyn, 2009). In this research, I have sought to foreground the perspectives of disabled students at a frontier of social media, to engage critically with the pro-social claims made for Web 2.0. I have found that the experiences of disabled students crystallize many of the contrary issues raised by the movement of the academy into the digital domain.

## 1.1 My Project

This thesis reports my investigation into disabled students' networked experiences at university. I present an analysis of the ways in which discourses of disability and ability are produced and mediated by social networks. Using internet enabled methods, I conducted 36 interviews with 18 disabled students at three English universities. Participants include students with physical, sensory and cognitive impairments, long term medical conditions and mental health issues. I approached my fieldwork with a belief that disability is discursively constructed and represents a 'complex and contested sociopolitical space' (Goggin and Newell, 2005: 276). Thus, I focused on understanding the socio-structural conditions through which disability is realised in student sociality.

Social and poststructural models of disability (for example, Oliver, 1996; Finkelstein, 1996; Davis 1995; Reeve. 2002) highlight the aspects of disability, impairment and self that are socially and culturally contingent. Since new media can create new and different ways of relating to others (Wesch, 2009), I considered whether it was possible for new media to instigate new modes of ascription, experience and reflexivity. In this way, the conditions of disability might change.

As my project unfolded, disability was seen to be realised at two levels; in student experiences of the didactic, received costs and affordances of the *social networking site* (SNS) as a tool, and in the dialogic space of public interactions that is characterised by the *networked public*.

At the level of the tool I found that social networks confer disability and ability in a mode that resonates with the arguments of Goggin and Newell (2005). Disability and ability continue to be 'built-in' to technological networks as some disabled users are disadvantaged or locked-out of mainstream interactions by technical barriers that produce them as 'disabled'. As will be seen, this represents a digital divide, with tangible social outcomes. Above the technology, at the level of the networked public, more complex socio-technical dynamics come into play. These dynamics coalesce around notions of visibility, and the network as a network of necessity.

When I began my research, Facebook was not a dominant force in student life. Since then, the increasing ubiquity of Facebook membership amongst students (Selwyn, 2009) has highlighted a convergence of purpose. A student's transition into higher education is an important one, frequently marking a point of departure in terms of self-determination and the assertion of a new identity (Leathwood and O'Connell, 2003). Social networks are uniquely positioned to support and mediate a reflexive refashioning of the self, allowing individuals a seemingly precise and controlled means of representing themselves to their peers and a wider public (Boyd and Ellison, 2007). Social networks also allow students to access and integrate with wider student culture. Facebook itself has been developed to directly augment student sociality and student culture is also spontaneously self-adjusting to converge on Facebook. This intersection between student culture and social networks is potentially a potent one, particularly for disabled students.

I observed that disabled and non-disabled student's use of social networking sites is driven by a desire to socialise and engage with their peers, however, participation is also necessitated by a need to manage a digital identity and maintain social capital. This highly social aspect, in conjunction with the transparent and visible nature of interactions, leads students to reflexively observe intensely normative conditions in the network. Within these normative conditions, many disabled students expressed a variety of views relating to the exposure of impairment and impairment effects to the wider network. For the majority, the exposure of impairment represented an unwelcome extra-visibility that could incur deviant status. As a result, students frequently sought to manage and negotiate perceivable aspects of a disabled self. Strategies for disability management gravitated around four distinct strands of action for self determination: *self-surveillance*, *self-discipline*, *self-advocacy* and *self-affect*. These strategies highlighted a key paradox of the socio-technical effects of the network in action, it is both empowering and oppressive.

Importantly, the technical production of disability is not a direct mimic of pre-existing modes of disablement. The network represents a re-definition of disability. What can be seen or perceived to be a disability changes. For some students, a close functional fit with the technology allows some students to move to non-disabled subjectivities, disability becomes irrelevant. Other students are required to manage

and negotiate a disabled identity, frequently suppressing difference and adopting non-disabled interactions to prevent ascriptions of deviance. As a result, this thesis is a thesis about normalcy and power relations. It establishes the social networks as a tool that is potentially liberatory for some, but disciplinary and punitive for others.

In conclusion, I observe that the representation of diversity is suppressed amongst those students who are enabled, or able to adopt non-disabled interactions. At the same time, the possibility of disability entering 'normal' discourse as a valid and ordinary facet of life appears diminished. In this way, I find that the network conveys deeply conservative, normalising power relations both through and onto disabled students. It produces disability and at the same time propels disabled students to perform or adopt 'non-disabled' modes of interaction. In this way, diversity is suppressed and those students who are cannot or will not access the network on the basis of disability are seen to be doubly disadvantaged as disability is rendered invisible and the social and digital divide of the network is re-enforced.

To explore and theorise disabled students socio-technical practices, I call upon Foucauldian notions of power and resistance, governance and agency. The result is a post-structural account of how social networks have disrupted and (re)mediated student experiences of existing 'hierarchies of impairment' on campus in higher education.

### **1.1.1 Organization of the Thesis**

The central parts of this dissertation are organized around a concern with power relations in research, and power relations in the network. To frame this concern, I begin with an account for the context(s) within which my project is bounded in my literature review. Chapter two seeks to give a detailed account of what is known with regard to disabled students in the context of Web 2.0, non-academic and networked experience. Here I draw on important investigations of disabled students' experience in higher education and cite wider investigations into disabled people's experiences of sociality online to underpin my project. The chapter culminates with a statement of research questions.

In chapter three I detail my conceptual framework. In this chapter I engage critically with the notion of disability and representation in depth. This discussion highlights

the praxis of disability, that is, the strong relation between ideas about disability and their material expression. Critical models of disability are examined in light of the particular problem of defining what disability is and how this relates to the mechanics of category making in research and higher education. Here, I account for my adoption of an interpretive and Foucauldian research stance. Current methods of data collection in higher education are examined to evaluate the statistics that constitute disability benchmarking, and to divine both practical and ethical ways forward.

My methodology, chapter four, introduces my interpretive stance, my initial adoption of activity theory and phenomenography and my subsequent attempt to reconcile activity theory's focus on socio-cultural mediation with an emergent account of normalcy arising from student testimonies. These two positions could not be reconciled. Consequently, I describe a *bricolage*; as I move to adopt discourse analysis and case study as my primary modes of analysis over the course of the research process. The chapter also outlines participant demographics and answers the challenges of mobilising a holistic and accessible method that appropriately meets the demands of both ethics and efficacy.

18 participant case studies are reported in chapter five to introduce the participants in context. Cases are arranged to highlight non-disabled subjectivities and more mobile identifications. As I report results and findings from chapter five onwards, the term 'dis/ability' is used to identify the occurrence of disability in the network. This term draws attention to the fact that whenever disability is evoked, a bio-standard of non-disabled is also implied. In this way, dis/ability refers to a social distinction that is made between non-disabled and disabled, normalcy and deviance.

Within cases I detail the participant's technological landscape, the occurrence of disability in the network, and the student's experiences and management of disability. An introductory overview details participants' ownership of technology, assistive technology and broad relations with social media. For those seeking more detail about the features of Facebook and other social media described in this thesis, appendix one supplies an overview of the technologies cited and their arrangement and functionality at the time of data collection.

In chapter six, I mobilise a cross-case discussion to observe how the boundaries of disability and impairment are reconfigured by the network and how this is experienced by participants. Issues of ‘fit’ and extra-ordinary experiences are outlined. Experiences are themed according to the received structural and technological conditions of the network, and the socio-technical aspects of the network in use. Here, notions of visibility and the unequal gaze are specified and I begin an analysis of the knowledge and power based on participant reflections.

Chapter seven abstracts the techniques and strategies that students employ to manage disability as a socially ascribed identity within their networks. Self-surveillance, self-discipline, self-advocacy and self-affect strategies are each detailed in an account of student agency and resistance practices. Chapter eight then turns to discuss students’ experiences and management of disability in the network in light of wider theory. I draw on Foucault’s conceptions of power, resistance and agency to argue that amongst SNSs, Facebook functions as a ‘technology of power’ and domination that must be resisted for some, whilst for others it represents ‘technology of the self’. These ‘technologies’ represent important self-practices with divergent outcomes. The governing influence of both the University and technology and their role in proscribing normalcy and a ‘docile’ disabled subject is explored, alongside a recognition of student’s active roles as protagonists in their own lives.

In chapter nine, I conclude with a discussion of the implications of my findings, arguing for a re-envisioning of disabled students, to ensure that normalcy is challenged and the apparent disappearance of disability within the network is not corroborated by researchers, educators and technologists.

I now turn to define key language used within the thesis, prior to a discussion of the motivating factors spurring my investigation.

## ***1.2 Terms of Reference***

It is useful to define key terms with a view to establishing a common language at the intersection of three fields – disability studies, education and social media. In each of

these fields, language is culturally and socially situated, dependent on national and international context with different meanings construed across different disciplines. This early exercise in definition is offered to give a precise outline of how I conceptualize disability and define the social network to supply the reader with a contextual baseline that underpins later chapters.

### **1.2.1 Disability and Impairment**

There is no neutral language with which to discuss disability (Altman, 2001, Williams, 1996, Zola, 1993). ‘Disability’ is multi-dimensional and highly complex. Throughout the thesis I adopt a ‘social modelist’ language of disability. The social model of disability asserts a division between ‘impairment’ and ‘disability’ (UPIAS, 1976). Impairment represents a particular limit on a given individual’s functioning; Disability describes the social ascriptions that follow this limit. It is important to emphasize that this is not a clear cut dichotomy, and, as we will see, student experiences of impairment and disability in social media challenge the limits of this conception. In later chapters I assert that both impairment and disability are discursively produced. Nonetheless, ‘impairment’ and ‘disability’ offer the most straightforward way of shifting emphasis between impairment affects and the socio-structural properties of disability in this research. As a result, I use ‘impairment’ to emphasize material function and ‘disability’ to emphasize social concerns.

#### **Disabled Students**

In the UK and elsewhere, sensitivity to the power of language has led to intense debates over the proper description of disabled people. Opinion is split. In the UK, disability scholars and activists predominantly (but not exclusively) use the term ‘disabled people’ or ‘disabled students’. Readers may be concerned that this phrasing emphasizes disability, and that the ‘people first’ expression ‘people with disabilities’ or ‘students with disabilities’ would be more appropriate. However, Oliver (1996) rejects this people-first form, as it implies that disability is a characteristic of the individual – that their impairment or disability *causes* them to be a disabled individual. As an alternative ‘disabled people’ identifies how a person is disabled by

social and environmental barriers. I elect to use ‘disabled students’ to describe my participants to maintain this socio-structural focus.

### **1.2.2 Social Networks**

The Web is a dynamic research environment which requires a precise and fleet-footed response. In five years (or less), much of the language in this thesis may appear antiquated. Over the course of this research language has changed. Futuristic terms like ‘cyberspace’ have become quaint. In social media, brands become verbs. As the internet continues to evolve, attention to terminology is useful as it allows us to identify the essential properties of the technology, properties that will be maintained even after the technologies themselves have apparently transformed beyond recognition. ‘Social network’ is a blunt term that requires nuanced application to differentiate between services, communities and effects.

#### **Social Networking Sites**

Boyd and Ellison (2007) define social networking sites (SNSs) as web-based services that allow individuals to:

- (1) construct a public or semi-public profile within a bounded system,
- (2) articulate a list of other users with whom they share a connection, and
- (3) view and traverse their list of connections and those made by others within the system.

These essential properties are refined by a further distinction. Boyd and Ellison distinguish between ‘social network sites’ and ‘social networking sites’:

We chose not to employ the term "networking" for two reasons: emphasis and scope. "Networking" emphasizes relationship initiation, often between strangers. While networking is possible on these sites, it is not the primary practice on many of them, nor is it what differentiates them from other forms of computer-mediated communication (CMC).

What makes social network sites unique is not that they allow individuals to meet strangers, but rather that they enable users to articulate and make visible their social networks. [...] On many of the large SNSs, participants are [...] are primarily communicating with people who are already a part of their extended social network. To emphasize this articulated social network as a

critical organizing feature of these sites, we label them "social network sites." (Boyd and Ellison, 2007).

This emphasis on building existing, if precarious, connection is born out in the present research. Nonetheless, the label 'social networking site' is the term most commonly applied in wider media and by students themselves. Whilst the distinction Boyd and Ellison make is important conceptually in research terms, it confuses a commonsense usage. As a result, in this research, I apply the term 'social networking site' to precisely identify the tool, for example, Bebo, Facebook or MySpace – without allusion to particular kinds of performance that the term 'social networking site' might convey.

### **Networked Publics**

The 'networked public' refers to interpersonal, social aspect of the social network. This term is used to highlight the visible social spaces of an online social network. In particular it draws attention to a key difference between networks such as Facebook and MySpace and other communication and networking tools, for example, phone, text and email; namely, the network is a public. Social activity is visible and played out in a shared space.

### **The Network**

The 'network' is used to surmise both the site and its population.

## ***1.3 Research Motivations***

There is a lack of research into disabled students' social uses of networked technology in higher education. As a result, this exploratory research was instigated to answer several perceived gaps in educational research. Here I outline core concerns; the importance of prioritising social experiences of disability, breaking cycles of inaccessibility, expanding notions of ordinary experience, and researching 'in the wild'. Each concern represents an action to bring disabled students perspectives into view. These concerns cannot be answered in a single project, nor do they represent the total research concerns or contributions of the thesis. Instead, they

are offered as instigating factors, motivations that identify a need for work of this kind.

### **1.3.1 Prioritising Social Experiences of Disability**

Disabled students' experiences of social networking have attracted limited research attention in education. Indeed, research attention to disabled students' experiences of technology has tended to focus on accessibility in formal educational settings to answer ethical, pedagogic and legal imperatives, and with good cause. Digital divides between disabled and non-disabled students are well documented in education, despite a wider perception that high levels of computer and internet access render students exempt from such distinctions (Seale, 2006). These barriers include digital divides relating to the provision of assistive technology and accessible e-learning (Waterfield and West 2006; Goode 2007; Elliott and Wilson 2008; Brunton and Gibson 2009; Harrison et al. 2009; Fuller et al., 2009; Jacklin et al, 2007).

Digital divides are not simply a matter of technology ownership or connectivity. Writing on disability, Blasiotti et al. bring digital divides into sharp focus:

The “digital divide” is not just between technological “haves” and “have-nots.” Additional concerns must be raised about technical literacy and the ability to use electronic communication and information dissemination capabilities. (Blasiotti et al., 2001: 337)

Burgstahler (2002) places accessibility at the heart of this ‘second digital divide’. This divide is conveyed as the ‘result of the inaccessible design of many electronic resources’ (Burgstahler, 2002: 420). In this respect, barriers to technology enhanced learning (TEL) and digital experiences remain a key concern for those trying to ensure access and equality, closing digital divides between disabled and non-disabled students.

This focus on disability, educational materials, services and systems is important, but it is not sufficient. Beyond access, a third ‘digital divide’ is identified. In 2003, Goggin and Newell observed how disability might be socially constructed in new media in one of the first publications to grapple with the subject of disability and sociality online. Goggin and Newell argued that the internet threatened to create new

arenas for the social creation of disability; this was not simply a matter of ‘digital divides’ relating to availability, connectivity or forms of access. The development of systems that assumed non-disabled patterns of activity and ignore disabled users would create spaces in which disability, a social ascription, is exacerbated rather than reduced (Goggin and Newell, 2003). The authors highlight the inter-personal aspects of disability that are expressed through networked technologies. In this way, new media create both new opportunities and new restrictions in terms of accessibility, but also in terms of self-identity and action. Since Goggin and Newell published *Digital Disability* in 2003, Web 2.0 has insinuated technology into the very fabric of student life. As a result it becomes important to ask whether ‘digital divides’ are now occurring outside formal educational concerns, within student experience and, perhaps, the fabric of friendship. This concern persists. Carr (2010) reiterates the importance of recognising the social facets of disability online:

A focus on accessibility is legitimate. Yet, if the education [...] community adopts this perspective without deliberation, there is a risk that central concepts (relating to identity and disability in online contexts, for example) will remain under-theorised. (Carr, 2010: 52)

This research seeks to answer this call by providing a social-theory driven account of disability, identity and social networks in the context of higher education. In this way, I seek to dilate understandings of digital divides in Education and expand inter-disciplinary theoretical discourse.

### **1.3.2 Breaking a Cycle of Inaccessibility**

In recent years there has been a concerted push towards accessibility in technology enhanced learning across all levels of education. However, accessibility represents a shifting frontier. As technology evolves, so too do issues of equality and access.

The term ‘accessibility’ is broadly used to describe the degree to which a service or product gives learners the ‘ability to access’ functionality, services or materials. Web accessibility is often deemed particularly relevant for disabled students who may use assistive technologies to negotiate digital spaces. In this sense, Seale (2006: 28) observes that ‘accessibility’ implies two essential aspects:

- Access by any technology (Caldwell et al., 2004, Pearson and Koppi, 2001)
- Access in any environment or location (Chisholm et al., 1999, HREOC, 2002)

In the UK and elsewhere, accessible practices answer moral, pedagogic and legal imperatives for ‘reasonable adjustment’ to the requirements of all learners. This has mobilised a wave of accessibility auditing of the digital and built environment. In the UK, disabled people have only had explicit legal rights in education since 2002, when the Disability Discrimination Act (Part IV) came into force (SKILL, 2009). Simultaneously, ambitions for an information economy have manifested in government strategies to embed technology in the seminar and classroom (for example: HEFCE, 2005). Taken together, these policy moves have resulted in greater diversity in higher education and a more complex digital landscape.

The pace of innovation and a need to promote accessibility expertise in technologist disciplines (Rosmaita et al., 2006) has meant that accessibility has frequently been an afterthought or bolt-on within e-learning development, rather than integral to new design (Freire et al., 2007). This is compounded by the normative views of an ‘average’ or proto-typical student expressed in much e-learning commentary; For example, Prensky’s *Digital Natives* (2001). The ‘normate’ learner (Garland-Thomas, 2009), undergraduate, full-time, young, male, white, middle class and non-disabled, is increasingly out-of-date, but remains a resilient presence in TEL research. Within this context, disabled learners are invisible and the pedagogic effects of digital barriers and affordances are relatively unknown.

As a result, those striving to ‘accessify’ educational materials and systems find accessibility a matter of constantly catching up and fire fighting. This factor has been exacerbated by the fact that many of the assistive technologies that mitigate impairments are developed reactively. As Dobransky and Hargittai (2006) note ‘by the time accommodations are made technology has often moved another step forward’ (2006: 316). Taken together these factors have resulted in a lag that has placed disabled students at a distinct disadvantage in online spaces.

To combat this cycle of adoption and catch-up, there has been a concerted effort by activists to integrate accessible principles at the heart of design and development, via global Web Standards and the application of anti-discrimination law amongst multi-national technology companies. Other approaches include promoting holistic approaches to accessibility and critiquing current practice (Kelly et al., 2004, Phipps and Kelly, 2006, Kelly et al., 2007; Kelly et al., 2009), developing science and technology studies as a critical disability discipline (Goggin and Newell, 2003, 2005), raising knowledge amongst educators (for example, Cooper et al., 2007, Seale, 2003, Seale, 2006) and reflexively researching accessibility approaches across academia (for example, Freire et al., 2010). As a result, important progress is being made. The present research has also sought to challenge the reactive status quo by anticipating the appropriation of social networks for TEL. I have sought to investigate student perspectives outside formal learning environments, but inside institutional social environments, to explore the potential impact of this adoption, resulting in new and diverse insights. I have prioritised disabled students' perspectives on new technologies in an attempt to highlight and break the cycle of the adoption and application of inaccessible and divisive tools in higher education.

### **1.3.3 Expanding Notions of 'Ordinary' Experience**

Disability is not a closed and limited category; it is by its nature contingent, emergent, heterogenic and permeable. At the instigation of this research I consciously adopted a post-modern approach that states 'the margin constitutes the centre'. By probing what current e-learning and mainstream technology research might construe as peripheral, disabled perspectives on social technology, I hope to return new insights. The resulting findings may then expose assumptions and apparently neutral norms, and demonstrate how disability as a social force operates in wider 'mainstream' networked student culture. As such, it is hoped that by citing 'disability' in the title of this thesis, this research is not disregarded by a majority e-learning audience as a niche or inclusion subject. In conducting research into disabled students' experiences, I do not wish to silo or ghettoize disabled students' perspectives. This research is not undertaken to establish disability as an experience wholly separate and Other to non-disabled experience. Indeed, this research is conducted to problematise the

dichotomy of disability and ability, observing the axiomatic, seemingly self-evident relation between non-disabled and ‘normal’, disabled and ‘other’.

A focus on disability, it is hoped, will have broader benefits for other students at the margins of higher education. Riddell et al. (2005) observe that disabled students pose a particular set of challenges to universities ‘that go beyond physical access’ and this challenge is present in online environments. The synergy of a campus and a social network such as Facebook can be understood holistically as a facet of the university – or more formally, by projecting forward into the emergent mainstreaming of Web 2.0 technologies for e-learning and communication. In this respect, disabled students are a litmus test for the ability of an institution (be it Facebook or the University) to recognise a wider group of diverse learners and a way to understand unanticipated outcomes for marginalised groups (Riddell et al., 2005).

It is important to recognise disabled students as valid constituents of the wider student populations. My participants are students who have been categorised as ‘disabled’ for educational purposes; however, this label does not automatically place these students outside mainstream experience. Disabled students’ experiences are part of a continuum of usual and regular experience that is simply unrecognised in mainstream, practice and research. Garland-Thomson identifies this in terms of the ‘extra-ordinary’;

Thus the ways that bodies interact with the socially engineered environment and conform to social expectations determine the varying degrees of disability or able-bodiedness, or extra ordinariness or ordinariness. (Garland-Thomas, 1997: 7)

This definition need not be limited to physical impairment. Within this thesis I extend Garland-Thomson’s assertions to include those with cognitive impairments, including mental health issues. In this way, the research seeks to problematise notions of impairment and disability. It is hoped that this problematisation will return the most significant benefits. By highlighting the ways in which non-disabled and disabled students are both produced by networked contexts, normativities may be more fully realised and critiqued. It is to this end, the expansion of notions of

ordinary and normal in research and practice, that the ambitions of this thesis most fully attend.

#### **1.3.4 Researching 'In the Wild'**

Due to the speedy evolution of internet technologies, prior research exploring disability in online social environments outside education (for example, Bowker and Tuffin, 2002) has tended to focus on text-based, remote and anonymous spaces, rather than the profiled, immediate networks that now dominate the Web. Another characteristic of prior research has been to target members of a community of practice, or community of interest, where members represent a particular impairment group and/or congregate around a disability issue or topic (for example: Thoreau, 2006, Seymour and Lupton, 2004).

Furthermore, because much of the research into disabled student experiences has been conducted with an educational focus, research, discussion and analysis in higher education has necessarily focused on formal learning technologies and concrete educational impacts. As a liminal space outside the direct control of the university, but central to student life, represents a nascent research territory.

This research project maintains a wide understanding of impairment, to involve students that can be overlooked in both accessibility research and disability research. I have also sought to recruit disabled students' outside 'disability' structures engaged in mainstream and integrated practices.

I have also striven to engage disabled students on their own terms, using their own technologies. This over-the-shoulder approach has been developed for this research, and has only been possible with recent developments in mobile internet technologies. As a result, the research represents a new contribution to accessible technological methods, as well as seeking to offer new vistas on emergent technologies. It is hoped that these methods will assist other internet researchers to engage disabled participants within mainstream internet research, and allow the subterranean discourses which circulate beneath the surface of screen content to be fully explored.

In the next chapter I survey the research context, establishing the current terrain in which networks and students interact and situating my project within a wider literature.

## Chapter 2. The Research Context

---

In this chapter I consider the research context(s) that my research inhabits. I argue that disabled students' experiences with technology have been all too frequently overlooked by researchers, policy makers and learning technologists in higher education as a result of competing interests. For institutions, accessibility arguably dominates notions of disability – resulting in accessibility becoming a primary site of technology research in education. Barrier removal is a vital part of ensuring access for disabled students; however, it is not in and of itself sufficient to ensure an equitable experience of university life. Too often disabled students represent a constituency that represents ‘the other “Other”’ (Wendell, 1996), falling between policy agendas or buffeted by swathes of legislation that do not account for one another. This has led to a situation in which the digital lives of disabled students represent a ‘blank spot’ (Wagner, 1993) in research and educational understanding.

To map this argument and my research terrain I consider the recent developments in social justice and economic policy, social media and e-learning in higher education. Each of these strands has a tangible impact on the experiences of disabled students, establishing the social, political and practical urgency for this research. I then consider the advent of Web 2.0, social networking sites (SNSs) and their impact on the academy and student life, before considering reports on current University uses of SNSs. Next, I turn to consider digital disability in the era of Web 2.0. As Facebook emerges as the dominant force in student sociality, I find it necessary draw on diverse literature from inside and outside academia to sketch disabled perspectives on the network and student life. This review gestures to complex and conflicted social experiences that require further investigation. Here, I also describe the benefits to the area as a whole that addressing these gaps may provide. Finally, I report my research questions.

## ***2.1 Social and Political Changes in Higher Education***

Since 1997 a revolution has taken place in higher education. In the UK, higher education has been transformed from an 'elite practice' to a 'mass system' (Fuller et al., 2009: 6). In 1997, New Labour made education a top priority for government, seeking Dearing's 'Learning Society' (Hurst, 1999). In doing so they invested education with the rhetoric of economic potential; education was cited as an 'economic necessity for the nation' (Labour Party Manifesto, 1997: 12). Moreover, technology was deemed an essential aspect of this new triumvirate. New Labour cited 'too little investment in education and skills, and the application of new technologies' as an 'underlying cause of inflation, of low growth and of unemployment' (Labour Party Manifesto, 1997: 19). By 2003, this association had developed into tangible legislative outcomes for UK Universities in the form of the Government White Paper, *The Future of Higher Education* (DfES, 2003a), parent to the Widening Participation Agenda (DfES, 2003b).

New Labour stipulated that half of young people under 30 should enter higher education by 2010. This target for Widening Participation represented both an economic ambition and an inclusion aspiration. In this sense Widening Participation has dual lineage in social justice and economic policy. In practice, however, the convergence of these two founding elements demonstrates two fundamentally different policy making stances, with confused outcomes. The economic component is anticipatory and proactive, whereas the social justice aspect represents a more reactive discourse that has accrued over time. Unlike economic policy, social policy mobilises around naming. Social legislation is built on a fundament of legislation that classifies parts of the population, and, in doing so created 'members of a kind' (Hacking, 1995), potentially altering those members' self-perceptions (Tremain, 2005). This forges a group identity, which in turn can be seen to mobilise to demand changes to classifications and recognition, spurring juridical change. This split is of note, as Barnes (2007) observes, economic and social justice agendas in the UK are traditionally distinct. Moreover, he asserts that increasing influence of economic forces upon universities is directly opposed to the interests of widening participation (Barnes, 2007). Indeed, in practice, unanticipated collisions between different strains of legislation have left some students potentially disadvantaged in the new education/

technology/ economy trichotomy. As the application of policies relating to new technologies in education have been enacted and scaled (for example, through virtual learning environments) the accessibility requirements of disabled students have been shown to be frequently unresolved (for example, Dunn, 2003, 2007).

In concrete terms, Widening Participation aimed to address participation rates amongst students from less-advantaged socio-economic backgrounds for purposes of social mobility. In practice, the impact of these policy changes has gone far beyond the groups identified however, due to important intersections with Disability Discrimination Laws. Thus, as higher education has increased in size, it has also diversified. Alongside New Labour's economic and educational aspirations, significant social justice legislation was enacted, with significant outcomes for the diversity of new university cohorts. National policy interventions have given many disabled young people access to higher education as never before. In September 2002, Disability Discrimination Act (DDA, 1995) duties were applied to education for the first time under the auspices of the Special Educational Needs and Disabilities Act (SENDA, 2001). Together, these legislative moves inscribed the rights of disabled people in higher education for the first time. In 2005, definitions of disability were expanded (DDA, 2005) and in 2006, the Disability Equality Duty came into force. This trajectory continues with the immanent enactment of the Equalities Act (2010).

Notably, many of these legislative moves have equivalence outside the UK reflecting a wider concern for the rights of disabled people in education; for example, the Australian Disability Discrimination Act (1992) and Access and Equity agenda in Higher Education; the Americans with Disabilities Act (1992) and its recent amendment in 2008. Globally, Article 24 of the UN convention on the Rights of Persons with Disabilities (2008) recognises the right of disabled people to 'all levels' of education.

In the UK, these moves have contributed to a more diverse student body. In the academic year 2008-2009 approximately 55,245 (7.2%) of UK-domiciled, first year, full-time undergraduates declared a disability (HESA, 2009). This represents a relatively steady rise from a level of 5% in 2003. However, this slight, but steady progress is not without issue. Disabled students continue to be under-represented in

higher education (DIUS, 2009). Gosling (2009) asserts that this may be due to diverse factors; underachievement in school, low aspirations, economic status, ethnicity and class. However Gosling also notes:

We cannot rule out the possibility that prejudice against disabled students and ignorance about that they are capable of, with appropriate support, has also contributed to their under-representation. (Gosling, 2009: 127)

Within higher education, multiple studies have also demonstrated a gap between policy designs and HE practice and above average rates of attrition amongst disabled students. This gap is particularly conspicuous in e-learning and TEL, a concern examined in the following arguments.

Government ambitions for technology in higher education are strongly evidenced in policy. For example, in 2005, the HEFCE strategy for e-learning recommended the embedding of e-learning across departments, their aim being to instate ICT as 'commonly accepted into all aspects of higher education, with innovation for enhancement and flexible learning, connecting areas of HE with other aspects of life and work' (HEFCE, 2005: 9). Such directions have led to an attendance to blended learning, combining e-learning with more traditional modes of delivery. Although great claims were made for the capacity of such ICT to widen educational participation, critical commentators noted the lack of any research grounds for these arguments regarding digital inclusions, and refuted them with empirical evidence to the contrary:

Central to this rhetoric are a series of largely untested assumptions about the potential of ICT to increase and widen levels of educational participation to include those groups of learners who have been previously excluded. (Selwyn and Gorard, 2003: 169)

With regard to disabled students, the most significant outcome of policy ambitions for the virtual and technology-enhanced classroom has been the development of a concerted attention to accessibility and barrier removal. Technology research involving disabled students has tended to focus on user testing, accessibility audits of particular domains of activity (Dunn, 2003, Farrar, 2004), the development of guidelines (Pearson and Koppi, 2001, Blankfield, 2002), application of web

standards (e.g. Caldwell et al., 2008) the sharing of best accessible practice (Burgstahler et al., 2008, Cooper et al., 2007) and approaches to accessible delivery (Kelly et al., 2004, Sloan et al., 2006). Notably, these projects do not contest the use of technology in learning in terms of inclusive pedagogies. They are reactive projects that seek to ‘accessify’ current practices.

Beyond accessibility, disabled students initially lacked visibility in wider educational research. As Fuller et al. observed: ‘Despite a growth of interest in widening access and participation and in inclusive higher education, the voices of disabled students themselves have hardly been heard’ (Fuller et al., 2004: 455). Recent research into the learning experiences of disabled students increasingly seeks to answer these ‘earlier silences’ (Rickinson, 2010: 19). Nonetheless, experiences of technology are rarely the object of these studies which focus instead on disciplinary differences, particular impairment groups and particular domains of activity (for example, transitions into university). Thus, whilst many of these studies touch upon issues such as to barriers to the use of assistive technologies, internet based learning materials and digital resources (Goode, 2007, Fuller et al., 2009, Elliott and Wilson, 2008); few are able to supply more sustained research attention to the impact of technology on disabled students’ learning experiences. As Seale asserts:

Compared to other groups who are potentially excluded from our digital society, very little research has been conducted exploring the role that technology plays in the learning experiences of disabled students in higher education. (Seale et al., 2010: 447)<sup>1</sup>

Such observations are particularly significant considering the technological sea-change currently being affected in students’ lives.

## **2.2 Technological Advances: the Advent of Web 2.0**

There have been huge global developments in internet technologies over the last decade. The Web has developed from a dial-up, narrowband network delivering content hierarchically to users for information retrieval (retrospectively assigned as

---

<sup>1</sup>This call is echoed at secondary level by GWERNAN-JONES, R. (2008) *Identity and disability: a review of the current state and developing trends*, Bristol, Future Lab.

Web 1.0) to a dynamic and interactive space characterised by high speed connections, multiple forms of access, multimedia and social content. This development has been branded as 'Web 2.0', or the participatory Web. Commentators define this second generation of web tools on the basis of significant shifts in technology, structure and social aspects (O'Reilly, 2005).

Where Web 1.0 was largely static and hierarchical, delivering fixed content to a passive user, Web 2.0 services provide utilities that focus on communication and the sharing of resources. Importantly, the value of a Web 2.0 service is contingent upon a critical mass of participating users. Content is social. Users upload, create and refine content that is then shared across networks, applications and contexts. As a result, Web 2.0 services actively encourage participation, collaboration and sharing. Web 2.0 is also characterised by an increasing use of multi-media that position the Web as a platform, rather than a portal. Video, text, images and sounds are distributed, with less impetus on the user to have access to mediating software, pre-installed on their computer. Examples of Web 2.0 services include blogs, wikis, video-sharing sites, SNSs and social bookmarking sites (also known as folksonomies). Amongst these tools SNSs have become the most popular online destination for internet users (Hargittai, 2007), boasting millions of users, and year on year expansion.

SNSs provide a collection of tools for interaction and self-display, allowing users to interact *asynchronously* through email, notice boards, discussion groups, tagging, gaming, video, music, sound and image sharing and *synchronously* through voice over internet protocols and synchronous messaging and so on. In this respect, the SNS represents a collection of social tools, an umbrella system combining aspects of blogs, wikis and folksonomies. Activity is usually focussed on a profile that contains information such as interests, a photo, contact details, membership of groups and a visible list of connections with friends. Taken together this information signals the social identity of the owner to their network and beyond. Such social networks differ from previous forms of Computer Mediated Communication (CMC) in several important ways. SNSs are not anonymous spaces. The complexity of cues articulated through a profile strongly gesture to the identity of the owner. The public display of connection is also a crucial differentiator for SNSs (Vaucelle, 2009; Boyd and Ellisson, 2007), allowing new activities for users such as social research across peer

groups and the assertion of a social self. Business interests have also entered this social sphere. The massification of SNSs has resulted in a huge captive market for advertisers, leading to an emphasis on bounded systems. These boundaries mean passwords and user profiles have become ubiquitous across providers. A further distinction from Web 1.0 interactions is that SNSs are web-based, as a result providers have adopted a state of 'perpetual beta' characterised by ongoing development (O'Reilly, 2005). SNSs are regularly updated and expanded, with new tools being added and interfaces being reworked gradually over time. More controversially, terms of use and privacy settings are also unstable as a result of this shifting context.

Amongst Web 2.0 technologies, SNSs have received significant research attention (for example, Boyd, 2011<sup>2</sup>). Internet researchers from a multitude of disciplines have examined social networking practices relating to performance, curation, privacy and identity exchange amongst a host of other facets. Within education however, this research landscape contracts significantly.

### ***2.3 Social Networking Sites in Higher Education***

SNSs are increasingly embedded in student life. Mori (2007) found 95% of a total of 501 students surveyed in June 2007 used SNSs. They conclude that SNSs, amongst other networked technologies are 'fading into the foreground' (2007: 15). In the academic year 2008-9 Mage et al. (2009) expand this 95% estimate of SNS usage to all 744,000 undergraduates in the UK. Facebook has its origins in University life. It was originally conceived at Harvard, expanding to open access in 2006<sup>3</sup>. From its origin as an elite university system, Facebook has expanded, whilst retaining its status as a rite of passage for students bound for tertiary education. In 2005, Facebook opened to wider educational communities, before opening access to all in 2006. In the UK over the course of this research, Facebook has overtaken its rivals to become not only the most populous SNS, but also the most trafficked website in the UK. Services such as Facebook, Bebo and MySpace represent millions of profiles

---

<sup>2</sup> Boyd's *Bibliography of Research into Social Network Sites* identifies some 367 published articles in this fast-expanding area. This list is by no means comprehensive.

<sup>3</sup> More information about Facebook's functionality, timescale and population is available in appendices one and three.

and are particularly popular amongst young people<sup>4</sup>. As a result, year on year, Facebook's presence extends within the academy. Educational interest has followed, attracted by the implicit social pedagogies that SNSs are seen to promote. In educational terms, Web 2.0's architecture of participation lends itself to reflexivity and social pedagogies, dialogic (Wegerif, 2007), collaborative and participatory (McLoughlin and Lee, 2007), social constructivist (Barnes and Tynan, 2007) and problem-based learning (Kaldoudi et al., 2008). Furthermore, Minocha reports how educators are drawn to such networks based on assumptions regarding students' familiarity with SNSs and their popularity that are not borne out in practice (Minocha, 2009). Over and above this, educational rhetoric at the policy level continues to equate new technologies with the economic future of the academy. For example, in *The Edgeless University*, think-tank DEMOS asserts that Universities must harness social networks such as Facebook as delivery mechanisms for materials and engagement with learners:

The challenge is to get the relationship between the institution and the technology the right way round. Open repositories of online content, social media networks like Facebook and the use of virtual learning can all help universities provide more flexibility and new ways for people to access scholarly and research material. Technology can help universities move from where they are now to where they need to be. (Bradwell, 2009: 11)

Such powerful, but untested rhetoric remains a potent force shaping the direction of higher education. Moreover, there is a concern that educators' and policy makers' approaches to SNSs and Web 2.0 more widely repeat a cycle of new technology adoption identified by Cuban (1986). Cuban's sobering arguments demonstrate how education has reliably sought to borrow from each new recreational technology, from the broadcast era onwards. This adoption is characterised by uncritical optimism, a lack of research grounding and the resilience of existing teaching practices. As Crook and Lewthwaite (2009) surmise:

The technology not only engages its users, but it may also seem to be drawing them into learning. That learning may be 'informal' yet, often, it displays an

---

<sup>4</sup> An introduction to the particular arrangement and function of these UK market leaders is contained in appendix three.

enviable vigour. This energy encourages educators to search for links and continuities into their more formal learning contexts. (Crook and Lewthwaite, 2009: 440)

The impact of this growing enthusiasm for SNSs on disabled students is, as yet, unknown. As Mage et al., (2009) note, there is a dearth of research assessing the role of SNSs in student experience. Within this context, disabled students are invisible. SNSs represent an emergent technology in education, increasingly being appropriated and tested across Universities (Minocha, 2009). Within this emergent research and educational context, attention to disabled students is also notably lacking. Whilst optimistic claims are made with regards to the potential for Web 2.0 in ‘reworking hierarchies, changing social divisions, creating possibilities and opportunities, informing us and reconfiguring our relations with objects, spaces and each other’ (Beer and Burrows, 2007), such claims for digital inclusion are untested (Selwyn and Gorard, 2003). Indeed, when considering inclusion policy and the reality of research at this cutting edge of technology enhanced learning, it appears the gap between inclusion policy and educational practice is at its widest.

As we have seen, the battle for accessibility has meant that social, interpersonal elements of disability online remain largely unexamined. As research into social pedagogies are invigorated by SNSs, the consequences for disabled students are unknown, and the prospects for the development of approaches that account for diversity appear bleak as the academy shifts inexorably into the social network.

## ***2.4 Researching Social Experiences of Disability in Higher Education***

The experience of the student is at the heart of higher education.  
(Innovation Universities Science and Skills Committee, 2009)

To gauge the relevance of social networks to disability, it is useful to consider recent research into disabled students’ offline networks. Following the exhortations of Fuller et al., (2004) and others for attention to disabled student voices, research into disability documented as a facet of student experience is gaining leverage.

Experiences of disability are not only the results of physical and structural barriers in

an academic environment; disability is also a social, negotiated aspect of experience. The work of Low (1996, 2009) Riddell et al., (2005) and Goode (2007), highlight this interpersonal dynamic.

Low (1996, 2009) states that disabled students struggle to integrate within the broad setting of the university. Whilst they may experience a non-disabled identity amongst intimate friends, their experience of wider non-intimate relations within the built environment of the university is more fraught. It is here that identities must be negotiated 'in the largely impersonal world of the university campus' (Low, 2009: 236). In this context disability is found to be experienced as stigmatised and discredited (Goffman, 1963). Riddell et al., (2005) highlight the range of identities that are 'performed' by disabled students in higher education. Their work shows students' constructions of disabled identity to be temporal, contingent and negotiated. Their research also reports the greater externally-imposed constraints that some disabled students experience, which limit the parameters for negotiating and managing identities. Goode (2007) also substantiates the impact of disability as a socially ascribed identity. Her work demonstrates how students are required to actively 'manage' disability. In identity terms, transitions into higher education can mobilise new perspectives on impairment. However, in educational and social interactions, disabled students are required to repeatedly manage disclosure of disability, the invisibility of their requirements and extra-visibility of making impairment related needs known. Further to this, Goode reports the emotional work (Hochschild, 1983) that students are obliged to undertake when managing identity as a person with impairment. Importantly, this emotional work is often undertaken on behalf of others (Cahill and Eggleston, 1994) 'as students try to help them [non-disabled peers] with their discomfort' (Goode, 2007: 43). All such experiences highlight the importance of attending to interactional experiences of disability in student experience.

With regard to offline social networks, existing research into student experience, disability and higher education also gestures strongly to the value of disabled students' social networks for building necessary social capital. As Riddell et al. assert:

... it has been argued that horizontal links, sometimes described as bonding social capital, are essential to getting by, whereas vertical or bridging forms of social capital are vital for getting on. Disabled students may have strong social links with a disabled student adviser, a personal assistant, a mental health support tutor or a small group of friends, but they often lack the myriad loose connections which are a vital part of the higher education experience for many students. The full benefits of higher education may therefore be elusive. (Riddell et al., 2005: 153)

Jacklin et al., (2007) also found that the transition into higher education was identified as a time of potential vulnerability, particularly in the development of social networks. Elliott and Wilson (2008) reiterate this finding, reporting that social networks are vital to disabled students in their research with students with hidden disabilities including dyslexia, mental health difficulties and Asperger's Syndrome:

The importance of creating friendships and in particular friendships for mutual support with students, particularly those with similar impairments was highlighted by the students in this study. A number of the students who would benefit from the peer support clearly find it more difficult than their non-disabled peers to create and maintain relationships for reasons relating to their disabilities. [...] Disabled students could be offered options to discuss social networking issues if desired. (Elliott and Wilson, 2008: 67)

More recently, Fuller et al., (2008) similarly gesture to the importance of disabled students' 'student experience', their social relationships and emotional lives:

This research focused mainly on learning, teaching and assessment. However, it was clear from the student interviews that there was considerable variation between students in their ability to engage with the social aspects of university life. This suggests that there is a need to pay greater attention to the social and emotional aspects of learning in higher education, including additional support for vulnerable students at points of transition. The interviews also indicated that students felt best supported in situations where they could build effective personal relationships with academic and support staff. (Fuller et al., 2008: 3)

None of the above studies touched on SNSs. However, taken together, research into social experiences of disability and the social barriers faced present an imminent need for inquiry. SNSs are now woven into the fabric of student experience. It is unclear whether such SNSs present an opportunity or barrier to disabled students,

nonetheless, the social network is an emerging social and educational concern in disability research.

## ***2.5 Researching Social Experiences of Disability Online***

Research has been undertaken into social experiences of disability online outside academia. Indeed networked technologies have been of significant interest to disability studies, which has engaged strongly with the inheritance of cyberfeminist theory and research from the 1990s. In the early 1990s, cyberfeminists explored virtual reality's ability to deconstruct the embodied, physical self to allow new identifications that are non-gendered, non-binary and to challenge material essentialism (Haraway, 1991, Hall and Bucholtz, 1995, Plant, 1996). More explicit engagement with impairment and digital spaces followed at the turn of the millennium. Disabled people engaged with new technologies critically:

Clearly, new networking technologies offer great potential that could facilitate or limit the integration of people with disabilities into broader circles of social, business, cultural, and educational activity. Radical changes appear possible – and perhaps probable – in how disability studies research will be conducted in the future and how people with disabilities will participate in shaping both disability studies research and curricula. (Blasiotti et al., 2001: 345)

Significant research into the experiences of disabled people online has been undertaken by Bowker and Tuffin (Bowker, 2003, 2009; Bowker and Tuffin, 2002, 2003). Their research highlights many of the social affordances of disembodied media for disabled people; control over disclosure, the benefits of anonymity resource. Such examinations focussed on contemporary text-based, anonymous and distance forms of CMC. Another approach has been to target members of a community of practice, or community of interest, where members congregate around a disability issue or topic (for example, Thoreau, 2006, Seymour & Lupton, 2004). Conditions have changed; however, seeking disabled perspectives on SNSs is far from straightforward.

## 2.5.1 Social Networking Sites and Accessibility

With the advent of SNSs as a mass medium, Accessibility research demarcates the earliest attention to the practicality of SNSs for disabled people. Over time, specific audits and advice for particular impairment groups have become available. Snippets of information about the social and emotional experience of using SNS utilities as a disabled user are scattered across such reports.

In January 2008, AbilityNet's 'State of the eNation' report (AbilityNet, 2008) focussed on SNSs, resulting in a significant catalogue of accessibility failings. The review, compiled by disabled users showed that none of the sites reviewed, including Facebook, MySpace, YouTube, Yahoo or Bebo would allow users to log-in without completing a visual verification task that disbars screen-reader users. Audio equivalents were found to be unusable. The authors assert a 'virtual lock-out' imposed on disabled users. Within the sites, further barriers were demonstrated, from structural failings to complexities caused by other users' inaccessible contributions. Importantly, although the AbilityNet assessment is technical and frequently standards based, the authors make important assertions regarding the social losses to disabled people that may result from the inaccessibility of such prominent social utilities.

Other audits of accessibility and guides to Facebook use have followed.

Web2Access<sup>5</sup> (established July 2009) is a website commissioned by the UK's JISC TechDis. It supplies educators with information about the general accessibility of Web 2.0 services to assess the suitability of any tool for a given task. Web2Access adopts a less standards based approach, instead evaluating Facebook on user experiences across different impairment groups. Facebook receives an accessibility 'score' of 69%. This is helpful to educators, but does not address societal facets of use. Elsewhere, the American Foundation for the Blind (AFB) has issued guidance on how to use Facebook (Ingber, 2009) despite its limits. Ingber refers to affordance but also frustration. Facebook requires 'a lot of skill' and 'patience'. It is frustrating, 'some screen reader users will find using Facebook to be too difficult'. Nonetheless, Ingber asserts the social affordances: 'even if you do not use all its features, you can

---

<sup>5</sup> <http://www.Web2Access.ac.uk>

reunite with old friends, meet new people, and join common interest groups’ (Ingeber, 2009). Likewise, Jellinek (2010) asserts the importance of SNS for people with motor disabilities. His review suggests that disabled people are more networked than non-disabled people, conceiving SNSs as ‘indispensable’ prior to a focus on accessibility. Jellinek states that the average person with a disability has 250 friends, compared with an average of 130 for non-disabled people.

All these reports reiterate the resistance of Facebook’s interfaces to assistive technologies, the challenges its changing layout poses for disabled users and the threshold barriers presented by the registration process. The addition of Facebook’s mobile html-only version has made Facebook a ‘good choice for people with disabilities’ according to Cahill and Hollier (2009). They amongst commend Facebook for its increasingly responsive approach to accessibility. Notably, in 2007, AFB intervention led to Facebook instating an ‘Accessibility and Assistive Technology’ page<sup>6</sup>. In 2008 Facebook consulted with AFB as part of its site overhaul. Nonetheless, significant barriers to use remain, with unknown impact upon disabled people’s lives.

## **2.5.2 Social Networking Sites in Higher Education**

Studies accounting for disabled students’ experiences of SNSs in higher education are scarce. An important exception is the LexDis project (Seale et al., 2008). The authors note a dearth of research considering disabled students’ uses of technology in education (Seale et al., 2010). Indeed, LexDis marks the most significant assessment of the disabled students’ everyday use of technology found during this review. Seale et al., (2008) find that the majority of 30 disabled participants used SNSs such as Facebook for varied activities. Amongst these, some participants had deployed the network as a tool for learning, but the network was conceived more generally as a social space, echoing Selwyn (2009) and Mage et al., (2009). Participants cited a variety of networked activities undertaken, sharing links, materials, videos and photos with peers. Some created Groups and engaged in discussion in the networked public. However, use was not stable, and the researchers discovered a trend in disabled students’ determination of SNS use:

---

<sup>6</sup> Facebook: Accessibility and Assistive Technology <http://www.facebook.com/help/?page=440>

Many have used these tools [SNSs] for personal or social reasons, but have given them up because they were too distracting or time consuming. Disabled learners have to make decisions about what they can afford spending their time using and social networking tools are frequently discounted as “not for learning”. (Seale et al., 2008: 5)

Importantly the authors also identify an emergent cost-benefit analysis undertaken by some disabled students using technologies that results in Catch-22 situations. SNSs were implicated within this analysis in one example. ‘Hannah’ identified a particular moral concern regarding whether it was appropriate to the use Facebook in an Assistive Technology Suite (ATS):

Hannah talks about how use of FaceBook is influenced by her anxieties about not disturbing people around her, but also whether or not FaceBook is considered a work or leisure activity:

**Hannah:** ... I wouldn't want to look at FaceBook in case – because there's so much demand for ATS, I think it's wrong to be taking FaceBook. But then, again, if you've been working for 4 hours, you need a break. (Seale et al., 2008: 74)

These issues of time and appropriateness suggest complex negotiation of use within the experiences of disabled students. However, the educational slant of the research places SNSs on the margins of the researchers' investigations. Social experiences of disability in social network interaction are not explored, since a focus on disabled student's digital skills ('digital agility' and 'digital decisions', Seale et al., 2010) was the motivation for the research.

### 2.5.3 Seeking Disabled Perspectives Beyond Higher Education

Seale (2006) observes that disabled students' authentic voices can be sought beyond the abstracted and edited research accounts of academia in non-academic domains. She asserts that sources such as SKILL<sup>7</sup> and Ouch!<sup>8</sup> offer a less mediated view on student life in general. Unfortunately, although both Skill and Ouch! correspondents refer to SNSs within student life, they do so in descriptive, functional terms only.

---

<sup>7</sup> <http://www.skill.org.uk> Note: the National Bureau of Students with Disabilities closed in April 2011.

<sup>8</sup> OUCH is a disability lifestyle website that is administered by the BBC <http://www.bbc.co.uk/ouch>

Nonetheless, Ouch! represents an early bell-weather for indications about disabled peoples' experience of mass-media. Ouch! supplies two early critical viewpoints on Facebook from 2009, highlighting the negotiation of disability as an interactional identity and highlighting experiences of disabilism. In her article 'Face to Facebook' Ouch! Writer and blogger Franklin (2009) describes a 'love hate relationship with the big site that everyone seems to be part of'. She describes a conflicting appreciation of the tool in relation to her interactions with old friends who are unaware of her progressive impairments:

When I'm going through a bad patch, it can really help to be able to use sites like Facebook to escape into an online virtual world. While there, these very personal questions about my disability can feel like a huge burden. The responsibility of having to spare other people's feelings and provide the reassurance they need to hear is too much when I just want to scream, "No there is no cure, treatment or exorcism. It is what it is and if you can't handle that, it's your problem!"

(Franklin, 2009)

This article resonates with the emotional work identified by Goode (2007) on campus. Tom Shakespeare raises another angle in 'Not Such a Pretty Facebook' (Shakespeare, 2009). He describes the worrying emergence of disabilist hate Groups within Facebook's networks, along with Facebook's relative ambivalence to disciplining such groups. Such experiences are without precedent in education and raise serious questions about the suitability of the networked public as a forum for formal education. Both writers' accounts identify disability as a networked social experience. In these terms, there is an asserted need for research in this area before universities adopt or deploy such tools for general use.

Aside from these lucid accounts and despite the fact that many disabled people and representative organisations are increasingly represented within SNSs, reports of disabled people's experiences of SNSs outside education remain disappointingly few and anecdotal. Nonetheless, such vignettes may gesture to the role of SNSs in student life. Heasley (2010) reports on the experiences of Sally Harrison, a North American disabled woman who used Facebook to allow her friends to surveille her progress as she made the transition from a highly-supervised group home to independent living

(Heasley, 2010)<sup>9</sup>. Benefits cited by Harrison and her support colleagues include improved self-esteem, facilities to dispel and challenge stereotypes and an increased sense of acceptance in the community. These benefits may have a tentative resonance for disabled students leaving a parental home for university campus environments. However, such assertions require substantiation before conclusions can be drawn or wider claims made about the efficacy of Facebook as an empowering, or disempowering, technology.

The paucity of disability research into SNSs suggests to me a key concern; whilst excellent research has been undertaken examining disability and CMC, there appears to be a lack of capacity in disability studies to respond quickly to significant shifts in the technological landscape. At the same time, disability researchers focussing on traditional ‘disability’ concerns (for example, education, health, rights and independent living) have yet to attend to the incursion of digital influence in these realms. This study hopes to address the dearth of empirical research in this area, to promote a move from current rhetoric and conjecture based on anecdotal evidence, to a grounded, analytic and theoretical account of disability in social networks. This seeks to expand ‘digital’ disability studies, and supply Science and Technology Studies with a social theory driven account of normalcy in online contexts. In this way, I aim to expand the vocabulary of each, and foreground the value of disability studies and marginalised experiences for developing mainstream understanding of technology in social action.

Aside from these research aims, I hope that my findings will disseminate to allow users to critically engage with the network, employ social networks more strategically with a better understanding of the costs and benefits that the application of such tools evokes at a personal and social level. As we have seen, there is a call for an analysis of the social impact of social networks with regard to inclusion and equality. Discrepancies in student experiences based upon disability highlight indices of marginalisation and power with implications for all users. At an applied level, it is therefore hoped that this research will engage students, advocates, disability and academic support practitioners, accessibility advocates, technologists and educators

---

<sup>9</sup> An edited version of this story was also repeated by DisabilityScoop and the EconomicTimes.

by developing understanding of how social networks mediate experiences of disability. In sum, I aim to instigate a research dialogue that affirms the place of disabled students as visible agents within digital communities and challenges their marginal status.

## **2.6 Research Questions**

SNSs are important spaces for self-identity and student experience. However they also represent liminal spaces, central to student life, but on the threshold of the university. In this sense, social networks are not recognised by the university or the university-sponsored support structures in place to uphold disabled students. A concern is that social networks could represent exclusion for disabled students, evidence of social and structural barriers entering ‘regular’ student life for the first time – exacerbating disability rather than negating it. Building on the observations of other disability and technology scholars, this literature review has established significant gaps in research and theorisation of networked disability, both within and outside academia. This suggests to me that disability in social networks represents a relative ‘unknown, unknown’ for the majority of educators, policy makers, technologists and developers. As a result, the objective of this study is to assess and understand how disability/ability difference is constructed and mediated by SNSs and networked publics at university. In total, I seek to answer three research questions:

RQ1: How and where does disability occur within disabled students’ networks?

RQ2: How do disabled students experience disability in the network?

RQ3: How do disabled students manage disability in the network?

By addressing these questions, I hope to shed new light on this area, offering an empirically based description, analysis and theorisation of disability within social networks. This will contribute to a nascent body of knowledge in the field by supplying an evidence base that allows a social theorisation of disability and social media to progress and challenge the normalcy and dominance of non-disabled technology discourses. With these research concerns I seek to illuminate the

interpersonal facets of social networks, to understand how dis/ability as a social construct is negotiated within these spaces. As such, this research is proposed as a stepping stone towards a wider investigation of marginal identities and the construction of ability and disability in social networks.

## **2.7 Summary**

In this chapter I have considered the context of higher education and the place of disabled students' social experiences of technology within current research. I have observed that disabled students are under-represented in research into technology enhanced learning. With few notable exceptions, research into the experiences of disabled students has necessarily gravitated towards research into accessibility and learning experiences in a project of barrier-removal. At the present time, disabled students' social experiences outside the academy in the networked publics that constitute a significant students digital pastime are relatively unknown. Research into physical networks and the challenges faced by disabled students on campus suggest that SNSs may provide important opportunities for integration and building social capital. At the same time, vignettes from outside education suggest that experiences of disability within SNSs may prove beneficial or problematic. In either event, research is necessary as, despite critical concerns expressed by Selwyn (2009) and others, SNSs are increasingly represented within formal teaching and wider university administrative and publicity practices. There is a concern that Facebook will be appropriated *anyway* regardless of its impact on disabled students and that the research and pedagogic streams such a move may precipitate will continue without reference to disabled perspectives.

In the next chapter, I consider the conceptual framework for this research, attending to the nature of disability itself and issues of representation and classification in qualitative research.

## Chapter 3. Conceptual Framework

---

This chapter examines the a priori issues that underpin research as an activity in the context(s) of disability. I focus on discursive representations of disability and the mechanics of category-making to expose two core problems of conducting disability research; first, that disability is the quintessential postmodern concept. It defies classification because it is ‘so complex, so variable, so contingent, so situated’ (Shakespeare and Watson, 2002: 19). Second, that the process of classification itself represents an exercise of power. Thus, this chapter attends to Corker’s concern with distinctions between disabled and non-disabled, disability and impairment:

... ‘social systems that are exclusively built on systems of classification – including both the socially created and the socially constructed classifications ‘disability’ and ‘impairment’ – are generally undemocratic, oppressive and exclusionary (Young, 1990, Butler, 1993).’ (Thomas and Corker, 2002: 22, emphasis in the original)

A concern of disability research must, therefore, be that the process of researching involves in some way affirming disability as a category. This affirmation is problematic, as Liggett states:

From an interpretive point of view the minority group approach is double-edged because it means enlarging the discursive practices which participate in the constitution of disability. [I]n order to participate in their own management, disabled people have had to participate as disabled. Even among the politically active, the price of being heard is understanding that it is the disabled who are speaking. (Liggett: 1998: 271, in Shakespeare, 2006:78)

In light of these issues, I seek to problematise representations of difference and the *process* of differentiating in research. I begin by outlining alternate models of disability. This review is undertaken to examine what is commonly meant by ‘disability’ to expose the close relations between disability theory and disability practice. Any conception of disability implies a certain way of doing things; disability theory *is* practice. This inducts a concern with ‘practical ethics’ (Paras,

1999) at the heart of the research venture. From this point I discuss the hierarchical relations of power and knowledge in the context of disability and higher education. To explore this terrain, I consider ‘juridical’ representations of disability enacted in university statistical projects to observe how empirical representations of disability shape the ‘conditions of possibility’ (Foucault, 1974:89) afforded to disability researchers and delineate disabled students’ experiences. Subsequently, I utilise Foucauldian poststructuralist approaches, with supporting observations stemming from information sciences, to illustrate significant flaws in category-based approaches that attempt to ‘fix’ disability in universal terms.

In light of this applied critique, I propose a ‘faceted’ representation of disability that explicitly acknowledges the multiple discourses that converge at the site of the ‘dis/abled’ body, and addresses the limits of process and context. This intersection between critical perspectives and the pragmatism of information science offers what I consider to be an ethical and strategic way forward, resisting totalising discourses and culminating in a commitment to a Foucauldian *bricolage* in my research methodology (chapter four).

### **3.1 Representations of Disability**

There are multiple epistemologies regarding the meaning and constitution of disability; These approaches to disability are not necessarily mutually exclusive, but each has a different emphasis, and, importantly, different implications for the conduct of the present study. In this sense, theory and practice are closely interrelated and the representation of disability is contentious.

A linear discussion of disability discourse is difficult, in part because its history and chronology has been neglected within disability studies (Watson and Woods, 2005). Moreover, such histories are dependent upon dominant contemporary narratives that are themselves imbricated with the contexts through which representations of disability, or more specific debates over *authorship* of disability, emerge (Mallett, 2007: 23). Within disability literature, however, a usual path through the iterations of disability follows a trajectory beginning with the medical model of disability and

ending with more recently defined, pluralistic approaches. It is from these pluralistic approaches that my poststructural research design stems.

### **3.1.1 The Medical and Social Models of Disability**

Since the Enlightenment, a bio-medical model of disability has come to dominate popular conceptions of disability (Oliver, 1990). This model encompasses views that situate disability within an individual as an intrinsic, physical marker of biological difference. Disability is a matter of pathology that deviates from a norm. Moreover, disability is a medical concern, a matter of treatment, correction and subject to professional clinical expertise.

In the UK, the foremost indigenous challenge to dominant medical discourse stemmed from the publication of *Fundamental Principles of Disability* (UPIAS, 1976). *Fundamental Principles* established what has become known as the British social model of disability<sup>10</sup> by conceiving disabled experience as oppression and foregrounding the social and material barriers that disadvantage disabled people. This approach to disability was conceived as diametrically opposed to the medical model, severing the causal link between impairment and disability and identifying these two factors as fundamentally different:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. (UPIAS, 1976:4)<sup>11</sup>

---

<sup>10</sup> The British social model is not alone in stressing the societal and contingent aspects of disability. Shakespeare and Watson (2002) observe that theorists outside the UK such as Hahn (1985, 1988), Albrecht (1992), Amundsen (1992), Rioux and Bach (1994), Davis (1995) and Wendell (1996) have also explored important social, cultural and political dimensions of disability, identifying a family of social models. However, the authors also note that ‘none have made the firm distinction between (biological) impairment and (social) disability which is the key to the British social model’ (Shakespeare and Watson, 2002: 4).

<sup>11</sup> Subsequently, some have modified and reconnected impairment and disability, adopting this social model in a less radical form (for example, Crow, 1992).

In this way, disability and impairment are represented as qualitatively different. Disability is socially contingent; dependent upon the economic and social ferment within which it is found, rather than resulting from the biological impairments an individual may possess or experience.

Where medical perspectives site the origin of expertise on a disabled body within a professional and institutional sphere, the social model places disabled people at the centre of knowledge about disability. By locating the origin of disability in society, the social model directly challenges individual and medical understandings, but also tragic and charitable perspectives. In this way the UPIAS definition demanded social change, becoming a rallying point for disabled people's organisations. Disability was no longer about medical misfortune; it was about oppression, segregation, rights and the need for change.

### **3.1.2 Postmodern and Poststructuralist approaches**

Poststructural and postmodern positions frequently draw on the work of the theorists Foucault and Derrida. Both theorists critique the hierarchic relations of power and knowledge that produce the 'Other', the subordinated and marginalised subject of difference. Each offers differing methods of deconstruction that can intervene in this process of production, and hence, the exercise of power. Together, their works have been progressed to locate disability within linguistic, discursive and cultural practices (for example, Thompson 1996, 1997, Allen 2008, Fox, 1993; Reeve, 2002; Tremain, 2005).

Foucauldian thought has gained significant traction amongst those seeking to characterise the disability in terms of power rather than biological function. Foucault defines mental illness (1975) and deformity (1999) amongst other forms of ascribed social deviance as social constructs generated by an increasingly moralistic and institutional social order, founding the notion of the 'Other' and the basis for many poststructuralist interpretations of non-normative embodiment. Foucault conceives the rise of medicine as the emergence of a new empirical system. This 'birth of the clinic' (Foucault, 1973) marks a seachange in epistemology, rather than the simple accumulation or progression of medical knowledge. In brief, medicine has become a way of organising knowledge that in turn mobilises medicine as an organising

structure; an institution and a totalising discourse. According to this line of thought *both* disability and impairment have an arbitrary association with the ends they describe, being prerogatives of power, rather than neutral descriptors.

Derrida is similarly focussed on the ‘Other’ in hierarchical oppositions, expressing a call to ‘overturn the privilege of the high side and celebrate the secondary, derivative, low side: the supplement’ (Boyne, 1990: 127). His works also seeks to disrupt familiar certainties, and attacks the structurality that characterises the Marxist and positivist fundament of the social and medical models respectively, identifying these positions as logocentric – dependent on the notion of a pre-existent grounds or foundation which is ever-needed but never present (Derrida, 1997). In light of this deconstructive position, the social model of disability represents a disruption to medical ways of knowing, nonetheless, ‘the social model – in spite of its critique of the medical model – actually concedes the body to medicine’ (Hughes and Patterson, 1997: 329). Whilst the social model asserts disability as a social phenomenon, inverting medical principles, the introduction of impairment displays a materialist fundament:

...there is a powerful convergence between biomedicine and the social model of disability with respect to the body. Both treat it as a pre-social, inert, physical object, as discrete palpable and separate from the self.  
(Hughes and Patterson, 1997: 329)

In this respect, both the social and medical models of disability adopt a binary, Cartesian understanding of the human constitution. In these terms ‘the definition of impairment proposed by the social model of disability recapitulates the biomedical ‘faulty machine’ model of the body’ (Hughes and Patterson, 1997: 329). As such, the social model is an adjunct to the medical model, rather than its successor.

Poststructural analyses seek to fundamentally disrupt Cartesian binaries *and* their underlying epistemological assumptions, noting that both the social and the medical model of disability presuppose an ‘ahistorical standpoint from which to understand the human mind, knowledge, society and history’ (Corker and Shakespeare, 2006: 5). This suggests a pre-existing ground or centre that somehow escapes the structurality

described. For Derrida, this is the 'ultimate referent', a paradoxical contradiction, since reality can never be known in an unmediated, pre-discursive form.

In contrast, poststructuralism asserts that no single structural account (social or medical) can be held to be universal. This foregrounds pluralistic, situated understandings of disability that reflect different locations and histories, fundamentally rejecting the meta-narratives of 'grand theories' and totalising systems. In this way, poststructural approaches undermine, decentre and subvert dominant systems of knowledge. Both Derrida and Foucault share an anti-foundationalist stance. They refute traditional claims for the existence of self-evident foundations that guarantee the validity of knowledge, truth and meaning (Abrams, 1999).

Derrida's methods of deconstruction have an applied legacy for disability studies, focussing on internal contradiction and seeking to 'twist free of the containing effects of both essentialism and conventionalism' (Caputo, 1997: 103). This deconstruction requires hyper-vigilance; it is a 'philosophy of hesitation' (Critchley, 1999) directed at 'decidability' and interrupting closure. It is only when this anti-categorical lens of undecidability is acknowledged, and brought to bear on the praxis of disability, that ethics and politics can begin (Derrida, 1992a, in Allen 2008).

Through deconstruction, notions of disability and impairment have been shown to be unstable. Questions such as 'where does impairment end and disability begin?' are seemingly unanswerable, foregrounding the insecurity of these notions. Indeed, for Shakespeare and Watson (2002), disability is the quintessential postmodern concept, because it is 'so complex, so variable, so contingent, so situated' (2002: 19). They continue:

It [disability] sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality. (Shakespeare and Watson, 2002: 19)

As Haraway has also observed, the 'leaky distinction' between human and machine also deserves a place within this list of intersections:

Late Twentieth Century machines have made thoroughly ambiguous the difference between natural and artificial, mind and body, self-developing and externally designed, and many other distinctions that used to apply to organisms and machines. (Haraway, 1997: 475)

When concerned with the potential impact of networks and technologies upon identity, the disintegration of such dichotomies appears directly opposed to the categorical and definitive demands of research and policy. Critically engaging with the nature of categorisation itself allows us to make some progress in this analysis. In these terms, Derrida's deconstruction can be applied to problematise knowledge, however, this deconstruction has been strongly criticised on the grounds that, as a tool, it lacks the defining properties that are essential to effecting change.

Within disability studies this is where the application of Derrida's poststructuralism cedes significant ground to Foucault. Both theorists examine difference to explore meaning and possible meaning, however, their deconstructive methods are dissimilar. For Foucault, the Other expresses a new realm to be explored, whereas Derrida attacks this aspiration to 'know difference in its pre-rational purity' as impossible and utopian (Boyne: 1990: 167). This opens Derrida's stance to charges of relativism.

Foucault's approach is arguably more radical, highlighting the discursive assemblages in which the subjugated and subterranean discourses of the Other can be mobilised. Within this frame of reference 'norms' cannot necessarily be extinguished, but they can be made to be more inclusive and generous. In addition, Foucault offers the most complete and applied analysis of power with relation to difference, the body and the social science project. It is this analysis which opens a new critical vista onto the categorical pragmatics of both the social and medical models in action. It is to this critique, and the articulation of alternative ontologies of disability in action, that I now turn.

### **3.1.3 Difference, Knowledge and Power**

The material significance of medical and social approaches to disability lies in their *juridical* application; their confluence with policy and the dominant organising systems of knowledge that shape our day to day lives.

Many proponents of the social model are keen to point out that the social model is a model, not a theory, ideology or concept (Finklestein, 2005; Oliver, 2005). Oliver and others stress that the social model is a tool, and that, as a tool, the social model has proven itself to be a powerful political catalyst. The social model-as-tool launches a strategy for social change. By identifying the locus of disability within society, rather than the individual, an emancipatory agenda is inducted. Society must identify and dismantle socio-structural barriers to participation. By identifying society's disabling role, the social model has arguably put in train a trajectory of change culminating in the Disability Discrimination Act (1995, 2005). Such moves have ostensibly inscribed the rights of disabled people at the heart of the UK statute, investing an agenda for social transformation.

The strength of the social model lies in its ability to differentiate. It is increasingly 'used by the disabled people's movement to distinguish between organisations, policies, laws and ideas which are progressive, and those which are inadequate' (Shakespeare and Watson, 2002: 3). In this sense, it has become the 'ideological litmus test of disability politics in Britain' (Shakespeare and Watson, 2002: 2). This apparent simplicity lends itself powerfully to policy, as does the social model's sequestration of the body and impairment to medicine. The utility of the social model cannot be ignored in terms of research, as adopting a social modelist approach would have immediate and effective methodological implications.

A poststructural intervention which problematises the boundaries of disability and impairment, disabled and non-disabled, potentially complicates practice, but motivates new lines of enquiry. As Shakespeare observes, a postmodern approach opens a focus on the cultural construction of embodied experience that can map socio-political arrangements whilst articulating the practical dimensions of disability as a facet of life (Shakespeare, 2006). In addition, poststructural analyses identify grey-areas that bear investigation, attending to nuance. As Thomas states in her exchange with Corker:

In their attempt to distance themselves completely from the 'impairment causes disability' stance of the individualistic or medical model of disability,

most social modellers have paid insufficient attention to the ways in which different forms of impairment come to be associated with different forms or manifestations of disablism. (Thomas and Corker, 2002: 20)

In this way, Thomas calls for impairment to be addressed more centrally in disability studies, identifying *impairment effects* as a frequent medium for the enactment of socially exclusionary and discriminatory practices.

Shildrick (2005) goes further, however. Her analysis identifies a crucial antagonism between deconstructive and social modeller principles, highlighting how the legislative and policy affinities of the social model expose it as part of a system of domination:

The deconstruction of normativities, which is strongly but differentially linked to the work of both Foucault and Derrida, continues to theoretically ground transgression not in the self-regarding play of cultural rebellion, but in a deadly struggle against what manifests, above all, as the force of law. (Shildrick, 2005: 30)

Medical, juridical and governmental forces converge to institute disability, conveying what Foucault calls *biopower*.

Decentralised biopower becomes the principle instrument of regulation, supported by an inescapable system of normativities that both constitute and categorise embodied subjects. (Shildrick, 2005: 31)

The medical epistemology that has come to dominate knowledge of the body is related to emergent late 18<sup>th</sup> Century statistical accounts measuring birth and death rates, fertility and so forth. In this way a general population is conceptualised, and simultaneously subjected to a 'principle organising binary' of 'normal and abnormal' (Tremain, 2005: 32) systematically applied to entire populations for the first time.

For the past two centuries... a vast apparatus, erected to secure the well-being of the general population, has caused the contemporary disabled subject to emerge into discourse and social existence. (Tremain, 2005: 5)

In this way, Foucault argues that the law is increasingly invested with norms, and increasingly operates *as* a norm (Dean 1999: 188). The social sciences are implicated at the heart of *biopower*, underpinning this normative and juridical practice.

[A] power whose task is to take charge of life needs continues regulatory and corrective mechanisms... such a power has to qualify, measure, appraise, and hierarchize, rather than display itself in its murderous splendour; it does not have to draw the line that separates the enemies of the sovereign from his obedient subjects... it effects distributions around the norm... [T]he law operates more and more as a norm, and ...the juridical institution is increasingly incorporated into a continuum of apparatuses (medical, administrative, and so on) whose functions are for the most part regulators. A normalising society is the historical outcome of a technology of power centred on life. (Foucault, 1978: 144)

The statistician and social scientist are implicated within this web of power as part of the regulatory mechanisms that forecast, measure and maintain an equilibrium concerned with norms (Tremain, 2005:5). Grouping, coding, classifying, standardising and generalising are key parts of the social science project. Implicitly, a classification system segments the world for a purpose. The idea of ‘social divisions’ is one of the most useful and powerful tools available’ (Payne, 2000: 1). In the case of disability, the intervention of sorting, classifying and dividing is frequently legislative or bureaucratic. Foucault argues that this is not a *casual* relationship, it is *causal*. In this way, biopower and its judicial mechanisms enact disability as a resolute Other, constituted wholly in terms of deficit and deviance from an increasingly axiomatic, unquestioned norm. The social model, in its project of barrier removal, does nothing to challenge the notion of physical deficit as the root cause of disability. As a result, as Tremain asserts: ‘it would appear that the identity of the subjects of the social model [...] is actually formed in large measure by the political arrangements that the model was designed to contest’ (2005, 10). In light of this, grounding research within a social modelist perspective could inadvertently extend those arrangements (Tremain, 2001, 2002).

On this basis, I propose a post-structuralist account of disability within my project. In this respect, disability represents a ‘complex and contested socio-political space’

(Goggin and Newell, 2005:276) constituted by discourses (Fulcher, 1989). However, it is important to recognise that this position is not without its critics.

### **3.1.4 Critiques of Foucauldian Poststructuralism**

Poststructuralist positions have been roundly criticised on essentialist and reductionist charges. A foremost concern is that poststructuralist accounts of disability replace biological essentialism with discursive essentialism; poststructuralist perspectives once again ‘annihilate the body’ (Hughes & Patterson, 1997: 333). As Hughes surmises, ‘if language is to be reduced to its effects, as poststructuralists contend, then even somatic sensations like pain [...] are primarily discursive products’ (Hughes, 2004: 65). They argue that this returns us to the relative impasse of visceral experience and the neglected body. In extension to this, Hughes (2005) strongly criticises Foucault for underestimating the body as agent of self- and social transformations. Hughes (2005) contends that Foucault stands outside the phenomenologically-informed stances recognising body-as-subject (Crossley, 2001) and the body as the material source of self and culture (Csordas, 1994), ‘thus he cannot theorise, or appreciate the ways in which ‘practical sensuous activities constitute social life’ (Hughes, 2005: 80). Hughes argues that whilst ‘one should not reduce disability activism to the intentions of atomic disabled actors, it is equally misguided to reduce it to the disembodied play of discourse.’ (Hughes, 2005: 80). This is a salient point that has led to critical realists striving to reconcile mind and body, discursive and material, culture and nature within disability studies.

Aside from this concern with embodied experience, Hughes’ arguments also raise the issue of individual agency within discursive practices. Medical, social and poststructural models of disability arguably mark a foreclosure on individual agency, with people being conceived as predominantly subject to social forces, rather than protagonists in their own lives. Foucault attends to this issue of agency (rather than resistance) in his later works concerning ‘technologies of the self’. At this point in my project, however, a third concern is more immediately pressing. From outside Disability Studies, information scientists and other post-positivists and make a strong

critique of critical and poststructural positions on disability difference and identity. As Bowker and Star (1999) observe:

Despite the contentiousness of some categories, [...] none of [the critical] disciplines or social movements has systematically addressed the pragmatics of the invisible forces of categories and standards in the modern built world, especially the modern information technology world.  
(Bowker and Star, 1999: 5)

The authors cite Foucault's exploration of 'the concept of order and its implementation in categorical discourse' (Foucault, 1970: 5). They argue that Foucault's expositions in *The Order of Things* (1970) and *The Archaeology of Knowledge* (2002) do not 'systematically' answer the question of how processes of discrimination and categorisation inform our day to day lives in modern information economies.

This assertion exposes two diametrically opposed points. Firstly, information management seeks neutral language, whereas critical discourse exposes all knowledge as partial. When Bowker and Star request a 'systematised' account of discrimination, they fail to comprehend Foucault's poststructuralist project to *disrupt* systems of knowledge. Secondly, perhaps more precisely, however, Bowker and Star imply a more fundamental question: How can difference be managed, if not through hierarchical ordering? What is the alternative? What does a post-hierarchical politics look like?

To this end, Foucault supplies two strategies, amongst wider theorisations into the relations of knowledge and power. Firstly, researchers must agitate on the behalf of marginalised groups, lending weight to disparate voices whilst supporting the group as a whole (Boyne, 1999). This simultaneous recognition of difference and identity requires an 'ethics of subjectivity' through which researchers 'disencumber themselves from dominant social interests and redefine their role as supporters rather than leaders'.

This might be seen as the personal-political corollary of deconstruction in so far as it involves the overturning of the personal priorities which are encouraged within hierarchical society. (Boyne, 1999: 133)

The second strategy derived from Foucault and involves a ‘watching brief on the modes of socialization: it involves continuously asking if they are changing and how they are changing’ to seek the formation of new, better adjusted forms of social subjects (Boyne, 1999: 134). It is here, where Derrida rejects the definition of a deconstructive method<sup>12</sup>, that Foucault offers a middle way to those reflexively negotiating power and knowledge-making in research.

To move forward towards a post-hierarchical project, I take up a deconstructive, poststructural stance to elaborate the interests at stake in particular kinds of knowledge and social action, as part of my own reflexive commitment to practical ethics. I adopt a Foucauldian perspective to examine what categories do within my field of research, to clarify what they legitimate and what they imply. I adopt a watching brief concerned with the emergence of new practices of self with new technologies, and consider the context of definition this take place within. This Foucauldian intervention is modified with an additional sensibility adopted from Derrida, concerning a reflexive dedication to ‘undecidability’ (Allen, 2008). This ‘undecidability’, is an ongoing critical commitment that seeks to ensure ethical choices are not foreclosed as a result of structural instinct or predilections.

In the next section I use this lens to explore representations of disability that are active within higher education and scrutinise the project of differentiation, of coding and categorisation. I use this discussion to evaluate and synthesise an epistemology informed by poststructural understandings of disability that best match the empiric, practical and ethical requirements of doctoral social research. This epistemology is closely bounded within a poststructural *practical ethics*. This aims to explicitly delineate disability in the terms of the research context, its location and particular aims, rather than a fixed universal approach. In this way, I acknowledge my route into the distinctions of disabled and non-disabled, impaired and non-impaired as a single perspective on a diverse emergent territory.

---

<sup>12</sup> ‘The function of deconstruction is to interrupt closure and certainty within texts and to create undecidability about their meaning and intent’ (Allen, 2008: 73). In this sense, moving beyond Derridean hesitation and intervention is necessarily uncertain.

### **3.2 Categorising Disability in Higher Education**

To appropriately code and understand the impact of coding in research such as this, it is useful to consider the practice and coding already taking place within higher education and research. This supplies some insight into the discourses and practices at work, as well as guidance to formulating an epistemology. However, in categorical discourse disability and impairment represent heterogenic and diverse categories. Impairments themselves may be congenital, acquired or temporary, with different implications for self-identity. Shakespeare and Watson outline impairment in the following way:

Analytically, it is clear that different impairments impinge in different ways. That is, they have different implications for health and individual capacity, but also generate different responses from the broader cultural and social milieu. For example, visible impairments trigger social responses while invisible impairments may not - the distinction which Goffman (1968) draws between 'discrediting' and 'discreditable' stigma. [...] Some impairments are static, others are episodic or degenerative. Some mainly affect appearance, others restrict functioning. All these differences have salient impacts at both the individual and psychological level, and at the social and structural level. This is not an argument for disaggregating all disability, and referring solely to clinical diagnoses, but for recognising that the different major groupings of impairment, because of their functional and presentational impacts, have differing individual and social implications. (Shakespeare and Watson, 2002: 12).

As an aggregate, the complexity of dis/ability and impairment resists categorisation. Each are invoked with a reference to a scale or a hypothetical norm, indicative of empirical value systems. Attention to post-positivist accounts of categorisation sheds light on these values.

According to Bowker and Star, classifications are 'boundary objects'. They are 'objects for cooperation across social worlds' (1999: 15). Importantly, Bowker and Star do not identify the claims for neutral knowledge that are implicit within these systems. They assert that they are more interested in what categories *do* in any given environment. In disability studies, divisions and hierarchies of impairment and disability have been scrutinised. For example, Vernon and Swain (2002) consider

disability within the wider matrix of situated identity, multiple oppression and other 'component identities' (Vernon and Swain, 2002: 79) reviewing intersections with ethnicity, gender, sexuality, and class. As the 'Other' of the 'Other' (Wendell, 1996), disabled people are frequently aware of the ways in which mainstream culture situates disability as a minority interest amongst other marginalised groups. However, whilst the boundaries and hierarchies of disability and impairment are contested, scrutiny of the *activity* of applying such boundaries is less well understood. Since the action of classification frequently results in the substitution of precision for validity (Bowker and Star, 1999) and the exercise of power (Foucault, 1972), this a key research concern.

The act of classification implies three key elements:

1. That there are underlying principles to the classification,
  2. That the categories in operation are mutually exclusive, and
  3. That the system is complete.
- (Bowker and Star, 1999: 10;11).

In practice it is difficult for any system of categorisation to meet these criteria. A clear case of the problem of meeting these criteria in the real world is the categorisation of impairment currently articulated by the UK Universities and Colleges Admissions Service in Higher Education. In higher education, the influence of categories and the models of disability that they convey, highlight how such categories permeate my study as the benchmark of research activity in disability and higher education.

In higher education, categories of disability are applied by the Higher Education Statistics Agency (HESA) and the Universities and Colleges Admissions Service (UCAS). Both HESA and UCAS apply a taxonomy of disability in their data collection.

Taxonomy is a system for naming and organising any phenomena into groups on the basis of similar characteristics. Thus the taxonomies of disability bear consideration as they introduce the working conceptions of impairment that students must navigate in their transition into higher education. These taxonomies also represent the

foundation of the quantitative data that serves as a baseline for the majority of qualitative and quantitative disability research in higher education. Furthermore, the HESA and UCAS taxonomies demonstrate the real-world challenges of defining disability. In the following discussion I evaluate and deconstruct the HESA/UCAS taxonomies, leading to an examination of alternative, ethical and pragmatic modes of classification.

### **3.2.1 Counting Disability**

Fuijura and Rutkowski-Kmitta observe that counting is a necessary enterprise for governments, policy makers, social scientists and disabled people (Fuijura and Rutkowski-Kmitta, 2001). According to their argument, regardless of debate, institutions such as universities and government need to identify and count disabled people to make appropriate provision and make the environment more accommodating. In higher education, ‘disability’<sup>13</sup> is counted for three stated purposes; as part of the admissions procedure to ensure that students receive the appropriate services and support, for research analysis and as part of equal opportunities monitoring. Within these terms UCAS publish data relating to the annual number of applicants and accepted applicants to its member institutions. The data is collected from the application forms completed by applicants online. Provision of information on disability is voluntary and applicants are advised they may choose only to inform the institutions to which they apply directly. Disability data is available only for home (UK domiciled) applicants on full-time undergraduate courses.

HESA maintains staff and student records for all UK Higher Education Institutions. The HESA student record includes information on self-reported disability; as with the UCAS form, this is broken down into a list of impairment types. It also contains information on the number of students that report receipt of Disabled Students’ Allowances (DSAs) to their institution. HESA monitor ethnicity and disability at the request of the funding councils, for government. They state that data is collected:

---

<sup>13</sup> Both HESA and UCAS conflate disability and impairment.

To permit disability-based analysis; for monitoring levels and trends in participation by particular groups of people;  
To monitor take-up of Disabled Students' Allowance as Disabled Students' Allowance is now not means tested;  
To permit analysis based on type of disability. (HESA, 2008)

### **3.2.2 A Medical Base-Line**

The UCAS and HESA models of data collection have been criticised from both positivist and interpretive positions. This controversy centres on self-reporting and medical criteria underpinning the category of disability.

Currently all students are asked to disclose any disability on their UCAS form. The categories available (see figure 3-1) are individual and medical. As the UCAS form potentially constitutes the first act of disclosure upon entering higher education, this model is iterative. Researchers concerned with the impact of such a model on student self-identity observe that these administrative arrangements 'promote a medicalised concept of disability' (Riddell et al., 2005). Students are encouraged to consider themselves in categorical and deficit terms:

In order to claim legal protection or state benefits, the disabled student must locate themselves within such a definition, thus implying a degree of acquiescence. (Riddell et al., 2005: 17)

Thus the dichotomy of disabled/non-disabled begins to shape not only the resources and support available to a student, but also the self-identifications they must undertake. For some statisticians, however, this measure of disability is not medical enough. With respect to the HESA data, a DIUS report complains:

[...] disability is self-reported so it will suffer from the same weakness as the UCAS data, and it becomes virtually impossible to disentangle changes in the numbers of students reporting a disability from actual changes in the proportion of students who are disabled. (DIUS, 2009: 43)

In this way, DIUS suggest a discrepancy exists between the number of students self-reporting a disability and the 'actual' proportion who are disabled. In addition, the equation of disability with medical deficit is marked in this statement. Not only do

the authors assume that impairment is a stable property of the individual, they also use medical terms to describe statistics; Self-reported HESA codes ‘suffer’ a ‘weakness’. In this respect, DIUS not only conceive disability as a medical deficit, they imbue their statistical language with this medical deficit perspective. In Foucauldian terms, this is indicative of the Clinic’s continuing and totalising dominion over statistical process.

Subsequently, DIUS state a preference for HESA measures that indicate a student is in receipt of Disabled Students Allowance (DSA):

DSA receipt is considered the more robust of the HESA disability indicators and is used in their performance indicators. (DIUS, 2009: 43)

Financial support in the form of the DSA is dependent upon professional medical and psychological assessment. In this way, statisticians privilege medical systems of knowledge above personal judgements. The ‘fact’ of disability is conceived strictly as a matter of medical expertise, rather than social ascription, conveying the ‘ideological doctrines of disembodied scientific objectivity’ (Haraway, 1988: 576) critiqued by Haraway (1988), Harding (1986) and others. Such ‘objective’ requests appear impossible to reconcile with the situated knowledges sought by Riddell et al., (2005) and others. These diverse perspectives on the same act of disclosure demonstrate the disparate research communities this dataset serves and highlights disability as the site of multiple discursive interactions and controversies.

### **3.2.3 HESA and UCAS Definitions of Disability**

HESA’s categories of disability are not based upon any recognised national framework, although HESA state that, where frameworks are recommended or nationally appropriate, they are adopted. HESA could seek to shortcut the taxonomy development process by adopting an external taxonomy wholesale. However, the lack of an equivalent taxonomy highlights the general lack of progress in this area across government departments.

Since HESA inherit much registration data from UCAS, their categories are broadly similar, reflecting some dependency upon UCAS, and a close association between

the two agencies. However, over the last decade HESA's categories have developed in-house with some incremental changes that reflect wider developments in discourse around the nature of disability. This adaptation has been positive in terms of better reflecting HEIs' calls for appropriate measures; however, this has also led to instability in the way in which disability is recorded between agencies, highlighting more fundamental challenges in the ways in which impairment is coded.

Ramsden (2005) has concluded that attempts to assess formal participation rates for disabled students are compromised by four factors. To paraphrase:

- There is no generally recognised definition of disability, and no general taxonomy of subsets of disability.
- Disability within population statistics is essentially self-assessed
- The coding frames which are used in national statistics and higher education statistics are significantly at variance.
- Within the Higher Education constituency, there is no consistency of definition as between the HEIs and the Further Education Colleges which provide Higher Education courses (Ramsden, 2005: 37)

The lack of a generally recognised definition reflects a slow aggregate of perspectives. The HESA/UCAS codes function most precisely as a nomenclature, an agreed naming scheme that attempts to answer the requirements of the bodies and organisations involved in its use. In this sense, whilst all prospective students are bound to disclose themselves as either disabled or non-disabled according to the categories presented by UCAS, the nomenclature in use does not function universally. In reality it serves the dominant community of practice and is organised by university work requirements. This aggregate of perspectives is set to be radically altered as these measures are in the process of being revised. However, this revision sheds further light on the problem of definition.

For the 2010 cycle, the disability descriptors used by UCAS will change, with new codes being introduced. These codes are shown alongside examples of coding schemes for previous years in figure 3-1. UCAS cite this as aiming to bring the list

more in line with Equality and Human Rights Commission guidance. Indeed, the codes have been drawn up in consultation with HESA and SKILL (the National Bureau for Students with Disabilities). The new codes have been trialled with academic staff for the academic year 2008-2009, marking a departure from previous piecemeal approaches, to determine a more effective coding of disability.

The new codes (figure 3-1) demonstrate an attempt on by the coding body to more precisely describe and itemise impairments. Some nuance is introduced: however, a medicalised view is still clearly evident. HESA's projected approaches to coding student disability double the opportunity for self determination. More than one disability can now be reported over two coding opportunities. Not only are the categories more nuanced in comparison to previous codes, they are more clearly defined and, more importantly, allow those with multiple impairments to more fully describe those impairments that tangibly affect their lives.

As a hierarchical representation of disability, these categories are weighted to recognise multiple impairments more fully (by allowing a person to report more than one impairment across two codes). Neurodiversity is also more broadly and precisely recognised; 'general learning disability (such as Down's Syndrome)' has been added, recognising the place of people with learning disabilities other than dyslexia and dyspraxia in higher education. Illness and health conditions such as cancer are reflected, in keeping with the DDA's (2005) expanded definitions of disability. Description has been added to each option to give definition to the categories. The language of the categories also seeks to recognise the complex nature of disability. In HESA's trialled model 'a disability not listed above' has been replaced by 'other type of disability' expressing a less singular and itemising taxonomy. Conversely, the use of 'serious' rather than a less emotionally weighted term such as 'significant' potentially projects a tragic model of impairment onto the individual.

UCAS disability and impairment codes, 2007-2008:	HESA student codes, 2007-2008:	Proposed HESA codes trialled with academic staff, 2008-2009:	
<p>0 None</p> <p>1 Specific learning difficulty (e.g. dyslexia)</p> <p>2 Blind or Partially Sighted</p> <p>3 Deaf</p> <p>4 Wheelchair or Mobility Difficulties</p> <p>5 Autistic Spectrum Disorder or Asperger's Syndrome</p> <p>6 Mental Health Difficulties</p> <p>7 Unseen Disability (e.g. diabetes, epilepsy, heart condition)</p> <p>8 Two or more of the above</p> <p>9 Disability, special need or medical condition not listed above.</p>	<p>00 No known disability</p> <p>02 Blind/partially sighted</p> <p>03 Deaf/hearing impairment</p> <p>04 Wheelchair user/mobility difficulties</p> <p>05 Personal care support</p> <p>06 Mental health difficulties</p> <p>07 An unseen disability, e.g. diabetes, epilepsy, asthma</p> <p>08 Multiple disabilities</p> <p>10 Autistic Spectrum Disorder</p> <p>11 A specific learning difficulty, e.g. dyslexia</p> <p>96 A disability not listed above</p> <p>97 Information refused</p> <p>98 Information not sought</p> <p>99 Not known</p>	<p><b>024: Disability 1</b></p> <p>00 No known disability</p> <p>51 Specific learning disability (such as dyslexia or dyspraxia)</p> <p>52 General learning disability (such as Down's syndrome)</p> <p>53 Cognitive impairment (such as autistic spectrum disorder or resulting from head injury)</p> <p>54 Long-standing illness or health condition (such as cancer, HIV, diabetes, chronic heart disease, or epilepsy)</p> <p>55 Mental health condition (such as depression or schizophrenia)</p> <p>56 Physical impairment or difficulty using arms or using a wheelchair or crutches)</p> <p>57 Deaf or serious hearing impairment</p> <p>58 Blind or serious visual impairment</p> <p>96 Other type of disability</p> <p>97 Question not answered</p>	
<p>025: Disability 2</p> <p>51 Specific learning disability (such as dyslexia or dyspraxia)</p> <p>52 General learning disability (such as Down's syndrome)</p> <p>53 Cognitive impairment (such as autistic spectrum disorder or resulting from head injury)</p> <p>54 Long-standing illness or health condition (such as cancer, HIV, diabetes, chronic heart disease, or epilepsy)</p> <p>55 Mental health condition (such as depression or schizophrenia)</p> <p>56 Physical impairment or mobility issues (such as difficulty using arms or using a wheelchair or crutches)</p> <p>57 Deaf or serious hearing impairment</p> <p>58 Blind or serious visual impairment</p> <p>96 Other type of disability</p>	<p>(HESA, 2008)</p>	<p>(HESA, 2009b)</p>	
<p>(Sheffield Hallam University, 2009)</p>		<p>(HESA, 2009)</p>	<p>(HESA, 2009b)</p>

Figure 3-1: UCAS and HESA Coding by Disability

### 3.2.4 Shifting Conceptions of Disability

When we return to the three elements of classification identified by Bowker and Star it is clear that HESA's data collection fails to meet core criteria according to its own taxonomic standards. The system did not appear complete, even on its own terms. Many of the categories in operation were mutually exclusive – aside from multiple impairments, overlaps are evident. In previous years (2004/2005), DIUS observe that:

it would appear that there is some overlap between the HESA (“Unseen” + “Dyslexia” + “Other”) categories and the UCAS (“Unseen” + “Dyslexia” / “Learning Difficulty” + “Other”) categories. (DIUS, 2009: 43)

Importantly, these three categories accounted for approximately 82% of all reported impairments on both datasets at that time (2004/05 data). It is not surprising that the code for ‘unseen’ impairments has been identified as the most problematic for statisticians. ‘Unseen’ as a code, inherently acknowledges the social ascription of disability based on how an individual is visibly perceived, rather than identifying how an impairment might medically manifest itself. This coding move implicitly acknowledges social notions of stigma and visibility as disabling. However, whilst the new codes make better medical sense and seeks to disrupt a social hierarchy of visible and invisible disability, a social understanding of disability is arguably further marginalised. Medicine still gives the greatest semblance of the most complete system of impairment and disability. As such, medical expertise will remain the organising principle bounding of disability.

In tracing the emergence of discourse of knowledge within the sciences, Foucault distinguishes *levels of emergence* of any given discursive formation (1972: 186). Two have relevance for the case in point.

The first level is the *threshold of positivity*. Which refers to the point at which a discursive practice achieves individualist and autonomy, the moment when a single system of the formation of statements is put into operation (1972: 186) (in Olssen, 1999:27)

A *threshold of epistemologization* pertains to the point when, in the operation of discursive formation a group of statements is articulated and claims to

validate (even if unsuccessfully) norms of verification and coherence, and when it exercises a dominant function over knowledge

A threshold of *scientificity* is crossed when a discursive system obeys formal criteria and when its statements comply with the laws and rule for the construction of propositions and so on (1972: 187)

And a threshold of *formalization* is passed when a scientific discourse is able, in turn, to define and proscribe axioms necessary to it, the elements that it uses, the propositional structures that are legitimate to it, and the transformations that it accepts (187)  
(Olssen, 1999: 27)

At this moment of reconfiguration, the HESA categories of disability seemingly move from the threshold of epistemologization to a threshold of scientificity, seeking to meet formal criteria and comply with both medical and social policy formulations of disability. In this respect, it passes closer to invisibility – as new definitions of disability cease to be so problematic, and defer more readily to increasingly axiomatic conceptions of impairment. Shildick observes that such defining acts produce the disabled body:

Although in the very act of designation, the disabled body is produced in multiple ways – as blind, as mobility impaired, as congenitally or accidentally deformed, each with its own specificities and norms – transgressive possibilities ... seem reduced to conformity and docility. (Shildrick, 2005:36)

In short, the specific extension of recognition and rights accruing to disability is not an unproblematic good, it is also an intensification of the disciplinary grasp of bio-power.

As we have seen, the taxonomies of UCAS and HESA data collection demand student acquiescence. However, whilst these remain medical and individual, consultation with SKILL and the DRC means that disabled people have themselves had an opportunity to represent their views in the creation of the measures. This accounts for the use of the social model language of impairment and recognises the importance of the measures in the juncture of student identity.

Importantly, acquiescence can serve a dual function. Whilst a taxonomy might colonise an individual, reinforcing medical models, it may also scaffold a new perspective. This to some extent explains the confusion of language evident within the measures, ‘specific learning difficulties’ is at once medical, but also gestures to students’ experiences in high school and college. In this sense, the new measures are evidence of an attempt to scaffold new students’ perspectives on impairments and disability from Special Needs high school and college discourse into impairment specific language that seeks to acknowledge the social model of disability. In this respect, the UCAS categories are predicated upon the fact that people frequently subvert formal category schemes, using work-arounds (Atran, 1990) and combining them with informal, vernacular (folk) classifications (Bowker and Star, 1999: 54). This lends another tier of complexity to the question of what constitutes disability difference.

A statistical analysis observes HESA data is not perfect. Only students disclosing on the UCAS form or at registration are recorded. Currently, if a student develops, discovers or discloses a disability in the course of their studies, their presence in the cohort is not currently recognised. Further students will be omitted as they either do not wish to disclose a disability, or they simply do not identify with disability as an appropriate label for their experience. If we consider these factors in tandem with the Disability Rights Commission’s (DRC) previous assertion that 48% of people covered under the DDA (DRC, 2003) do not consider themselves disabled<sup>14</sup> it becomes clear that even a sensitive quantitative and categorical approach to assessing levels of disability must be laden with caveats<sup>15</sup>. Estimates based on any of these measures must be conservative. Nonetheless, the HESA data sets remain a key statistical indicator of disabled student participation in higher education in the UK.

---

<sup>14</sup> [http://www.publicservice.co.uk/article.asp?publication=&id=189&content\\_name=Human%20Resources&article=4676](http://www.publicservice.co.uk/article.asp?publication=&id=189&content_name=Human%20Resources&article=4676)

<sup>15</sup> Distance educator the Open University is not included amongst those institutions included in the disability data. Furthermore, HESA states that dormant students (those who have ceased studying but have not formally de-registered), visiting and exchange students, British students studying abroad, students on sabbatical and post-graduates in ‘thesis pending’ are all excluded from their research population.

HESA data will be presented in conjunction with the results of participant recruitment within this research (4.7.1). The limits of the HESA data must be acknowledged. However, in terms of establishing a base-line understanding of UK patterns of participation and levels of disability, it is hoped that, in conjunction with sound qualitative approaches, the HESA data will establish those representative characteristics of the research cohort.

In summary, taxonomies of disability have here been shown to have grouping power and explanatory power; however, these powers trade in validity at the expense of nuance and dialogue. Any taxonomy is influential, as it forces the participant to adopt the perspective of the taxonomy's designers. This reveals taxonomy to be both a measure and a way of forging views, for better or worse. Importantly, this proscriptive element can scaffold new understandings, articulating alternative approaches to disability.

Taxonomies exert power as they implicitly suggest a complete, conventional and common-sense system, even when they lack consistency. Often, real-world complexity is substituted for certainty, as categories become mutually exclusive and impermeable. This static quality is unhelpful.

### **3.2.5 Fossilisation and Looping Effects**

Taxonomies are static; they resist change due to the inertia of gradually accumulated and inherited systems. It is difficult for subsequent researchers to maintain the taxonomy as a reference point, whilst navigating grounded or contrary approaches. As more effective divisions are adopted, it seems clear that these too will be culturally and historically bound and subject to change. This highlights how quickly taxonomies 'fossilise' (Bowker and Starr, 1999). It also implies huge issues of data legacy for those trying to progress research based on, or relating to these categories, as well as for HESA itself as it attempts comparison year on year.

Importantly, Foucault observes an additional discursive taxonomic affect that renders taxonomies obsolete. He identifies how groups that are *juridically constituted*, respond and resist such labelling. Hacking (1995) progresses this notion with respect

to critical examinations of the bounding of autism, madness and multiple personality disorder. In his engagement with medical, juridical and psychiatric classifications, statistics and other social scientific measures, Hacking coins the term ‘looping effects’ (1995: 351) to describe the ways in which subject(s) re-mediate the power/knowledge dichotomy, by resisting or negotiating ascriptions and repositioning themselves as subjects. As Tremain summarises:

...the people who are classified as members of a kind come to have knowledge of the relevant kind, which changes their self-perceptions and behaviour, motivates them to forge group identities and often forces changes to the classifications and knowledge about them. (Tremain, 2005: 7)

In this respect, struggles over the boundaries of disability are ongoing as hierarchic taxonomies integrate new identifications and resistance.

### ***3.3 Expanding the Taxonomic Practices of Disability***

At best, taxonomies are intuitive and understandable, conventional, explanatory and principled. However, these implicit elements are not guaranteed. In the real world, such taxonomies are hard to design. This is particularly true of taxonomies of ‘disability’ for several reasons. Firstly, disability research can be complicated by the multiple functions the research is expected to perform for a multitude of stakeholders. Secondly, ‘disability’ as a research term appears deceptively straightforward, but within taxonomies of disability (or accessibility) it can in fact function as nomenclature, a tacitly agreed definition that in fact functions in different ways for different users.

Further challenges are that taxonomies are prescriptive; static, and mutually exclusive and express only a single point of view. Their enaction can lead to the creation of legacy effects that defy recalibration to ensure continuing effectiveness. They are also pedagogic and iterative, constituting a movement of power in the creation of knowledge.

Within a thesis, or any other static publication on disability, it becomes increasingly clear that mobilising a more nuanced approach to disability is essential to ensure the ongoing relevance and efficacy of that document, offering spaces that acknowledge the ‘undecidability’ of disability.

Two approaches emerge that engage core problems with defining disability. Both approaches attempt to account for the contingency of disability – the first using a relational appeal to context; the second using a form of faceting. The relational approach<sup>16</sup> is borne out of problems defining disability across context, culture and over time. This can be illustrated in policy in the UN Convention on the Rights of Persons with Disabilities. Faceting is an information architecture approach that incorporates multiple-perspectives, and, I will argue, an approach that aligns with post-structural principles of applied ethics.

### **3.3.1 Relational Taxonomies**

In policy, the problems of fossilising and looping effects have traditionally been addressed by repeated new iterations of disability legislation, drawing on consultation with disability groups. Notably, policy such as the UK’s Disability Discrimination Act (DDA) and equivalent legislation in industrialised nations such as the USA and Australia have all been amended over the course of their relatively short histories, to redefine who is considered disabled. For example, the UK DDA part IV (2005) extended the 1995 definition of disability to explicitly cover those with HIV, cancer and multiple sclerosis from the point of diagnosis<sup>17</sup>. Together, such policy revisions highlight disability as a rapidly evolving concept, just as the new iterations of HESA and UCAS code indicated.

To account for the diverse and shifting ascriptions and experiences that are circumscribed by ‘disability’, the UN Convention of the Rights of Persons with

---

<sup>16</sup> Barnes and Mercer (2010: 40-41) identify a relational or ‘relative interactionist’ approach to disability as a dominant Scandinavian model of disability.

<sup>17</sup> Likewise, the Australian DDA (1992) has also seen key amendments with implications for higher education. The Act’s definition of disability has been extended to cover behaviour that is a symptom or manifestation of the disability with the enactment of the Disability Discrimination and Other Human Rights Legislation Amendment Act (2009). In this respect, behaviour may be deemed an adjunct of an impairment and require ‘reasonable adjustment’ (AHRC, 2009).

Disabilities, explicitly recognises disability as contingent by refusing to define ‘disability’ at all. This move seeks to contest obsolescence between cultures and over time. The UN’s preamble sheds light upon the reasons for this refusal:

...disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. (UN, 2008)

...Consequently, the notion of “disability” is not fixed and can alter, depending on the prevailing environment from society to society. (UN, 2008b)

In short, the convention breaks with the instinct to define disability in fixed terms. Instead it acknowledges the multiple-perspectives and contexts in which disability will occur in constituting member countries. In this sense, the Convention aims to supply a relational notion of disability rather than a didactic, static and hierarchical taxonomy. This document marks a concerted attempt to move the conception of disability from the individual to the contextual level. This more nebulous approach to definition is useful to the present research.

Research is hierarchical, in the sense that, as research originates, someone must decide who qualifies as a participant prior to enabling or requesting other researchers/participants to respond to that category. In this sense, all research begins with a set of claims about the world. As I consider the boundaries of impairment and disability, the UN’s attention to a multi-perspective stance offers an approach that is contingent upon an interaction with context. This suggests that by explicitly recognising the limits of research design, the perspective of the researcher and the context of the investigation, disability may be defined actively within the research situation, rather than according to a predefined, research-side, universal measure. Such an approach represents a commitment to the recognition of disability in the circumstances in which it occurs, rather than pre-assigning a category in advance of data collection. An objection remains, however, that under this appeal to context disability-as-juridical deficit continues to be implied.

### 3.3.2 Faceting Approaches to Disability

Faceting articulates a poststructural understanding of disability. It asserts that an understanding of disability depends entirely on the activity undertaken and the perspectives of those involved. Whereas a fixed hierarchic or flat taxonomy defines a single perspective on a subject, facets allow multiple perspectives. They allow the features of a phenomenon to be bounded in an intuitive and explanatory way, supporting multiple roles and goals. So, just as an apple may be understood to be a 'fruit' rather than a 'vegetable', so it may also be understood to be organic, red or sweet. Each perspective on the subject (organic, red, sweet) represents a facet, dependent on context and perspective, in conjunction with the properties of the subject. According to this approach – the social model of disability could be seen as faceting the nature of disability, allowing it to be understood to address two perspectives, a social perspective on disability (as social oppression) and a medical/individual perspective on impairment (material aspects). Theoretical actions to augment understandings of disability appear to apply a different perspective onto the same phenomena. In this way, each perspective foregrounds different aspects of the issue. This has an explicit convergence with Corker's argument:

... 'social systems that are exclusively built on systems of classification – including both the socially created and the socially constructed classifications 'disability' and 'impairment' – are generally undemocratic, oppressive and exclusionary (Young, 1990; Butler, 1993).' (Thomas and Corker, 2002: 22, emphasis in the original)

Her emphasis states that as a universal system, categorical systems must be oppressive and exclusive. Any ethical theory of disability must therefore recognise multiple ways of being.

In seeking to recognise that there are multiple ways of knowing and ways of being, the research project is thrown into a new light. Necessarily this thesis can only recount the researcher's perspective on the research; however, the use of mixed methods alongside a transparent account of the research aims, motivations and context can go some way to negating the influence the research exerts as a creator of difference; presenting instead a detailed 'facet' of investigation that sheds light on

approaches and the relational discursive phenomena of disability. Already, in considering this approach, it becomes clear that a claim for positivism and objectivity maybe made. However, interpretive and critical facets should be possible, as long as the decision making process is laid bare and offered as situated and ongoing. Indeed, this faceting can allow the pragmatics of real world research to engage meaningfully with more ideological stances on disability in a transparent way.

When quoting Fraser and Nicholson (1990) Thomas and Corker establish that a feminist approach complements postmodern concerns:

...a critical synthesis of the postmodern deconstruction of monoliths and a feminist commitment to radical politics can provide the basis for a powerful social theory of disability that overcomes the limitations of the two. Such a critical synthesis indicates that the emancipatory project is based on active and engaged dialoguing across difference, not the suppression of difference. (Thomas and Corker, 2002: 22)

This approach is directly aligned with the situated postmodern approaches to ‘situated knowledges’ described by Haraway and other feminist writers. In this sense, there is a strong confluence between feminist methodologies and faceting as it is understood within information science, arguably mobilising “practical ethics”. If disability is considered in these terms, it becomes vital that the perspective adopted is matched to the circumstance under scrutiny.

### ***3.4 Faceting Disability in My Research Project***

In the UK the boundaries of disability are repeatedly defined and revised over the course of a student’s journey through education. The process of defining is a process of separation that echoes at the micro and macro level; whilst Inclusion agendas purport to bend the education system to the individual rather than the individual to the system, the category of disability implicitly expresses a discourse of ‘same’ and ‘Other’ that undermines inclusion (Florian, 2009). This returns us to Liggett (1998: 271), and the observation that the process of researching involves a representation of disability that enlarges its discursive practices.

To undertake research, a structure is established, either consciously or tacitly by the researcher. However, as the research proceeds this structure can be removed to allow the integration of other voices and the deconstruction of categories affected. This is not simply a pragmatic act. As Price and Shildrick (2002) argue:

The adoption of pragmatics alone, as though it closes the question of ethical, speaks to a denial rather than radical recognition of difference, a difference that is both multiple and irreducible. (2002: 73)

In short, to pursue a wholly pragmatic strategy of hierarchical definition, disavows difference and cleaves to the hierarchic norm. Shildrick (2005) argues that disability can never be resolved within epistemic frameworks, it is, in essence, anti-categorical.

Yet, if disability in its many forms always in some way transgresses the law, and frustrates social, cultural and legal normativities, then what will ground the ethical response and responsibility to the other who exceeds the confines of regulation? (Shildrick, 2005: 31)

Here, the insights of Derrida offer some respite. A significant critique of postmodernism is that, even where the deconstruction of conventional models of power and knowledge are well-founded, poststructuralism is unable to deliver an alternative ethical way forward (Paras, 2005; Price and Shildrick, 2002). Derrida answers this argument by stating that ethics itself must be rethought (Price and Shildrick, 2002). In response, Shildrick looks to Derrida's notion of a non-provisional, or radical 'hospitality', an ethics without formal limits:

I believe there is no responsibility, no ethico-political decision, that must not pass through the proofs of the incalculable or the undecidable. Otherwise everything would be reducible to calculation, program, causality. (Derrida, 1991: 108)

In other words, a closed system of rules cannot be calculated in advance of application – since this asserts that there is a knowledge of the subject, that thereby creates the subject. Researchers must engage with ambiguity:

... ethical engagement – what he [Derrida] sees as the moment of decision between self and other – can only claim that name if it opens itself to radical difference and undecidability. It is in the uncertainty and risk of response to

the unknowable other that real responsibility lies.  
(Price and Shildrick: 2002)

Thus, at the instigation of this research, disability must be defined in broad terms, recognising that bureaucratic definitions of disability do not necessarily represent all those who could be included in the research population. There are students within structures of support and data collection who identify as disabled, there are those that qualify as impaired, but reject the label of disability. Furthermore, there are groups outside these bureaucratic systems; those who identify as disabled who do not receive support or 'qualify' according to academic criteria and those who do not identify as disabled or impaired, despite experiencing major social barriers predicated upon material impairments that others might determine as a disability.

Attention to this process reveals the dangers of maintaining either a fixed critical perspective that is tied passively into an orthodoxy of ideological approaches, or the inadvertent claims towards an objective, disengaged reality that are implicit within any statements about the world.

Both these actions, I believe, would be disingenuous, subjugating the research process to either pre-established models on the basis of a closest fit, or the invisible forces of naming and method. The Derridean notion of a dispersed and undecidable subjectivity shows an alternative route.

The conventional ... might give way to an embrace of difference that was celebrated precisely in its uncertainty, its fluidity and its interconnections  
(Paras: 2005: 39)

Within this mode of reckoning, the 'monoliths' identified by Thomas and Corker (2002: 22 see 3.5.3) could be more broadly conceived as alternate schools or modes of discourse, each with its own ontology, epistemology and methodology. Alone, such bounded ways of doing and their associated ideologies, be they explicit (Marxist/materialist) or more covert (positivist/objectifying), exert a powerful force upon the form of research. Poststructuralist and feminist research approaches remind us that it is important not to become passively subject to discourse. To find a middle way between the research requirements of information management and a

Foucauldian poststructuralism calls for an active engagement with methods that lead ultimately to the *bricoleurs*' understanding that 'theory is not an explanation of nature – it is more an explanation of our relation to nature' (Kincheloe and McLaren, 2005: 317). As Shakespeare and Watson note:

an adequate social model of disability would include all the dimensions of disabled people's experiences: bodily, psychological, cultural, social, political, rather than claiming that disability is either medical or social. (Shakespeare and Watson, 2001: 20)

Thus research becomes an active matter of constructing methods from the tools at hand rather than passively receiving the 'correct' universally applicable methodologies (Kinclowe and McLaren, 2005: 317). By extension, it is also important to reflexively examine the ontologies and epistemologies that are frequently part and parcel of such methodologies over the course of the research process.

As will be discussed in the next chapter, I have attempted to mobilise mixed methods as they have appeared practical and ethical. Frequently these have developed from the ground up, methods first, as well as top down, in concurrence with a particular school of thought or model. This allowed me to navigate a path between all-encompassing ontologies and their associated epistemologies and methodologies, whilst retaining some of the critical aims of the research, to challenge assumptions based on non-disabled research cohorts, to convey student experience and to identify how and where disability happens online in social environments.

### **3.5 Summary**

This chapter has outlined discursive representations of disability identifying the close relationship between theory and practice. Critical and social models have been examined in light of the particular problems of defining what disability is. This examination has been illustrated through current models of disability articulated through higher education. Universal definitions of disability have been considered and rejected. Analysis of UCAS and HESA modes of categorisation in higher

education has highlighted the failings of ‘objective’ statistics and substantiated the practical need for a faceted and multi-perspective account of disability that allows for context to be mobilised early in the research process. Such an approach necessarily pays careful attention to the perceived boundaries of disability, and implicit frameworks evoked through the research process. In short, the actions of category making in research are not necessarily contrary to ethical, critical understandings of disability so long as the structure of the activity is recognised as a tool for instigation, for articulating research that reflexively recognises the social ferment in which it operates. From this point, structures of definition can be dissolved to allow disability and impairment to be recognised contextually, holistically across dichotomies, as it is experienced.

In the next chapter I establish a multi-perspective method that seeks to respond to context.

## Chapter 4. Methodology

---

This research lies at a juncture between disability studies, educational research and new media; hence, this chapter outlines and answers the challenges of mobilising a holistic, robust and accessible method that appropriately meets the demands of discipline(s) and context(s).

This chapter is chronologically organised to reflect my research journey. It comprises three main sections. The first section considers my entry to the field, my epistemology and methodology. It begins with my aims and my position in the research. I establish the grounds for my initial adoption of activity theory and phenomenography as complementary methods. This research engages an interpretive approach informed by critical viewpoints. As such, I articulate my research as an emergent bricolage. This allows me to position myself more fully within the project, acknowledging the ways in which my research design was mediated and remediated within a nexus of (sometimes) competing structures, interests and tools. Importantly, here I also describe the development of my method from an *activity* and *phenomena* based exploration of disability and social networking, to a *discursive* account of networked power and identity; the discursive practices that arose as central aspects of disabled experience in interviews. I identify the limits of activity theory and phenomenography and how I moved from these methods to take up discourse analysis as my primary tool to more adequately account for emergent discursive narratives and participant voice. In addition I describe the piloting of my methods; to take advantage of new technological affordances; to navigate access barriers and opportunities and to convey an ongoing commitment to practical ethics.

In the second section I describe the interview itself, how the research was conducted and how the methodology was mobilised in the event. I report how my research questions translated into action, and the ethical protocols required to address power relations in the interview.

In the third section, I report participant demography in relation to wider accounts of the student body, prefigured in chapter 3. I outline the data set and the analysis and presentation of my data using discourse analysis and case study.

#### ***4.1 Defining My Study***

This research gives a qualitative account of the networked experiences of disabled students in higher education. My research questions are:

RQ1: How and where does disability occur within disabled students' networks?

RQ2: How do disabled students experience disability in the network?

RQ3: How do disabled students manage disability in the network?

These questions aim to explore disability as a socially-constructed, networked phenomenon. This study is interpretive. It seeks to engage with participants' experiences and subjectivities, personal constructs, negotiated meanings and perspectives. However, the study also seeks to address the critical remit of disability research, recognising political and ideological interests, such as collective experience and the operation of power on the individual.

A particular problem of this research has been finding an appropriate way to negotiate interpretive and critical research perspectives. To this end, the research is allied to what Denzin and Lincoln (2005) refer to as 'bricolage'. Bricolage is a French term borrowed and redefined in qualitative research. In its popular use, it identifies the work of a handy person in making and fixing, utilising whatever is available (irrespective of its original purpose) for the task at hand. This has been likened to metaphors for quilting and montage that are also used in the scrutiny of real-world research methods. Within this research, the practice of bricolage is expressed on various levels; most obviously in the novel use of new technologies to articulate research methods, as will be discussed later. However, bricolage also implicitly identifies the partial nature of a methodology (gathered from what is available in discourse, rather than perfect knowledge). More importantly, bricolage

helps to denote those processes involved in articulating multi-perspective research methods (Kincheloe, 2001). Feminist research perspectives frequently advocate adopting multiple research methods and working across disciplines (e.g. Cohen et al., 2000: 36). Likewise, Kincheloe and McLaren (2005) advocate the use of multiple frameworks and methodologies to produce more rigorous and ‘praxiological’ insights into socio-political and educational phenomena. In short, Kincheloe describes how multiple vantage points upon a domain of study must be realised to address ‘ontological complexity’ and the ‘critical complex’ (Kincheloe, 2008: 242). Thus:

The interpretive bricoleur produces a bricolage – that is, a pieced together set of representations that is fitted to the specifics of a complex situation. (Denzin and Lincoln, 2005: 4)

This path through the investigation allows a pragmatic application of both interpretive and critical approaches to better elucidate the research landscape. It recognises the intuitive processes that are central to the search for meaning (Stark, 2000). As Weinstein and Weinstein observe, the researcher *bricoleur’s* method ‘is an [emergent] construction’ (Weinstein and Weinstein, 1991: 161) that may attest to the problematisation of boundary-making expressed in chapter 3.

## **4.2 Methodology**

Within disability studies and activism, there has been a strong concern with academic research and its frequently ambiguous role in the lives of disabled people. Before the 1980s, academic interest in disability was confined almost exclusively to ‘conventional, individualistic’ research tied to medical concerns (Barnes, 2005). Technology research focussed on disability as a deficit, for which technology supplied a ‘fix’. In this respect, universities have traditionally been allied to medical biopolitics. Barnes outlines the risk of academic research:

By attempting to incorporate and re-interpret lay knowledge and experiences, academics and researchers are in serious danger of doing what they have always done; that is, colonising ... the ideas and experiences of others. (Barnes, 2005: 31)

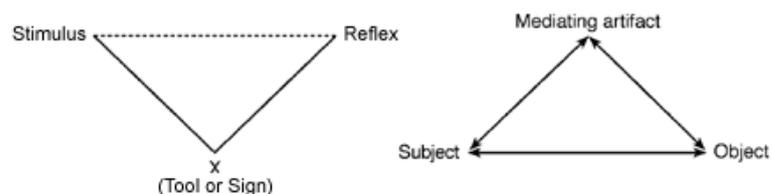
To challenge this status quo, Barnes identifies and critiques three academic approaches to relate internal disabled perspectives (inside) and external research scrutiny (outside). The first approach represents is the ‘outside-out’ perspectives of the positivist academy, which lay claim to political neutrality and objectivity. This is fundamentally opposed to the ‘radical politics of oppressed groups’ (Barnes, 2005: 31). Barnes conceives interactional and phenomenological approaches as ‘inside-out’, the second of his triad. Inside-out approaches are unhelpful insofar as they limit experiences to the individual level, reducing them to ‘sentimental biography’ (Hunt, 1996: ix). Barnes argues that this negates meaningful analysis and policy recommendations. The final alternative available to the academy is an ‘outside-in’ perspective, through which ‘disabled people’s experiences (inside) are located within a political analysis (outside)’ couching experience within the societal structures that forge it (Barnes, 2005:32). It is in this way that academic concerns located within a wider analysis can be seen as commensurate with the values of disability advocates (Finkelstein, 1996).

To walk this path between experience and contextual critical analysis, I used two complementary methodologies through interviews; activity theory and phenomenography. Activity theory (Engeström, 1984) is deployed as a framework for developing and applying the research method and analysis to ensure the multiple factors influencing disabled students’ experiences are fully recognised and also to create comparability across instances of research. To complement this contextual focus, and to directly investigate the disabled students’ own experiences, subsequent data collection is completed through ‘in-depth’ phenomenographic interviews (Marton and Booth, 1997). Both approaches are applied with reference to onscreen phenomena and other observational data collected in the form of digital photographs and artefacts identified by the researcher and participant. However, in the event, participant testimony challenged the efficacy of both methods for analysis, leading to the adoption of discourse analysis and case study for the examination and presentation of data. I describe this development at length.

## 4.2.1 Activity Theory

The central concern of this study is students' experiences of disability and social networking. Disability is conceived as a complex interaction, occurring within and across multiple discourses. The network is varied and dynamic, representing a constellation of tools that are themselves built upon varied technological surfaces. Meaning emerges through use, but use also affords new actions. In this respect, the network mediates action. Activity theory, or Cultural-Historical Activity Theory represents a framework through which to enter this dynamic field with specific attention to mediation.

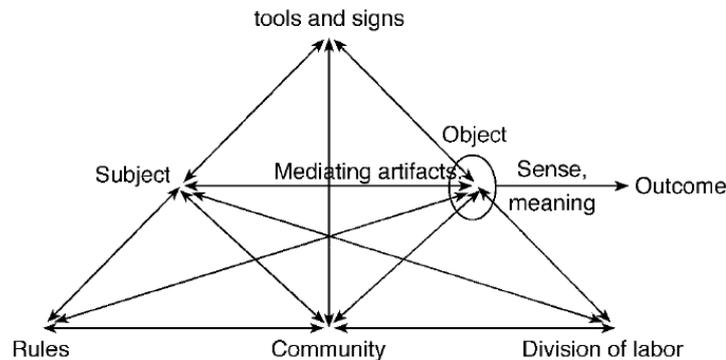
Activity theory originated in Vygotsky's Model of Mediated Act (Figure 4-1) and Leont'ev's materialist conception of activity. The Mediation Model suggests that individuals' interactions with their environments are not direct; instead the relationship between the Subject and the Object is mediated through the use of a Tool. Vygotsky categorises artefacts into a) tools (material tools), orientated to external actions, and b) psychological symbols, used in actions to master oneself (Vygotsky, 1978). Psychological tools include: 'language, different forms of numerations and counting. [...] writing, schemes, diagrams, maps, blueprints ...etc'. These psychological tools are the product of human (socio cultural) activity.



**Figure 4-1: Vygotsky's Model of Mediated Act; its common reformulation (Engeström, 1987:134).**

Leont'ev (1978) configured this model of social and cultural mediation as a hierarchical model that has still more recently been expanded and reconceptualised by Engeström (1987) into the activity triangle model (Figure 4-2). For Engeström (1999) Vygotsky's classic triadic model of mediation did 'not fully explicate the

societal and collaborative nature of [...] actions'. In this respect, Engeström seeks to acknowledge activity within its collective social setting.



**Figure 4-2: The Structure of a Human Activity System**

This activity system constitutes the subject (student) and object (social networking). The subject's interaction with the object is further mediated by tools (for example, computer, hardware and software) and a community that shares the same object (peers in the social network itself):

The *division of labor* refers to both the horizontal division of tasks between the members of the community and to the vertical division of power and status.

Finally the *rules* refer to the explicit and implicit regulations, norms and conventions that constrain actions and interactions within the activity system. (Engeström, 1996)

To be able to interact with the community, the relationship between the community and the subject is further mediated by rules. Division of labour, in turn, mediates the relationship between the community and the object. From an activity theory standpoint, experience is gained during goal-oriented activities as an expansion of one's scope of action. Importantly, there is no 'context' in the traditional sense, as all the mediating factors outlined are part of the activity system. In this way 'an activity system integrates the subject, the object, and the instruments (material tools as well as signs and symbols) into a unified whole' (Engeström, 1996). Each activity system is located amongst other systems, and does not exist in a vacuum. Intrusions may come in the form of rules (university regulations) or instruments (new mediating

technologies bought with a Disabled Students Allowance). In this way, outside influences are manifest in a system; however they are also appropriated and modified by that system as they come to be internalised (Engeström, 1996). In addition to the delineations of key aspects of the activity system, five core principles govern the activity system. These principles can be summarised as:

First principle: an activity system is the unit of analysis: individual and group actions are only understandable when interpreted against the background of an entire collective, artefact-mediated and object-orientated activity system.

Second principle: an activity system is multi-voiced. 'The division of labour in an activity creates different positions for the participants, the participants carry their own diverse histories, and the activity system itself carries multiple layers and strands of history engraved in its artefacts, rules and conventions' (Engeström, 2001: 126).

Third principle: an activity system is transformed over time.

Fourth principle: an activity system has inherent contradictions. These contradictions are the source of disturbance but also of change and development.

Fifth principle: an activity system is capable of expansive transformation. Such transformations reconceptualise the object and motive of the activity to embrace a wider horizon of possibilities than in the previous mode of activity. (Signorini, 2010: 122-123)

I have outlined Activity Theory's conceptual basis, and the principles shared by activity theorists. In view of these principles, the appeal of activity theory lies in the way it allows complex and dynamic situations to be effectively mapped, creating comparability between interviews and diminishing the risk of being overwhelmed by rich qualitative data. In this sense, activity theory offered a research lens on social networking and disability that can accommodate and manage nuanced understandings, recognising activity within context without being necessarily ruled by ontologies. Furthermore, it offers a practical way to map the role(s) of technological affordances and limits in mediating in social relations. This is particularly important in a shifting internet landscape in which SNSs and other Web 2.0 services are characterised by their instability and the ongoing refashioning of functionality, affordances and legal context. Finally, activity theory recognises socio-cultural aspects as inherent to human behaviour but not at the cost of individual agency.

Initial reservations occurred when activity theory's focus on doing and itemising threatened to strip the participant(s) and context of their human and visceral qualities. To reintegrate these facets and give voice to the participant, activity theory has been used in conjunction with the collaborative approaches of Phenomenography.

#### 4.2.2 Phenomenography

Phenomenography complements the activity/contextual focus of activity theory by directly investigating participants' experiences. The term has its etymological roots in the Greek: 'graphy', from the stem 'grafi', 'to describe' while the noun 'phainemenon' is 'that which is revealed'. Phenomenography has been deployed successfully in research into disability and experiences of the internet (Anderberg and Jonsson, 2005). Instead of adopting a traditional first-order approach to qualitative research, as with ethnography or grounded theory, phenomenography aims to articulate second-order experiences describing alternative views of a phenomenon as people of certain groups conceive it (Uljens, 1991). By addressing experience from the participant's perspective (figure. 4-4), phenomenography can ask 'how do learners gain knowledge of the world, and why do some do it better than others?' (Marton and Booth, 2006:16). As Säljö (1988) argues, "Access to the learner's perspective on the activities of teaching and learning is essential for understanding educational phenomena - and for improving education" (emphasis in original, Säljö, 1988).

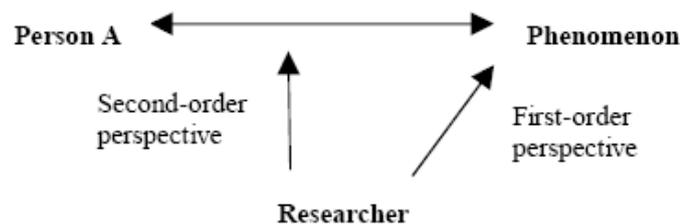


Figure 4-3: First-Order and Second-Order Perspectives (Uljens, 1991).

As the use of learning language in these quotations suggests, phenomenography originated in pedagogical research, emphasising learners' voices in educational research. From this origin, phenomenographic data collection has developed as qualitative, unstructured and dependent on 'deep' or in-depth interviews.

Experience and awareness are the research objects of phenomenography. To access experience and awareness, the interview is constituted as a collaborative act. The researcher/interviewer's dialogue with the participant considers previously unthematized and implicit conditions as objects of reflection, making them thematized and explicit in an exploration of the participant's own awareness (Marton, 1994). This has several key benefits in terms of the research. Activity theory provides a view of activity as seen from the outside; phenomenography aims to realise experience from the inside. This approach recalls the urge for 'inside-out' disability research perspectives advocated by Finklestein (1996) and Barnes (2005). Secondly, activity theory considers unreflected actions as 'operations' rather than activities. Actions are differentiated because they are conscious (Engeström and Miettien, 1999; Nardi, 1996). Operations are routinised and unconscious practices (Nardi, 1996). Phenomenography's focus on drawing previously implicit conditions into view and making them the subject of awareness allows operations to be reflected – answering a 'blind spot' (Wagner, 1993) in an activity theory as a methodological approach.

The use of phenomenography also aims to fully recognise the experiences of disabled students and allow a forum in which these experiences can be expressed in the participants' own words. It was hoped that this approach would ensure that any conception of an activity system on the part of the researcher, did not lead the research too proscriptively. Phenomenographic analysis is structured to ensure that different meanings that emerge from the data are not constituted independently, but in relation to each other, ensuring minimal data reduction. On the one hand this arguably protects student voice, on the other, it maintains the impetus to avoid 'sentimental biographies'; accounts 'preoccupied with the medial and practical details of a particular affliction' that Hunt (1996: ix) identifies as a pitfall of experiential research and an individual, interpretive focus.

Despite the aspirations of my research design, and the successful completion of interviews (documented in section 4.4), students reflections on power and discursive practices were not adequately recognised within activity theory and phenomenographic analysis. It is this significant failing, and the resulting application of discourse analysis as a methodological intervention that I discuss next. I begin by

tracing how I anticipated my methods would attend to power in the data [4.2.3] before turning to my experiences in the event [4.2.4].

### 4.2.3 Activity Theory and Power

Jager and Maier (2009) cite activity theory, as developed from Vygotsky by Leont'ev as 'essentially an approach to the critique of ideology' (Jager and Maier, 2009: 42), recognising Leont'ev's work as couched within the Marxist and the materialist ferment of early Twentieth Century Russia. Indeed, Daniels (2007) highlights Vygotsky's explicit use of Marx's sixth thesis on Feuerbach which states that "the human essence is not an abstractum inherent in the individual. In reality, it is the ensemble of societal relations" (Marx and Engels, 1946/1968: 6). Such relations suggested to me an ontology commensurate with post-structuralism. In Foucauldian terms, Jager and Maier cite this as a problem – activity theory is fundamentally materialist, whereas Foucault's conception of a discursive reality 'overlooks the fact that the materialisations of work are part of reality' (Jager and Maier, 2009: 43). Foucault's position is more complex, however. It is not that Foucault entirely refuted a material interaction with discourse, as Realist leanings in later works have been taken up at length (for example Olssen, 1999). However, Foucault avers that one cannot know reality except through discourse – resulting in an endless deferral of 'real' experience.

Jager and Maier offer activity theory as an approach that closes the gap between discourse and reality as it demonstrates how meaning is assigned to an object through use. This emphasises the iterative nature of mediated activity. Foucault himself appears to gesture to this in *Technologies of the Self*, when he describes the use of a journal as a tool for reflexive self improvement (Foucault et al., 1988). However, Foucault does not reference activity theory directly. Jager and Maier speculate that Foucault may have rejected activity theory for centring too much on the subject (Jager and Maier, 2009: 66). Despite this, Jager and Maier argue that Foucault himself sees discourse as tied to the world of things through activity. As Foucault writes:

[I]t is not the objects that remain constant, nor the domain that they form: it is not even their point of emergence or their mode of characterisation; but the relation between the surfaces on which they appear, on which they can be delimited, on which they can be analysed and specified. (Foucault, 2002: 52)

Jager and Maier state this in the following way:

If the discourse changes, the object does not only change its meaning, it turns into a different object. It loses its previous identity. This may happen abruptly, or as a result of a long process that impalpably but thoroughly changes everything. (Jager and Maier, 2009: 66)

They continue by observing that:

Foucault does not want to define objects ‘with reference to the ground, the foundation of things’ (ibid 53) but ‘by relating them to the body of rules that enable them to form as objects of a discourse and thus constitute the conditions of their historical appearance’. (Jager and Maier, 2009: 66)

As we have seen, rules are recognised by Engeström’s activity system, as are hierarchical divisions of labour. In this way, I hoped that activity based accounts of social networking and student experience of disability would account for discursive power relations, in conjunction with a recognition of the social network tool at the heart of production. This would not be the case, however. At present, activity theory lacks a language of description which allows for the parameters of power and control to be considered at a structural or interactional level of analysis (Daniels, 2007: 98). Thus, I found that activity theory represents a conservative (rather than radical) praxis. Despite claims for micro and macro analytic insight, in discursive terms, activity theory is overtly local (as Avis, 2007, asserts). For these reasons, I exercised bricolage during analysis, adopting discourse analysis as my method for thematically analysing and theorising student’s descriptions of experiences of disability, and disability management within the network.

#### **4.2.4 A Discursive Intervention**

Activity theory offers a useful theoretical lens for discovering the *unit* of analysis; however, activity theory does not suggest a *mode* of analysis. Thus, emergent themes were initially drawn from the data and coded, using a grounded, phenomenographic

approach that is acknowledged as both a discovery and a construction. Contextual factors relating to activity systems were labelled and collated.

Beginning coding in this way was helpful – it helped to distinguish the key sites of disability, identified and experienced by participants, but also those available to me as a researcher, with a ‘privileged outsider’ view of wider emergent practices, structures and protocols. The analytic process resulted in a ‘constant sifting through the incoming data’ (Bassegy, 2004: 120) moving between induction and deduction with relation to the foundational literature review (Merriam, 1998). In this process, the sites of disability were located across each facet of the activity system (see appendix five). However, this process of locating the ‘contradictions’ of disability, was found to be descriptive, rather than analytic. Importantly, whilst I felt the application of the activity system allowed an organised point of entry to the interview and in conceptualising those mediated aspects of activity over which experiences of disability clustered, this mode of analysis neutralised the data. Student voice was reported, but the student narratives of inclusion and exclusion, normativities, domination and resistance that were forcefully recounted at interview could not be sufficiently theorised or expressed within activity theory or phenomenographic coding frameworks. Neither approach accounted for the ‘keyness’ (Braun and Clarke, 2006: 82) of student testament to the discursive movement of power in their lives.

This was exacerbated by the fact that the participants were demonstrating multiple activities within the same task. Thus, whilst phenomenographic ranking of complexity and experience could begin in terms of participants’ engagement within the network as tool, the ‘phenomenon’ of the social network and the ‘activity’ of social networking, represented, instead, diverse phenomena and actions. In addition, in terms of phenomenographic analysis, ranking experiences of the network according to complexity proved untenable in some cases, based upon the highly reflexive stances of disengagement displayed by some students. Importantly, interviews indicated that qualitative and quantitative levels of student activity within a SNS is *not necessarily* related to the complexity of a student’s experience or engagement with that network. In this way, during the analysis phase of the research I identified particular ‘blind spots’ (Wagner, 1993) in my method.

The most significant issue pertained to the relations between discourse and activity in student talk. As stated in 4.2.3, Foucault may have rejected activity theory for centring too much on the subject (Jager and Maier, 2009: 66). For Foucault, it is *discourse* that produces knowledge/power, not the individual (Hall, 2001). In analysis, participant descriptions of disabled experience were skewed towards implicit *rules*, and within this, discursive and normative practices. The apparently symmetrical arrangement of Engeström's activity system, in which the subject operates amongst a balance of mediating forces, was not the system that participants expressed. I found that, as discourse was enmeshed with participant experience of power, activity theory lacks the granularity within the concerns of 'rules' and 'division of labour' to sufficiently account for the discursive conditions emerging through student talk. When reconnecting with the literature, it became clear that this is not a problem limited to my research.

Daniels (2007) considers activity theory accounts of discourse in research, seeking to enhance the analytical capabilities of activity theory, with a review of research into identity and social positioning. He asserts that Vygotsky failed to adequately develop linguistic discursive principles in his work, with consequences that still resonate in contemporary formulations of activity theory. Indeed, Engeström and Miettien (1999) acknowledge this continuing weakness.

Daniels identifies Vygotsky's lack of attention to discourse precisely. He observes that Vygotsky did not account of the way that language regulates inter-personal relations, how language is produced through patterns of social relations and how discourse subsequently manifests as social regulation (Daniels, 2007: 95). Bernstein extends this critique, asserting that discourse is not simply a matter of cognitive regulation: discourse is central to shaping 'dispositions, identities and practices' (Bernstein, 1990: 3). From this premise, Daniels asserts that 'the theoretically powerful move would be to understand the discursive regulation of interpersonal relations in terms of processes' clustered within rules and division of labour, however, it remains unclear how an account of discursive practices can be 'directly related to the regulation of the activity as it arises' (Daniels, 2007, 95).

It is in this area, the relation of discourse to disabled identity and practices, that the use of activity theory in analysis stalled. I had set out to assess the occurrence of disability as an interaction across a socio-technical network. In the event, I had underestimated identification and the discursive practices of identity that represented a powerful sub-text to my research questions, and therefore necessarily emerged in the interviews and data.

Daniels identifies how the notion of subject remains unproblematised in many studies of activity theory. Whilst a subject is selected, and ‘subject perspective’ is used to infer the subjects position ‘this does little to illuminate the formative processes that gave rise to this perspective’ (2007:97). Daniels cites Roth’s (2007) exploration of applied ethics to identity as providing the beginnings of a theoretically consistent link between discourse and action. However, this work is nascent. Thus, within this project, discourse analysis was applied as the dominant mode of data analysis. This aspect of the method is discussed in section 4.7.

### ***4.3 Developing Field Methods***

Prior to the interviews, it was necessary to develop aspects of my research design, with respect to technical methods, recruitment and ethical issues regarding accountability. I begin with ethics.

#### **4.3.1 Ethical Considerations**

This project has been approved by the University of Nottingham’s School of Education Ethics Committee, and has ensured explicit compliance with the University of Nottingham’s code of practice (Dale, 2003) the British Educational Research Association’s Revised Ethical Guidelines for Educational Research (BERA, 2004) and the Data Protection Act (1998) throughout. In this section I expand upon particular issues relating to ‘vulnerability’ and power within the interview. I relate key anticipatory ethical practices relating to accountability, prior to embedded discussion of ethical protocols that I set in place in the field [see 4.4].

Situated notions of ethical decision-making attend closely to power relations within the interview, identifying a balance to be struck between researcher and researched (for example, Simons and Usher, 2000). This concern is intensified when combined with the power relations extant between non-disabled researchers and disabled participants, alongside other marginalised identities ascribed on the basis of ethnicity, gender, religion, sexuality and so forth. In ethical guidelines, ‘vulnerability’ is used to identify additional groups of individuals who may be open to exploitation (whether physical, emotional or psychological) on the basis of impairment, minority status or an otherwise disempowered position in society (Trueman, 2010). Within this matrix, ‘vulnerable’ is an externally imposed category, as such it is a label that some ‘vulnerable’ groups would challenge. Nonetheless, Stone and Priestly (1996) after Stanley and Wise, identify attention to vulnerability as ‘the only satisfactory – because effective – way of tackling fundamental features of the power relationship existing between researchers and researched’ (Stanley and Wise, 1983: 206). The authors relate this to dis/ability precisely:

This is particularly important for non-disabled researchers because the inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider world. (Stone and Priestly, 1996: 700)

To answer this assertion, vulnerability was not conceived according to the model of ‘tragic victimhood’ that dominates public perceptions of disabled people (Gill, 2001) but as a matter of rights and power. Central to addressing this imbalance is accountability. In addition, ongoing attention to the wellbeing of participants [4.4.4], informed consent [4.4.5], the role of payment (recognising the economic status of disabled students) [4.4.7] privacy [4.4.6] and confidentiality [4.7.3] was essential.

### **4.3.2 Accountability**

To ensure that the research was equitable and accountable to all stakeholders, including participants, I sought to align the research with disability research and participation principles (for example, Barnes, 2005; Barnes and Mercer, 1997, Stone and Priestley, 1997, Priestley, 1997). As discussed in chapter 3 and 4.2, traditional modes of academic research have been strongly criticised as part of the mechanics used to subjugate and disempower disabled people and constitute biopower. For this

reason, it was necessary to open the research to the widest possible scrutiny, involving disabled people, experts and activists in consultation on methods, process and desired outcomes. In this way I sought to attain the ‘ethics of subjectivity’ Foucault commends [see section 3.1.4] and align my project and personal priorities with the priorities of disabled people. Prior to the research’s commencement I consulted widely with individuals, groups and additional stakeholders comprising:

- Disabled student advocates, disabled students’ organisations (for example, via Student Union Students with Disabilities Associations), participants, alongside formal and informal advice from post-graduate disabled peers.
- Disability studies researchers and disabled academics (via research fora, disability research networks and events)
- University Academic Support and Disability Liaison staff at central and departmental levels
- Information Services and Accessibility Support ICT practitioners
- Computer Science and Accessibility experts

This contact led to numerous improvements in my methods, instigated collaborative recruitment strategies and directing me to new lines of thought in the research literature, as well as giving me confidence in my inquiry. This did not, however, result in a resolved universal method. Consultation was ongoing and research methods were evaluated throughout the data collection period to allow methods to be tailored to the requirements of participants and to allow greater focus on emergent findings as they arose, aligning with Cohen et al’s call that;

Researchers should never lose sight of the obligations they owe to those who are participating, and should constantly be on the alert for alternative techniques should the ones that they are employing at the time prove controversial. (Cohen et al., 2000: 58).

### **4.3.3 Piloting and Technical Methods**

Previous studies considering online interactions and disability have lacked the affordance to synchronously engage and record onscreen phenomena within interviews (e.g. Bowker, 2003; Seymour and Lupton, 2004; Anderberg and Jonsson,

2005). New developments in internet technology over the course of this study gave rise to the opportunity to use and combine new technology-enhanced and accessible research methods during research interviews with disabled students for the first time. This section charts the work undertaken prior to formal data collection, through which flexible and accessible technology-enhanced, student-centred interview methods were developed.

With a tentative methodology in place, I interviewed 10 non-disabled students in a laboratory situation using the internet and screen capture software<sup>18</sup>, to broadly assess the sphere of social media used by students, and the relative compatibility of activity theory and phenomenography with internet enhancement. Throughout this piloting, the prevalence of social networks, and in particular, Facebook's dominance, foreshadowed the central role of Facebook in disabled students' digital lives. In addition to these factors, it became evident that personalisation and accessibility would be key to achieving successful interviews.

The research laboratory is a staple location for many kinds of research, however, for the purposes of my study, an accessible research laboratory would be required, akin to the accessible e-learning development labs at universities such as King's College London and the Open University<sup>19</sup>. This approach was investigated, but dismissed for key reasons relating to cost, location and personalisation. Initially it was clear that developing or regularly accessing such a resource would be prohibitively expensive. On a practical level, however, a laboratory setting also is removed from a participant's location. It was important that mobility did not become a barrier to attendance, or place excessive demands upon participants. For this reason it was crucial that interviews took place at a time and, importantly, location convenient to the participant (Bostock and Freeman, 2003).

Personalisation was also a significant issue. Even within a well resourced laboratory situation it would be difficult to pre-empt every configuration of assistive

---

<sup>18</sup> 'Screen capture' refers to the process of recording onscreen activities into a video format.

<sup>19</sup> These state-of-the-art data capture suites are designed to allow researchers to study how users interact with educational media and technologies. Leading assistive technologies are preinstalled and data capture is embedded allowing video, screen and audio recording, alongside other opportunities for data capture such as keystroke and eye-tracking.

technologies that a participant might usually deploy. For example, the use of navigational keyboard short-cuts (hot-keys) varies widely, resulting in directly contrary requirements in a research setting. Where assistive technologies are appropriately supplied, difficulties remain pronounced for technologies that differ from edition to edition. Further challenges occur with assistive technologies that require personal 'training' to become effective, as in the case of speech recognition software. Ultimately, a laboratory condition could not supply the constellation of personal settings a student might develop, manage and deploy themselves. Furthermore, any limits incurred by a partial assistive lab situation could create normalising conditions and inequitable interviews with potentially significant negative consequences for research efficacy. This outcome would be ethically questionable as a lack of adequate provision arguably *creates* a disabling experience.

A partial laboratory condition was identified as insufficiently hospitable early in the research and attention was centred on developing a viable alternative. As a result, following interviews with non-disabled students, I designed and piloted flexible field interview methods that utilised recent developments in internet based communication technologies within a new social science context. This resulted in a student-centred model, devised to ensure that disabled students are able to use and apply any assistive technologies or modes of access that they might usually use when browsing the internet. By moving to field locations usually used by students, I sought to:

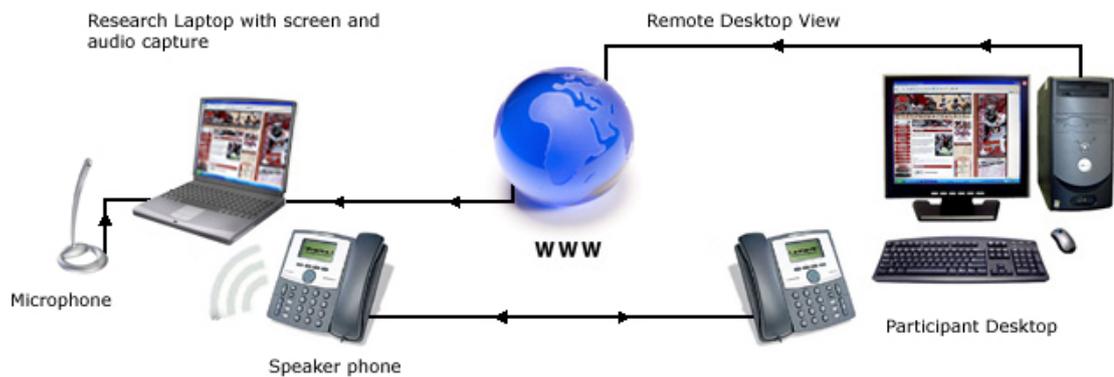
- Ensure that no unnecessary barriers to internet use were brought to bear during the interviews
- Ensure that the *tools* of data collection did not disrupt or remediate student engagement with their network

However, this approach required agile data collection on the part of the researcher. To achieve this, a suite of technologies and media services were applied concurrently.

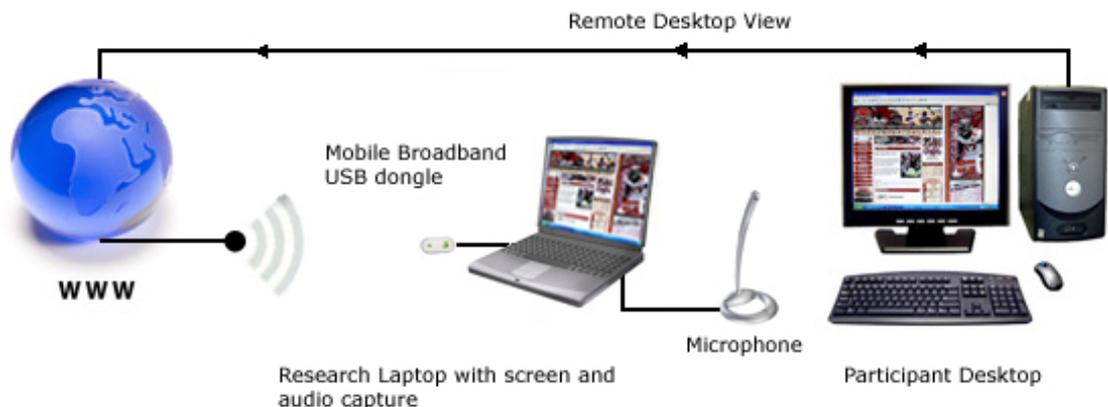
Brand	Type of Product	Service Rendered
Techinline	Web-based remote screen viewing service.	Service supplying a secure remote view of the participant's screen to the researcher's laptop.
'3' mobile modem	Mobile broadband connection using 3G (Third Generation Broadband).	Allows access to the internet from any location without local 'guest' protocols.
Camtasia v4	Screen and audio recording software.	Records all onscreen and audio data appearing on researcher's laptop

**Figure 4-4: Technologies Used to Capture Onscreen Data**

The arrangement of these technologies, along with supporting infrastructure (including student-side Broadband connections and phone) is illustrated in figure 4-5 and figure 4-6.



**Figure 4-5: Arrangement of Technologies Used for Telephone Interviews.**



**Figure 4-6: Arrangement of Technologies Used for Face-to-Face Interviews.**

Figures 4-5 and 4-6 illustrate how the internet was used to convey a web-based remote desktop viewing service from the participant to the researcher. This remote desktop view allowed screen capture to be completed on the researcher's laptop. Each of these technologies was dependent on the others for success. Each, necessarily, had affordances and limits that had to be recognised within the interviews. I discuss these in turn.

### **Remote Desktop Viewing**

During interviews, 'Techinline' was used to access students' onscreen activity and facilitate screen capture. Techinline is a tool predominantly used by IT support personnel for remote customer support. In the research, this service allows the researcher to view the desktop of any participant with an internet connection, from a second networked computer. Audio/voice information is then conveyed by speaker phone and digitally recorded separately. Techinline was also used for face-to-face interviews to transmit the participants' desktop view to the researcher via the internet, within the same room. In this local situation, audio/voice was captured directly. This arguably innovative approach was notably dependent on internet access and screen capture for success (figures 4-5 and 4-6).

Techinline had several key strengths that demarcated it as suitable for social science research. It is intuitive, secure, and relatively inexpensive. In contrast to many of its competitors, Techinline allows a 'view only' option. This meant that the researcher was unable to influence the participants' actions onscreen, or gain access to any information that was not presented or vetoed by the participant. Thirdly, Techinline was broadly accessible.

As the only part of the system to be directly encountered by participants, the accessibility of Techinline was key. I conducted thorough technical and evaluative piloting to establish the suitability of the user-facing pages of the remote desktop with colleagues. In conjunction with advice from accessibility experts, consultation with Techinline, and using my own expertise<sup>20</sup>, I applied a series of adaptations and assistive technologies to Techinline's Client ID web page (figure 4-7). I recognised

---

<sup>20</sup> Prior to my postgraduate studies, I worked to develop accessible e-government websites to WAI WCAG AA standards.

that this did not represent a simulation of use, or a universal test, however, this process of offered some confidence in the appropriateness of technologies chosen.

## Usability, Accessibility and Adaptability

The remote view was relatively easy for both the participant and researcher to implement. The participant is given a short URL directing them to a Client ID (figure 4-8). The participant relays this number to the researcher who then requests a desktop view. This request can then be approved or denied by the participant.

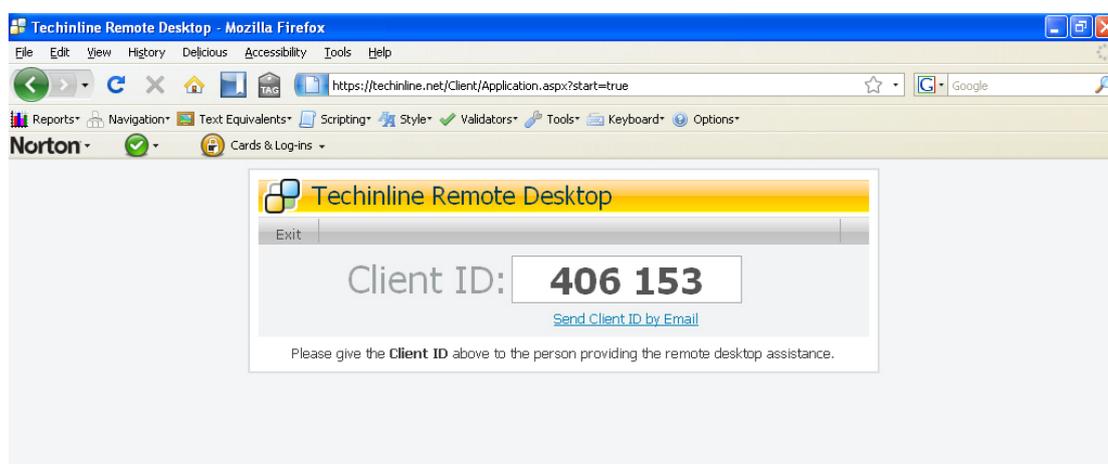


Figure 4-7: Techinline Client ID window

Techinline was accessible to all participants. However, Techinline's interface is not W3C WAI standards compliant for either HTML or CSS<sup>21</sup>. In this sense, the research was not *technically* accessible. Instead I adopted a 'holistic' (Kelly et al., 2004; Phipps and Kelly, 2006) approach to engaging participants. This approach recognises the value of deploying tools that may fail standard validation techniques for technical accessibility, but which nonetheless offer affordances with real benefits for disabled users. Moreover, the method was applied flexibly in negotiation with participants to ensure that any conception of disability as an aggregate did not undermine the specific requirements an individual might have. This approach concurs with Kelly et

---

<sup>21</sup> Subsequent to the data collection, conversations with researchers at the Open University have indicated that Elluminate can be used in a similar way. Elluminate is an accessible system that allows resources/screen-views to be shared alongside VOIP teleconferencing within one integrated service. In addition it meets W3C WAI standards. Elluminate has been cited as failing to relay screen magnifying activity. Notably, within this research project, no students deployed a screen magnifier during an interview (despite one student using this assistive technology). It should therefore be noted that remote viewing services may not recognise magnification, as this is a layer of activity added 'above' the level broadcast in the connection to a researcher.

al's notion of 'adaptability' (2009). The authors summarise adaptability within the following framework:

Accessibility 1.0 is characterised as a technical approach in which authors are told how to construct resources for a broadly defined audience. This is known as universal design.

Accessibility 2.0 was introduced to point to the need to account for the context in which resources would be used, to help overcome inadequacies identified in the purely technical approach.

Accessibility 3.0 moved the focus on users from a homogenised universal definition to recognition of the idiosyncratic needs and preferences of individuals and to cater for them.

All of these approaches placed responsibility within the authoring/publishing domain without recognising the role the user might want to play, or the roles that other users in social networks, or even Web services might play.

Adaptability shifts the emphasis and calls for greater freedom for the users to facilitate individual accessibility in the open Web environment.  
(Kelly et al., 2009)

Within this framework, this research aims to facilitate the individual participants' engagement, recognising context and refuting the inadequacies identified by purely technical approaches.

## **Viewable Area**

Techinline was able to mitigate differences between the researcher's and the participant's screen area. For field portability, a 15" laptop was used throughout the interviews. In several instances participants used larger 17" and 19" screens. Two students with visual impairments used considerably larger monitors: the first used two monitors daisy-chained together initially, and later a 24" monitor; the second used a 32" TV. This was not unexpected. In cases where the remote screen(s) are larger than the screen available to the researcher, Techinline locates and follows activity (for example, mouse movement or keyboard tabbing) around the screen. For analysis, screenshots can be edited together to give the total screenview (see figure 4-8).

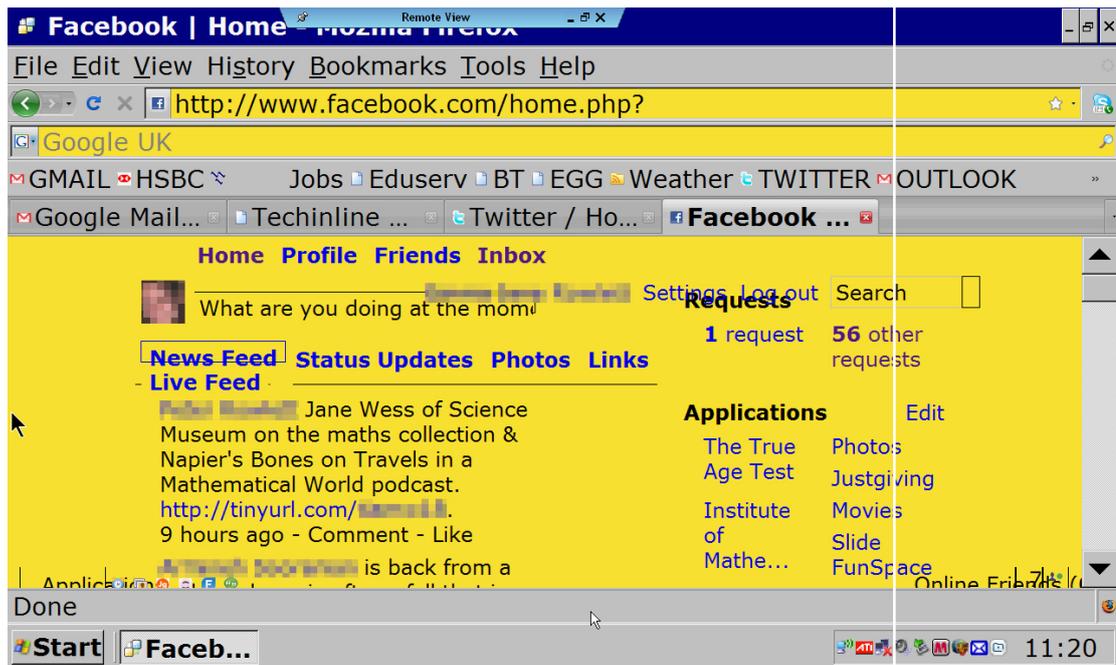


Figure 4-8: Stitched view of 32" desktop, with white line indicating point of screenshot overlap

From this point, screen, audio and voice capture can then be completed from the researcher's side in the usual way.

### Screen Capture

As interviews involved frequent references to the Web, screen capture was desirable, to ensure visual data was available for post-interview analysis. The screen capture software used for this research was Camtasia (v4). Camtasia allows onscreen data to be recorded along with synchronous audio collected by microphone (for the speech of the interview) and the connection with the participant's computer (for example, music, sound effects or other auditory data). Screen capture was not always possible. In total 3/34 interviews produced only audio data, with one interview also featuring interrupted screen-view. Barriers to screen capture included:

- Participant bound by legal agreement with private employer protecting desktop from external views for Intellectual Property purposes.
- Student-side, university-supplied internet failure for duration of interview.
- Participant concern over internet security protocols.

## **Internet**

Interviews were frequently conducted at a place where the student regularly used the internet. Whilst this generally implied that an internet connection was available to the participant, there were rare cases (see figure 4.6) where a participant's internet connection was patchy, or non-existent. Total internet failure occurred in one instance. Many of the new undergraduates living in Halls reported such interrupted service; as this was a facet of their networked life, interrupted interviews were not rescheduled. Whilst the flow of onscreen data was interrupted, these interruptions were authentic and for this reason constitute important contextual cues.

## **Developments in Mobile Internet**

As the researcher, internet was available to me through wireless 'hotspots' where they converged with interview sites. However, connectivity could not always be guaranteed. This challenge was resolved in summer 2008 with developments in the connectivity and affordability of the UK's 3G Mobile Broadband network. A 3G modem was used to ensure complete mobility across research sites. Although the data transfer rate of this device was more limited than wifi/broadband, this mobile connection allowed the researcher to complete screen capture in situ during interviews without reliance on local wifi. This had a knock-on effect for data collection, allowing wider ranging interviews that could recruit from additional research sites.

### **4.3.4 Evaluation of Technical Approaches**

In interviews, the constellation of technologies applied to achieve the data collection worked well. However, each element was interreliant. In the event, only the internet connection proved problematic, often for reasons authentic to the research location. In terms of accessibility, the deployment of these services worked well, engaging participants and recognising their particular use of assistive technologies, browser settings, multi-media use and social networking activity. In particular, the familiarity of the participants' own set up encouraged greater participation in terms of showing, illustrating and demonstrating activities of interest. The field setting also implicitly recognised the 'always on' and communal nature of networked student life. Such

field affects offered enhanced observation opportunities, and a window on student life.

The development process highlights the importance of granularity when assessing both the research tools being deployed *and* the social networking tools being scrutinised. Tools represent a central mediating factor within the students' activity system. As discussed in 2.3, social networking sites (SNSs) are an aggregate of different tools, and in this chapter we see that the network is dependent on other technologies; a browser, internet connection, computer or device and power supply. To represent this granularity it is useful to apply the notion of 'surfaces' applied by Pearshouse et al., (2009). The browser, connection, computer, and power supply each represents a technological surface. These surfaces are inter-dependent. Further low-tech surfaces may comprise the furniture necessary to support hardware. Assistive technologies may add a further surface that must also be recognised.

Whilst methods were developed to recognise specific adaptive of assistive measures, all users access the internet in distinct and individual ways. Assistive technologies can be understood in terms of disability; however, recent developments demonstrate how the boundaries between assistive technology and wider multi-media are becoming increasingly indistinct. Technologies that were until recently conceived as specialised assistive technologies, for example, screen magnifiers and voice recognition, are now being mainstreamed, particularly in mobile devices, allowing all users to zoom and enlarge content or make voice commands. Likewise, a strong case has been made in widening understandings of assistive technologies to appreciate the affordances of multi-media in offering disabled users multimodal points of entry to Web resources (Sloan et al., 2006). In light of these developments, accessible methods that accommodate diverse user activity have a universal application that prioritises the individual, and understands technology as it is constituted in its use, rather than formulating more proscriptive, limited conceptions.

The development of these methods was not without cost, however. I was determined not to disadvantage students by presenting inaccessible research methods. As a result, the development and piloting of these methods took time, with a knock on effect for recruitment and interviewing within the timeframe of the PhD. In addition, while I

was able to conduct technical evaluation beforehand, the methods could only be tested with participants in the field once the research was underway. The success of the method suggests that my evaluation had been appropriate – however, it was necessary to constantly review the suitability of the methods across the data collection.

#### **4.3.5 Recruitment**

Disabled and non-disabled are not binary conditions; they are a matter of identification, context and culture. As a result, the recruitment of participants was designed to be as open as possible to encourage the participation of those who might consider themselves disabled, but not be in receipt of Disabled Students Allowance (DSA) or more formal support. A range of student participants were sought for this research, including students with mobility and fine motor impairments, sensory impairments, cognitive impairments, learning difficulties, mental health issues, and long-term medical conditions. Within these groups, it was expected that it would be particularly difficult to recruit participants with mental health issues such as depression and impairments such as schizophrenia, where great social stigma frequently disbars disclosure (Riddell et al., 2005). Such groups tend to be under-represented in both education and accessibility research. It was also anticipated that it would be difficult to recruit those students who might not identify with the label of disability, for example students with long term or significant medical conditions, such as cancer or HIV. With this target to recruit widely, no respondents were turned away, and, whilst this sampling strategy was not affected as a quota to be fulfilled, attention was paid to representation (see sample demographics 4.5).

#### **Participating Institutions**

Participants were recruited from three English Universities. A University in central England was the primary site of the research, with its students constituting 15 of the total 18 interviewed. This university was selected on the basis of locality and access, based on pre-existing relationships with academic support staff with whom I had previously worked professionally and during my MA data collection. My knowledge of the university, its structure, digital and built environment and disability support practices were all useful for mobilising recruitment and conducting the research.

In addition, two interviews were conducted with students from a northern university, and a final participant was recruited from a metropolitan university. These sites were accessed more opportunistically, on the basis of disability networks that grew over the course of the research, to take advantage of personal and informal contacts to engage disabled students from populations that are less frequently represented in research of this kind (see section 4.5). In this way, the choice of research site was pragmatically driven.

### **University A: Midlands University**

University A is pre-1992 research-intensive university. Students declaring a disability at registration represent 7% of the total student population for 2007-08. This level was stable in 2008-09 (the academic year in which the data was collected), however, the level of disclosed disability amongst undergraduates rose from 8% (18,805 for 07/08) to 9% (19,688 for 08/09). In line with national averages, the vast majority of students declaring a disability cite dyslexia and ‘unseen’ disabilities. The university has four campuses. Although the majority of teaching and residential buildings are accessible and served by free minibus service for students with mobility impairments, the main campus covers a large, parkland site that can be challenging for some disabled students. The second campus is built on a level site a mile from the main campus. This campus poses fewer accessibility challenges.

### **University B: Northern University**

University B was established in 1992. It is a large English university with two campuses, one being in a city centre, the second in the suburbs. In the academic year 07-08, 1,799 students were known to have a disability, with 1,300 ‘not known’. This constituted totals of 7.07% and 5.11% of a total 25,414 students respectively.

### **University C: Metropolitan University**

University C is a research-led large metropolitan university based in the South of England. It has 4 inner-city campuses. Data from HESA cites the number of disabled students receiving DSA for undergraduate study at the level of 2.7% (academic year 07-08), significantly lower than the mean average of 4.5%. However this level rises to 3.9% of a substantial postgraduate cohort. At time of writing, more precise data

relating to a potentially higher total for all students disclosing a disability is not available.

## **Modes of Recruitment**

Strong relationships with University gatekeepers were essential to the recruitment of participants; these took significant time to develop and were often based on prior connections. In addition, the university year dictated the availability of participants to the process. Posters advertising the research within the Academic Support building, where many disabled students meet with advisors at the beginning of term were put in place. These were most effective at the beginning of the summer term. Posters were also located in AT rooms and general recruitment hot-spots (for example, public boards in central buildings and the Psychology Department message board). This recruitment method was recommended by Academic Support, however, an early concern was that posters would fail to engage students with visual impairments and those with mobility impairments, or others who do not necessarily frequent public thoroughfares. An email invitation to participate via a third party to maintain anonymity was a preferred mode of recruitment. It had been hoped that early in the research process an invitation to participate might be circulated via email by Academic Support at the primary research site. However, despite the development of strong relationships with staff and disability advocates, and a broad support for the aims of the research at the institutional level, this mode of invitation was not available or sanctioned. This represented a significant setback.

Whilst email recruitment was not possible through institutional routes, two participants were recruited via a nascent Disabled Students Association mailing list and two responded via a Disability Studies course at University B. A further participant was recruited via a parallel research project mailing list into visual impairment and accessibility. An example of recruitment material is available in appendix four. As relationships with gatekeepers at University A evolved, the opportunity to present myself and my research at a pre-term induction event for new first year students was presented as a supplementary recruitment prospect. At this event I would be able to pitch the research and distribute flyers. As a result, I developed the research design to take advantage of this option in the third year of the PhD. Research into disabled students' moves into higher education highlights that this

transitional period marks an important step in the development of students' identity and understanding of disability (Borland and James 1999, Goode, 2007). The first term at university also represented a potentially rapid development in networking practices. To capitalise on this explicit juncture between identity and network in the lives of disabled students, I determined to recruit at the induction event with a view to undertaking repeat interviews with new undergraduates, to better gauge the ebb and flow of the academic term, and examine students' experiences of transitions into a new, networked context. At the induction event, six interested students submitted their details and preferred mode of contact with a view to taking part. Five were subsequently involved for the duration of the project, with an additional first year undergraduate joining two weeks into the term in response to a poster advertisement.

Informal networks also proved successful for recruiting those at the margins of the research. Three student participants responded through my own peer and friendship networks, including a student who had received treatment for Cancer over the course of her studies and did not identify as disabled, and a student who identified as disabled, but refuted medical ascriptions of 'learning disability'. In this way, informal and opportunistic recruitment offered some success for accessing groups identified as hard to reach.

Recruitment ceased in January 2009. At this point I felt that it was important to proceed with analysis and writing, and the management of my ongoing engagement with participants over a reasonable time frame. I was also satisfied that the group was referent to wider disabled populations in higher education incorporating 'typical' and 'salient', politically important informants (Kuzel, 1992; Patton, 1990).

#### ***4.4 In the Interview***

In this research I have undertaken exploratory interviews designed to establish familiarity with the participant and their network. Interviews were conversational, semi-structured and participative, allowing collaboration between the participant and researcher that brought reflections into view in a transparent way. In this sense, the interview was participative, pedagogic and represented a knowledge exchange. Here

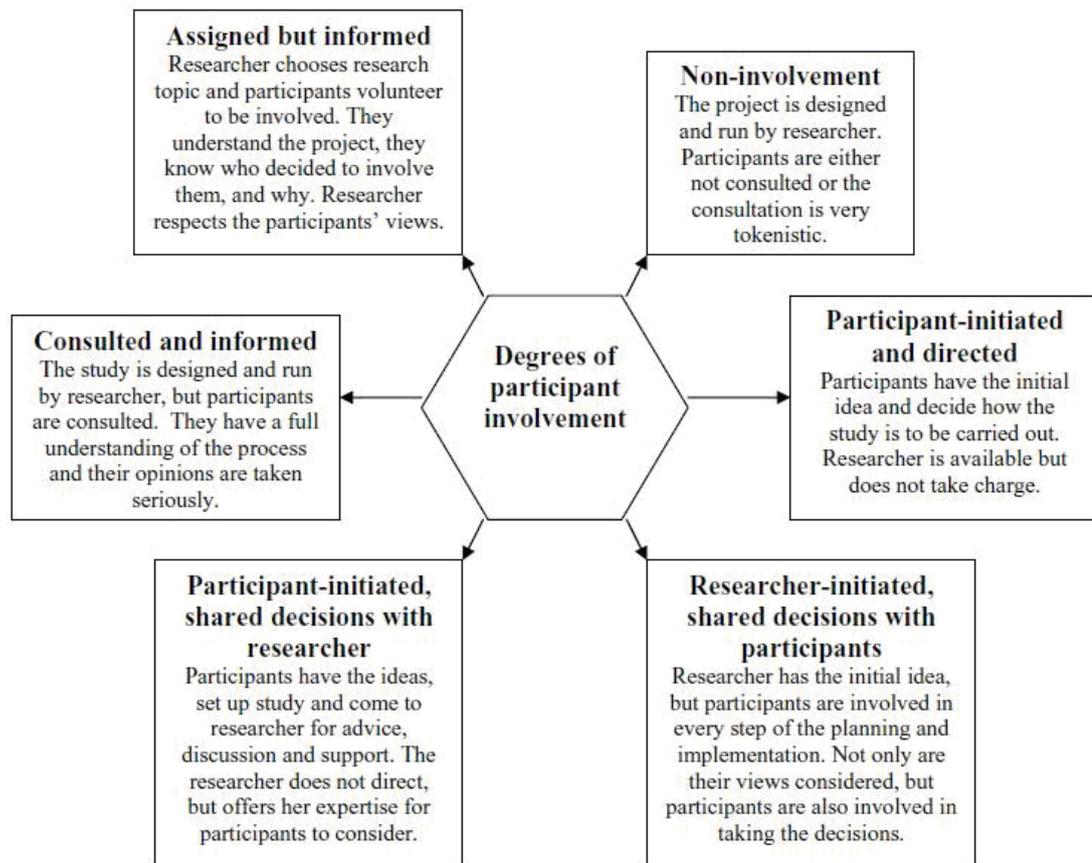
I document issues of participation, followed by a step-by-step account of the interview with respect to methods and ethics.

#### **4.4.1 Participation**

Since the phenomenographic interview relies upon awareness, it is necessarily both collaborative and pedagogic, as new reflections are created. Marton and others state that phenomenography is ‘participatory’ as participants may lead the line of the interview, the research process is transparent, and the reduction of data is actively avoided, foregrounding the voice of the participant. In terms of disability research, however, the use of the term ‘participatory’ must be used with caution. Marton refers to phenomenography as participatory, in the sense of a participatory model of *learning*. Here learning is conceived as an active process of engagement on the part of the participant. Within critical traditions, participatory *research* has been identified very differently as the restructuring of the hierarchies of research production. Participatory research can be distinguished from other forms of social research by three key attributes:

- Shared ownership of research projects,
- Community-based analysis of social problems
- Orientation towards community action

However, participatory research is not a check-list. Blunt demarcation of the boundaries of participation can prove unhelpful. Radermacher (2006) considers disabled people’s experiences of participatory research. Her authoritative account describes the ways in which participatory approaches can be conceptualised by degrees. This research has informed participatory disability and technology research such as the LexDis project (Seale et al., 2008).



**Figure 4-9: Degrees of Participant Involvement. Adapted from Fajerman and Treseder, in (Radermacher 2006)**

Radermacher argues persuasively for a non-hierarchical formulation of participant involvement that is contextually situated:

Thinking of participation as non-hierarchical avoids the common assumption that there is an ‘ideal’ form of participation - that of having and being in total control. [...] What becomes important, therefore, is that people have access to and are provided with opportunities to participate in whatever way they desire, and that they have a choice to participate in the first place. (Radermacher, 2006: 25)

According to Radermacher’s conceptualisation, the current research is *researcher-initiated*. Whilst disability advocates and disabled students have evaluated the research design prior to, and during piloting and data collection, this has not constituted the greater part of planning and implementation. External limits to the recruitment process have necessitated that participants have joined the project at

differing stages with differing levels of engagement. All were *consulted and informed*.

Radermacher cites Ife's 'conditions' to encourage genuine participation (Ife, 1995).

These state that:

- 1) People will participate if they feel the issue or activity is important;
  - 2) People must feel that their action will make a difference;
  - 3) Different forms of participation must be acknowledged and valued;
  - 4) People must be enabled to participate, and supported in their participation;
  - and 5) Structures and processes must not be alienating.
- (Ife, 1995 in Radermacher, 2006: 105)

This research aimed to meet these criteria, with some success borne out by the data and participant input and feedback. Participants were able to, and did offer up new lines of enquiry, demonstrate tools and, in three cases, offer new modes of data collection, technical expertise, alternative interview technologies and the collection of artefacts and network mapping tools that were carried into subsequent interviews. This process was especially transparent to those engaged in repeat interviews, and those who, when asked, affirmed that they would like to keep up to date with the research and its progress.

Phenomenographic interviews gave the research design the flexibility to engage participants meaningfully in the research relationship during interview. This was essential, not only in terms of disability research, but in terms of research efficacy. Without this participant engagement, or enthusiasm for the research, any insight would have been impossible.

### **My Role: Researcher Participation**

As a researcher, it is important that I recognise my own role within the research. The research is borne out of my particular experiences, values and political affiliations. My research design necessarily applies certain perspectives that highlight specific facets of discursive practice. Within the interview, I am an active participant, and, in writing the research I determine within a given framework what is seen and what is unseen. In this respect, I mediate and remediate the research, the participants, the

findings and conclusions. Within this context, the responsibility to adequately represent student voice is at once ‘ethically compelling and methodologically challenging’ (Baily, 2009), since, in discursive terms, by writing this text, I become involved in ‘making up people’ (Hacking, 1986: 222) according to the discourses available to me. At a practical level, escaping this discursive bricolage is impossible. As Baily observes within his own research:

Whilst I might claim to acknowledge the relativising and subjectivising dangers of the research strategies I have employed, they cannot be eradicated, only opened to awareness, reflection and contestation. (Bailey, 2009: 47)

Whilst I have sought to represent the participants without undue bias, I must acknowledge that this research project represents one interpretation of the data, and that the checks and balances applied throughout are equally discursive. As a result, a reflexive position is critical to the research. Acknowledging a partial position can be criticised on the grounds that any ideological allegiance can only perpetuate itself in politically committed research. In addition, a committed position can lead to privileging certain perspectives, actions and beliefs above others (Silverman, 1998). These criticisms, however, can be made of all research methods. As Abberley (1992) observes, quantitative studies and research conducted by advocates of value-free objectivity are more easily and frequently subjected to covert political manipulation (Abberley, 1992). In short, acknowledging my own perspective and research journey is part and parcel of the ethical commitment to transparency and accountability equal with the values of disability research set out by Barnes (2005). When I recognise myself as active participant in the research situation, this necessarily leads to an examination of the interview situation and my partial position within it. Säljö (1996) and Uljens (1996) allow for phenomenographic researchers to use their experiences as data for analysis. They also encourage reflexivity to situate the investigators’ perspective;

the researcher himself (sic) – his beliefs, interests, previous experience, network of discussions, even personality, - is essential for the outcome of a project and become, to a certain degree, part of the results. (Berglund, 2005: 35)

At an ontological level, this methodological position simply reflects the notions of ‘co-created findings’ and ‘interaction between an individual and their given cosmos’ that stem from an interpretive ontology and epistemology (Heron and Reason, 1997: 284). But there is also a power relation at work. I must necessarily make myself and my decision process open to the reader, thus ‘inasmuch as the focus is, by implication also on our [researcher] practice, a secondary spotlight shines on our professional selves’ (Knobel, 2005: 35). In this respect, my research journey charts my development as a researcher alongside the process of investigation and ‘production of new knowledge’.

#### **4.4.2 The Structure of the Interview**

Although Marton and Booth (1997) advocate unstructured interviews, Mason reasonably argues that ‘it is not possible to conduct a structure-free interview, not least because the agendas and assumptions of both interviewer and interviewee will inevitably impose frameworks for meaningful interaction’ (Mason, 2002: 231). Questioning therefore followed a semi-structured format, also drawing on questioning following from the participants’ flow of conversation and with concrete cases being used as the point of departure for encouraging reflection on the situation, text or problem and the participants’ ways of responding to it.

Interviews were up to an hour in length. They took place in a multitude of locations, face to face and by phone<sup>22</sup>. During face to face interviews, where possible I positioned myself beside the interviewee to avoid a ‘confrontational setting’ (Lee, 1998). This was frequently intuitive as both researcher and participants focussed on onscreen activity for significant parts of the interview. Initial questioning led with closed structured questions seeking to put the participant at ease and establish the grounds that the rest of the interview would explore (an interview schedule is available in appendix four). Early questions dealt with demographic information. Participants were asked to describe their impairment in their own words. Contextual questioning, guided by activity theory, then was used to orientate the researcher in the participant’s activity system, and, as the interview progressed, to establish a

---

<sup>22</sup> Precise details of mode and venue are supplied with the case studies in chapter five.

framework within which I could locate disability as a mediated experience, using the experiential focus of phenomenographic questioning.

Attention to the components of Engeström's activity system allowed each instance of research to be clearly mapped at the start of analysis, giving equivalence across all instances of research. This is particularly important given a diverse research population, engaging in social networking activities that may vary widely in terms of rules, communities and the tools which couch these experiences (the network themselves in conjunction with assistive technologies and other hardware and software). As such, the component parts of Engeström's model of activity, Activity, Object, Subject, Tools, Rules and Regulations, Division of Labour, Community and Outcome underpinned *both* reflexive questions for the researcher in terms of driving the research towards a coherent instance of research *and* the contextual questions of the semi-structured interview. Mapping the student's landscape in this way quickly orientates the researcher in that particular student's context.

Thus, following demographic questions, questions focussed precisely on the participant's networking *tools*, identifying the social media that the participant was using, their regular practices in terms of times and places of access and the use of any assistive, adaptive or other bespoke technologies that mediated their activity. Next, the student was invited to demonstrate a usual route through their social networks, as I sought to position myself as the 'learner' and the participant as the 'expert' within their online environment. From this point, the interview moved to more open questioning strategies that sought to probe and elaborate *both* the concrete aspects of activity evinced in the social network, *and* the participant's awareness and understanding of their network.

In this way, activity theory was used to map activity; attending to RQ1: How and where does disability occur within disabled students' networks? As the interview unfolded, I frequently asked students to elaborate on different aspects of the activity system as they naturally arose. Where gaps occurred, I offered questions to draw out such detail. Notably, aspects of the activity system itself were found to be foregrounded within networks, so a discussion of a Friend List precipitated discussions around *communities*, who was present within the network and who was

not, who the participant interacted with and in what ways. Recent posts and updates were examined, to discover what typified the participant's networking activity and what *rules* and *norms* governed their actions; why had the participant created the post? Why in that particular way? For what audience? In each aspect, as a researcher, I was alert to the student's take on the relevance or incidence of disability within such networked activity, and how they perceived issues of impairment in this mediated landscape. It was this aspect that required crucial discursive critique. In this sense the networked computer offered an 'object-to-think-with' (Turkle, 1995: 6); the presence of the computer, the internet and the SNS was both instrumental and evocative, iterating new lines of inquiry, eliciting reflection and allowing discussion to be remediated by onscreen evidence. Frequently, participants spontaneously took the lead, demonstrating their profile, their modes of activity, and their own critical reflections. Phenomenographic questioning subsequently sought to explore these conceptions and intersections with disability as they arose.

Catalytic, phenomenographic questions were used to instigate new reflections; these also referred to SNSs in both the abstract and concrete sense. In this way, experiential reflection was encouraged to answer [RQ2] How do disabled students experience disability in the network? And the related question [RQ3] How do disabled students manage disability in the network? As discussions progressed, answers could be anchored in the network, using instances and examples of certain management practices. As Marton observes:

Most often, [...] a concrete case makes up the point of departure: a text to be read, a well known situation to be discussed, or a problem to be solved. The experimenter then tries to encourage the subjects to reflect on the text, the situation or the problem, and often also on their way of dealing with it.  
(Marton, 1994: 4427)

Interviews were internet enabled, allowing the interview to follow a flow of conversation, and use onscreen patterns and traces of activity for exploratory talk to navigate and illustrate the participant's onscreen life. In this respect, the multimodal SNS represented the 'text to be read', the 'situation to be discussed' and, in terms of disability 'the problem to be solved'. However, since social networks are imbricated with the real world and this is an essential part of their value, within interviews the

discussion also moved to related issues such as provision of assistive technologies, pre-university experiences, changing understandings of disability and off-line experiences of disability. Such discussions were not considered off-piste; indeed, they were essential to understanding the student perspectives on disability and technology that comprised core aspects of student context and lived experience<sup>23</sup>.

#### **4.4.3 Repeat Interviews**

Repeat interviews were deployed opportunistically to take advantage of a new student intake and opportunities for a more prolonged engagement with new students at a critical point in the development of their digital and social identities. Where repeat interviews were deployed, participants could demonstrate their general activity since the last interview using network evidence of times and places. These interviews differed significantly from one-off interviews, as greater participation and collaboration was possible. As a result, participants could be engaged in more meaningful participation, in some cases volunteering actions between interviews (for example, several students photographed their work stations, others suggested tools and new lines of enquiry), and gaining a stronger insight into the progress and aims of the research. Greater rapport could be developed and the processes for setting up the interview were streamlined. It was also possible to revisit particular themes, and consider the ways in which participants' activities and views had changed over time. Methodologically, this developed the research from a series of snapshots of individuals to better recognise change over time. Witnessing changes in the participants' networks and experiences reasserted the fluidity of both the students' network and students' identities; re-establishing the need to historically situate the research and specify my study as a particular moment at a particular time and place, mediated by myself as a researcher likewise situated. However, repeat interviews also represented a shift away from phenomenographic methods, as the necessarily pedagogic aspect of realising previously implicit conditions could not repeatedly evinced. On the other hand, participants' expertise in their own networks deepened. This evokes an ethical dimension, amongst many specific to 'depth' interviews that are discussed in the next section. In addition, the detail and depth of the repeat

---

<sup>23</sup> This is demonstrated in appendix five in the example of a participant transcript and the sample of coding process.

interviews also anticipated a re-assessment of my mode of analysis, discussed in section 4.2.4.

#### **4.4.4 Sensitive Issues**

A central ethical concern with semi-structured and ‘depth’ interviewing is that the precise terrain that will be covered is unknown (Lee, 1993). As a disability researcher, I recognised that there was potential for the negative psycho-emotional dimensions of disability that disabled people negotiate daily (Reeve, 2002), to become the subject of the interview. As disability represents a marginalised and excluded identity in society (Stone and Priestly, 2005), reflecting on ‘disability’ could involve reflecting on the damaging effects of exclusion, discrimination and prejudice (Reeve, 2002). Shakespeare et al. identify anger, self-loathing and experience of rejection and humiliation as ‘among the hardest aspects of being a disabled person’ (1996: 42-43). Exploring awareness of disability or impairment could therefore be distressing for participants. Additionally, there is a concern that self-scrutiny could potentially alter the students’ conceptions of self, ability and autonomy. A risk identified by Lee is that through the interview ‘the exposure of hitherto private feelings may encourage a growing sense of a particular identity’ (1993:107). For these reasons, it was imperative that the interview conversation itself did not exacerbate disability, or unduly distress participants. Thus, I sought to ensure that whatever participants raised with regard to impairment or disability, was done freely and on their own terms.

In accordance with BERA guidance (2004: 7-8), I took all necessary steps to reduce any sense of intrusion, and to put participants at ease. Informed consent, knowledge of the research aims and my credibility were central to establishing the trust and rapport necessary to demarcate a safe interview dialogue. My task during the field work was not to be ‘a judge, therapist nor a cold slab of granite – unresponsive to human issues’ (Merriam, 1998: 214). Where sensitive subjects were raised by students, these were privileged and valued. I ensured that researcher-side factors such as progress through an interview schedule did not interrupt or mechanistically divert from such narratives. In all discussions, I sought to listen, asking probing questions to elaborate or clarify where appropriate, taking care not to

prompt, or direct answers. In this way I hoped to mitigate issues of ‘countertransference’ (Laslett and Papoport, in Lee, 1993):

*Countertransference* identifies situations where the interviewee develops an identification with the interviewer, or vice versa. As a result, respondents may produce what it is assumed the interviewer wants to hear, or interviewers may accord particular features of the respondents experience undue prominence. (Lee, 1993:105)

When exploring participant notions of disability and networking, it was important not to impose or promote a particular preconception of a given impairment onto the student. Irrespective of whether any impairment had been disclosed by respondents, I worked to ensure that I did not inadvertently seek a performance of disability or impairment that matched any preconceptions I might have. However, it would be naive to assume I was unable to entirely control for this effect. Since the research was dialogic, the shared space of dialogue meant such identifications were a constant implicit negotiation. I was not alone in my desire to manage safety within the interview space. In the pre-amble to recording, three students disclosed specific impairments and impairment affects in terms of the interview (memory recall, potential agitation, communication difficulties and eye contact). I was aware that in each instance, the students were seeking to neutralise a potentially negative response, mis-judgement or outcome on my part. In each instance, I tried to put the student at ease and reassure them that such impairment effects were not detrimental. However, this brought home the fact that I could not wholly control the students’ conceptions of me or of the purpose and nature of a ‘research’ interview. Whilst I sought to create a non-judgemental, conversational and safe space within the interview, I could not account for participants’ prior experiences, which shaped their anticipatory actions. I could put protocols in place, and respond in an appropriate way – but the interview was necessarily collaborative; trust and rapport could not be established instantaneously and so interpersonal emotional work was undertaken by both researcher and participant on behalf of ourselves (Hochschild, 1983) and each other (Cahill and Eggleton, 1994).

#### 4.4.5 Informed Consent

Informed consent is the keystone of ethical research. Because of the semi-structured and potentially sensitive nature of the interview, consent necessarily represented ongoing communication between myself and participants. Within consent, notions of ‘capacity’ have been identified as core to disability research (Mitchell, 2003); Capacity describes the extent to which a participant has the ability to understand the implications of a consent agreement;

“The matter of determining capacity may be especially complex in some disability research. This is likely to be the case, for example, where the focus is on [...] people with intellectual disabilities, people experiencing mental distress or people utilising some forms of medication, [...]. There is then a further, and related question, as to who can and/or should make a determination in the matter of capacity.” (Mitchell, 2003: 7-8)

Several participants could be categorised within groups described by Mitchell. However, given my accountability to wider disabled communities, my confidence that the research was not exploitative, and that ongoing consent and protective measures (as follow) were in place, I felt that deferring to medical, or other external expertise, at the expense of the students’ own self-knowledge represented a breach of their autonomy. To ensure this position, consent forms (appendix four) and information sheets were delivered at interview in multiple accessible formats (large print, high contrast, braille and aurally) and were talked over with all the participants, using plain language and avoiding technical jargon. Time was set aside for informed consent, to ensure this legal mandate was not mechanistically delivered and to allow for participants’ questions. Participants retained a copy of the consent form, including contact details for myself, my supervisor and the School of Education’s Ethics Coordinator, to ensure communication lines remained open (Sieber, 1992: 26) and recourse was available to senior colleagues. Reiss (1997) observes that an important concern with collecting informed consent prior to the interview is that ‘once given, the burden of liability shifts from the investigator to the subject should something in fact go wrong’ (Reiss, 1979; in Lee, 1993; 31). In addition to the points outlined in the interview materials (for example, right to withdraw and so forth), I therefore stressed that the student could strike anything that had arisen from the record at any point during, or after the interview, without their status and

participation being in any way affected. Following the interview, during the debrief, I re-emphasised issues relating to consent and protection of privacy.

#### **4.4.6 Privacy**

Research conduct and process has been informed by privacy concerns specific to internet inquiry. For example, ethical issues particular to online communication are those of anonymity, reproducibility, diminished trust and consent (Johnson, 2001). This research considers participants' networked activity. In essence this is social research, engaging potentially hundreds of the participants' peers either directly or indirectly. To access these spaces required proxy consent, insofar as the participant allows access to authentic representations of their networked peers during interview. As such, alongside the usual statements regarding confidentiality, peer confidentiality also had to be guaranteed.

Whilst the research conversation and movement through password-protected online spaces was sometimes wide-ranging, a decision was made prior to the research to make sure that only networked public spaces were accessed, that is, spaces available to the student's own network. Personal, non-visible spaces, such as email and direct messaging, were considered private. Participants were informed that if sensitive data was uncovered unexpectedly they could withdraw specific information at any point either during the interview or at any point subsequently. The decision to allow access to their own networks, to move through networked spaces and to pursue links was theirs to make. At several junctures, photos, screenshots and details from screen-capture are presented. Given the detailed and personal information that network profiles convey about participants and their networks, care has been taken to anonymise and disrupt any information that might allow the participant or any of their peers to be identified.

At no point did the researcher control the mouse or any other input device. It was established at the very start that the screen recording software could not extract passwords from the connection to each participant's desktop, or influence their computer in any way.

#### 4.4.7 Inconvenience Allowance

Participants were paid £10 for each interview. A contingency fund was also maintained to ensure participants could be reimbursed for any travel cost incurred for themselves and/or any personal assistant or BSL interpreters. Respondents were informed from the outset about the availability of such monies. None requested this contingency. Those students who participated in repeated interviews over the course of their first term were also offered one of 7 sets of VOIP Headsets (featuring headphones and a microphone with volume control) as a token of appreciation for their participation over a four month period.

I provided an inconvenience allowance in line with *reimbursement* models of ethical remunerative practice (Permutch-Wey and Borenstein, 2009), to ensure that participants should not suffer financial cost for research participation. In this way, I sought to provide compensation for, and recognition of the participants' time, effort and collaboration (Grady, 2005). Debates over participant payments are ongoing; however, some researchers argue that payments are unethical, instigating a commercial relationship that ruptures the researcher-participant relationship (Dickert and Grady, 1999). Financial incentive may also represent an undue inducement to participate in the research (Macklin, 1981). What constitutes 'undue' inducements is a moot point however. As Tishler and Bartholomae (2007) observe, financial incentives are necessarily both subjective and relative – the nature of incentive is not fixed. Students will attach different values to payments and, as a result, relative incentive will vary. Notably, disabled students often incur extra costs associated with their disability whilst at University, such as travel, equipment and personal care (SKILL, 2011). In addition they are less likely to be able to take on part time work (SKILL, 2011). As a result, disabled students (including those in receipt of DLA) may be financially disadvantaged in comparison with their non-disabled peers. This can lead to the criticism that disabled students represent an economically disadvantaged population in higher education and are therefore more vulnerable to undue inducement by financial incentive. It is my position, however, that refusing remuneration on such a basis limits disabled students' options, rather than protecting them, and could invoke a more serious charge of "unwarranted paternalism" (Grady, 2005; Resnick, 2001).

Payment was appreciated by the majority of participants. However, two undergraduate participants were initially resistant to payment (until reassured that the monies were supplied by my funding body and did not represent a personal cost to me). A further two of the 18 refused payment, on the basis that they valued participating and did not want monetary reward. In these cases, payment-in-kind was offered; this consisted of proof-reading, and sharing technical expertise around assistive technologies and social networks themselves.

#### **4.4.8 Debriefing and Ongoing Contact**

All students interviewed were offered a copy of the video and transcripts resulting from their interview. Transcript validation was not mandatory, as I was concerned that, for some students, checking and returning a 7-10,000 word transcript would represent an undue 'bureaucratic burden'. For this reason, participant validation of transcripts as an accurate record of the interview was an 'opt-in'. In this way, I sought to minimise the impact of my research on the normal working and workloads of participants (BERA, 2004: 8), recognising the time pressures of student life, and the additional contraction of time resource that management of disability can require (Elliott and Wilson, 2008). Instead, I established ongoing contact with participants following data collection, contacting students to update them on the progress of the research. As soon as a complete draft of each case was available, these were shared with participants, along with a summary of the research findings. Due to the timescale of the PhD, six participants graduated before this process was complete. As a result, three students were untraceable; a further three were contacted through Facebook. 12 remaining students received their case studies directly. I was sensitive to the fact that returning the participants to the time of the interview, and some of the issues covered, could be potentially difficult for some. Therefore, I ensured that the opportunity for a face to face, telephone or email meeting was possible, to allow feedback and discussion of my interpretation of the interview and any changes that were required, or any personal or privacy issues raised. Students' responses were very positive, and supportive of the project and its account of the network and disability. No changes were requested.

## **4.5 Sample Demographics**

18 students were interviewed. The group included 13 undergraduate students, two Masters and three Doctoral students. Amongst these, a group of six new first year students were interviewed repeatedly over the course of their first term living on campus. A total of 34 interviews were completed in all. Participants came from 11 departments, at various stages of study. Interviews took place in a variety of locations including student Halls of Residence, libraries, student Study Rooms, bedrooms and remotely by phone.

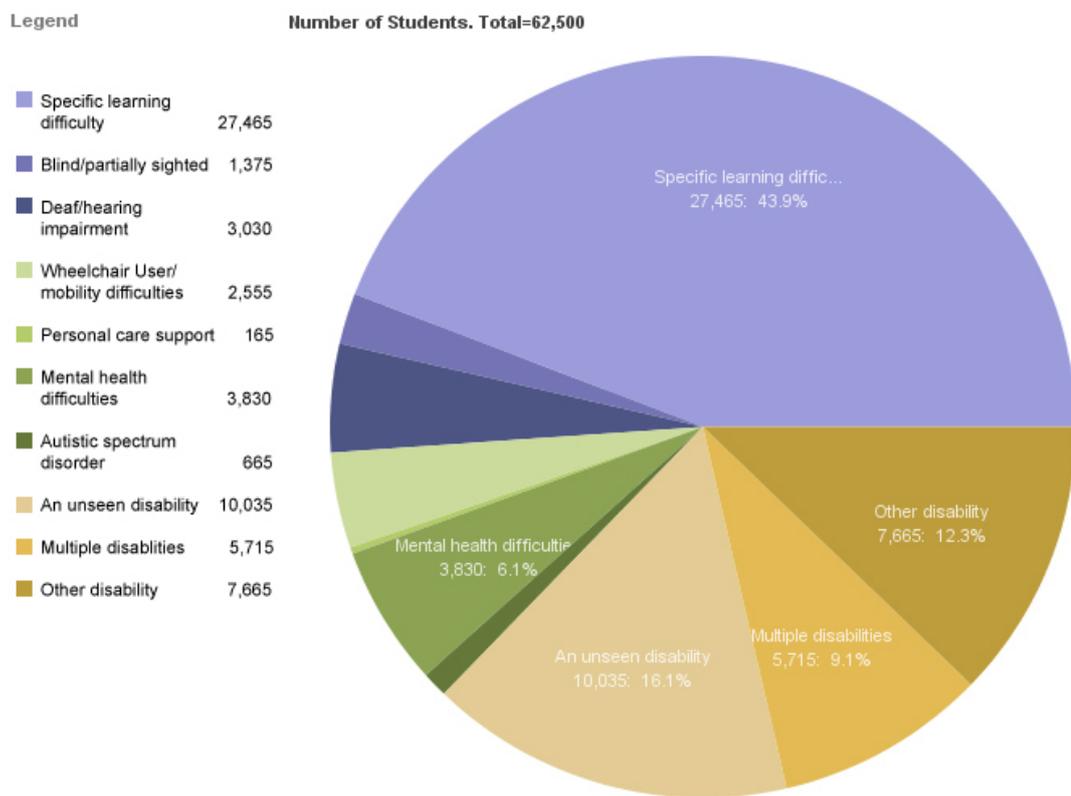
### **Gender, Ethnicity and Situated Identity**

Of the students interviewed, 10 were men and 8 were women. The sample was predominantly white and British, with four exceptions: two postgraduate students; one from Pakistan, the other originally from Romania; two British undergraduates with close familial ties to Eastern Europe and South America respectively. No gender specific aspects presented in the data; however, participants brought multiple situated perspectives to the interviews. A range of associations, including disability, class, feminism, eco-feminism, religion, politics, self-identification as 'Parent', 'Geek' or 'technophobe' were brought to bear upon networking activity. Whilst this research is undertaken to evidence common socio-cultural experiences of disability relating to impairment, it is important to recognise that disability is situated within this wider nexus of roles and grouping perspectives. Shakespeare (1996) argues that, in these terms, disabled groups must be understood uniquely, rather than 'additively'. This is not an argument to disaggregate disability necessarily, but an important warning against viewing disability as 'sole and significant identity' (Shakespeare, 1996: 110). Indeed, disability was not always reported as the most salient factor implicitly effecting students' networking; however, the management of disability proved to be central facet of many students' negotiation of networks.

### **Disability**

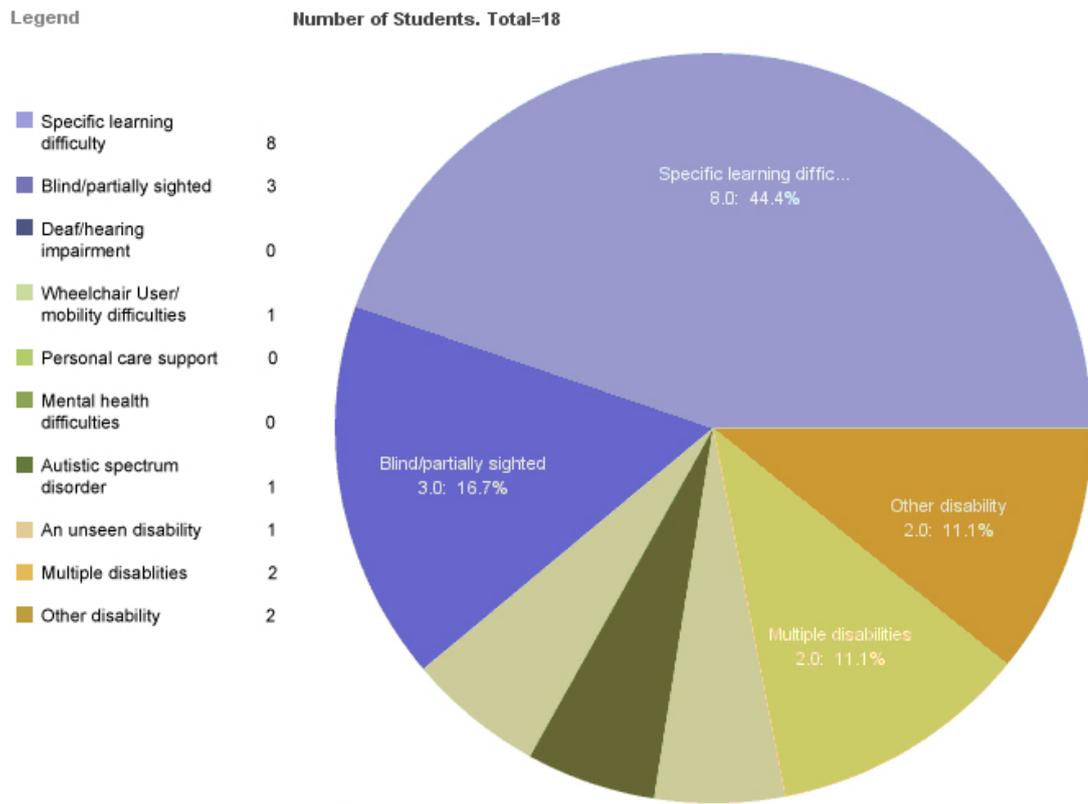
In terms of grouping participants by disability for representative purposes, caveats are important. Chapter three already documents significant failings in the way that disability is measured in official data collection. As such, participants were not asked to place themselves within such categories when asked to discuss their impairments

and/or disabilities. Besides which, this overtly individual and medical compartmentalisation is not a mode of analysis that is relevant for the aims of the present study. However, since such official data represent the only statistical touchstone for research of this kind, in this respect, with caveats, it is employed here as a baseline for a broad overview of representation within the research population.



**Figure 4-10: Students by disability 2007-2008 (HESA, 2008b).**

Figure 4-10 shows the predominance of Specific Learning Difficulties amongst disabilities disclosed in higher education. Specific Learning Difficulties account for 43.9% (n = 27,465) of the cohort in receipt of DSA. The next largest group reported are those with unseen disabilities (16.1%, n = 10,035). The undefined ‘Other’ disabilities (12%, n = 7,665) and those with multiple disabilities (9.1%, n = 5,715) make up the next most substantial groups according to the categories ascribed by HESA.



**Figure 4-11: Participants by disability (according to UCAS/HESA categories)**

Figures 4-10 and 4-11 show some equivalence between the participant group and national averages in the UK student body according to these measures. However this categorisation masks diversity within and across groups. Over half the participants (11) reported having a specific learning difficulty; eight with dyslexia and three reporting dyspraxia or a combination of dyslexia and dyspraxia. This was not a homogenous group. For several participants, dyslexia was one of multiple disabilities and as a result, not reported as a primary impairment. Notably, this group also includes students with other impairments, including a student with ADHD and another ‘categorised by IQ tests as having learning disabilities’. Thus ‘Specific Learning Difficulties’ represents a diverse group. Two students fall into the ‘other disabilities’ catch-all category for the purposes of comparative analysis. One student had a long term health condition; the second reported a fine motor impairment that is not easily bracketed with mobility impairments. In figure 4-11 the representation of students ascribed as ‘mental health difficulties’ and ‘Deaf/hearing impaired’ is unclear; it should be noted that two students stated ‘multiple impairments’ that included hearing impairments and mental health difficulties respectively. Notably, other students who identified a primary impairment also cited experiences of

secondary impairments that they had not received formal support for or diagnosis for, but which constituted significant aspects of their experiences of impairment.

Despite this diversity, representational gaps do occur. No wheelchair users or students who require personal care support responded to the call for participants. Furthermore, none of the respondents identified themselves primarily in terms of mental health issues. Notably two participants disclosed significant mental health issues amongst other disabilities and the experiences of both these students have had valuable implications for the resulting data. However, the lack of a response from students with mental health issues reiterates Riddell et al.'s observation that the benefits of declaring a mental health difficulty within the context of higher education are small, whilst the perceived costs can be great in terms of stigma and risk (Riddell et al. 2005).

### **Age and Discipline**

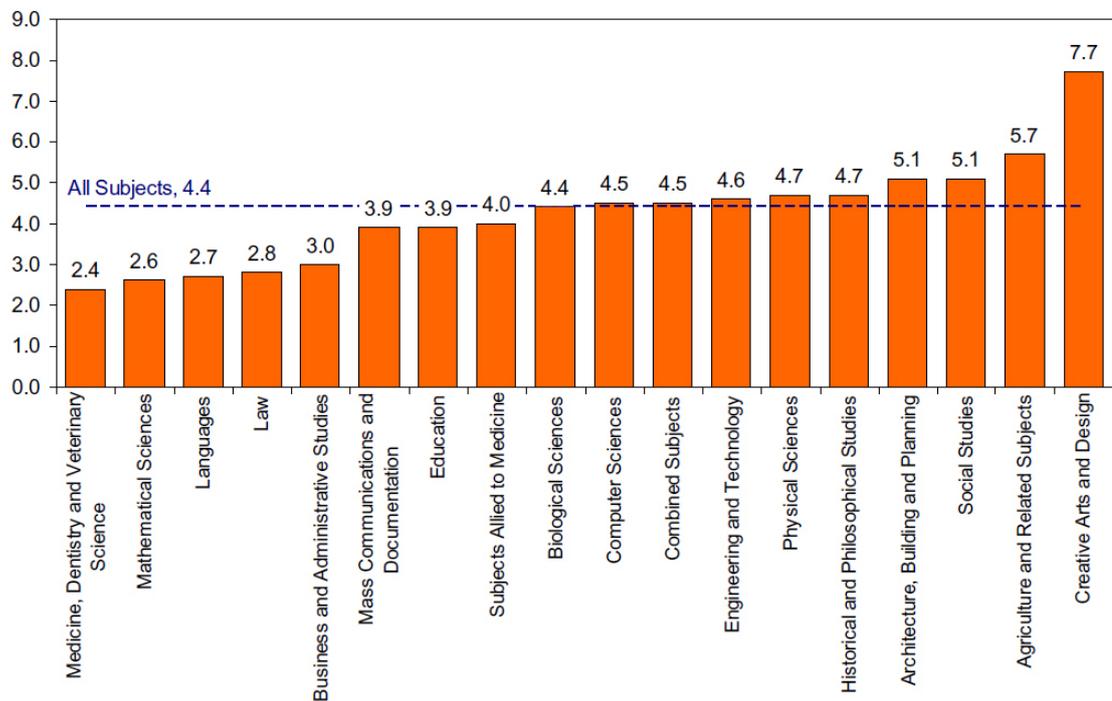
DIUS<sup>24</sup> (2009) extrapolate several characteristics amongst the disabled student population in higher education<sup>25</sup>. Their analysis states that disabled students are less likely to be in higher education by the age of 19, as they tend to have entered higher education through non-traditional routes, thus disabled students' age upon entry tends to be higher. DIUS also assert that students reporting a disability in higher education are more likely to be undergraduate (compared to postgraduate) male (compared to female) and in full-time (rather than part-time) study. Finally, DIUS observe that more disabled students are found in creative disciplines, alongside Agriculture, Social Studies and Architecture. Conversely, Medicine, Mathematical Sciences, Languages and Law are identified as having particularly low concentrations of students in receipt of DSA (DIUS, 2009). Amongst the participant group, these trends were not visible. All the undergraduate participants had progressed through a traditional route (following A-Levels) into higher education. All the participants had an average age within the same range of those with 'no known disability'.

---

<sup>24</sup> DIUS has since been reformed into the Department for Business, Innovation and Skills which retains responsibility for tertiary education.

<sup>25</sup> The DIUS analysis is based on a range of sources including Youth Cohort Study (YCS) UCAS, HESA, the Student Income and Expenditure Survey (SIES) and the Labour Force Survey (LFS).

In terms of discipline, participants represented 11 departments, predominantly in the humanities and social sciences, with representatives from a range of subjects including theology, languages, law, computer science, maths and engineering, education, business and economics. DIUS analysis shows that nationally more disabled students are found in creative disciplines, with Creative Arts and Design demonstrating particularly high concentrations of students in receipt of DSA (see figure 4-12). Other subjects DIUS also cited as demonstrating above average levels of disabled student participation include Agriculture, Social Studies and Architecture.



**Figure 4-12: Proportion of students in receipt of DSA**

At the primary research site, Fine Arts and Design constitute minor subjects within larger departments (for example, Architecture and Education). Agriculture is not offered as a field of study. Figure 4-14 offers a comparison chart stating the overall levels of disclosed disability at University A by discipline.

Disabled Students at University A by Discipline

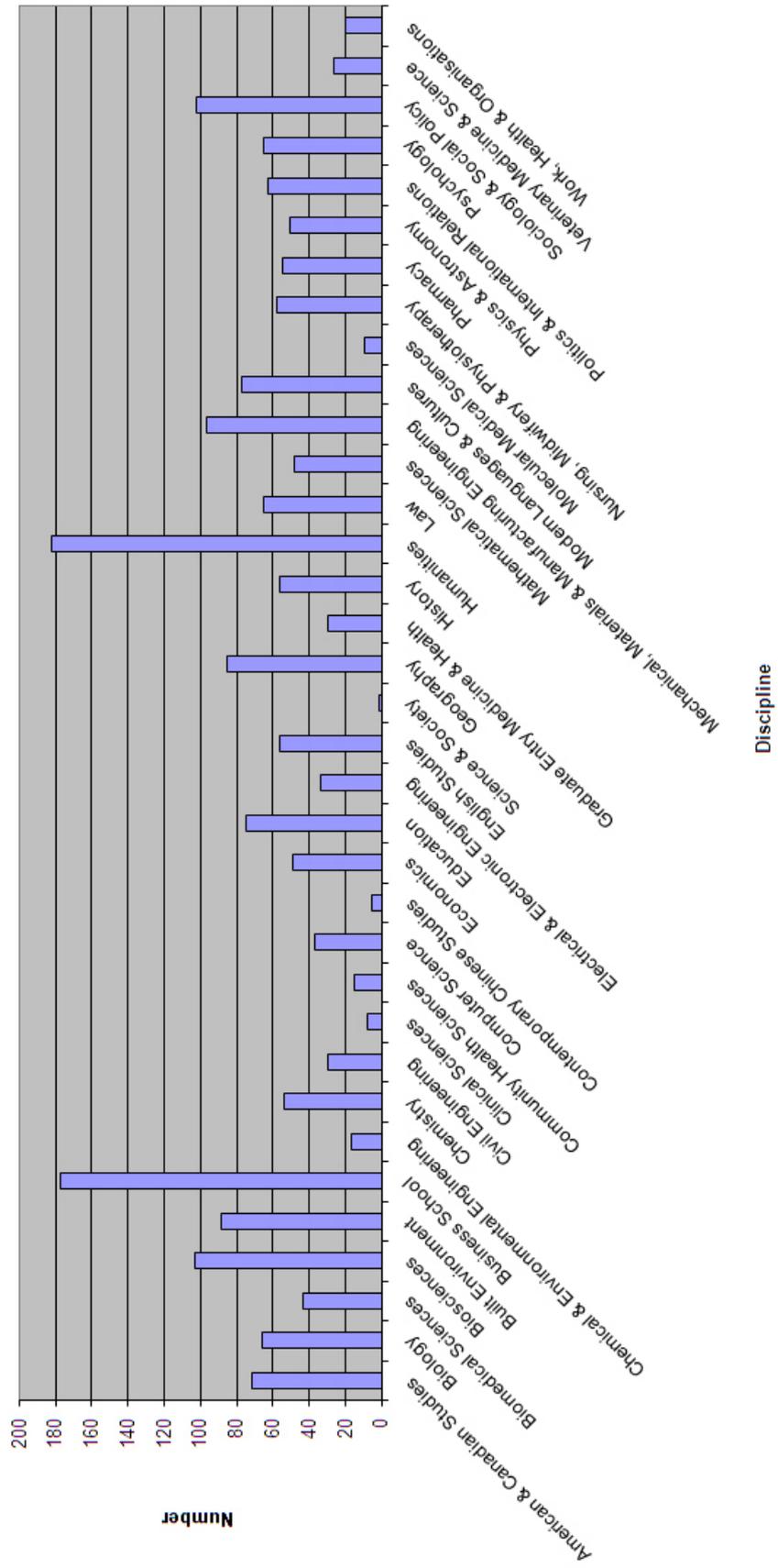
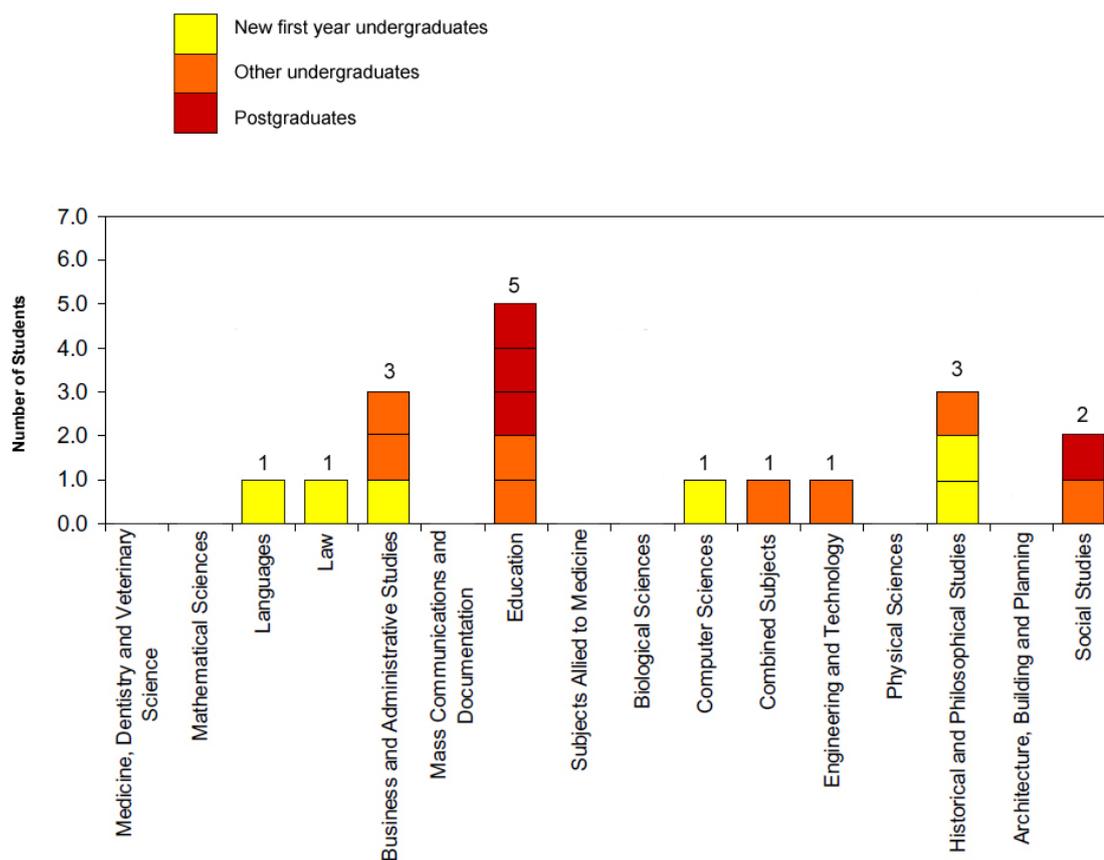


Figure 4-13: Number of Disabled Students at Research Site University A by Discipline

As a result, figure 4.14<sup>26</sup> (below) shows participants by subject group, with these fields omitted.



**Figure 4-14: Participants by subject group**

It was not possible to recruit participants from all disciplines within the limits of the study. However, whilst no architecture students were interviewed, many respondents represent social and applied science backgrounds, especially Education, Sociology and Business Studies. The dominance of Education and Sociology amongst postgraduates may indicate willingness to engage with social research processes, rather than any specific trend amongst respondents.

Conversely, DIUS identify Medicine, Mathematical Sciences, Languages and Law as having particularly low concentrations of disabled students (DIUS, 2009). There were no research respondents from medicine (or ‘allied subjects’), biological

<sup>26</sup>The combined studies popular with many students are not easily represented amongst the categories used by DIUS. As a result figure 4-14 is advised as a rough guide to the participants’ disciplines.

sciences or ‘architecture building and planning’ subjects. However, exceptions do occur, with one participant studying Law and three others undertaking combined studies, one in Electrical and Electronic Engineering and Maths, and two others combining social sciences with languages; in one case, Business with French, in another American and Russian Studies, with a language component.

#### ***4.6 Managing Data***

A total of 34 one hour interviews resulted in 34 hours of audio data and 31 hours of screen capture video, with supplementary screen shots and digital photos taken in instances where connectivity had been interrupted. Other data produced during repeated interviews included network maps and photos of work spaces. In two instances research objects were collected.

All interviews were fully transcribed. Transcription has a low status amongst research processes (for example, Stark, 2000). However, early in the research, it became clear that verbatim transcription was vital to the success of the project. Qualitative analysis would be built upon verbal data, alongside screen capture, thus it was imperative that interview talk was accurately reflected in the text, with annotation where necessary to depict instances of paralinguistic cues, such as laughter, sarcasm etc.

To produce accurate transcriptions in an effective and timely way, I deployed the speech recognition software Dragon Naturally Speaking (v10). This software is commonly used as an assistive technology for people who wish to dictate rather than type when creating a document or other text on their computer. This is advantageous for people with fine motor impairments, dyslexia and other print impairments. This process is also now used by for legal stenography and supplying closed-captions for live audio-visual broadcasts, as it allows the quick and efficient reporting of audio into text. The use of speech recognition for transcription means that the researcher/transcriber listens to a recording of an interview and repeats the speech of both interviewer and participant(s) into a microphone. From this point the software converts this speech to text, adding automated punctuation.

In many cases, this method allowed a quick, near synchronous rough draft of each interview to be created. During the first listen-and-repeat, the recording is played back, with as much repeated as possible to create the first draft. This rough draft usually lacks the correct punctuation and will have mistakes in voice recognition that require correction, along with additions where any specific words or technical phrases, slang or dialect have been missed, or mis-reported by the software. Notably, as Dragon is designed to be trained to the user's voice, repeated mistakes by the software could be mitigated by applying overrides. To an extent however, the user also becomes trained to dictate in a manner that Dragon recognises – effecting clear enunciation and the suppression of any UK/regional accent. In this sense, speech recognition does not report natural speech; this process is known instead as 're-voicing' (Wald, 2006: 15).

A second run through clarifies any sections of speech that may be inaudible or require careful listening. Using this system one hour of audio data could be transcribed verbatim in approximately 5 hours, allowing for detailed proofing. Any emergent themes that arose during this process were noted separately. Transcripts in Rich Text Files could then be imported directly into qualitative analysis software for coding and analysis. From here, transcripts are stitched into the video using time cues that allow in-depth analysis of visual and audio data according to themes arising from the data.

The process of simultaneously listening to the interview, speaking the interview aloud, and reading and re-reading each interview in transcription offered a valuable means of learning the data. In this respect, the transcription activity, whilst requiring concentration, ceased to be a mechanical drudge process, instead becoming a valuable entry into analysis. My previous experiences of transcription had required frequent shuttling backwards and forwards through audio as I needed to slow recorded speech to a typing speed. As a result, instances of interview talk become disjointed and lost their meaning in relation to the wider flow of conversation. By re-voicing, transcription could take place at a more natural speed. Using the emergent

draft and re-draft approach, meaning was retained and the interviews became more memorable<sup>27</sup>.

## **4.7 Thematic Analysis and Presentation**

Verbal, textual, video and photo data were analysed using NVivo 8, a qualitative analysis software that allows multiple streams of multi-media to be thematically categorised and sorted, coded and explored in an integrated way. Advances in the coding facilities of NVivo meant that it was possible to keep speech-as-text synchronously linked with video and audio data, so that video, audio, text, coding and annotation were available simultaneously. This allowed speech to retain its context and innuendo. This had the benefit of affording a quick negotiation of onscreen phenomena linked to themes in conversation, as the video transcript and time coding allowed different modes of access and reference to the data. As previously stated, data analysis began from an activity theory and phenomenographic stance. This was discontinued due to a lack of sensitivity with respect to discursive practices and the movement of power in participant accounts – leading to the application of discourse analysis and case study.

### **4.7.1 Discourse Analysis and Case Study**

Within participant talk, repeated reference to the highly normative conditions of Facebook and student life lead to analytic attention being directed to the implicit rules, norms and power relations that constituted disability in student experience. To this end, discourse analysis was applied to participant transcripts and videos, to fully recognise the discursive fabric of participants' lives in terms of the social and institutional dimensions of discourse. Discourse analysis has three unifying assumptions:

---

<sup>27</sup> In higher education, the value of speech-to-text and re-voicing are increasingly evidenced. In lectures, live captions provided either within the room (Robison and Jensema, 1996, cited in Wald, 2006) or via remote channels (Brett, 2006) have had proven value for deaf students. Wald (2006) further identifies the benefits of linking the subsequent transcripts with multimedia. However, throughout such instances research has focussed on the recipient of the transcript as distinct from the creator of the transcript. In social research, it appears that researchers can benefit from both the transcription process and results. In terms of future research, re-voicing has two further advantages over traditional data input in terms of comfort and non-reliance on typing skills. Both factors are important given the increasing opportunities for researchers and their participants to collect multi-modal data through near-ubiquitous mobile technologies in the field.

1. Anti-realism: Discourse Analysis is resolutely against the assumption that we can treat accounts as true or false descriptions of 'reality' As Potter puts it: 'Discourse Analysis' emphasises the way versions of the world, of society, events, and inner psychological worlds are produced in discourse'.
2. Constructionism: Discourse Analysis is concerned with 'participants' constructions and how they are accomplished and undermined'.
3. Reflexivity: Discourse Analysis considers 'the way a text such as this is a version, selectively working up coherence and incoherence, telling historical stories, presenting and, indeed, constituting an objective, out-there reality' (Potter, 2004: 202) in Silverman (2006: 224)

These terms are commensurate with fundamental aspects of the research design, and allowed an explicit focus on social construction, identity, power and resistance.

Moving into analysis I coded and reported on the aspects or events within the data that were significant to the participants in light of this discursive framework, in the context of the literature review and my research questions (see appendix five). On this basis, prevalence and quantitative frequency of an event was not considered important to the research. This was not considered to be an 'unmasking' of what was 'really' going on. I was anxious that my analysis did not ironise participant perspectives. As a result, I sought to reflexively recognise my own role in mediating student voice within analysis, based on the coding groundwork already undertaken.

The research results are introduced in a series of theory-seeking case studies. I adopted case study amongst interpretive methods to deploy multiple presentations of data in an attempt to construct a multi-perspective description of cases (Stake, 2000; Merriam, 1998; Bassey, 1999). Thematic, cross-case analysis follows these cases to elaborate the interpretive and critical concerns of the research.

The strengths of the case study have particular relevance for this research, where complexity, subtlety and the accessibility of disabled students' perspectives to the reader are key factors. Adelman et al state:

- a) Case study data, paradoxically, is 'strong in reality' but difficult to organise. In contrast other research data is often 'weak in reality' but susceptible to ready organisation...
- b) Case studies allow generalisations either about an instance or from an instance to a class. Their peculiar strength lies in their attention to the subtlety and complexity of the case in its own right.
- c) Case studies recognise the complexity and 'embeddedness' of social truths. By carefully attending to social situations, case studies can represent something of the discrepancies or conflicts between viewpoints held by participants.
- d) Case studies, considered as products, may form an archive of descriptive material sufficiently rich to admit subsequent reinterpretation.
- e) Case studies are 'a step to action'. They begin in a world of action and contribute to it. Their insights may be directly interpreted and put to use...
- f) Case studies present research or evaluation data in a more publically accessible form than other kinds of research report, although this virtue is to some extent bought at the expense of their length. (Adelman et al., 1980: 59-60) in (Bassey, 2008: 23)

It is particularly important to account for complexity in disability research, reiterating the multifaceted nature of disability and acknowledging this in the analysis of experience (Zappone, 2003). In this way, the case study offers an important way forward, negotiating a path between complexity and coherence prior to discussion of themes and findings. As Merriam (1998) observes:

the qualitative case study can be [...] the process of actually carrying out the investigation, the unit of analysis (the bounded system, the case), or the end product. As the product of an investigation, a case study is an intensive holistic description and analysis of a single entity, phenomenon or social unit'. (Merriam, 1998: 34)

I present each participant's experiences in a case format to maintain a position that is complex, subtle and 'strong in reality'. The construction of a case study is a key state of data analysis (Stake, 1995; Bassey, 2004). Therefore, strategies to ensure quality included:

*'Member checking'* (Stake, 1995: 115): through which emergent results, case studies and research summaries were checked with participants to seek alternative interpretations.

*'Reflexivity'*: through which efforts were made to reflect on my own potential research bias and the effect on the research process and interpretation of data.

*'Prolonged engagement in the field'* (Cohen, 2000:18): Although it is difficult to establish what represents sufficient time in the field, the opportunity for repeat interviews with participants gave more time for a more detailed account of students' experiences to unfold in collaboration with participants.

*'Data triangulation'* (Merriam, 1999:204): This triangulation indicates 'the process whereby data collected from different methods [...] are crossed to help the researcher construct a holistic understanding of the situation' (Merriam, 1999:204). To this end, I used screen capture recordings to augment instances of student talk where possible.

#### **4.7.2 Onscreen Phenomena**

The internet supplies rich data through screen capture for analytic and illustrative consideration. Content analysis has not been a primary concern of this research, however. In analysis, the results of screen capture have been used primarily for illustrative purposes, for reference and data triangulation (Merriam, 1999). This has been for several reasons. Firstly, from an ontological position, I have felt it important to recognise that shifting the focus of research from the individual to their onscreen representations would fail to report authentic understandings of this content. Privileging my own view on student screen phenomena arguably instigates a research hierarchy that privileges the researcher's observation over the student construction of meaning that those artefacts realise.

There is also a potential ontological issue at stake here, available to us through arguments posited by Hayles (1999). Hayles actively seeks to complicate the abstract dichotomies present in dominant technology discourse. In a statement of intent, she problematises the leap from embodied reality to abstract information, with important implications for research straddling these spaces:

Abstraction is of course an essential component in all theorising, for no real theory can account for the infinite multiplicity of our interactions with the real. But when we make moves that erase the world's multiplicity, we risk losing sight of the variegated leaves, fractal branchings, and particular bark textures that make up the forest. (Hayles, 1999: 12)

Hayles continues to identify two moves that she deems central to the construction of an information/materialist hierarchy that distorts understandings of the real world and its online equivalents. She terms these the 'Platonic backhand and forehand':

The Platonic backhand works by inferring from the world's noisy multiplicity a simplified abstraction. So far so good: this is what theorising should do. The problem comes when the move circles around to constitute the abstraction as the originary form from which the world's multiplicity derives. Then complexity appears as a 'fuzzing up' of an essential reality rather than as a manifestation of the world's holistic nature. (Hayles, 1999: 12)

This back-to-front semblance of the real world in theory is important, but not complete. When considering the interface between 'real' and 'virtual' realms, the 'platonic forehand' comes into play:

Whereas the Platonic backhand has a history dating back to the Greeks, the Platonic forehand is more recent. To reach fully developed form, it required the assistance of powerful computers. This move starts from simplified abstractions and, using simulation techniques such as genetic algorithms, evolves a multiplicity sufficiently complex that it can be seen as a world of its own. The two moves thus make their play in opposite directions. The backhand goes from noisy multiplicity to reductive simplicity, whereas the forehand swings from simplicity to multiplicity. They share a common ideology - privileging the abstract as the Real and downplaying the importance of material instantiation. When they work together, they lay the groundwork for a new variation on an ancient game, in which disembodied information becomes the ultimate Platonic Form. (Hayles, 1999:12-13)

When conceptualising online spaces, it is thus desirable to recognise any instinct towards the abstraction of the Real, and, arguably, over-estimation of the complexity of online representations. For this reason, interviews privileged students and the meanings they ascribed to online phenomena and activity, rather than the 'authentic' onscreen phenomena itself. Where dissonance between onscreen phenomena and student talk occurred, this was raised within the interview. In this way, the interviews

could be characterised as ambulant; moving through online spaces, charting them with respect to the guidance offered by participants.

### **4.7.3 Confidentiality and Representation**

Strict attention to participant confidentiality has been forefronted. Merriam (1998) and Malone (2003) warn against believing that full protection of identity is possible. However, I have tried to conceal the identity of participants to external readers using the sum of approaches outlined by Frankfort-Nachmias and Nachmias (1992, in Cohen, et al. 2000: 63). In reporting of data, I have deleted ‘identifiers’ (names, and other means of identification). I have ensured ‘crude report categories’ particularly with respect to the students’ disciplines. I have also used ‘error inoculation’ to deliberately introduce errors into individual records, whilst leaving the aggregate data unchanged. Such techniques seek to ensure ‘non-traceability’. This is essential, as, due to the relatively low numbers of disabled students in higher education during the timeframe of the research, it would be relatively easy for a student to be identified through a combination of cues (for example, course and impairment) and inferences regarding institutions to be drawn. At the same time, I have sought to balance confidentiality with issues of representation. As Stake notes, it is ‘the researcher who ultimately decides criteria of representation (2000: 441). As previously stated [4.4.1] I am aware that in writing the research I am ‘creating’ my participants. In the process of writing I have therefore sought to provide illustrations and a vivid account of data to ‘maximise the reader encounter with the complexity of the case’ (Stake, 1995: 126). As a result, wherever participant contributions are quoted, quotes are reported verbatim. Contributions are not edited for grammar, repetition or phrasing. The symbol [...] is used to indicate where words or phrases have been edited out for brevity. Where possible, longer quotes have been used to allow participants’ views to be fully expressed. Occasionally the subject of talk is inserted in brackets for clarity. In addition, participant contributions are given with name only. This is a conscious move to maintain emphasis on the participant rather than their impairment. To assist the reader where necessary, appendix two supplies 18 short participant profiles to offer a reference point for later chapters. Profiles incorporate the students’ language of impairment, to resisting a research intervention of unnecessarily reductive or medicalising language.

## **4.8 Summary**

This chapter has described the research aims and methodology, recounting the methods used to articulate the research with special attention to issues such as power, representation, the ethics of digital disability research and accessibility. In the next chapter, the research participants are introduced.

## Chapter 5. Case studies

---

This chapter introduces the participants with 18 case studies that explore disabled students' experiences and management of social networks and disability.

To produce these case studies, transcripts were analysed and annotated in conjunction with visual screen data and audio. Coding began within an activity theory framework, attending to disability in terms of tools, communities, norms and roles. However, this framework did not sufficiently scrutinise the emergent identities, normativities and power relations expressed by students and visible in their interactions and reflections. As a result, I moved to use discourse analysis as my primary optic for understanding student accounts.

Discourse analysis has allowed me to address to the research questions within a wider Foucauldian, discursive framework. On this basis, it is important to observe that although I describe student's experiences, this report is not direct. Students related their experiences to me at interview and I, in turn, have mediated student voice in my analysis and accounting. The cases have been shared with participants to ensure recognition. Nonetheless, this chapter represents a series of snapshots, each a facet of 'dis/ability' refracted through my voice, my particular theoretical lens, my analytic instincts and the wider PhD process.

### 5.1.1 Selection of Case Studies

I have elected to present all 18 participant case studies. This was decided on the basis of several key factors. Previous drafts of this thesis tested smaller vignettes against a selection of exemplar case studies; however, I was concerned that such an approach did not sufficiently recognising the diversity of the wider group, instead suggesting archetypes that I was concerned might foreclose on meaningful engagement with complexity prior with later necessary moves towards abstraction and theory.

In addition, through the process of thematic analysis, disability was found to be dynamic and discursively realised. Impairment is not found to be the determinant of dis/abled experience in the network. All the participants recognised that they are deemed to have a disability or learning difficulty in an educational context. Outside education in a social, digital context however, the boundaries of ascription are reconfigured. For some, the network represents a space in which disability was irrelevant, constituting a non-disabled experience, for others the network created new indices of impairment and disability that were not experienced in adjacent contexts. Discussion of 'disabled' experiences constitute the main part of later chapters, however, recognition of 'non-disabled' participant experiences are important as they emphasise the relative nature of ability and disability and provide important insights into the production of both as particular subjectivities that inform actions that may support or challenge the wider status quo.

In sum, I present all 18 cases as I deem each salient to the thesis. Each offers an opportunity to deepen understanding and problematise the 'essential' characteristics of disability. Particular cases are expanded in discussion in later chapters, to illustrate particular facets of disabled experience.

### **5.1.2 Order and Structure of Case Studies**

Some participants are found to be disabled by the network, others are afforded a non-disabled experience. Case studies are therefore presented tentatively in this mode under the titles 'enabled perspectives' and 'dis/abled perspectives', with caveats.

Whilst all participants have impairments according to educational norms, student perspectives on external restrictions and self-identifications varied widely. Some students expressed non-disabled subjectivities in the network and reported no restrictions. These constitute 'enabled perspectives'. Amongst the greater number of participants, experiences were more complicated. Few identified themselves as 'disabled people'. Instead students are seen to traverse disabled and non-disabled identities to negotiate and anticipate external ascriptions. In short, whilst some student identified themselves as more, or less dis/abled, they were never between these states. In addition to these self-perceptions, I noted that externally imposed

restrictions created instances of 'disability' that were at time unreflected, creating another dimension of dis/ability. Disability is therefore found to be multi-indexical, dependent on numerous factors, including (but not limited to) student identifications, practices, peer interventions and social and technological affordances. Experiences may be cumulative or barely reflected. Each of these aspects is dynamic and prone to change. Thus, these 'categories' of 'enabled' and 'dis/abled' are not static or exclusive.

Each case study supplies a brief introduction to the student and their conception of their impairments and disability. From this point their 'technological landscape' is introduced, outlining the technologies the participant uses, key characteristics of their online activity and their past and present use of social media. Case studies are then presented in terms of the three research questions outlined in the opening phase of this thesis. To reiterate;

RQ1: How and where does disability occur within disabled students' networks?

RQ2: How do disabled students experience disability in the network?

RQ3: How do disabled students manage disability in the network?

Each case answers these questions in turn. First I move to focus on impairment and disability within the network. 'Disability and the Network' in each instance identifies where dis/ability difference is identified in the student's network and supporting systems. 'Experiences of Disability and the Network' explains the student's awareness of disability in their interactions with the SNS and networked public; 'Managing Disability and the Network' reports management techniques and strategies undertaken by participants to govern their experiences.

Frequently ascription was observed to be built over issues of 'fit' and 'misfit' at two levels; at the tool level of the SNS, and at the community level of the networked public. Fit is a term that has been used in accessibility discourse (Kelly et al., 2009) and in social research (Selwyn, 2006). In disability studies, Misfit evokes identity politics (Garland-Thomas, 1997). As a result, fit and misfit are highlighted at a technical and social level to pinpoint the way in which normativities of non-disabled

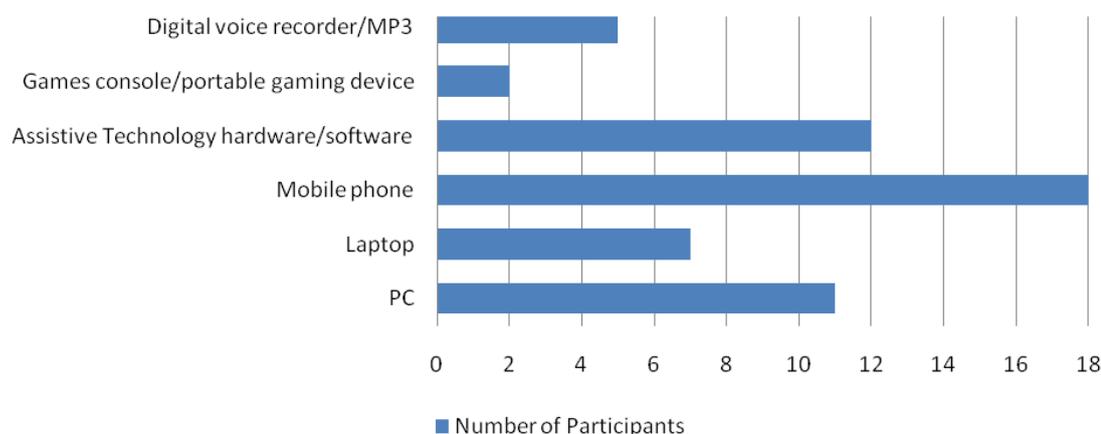
and disabled are located as the central determinant of dis/abled experience. This is aspect is expanded in the analysis of chapter six.

Students expressed a variety of different perspectives on technology and demonstrated diverse interests and activities. To assist navigation of such thick data, prior the case studies, I now supply an overview of participants' social networking activity.

## 5.2 Network Context

This section begins with general observations about the participants' technological circumstances and then moves to consider key aspects of the participants' networks and activities.

### 5.2.1 Ownership of Technology



**Figure 5-1: Ownership of Technology. N = 18.**

All the participants had a mobile phone and dedicated networked computer for their sole use, either at home, in their student residence or in a shared study room (see figure 5-1)<sup>28</sup>. For all students, their laptop or PC represented their primary mode for accessing the internet. Assistive Technologies (ATs) made up an important part of the technical and social landscape in which students live. Disabled Students' Allowance (DSA) provides financial resource for disabled students to pay for

<sup>28</sup> No participant reported using their mobile to access the internet. Interviews took place before the mobile web was established with the research population or student body as a whole.

specialist equipment to study and perform on an equal basis with other students. ATs fell into two broad categories, specialised assistive technologies and generalised technologies deployed for assistive ends. Roulstone (1998) categorises types of AT by use, according to those ‘specifically designed/adapted’ (specialised) and those that are ‘mainstream with minor adaptations’ (generalised). According to these styles of use, participants deployed technologies assistively in the following ways:

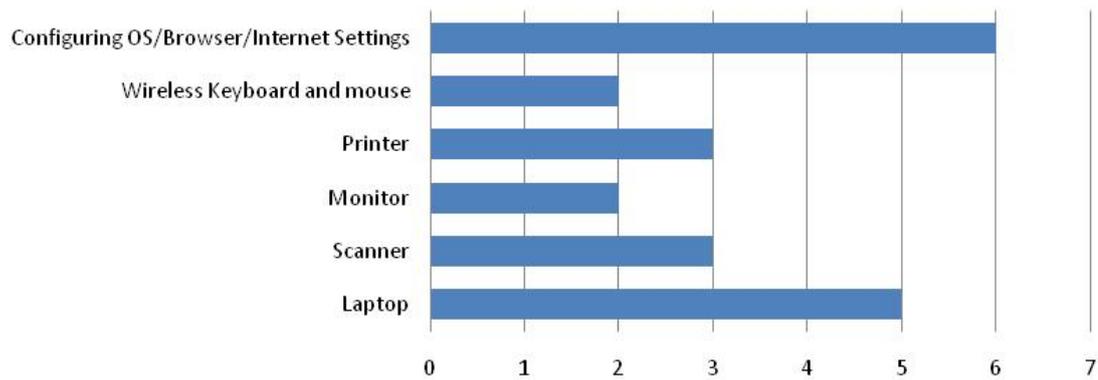
		<i>Number</i>	<i>Percentage</i>
<b>Assisted</b>	<b>Mix of technology types</b>	6	33%
	<b>Specialised designed/adapted</b>	2	11%
	<b>Generalised / with minor adaptations</b>	3	17%
<b>Unassisted</b>	<b>No technological support</b>	<b>7</b>	<b>39%</b>
	Awaiting DSA	3	
	Choosing not to use	2	
	Not relevant	2	

**Figure 5-2: Assistive Technology Use by Type. N = 18.**

More than half of the participants (11/18, 61%) used assistive technologies. However, a significant proportion did not (7/18, 39%). This group included three students (17%) awaiting assessment for DSA. Two more students had experimented with speech recognition and found it unhelpful. Two further students felt that ATs were not relevant to them, as their impairments (Cancer and ADHD respectively) could not be offset by current AT provision.

### **Generalised Technologies for Assistive Purposes**

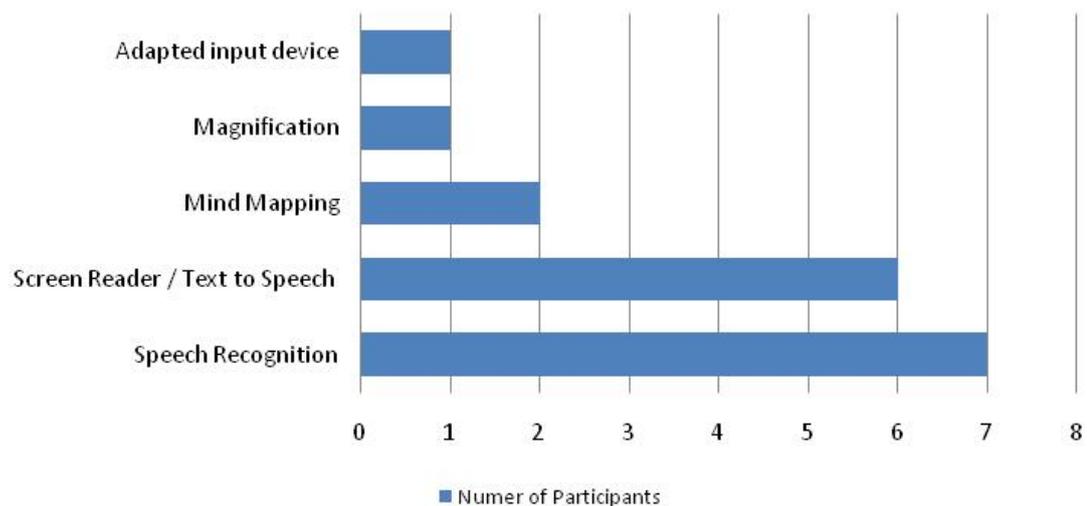
Nine students used mainstream tools in an assistive capacity. Of these, eight students deployed a mix of hardware as part of their assistive set up. This included large monitors for students with visual impairments and altered computer settings and style sheets for internet browsing, altering font formats, contrast and background for better content visibility.



**Figure 5-3: Ownership of Generalised Assistive Technology. N = 9.**

### Specialised Technologies for Assistive Purposes

Eight students used specialised technologies to assist their computer use. These specialised assistive technologies were predominantly software; however, one student deployed an adapted roller ball mouse. Further to this, two students reported using low-tech solutions for mediating their computer activity; examples include high-contrast stickers on a regular keyboard, and a piece of yellow cellophane taped across a laptop screen.

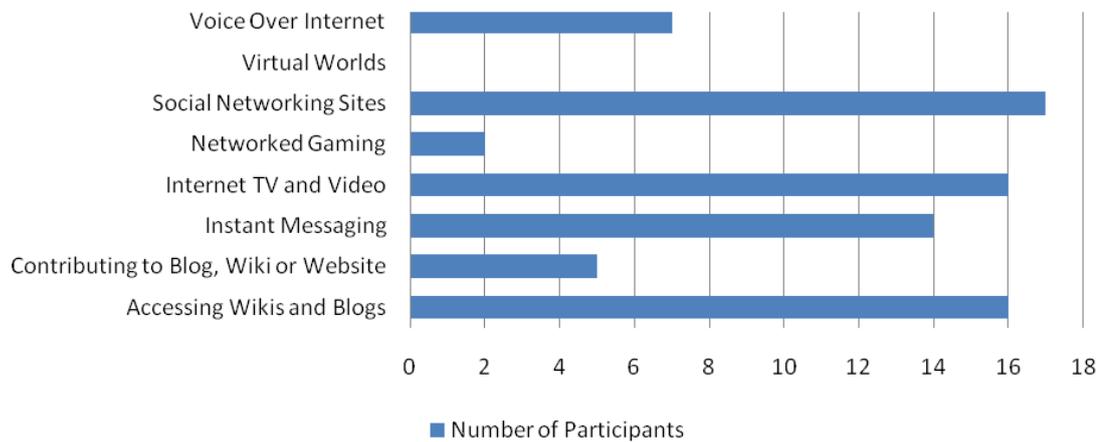


**Figure 5-4: Ownership of Specialised Assistive Technology. N = 8.**

Participants' assistive technologies and their interactions with social media are discussed in the case studies and analysis of chapter six.

## 5.2.2 General Internet Use

All 18 participants used the internet daily. Regular activities amongst all participants included the use of search engines, personal and university email and accessing a university portal for learning materials.

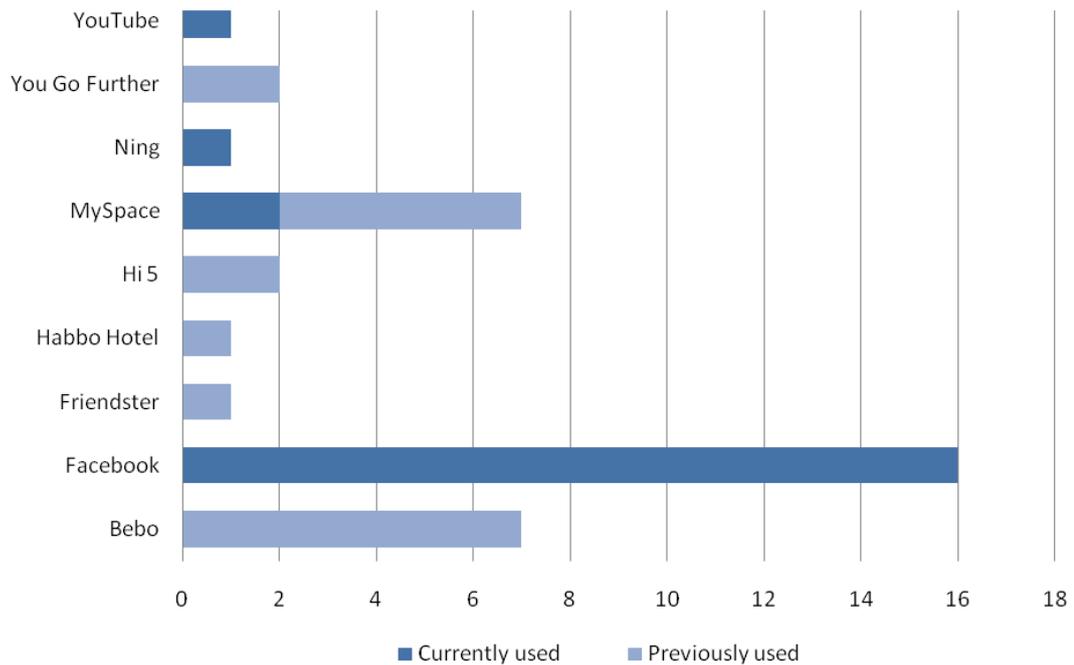


**Figure 5-5: Participant Online Activity. N = 18.**

Social networking was the most prominent social activity online. Other tools such as Skype and MSN were listed by students for directed communication purposes, with Instant Messaging cited as a tool used regularly prior to university. Notably, short messaging had been largely supplanted by SNSs at university, a factor that few students had anticipated. Many reported that this had been an important part of their networking activity at secondary school. As regular school hours are discontinued, however, this synchronous communication is abandoned.

In terms of more emergent technologies, few students had heard of immersive virtual worlds such as Second Life. Likewise, social bookmarking services such as Delicious were virtually unknown. At the time of the interviews micro-blogging service Twitter was only used by one participant, Claire.

### 5.2.3 Participant Use of Social Networking Sites



**Figure 5-6: Participant Use of Social Networking Sites. N = 17.**

Facebook dominated students' social networking. It was the internet service that was most actively used and contributed to.

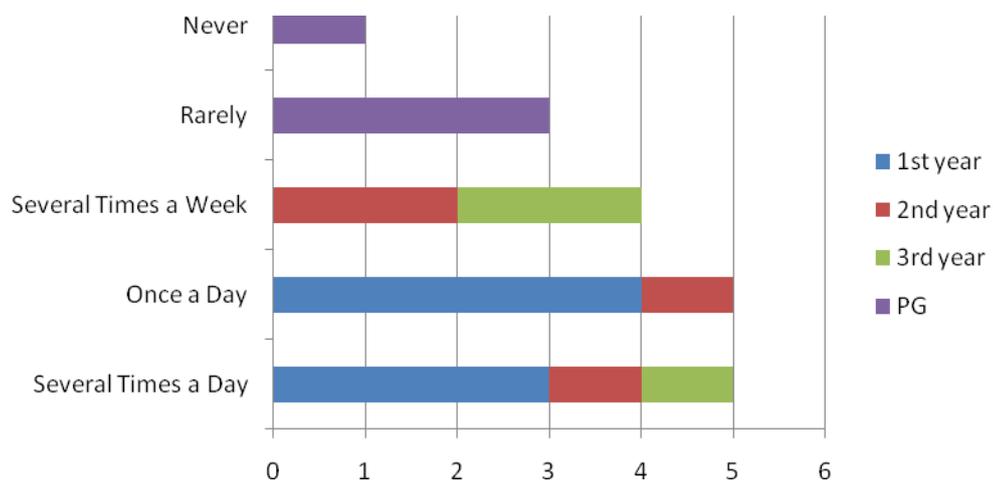
Since Facebook was conceived within a University, targeting an undergraduate demographic, it is arguably the social network most attuned to the rhythms of university life, with affordances and capabilities built to mesh with student culture. This synergy with higher education is amplified by the fact that networks are banned at the vast majority of English schools and colleges.

Other SNSs cited by participants comprised Friendster, Habbo Hotel, Bebo, Hi5, MySpace and very brief exploratory use of YouGoFurther<sup>29</sup>. One participant, Ben, used a YouTube profile as an adjunct to Facebook to interact with a friend who was a film-maker. With the partial exception of MySpace and YouTube these networks were cited as dormant, cursory, or out of date. Such accounts had rarely been deleted; however, log-in information had often been lost or forgotten. MySpace proved more resilient, in large part due to its status as a music portal.

<sup>29</sup> A glossary of social networking sites, terms and jargon is supplied in appendix one.

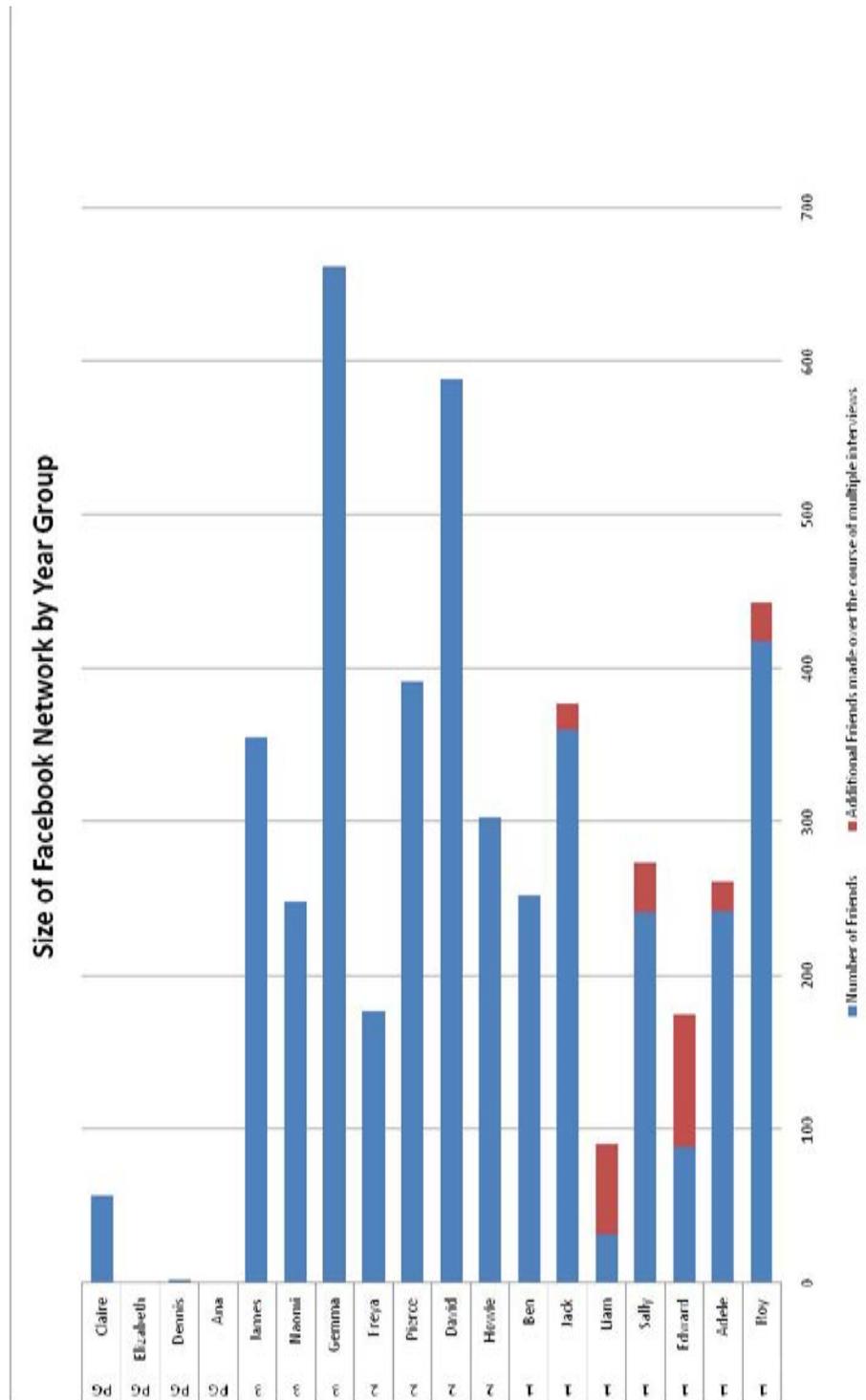
Participants' movement through these sites demonstrated an important objective of networking activity; that of entering student life. Seven participants had begun their social networking activity in high school on Bebo; from there they moved on to MySpace as Bebo was deemed too 'childish'. Facebook had then supplanted MySpace as a more adult alternative, anticipating University.

This picture is not a complete one. Attention to frequency of access (figure 5-7) shows new undergraduates are the most frequent users of the network whilst postgraduates are the least. This highlights an apparent division in undergraduate and postgraduate culture. This division is also highlighted in the size of participants' networks.



**Figure 5-7: Average Frequency of Access to Facebook by Year Group. N = 18.**

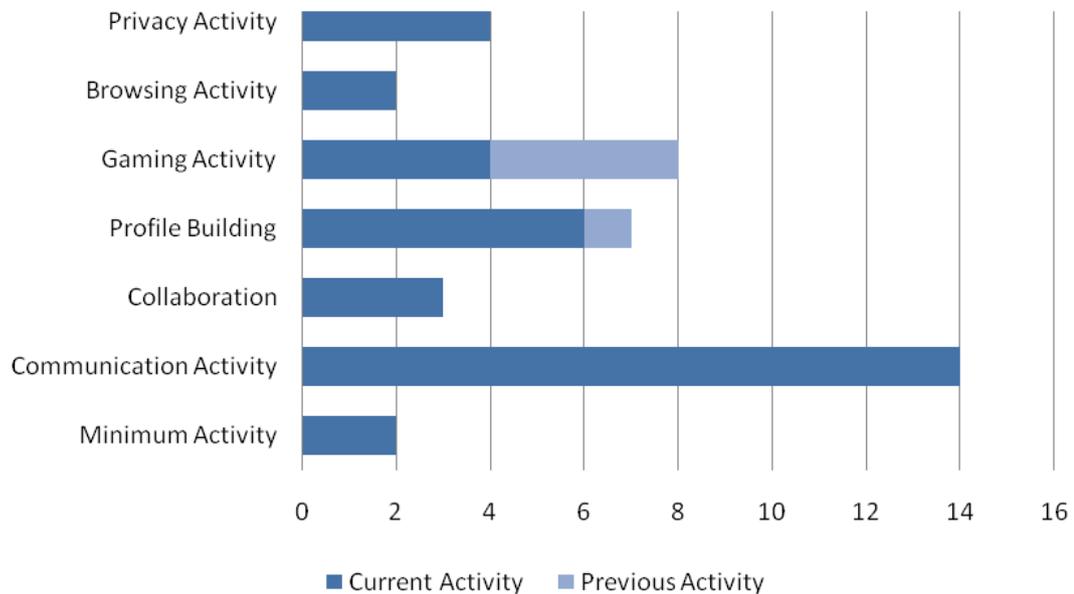
Undergraduates were found to have extensive online networks, in stark contrast to postgraduates. 1<sup>st</sup> year students had on average 234 Friends at the time of their first interview. 2<sup>nd</sup> years had 356 Friends, and 3<sup>rd</sup> years 422 Friends. Postgraduates had on average 15 Friends. This cannot be considered representative due to the small number of participants. However, figure 5-8 suggests that there is an accumulation of Friends over the course of a university career. It also reaffirms the ambiguous status of postgraduates in the network.



**Figure 5-8: Size of Facebook Network by Participant and Year Group**

Undergraduates experienced their social lives as deeply networked. The internet was not conceived as a distant location; student life was rarely wholly online *or* offline, supporting Valentine and Skelton’s assertion that online and offline realms are ‘more nuanced, complex and mutually interdependent than early polar characterisations

suggest' (Valentine and Skelton, 2008: 481). In theming types of activity, I drew on students' interpretations of their own and their peers' behaviour. This nomenclature represents a descriptive 'rough guide' to student activity.



**Figure 5-9: Facebook Activities. N = 16.**

Participants' talk evoked five types of Facebook use:

1. Minimum activity
2. Communication activity
  - Facilitation
  - Profile building
3. Browsing activity
4. Gaming activity
5. Privacy activity

**1. Minimum activity:** All networked participants had created at least a basic Profile (displaying a name, gender, photo, and birthday), sent and received private email, joined a network, joined a Group and accepted a Friend request.

However, two participants had not moved beyond this activity at the point of interview. Their use was reactive rather than proactive. One described his Profile as 'dormant'.

2. **Communication activity:** Beyond establishing a Profile, the vast majority of participants took part in regular communication. Activities included inviting and accepting Friends, responding to comments and posting comments on friends' Walls and photos, keeping track of Events, Birthdays, using Facebook's Chat/Short Messaging function, 'poking' peers and composing Status Updates. For some participants, this activity expanded to embrace Facilitation and Profile Building.
  - a. **Facilitation:** Amongst communication activities a small group acted as producers to instigate new interactions, uploading photos and Video, Tagging photos, setting up Events, setting up Groups, using Apps to express political sentiments ('Bumper Stickers') and blogging.
  - b. **Profile building:** Profile building was also a core part of many students' activities. This was characterised by self-representation through more frequent Status Updates, regularly updating of Profile image, detailed attention to maintaining an engaging profile that curates Quotes, Interests, Groups and Friends. This could also be seen to be affected through more intensive communication activity as a whole.
3. **Social browsing activities:** Social browsing focussed on exploring other people's profiles and networks, investigating lines of interest, navigating across photos, contacts and materials shared by others.
4. **Social gaming activities:** Gaming activity centred on Applications or 'Apps' that allow playful interactions ('Super Poke' or 'Throwing a Sheep' at someone) or more traditional individual games that rank the user against their friends. Others allow more social gaming, for example turn-taking games such as Scrabble or Poker.

**5. Privacy activities:** All students were aware of privacy issues. However, a small group characterised their Facebook activity as strongly centred on anti-social methods deployed to establish private spaces within the networked public, or to withdraw altogether. Activities included controlling privacy settings, de-tagging images and removing comments.

As figure 5-9 suggests, some students identified changes in their online behaviours, moving from extroverted or time-consuming modes of activity to more utilitarian private forms of use.

I now move to examine these observations in more detail through the presentation of case studies.

### ***5.3 Enabled Perspectives***

#### **5.3.1 Freya**

Freya (20) is a second year Education and Social Sciences student. She has ‘visual impairments’ and a close grasp of the social model of disability. Freya states that she has only basic ICT literacy for ‘internet, word processing, that’s about it’.

Nonetheless, Freya wryly observes that ‘some might say’ she is a ‘Facebook addict’, evoking a comparison amongst her networked peers. Freya took part in one face to face interview for convenience in her department.

#### **Technological Landscape**

Freya uses the internet daily for her academic work and socialising with a Facebook network of 177 Friends. Despite her modest assessment of her computer skills, Freya uses iGoogle as her homepage; she applies bespoke browser and computer settings in an assistive capacity and she deploys a Favourites bar that links her to essential resources ‘while I’m doing my essays’.

Freya has been using social networks since she was 16:

I did have MySpace, but I didn't, I didn't like that one, and Bebo. But then Facebook came along, and that was the bigger, the bigger network.

Freya's daily activity revolves around 'MSN, Facebook and Blackboard, really'. Blackboard was used primarily for contact with tutors. For Freya, the distinction between academic and social spheres should not be blurred:

You have like your academic life [...] which would be Blackboard, and then you have, like. Your social life should be this [Facebook].

Freya uses Facebook for communication, profile building, social browsing and social gaming activities. Nonetheless, aside from purely social uses, Facebook supplied a level of interaction over and above those sponsored by the institution. Freya was closely networked with her classmates. As a group they had moved class discussion from Blackboard into Facebook. Away from tutors and formal scrutiny, Freya and her peers 'just talk on Facebook about our work'. Despite this informal class discussion, Freya characterised her use of Facebook as contrary to her academic aims:

When I'm in the library, I'm in the library. I'm supposed to be doing work, it's such a distraction, especially when it's linked up to your emails.

In this sense, Facebook permeates Freya's academic and social life, insinuating itself into every time and place:

Yes, check it at four o'clock in the morning. Yeah [...] all day, everyday.

## **Disability and the Network**

The particular browser and computer settings deployed by Freya enabled her to use Facebook without issue:

You can change things on the computer, that enables me to use it [Facebook] and, I suppose it's all because it's all visual.

*Does Facebook represent any difficulties for you?*

No, not really. I was thinking about this earlier. It's quite, because the background is just white, and contrast is quite good. Often, you can change the size of the font and things on your computer. So no, not really.

In this sense, Freya was seen to deploy generalised technologies in an assistive capacity. With adjustments to font size, and the benefits of the high contrast presentation of Facebook's interface, Freya's impairments became irrelevant. This match was not necessarily available through other social networking services. In comparison to Bebo and MySpace, Freya states Facebook 'is just easier to navigate round and use'.

### **Experiences of Disability and the Network**

Freya is a prolific social network user. In her own words:

I'm visually impaired, I don't know what to say. It doesn't really...I... It doesn't really affect me. Not in a big way anyway. So, yeah.

In this sense, Freya enjoys a non-disabled experience of the network. This positive fit is underscored by Freya's account of her previous experiences of disability in Education. Prior to the advent of the internet, Freya's relationship with assistive technologies in educational environments was saturated with stigma:

I had a laptop when I was at school... about Year 6, but I didn't like using it because it was the whole issue of having to sit near a plug for one thing, so you'd be at the back of the room. To me sat there with a laptop with the rest of the group just writing was... drew attention to me completely. It was bad enough having some, like, classroom support assistant with me all the time.

Not only did Freya have to take her laptop everywhere with her – she also had to carry a folder of enlarged A3 papers. This resulted in unwelcome extra-visibility amongst her peers:

It was a nightmare. Now, I'm just like: 'No, I don't need it enlarged, it's fine. I'll just get it on the Internet. I can read it'.

For Freya, disability is extra-visibility and perceived difference. By owning and transferring her support strategies to the internet, Freya is able to neutralise the visibility of her impairment affects. Within the networked public, Freya's impairments are invisible, or known and already ordinary to an immediate circle of friends and peers. At the same time, the social networking service offers general affordances that are unavailable in the day to day world. As a result Freya conceives her position as positive and enabled.

From this vantage, Freya assessed Facebook more broadly against her notions of disability:

Another thing with Facebook and something like that, is you don't have to. Like, unless you've got visible impairments, unless your profile and photos, you don't have to. You don't have to say you're impaired, so you know, you could go on. [...] but then there's dyslexia and things like that.

In this respect, Freya established her position comparatively within the network, recognising how Facebook could potentially enable and disable more broadly, disclosing visible impairments and text based impairments to re-orientate hierarchies of impairment. Freya positioned herself outside these social aspects of disability.

## **Managing Disability and the Network**

Online, Freya does not identify herself as disabled. Whilst she may still have to take alternative or adjusted steps to access materials and networks by asserting personal settings, tweaking contrast and font size, these steps are manageable, invisible to peers and offer no intrusion on her newly enabled identity. In this sense, impairment is managed as a matter of functionality and technical, pre-social countermeasures. In this context, Freya easily retains the locus of control. As such, network management does not relate to impairment or disability, it is focussed on more mundane issues of socially mediated self-representation, security and overuse. All of which Freya conceives outside the bounds of a managed disabled identity:

Although I am on Facebook a lot, it can get boring. I just try and leave the computer behind and find other things to do.

### **5.3.2 Adele**

Adele (18) is a softly spoken first year arts undergraduate combining American Studies and Russian Studies. She is an amputee with some mobility and fine-motor impairments. Adele participated in three phone interviews, two from her room in halls, one from home, and one face-to-face interview in her Hall of Residence.

#### **Technological Landscape**

To support her academic work, Adele has speech recognition software and a digital voice recorder that she uses to record lectures and then plugs into her laptop.

Adele graduated to Facebook from MySpace and Bebo in sixth form. She has a substantial network of 242 Friends that grew to 261 over the course of the term. For Adele, Facebook, her phone, MSN and Skype are the essential tools that she uses to communicate with her now long-distance boyfriend and a tightly knit group of friends from back home, newly spread within Universities across the UK. She uses Facebook daily for communication activities, but also social gaming activities and social browsing at weekends. Coming to university had not resulted in the sea-change in identity that some other first year students were beginning to experience and affect, as Adele has striven to keep up prior close ties. Her network profile pays homage to these close relationships and the support they give her, although her network reflected a general trend of expansion to account for new friends at university.



Figure 5-10: Adele's workspace (08.12.08)<sup>30</sup>.

## Disability in the Network

Facebook did not present any barriers to use for Adele. Although she used assistive technologies for work, these were not necessary for the light touch interactions of her network use. When asked if impairment was a factor online she stated:

Not when I'm using the computer, because it's, it's fine. Especially things like with Facebook where you're just using the mouse and typing the thing.

Speech recognition was only required for long essays and extended note-taking. However, the connectivity that the Network was dependent upon was not so straightforward:

---

<sup>30</sup> Figure 5-10 shows Adele's desktop at the end of term, when her monitor and peripherals have already been sent home for the Christmas holiday.

It was quite frustrating at the beginning, because I had quite a few problems. I couldn't get onto the network to begin with, and then, when I could, it wouldn't let me onto websites.

Indeed, as a result of lack of connectivity, one remote interview was conducted entirely by phone, without Remote View, as Adele was unable to sustain an internet connection at any point during that hour.

## **Experiences of Disability in the Network**

Adele did not identify disability as a networked experience at any point. This was underpinned by a seemingly equivocal understanding of disability:

You could be technically called disabled, but you could be, not, not really notice it much in your everyday life. Whereas with somebody else, it probably, it affects everything that they do in difference as well as severity. So I think you have to think of both.

In this sense, Adele questions the efficacy of the term 'disability' for describing diverse experiences:

It's such a broad term [disability] isn't it? It doesn't really, you know, some of the difficulties I can face can be worlds apart from what other people face so I wouldn't, I wouldn't necessarily say that.

Further to this, in terms of networking as a reflected activity, Adele characterised her own use as a matter of habit – reflecting that her use was determinedly *unreflected*:

It's just another way of keeping in touch. You wouldn't think about texting someone or think about why you do it, why you're texting, in particular I think. I guess probably because it's become habit, because I'm doing it every day. Just log-on, check emails and stuff, so.

Adele conceived the network very much in the way she would use other communication technologies such as Skype, her phone or MSN:

If I'm sending a very quick 'Hello' just to catch up because it's been a while then probably use their Wall to send a message. Otherwise I'd send them an e-mail.

In this sense, Adele was more interested in the functions of the SNS than self presentation, appearance or reflexive identity play. However, Adele does cite Facebook's distinct social structures and content as having a positive influence on her emotional wellbeing in her first term:

I feel, I feel more comfortable maybe than I would if it [Facebook] wasn't there, because it does make you feel closer to everyone. So it's kind of, yeah, comforting to have it there. [...] especially at weekends, it gets quite quiet, like a lot of people go home. So it's nice because you don't feel as lonely. If there's not many people around then you've always got someone to talk to on here, or look at some photos on here and things.

In this way, the network offset some of the emotional strains of coming to university, allowing Adele to maintain essential relationships and support structures.

## **Management of Disability in the Network**

As Adele did not identify with a disabled identity, or identify any occurrence of disability or impairment effects within her network – she did not report any conscious strategies to manage her activity. In this sense, her use of the technology remained *operational* rather than *active*. However, Adele was seen to closely regulate her social networking activity in other ways, applying strategies of self-discipline and self-advocacy.

### **Self-Discipline**

Adele affected her own rules for social networking. These revealed a tension between learner identity and social demands. Within this, time is a valuable resource:

I'm quite busy at the minute. Like, through sixth form I was quite busy so I didn't get time and there were other interesting things to do. I do check it quite a bit because everybody stays in touch with it and things. So I check it every night, but I don't stay on it for ages.

More precisely, Adele cited half an hour's use in the evening, always either at home or in her student room. Occasionally she would check Facebook prior to beginning an essay as part of a routine sweep of email and other notifications before beginning a more prolonged task. In this sense social practices were balanced against educational practices.

Adele's routine network access answered a social convention: 'people expect you to look at it every day'. Adele also cited this daily action as a direct response to the flow of social information, a flow that required social organisational skills.

### **Self Advocacy**

Between both educational and social computer use, the breakdown of connectivity required advocacy on Adele's part, to improve general levels of internet connectivity to her room:

I phoned them [IT support] up, and then had to do something with the proxy thing. I don't really know that it's fixed anyway.

In this way, the management of the network represented a management of social and educational life. Disability did not enter this sphere directly through representation, impairment effects or operationally in access issues. As such, Adele asserted a non-disabled experience, an experience enhanced by the network.

### **5.3.3 Ben**

Ben (20) is in his first year studying a combined Undergraduate Degree and Masters in Engineering and Maths. He has Attention Deficit Hyperactivity Disorder (ADHD) and Dyspraxia. He plays drums, studies martial arts and considers Facebook a 'Killer App'.

Ben took part in one interview in his Hall of Residence. Due to contracted development work Ben was completing on his desktop, screen capture was not possible as this would have breached pre-existing employment terms.

## **Technological Landscape**

Ben has been using social networks for 5 years. His route through social media reflected an ongoing pick-and-mix approach to new media and a devotion to functionality and usability:

I started on MySpace, concurrently with Hi-5. Then I went to Bebo for a while. Didn't like it much, went to Friendster, didn't like it much, back to MySpace for a bit, and then Facebook came and now that's all I use.

Ben also cited use of HaboHotel and a 'teen phase' in voice-linked networked gaming (Mig Warrior and NeverWinter Nights 2) accompanied by a knowledge of the disability subcultures within immersive gaming. He conceived the movement between services and the emergence of new technologies as a matter of 'fashion':

There are new ones [networks], and there are crazes of moving from one to the other one. But like many computing applications, Facebook was the killer application.

Ben was the only student interviewed to have heard of Second Life, but for him it held no interest. He compared this unfavourably to his gaming experiences, citing the game as the 'authentic' point of immersion rather than the virtual world:

I mean, the whole idea of an immersive world as an immersive world is a modern concept, but it was a game that you immerse yourself in, so I think it was more authentic for me than Second Life.

At university, Ben uses 'Facebook for everything' accessing his network of 252 Friends repeatedly over the course of each day. Indeed, Ben used Facebook for significant communication, facilitating, profile building, social browsing and social gaming activities.

In the evenings, when I come home. If I don't come home obviously, then sometimes I come in at 2 AM, stumble onto Facebook.

Whilst his activity was grounded in Facebook, Ben's networked activity occasionally traversed his YouTube profile. Ben was the only student interviewed to use a

YouTube for social networking, although this punctuated Facebook's network, rather than relocating it:

I keep up with a friend or two on YouTube. Not much though. Just one friend, because we like music videos. She leaves me videos. She leaves me YouTube videos on my Facebook, and I'll message her back on Facebook, or YouTube.

## **Disability and the Network**

Ben does not use any assistive technologies for his social or academic internet and computer use. However, in a generalised sense, Ben was seen to technically evaluate and employ multiple wider applications and services – always seeking the support facilities for whatever task he undertakes.

Ben demonstrated his computing and networking expertise across the interview, assessing Facebook in highly technical evaluative terms. For example, referring to 'intuitive' interfaces, the 'best implementation', 'proliferation' amongst certain groups, citing 'work-arounds' and counter-surveillance apps that allow users to monitor how their Profiles are used by others. During the interview, he rifled between browser windows, substantiating each point. In this sense, Ben identified strongly with Facebook as an enabling and highly functional tool that offered no barriers to use.

Ben was also highly reflective on the culture of Facebook, its genres and norms. He recognised that its socio-technical dynamics had some negative outcomes:

Facebook is not a place for an expression of negative emotion, and in that sense it is quite vain and egotistic. It's not some way, it's almost it's almost a promotion of oneself.

He also responded negatively to the consolidation of identity that could be seen to take place as different networks of friends and relatives coalesce:

Voltaire put it wonderfully. He said that, what was it? He said 'Too Much Truth Is Fatal'.

Ben did not identify any interactions in which his impairment was enacted or disability was ascribed. Indeed, he did not locate himself within the category of disability:

It's very hard to say. Your experience is normal, because obviously if you've never experienced something else you're not going to see a distinction.

In this way, Ben asserted his own perspective as the locus of 'normal'.

### **Experiences of Disability and the Network**

Ben's assertion that 'your experience is normal' was not completely without points of reference. In terms of the network, he identified a potential functional comparison relating to the social networking service as tool:

If I had difficulties with motor control or tracking, like eye tracking, then it probably would have a more significant impact.

Notably, here Ben describes impairments using a language of user experience testing rather than medical language. As such, Ben's talk about impairment aligns him closely with his discipline and emerging academic identity. In this sense, Ben conceived impairment more broadly in operational terms rather than social, medical, charitable or interactional terms.

### **Managing Disability and the Network**

Within the interview, Ben did not conceive his impairments as affecting his onscreen interactions in any way. As such, he did not take active, reflected steps to mediate or manage either his impairments or any impairment affects.

Whilst un-reflected in the interview, in analysis, it appears that Ben's interview is given using highly reflected disciplinary forms of talk, using technical and evaluative language. This language also permeates Ben's talk about impairment. In this sense, Ben may be seen to manage his impairment by adopting a university sponsored,

disciplinary position that supports his conception of the network and his place within it.

### **Emotional Detachment**

Beyond functionality, Ben was aware of the socio-technical aspects of the network, but repeatedly refuted deterministic social ascription and interpretation more broadly:

I think you see people in different ways to the way you observe them in the real world, because to a degree. When you're doing something on Facebook, you can't really think about how 252 different people are going to react to it in the same way, if you're with me.

Facebook gives you, it's almost like a photograph. It sort of gives you a series of snapshots of someone's identity and life. You use these different ideas to, to correlate a sense about someone. So, no, I mean. It's a bit like judging, judging a book by its cover. There's not really enough to go on to, to really judge someone.

Thus, in terms of a social representation of impairment, Ben noted that Facebook was not authentic; it could only suggest identity and life. In this respect, Facebook could not affect a new identity or ascribe disability; it could only refract glimpses of identity and life.

### **5.3.4 Howie**

Howie (23) is a second year undergraduate in the Business School and self-confessed 'Xbox nerd'. He describes his impairment as a 'minor disability'; Howie has writing difficulties and has been diagnosed as having a variant of Repetitive Strain Injury due to an injury in his late teens. His conception of disability is 'stereotypical', but his statements belie evidence of a self-aware, nuanced understanding of disability and identity management, couched firmly in social vignettes; he is anxious about the examiners' negative judgements on the author of an incomprehensible scrawl; his heterogenic understanding of disability is conflicted by his identification with non-disabled peers:

We always joke about it, me and my mates ... They'll be like "Oh, Howie's disabled" and stuff like that and I'm like "yes, I am" sort of thing, like, jokingly. But the kind of image I've got of someone disabled is obviously so stereotypical, like somebody in a wheelchair ... when obviously, like, the word disability is like, oh, so big and can mean a million different things.

Howie took part in one interview at a lab convenient for his course.

### **Technological Landscape**

Howie uses Facebook for privacy activities and limited communication activities with an established network of 303 Friends. He accesses the network several times a week. He cites no other network profiles:

Only really Facebook. I'm not a big fan of it, but kind of it seems that it is quite a necessity in that like, if there's ever a party of anything like that, that seems to be, that seems to have taken over the role of text messages in making people aware. Probably primarily due to cost.

Prior to Facebook, Howie used MSN alongside other more anonymous and synchronous social spaces:

Sometimes use like health forums and things like that. Chat rooms, not anymore. When I was like 15, I used them quite a bit, but I think that was just a novelty thing.

In terms of other collaborative Web 2.0 services, blogs and wikis 'seem useful' but Howie has not exploited them.

Howie does not currently use any specialised assistive technologies to access the internet or for academic work, despite receiving speech recognition software to support his computer use as part of his DLA. The assistive technologies that Howie uses are general, a Bic biro that's easy to grip and a laptop.

### **Disability and the Network**

As a tool, Facebook as a SNS offered a positive operational fit with Howie's fine motor impairments. In this respect, digital technologies such as Facebook, accessed

through his laptop, actively reduced the functional aspects of impairment for Howie. Howie became non-disabled in the network.

## **Experiences of Disability and the Network**

Howie does not consider himself impaired online, since his disability is only enacted when he is required to write by hand for prolonged periods. In exams and some academic scenarios, this was deemed a disability. However, since Facebook is reliant on keyboard input, what Howie considered a ‘minor disability’ and spoke of as an injury, remained un-reflected in online:

Like there’s not like a handwritten version of Facebook out there, if you get me, so I can’t really, there’s nothing to contrast it to.

This non-disabled experience was confirmed for Howie by his experiences with supporting surfaces; assistive technology which proved to be ‘more hassle than it’s worth’:

I don’t think it’s too relevant, myself, to be honest.

Together, digital affordances and the irrelevance of assistive technologies meant Howie experienced his impairment on the cusp of disabled/non-disabled:

I don’t think my disa-, like my writing or typing problem’s severe enough to merit, or sort of utilise the benefits of something like that.

This brought about a moral dilemma for Howie. Whilst he initially welcomed the technical support and assistive technologies he received, it didn’t suit him:

I felt quite bad to be honest, because it cost [...] a considerable amount of money. [...] Now I don’t use it at all.

However, disability was seen to occur tangentially in Howie’s wider network.

## **Witnessing Disability**

Howie recognised Facebook as a social necessity; however, he did not enjoy its socio-technical aspects, responding negatively to aspects such as surveillance and the resulting conservative culture:

I'm not a big fan of Facebook, because I kind of feel like it's kept under constant watch and constant tabs, like nothing you can do can to, kind of, escape it, and things like that. So I tend to like, I don't really like using it.

Howie identified the networked public as a superficial space, questioning the authenticity of interaction. These feelings centred on a rupture in the network; the suicide of an acquaintance:

This guy I know a bit committed suicide and like, basically his Facebook profile just got, like, flooded with comments like 'rest in peace', like, 'you'll be missed' and things like that. And one, it quite annoyed me because, like, I think one of the reasons which it happened was he was actually quite a lonely person, but all of a sudden this happens and, you know, all these people that he hardly ever spoke to were, like, offering their sort of like deepest like apologies and stuff. So it was like, kind of like, a false, seems like, quite false. [...] it just seemed like people were doing it for the fact that when somebody else does it they see their name there and go 'Oh, that's a caring person, they've written a message on Facebook saying how sorry they are'. Kind of like, very pretentious.

*So there's an issue for you about authenticity?*

Yes, most certainly. [...] The other thing as well is like, especially with people you don't, you couldn't, you interact with solely through like, social networking sites, you don't have to worry about some sort of connection between the online entity and the actual entity in reality, so then those people can actually create like a whole fictitious sort of character, which is like, frustrating me, because it is very artificial.

Importantly, Howie identifies how 'caring' behaviours can be identified as a matter of performance to gain social status. For Howie, this event exposes network interactions as cosmetic and dehumanised. As a result, Howie identifies himself against Facebook's norms, refusing to participate in the usual way. Howie's narrative appeared bound to issues of mental well-being and an acknowledgement of depression as an authentic but excluded status in the network. Howie himself did not

reflect upon these aspects as ‘disability’ issues, however, as a researcher, I cite this reflexive disjuncture, and Howie’s resulting network management strategies as directly evoking sensitivity to cognitive dis/ability difference.

## **Managing Disability and the Network**

### **Managing Privacy**

Howie has been seen to identify his impairment in purely functional terms that locate his disability within an academic, offline environment. Whilst he responds to the benefits of technology, he refuses to identify with Facebook, identifying it as a practice that implicitly affects identity, creating an inauthentic and socio-technically mediated identity that is unwanted. Evidence of the networked public’s failure to account for cognitive difference has led Howie to attempt to leave the network. However, this self-assertion has been impossible to manage:

There’s no escape, if you understand me? Like, no matter what you do, like if you go out like one night, like no matter what you do, whether you want to be sort of publicised or not, it’s going to be. And like, it’s just a case of going through and like, de-tagging pictures and deleting messages, stuff like that.

In this respect, Howie has found that it is impossible to leave the network. University life is networked, whether or not the individual wishes to be. As such, a student will be represented within the network via communal activities. To withdraw, Howie recognised that, pragmatically, he must remain connected to extricate himself and ‘clean’ his profile. This is a paradox, as Howie must connect to resist connection.

## ***5.4 Dis/Abled Perspectives***

### **5.4.1 Roy**

Roy (18) is a first year Law undergraduate who took part in a total of four interviews over the course of his first term. Interviews were conducted face to face in Roy’s

shared study room in his Hall of Residence at his request. Interviews used audio, voice and screen capture. Roy describes his impairment briefly, in the following way:

I would probably describe it first of all as a visual impairment, but that comes from albinism.

Roy identified how barriers in the campus' built environment resulted in this sensory impairment becoming a mobility disability.

Roy is reflexive and experimental when considering his impairment in the new context of university, placing varying levels of emphasis upon impairment in terms of his identity and online social activity. For Roy, disability is a relational identity, 'my attitude constantly changes'.

### **Technological Landscape**

To support his computer use, Roy uses generalised assistive technologies; a large monitor, alongside a printer and scanner for enlarging books and other text materials onscreen. As with many other first year participants, his set-up changed over the course of the first term due to factors including delayed receipt of his DSA support, and, as the holidays approached, anticipating going home for Christmas.



**Figure 5-11: Roy's workspace (01.10.08).**

Figure 5-11 shows Roy's study set up at the time of his first interview. Pictured are a laptop and 19 inch monitor configured in dual screen mode. A USB hub, iPod, mobile phone and landline are visible. On the top-shelf is a printer. Under the desk is a fridge and also a Nintendo X-Box. Headphones and webcam are also visible.



**Figure 5-12: Roy's workspace (09.12.08).**

Figure 5-12 shows Roy's study space at the time of his final interview. Pictured are the landline and power extension (as before) and a new printer/scanner combo. A new laptop is connected to external 24 inch monitor. A phone (new handset), digital camera and digital video camera (top shelf) are also visible.

Roy was amongst the most prolific and experienced participants using SNSs. He has accounts registered with Bebo, MySpace, and Facebook. His network activity now focuses on Facebook through which he accesses an expanding network of 417 Friends several times a day. Roy's Facebook activity included communication activities, profile building, social browsing and traces of social gaming. Roy's social life was highly networked. During the interviews, feeds and updates rolled into view onscreen, at the door visitors stopped by ('Don't mind me', 'Can I borrow some Scissors?', 'Are you coming to lunch?'), Roy's phone buzzed with text messages. Facebook was at the heart of this student network. Within Roy's Hall, the door to every student room was embellished with a makeshift post-it notice containing vital information: name, mobile phone number, Facebook name, and comic likes and dislikes.

## **Disability and the Network**

Facebook as a tool offered a close functional fit with Roy's impairments – whilst using his monitor and personal set-up, Facebook did not present any accessibility barriers. Roy enjoyed the multiple affordances of the network for events, societies, developing friendships, connections and gathering social information. However, beneath this network surface, supporting tools proved problematic. Roy's DSA assistive technologies arrived late, seven weeks into the term. His Hall also experienced disrupted internet connectivity:

The internet at university is so much slower than home.

Connectivity barriers put Roy at particular disadvantage in terms of accessing his networks and other services [some of which constituted 'reasonable adjustment'], as despite owning mobile technologies, he relied upon his monitor to make onscreen information visible:

I got this one [laptop] because it's portable. It's kind of like, portable – and not see it, or not-portable, but then it is *not* portable, I've got this [desktop] anyway. So it's kind of a no-win situation.

In this sense, other students could more easily access the internet through centralised provision in other locations. For Roy, barriers in the built environment in conjunction with bureaucratic delays and interrupted connections placed him at a disadvantage.

## **Experience of Disability in the Network**

Roy's experiences revealed important insights as to how disability as an experience was distributed across his interactions and mediated by tools, proximal and distance communities. Roy's experiences procuring assistive technologies were frustrating, but also ambiguous. The mode of assessment and delivery of assistive technologies put Roy in an ambiguous position. Roy reported that assessors' decisions prior to university regarding the equipment a student should receive were not personalised, being instead 'excessive':

When I received the stuff from the DSA, I hadn't, I hadn't said 'I want this and this'. Someone had assessed me and basically told me what I was going to have [...] I just thought, it's almost like they're gone to town playing the system instead of - I mean, it was nice - but a lot of it I've not got uses for. ...It's not a situation I've asked for.

These supporting technologies also resulted in unanticipated social outcomes as they were visible to peers in his shared study space. In this respect, managing a perceived impairment was bound into the technological and social landscape. Within the network, Roy did not disclose his disability – however, remote groups of friends knew of Roy's impairments, and understood them as normal. In this sense, Roy's experience of dis/ability was grounded in the real world, not the network.

## **Management of Disability in the Network**

Roy's management of disability was expressed in four strategies; self-advocacy, self-surveillance, managing disclosure and encryption.

### **Self-Advocacy**

Roy had to lobby to get his DSA equipment, which arrived seven weeks into the term:

I had to ring up a number of times and say 'look my laptop isn't working very well. When's the stuff coming?'

This was the first time Roy had had to advocate on his own behalf in relation to his impairment. Subsequent to this, the arrival of assistive technologies represented new, unexpected indices of disability.

### **Self-Surveillance**

Roy was sensitive to ATs as evidence of impairment and the potential this had for affecting his relationships with peers in halls, disrupting earlier attempts to 'be normal, or whatever that means'. Upon the arrival of these technologies, Roy then had to manage the potential disclosure these ATs represented as a public marker of his impairments. To affect this, Roy undertook two relational approaches. The first

constituted an assessment of what constituted 'normal' student requirements and what represented the extra support he needed. To assuage an uncomfortable position, he took control:

The choice now has come to me though. Like, I can claim back all the book costs, I can claim back all the ink and paper costs and my Internet connection costs. And I probably will claim back some of the book costs because having to make them large print costs an awful lot of money and I think that's a valid use of the system. I'm not going to claim back the Internet costs really. I think, I mean, I could do, but every student in the University needs the Internet.

### **Managing Disclosure**

To manage his new peers' responses to his ATs, Roy described a drip-feed of information that he used to manage disabled identity:

The more I've been at university, the more people that are close to me have become aware of more information I've given them. But the disability itself is pretty much, it's a constant, it doesn't change so...

*Has your attitude towards it changed at all?*

I think my attitude constantly changes. Sometimes, sometimes I think it's a massive big deal and other days I think 'Well actually everybody's got something about them that you know, makes them 'different' or whatever the term'. However, I don't know. I think that it's, it's starting to become apparent to people now, how much help I'm getting, and so they're, more often than not, they're like 'I wish I could have that', things like the bus pass, like 'I wish I could have a bus pass'. The fact that I can claim a paper allowance and a printer ink printer they're like 'Oh I wish I could do that', you know, 'I'm running out of black ink' and stuff. So in that respect it helps, but I don't, I think at the end of the day it's, it's just going to keep developing and changing as I meet new people and if someone has an adverse reaction to it then that's going to make me think 'Oh it is an issue', but when people are like positive about it... I think it really does depend on who you're with.

*Yes. So basically it's been the people you've been with which has affected your attitudes?*

On everything really. The disability is part of that, but also on, like, where I want to live next year, how much should people drink, just things like that. It's kind of... you, your standards're set by the people that surround you.

This social and flexible analysis of impairment and Roy's broader reflections on disability couch ability difference in terms of normal experience rather than a positive or negative discourse. Although these factors are not explicitly networked – they underpin important aspects of Roy's activity.

### **Encryption**

Within the network, Roy describes an encrypted communication with intimate friends from college and home in a manner that ensured privacy within the networked public:

It's very, very kind of restricted what people write on Facebook usually. It's *never* the whole truth. It's always, maybe there's a few in jokes, and maybe a few digs and stuff like that, they could even be disability related. But they have to be decrypted as such by the people who read them, they, kind of have to know. They have to be in the know to get it; otherwise it would just appear to just ... a throwaway comment.

In this sense, the drip feed of self disclosure associated with close friendships culminates in a private encoded space within the networked public.

### **5.4.2 Edward**

As a first year Computer Science undergraduate, Edward (18) was one of the most technologically adept students interviewed, with a sharp and humorous take on social media. Edward has Dyspraxia, a fine-motor impairment and Asperger's Syndrome. He is a writer, cyclist and Christian. Asperger's, in his words, sometimes holds him back socially but makes him more academic. He considers it an attribute relating to his very dry sense of humour, outlook and personality rather than a label, badge or barrier.

It doesn't really affect me because it's like affected me all my life. But it doesn't affect me now because it's my 'normal'.

All Edward's interviews were conducted face-to-face at his request, three times in a research situation convenient for his course, once in his Hall of Residence.

### **Technological Landscape**

As a computer scientist Edward used computers and the internet intensively. Outside his studies, Edward remained strongly connected through MSN and a developing network of 88 Facebook Friends that he engages with several times a day. Facebook is Edward's only social network. Prior to this he very briefly experimented with YouGoFurther, anticipating university.

Over the course of the first term, Edward's network doubled in size to 175 Friends, reflecting his enthusiasm for Facebook and networked student life. Edward engaged in communication activities, facilitation activities, social gaming and intense profile building for his burgeoning role as the new student Welfare representative in his Hall of Residence.

In terms of assistive technologies, Edward deployed a mix of conventional hardware for their assistive properties. For example, his wireless keyboard and mouse contributed to a clear workspace; Cluttered spaces 'make it difficult for me to think'. Technologies supplied through DSA had not arrived prior to the final interview in the penultimate week of the autumn term.



**Figure 5-13: Edward's workspace (11.12.08).**

## **Disability and the Network**

As might be anticipated from Edward's choice of studies, the network offered a positive fit with his impairments. Edward did not identify any barriers to use or occasions relating to impairment or impairment effects in the network, instead he relished many of the affordances the technology had to offer.

## Experiences of Disability and the Network

Edward experienced a powerful positive fit with Facebook as a network and capitalised upon its pro-social role in forging relationships and allowing self-expression. This experience was underpinned by two key factors: a euphoric sense of arrival at University: 'Coming to Uni, it's just like bliss'; and a strong conviction in the positive potential for networking technologies:

[Facebook] brings the world together. It chops down stereotypes [...] The internet is quite cool like that, it changes difference. It makes the world smaller.

Edward's perspective was not naive. He was sensitive to the risks involved for people with marginalised social identities online, observing experiences relating to religious identities and sexuality – also noting that Facebook can bring 'people with similar interests and hatreds together'. However, Edward identified strongly with his network as a safe and pro-social space full of possibility. Indeed, in a graphic vignette, Edward recounted an unequivocal case of Facebook evangelism:

Pretty much when you get university if you don't have Facebook, you have to get Facebook. You're forced to get Facebook. We literally bombard their rooms and make them get a Facebook!

*So just tell me about an instance where this is happened because I'm really interested in this.*

There was a girl, she, she, she didn't really see the point of Facebook blah, blah, blah, but we were just like 'you don't understand the beauties of Facebook, you can do so many different things' and she said 'you'll have to show me'. So we showed her and she said 'ah, that's quite cool but I still don't really know'. And so one night we just went, knocked on her door and she's like 'oh, Hi' and we all went in and just like saying 'you're on Facebook now, come one let's do it!' and she's just like 'no, no, no!', and yeah we forced into it, it was quite fun.

*So she was literally sitting there with the computer?*

Yeah.

*And making her make-up her profile?*

And she has used it a lot, so (laughs) we converted her!

This account underlines Edward's strong association with his peers around and through the network, highlighting his understanding of the network as a space for inclusion and integration.

Whilst some elements of his impairment required management, over the course of the term Edward found that networked student life actively reduced the anxiety-related symptoms that had previously inhibited his communication. Although Edward was distinct from other participants as having previously lived away from home as a boarder – this unanticipated change in his impairment effects had a powerful positive impact on his identity and conception of self.

## **Managing Disability and the Network**

Edward articulated three approaches to disability in his networked activity, managing reflexivity, using self-advocacy and seeking self-affect.

### **Managing Reflexivity**

Edward's strategies for managing perceptions of his disability online directly mirrored his real-world strategies and were characterised by a resilient attitude. For example, when questioned he relates network disclosure to his approach to disclosure as a whole:

*Have you talked about that on Facebook?*

About my disabilities?

*Yes.*

Not really. People seem to understand, well they don't understand me. But they kind of half know what's, what affects what. And... I suppose, I don't

know. Yeah. I don't know. I don't really talk about my disabilities... much at all.

In this respect, impairment was an ambiguous issue that was not necessarily understood by his peers. As a result, Edward proceeded regardless.

### **Self Advocacy**

Importantly, Edward's understanding of the network was affected by one clear strategy, maintaining his network as an inclusive space. In a key respect this involved maintaining a safe space populated by genuine friends:

It's good because only people who are going to see your information are people that you trust; otherwise they wouldn't be on your Friends List.

Importantly, Edward also strove to affect the pro-social and inclusive network of his convictions more widely. During the term, Edward worked to use Facebook to support his role as an elected Welfare officer at his JCR. He acknowledged that the lack of anonymity within the system had a potentially negative effect on its efficacy in this context, but worked to mitigate this through availability in other media. In this sense, Edward deployed Facebook as a generalised assistive technology for all.

### **Self-Affect**

Networked student life was seen to have a positive effect on Edward, reducing some of the anxiety related symptoms that constitute impairment affects. Edward was not passive in this experience; he used the network to enhance and affirm his social world. For example, Edward used the FriendWheel App to visualise and explore his growing network; he found this a positive tool for affirming a successful social self.

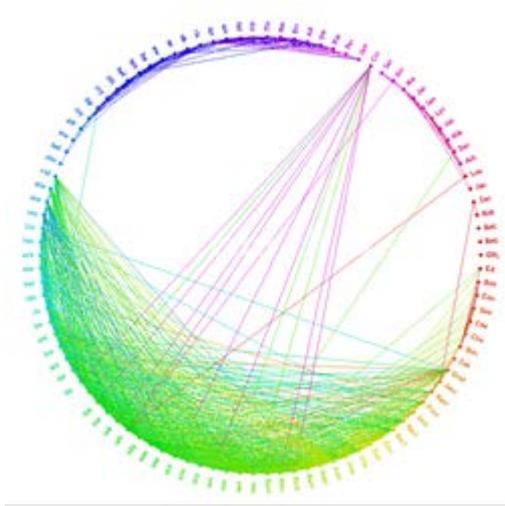


Figure 5-14: Edward's network (29.09.08)

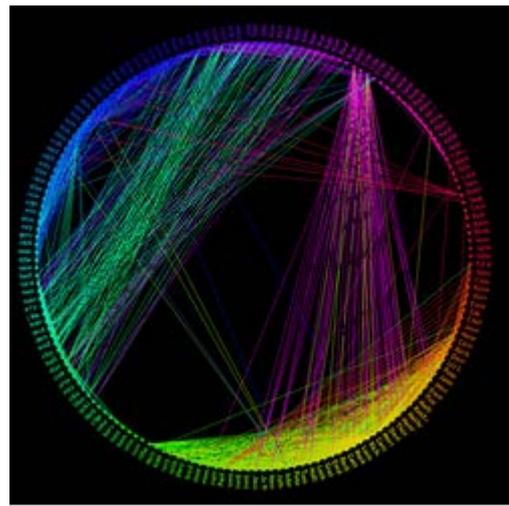


Figure 5-15: Edward's network (11.12.08)

FriendWheel allows a user to create a visual map of their Friends' connections to one another. Friends appear as nodes on the outside of the circle, relations between friends are shown by connections between nodes. Over the course of the term clear developments in size and nature of Edward's network are demonstrated. Established home networks (represented in green in figure 5-14) are overtaken by new student networks representing residential groups, SU societies and course mates. Notable connections are also forged by individuals between the old and new networks.

In summation, Facebook allowed Edward to amplify the positive effects of student life on his impairment.

### 5.4.3 Sally

Sally (18) is a first year Economics student who has dyslexia, she describes memory as her 'main problem'. As a child she was diagnosed with a hearing impairment, and she ascribes much of her success with text and the written word directly to this experience:

In some ways, I think it was actually a blessing, because I found like, teaching so difficult during the early stages. I sort of took books on from quite a young age. I loved to read because it didn't involve my ears and stuff. And, as a result, I think that's why I managed to get through the dyslexia so

quickly, because I was so determined to be able to read. So although I'm dyslexic in some ways I'm more literate than other dyslexics, somebody said, one of the assessors said. So it's interesting in that respect, that maybe, had I not been partially deaf, then I wouldn't be able to read. Which would have been a lot more of a hindrance, I think.

This approach illustrates both Sally's self-efficacy and her sensitivity to the hierarchic relations between disabilities and the barriers disabled people face in society. Both implicitly affect Sally's internet approaches which are deeply egalitarian and concerned with fairness.

Sally completed four interviews, two by phone and two face-to-face, in the lab and her Hall of Residence respectively.

### **Technological Landscape**

Sally is considered something of a techno-wizard and innovator amongst her peers, discovering tools that her friends then adopt. Sally describes her progression from previous networks to Facebook in the following way:

Bebo was sort of at school, everybody was joining it and you know, you get all the, everybody invites you and you get all these emails. So it was almost just to stop getting all these emails saying 'please come'. And then once you start doing it you see what a good resource is it. And then, as Bebo became less popular, and also I have a lot of older friends, who said to me 'oh, you don't want to be using Bebo, that's really childish. Everybody now uses Facebook', and gradually most people turned off Bebo and onto Facebook, and that was basically alright really. And I think it's a lot easier, Facebook, to use. It's a lot more accessible.

Over the course of the term, Sally's Facebook network increased from 241 to 273 Friends. At the start of term she accessed her network 'at least once a day' in Halls. However, this access became more consciously controlled as the term progressed. In terms of activity, Sally was the only student interviewed who had administered a Facebook group, her use focussed on communication activities and facilitation activities. She stated a previous interest in social gaming, but increasingly rejects this activity.

Sally does not own any assistive technologies, however, she deploys a suite of social software and is experimental in her approach to discovering functionality; for example, Sally cited using The Guardian newspaper's list of '100 Best Websites of All Time' to research web tools. Her desktop and browser streamline her activity; Short cuts on her homepage linked to Google, Facebook, her University Portal, Internet TV channels, eBay, Amazon, YouTube and Wikipedia. Facebook's password fields are automatically completed onscreen.



Figure 5-16: Sally's workspace (23.10.08).

## Disability and the Network

Whilst Sally had organically developed clear strategies for her internet use, this use was not augmented by specialised assistive technologies. Sally was troubled by the bluntness of the term 'disability'. She had not initially declared her disabilities in her University application and felt uncomfortable requesting support that she felt could be more usefully deployed elsewhere. As a result, she did not have or use any specialised assistive technologies for her networked activity; she also identified how

failings in the support system meant that the provision of assistive technologies was problematic anyway:

I don't need the support, it's other people who need the support. It's just like, if I did need the support, there's nothing there, but I'm fortunate enough that I don't really need the support, like my parents have given me a computer already and that sort of thing.

Sally did not identify with the term disability, and did not feel that she was disadvantaged within the network. She explained her un-assisted use of Facebook thus:

I think, because it's a lot of Commenting, Commenting is not so bad, you know. It's just a short thing. [...] You do, like, learn to cope with it [...] so I've managed to conquer quite a lot of stuff. Commenting is definitely not a problem, but long emails can sometimes be arduous, but I think Facebook is quite good in that respect, because most of it is commenting and I quite like that.

Here, Sally makes a slightly relative statement. By stating that Facebook is 'not so bad' she identifies a pragmatic approach that recognises the situation could be less than ideal, but nonetheless, within a range of acceptability.

## **Experiences of Disability and the Network**

Sally did not identify disclosure or interaction as a site of disability in the network. Comments did not present a barrier for her, and, whilst she perceived that dyslexia is not commonly foremost amongst disabilities, Sally had not experienced any stigma that impacted upon her approach to self-presentation online, despite awareness of the nature of risk in the networked public:

You have to be a bit careful about what you write and you never know what... what might come back and haunt you.

[Facebook] is a lot easier to search through for people. Having said that, it doesn't have everybody and it's very easy to do things more publically, which can sometimes be a bit dangerous.

Despite this, Sally did not experience disclosure or indirect disclosure through impairment affect as an issue or concern:

I was never really worried about saying to someone ‘well, yeah. I’m dyslexic’

Indeed, Sally enjoyed the connectivity of the networked public and the affordances of the SNS:

The reason I started off using Facebook that time you saw when I e-mailed loads of people, because there were one or two contacts that I didn’t have in my email, so it’s quicker to do it all through Facebook and just do like a message to all of them.

However, Sally was not wholly comfortable with a networked and social university experience. This concern focussed on the amount of time Facebook takes up and its role in a constellation of distractions:

Everybody’s finding that you sign into MSN, and you do your email and then you do, because I’ve got two emails, for personal and University; And then you’ve got, if you have a Facebook update, you can go and look at that. And then, then you maybe do a tiny bit of work and then you get sidetracked again.

Importantly, Sally identified prolonged social networking as a moral issue relating directly to her dyslexia; Social networking at the levels her friends in Halls maintained could not be justified when extra time was needed for coursework and academic preparations.

I think the difficulty for me is that I don’t use Facebook that much, but because I have... Work for me takes longer. I can get quite stressed if I haven’t done my work and if I spent time on Facebook it feels like I’ve done something naughty or something, spending time on Facebook rather than working productively.

## **Managing Disability and the Network**

Sally expressed two distinct strategies relating to disability within the networks. These were characterised by a commitment to advocacy and an emergent self-discipline.

## **Self-Advocacy**

Throughout her interviews, Sally expressed a strong commitment to egalitarianism, constantly questioning her own situation in relation to peers:

People need to be treated equally, so they all get the same level. Not so people who are underperforming get pushed much higher than those who are performing.

Sally also acted on her principles to extend her friends and family's network capabilities; she shares the best tools she finds with her less-technical peers and has devoted significant time to supplying her grandparents with informal computer lessons:

I'm quite proud of it, because my Grandma is now saying 'how do I use the webcam, I want to be able to talk to you with the webcam'.

In the network this was expressed by a commitment to clear language over text-speak and other complicating language practices.

## **Self-Discipline**

Sally identified a balance that must be struck between work and recreational activities. She identified her dyslexia as requiring extra time resource that necessarily precludes the levels of networking activity she observes in her non-disabled peers. As a result, Sally explicitly limited her internet and social networking time to once a day, in Halls in the evening:

[I] generally keep it to one time, simply because I already spend way too much time on it.

I've got much better at working during the day in the library and then coming back here and messing around.

Sally's use of Facebook as a tool is carefully marshalled. Importantly, this experience highlights the extra work that Sally must undertake individually to manage her impairments, without allowances for 'regular' extra-curricular activities

being provided by the university. It is also notable that Sally experiences this pressure as a moral one; she has seemingly adopted both an institutional and disciplinary academic identity to protect self-efficacy. Productivity is good – networking is ‘naughty’.

Importantly, this self-discipline extended into Sally’s profile. Despite a predilection for ‘soppy’ Apps, Sally described becoming ‘infuriated’ by distracting Apps, and clearing out her profile:

‘My Aquarium [App], I haven’t used it, all my fish are dead by now. I don’t know whether they can die’.

When considering this App, Sally highlighted its superficial properties:

[*with heavy irony*] ‘Like, “Oh, shall I do my work? No, I’ll customise my Aquarium [App] with glitter text”!!!’.

In this respect, Sally appeared to forge her academic identity at the expense of her social identity both within and outside the network. Whilst this may be seen to be a general student practice, Sally’s awareness of the extra time her dyslexia demanded in terms of work demonstrates that she must be more disciplined than her non-disabled peers. This suggests a disparity can be rendered visible in the network.

#### **5.4.4 Liam**

Liam (19) is a theology student and ‘reluctant’ social networker. His background is rural, and Christian. In terms of impairment, Liam cites ‘dyslexia slash dyspraxia’ and a heart condition which he doesn’t find disabling, but has informed his notions of disability since he was a child:

I’ve never seen it as a particular disadvantage; it just means that I can’t do certain things or whatever, kind of thing. So I guess that maybe that influences how I would view then being dyslexic or whatever. And you know, I just, I suppose I accept it, perhaps more so than other people might.

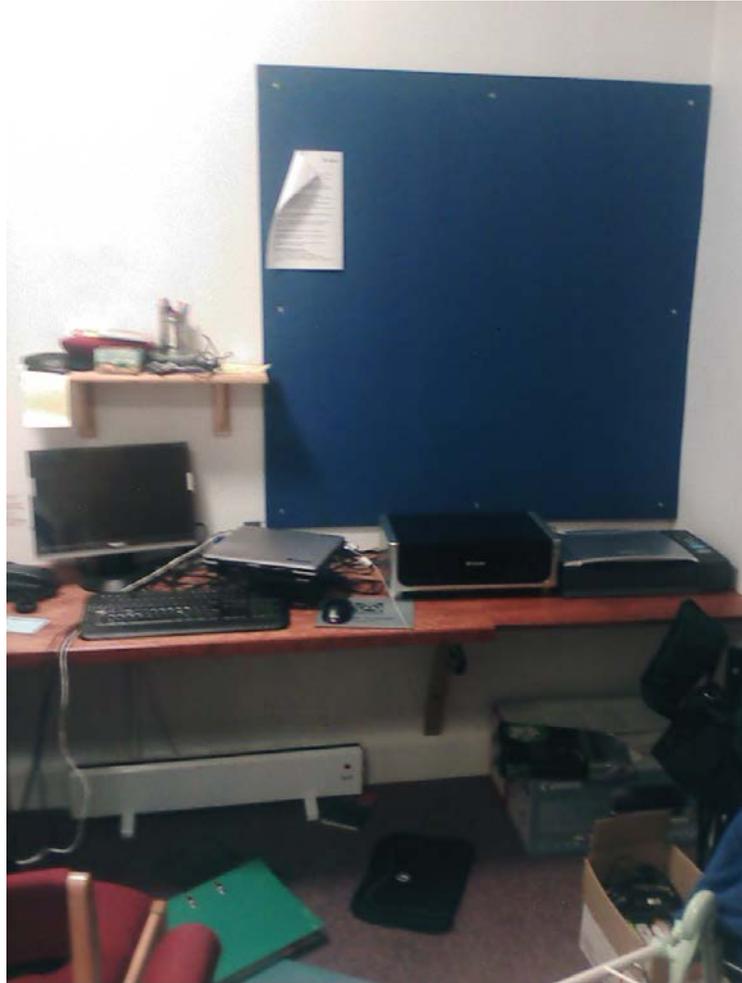
Liam expressed a nuanced reflection on the nature of disability and learning difficulties. He asserts disability's anti-categorical nature:

I don't know, it's a difficult phrase, isn't it? It's such a broad term. It's kind of a very wide spectrum. And it's used for a lot of things that you might not, I might not myself necessarily consider a disability. Which raises the question, I suppose, of what is a disability? I mean, you know, what are you, if you are disabled? I suppose. I don't know, I mean, I don't, I don't think of myself particularly as disabled, but then I guess that's a kind of, because I take a very stereotypical view [...] I've got maybe, dyslexia is a difficulty maybe, but then everyone's got their own difficulties I guess.

Liam also recognises the diversity of impairment and experience present in dyslexia as a 'grey area' constituting a wide spectrum within which impairment 'can affect you in a lot of different ways'. Two interviews took place in a central university site where, with the third taking place in his department. A further interview was disrupted by a second bout of Fresher's 'flu.

### **Technological Landscape**

At university, Liam uses Dragon Naturally Speaking for dictating, the screen reader Read and Write Gold, and Inspiration for mind-mapping. He also deploys more generalised assistive technologies to support his academic work.



**Figure 5-17: Liam's workspace (12.12.08).**

Figure 5-17: Liam has begun packing for the Christmas holiday. Generalised assistive technologies pictured include a flatbed scanner, printer and laptop. The photograph is taken by Liam on his mobile phone.

For communication, Liam uses MSN, Windows Live Messenger and has used Skype 'briefly'. Liam has experimented with SNSs prior to university, but to no avail: 'I was briefly on Bebo, but decided not to be on Bebo shortly afterwards'. Facebook is the only SNS he uses, and then only 'reluctantly' accessing the site every few days. Liam recalls that one of his first status updates read: 'Liam is wondering what the point of Facebook is.' When asked why he joined, he reflects:

Essentially because I had a lot of, like, I missed out on several social events because people were only using Facebook to communicate. And since I was only using email and MSN I didn't hear about some things which annoyed me slightly. And also I figured in some ways at university everyone would be on

Facebook, to a certain extent, it would be kind of useful for that. But I don't know, I haven't really found it overly inspiring, thus far.

At the beginning of term, Liam had a small network of 30 Friends, by his final interview this had increased to 90. In his first interview he described Facebook as 'bizarre', 'random', 'boring', and 'perplexing' or puzzling at best:

I thought my perspective would change when I joined but it's actually remained fairly similar to what it was before.

What onscreen activity Liam did initiate, toyed with implicit networks rules through gently comic subversion. His Facebook activity was minimal. By the end of the term, however, Liam had become sufficiently integrated to have joined two groups and the university network. With this, Liam admitted he had moved on to a new level of engagement characterised by 'procrastination' and 'prattling around'. These were not more common communication activities, Liam had become hooked into social gaming activities. He demonstrated the Word Challenge App in his final interview:

I saw a friend playing and was like, I was in his room and started shouting out words and I thought I need to get on this. [...] Then I discovered Geo challenge which is, which is really what it's all about. [Laughs]

## **Disability and the Network**

Liam cited his impairment affects as having very little impact on his networking experience. He did not use any generalised or specialised assistive technologies to support his social networking. Nonetheless, Liam was aware of his print impairments and how these might potentially complicate aspects of his online interactions through text. For Liam this was seen to be an issue of efficient communication, rather than one of stigma or extra-visibility. In this respect, overtly textual modalities represented a slight misfit, but one that was glossed over by the informal, social context.

## Experiences of Disability and the Network

Liam recognises that dyslexia is frequently experienced as a greater sensitivity to how text-based communications may be received and negatively interpreted:

Obviously a dyslexic person is so much more, you know, paranoid about it all. Sensitive to it, I guess.

However, Liam does not identify with this sensitivity within his networked public:

I'm not too self-conscious about it [...] I'm usually not too bothered, I mean maybe I would take more care than some people to make sure it's coherent, at least, even if punctuation or whatever is shocking. But then, as I say, I don't think that matters too much because most people think don't pay a lot of attention to it anyway, and, you know, I've had messages that made even less sense than messages I've sent, so from that point of view it's not too bad!

Liam reflected on his experiences of dyslexia in a highly contextual way, citing the audience and location of his interactions as the most important determinant of his attention to impairment:

Depends on [*who I'm*] talking to. Generally I'm not too bothered because, you know, its people I know most of the time, and, you know, people, my friends I would talk to would write in equally bad English anyway, kind of thing, because it's just, you know, it's a message, it's not a formal letter in the thing, you know? I might even write in text speak or whatever, depending on what I'm doing, kind of thing. So I'm not too worried.

For Liam, Facebook constituted a neutral space where informal communication with friends takes place outside formal grammatical and orthographical rules of spelling, hyphenation, capitalisation, word breaks, emphasis and punctuation. In educational circumstances, these rules must be attended to, however, in Facebook, Liam observes that standard practices are different: 'people, my friends would write in equally bad English anyway'. This was repeatedly evidenced onscreen. As a result, the informality of general text practices in Facebook negates the effect of dyslexia as an orthographical difference.

Above issues such as spelling, Liam retained some sensitivity to the efficacy of his communications. He recognised several ‘tendencies’ within his compositions that locate him outside usual practices. These relate to length and sense making:

I may need to be careful that I'm being coherent and not sort of waffling too much and not making any sense at all, because obviously even if they [friends] understand that [I'm waffling], they're, it's not going, to understand [the message] anyway, kind of thing, if that makes sense.

Liam discovered this difference in interaction. He interpreted responses to his messages symbolically:

The way in which I would put my thoughts down don't often make sense to anyone except me, which comes across in other peoples replies! [Laughs].

If I'm writing about something that's quite complicated, like explaining myself. I think sometimes it's, I find it a bit irritating because it seems that they're struggling to understand. So, like, here I wrote a massive thing and he hasn't actually replied to it. But... which is probably indicative of his lack of understanding.

Importantly, in such instances, Liam experienced his impairment as an ‘irritant’ and an ‘annoyance’. When explicitly reflecting upon this, Liam felt an impetus to manage his impairment – but noted that, in the event, he does not:

it's just it's a bit annoying when you're trying to get someone to understand something. If you know what I mean? So in that sense it is a bit irritating and maybe I, but then I suppose, I didn't really I don't really bother to spend more time on [*writing*] though, and I suppose really then, I should, I should do, but I don't.

## **Managing Disability and the Network**

Liam was not seen to actively use any techniques or technologies to manage his impairment online. However, Liam was seen to deploy comparison to find his place in the networked public.

### **Comparison**

In his reflections, Liam used comparative evidence to locate his activity and participation within normal peer-practices:

I don't think you should have anxiety about it, but I think everyone does. I guess it's this whole thing about the norm again isn't it? What is the norm?

This attention to comparison was built upon an understanding of his own impairment as being situated within a diverse scale.

Although Liam did demonstrate attention to a network audience, it was clear that he did not experience any stigma relating to dyslexia. In this respect, a new academic identity was affirmed by an institution that supported these assertions of diversity as normal. Liam observed that dyslexia was better understood at his University than within school environments where he had been identified as 'far too bright to be dyslexic'. In this sense, the wider academic environment was supportive and recognised diversity:

At secondary school I still kind of... They haven't really realised, kind of, perhaps what dyslexia is, or what other disabilities are. That aren't perhaps that aren't so obvious [...] I think universities are a lot better and people are less... people have cottoned on a lot quicker. And when you get to university you get a lot of help.

This is not to say that Liam did not experience disability.

I think if you're dyslexic or whatever, it can be quite frustrating and you want to be able to do things that other people can, kind of thing. And you know, when you can't do that obviously it's quite frustrating, and you kind of, in a sense you feel quite bad because you can't do it, if you know what I mean. Because you feel like you're less than normal or whatever. [...] I had some difficulty in accepting that at times.

However, the networked public was seen to offer a broadly enabling space for Liam's self-expression:

I'm not overly bothered. I'm more bothered if I spell something wrong that's to do with my course, actually.

In this way, Liam managed his impairment as an educational ‘learning difficulty’ expressed in supported university conditions, rather than a social impairment within the network.

#### **5.4.5 Jack**

Jack (19) is a sociable first year English Studies Undergraduate with dyslexia. He conceives his dyslexia as a learning disability:

I guess there’s less of a stigma with dyslexia than there might be with other disabilities, because it’s kind of, it’s just a kind of, it’s only a disability as far as academic things go, whereas other disabilities might get in the way of other facets of people’s lives.

In this sense, Jack does not find his dyslexia ‘obtrusive’:

I don’t read as fast as other people do. And it’s not really a problem in day-to-day life. It does sometimes become a problem when it comes down to academic work. The only instance in day-to-day life when I notice it is sometimes I kind of stutter and I can’t think of a word or something.

Jack did not associate his dyslexia with a disabled identity:

I don’t really know any other dyslexic people and I’d quite like to kind of talk to them and like learn about their experiences and stuff, because it’s not a massive part of my life, it’s not, you know, like a crippling disability that, you know, or it’s not really severe dyslexia where I honestly, you know, have real problems, real problems reading. Obviously I have slight problems reading. But I don’t really feel, I don’t think it’s a label at all. I don’t feel that way.

Jack was interviewed three times over the course of the term in his Hall of Residence.

#### **Technological Landscape**

Jack uses his laptop for all his academic and networked social activity. He does not own or use any specialised or generalised assistive technologies for his work or

internet use. However, Jack sometimes applies a coloured filter to the screen of his laptop when dealing with a lot of text:

It's just like a see-through piece of plastic which is really meant for just reading books and stuff, but you can put it on the screen and it just, it helps. ... I wouldn't define it as a use of technology.



**Figure 5-18: Jack's workspace (30.10.08).**

In figure 5-18 Jack shows his laptop with selected text highlighted onscreen in yellow to assist reading. Aside from losing and finding this filter between his first and second interview, Jack's assistive technology situation did not improve over the course of the term. His formal assessment for DSA took place too late in the term to influence his set up during this period.

Jack occasionally uses MSN and Skype, he chooses Firefox as a superior browser, and demonstrates organic strategies for using the Web that offset his reading impairments, for example, utilising book synopsis' on Wikipedia to support his academic reading. Jack joined Facebook at the end of his school career, just as the service opened up to users outside university settings. Prior to this he has used MySpace briefly, but not 'to any significant extent'. He now checks Facebook daily

to keep up with a well established network of 360 friends, many of whom are friends from home. By his final interview, this network had grown incrementally to 377.

Jack identified how this increase was fuelled by network ubiquity on campus:

It's kind of like, you meet people and you say 'Oh', you know, 'have you got Facebook?' It's strange, because the first question used to be when you start meeting people is like 'Oh, can I have your phone number?' and now the new thing is 'Have you got Facebook?' because it's more informal than even mobile phones and stuff, you can just have people as a Friend and, you know. I think it's a big, big thing these days.

Jack identified some gaps in the network, but observed that these were generally seen to be exceptions rather than the rule:

A girl in my drama group actually said 'I don't have Facebook' and everyone was quite shocked that she didn't. But I think most of the people I talk to generally have Facebook.

Jack's wider reflections on the ubiquity of Facebook amongst undergraduates establish how the network operates as a 'secondary social function':

I wouldn't say Facebook's essential, but [...] It's kind of like, you've got your life as in you and walking around talking to people, and then there's you being a kind of social being on the internet, on Facebook, as well. And I think because it is becoming like the primary social networking site, it's kind of become more of a, like a secondary social function.

I think a lot more people are using it as a kind of augmentation to kind of normal social interaction.

This conception reflects Jack's network use, which focussed heavily upon communication activities.

## **Disability and the Network**

Jack did not perceive any accessibility problems within Facebook as a social networking service. Moreover, he reflected that, where dyslexia was disclosed, it did not represent a negative identity to the wider group.

## **Experiences of Disability and the Network**

Jack did not experience any accessibility issues or barriers to his use of Facebook. He found it a broadly enabling environment:

I think that's why it's got so universally accepted. I don't think there's any other technology that's so, kind of, useful.

Jack characterised this accessibility as relating to the accessibility of the SNS, but also to the social context and the informal nature of electronic communication. Together, these factors meant dyslexia remained unreflected within his networked public:

you don't have to think about, you know, being grammatically correct or spelling everything perfectly. So no, I wouldn't say that it influences my, you know, when I'm on Facebook I wouldn't really think particularly about being dyslexic.

Jack recognised that the network did not represent every aspect of every person, a fact he relished. In terms of disability, he reflected that there was nothing in his Profile that suggested he was dyslexic. Jack valued such gaps in the network as, to him, they characterised non-conformity and spaces for the unconventional:

I guess one of the big attractions of Facebook is that, that, that it's inclusive, so what I'm saying is contradictory, but... I guess this is a reflection on kind of conventional society and like all the people who kind of do that and, you know, tick the box and they're normal and, you know, they're a young person, they have Facebook. But then there are some people who can exist without that.

## **Managing Disability and the Network**

Despite reporting a broadly non-disabled experience within Facebook, in reflection, Jack noted that two strategies he deployed within the network to manage his impairment; disclosure of impairment and a utilitarian, self-disciplined approach to SNS use.

## **Disclosure**

In the first case, Jack noted that there had been a couple of instances where he had actively evoked his impairment to manage instances of potential mis-communication:

I think there's been a couple of times [...] where I've maybe done that, said 'Ooh, sorry', you know, 'that's just me being, being a bit dyslexic there. That's maybe not what I meant to imply'.

Jack did not experience this act of disclosure as stigmatising or risky. In this respect, disclosure was intended to assist functional communication. Jack elucidated to identify how, at university, previous stigma he had experienced at school had been supplanted with a more accepting culture of openness and diversity:

everyone's a bit different, you know, you're not all from the same town and the same school and, you know, you don't all do the same thing, because there's so many different people from all different countries and wherever, you know, that's just another, it's just another kind of characteristic for me, it's just, you know, there's no stigma attached to it really. I don't feel like, you know, I shouldn't tell people or I can't tell people.

## **Utilitarian Networking**

Jack characterised his Social Networking as utilitarian, relating this to the broader time pressures of his academic work-load:

The good point that I wanted to make to you is that I mostly use Facebook as a kind of a tool, like a utility, like I said, to find out if any people are going out or if there's an event on or to talk to people I wouldn't otherwise, you know, be able to talk to or want to talk to and also for like pictures and showing people what pictures I've got and looking at other people's pictures. I don't use Facebook as a kind of time filler, which maybe these things are for. So I would say – I've never even thought about it before, but maybe the fact that I'm dyslexic means that I only really use Facebook for kind of utilitarian reasons instead of like going on there and kind of just filling time.

Indeed, in his interview debrief, when considering questions that were not raised during the interviews, Jack returned to this issue of focus and utility in design:

I just thought like, you know, you might be asking me more about, [...] how Facebook could be improved for dyslexic people or something, but I don't really, I haven't really got an answer.[...] I guess maybe I'd like to kind of remove myself from that whole, you know, Application, group-adding, this thing where people I don't really know just kind of click me into, you know, when they just click 'All Friends' and 'Invite' and I get sent these things which are just completely irrelevant, I don't really care about. I guess I'd like to be able to say, you know, 'I don't want to get any of this crap, I'm not interested in that, I'm here for different reasons'.

In this respect, Jack asserts utility as a valid point of difference, relating it to dyslexia and a positive, non-conformist identity. Importantly, this approach asserts a correlation between the extra time resource dyslexia requires and the types of social networking activity dyslexic students subsequently undertake. Jack's work takes longer and as a result he must use the network strategically – employing only the most valuable social functions and discounting the rest. In this respect, university expectations for 'normal' student productivity place Jack at a disadvantage. He must sacrifice social networked time to achieve expected levels of productivity.

#### **5.4.6 David**

David (20) is in his second year studying Management and French. He applied to participate in the research with his friend Pierce [5.15]. Both have dyslexia. Although David is 'not a technology expert' he states he is 'decent with computers'. David finds his dyslexia affects his reading and writing, he also cites it as a 'ridicule topic':

... dyslexia's always been sort of like a kind of a joke among like my friends and stuff, because everyone thinks they're, you know, when you get like, especially when we came to Uni when I had my test and then got a grant for like a laptop and all this, everyone all of a sudden was like 'Oh well, you know, I'm dyslexic, I could fake the test' and it sort of became a bit of like a ridicule topic.

#### **Technological Landscape**

David accesses the internet daily on his laptop at home and at other sites around campus. In terms of social media, he uses YouTube, Wikipedia and Facebook

regularly. Of these Facebook is his most active social forum, he checks it every couple of days, following up on messages to his inbox alerting him to activity. He used to use the network more regularly for social browsing, but his style of access has changed, focussing on communication activities for utility.

David began using SNSs at 'about 15'. His first network experience was with Bebo:

But I didn't really get that into it. I only had a profile for about a month or so because I really didn't like it. Deleted it.

At university he joined Facebook:

Most people at university have Facebook. I remember when we first joined sort of in the first couple of weeks everyone was asking for, you'd like meet someone and they'd take like your full names so they could look you up on Facebook, very formal. 'How do you spell your surname?' and all this.

At the time of the interview, David's network is extensive. He has 590 Friends: 'they're all people I've spent time with and stuff'.

## **Disability and the Network**

Due to the prevalence of text within Facebook, David experiences a misfit between the mode of the network and his impairment. David was sensitive to how his identity would be constructed by others based upon text within networked publics:

everything is text, you know, and when you're talking to someone there's no like sort of tone in your voice. It's all about how you write it is how you come across, really.

Moreover, David found that computers as a supporting technology exacerbated his dyslexia:

I don't know why with computers it just sort of makes it a little bit worse, like the letters, and I find it quite hard to read a very long sentence when it's really small.

Assistive technologies did not re-mediate these impairment effects. Although David had received support including generalised technologies and specialised assistive software such as Read and Write Gold and Dragon Naturally Speaking for his laptop and work, David did not use them for social networking:

No, I never use them [assistive technologies] with Facebook, because I'm not quite sure *how* to use them with Facebook. (...) I got given two sessions on how to use these programmes and stuff, but they never showed me how to link it with anything else really, apart from the basics.

Administration and support for David's use of ATs has not extended beyond desktop publishing. In this way, David's unassisted networking is structured by his university context.

### **Experiences of Disability and the Network**

The focus on text for expression created a new pressure for David, for whom dyslexia was previously conceived as an educational category, a 'learning difficulty'. With the advent of Facebook as a near ubiquitous network, text has become a central part of student social display, in this sense, dyslexia as a 'disability' rather than a 'learning difficulty' had presented itself as a factor within his social world for the first time. This led to new reflections on the self: 'when I'm on Facebook and I sort of almost feel a bit more self-conscious'. David stated in clear terms that he felt it was important that dyslexia did not confuse what he was trying to express online. This cast David's impairment in very functional terms:

I don't want it [dyslexia] to get in the way and for people to sort of think about that when they're reading the message, rather than what I'm saying.

David noted that his actions were 'self-conscious' and anticipated a critical reception; however, he was also aware that he did not judge others on the standards that he set for himself.

if someone spells a word wrong on my page, I don't think they're, like, [...] I wouldn't think 'Oh, he's dyslexic', do you know what I mean? But when I'm writing, I don't know why, I just sort of feel that.

David maintained that his perspective was irrational. Nonetheless it had tangible outcomes with regard to his activity in the network.

## **Managing Disability and the Network**

David's self-consciousness led him to actively deploy strategies to mitigate any perceptible dis/ability difference. Strategies for increased self-definition included proofing, self-surveillance and reduced and alternative modes of participation.

### **Drafting and Proofing**

David checked his Comments and Status Updates carefully before posting:

Every time I write a post I do check it at least once, like all the way through, to make sure. Because I often, when I'm typing, I make quite a lot of spelling mistakes and just like, I get words, I don't know, I just get like a couple of letters jumbled up in the middle.

David also deployed Microsoft Word as a generalised assistive technology – drafting text with the benefit of the spellchecker before cutting-and-pasting into Facebook. David observed that he was more likely than his peers to make mistakes. In an effort to control external perceptions, care and diligence was required:

I'm conscious that I'm more likely to do it [make mistakes] and I don't want people to sort of notice it every time I write a message, so I take quite a lot of care.

By stating he is 'more likely', David inducts a notion of normality into his talk, accepting a position outside the mainstream. From this position, he can control how he is perceived.

### **Self-Surveillance**

This sense of otherness and difference was identified by David as self-contained:

I think it's more my problem than, I think if I did end up spelling a load of words wrong they (friends) probably wouldn't, you know, even notice it, but

it's just my sort of – I'm lost for the word. It's just, it's more in my head than, you know, than an actual thing they'd think about, I guess.

Importantly, this ambiguous state is not related to disclosure, per se. David highlights that many of his friends know he is dyslexic:

everyone knows who's dyslexic [...] I don't mind people knowing that I'm dyslexic, I just don't really want it to sort of come across when I'm writing messages and stuff, like so blatantly, but, you know.

Much of David's talk worked to assert his impairment. However, David clearly felt uncomfortable conflating dyslexia with wider notions of disability:

It's labelled as a disability, obviously it's not like a very serious disability, it's just a learning disability, but I think it's, sort of, you don't really want to emphasise, you know, by spelling a load of words wrong it's sort of almost like highlighting you're disabled. I just want to sort of keep it as my own sort of thing to sort out. Do you know what I mean? And I feel like, it's almost like people alter their opinion. It's silly, because of the way you're writing. It's just sort of I don't want them to think of dyslexia when they think of me, do you know what I mean?

This experience highlights the challenge of substantiating disability. David does not feel able to claim 'disabled identity' – to do so would require acknowledging it as a 'serious disability' - however, as a 'ridicule topic' the reality of his condition has been challenged by his peers. Whilst his friends understand that David has dyslexia, this knowledge may be relatively cosmetic. As a result, disability discourse is not empowering within this sphere.

After his peers' response to the arrival his Assistive Technologies, the network represents the next moment in which David's disability might be disclosed. In this event, to maintain control of how he is perceived, David works to control the signifiers of his impairment in text. By controlling evidence of his impairment, David mitigates any risk (whether real or imaginary), removing and trace of dis/ability difference and allowing self-definition.

### **Reduced and Alternative Participation**

Despite David's early claims that drafting and proofing his work was not a major undertaking, as the interview progressed David stated that his use of the network had declined. He related this directly to an increasing accumulation of friends. As his network grew – so the work to control impairment effects became more necessary:

More people who are going to see what I'm writing and stuff. I mean, that might be part of the reason I don't use it as much anymore as well. I just, I definitely don't write on people's Walls as much as I used to.

David cited this effect as cumulative – as his network grew, he reflected that he had begun to use and contribute to the network less frequently. This did not amount to leaving the network; however, he noted an increasing preference for his phone:

Yes. But honestly, I still use Facebook, but I just, it's more to, it's less like a sort of network thing. I use my phone a lot more to sort of contact people and stuff. More than I used to. But I mean, obviously I'm still using it relatively regularly.

This move suggests that a misfit, combined with social pressure has led David to find more fitting modes of communication outside the network that do not convey his impairment effects.

#### **5.4.7 Pierce**

Pierce (19) is in his second year studying Management. He has dyslexia. Pierce's background is urban and working class. His take on social media and dyslexia was humorous, frank and pragmatic:

I don't feel disabled in the slightest. I wouldn't I ...the closest I would say I've come to feels like, feels a bit disadvantaged. But I think in the long run you've got to get over that.

I put myself in a spectrum kind of, of people who can't spell properly.

Like his friend David, Pierce feels his dyslexia exposes him online. Offline, Pierce identified that dyslexia incurred 'banter' and extra-visibility between and amongst his friends:

if I'm stupid they'll just say 'Oh, you're dyslexic' or something like that sometimes, but I'm not really conscious about it that much [...] they wouldn't say it to me if I couldn't handle it I don't think. Cause, if I felt really, like, conscious about it, I know they wouldn't do it.

Nonetheless, Pierce repeatedly noted that support for dyslexia was generally perceived to outweigh the disadvantage of the impairment. Some friends doubted the validity of dyslexia, seeing it as a 'very big benefit and I think they kinda of think, like, 'if I had that I would get better marks' and all of this so they kinda see it as an advantage'. This had sparked some resistance amongst Pierce and his dyslexic friends:

it's not really like 'let's stick together' but [...] Like, today, like...I was like 'oh, I almost got up late' and David was like 'oh, it's alright for a fellow dyslexic' like. All of this. And just like, taking the piss. It's just 'cause like, yeah, it's not like we rely on each other to get through the day, but it will be like...there will be points when we're in the room and one of my mates will make fun of him being dyslexic and I'll be like 'chill out mate, I'm dyslexic. Now you're attacking both of us rather than just him' so... but we only joke, we're not serious like...like I wouldn't get all aggressive, like: "what're you doing? This is really offending me". I just like give it back to them. You know like make fun out of their haircut or something.

Pierce took part in one face to face interview, in a lab convenient to his department.

### **Technological Landscape**

Pierce does not have any assistive technologies, having not yet received what he calls the DSA 'education hamper'. As a result his online activity is not supported. Pierce recognises that this leaves him at a disadvantage in comparison to both non-dyslexic and dyslexic peers: 'I am in my second year and I am still waiting for it'.

In terms of internet use, Facebook is the first and only SNS he uses, he has an extensive network of 391 Friends. Additionally, Pierce uses MSN 'of course', but not Skype: 'I don't think that is to do with dyslexia, I think that's just due to laziness'. For research and information, Pierce prefers 'visual blogs like on YouTube' rather than text equivalents. When asked if he used Wikipedia, he states:

No, I can't even spell Wikipedia [laughing] the other day I had to be corrected by a Google search [...] The only reason I use Wikipedia is 'cause sometimes in the books they assume you know more than you know, so like sometimes, like, it's not academically correct, like, I'm not *allowed* to do this for my essays, but if it is just like a phrase I'll just type it into Wikipedia, it'll come up, then there'll be a page on it and it. And it will be easier to understand than getting another book. I'd say I check it probably about 5-6 times a year.

These activities reveal strategies use of the internet for essential social and assistive academic services only. Indeed, Pierce's use of Facebook was characterised by 'checking' and communication rather than the more extensive social browsing or gaming that he observed his Uni friends participate in:

I would say that I would probably log into it every day but I don't do stuff on it every day I might just check it quickly and then maybe like if I am bored I will like 5 hours later I'll have another quick check as well. I'm not on it all day every day.

Another point of difference Pierce highlighted was related to his background. At university, Pierce recognised a close fit between the university situation and the properties of the social network site. Importantly, the social organisation of the Student Union activities required a network profile. This has led to a ubiquity amongst students that can, at times, supersede even mobile phone connectivity:

Like just the whole set up of Universities, 'cause last year it was like, you had to join up to the Facebook Group for your Halls, then they sent through all the information. So I was like in my Halls football so it meant that I would find out when football games were, when training was and when socials were and we'd get it all just...it's a lot better than using a phone to communicate with people I think ...the other day my friend's phone was switched off and we was going round his house so we just called our mate ...that was at home...like on Facebook Chat, tell him to come open the door and it worked, which was quite good.

However, Pierce's background was distinct from many other students interviewed, as computers were by no means ubiquitous in this context:

I have a lot more friends that don't use Facebook, than people at Uni 'cause it is, like, a lot of my mates, say, will never have had a family computer. Like,

so I know at least 4/5 of my mates that don't have computers at home, so don't have Facebook.

Despite the lack of computers, and Facebook accounts, Pierce demonstrated how these friends were still present within the networked public without their knowledge:

...like this party [gestures to photo]. Like the guy's on Facebook...No, the guy - his pictures are on Facebook, but the person whose party it is doesn't even have Facebook. So his party's pictures are on there but he isn't even. He is not gonna see them.

As a result, Pierce recognised that the network was pervasive, but also did not authentically reflect his life outside the university. Moreover, Pierce recognised a digital divide that privileges those within the network over and above those outside, but visible within it:

I think it is class thing, if ya know what I mean...I also think it is a necessity thing. A lot of people take computers for granted at the moment, and there are people that don't have it or won't have it, and they kind of like...like you wouldn't treat them differently at all, but I would say that maybe they get left out kind of because they have to find out everything second hand.

## **Disability and the Network**

Pierce cited a mixed experience of his 'disadvantage' in the network. On the one hand he recognised that affordances of the system, particularly within the University context. Although he lacked assistive technologies, he asserted that he could cope without them:

I just think I am normal and I wouldn't want to be un-normal. I don't know...err, I don't know. I think I'm...I could be alright without the applications I think, I won't perform to my best but I'd still be able to do it to a good standard ...I think.

On the other, Pierce expressed a misfit between his available time and what he perceived as usual social browsing practices. A further misfit was identified due to the prevalence and visibility of text within the networked public. Pierce was aware

that his impairment was rendered visible in text in the network. He was attuned to the fact that his identity was at risk as a result.

## Experiences of Disability and the Network

Within the network, Pierce's experiences of text production and receipt were mixed. Pierce was aware that his online activity was scrutinised, onscreen activity was seen to garner quick responses, he also cited more extreme cases of girls engaged in 'Facebook stalk' activity. This gave him some sensitivity as to how his identity was constructed by others through his profile and activity. In this context, his impairment affects would receive a negative interpretation. Pierce gestured to a recent incident:

Like the other day passed my driving test and on my thing [Status], I don't even know how I done it, but on my thing I spelled 'passed', 'pasted'. Instead of double 'ss' and I was like, pretty sure that everyone would just be looking at that and think 'Oh, what a retard'. So I just, I don't know, the next day, just changed it and didn't really think much more about it...



Figure 5-19: Pierce gestures to an error in his Status Update (05.11.08).

Simultaneously, however, Pierce asserted that there was no onscreen evidence to support his anticipation of this negative social judgement in the network:

Yeah, so, like, they [Commenters] don't care about...for me, like, I changed that.

As such, Pierce stated that the decision to alter his contribution was for himself, no others.

Importantly, Pierce's concern with text production and receipt was not based upon disclosure of dyslexia to the network: 'Everyone knows that I'm dyslexic'. In this sense, Pierce was not sensitive to his impairment being discovered; he was sensitive to his impairment affects being stigmatised and mis-interpreted as stupidity by an extensive network that lacked authentic knowledge of who Pierce is.

## **Managing Disability and the Network**

Pierce's management of disability within and outside the network was observed to focus on three general strategies, time management, self-surveillance and self-discipline in the form of a resilient attitude. In all three cases, management was undertaken at the individual level.

### **Managing Time Resource**

Pierce cites his dyslexia as affecting his reading speed, his writing speed, his spelling and his typing speed. As a result time was an important factor within the network, limiting online activity and commitment to different tools:

Facebook or MSN is the only real thing I use... 'cause I think a lot of people on the internet... like, I don't have time for them, cause it is like a struggle enough to make time for people in your real life so.

In this respect, network activity was task orientated and functional, reflecting Pierce's wider assistive use of the internet.

### **Self-Surveillance**

Amongst Pierce's peer group, dyslexia was a complex issue of identification, asserting requirements and comparison with those in more difficult circumstances. To manage the effects of his impairment, Pierce deployed certain techniques, for example utilising generalised technologies in an assistive capacity:

It's like on the internet and stuff, when I write stuff sometimes I will like write it in Word and then just copy and paste it over just so I know it is, like, all spelled correctly and things like that and with then no one will even, even notice.

## **Resilience**

Pierce repeatedly asserted the need to 'get over' his dyslexia; this was stated as a strategy within his control:

you can kind of learn to get over it, kind of. I won't get over it but I can like do techniques that help me get over it.

In Facebook, Pierce cited a resilient attitude as essential in addition, or in place of management techniques. In Facebook, constant proofing was not sustainable:

I've only done that like once or twice, because like on Facebook I don't really care what they think of me...like all my friends, like, loads of people that can see everything that I do. If I really cared then I would like never go on it like I'd be too scared, so I get over it.

In these terms, Pierce states that he must accept a certain amount of risk relating to the appearance of his disability online as part of a cost/benefit analysis. Micro-managing every post to the network is a demanding undertaking. To participate, he must set aside this concern. This resilience is an internal resource that Pierce continues to build using comparison online and offline to support his position:

I think when I was younger I think being dyslexic affected the way I acted more, but the older I got, the more you just realise everyone's got problems and everyone's got problems. Like, I would rather be dyslexic than have the problems, like, do you know? like...like not medical, but some of ...there are some people with worse problems but who are completely fine do you know what I mean? So, I think you have to get over it.

### **5.4.8 Gemma**

Gemma (23) is a third year undergraduate, close to the end of her Social Science degree, she is a student disability advocate with dyslexia and Spina Bifida. These are unseen:

It's difficult in a way, because they're unseen. So people have higher expectations, but then at the same time, I'm not sort of looked at and written off, so it kind of has its positives and negatives. I'm not very sure how I feel about it, really.

Additionally, Gemma declares a highly conflicted relationship with technology and networked publics. She took part in one interview in her university's central library facilities, a location where she regularly accesses the internet.

#### **Technological Landscape**

Prior to university, Gemma had used MySpace and cited copious use of MSN at school. Within MSN she had enjoyed the disembodied aspects of communication that allowed her to manage disclosure of her impairments when, and if, relevant. At the time of her interview, the majority of Gemma's networking activity is focused on a network of 662 Friends in Facebook. Her Facebook activity is currently characterised by utilitarian communication activities and privacy activities, belying previous facilitative engagement.

Gemma has two specialised assistive technologies installed on her PC in Halls: Read and Write Gold and Inspiration. She also deploys the Microsoft Word thesaurus and electronic dictionary in a generalised assistive capacity. Gemma does not use these technologies in conjunction with the internet however. In this respect, Gemma's tailored browser settings represent her only support for her networked activity.

## **Disability and the Network**

Gemma deemed Facebook essential for student life and cited some dependence on her profile for visibility on campus, as her mobility impairments meant she couldn't get around as she would like:

It's a way of them [people in Halls] sort of seeing who I am. I'm not wandering around a lot. I'm not in the dinner hall. My face isn't really around.

Gemma expressed a generally positive experience of fit between the technological surfaces of Facebook and her impairments. However, despite this functional 'fit' Gemma's experiences of Facebook were deeply fraught, highlighting socio-technical indices of disability that exist beyond questions of in/accessibility. In this way disability was observed to occur as an effect distributed across interactions between the subject, the tool and the networked public, in the form of ascribed norms stemming from implicit rules and power relations. For Gemma, impairment was not about function, it was about appearance: 'not what I do, but how I come across'.

## **Experiences of Disability and the Network**

Gemma experienced dis/ability at diverse locations within the SNS and the networked public. As a disability activist, she expressed strong concerns with the accessibility of Facebook. Although she had not faced accessibility issues herself, Gemma felt solidarity with other disabled users that influenced her engagement with the network:

Facebook has changed the technical things, some sort of formatting or something. Basically now it's not accessible for people with visual impairments, because they can't use things like Read and Write Gold. So I'm aware of that, it puts me off.

I just think it's horrible and pointless and stupid and all these things not to bother to do one small thing, which isn't that big a deal for you, to completely enable one or several thousand people's lives. I'm kind of in protest for them. It frustrates me, that.

In this way, Gemma's politicised self-identification as disabled led her to identify against Facebook as a tool. From this technical basis, Gemma's experiences of disability online were seen to be social and amplified by the properties of the SNS.

As a student who is not seen to have an impairment, Gemma was sensitive to the relationship between perceivable cues and misinterpretation. Offline, Gemma recounted examples of the scrutiny she receives in her day to day activities. For example, when using a disabled parking bay Gemma is given 'dirty looks' and verbal abuse by the general public:

...the automatic assumption that that person is bad rather than 'oh, they've got an unseen disability and look how well they're coping', you know, it's always a negative rather than a positive.

Prior to university, Gemma had been bullied at school because of her impairments and had only recently 'come-out' as disabled:

I never thought of myself as disabled, because I didn't see myself as like a person in a wheelchair, you know? [...] Then I kind of came to terms with it a bit more, but then, because I've been bullied for it at school, I kept it very much to myself. So I started taking better care of myself but keeping it to myself. But it's not until this last year of university that I've kind of 'come out' as we say, where I just kind of think well, you know, 'if you've got a problem then screw you', basically. And I feel I've got a bit more self-confident about it.

Forging this new identity in the face of an antagonistic public was vital to Gemma. However Gemma found the extent of Facebook's networks threatened this process and her negative experiences of visibility permeated the networked public. Some of Gemma's Friends were linked to former aggressors from back home. As a result, the protection usually afforded by University life as a fresh start in a new location had been thoroughly compromised. In response to a potentially antagonistic network, Gemma developed an acute sensitivity to cues and norms. She highlighted how the network created new unseen indices of disability in routine disclosures:

*So could you show me your profile page?*

Yeah. I hate it. I really, I worry about it all the time. I just, I just hate the thought of being judged so much, so...

*And where do you think the feeling, where do you think the anxiety comes from?*

People misjudging my relationships with people based on, like, how many friends I have. I mean, I'm not one to use the Wall much so does that look like I'm not really friends with people? Or is it... Because if people don't know me, it looks like, I don't know, am I uncool? [...] I'm in Hall not because I don't have friends; it's kind of a lot to do with my disability. [...] I just, I feel really insecure about being misjudged, I guess.

Here, Gemma graphically illustrates the relationship between information and social affect. Gemma shows how her information can be misconceived as cues relating to the particular personal and social arrangements in which she lives as a disabled student are outside the range of a generalized student experience. She highlights the ways in which students extrapolate nuanced social information by reading-between-the-lines onscreen; triangulating and interpreting information rather than accepting diversity in student self-representations. In this context, disability represents a positive identity, but it is unseen. As a result, by expressing impairment affects (in this case living in accessible university accommodation in her third year), Gemma risks becoming socially discredited.

## **Managing Disability and the Network**

Gemma sought to manage her impairment affects and exposure in the network through two key strategies; self-surveillance: attending to and controlling disclosure of impairment; and self-discipline: withholding information and enforcing privacy.

Gemma's exposure to a wider network led her to survey and protect her personal information, to close down sections of her profile and apply strict privacy settings:

I literally, I just have, like, who I'm friends with and I even had my Wall off at one point. And there's usually not much going on in my MiniFeed and my Pages, I didn't really have that until recently. So I was really private with it.

In this way, Gemma seeks to disrupt the transmission of her information. However, in the networked public this had unanticipated affects; Gemma's friends intervene:

in terms of like information people are like: 'ahhhh you don't have anything on there, it looks like weird'. [...]

This peer pressure leaves Gemma caught in a double bind, or Catch 22 situation. On the one hand, if she participates in the network, expressions of unconventional aspects of her life risk censure. On the other hand, however, attempts to withdraw or control participation are also discredited, leading to deviant status. As a result, Gemma was required to tread a careful path between these two positions. For example, Gemma answered her Friends' calls for a profile photo (in place of an abstract image). At the same time Gemma withdrew all her other photographs from Facebook:

And like the photographs [...] I look like maybe I've grown up into somebody who I'm not, you know. And I am quite, I'm really self-conscious of that, kind of, people misjudging, misunderstanding. I don't know if that kind of stems from the childhood experiences. I don't know. So I've taken my pictures off there.

Importantly, this activity could not be performed only once. Managing profile privacy is an ongoing task: 'I just try and kind of keep it but monitor it quite a lot and keep it quite clean'. Here, Gemma identifies as second important issue. Whilst social experiences within the network may be fraught and disabling; to wholly withdraw would be lose huge social affordance, affordances that off-set her mobility impairments. Again, Gemma proceeds by engaging with the network, but by purposefully limiting her time and interactions there.

Perhaps most importantly, Gemma's complex and difficult experiences were not evidenced in either her profile, or amongst her friendship group. When asked whether any of her friends felt the same way, Gemma replied:

I haven't really spoken to anybody about it to be honest.

In this sense, Gemma's impairments and experiences of disability are unseen and

unheard, rendered invisible online.

#### **5.4.9 Naomi**

Naomi (20) is a third year Social Science undergraduate. She has a scotopic sensitivity that leads to migraine and which has led to a prescription of highly coloured glasses. Upon arrival at University, Naomi found ‘there was no box to tick on the application form’, without a category for support her university suggested a dyslexia assessment. Naomi discovered ‘that I was slap bang on the borderline’. Now the support ascribed for dyslexia supplements her visual/cognitive impairment. Alongside these impairments, Naomi experienced a serious bout of depression during her studies. Naomi participated in one interview from home at her request via phone, Skype and a remote desktop view connection to her PC.

#### **Technological Landscape**

Naomi began using Facebook three years ago, anticipating networked student life at University. In this time she has collated a substantial network of 248 Friends. Prior to this Naomi’s networking was more limited:

I used MySpace for a while, but didn’t get on with it. It was too complicated for me, so I stopped using that when Facebook came about.

Naomi uses Facebook intensively for communication, facilitation, social browsing and social gaming activities. Aside from this social use, Naomi is also networked with course-mates through a Facebook group. She uses Facebook daily, alongside regular use of her University network spaces for work, and MSN and Skype for additional social communication facilities.

#### **Disability and the Network**

Naomi experienced significant misfit between her impairments and the networked public along two axes relating to her experience and management of dyslexia as a print impairment, but, more significantly, her experiences of depression in her

second year. Together the misfit between impairments and Facebook's networked publics is seen to be disabling, however, from this point, disability is remediated by Naomi's peers. This process was reported to actively reduce depression as an impairment. In this sense, peer intervention transforms Naomi and enables rather than disables, challenging notions of socio-technical determinism.

## **Experiences of Disability and the Network**

Naomi's experiences of her network were strongly informed by experiences in her second year. At this time, Naomi faced significant challenges to her sense of self at University:

I was living in the city. I didn't get on with my housemates at all, and ended up getting really depressed and not very well over it.

Naomi was suffering an identity crisis and on the verge of quitting her course:

my friends back home used to laugh at me, because in the city I wore jeans and trainers, and at home I wore high heels and skirts, and that was the sort of thing, like, personality I had for the first two years of Uni, because I thought I had to fit in, with the group that I'd met, and this is why I got so ill last year, because it just wasn't me, and I was pretending to be somebody who wasn't me.

As a result, Naomi's online activities changed significantly. She began to withdraw from the network. She could not perform the usual student practices of self-performance and pro-social display through humour and interaction:

Yeah, I mean during the, the time that I was not very well, my Status didn't show that at all. You know, it was 'Naomi is.' I never put 'is so depressed she wants to go home and never come back to uni'. It was just left blank, it wasn't, I never put anything, it was just dot dot dot.

Naomi's silence was noticed. Old friends from outside the university setting observed Naomi's change in behaviour. In response to this change, Naomi's friends also altered their mode of communication, setting aside publically scrutinised spaces in favour of personal and private contacts:

And so it was quite supportive to have random messages from people I've not seen in years, saying 'You never have nothing on your status', what's going on? Er, which was quite nice in a way, that I hadn't seen friends from school for five or six years, yet they obviously still looked at my profile to know that I wasn't me, if that makes sense.

The privacy of this process underlines the importance of non-public communications. In this respect, networked email provided an essential affordance for Naomi and her friends, allowing her friends to mitigate negative emotions as a dis/ability difference that are stigmatised within networked publics. In this way, private, authentic networks offered a safe space. From here, Naomi's friends were able to support her emotional wellbeing and scaffold her back into her usual interactions. This positive experience informed a lasting perspective newly sensitised to her visibility in the network and the care and support she felt:

they were still almost, not keeping an eye on me, 'cause that sounds wrong, but you know... Making sure that I was still on their radar. Which is quite nice actually, especially at the time that I needed people to know that, who knew me. For me to know that they were there if I needed them.

## **Managing Disability and the Network**

Naomi's experiences highlight how impairments may be socially effected and the strong impact connection can have on an individual. However, Naomi was not passive in her rehabilitation. She proceeded to create her profile as a space that she could use to rebuild and affirm a social self. Naomi was also seen to deploy self-surveillance strategies to manage her print impairment. Finally, Naomi was also seen to self-regulate, managing reflexivity to ensure she did not excessive micro-manage her dyslexia.

### **Self-Affect**

Naomi deployed her profile and network to help her manage her moods. This approach drew upon diverse functions and tools under Facebook's umbrella. Foremost amongst affordances, Naomi cites the anytime/anywhere nature of the network as particularly powerful:

Erm, the fact that it was there all night and no matter what time I left a message someone would pick it up. And it was also good just to, you could see which friends were online now. It was quite nice to go ‘oh, I’ve not spoken to them in ages, I’ll speak to them at 3.00 in the morning’ when I was awake, and things like that. And knowing that one of my friends who knew me as me was there to speak to at any time day or night, you’re guaranteed someone was online, kind of helped me an awful lot.

Significantly, Naomi used these connections with distance friends and remote networks to substantiate an authentic identity. Contrary to her University and student experiences, she defines Facebook as ‘more me than Uni’:

My Facebook profile, erm, has, you know, all ‘me’ things, like if I go onto boxes somewhere down here, erm, oh... it’s like they’re my friends back home would class me as those, and further down we’ve got like the bumper stickers<sup>31</sup>. Which are like a part of me, really. It’s things that I appreciate and most of them are about love and sappy things, but this is me, but then it’s like, may God grant me the serenity, I am a Christian, and I go to church regularly when I’m home, but for the two years I was away from home I never went to church once. Because there was no one at Uni who would go with me and I was, I lacked the self-confidence to go myself. But using my Facebook profile I could declare that I was, you know, a Christian and it didn’t matter who saw it.

*And it's been a space that you've created away from university life?*

Yeah, erm, yeah, it is more me than Uni, if that makes sense.

In this way Naomi built and performed a positive, authentic and visible self. Significantly, she also conceived her Facebook profile as place of refuge – an inward facing space as well as an interaction. To do this, Naomi drew on Facebook’s Apps.:

I quite like the applications. My profile picture’s, well, my old profile was absolutely full of applications. And personally, all my applications are still somewhere, I don’t know where they are [laughs] but it’s quite, because instead of just going onto Facebook to speak to people you could go on and play games and things like that, and I’ve got a lovely little puppy that I look after on Facebook. [...] I’ve managed to set it up there, so by clicking on Pokey, my little chocolate Labrador pops up. You can feed him and all sorts [laughs].

---

<sup>31</sup> Particular badges and slogans added to Naomi’s profile.

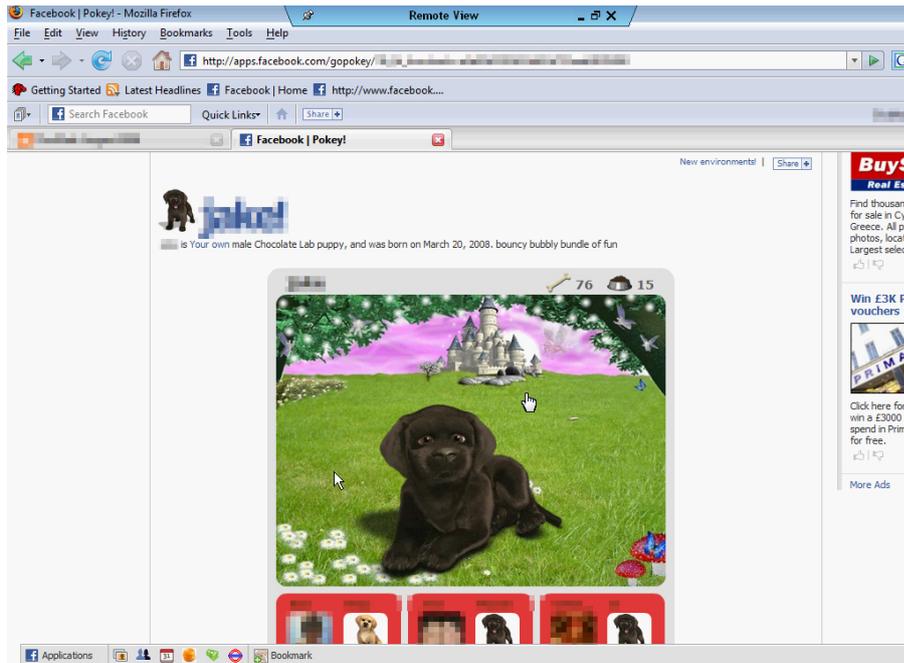


Figure 5-20: Naomi's 'Go Pokey' App (11.11.08).

Figures 5-20 and 5-21 picture an animated puppy that the user can interact with. At the bottom of the screen Friends who are also playing the game (synchronously or asynchronously) are shown with their own virtual pet.

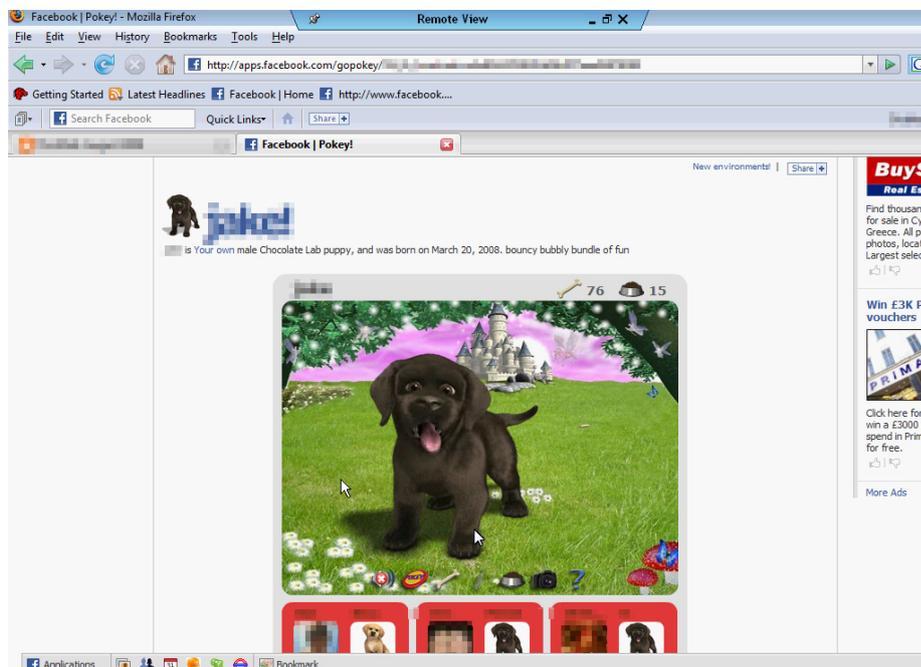


Figure 5-21: Naomi's 'Go Pokey' App (11.11.08).

Naomi cited the benefits of her App use as interwoven with her coping strategies whilst facing difficult times in her second year. Again, this experience is tightly bound to the affordances of tools available within the networked public. In this instance, Naomi cites her use of Apps:

I used this as a kind of safe haven [...] And things like this, where I could still talk to my friends but then play games at the same time and have [laughs] my puppy, it was quite good to kind of get away from things and live in that little surreal world.

In this way, the tool allows Naomi to actively manage her mood and environment, hastening her recovery and helping her to continue her studies.

### **Self-Surveillance**

Depression was not the only impairment that Naomi managed within the network. Prior to her social activity, Naomi cited strategies for managing the affects of her dyslexia online, utilising Microsoft Word's spellchecker as a 'cheat':

if it's a large body of text that I know I'm going to put on somebody's Wall, I tend to cheat and copy it into Word and check it for spelling [laughs].

Naomi did not link this activity to an issue of disclosure, noting that many of her friends knew she had dyslexia 'and really don't mind if I spell things wrong'. Nonetheless, Naomi reasoned that this management was necessary for peace of mind:

It gives me the peace of mind that if there is someone there that, erm, looking and going oh, she spelled that wrong, how stupid of her, you know, how stupid is she, you know, I tend to double think before I put anything up.

### **Managing Reflexivity**

Significantly, Naomi was also aware that self-surveillance itself had to be monitored:

if I look at things too much, erm, I see errors that aren't there [laughs]. So I've got to be very careful that I don't over critical, criticise myself.

Taken together Naomi's experiences and strategies highlight dis/ability as a complex interaction of disparate identities and affects.

#### **5.4.10 James**

James (20) is a political animal. A History student in his third year and a representative member of his Student Union, he enjoys public speaking and keeps up with a selection of national and international political blogs. James described multiple impairments relevant to the research, these affect his right side; as a result he has mobility impairments, visual impairments and cognitive impairments. He also has dyslexia, but he observes that his dyslexia places him amongst the 'very few people who have very high verbal and very low spatial awareness'.

James has a highly critical awareness of disability and debates over models of disability. He proposes a 'social-medical model of disability'; recognising society's need to change, but also stating:

I probably wouldn't survive without the medical profession, I mean, whether I identify as disabled or not, the medical profession has a place in British modern life.

James took part in one interview in central library facilities, a location he requested where he frequently accesses the internet.

#### **Technological Landscape**

James does not use any assistive technologies, having tested dictation software in the past and found it disruptive and inaccurate: 'it's a whole different way of doing, whole different way of producing documents':

you experiment with the things like, sort of, Dragon Dictate and stuff like that, but to be perfectly honest, I've just taught myself to type over the years'. [...] frankly, typing works for me.

Despite his aversion to specialised assistive technologies, James states that he is 'by no means a Luddite'. This was borne out in daily internet activity that engaged with

the political blogosphere, Facebook and more static and wiki-based resources. Amongst these, James cited resources as remaining the most important property of the web, despite media assertions to the contrary:

I think that resources are the most important thing on the internet. They are, you know, let's use some big words, 'democratisers'.

James had invested his own time in this commitment, having contributed to Wikipedia. James was more sceptical of other social media:

You know, everyone talks about YouTube as a great new political tool, but it's not. All it is, is that we now have cameras and we now have a way of putting it up on the internet. At the end of the day, it's still the same old communicating with people.

Facebook is the only SNS that James uses. He logs in daily whilst at University to keep up to date with his network of 355 Friends, but places this as the least of his online activities. This was characterised in his assessment of his digressions over the course of the interview:

I wish I could stop talking about politics, it just seems [to be] what I end up using the internet for.

James' network use focused on communication activities only.

## **Disability and the Network**

Facebook and its supporting digital surfaces represented a close technical fit with James' impairments, a fit James appreciated in terms of wider knowledge of potential accessibility issues. As a result, James was able to capitalise upon the technical affordances of the SNS:

It's a thing that, used properly, can be very useful.

Likewise, James' impairments and impairment affects were not visible in the network. As such, James did not identify any socio-technical junctures in which disability was enacted. However, in the social spaces of the network, James

identified a student culture that lacked depth. In this space, where identity was consolidated, disabled identity could not be expressed appropriately as a facet of the self.

## Experiences of Disability and the Network

James conceived his fit with the technical surfaces of Facebook as a matter of ‘luck’. This luck related to a comparative assessment of impairment:

My disability? I think, no, it doesn't, I mean I'm lucky. I'm not in a position where dyslexia would be a problem I suppose in Facebook.

In this sense, James recognised that dyslexia as a spatial impairment offered a better comparative fit with Facebook than dyslexia as a verbal/print impairment. James also strongly evoked accessibility barriers present in Facebook for students with visual impairments:

I know certainly partially sighted is *really* a big problem, I mean there is a **massive** [Facebook] issue with that.

In this respect, James' impairments were not enacted through Facebook as a technology. However, James' knowledge of Facebook's accessibility failures for other disabled students meant he experienced this fit as both fortunate and random. In this sense, the existence of accessibility barriers evokes disability, established a comparatively privileged position that James experiences as ‘luck’:

Um, beyond that organising things, involved in disabled, being a disabled student, no, I don't think it does [impact]. Because, because I'm lucky in that my disability doesn't really affect my ability to use Facebook, so I don't know if it comes into it particularly.

Importantly, James did not conceive disability online as a simple matter of technical fit with a tool. He relished situated perspectives in which his ‘disabled’ identity counts as one of many he adopts depending on context:

I'm almost postmodern on this concept [...] If I'm commenting on a political blog, if it's an American website, it's as an Obama supporter. If I've

commenting on a British site it's as a disaffected left winger. If I'm commenting on something on disability it's as someone who has, you know, as a disabled person [...] I think that's the wonderful thing about the anonymity of the internet, that you can just be... you're whoever you want to be. And of course there are obviously so many problems with that as a, sort of, you know, world, but at the same time I think it can add, can be very useful because you can, you can emphasis your own, a singular element of your personality.

Here, James articulates disability as a facet of identity best expressed and controlled within an anonymous blogosphere. In this realm, disability is not always the most salient identity; it is a matter of relevance and identification in a specific context.

In stark contrast, James asserted that Facebook represents 'the very opposite of anonymity'. The networked public closes down identity. Moreover, James noted that the culture of Facebook represented a 'hideous' and 'horrible inversion' of people. James identified how the networked public purveyed a profusion of the 'worst pictures' from nightclubs and other student social activities as normal, whilst 'serious' aspects of a person's personality were 'ignored' and unaccounted for.

## **Managing Disability and the Network**

James' concern with the consolidation of identity and skewed nature of Facebook resulted in two interrelated strategies for disability management; Within the network, he created distance between himself and his profile by withholding information; James also marshalled his networking activity to ensure he prioritise alternative participation. In this way, James could continue to enjoy greater freedom of expression relating to disability and other aspects of his person more anonymously in the blogosphere, or more personably, face to face.

### **Withholding Information**

To establish his separation from the network, James had ceased to update his Profile:

I haven't really changed the personal information for months and months and months, and it doesn't really reflect me anymore, which possible makes it worthless, but I can't be bothered, 'cause you know, I have too many other

things to do. [...] I'm making an anti-, I'm making a statement of laziness, if that works.

In this respect, James maintained his network profile as a communication tool, but simultaneously signalled his antipathy towards norms of self-display.

### **Reduced and Alternative Participation**

James also strove to prioritise face-to-face interaction amongst co-located student networks:

I prefer expressing myself face-to-face. I just, I don't, I find, I don't find, I don't think it [internet mediated communication] is as satisfying.

[In Facebook] You get a lot of stuff thrown at you, and it's all of equal weight so you have to sort through a lot of stuff, and you can't, often you can't really communicate with people, you don't know how they're dealing with things.

Whilst James recognised that face-to-face interaction represented a risk in terms of the visibility of his impairments and others' perceptions of his disability, he did not attend to this. Instead he asserted the benefits of embodied communication. These outweighed the benefits of even the most accessible and usable networked publics:

I'm not, well, I'm sure there *are*, but I don't notice so much the perceptions [of disability], which is probably a good thing. And, you know, so, I don't, I think there are, the disadvantages of the internet that, you know, it's not as personable. I think I, I find it more irritating to you, I don't find it difficult to use. I find it irritating.

In this respect, James used his Profile as a springboard. Upon receipt of a message or comment, James would then suggest a face to face conversation. In this respect, James used the network to complement his usual social activities, resisting online networking as an end in itself and the social ascriptions of the wider networked public.

### 5.4.11 Ana

Ana (37) is a former teacher who comes originally from Eastern Europe. English is her second language. She describes herself as computer-literate insofar as she is 'becoming, or in the making', compared to her background in Romania, the UK is like 'living in the future'.

Ana was diagnosed with Cancer a year ago during her Social Science MA. In her own words she has 'been through surgery, chemotherapy, radiotherapy ...everything, all the package that comes with it'. The illness, treatment and recovery process has resulted in various affects, for example, impacting on Ana's energy levels and mobility: 'you know there is times when you you're just tired in bed and you can't move'. Ana also identified a psychological battle that also had to be won for recovery. Within the interview, she highlighted the cognitive effects of her treatment:

I'm jumping from one thing to another after the chemotherapy I've got to warn you that sometimes I completely forget about things unless someone reminds me of it.

This warning indicates some of the work Ana continually undertakes to pre-empt the social effects of her impairments.

Despite these issues, Ana does not identify herself as disabled, choosing instead to experience it as 'a temporary thing':

I'd feel bad if I said, you know 'I'm disabled and I need help and I need you to provide me...' I'd, I'd feel like I'd be taking advantage.

Within this line of talk, Ana frequently referred to people she considered more disabled, particularly those for whom impairments might be more permanent. This perspective also evoked a 'mentality' and national identity:

I come from a context where I am used to working really hard and complaining as little as possible.

Ana has not requested support from disability services at her university – instead brokering only the extra time needed directly from her department.

## Technological Landscape

Ana works with the internet both at home and in her campus office up to 10 hours per day for her work and research. She banks online and uses Skype regularly. She has given up Instant Messenger 'because I think it's slow!'. Despite her internet use, Ana's use of SNSs is extremely limited:

I keep in touch with my friends by phone. It's a different kind of contact. I think I come from a different age and time [laughs] I come from the 18th century where people got together having tea and a chat! I don't see why I'd be online with a profile unless probably for a professional interest, maybe.

This position was informed by a deep scepticism of social networks, strongly informed by Ana's previous work as a teacher. At that time, in 2006, Ana created a false account with the SNS Hi-5 to better understand her students:

some of my students tipped me off: 'you haven't got a clue what's going on' they said 'you should just create yourself an account on Hi-5 and get online and see what's happening' [...]

This experience had made Ana highly sensitive to issues of risk, security and privacy:

there is such a fine line between socialising, getting to know people and revealing a bit too much about yourself and exposing yourself.

people have so much personal information online nowadays, to me it's scary.

However, this position was consolidated by intense time pressures brought about by Ana's illness and treatment.

As a result Ana did not participate actively in any SNSs. As the interview progressed, however, we discovered a nascent Profile that Ana had set up within her research centre's Ning network:

Sorry I should have said that from the very beginning; this is my name here but I didn't add any photographs I didn't write anything about me so far I just wanted to create an account to let them, these people know, that I wanted to

be on [...] if the professors, if the teachers are joining this I suppose it's alright, it's more than good enough for me to trust. I got trust!

Ana identified strongly with this network 'under the surveillance of the University', but lack of time meant Ana had been unable complete her profile or interact with her emergent network of 22 colleagues in any meaningful way.

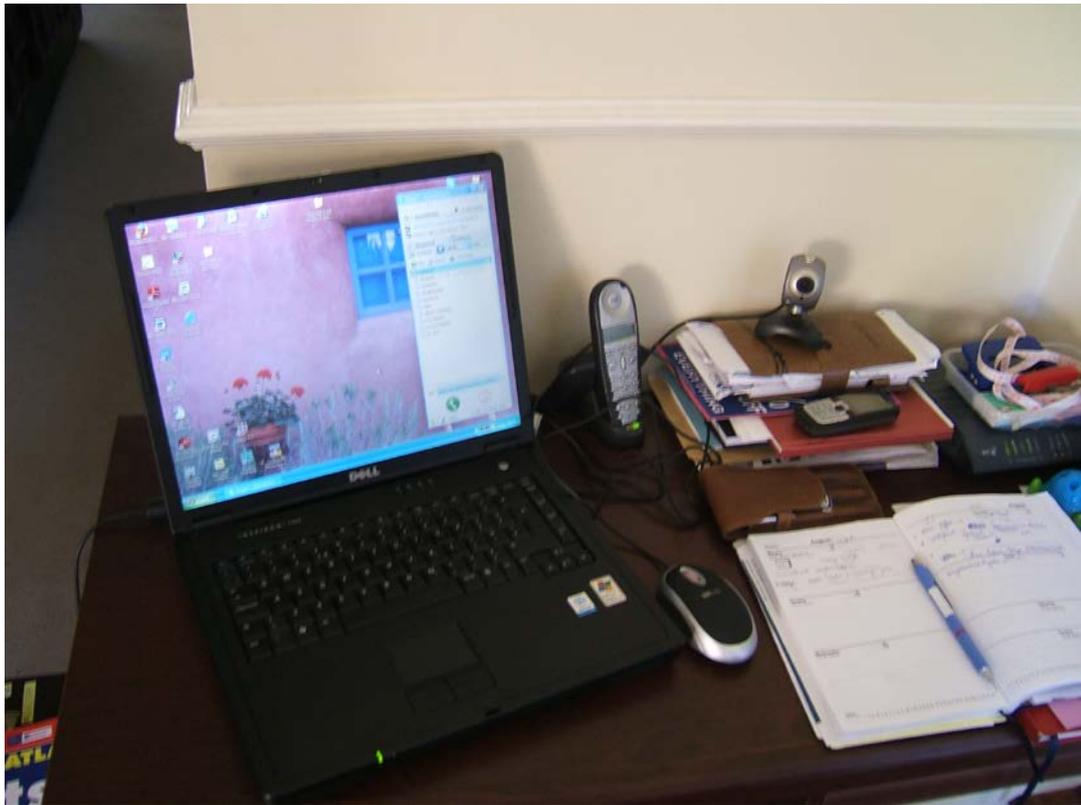


Figure 5-22: Ana's workspace at home (09.10.08)

## Disability and the Network

Ana uses the internet intensively. The impact of Ana's treatment means she has relied on internet technologies for study:

there were times when I wasn't able to participate in courses or participate in coming to University like I would have normally, so I had to I guess rely on technology.

She has also tapped online resources and communities for information about her cancer and treatments. In this sense, Ana has drawn on remote communities of shared interest as resources.

## **Experiences of Disability and the Network**

Ana's use of Charity and Cancer Research forums has resulted in a mixed experience, at times actively depressing: 'all this information pouring into your brain takes you down':

Chatting with people, and seeing people's experiences and letting it off your chest and saying, goes, you know... in a way you contribute with what you think you can, other people are behind you, but at the same time being *exposed*. You know? [...] but reading about all this, you're informed, it's all right, you know exactly where you are. But it takes you down a little bit, but then you've got to get back on your feet.

Ana expands upon this statement – the exposure is not of one person to a crowd, but of the individual to the reality of Cancer. In this respect, communities of interest represent a form of support, but also bring to mind the reality of the situation. Ana repeatedly evoked a balance between knowledge, 'facing facts' and depression 'taking you down':

I think I prefer exactly where, to know where I exactly where I am now to be able to plan ahead but that takes you down for a day or two or three depending on your psychic and then you get back on your feet and carry on and that's what I meant by taking you down.

Ana's talk about these communities suggested that participation involves support, but also a risk to mental health.

## **Managing Disability and the Network**

As we have seen, Ana was highly sceptical of social networks and did not use SNS for pastoral activities. Confidence in her institutional identity allowed her to take her first steps into developing a professional network, rather than building a student identity. Ana managed a limited time resource that disbarred greater engagement

with online support communities. Management of this precious resource was seen to dictate Ana's online interactions:

I've read a few comments and I've seen that there are forums in places where we'd, you can join and you can have that sort of conversation and you know that your comments and your experience and I feel that would be very helpful, the only reason why I didn't do that because I didn't have the time to be honest, it's been so busy with work and everything.

In this respect, Ana has had to prioritise her academic work and recovery, with little time for anything else.

In terms of identity, Ana was clear that a central strategy to maintain her recovery was to minimise her illness to maintain a 'positive frame of mind'. In this way, Ana consciously separated herself from disability as a negative identity:

I've tried to blank it is as much as I could and I've minimised it to have resources for the future because you never know what happens in the future if it strikes back [...] my idea is to try and minimise it now that's why I don't, I don't really feel disabled.

Ana recognised this strategy had potentially negative outcomes, as 'non-disabled' she felt less able to request support:

I don't feel like saying 'yes, I've got special needs, I want you to provide me with this and that' because I don't really need it. But then I'm thinking am I being truthful?

This dilemma may lead to counter-productive outcomes, but the necessity of maintaining a non-disabled identity is conceived as far more important, facilitating recovery and a positive outlook. In combination with Ana's time concerns, it is clear that her approaches to managing her impairment constitute survival strategies within which there is simply no space for social networking and reflexive identity practices.

#### **5.4.12 Elizabeth**

Elizabeth is 'thirty-nine years young' and a part-time doctoral student. Early in her interview, Elizabeth describes her impairments in the following way:

I've been categorised by the standard IQ tests as having learning disabilities and dyslexia.

Notably, this description of impairment is not a self-description. Elizabeth firmly locates the source of her impairments within a standardising and categorising (medicalising) society, not as a personal or individual attribute. Elizabeth does not, however, reject 'disability' as a badge, she identifies strongly with the Disabled People's movement. This attention to autonomy and agency is born out throughout her interview. Elizabeth took part in a one-off phone interview, and asked for her screen not to be remotely recorded or viewed due to her concerns over security.

### **Technological Landscape**

Elizabeth is a highly adept technology user, utilising a screen reader alongside dictation software for work and browsing the internet on her PC daily. Elizabeth recognises the functional benefits of ICTs for assisting productivity and accessing resources, but the interactional aspects of the web are problematic:

It does have its things [benefits] in terms of helping me organise myself and helping me to be more methodical. But, and also that, for like downloading papers and amendments, things I need to get done quickly. It is very useful for that kind of thing. It's very useful for downloading academic papers, it's very useful for information, getting information, downloading and organising information, but it's not useful for me as a social interaction thing, no.

Elizabeth has previously engaged in discussion groups focussing on politics and advocacy. She has also accessed Facebook and MySpace, but does not maintain a profile in either. Indeed, in recent years Elizabeth has begun to use the internet for interpersonal activity less and less. She reports her gradual withdrawal from online social spaces in a highly considered and reflexive way, offering a valuable perspective on the research questions.

### **Disability and the Network**

The networked publics of Facebook and other SNSs represented inaccessible spaces to Elizabeth. Particular points of issue identified by Elizabeth related to the memory

work involved in maintaining a catalogue of passwords across services, the time required to adequately interact online, the pace of interaction, the quantity and quality of social information shared, and the unequal power-relations engendered within online communities. Together, these socio-technical facets of the network constituted significant barriers to use and threatened Elizabeth's autonomy.

## **Experiences of Disability and the Network**

Elizabeth was clear that disability was not incurred through the technologies she applied to supporting her internet use. She conceived both her computer and assistive technologies as neutral tools:

The computer... mine, is a, is a functional thing that allows me to do... allows me to do what I need to do in my day-to-day life. [...] the screen reader isn't about my identity, it isn't about a representation of me, it's a function that allows me to check my work over, it doesn't, it has no control, you know what I mean? It has no control over what I say and what I do.

This perceived neutrality is not extended to SNS, however. When conversation focussed specifically on SNS, Elizabeth related how she had encountered Facebook's demand for user profiles and the passwords they entail:

I just can't be bothered, with entering all these bloody passwords, you know, and I find a lot of it overload, with the information. I just can't be bothered to be honest. I've got an e-mail. You always have to remember a password. Like for example, I had somebody, a friend of mine was quite ill and she, I prefer to speak on the telephone, she uses Facebook, when she tried to set me up, I can't remember the bloody password! I've got more important things to do with my life than remember the bloody password for Facebook! When I want to talk to somebody, you know? You know? I'm sorry, I can't be bothered to be visiting Facebook and things like that.

For Elizabeth, passwords represented an unnecessary and significant access barrier at the very threshold of the networked public. Her experiences within communities of interest and communities of practice also provided her with an informed understanding of the social shortcomings of networked interactions.

Foremost in Elizabeth's mind were issues of context and social cues:

Firstly, you don't know where people are coming from so you can't negotiate ... where, you know like if you're in a social setting you can. People say who they are, where they're coming from, so you know their roles, you know who they represent, so you get a sense that you can sort of navigate how to say things, not to say things, how to ... how to say things in a way that they can understand what you're saying. Yes? Now when you're on the internet all those social cues go out the window and you get completely misinterpreted ... yeah, I, you know, you end up being the difficult one - you end up, and I just find that lots of things - so that's one thing, the sort of social etiquette goes out the window, and I find that really difficult because I know I might be saying things that are not popular to hear...

Here Elizabeth demonstrates how the lack of contextual and interpersonal cues, combined with audience effects, can damage a person's sense of self-efficacy. In this respect she is forced to relinquish the social presence she experiences in face-to-face situations:

It's a different kind of subtle dialogue where you can deal more tactically and make judgements when, when, when it's best to be and when not, unlike the internet where you don't get that.

Arguably, in this way text-based discussion presents barriers, creating an ability difference. Elizabeth reported further concerns relating to the amount of time and resource that a discussion group commanded:

I think discussion groups are a false economy. Not in terms of money, but in terms of time. In terms of what you get, because I value my time.

You spend loads of time reading this stuff and actually that's not how I want to spend my time, reading everything and anything that people want that is related to a subject area.

Here, reading cannot be targeted or controlled. 'Everything' and 'anything' is termed as an external imposition, threatening autonomy. Indeed, information overload was a recurring theme:

Because that is the thing with discussion groups you get six or seven different threads they come in different times, different places...

If you don't read it there and then, then you've, you know, lost the thread.

Everything gets speeded up 10x the speed [...] everybody needs a response yesterday

Notably Elizabeth did not theorise these issues relating to synchronicity and complexity of dialogue as purely structural, neutral or given. Elizabeth was sensitive to these arrangements in terms of hierarchic arrangements of space and power:

I find that the way it's organised doesn't help you, you know? [...] I just find it's not, I don't really want somebody to control everything I'm doing.

Forms of social, interpersonal control include partial moderators and majority domination of discussion, both closing down avenues to dialogue. In one example, Elizabeth specified an instance in which she experienced partial moderation:

He didn't mind constructive criticism of the people *he* felt needed it [...] I felt I haven't got the time to battle with moderators, I've got a life out here.

Elizabeth also voiced experiences that run counter to prevailing arguments regarding online spaces as dis-inhibiting to all users:

I think there's definitely a lot of power shifting that goes on even though you can't see, you can sense it. Yeah.

*You've mentioned already, Moderators, and gatekeepers ... When you mention the different groups, is it just that some groups are more vocal? Or some are more hardline? How do they dominate?*

They dominate because they come in numbers and because you find that sometimes other people won't speak up, you know, when you say something.

Elizabeth also identified experiences where she had received censure for questioning materials presented to a group:

...apparently I pissed everybody off, 'cause the expectation was that I was just going to say, 'yup, that's fine'. *Actually* 'I've got some questions to ask here', which would, which would be very different. And I think some people use the internet I think to, to, to get consensus as opposed to enter into dialogue. [...] It's used, I think, to cut out discussion.

Together, experiences of these barriers led Elizabeth to question the salience of computer-based technologies for disabled people as a group:

I think IT is such an overrated tool for disabled people sometimes.

## **Managing Disability and the Network**

Elizabeth's management of dis/ability difference encountered online has led to a strategy of disconnection and alternative participation.

### **Alternative Participation**

Elizabeth found networked publics and public web fora to be disabling. To regain agency, she disconnected, both socially and professionally. Socially, she asserted physical connections:

I like people. I like contact. I like meeting people. I like dinner. I like the social aspects, I don't, I'll be honest with you ... I don't want to remember someone's password to be able to see them! I can't be bothered, I can't be bothered!

Quite frankly I use these tools as little as possible in terms of socially, socializing online. I don't like it.

Professionally, Elizabeth resisted invitations to join networks or participate in discussion online. From this vantage she could better demand alternative modes of communication, by phone, video conference, email or face-to-face. In these communication spaces, communication was perceived to be more efficient, transparent:

I just say 'no' now, I'm just not interested. If people want to discuss an issue, we do it face to face but not, or by telephone conference, but definitely not that way [online] anymore. I haven't been on, I haven't been on, for two or three years and I don't miss it to be honest.

This return to more embodied, synchronous forms of communication was important for Elizabeth, not only in terms of productivity, but also in terms of time commitments and a wider work/life balance:

I spend enough time at my computer! It's as simple as that. My life isn't dominated by bloody computer! When I finished doing the things I need to do on my computer, I can go out and meet somebody I can go for a walk, I can be out there. Do you know what I'm saying?

Honestly, I'm working 40 hours ... I'm working my arse off at the moment, I'm trying to get my PhD done, and I'm looking for another job, my brain isn't all geared up for doing a different password to speak to each individual person on a computer. I'm sorry, my brain ain't geared for that, and I'm just not interested. What is geared for is a ...telephone book in one place. If I want to speak to somebody my password would be their telephone number, if they give it to me.

In this way, Elizabeth recognises the affordances of alternative media, and plays to these strengths. In doing so she seeks to regain agency and affect an empowered disconnection, drawing others into her preferred realms of interaction. The memory work involved in crossing the threshold of the network and participating in its systems are not worth the aggravation. Elizabeth has withdrawn her voice from the networked public.

#### **5.4.13 Dennis**

Dennis (40) is a Muslim postgraduate in the Social Sciences. He is originally from Pakistan and English is his second language. His research is bi-lingual. Dennis has dyslexia which he self-diagnosed in the course of his studies, before receiving a formal assessment. Dennis does not believe that dyslexia is the sum total of his disabilities, but he has been unable to attain further assessment. In this sense Dennis' disabilities are multiple and, at least in part, unknown and formally undisclosed. He discusses his experiences vividly:

I wanted to, to be assessed for the other things, but, you know, the system here is not – as, as far as I've known through discussion with my tutor - the system here is not tailored towards assessing adults on these things, you know, separately. And the other thing is that I've, I've no, my concentration or my understanding is to, to, to adapt and to make use of my advantage, so I can see that there are elements of ADD, or there might be an element, element of a hyper activity, hyperactivity in that sense that it might not be physical but, but mentally it is so powerful that you would have tamed it in some way, but

that would be so powerful that it wouldn't let you do or concentrate on your work, so... and this is what I have been struggling with and what I struggle at times even now.

Dennis participated in one interview at his student office.

### **Technological Landscape**

Dennis comes from a highly technical background:

I used to run an Internet Cafe which used to have about 18, 19 computers and I used to manage that ... the network, in terms of troubleshooting.

Dennis states however, that things have changed, downplaying his IT credentials: 'it used to be very primitive technology'. Nonetheless the legacy of his technical background was still evident in sophisticated academic internet resource use and a residue of profiles:

I do have accounts in Yahoo! Yahoo Messenger, MSN messenger and I used to do a lot of chatting on MIRC if you remember that? Microsoft Internet Relay Chat, MIRC which is still in use, but that used to be very popular among students.

Dennis has a Facebook account that he occasionally uses, a move instigated by a need to connect with other research students. He responded strongly to the affordances of Facebook as a distributed system for supporting his academic community, identifying an important need to supplement central provision:

Because there were issues around communication in the University that er, you know people were not being able to communicate effectively with each other. Some students might be at other places, you know, or they might be part-timers, they might be in other countries. So if you have got such a, such a facility or provision, of, you know, having an active, I would say, active profile or community, that would keep you updated.

Dennis has registered with the network to stay up to date with his peers, acknowledging the potential of the network. However, his own role is not active. Dennis' Mini-Feed stated 'You have no recent activity', his network was very small,

displaying only two Friends. Dennis identified that most interaction had taken place through Facebook's email function: 'My role is mostly sort of dormant you may call it'. Indeed, much of Dennis' activity with social media was seen to be reactive. This extended beyond Facebook, for example Dennis identified himself as 'A sort of spectator' in different contexts, for example, his use of YouTube focussed on shepherding his children to age-appropriate content and accessing 'lectures on Islam and other discussions'.

## **Disability and the Network**

Disability was seen to occur in several key aspects of textual interaction within Dennis' network. In this sense dis/ability difference was constituted through the networks modality in interaction with audience effects. In short, text based communication represented an uncontrolled disclosure of disability. Text also complicated practice. Notably, Dennis did not use any generalised or specialised assistive technologies in his use of SNS or wider internet activity.

## **Experiences of Disability and the Network**

Dennis' experiences of disability and the network were complex, rooted in multiple indexes of marginalisation. Dennis identified disability, ethnicity, and a combination of gender and religion as factors determining his interactions and self-presentation online. Amongst these, disability was a salient factor, most specifically experienced as a print impairment:

I have no difficulty whatsoever in trying to communicate my ideas orally but when it comes to writing then it becomes a real, very difficult issue.

Although Dennis had used synchronous spaces in the past for anonymous chat and more personal interactions with his close family, he withdrew from this space citing misfit: 'I've never been comfortable with it', 'it didn't fancy me much', 'my orientation was different':

so I just slowly gradually tracked back from that, because the fact that I've had enough experience of seeing what this is about, how this is done and what sort of framework lies underneath.

In comparison to previous chat online, communication in the networked public represented a different interaction. In this environment anonymity is lost. As a result Dennis experienced the effects of an implied audience powerfully:

There is an element of, you know, should I say 'fear'? I don't know whether it should be seen as fear, or element of unrest, an element of insecurity in that sense. That you may then, to think as an dyslexic person that, you know, whatever you might fill [out] may not be seen as a common practice, which usually people do. So I think that's why there is an element of reluctance involved.

These experiences are founded on a notion of being outside 'normal' practices:

People who are normal, they don't happen to think about the processes which are involved in trying to say things. But I think with me, or maybe with other people who have got dyslexia, who are dyslexic, you know?, or who are disabled in that sense, they've got to, they have to think about the whole process itself which makes it difficult for them to clearly come up with, with appropriate words and appropriate communication experience.

Dennis cited his experience of the results of impairment effects vividly in strong emotional terms. These experiences related to highly sensitive, dialogic understandings of the networked public. Dennis identified this precisely. For him, text-based communication was not simply a matter of spelling, it was a matter of conducting 'usual', 'common practices', of 'bringing ideas along in a particular fashion', 'coming up with the appropriate words'. Dennis experienced dyslexia as a state of Otherness; understanding that his actions are perceived as different. In this respect, dyslexia was not an impairment, or text effect, but an 'element of uncertainty' of 'fear attached to what you would say, where'. Dennis noted that this experience was not stable. These feelings were amplified at times of stress or pressure:

This particular feeling is not all the time and I think that if, if, if, I'm stressed or anxious or worried about something, that would enhance many for this experience.

Importantly, dis/ability was not an attribute of the text itself, but a matter of public scrutiny, evoked by the receiver.

## **Managing Disability and the Network**

Dennis undertook several strategies to manage disability within Facebook; these included self-surveillance with attention to managing disclosure, and a balance between utilitarian, reduced and alternative participation and conscious moves to become more assertive.

### **Self-Surveillance**

Dennis was highly sensitised to how he was perceived in terms of dis/ability. This sensitivity was heightened by other aspects of identity. This was expressed in an exchange focussed on the reasons for Dennis' selection of his profile photo, which pictured his young daughter grinning:

*So, could I ask why you chose that photo?*

Because I didn't want to use my photo.

*Would you mind telling me why you wouldn't want to use your photo?*

It's a matter of, I think, I'm a bit, I would be a bit nervous if I see a person, because there are stereotypes. I would say that people would see me as a person who's very strict who's very religious and er, you know there is an element of extremism involved. [...] I think there is a strong element of media portraying a particular type of people, shown as, you know, extremists and terrorists. So seeing yourself from that perspective is a very daunting experience. And other thing is that, you know, I've ... and that's what I've seen, that, you know, people don't usually like their pictures!

Here Dennis describes how self presentation online demands reflexivity and an external perspective on the self. In response to stereotypical portrayals of Pakistani

Muslim men as ‘extremists and terrorists’, Dennis chooses to defuse visual aspects of himself that disclose his religion as a first impression to retain a pro-social presence. He also observes, with a gentle comic observation ‘people don’t usually like their pictures!’. This action is undertaken to create a space for a more gradual disclosure of information without being anti-social. Dennis’ strategies for managing disabled identity within the network reveal a difficult balance between the pro-social and anti-social. Additionally, Dennis has acted pragmatically, to develop his confidence on the one hand, and utilise equivalent communication tools on the other.

### **Alternative Participation**

Dennis rarely instigates communication through social technologies, preferring instead to express himself face-to-face, by phone, or, if required, email. In this respect, Dennis manages his disability by accessing communication tools outside the network, or beneath its public spaces. This allows him to control communication and impairment effects privately, in ways more conducive to his oral strengths.

### **Utilitarian Approach**

Dennis’ lack of instigation is also strategic. Dennis appreciated the potential affordances of the network, but also repeatedly expressed time pressures that precluded greater engagement. On an occasion where he did wish to express himself he states:

I wanted to write something [on Facebook], but I think due to time constraints I couldn’t do that.

### **Assertiveness**

Over and above concerns relating to time and identity, Dennis identified a further strategy of self development:

I’ve been working around it, trying to become more assertive in the things which I write.

Taken together, Dennis' experiences and management of dis/ability are complex and intersectional, situated amongst other identities. Dennis negotiates a social impairment within the networked public, and an educational impairment outside it. Despite this, Dennis recognises that the network may be useful, as such, with his minimal engagement he attempts to reconcile his status as 'Other' within the networked public.

#### **5.4.14 Claire**

Claire (28) is an advanced internet and assistive technology user and social scientist who has been involved in accessibility auditing and user research for universities and private companies over the course of her studies. She is close to finishing her PhD.

Claire has multiple impairments that she describes simply as 'visual and hearing impairments and mobility impairments'. These are unstable. She also has some fine motor impairments (RSI) and has been diagnosed with 'depression, stress and anxiety and slight OCD' whilst a student. Claire participated in one face to face interview in her home office.

#### **Technological Landscape**

Claire values networked publics and social media for the contact they give her with friends, colleagues and coursemates, as she works from home a great deal. She also enjoys the informal information social networks reveal. Claire was the only student to use the micro-blogging service Twitter as the primary site of her social and professional networking:

Well, it's [Twitter's] so important to me, because it's much easier for me to communicate through the computer.

Claire also uses Facebook for basic communication activities with a network of 57 Friends and blogs intermittently.

Claire employs a variety of generalised and specialised assistive technologies when accessing the web for both work and socialising. She deploys a mix of hardware and software adaptations in a sophisticated arrangement. This arrangement includes an adapted keyboard and mouse, 32 inch monitor, multiple operating system driver adaptations and browser adaptations, screen reader and screen magnifier. Shortcuts, favourites and 'remembered' passwords were also visible onscreen.

## **Disability and the Network**

Facebook proved largely inaccessible to Claire's specialised assistive technologies. As a result, functionality and dynamic content were often hidden. This meant Claire was unable to access 'usual' Facebook practices and interactions. This necessitated different patterns of activity, leading to different networked experiences and a filtered presence in the network.

Twitter offered a far better operational fit with Claire's impairments, representing an enabling environment. Nonetheless, within these networked publics, impairment affects and disability as a socially ascribed identity had to be managed between and across different communities. In this respect, disability was socially and technically evoked in both networked publics.

## **Experiences of Disability and the Network**

Claire's mobility and sensory impairments make it difficult for her to get around; they also make it difficult for her to talk and listen, and concentrate for long periods. In light of these impairments, social networks offer Claire significant assistance for inter-personal interaction and her visibility amongst her friends and peers. In mobility terms, the benefits are vivid:

If my back's getting... and I can't walk today, I can send messages.

In this way, SNSs are enabling, opening up new vistas of interaction and allowing her to engage with university sociality at a distance. Claire also finds it difficult to maintain relationships on Campus, a factor she relates to her visual impairment:

There were just so many people I lost touch with. And part of it I think is that when I'm walking around Uni sometimes I think 'that shape, is that someone I know? It might be, not sure'. So I don't say anything. [...] But something like this [Twitter] it says the name. It's just, I don't know, it's easier.

In this sense, the transparency of the networked public allows Claire to firmly identify her peers. Claire also cites the asynchronous nature of Twitter as assistive in terms of her hearing impairment and communication impairments more broadly:

If you're concentrating it's alright, but you know, when you just want a conversation it can be difficult. It sounds like a silly thing, but it does worry me quite a bit. So I'm a bit nervous when I go and speak to people. I'm so busy listening to, and what have you, I, someone asked me how I am, and I'll tell them and then think 'I haven't asked you. Oh God, that's really bad social manners!'. You know whereas it's... when you're on something like this [Twitter]. It takes time. You ask a question, you get a response - or whatever. Or it's just, you know, instant messaging, so you've got the time and this is so much easier because you can sit there and you can think and you're not expected to respond straight away. So that's easier. So in both those respects it's easier.

Here, Claire cites strong communication benefits, particularly in the asynchronous nature of interaction in comparison with face to face situations. In these terms, Claire is able to maintain social relations and offset the some of the isolation that her home office situation creates. She observes, however, that these circumstances are not perfect:

it's a bit of a sad state of affairs in a way. You know this, only dealing with people electronically, I mean, we're not robots.

However, social media proffers some autonomy in terms of effecting and controlling social circumstances. It also mobilises a new and positive identity:

[I'm] Desperate for conversation! So, he [Claire's husband] said he'd heard of Twitter, now he's a bit of a tech geek, and that sort of how it started. It's quite geeky, and so yes, I'm a lady geek!

Claire's positive functional experiences with Twitter did not extend to Facebook. Her expertise with assistive technologies allowed Claire to highlight many of the flaws

and barriers disabled people experience when accessing Facebook with specialised assistive technologies. For example, CAPTCHA<sup>32</sup> was an early issue for Claire, exposing one of the mundane rituals of Web 2.0 as deeply problematic in accessibility terms. For Claire, CAPTCHA is a bug bear. To access any ‘networked public’ she must recognise and reproduce a distorted image of letters that appear on screen (they are invisible to her screen reader, in the same way they are designed to be invisible to spamming robots). This is difficult, and Claire does not find the audio equivalents featured on more progressive websites much easier, as the ‘sound’ of the word is also distorted to thwart computers. This threshold had to be crossed with assistance and tenacity. Further issues became visible as Claire introduced her profile during the interview:

I don't normally come to this page [*Facebook profile page*], because as I have said, the only time I log onto Facebook is when I've had an e-mail that says, 'someone's added to you' or someone's done something, so I don't remember otherwise. I don't, I mean, Twitter I find really interesting, but Facebook's just a bit blur to me really.

Claire did not benefit from the flow of ambient feed information that characterises many other students’ experiences of Facebook. It did not give her the sense of networked co-presence that she enjoyed from other services. Claire was aware that some of the functionality of the system was hidden due to the failure of the interface to adapt to her browser settings. This fact was clearly demonstrated in one interview exchange concerning Status, a function privileged at the top of every Facebook page.

---

<sup>32</sup> CAPTCHA is a contrived acronym for ‘Completely Automated Public Turing test to tell Computers and Humans Apart’. It usually appears in the form of a distorted image of a word that must be decoded in a challenge and response test.

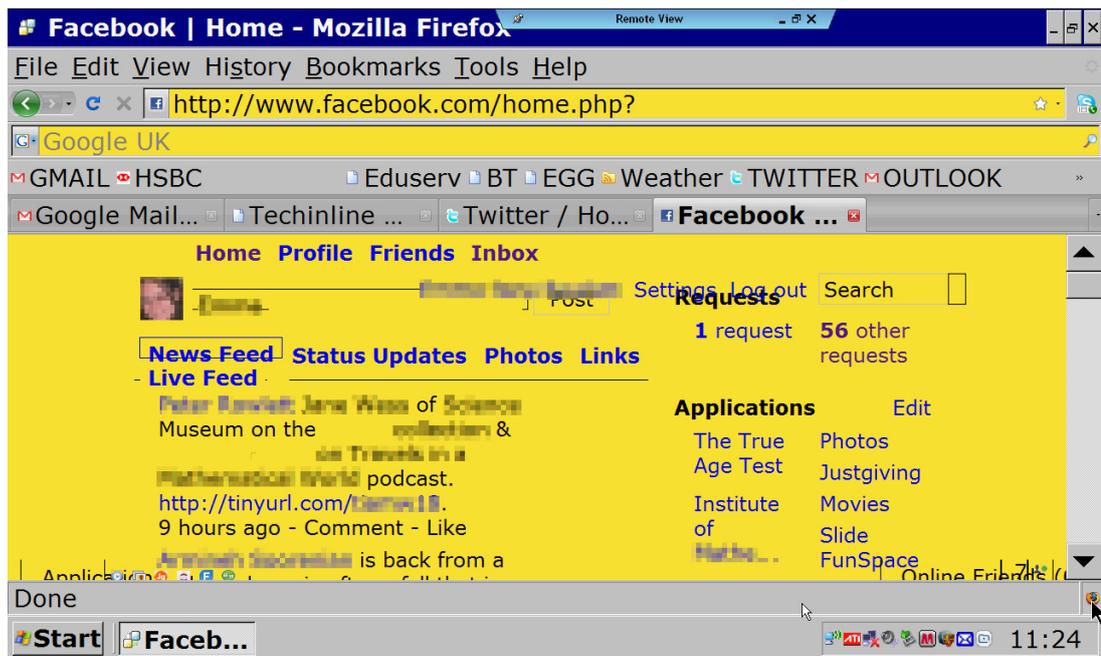


Figure 5-23: Claire's Facebook homepage (23.02.09).

Figure 5-23 shows Claire's Facebook homepage with her assistive technologies and adaptive settings applied. The status input field is hidden behind Claire's photo, name and other labelling information. In the following exchange, Claire demonstrates problems with the accessibility of drop down menus and inadvertently discovers the Status input field (figure 5-23):

But the thing is for something like the screen reader these drop downs are virtually impossible, and the thing is, is finding this here. I happen to know it's there. I can see, you can't quite find it. Getting to that is quite hard. And there's.. I don't know what this is, is this a box?... Oh lord, what have I done now?!

This short exchange highlights the 'blur' of Facebook, the invisibility of functionality and a resulting loss in social affordances. The lack of a perceivable interface impacts on the operations available to Claire. It also disbars the experimentation that frequently characterises participant discovery.

### Disability in Interaction

In Claire's networked publics the disclosure of impairment represented a source of unease. For example, she faced anxieties when seeking to express her experiences of

impairment, of pain or ill health, without alienating non-disabled friends, and friends she considered to be 'more disabled':

So, I don't want to say 'I'm sick of not being able to see' because some of my friends are totally blind, and I'd feel really awful about that.

She was also aware that within the public space of Twitter, disclosure of impairment, or impairment effects could lead to stigmatising assumptions and a visible loss of Followers. Within Facebook, Claire cited the difficulties involved in responding appropriately to greetings from old friends who are unaware of a new or unstable disability. Such greetings invariably query health:

...people will send to me things like saying 'how are you? I hope you're well', because I've not heard from them in years

In these situations, and situations where her interests and experiences intersect with unconventional patterns of living, Claire sought to manage her identity.

## **Managing Disability and the Network**

Claire undertook two approaches to managing disability within the network. She was careful to manage different forms of direct and in-direct disclosure of impairment; she also deployed digital and interpersonal self-advocacy strategies.

### **Managing Disclosure**

Claire reported some of the challenges of managing disability and identity, between and across different peer groups. In these mixed networks, Claire was seen to undertake careful self-surveillance, to manage any disclosures that might expose her to stigma or negative judgements, alienate friends or break with the upbeat culture of a specific network:

Thinking however you phrase something you've got to be a bit careful.

Strategies for mitigating this included withholding detail in response to direct questions: 'I just say 'well, health not great, but happy' or something' and self

ensorship 'I just sort of keep quiet about it'. In this respect, reducing the risk of disclosure significantly inhibited the authenticity of interactions that Claire could undertake in networked publics, requiring considerable emotional work on behalf of others.

### **Self-Advocacy**

In light of the multiple access barriers presented by Facebook, Claire's use of email notifications as a responsive route into interaction proved highly effective, a shortcut in an otherwise chaotic system. Whilst her role was often limited to reaction, her approach was pragmatic, ensuring she retained presence within Facebook and was seen to be open to interaction. This pragmatism was matched by a collaborative and magpie approach to accessibility. Claire accesses materials in a collaborative effort, referencing and sharing experiences of others. This entrepreneurial approach utilises discussion forums, peers and colleagues, disability and accessibility networks and the service providers themselves. Claire cited several occasions where she had contacted companies to gain access or 'work-arounds' for inaccessible services.

Claire described how the processes circumnavigation led her to explicit reflections on the nature of self-presentation and the management of Support professionals' conceptions:

I came across a forum that said 'contact this address, and they will remove that [requests for CAPTCHA] if you tell them you can't see'. So that's when I had my thing, because often I say: 'I'm visually impaired', because that could be anything. If I want to sound like I can see a lot I say 'I'm partially sighted', if I want somebody to just go 'Ok we'll help', I'll go 'I'm blind', because I am on the borderline and partially sighted at the moment [...] And I've got these three different things that I use, three different terms I would use depending on how I want to sound. [...] which I find interesting, because I know I do it and who else does?

These alternate presentations of the self as Visually Impaired, Partially Sighted or Blind elicit different responses. In these situations, Claire is leveraging support based on others' perceptions of disability. Claire may or may not identify with these labels, but these labels must be traded. They are required. In this respect, the management of

disability as a social property was seen to infiltrate the social systems that support networked publics as well as the Publics themselves.

## **5.5 Summary**

The transition into higher education marks a new departure in the process of forming an independent personal and social identity for students entering university (Goode, 2007). For disabled students this departure is pronounced as disabled students frequently have to manage a more complex set of social relations as part of this transition (Borland and James, 1999). Goode (2007) further identifies powerful evidence highlighting complex experiences for managing identity within this critical time. With the advent of SNSs, this departure has gained a new online dimension.

This chapter has introduced the participants and demonstrated their diverse accounts of dis/ability and social networks. Facebook dominates undergraduate networking. Amongst new first year students, the physical transition into higher education is echoed with a transition into campus networks. This move is seen to complicate and on occasion defuse experiences of disability, reflecting the complexity of social relations identified by Borland and James (1999). Some participants are disabled by the network, others are afforded a non-disabled experience. Amongst second and third year undergraduates with established networks, experiences are seen to change over time. Some participants are seen to experience contrary positions, negotiating between ascribed identities. Peers are seen to intervene for better and for worse. In each case dis/ability difference is seen to be socially and technologically contingent.

In the next chapter I highlight the key technical and socio-technical properties of the network and how these iterate types of experience, disabled and non-disabled. I then focus on those participants who experienced the most constrained 'disabled' circumstances to identify how dis/ability is articulated by the SNS and the networked public. In this way, chapter six examines the location and experience of disability, whilst chapter seven focuses on the outcome of these experiences.

## Chapter 6. Experience of Disability in the Network

---

The 18 case studies reported in chapter five recount a range of experiences of disability and ability in social networking sites (SNS) and networked publics. The vast majority of participants' social networking activity was seen to converge on Facebook. As such, disabled students' experiences of Facebook are the focus of this chapter, unless explicitly stated otherwise. Disabled students join Facebook to broaden their social horizons and connect more closely with their peers. However, this pro-social move is seen to have mixed consequences. Participants conceived the network across a spectrum of experience, from a walled garden, to a place of refuge, to a virtual Panopticon. The network was observed to both diffuse and amplify dis/ability difference.

The objective of this study is to explore how dis/ability difference is constructed in social networks at university to answer the questions:

RQ1: How and where does disability occur within disabled students' networks?

RQ2: How do disabled students experience disability in the network?

RQ3: How do disabled students manage disability in the network?

This chapter draws on the case studies to consider the nature of participants' experiences of disability within the network<sup>33</sup>. Chapter seven proceeds to discuss how the participants managed their experiences of disability in the network. A cross-cutting discussion is then mobilised in chapter eight, in which I consider the implications of my findings and arguments in light of wider theory and the University context as a whole.

This chapter begins by observing how the boundaries of disability are reconfigured by the network. Some of the research participants asserted a non-disabled network

---

<sup>33</sup> Participant contributions are given by name only. This is a conscious move to maintain emphasis on the individual and their perspective, rather than impairment. Appendix two supplies 18 short participant profiles as a Key for the analysis and discussion chapters, to assist the reader where necessary.

experience. Such reflections were seen to frequently converge on an expression of ‘fit’ between the technology, the networked public and the particular circumstances and impairments of the participant. Notions of fit and misfit are expanded in section 6.2. Next, in section 6.3, I identify the ‘extra-ordinary’ aspects of experiences that are also manifest for disabled students. Extra-ordinary experiences exist along a continuum of regular experience, however, the interaction between impairment and student life is seen to unduly magnify the barriers that all students face, for disabled students in particular. These disabling conditions place disabled students at a greater disadvantage than non-disabled peers, but, as these conditions are often in-direct, they are conceived within a framework of regular student trials and tribulations. This is important, as it means that disabled students may not recognise their experiences as disabling, despite being significantly disadvantaged on the basis of impairment.

With this vocabulary in place, I turn to student accounts of their experiences of dis/ability in the network. Chapter six is divided into two sections that reflect participant’s experiences of dis/ability difference within the network. Here I derive two socio-technical streams of experience of dis/ability that occur within the network and are evidenced in the Case Studies. These streams are characterised as ‘didactic’ experiences and ‘dialogic’ experiences.

In education, the term didactic is used colloquially to refer to instruction that is usually uni-directional, and delivered in a ‘command and control’ style. This educational facet is called upon, as the properties of the SNS scaffold certain behaviours and actions through a particular set of affordances (and limits). In this way, didactic experiences are seen to relate to the received structural and technological conditions, the interface and facilities of the SNS. The participant must encounter these technical surfaces prior to and during social interaction. Experiences of disability in this space relate to issues of in/accessibility where the network as a tool is seen to construct the impaired user as ‘Other’. This thesis does not represent an accessibility audit of Facebook. Indeed, the conditions of accessibility within any network are bound to change over time. This focus on accessibility is mobilised to highlight the ways in which the SNS places limits of possible conduct upon some disabled students, prior to their movement into more overtly social domains. I also identify how particular attributes of the network and its supporting technologies

constitute extra-ordinary experiences for certain groups. Within this discussion, I return to the experiences of Elizabeth and Claire amongst others, to elucidate didactic aspects of dis/abled experience.

Dialogic experiences refer to experiences of the social conditions of the networked public. Experiences of disability within the networked public relate strongly to issues of extra-visibility, difference and Otherness. In this section, I return to the accounts of David, Naomi and Gemma to expose the emotional aspects of disablism and stigma in the network. Extra-ordinary concerns relating to visibility, risk and difference are introduced to assist with this analysis.

Within didactic and dialogic spheres, disability and ability are ascribed. Participants experiencing technical and social fit are broadly seen to define themselves as non-disabled. Those experiencing a network misfit, constituted by either technical or social barriers, experience disability. Where disability is evoked, participants experience many of the negative psycho-emotional dimensions of disability more usually associated with face to face interactions. Extra-ordinary strains of experience are also identified relating to lack of time resource and connectivity. This was not always reflected as disabling but was observed to shape disabled students' experiences and actions in ways different from their peers.

It is important to state that disabled students are by no means 'passive' or 'helpless' (Thomas, 1982) within the network. In this chapter, the role of close friends ('intimates') and wider publics ('non intimates') are highlighted. Intimates are seen to intervene, mediating and remediating ability difference, and, in certain circumstances, actively reducing both disability and impairment. The student tactics, techniques, strategies and identity practices that are deployed by participants to resist, manage and negotiate experiences of disability are discussed at length in chapter seven.

### ***6.1 Experiencing Fit and Misfit***

Within the case studies, students express disability as a multitude of technical, social and socio-technical experiences. Whilst all of the participants are recognised as 'disabled' in an educational context, the suitability of this label was repeatedly

questioned by participants, reflecting the negotiated and contested nature of disabled student identity averred by Riddell et al., (2005). Riddell et al. found disabled students conceive disability in a range of ways; it is alternatively an equivocal identity, a misplaced ascription, a resisted identity, and a political identity. Outside education, in a new digitally mediated social context, I find participants' conceptions of disability are seen to shift again. Dis/ability is reconfigured by the network.

For some, the network represented a space in which disability was irrelevant, for others, the network created new indices of impairment and disability that was not experienced in adjacent situations. These understandings were observed to be built over issues of 'fit' and 'misfit' at two levels; at the level of the SNS and at the level of the networked public. Fit is a term that has been used both in accessibility discourse (Kelly et al., 2009) and in social research examining the efficacy of technology for diverse groups as 'Life Fit' (Selwyn, 2003). In disability studies, the notion of the Misfit ties environmental and social difference to identity politics (Garland-Thomas, 1997). In this section, I review each of these facets of fit and their relevance to the research. I begin by considering functional fit, proceeding to life-fit and concluding with misfit. I then use these aspects of fit to map experiences of dis/ability in the network in the main body of the chapter. It is at this point that detailed reference to the interview data is made.

### **6.1.1 Functional Fit Between the System and the Individual**

In accessibility discourse Kelly et al., (2009) assert an understanding of disability as fit that evokes the UN convention on the rights of people with disabilities, considering disability as relational:

The authors [...] consider that all people are disabled in some circumstances and that disability is a social construct not an attribute of the individual. In particular, resource accessibility is an attribute of the matching or otherwise of a resource to a user's individual needs and preferences, not an attribute of the resource. (Kelly et al., 2009: 1)

In terms of this relative interactionist fit, Facebook split the research group. For example, Freya and Howie experienced an excellent fit with the technology, which matched their requirements, needs and preferences. For others, such as Claire and

Elizabeth, a misfit was evoked by the network. Importantly, the ubiquity of Facebook has created a social condition in which membership is mandatory. In this sense, 'matching' to a more amenable tool cannot take place. As a result, accessibility becomes an essential issue. The inaccessibility of certain Facebook functions evokes dis/ability, creating difference between users prior to interaction. In this sense, technical fit or misfit represents the foremost site of disability in the network.

### **6.1.2 Life-Fit between the System, the Individual and Socio-Cultural Practices**

In digital inclusion research, Selwyn identifies 'life-fit' (2006: 284) as an important factor influencing the take-up of technology amongst a diverse population. Life-fit refers to the ways in which ICTs match an individual's social and cultural context. Facebook is engineered to harmonise with student culture, however, for some disabled students, social experiences of disability were seen to be conveyed, amplified and even created for some participants (for example, for Gemma and David).

### **6.1.3 Misfit Produces Dis/Ability**

The fit between an individual, the SNS as a tool, and the networked public as a community is paramount. Misfit is not simply a matter of inconvenience; it evokes disability, asserting a socially ascribed identity. Garland Thomson (2007) observes that misfit is a central aspect of disability; that 'ways of being, acting, looking, functioning, thinking or feeling that we think of as disabilities are mismatched – a misfit, if you will – with the environment in which a person must live' (Garland Thomson, 2007). In this sense, disability is 'being different from the way the world expects you to be, and from the kind of person that the world is built for'. This widens the lens of concern from the individual to the socio-structural landscape they inhabit. It also identifies the partial and discursive formation of technology itself as a social product. As Goggin and Newell observe, disability is 'designed in' (2003). Moreover, notions of 'fit' dilate the research focus from cognitive and physical functioning to include a life-course informed by experiences of impairment affect. Attention to fit also establishes the escalating role that norms play in establishing difference; a difference that incurs the negative psycho-emotional aspects of

disability, stigma and internalised oppression that a disabled student may encounter as a result. These are the central concerns of my analysis.

## ***6.2 Ordinary and Extra-Ordinary Experiences***

Aside from issues of fit and misfit, it is important to consider those experiences of disability that occur along a continuum of regular student experience. Many of the participants interviewed raised concerns that echo wider research into non-disabled students and young people's experiences of social networking. For example, Ana, Elizabeth and Sally cited the time required to engage with Facebook as a particular issue of use. For Ana, the lack of energy she experienced as a result of her Cancer and treatment, alongside work and family commitments meant Facebook represented a poor life-fit for her as a system. She simply did not have time. For Sally, the extra time she required for her course reading as a result of her dyslexia meant she could not devote the same time to Facebook that her peers committed. For Elizabeth, keeping track of online content resulted in 'overload'. In these three instances, students cite a lack of time resource as a central determinant of their network use and non-use, resulting in management strategies that are addressed explicitly in 7.3.1. Time may be also cited by non-disabled students as a networking factor, but the addition of impairment to this concern represents an extra-ordinary aspect. In this respect, disability is recognised as extra-ordinary to highlight indices of impairment and to add breadth to a continuum of ordinary experience. Recognising experiences of impairment affect in this way parallels new approaches to researching disability in higher education (for example: Madriaga et al., 2010).

In the next section I consider participant experiences of fit and misfit at the level of the social networking tool, before turning to the social spaces of the networked public.

### **6.3 Didactic Experiences of Dis/Ability: The Social Networking Site**

This section examines participants' experiences of the SNS to understand how the didactic properties of the SNS and its supporting surfaces incur dis/ability difference. 'Didactic' experiences are predicated upon the SNS and its framing surfaces (related tools and network surfaces). These experiences relate to the socio-structural conditions that the student first encounters prior to interpersonal interaction with peers. In this respect, this interaction with the network as tool, preceding social interaction, should constitute the most basic unit of networked experience.

Within this stream of experience, accessibility is a core concern; as are the perceived costs and affordances of the network: its ability to support the user and ameliorate impairment. For a student to 'enter' the network and interact therein, they must first deal with the didactic surfaces of the network. In instances where barriers to access are insurmountable, further progress into dialogic space is disbarred.

Didactic experiences bear close consideration as Adele, Howie, Ben and Freya explicitly reported that, for them, social networks offered a non-disabled experience. In this sense, the network worked as an enabling technology, allowing the student to reassess the physical and cognitive boundaries that demarcate 'disability'. For others, the network amplified disability and impairment in new and complicated ways. In this sense Facebook has the capacity to deliver dis/ability and attendant emotional effects. I examine these accounts to find that students engaged with the technical properties of the network with varying degrees of reflexivity. Many experiences of the network as tool were positive, some were negative. Use was accessible, task-orientated and functional. Alternatively, use was inaccessible, complicating practice and/or non-functional. I consider students' positive and negative experiences of the SNSs in turn.

#### **6.3.1 Receiving Ability: Positive Experiences of the Network**

Facebook has been shown to have many positive affordances for students at University as a source of social news and information, and as a communication tool (Liccardi et al., 2007, Ellison et al., 2007). Many of the disabled students interviewed

responded positively to the general affordances of this social network, appreciating the same facilities that benefit the wider student population:

I think that's why it's got so universally accepted. I don't think there's any other technology that's so, kind of, useful.

(Jack)

At each stage of interviewing Facebook was used by participants as an augmented email that offered greater functionality than University equivalents. Generalised functionalities recognised by all the undergraduate participants include: Sending messages and comments, accessing friends photos, organising social time through Events, using the enhanced email functionality within the University. New first years described the pro-social memory support that Facebook offers, social information that allows participants to rehearse and revise connections, forgotten names, friends of friends (Roy, Ben, Sally, Jack), communicating with family and friends at home (Edward, Sally, Adele, Naomi, Jack, Roy, Ben, Jack, Claire) and overseas (Ben). All undergraduate participants reported using Facebook to stay up to date and connected with their peers. For students building new social connections at university, such affordances are particularly important. Facebook allows students to review and discover the names of new peers through tagged photos. Weak ties can also be strengthened by triangulating the identities of course mates with a combination of different media; University email and Facebook (Roy, Howie). University experiences can be recorded and shared with friends at home and at other universities (Adele, Jack, Roy, Edward, Sally, Liam, Ben). In this way, Facebook supplies the tools that help all students to build and maintain social capital.

Beyond these general properties of the technology, some students identified how Facebook remediated disabling geographies of the social campus environment.

### **The Assistive properties of the Social Network**

At the level of the technology, 10 participants, Howie, Adele, Edward, Sally, Roy, Jack, Ben, Freya, Naomi, Gemma and James, all cited a broadly non-disabled, experience. Several students identified positive fit as denoting the irrelevance of impairment online, defining impairment purely in functional and operational terms.

The particular benefits of modalities, asynchronicity and Facebook's status as an 'anytime, anywhere' system offers a welcome operational 'fit' for these students. Facebook's content is multi-modal, comprising asynchronous dialogues, photographs, video, graphic gaming apps, shared links and synchronous chat. Participants cited many modalities as being accessible, and in certain instances, mitigating impairment. For example, Howie cited his impairment as predominantly affecting his handwriting. In exams and the academic sphere, this was deemed a disability. However, since Facebook is reliant on keyboard input, what Howie considered a 'minor disability' and spoke of as an injury, remained unreflected online:

Like there's not like a handwritten version of Facebook out there, if you get me, so I can't really, there's nothing to contrast it to.  
(Howie)

Adele took the same view, when asked if her impairments were a factor, she replies:

Not when I'm using the computer because it's fine. Especially things like Facebook, where you're just using the mouse and typing the thing. It's not, it's not, I don't really find it a problem.  
(Adele)

Likewise, Ben could not identify his impairment in his Facebook use. He characterised his impairment in a comparison with a more 'significant' misfit:

If I had difficulties with motor control or tracking ... then it would probably have a more significant impact.  
(Ben)

Students who deploy generalised assistive technologies in with Facebook also enjoyed a broadly enabling experience. For example, the particular browser and computer settings deployed by Freya enabled her to use Facebook without issue:

I'm visually impaired, I don't know what to say. It doesn't really...I... It doesn't really affect me. Not in a big way anyway. So, yeah.  
(Freya)

You can change things on the computer, that enables me to use it [Facebook] and, I suppose it's all because it's all visual.  
(Freya)

Facebook was seen to work particularly well for students with visual impairments such as Freya who appreciated its high-contrast format, and Roy, who deployed hardware adaptations.

For some students with dyslexia such as Sally, Jack and James, the light-touch nature of 'commenting' did not offer a significant barrier to activity:

I think, because it's a lot of commenting, commenting is not so bad, you know. It's just a short thing [...] So commenting is definitely not a problem, but long e-mails can sometimes be arduous, but I think Facebook is quite good in that respect, because most of it is commenting and I quite like that.  
(Sally)

For students with visual and mobility impairments who are challenged by physical barriers in the campus environment, Facebook represented a useful tool for gaining important social presence and visibility on campus. Gemma highlighted this aspect:

It's a way of them [people in Halls] sort of seeing who I am. I'm not wandering around a lot. I'm not in the dinner hall. My face isn't really around.  
(Gemma)

For Adele, the influence of Facebook was wholly beneficial:

I feel more comfortable than I would if it wasn't there.  
(Adele)

Roy also cited barriers in the built environment. For him, Facebook hotwires distance and movement:

...you can work out who the random girl you were sitting next to, or boy, in the lecture, was without getting off your chair. And then you can talk to them. As soon as you have identified a person you [can] contact them straight away.  
(Roy)

In sum, these accounts of the affordances of the network highlight how Facebook assists some disabled students in a generalised, but also a specialised way. Facebook offers the same affordances to disabled students that it offers to non-disabled students, however, some of these affordances are assistive, that is, they support the particular requirements of a student with impairments. Thus, the network assists students with mobility impairments, making social information available online, and allowing students with mobility impairments to maintain presence; greater visibility amongst their peers.

### **6.3.2 Receiving Disability: Negative Experiences of the Network**

Despite the affordances of the network, many of the participants engaged critically with the SNS, expressing nuanced evaluative judgements relating to functionality and operability, rejecting prevalent discourses, that position technology as a ‘value free’ tool (Goggin and Newell, 2003, 2005). For a further group, network usage was precluded on multiple grounds relating to a misfit between the network tool and the requirements of the disabled student. Inaccessibility was at the heart of this minimal and limited engagement, and it is this issue to which I turn now.

Accessibility barriers in the SNS included lock-out at the point of registration, non-integration with specialised assistive technologies and the particular challenges of Facebook’s primary modalities for particular groups of users. However, as highlighted in chapter 1.3.2 and 4.5.6, accessibility must be achieved across different levels of technology to ensure access to any particular service, activity or experience. In this section I therefore also examine the conflicted role of assistive technologies (ATs) and other supporting technological surfaces in supporting networked experiences. Many students were unable to deploy ATs for social purposes, highlighting issues of delayed resource for bureaucratic purposes as well as a lack of skills. Internet connectivity, whilst disruptive and affecting disabled students disproportionately was not considered by the students themselves to be a matter of exclusion. This emphasises how disabled students understand themselves within regular student experience, unless perceiving themselves to be individually disadvantaged. Ultimately, for students experiencing the limits of the tool, a critical

perspective is seen to emerge. It is this superordinate move from disrupted access to critical perspective that I chart in this section.

### **Access via Specialised Assistive Technologies**

12 students regularly applied assistive technologies in their internet use. Participants using generalised technologies were found to experience high levels of interoperability between their ATs and the network [see 6.3.1]. In terms of specialised assistive technologies, however, the scene changes. Eight students reported using ATs for work, however, only one student, Claire, persisted with specialised assistive technologies for her social networking activity. Claire identified how Facebook failed to support her screen reader and magnifier, citing a catalogue of failings and barriers to use:

And I know... [Screen Reader/Magnifier] has added some stuff to make Facebook work a bit better, but there are a lot of problems with Facebook. I have problems...  
(Claire)

As a result of such issues, those students who could cope without assistive technologies were often seen to continue without support. Factors structuring these decisions included institutional barriers and student cultural barriers. Ultimately the use and non-use of ATs had a profound impact on opportunities for self-representation and reflexivity.

### **Institutional barriers to the Network**

Network use was seen to be institutionally mediated by the participants' universities in two key ways; through the technologies supporting the network in the form of internet connectivity and through bureaucratic issues relating to the provision and implementation of assistive technologies.

### **Bureaucratic delays in the provision of ATs**

For six students, the non-use of assistive technologies was heavily structured by the institutional context of the university. All of the first year students interviewed

anticipated receipt of DSA, however, the efficacy of the delivery varied. For example, dyslexic students awaiting assessment could not access funds for assistive technologies or resources until after their assessment, usually scheduled for November/December, three months into their first year. For students with physical or sensory impairments such assessment was not necessarily required. Nonetheless, even where disabilities had prior formal substantiation, delivery of assistive technologies was not prompt or timely. First years Roy, Edward, Sally and Jack experienced delays. Second year Pierce had not received any assistive technologies at the time of his interview. Such delays in provision of ATs for disabled students are more widely reported by Fuller et al. (2009), Goode (2007), Brunton and Gibson (2009) and others. As the campus is now networked, with students reliant on the network for significant contact with their friends, SU societies and so forth, disabled students who regularly deploy ATs are inhibited by this compromise in their networking utility. In this way, university bureaucracy shapes participants' social lives.

### **Lack of Training**

In addition to receipt of technology, David identified lack of training as a key barrier to the use of his assistive technologies with Facebook:

No, I never use them [assistive technologies] with Facebook, because I'm not quite sure *how* to use them with Facebook. (...) I got given two sessions on how to use these programmes and stuff, but they never showed me how to link it with anything else really, apart from the basics.

(David)

In this case, the institutional administration and support for the assistive technologies David received did not extend beyond simple operations. Limited and delayed AT training echoes in other research into disabled students' experience, for example Fuller et al. (2009) and Shevlin et al. (2004). As such, non-use of assistive technologies is structured by the support context.

## Communications Infrastructure

Barriers to the use of the network and specialised ATs were compounded by further institutional disruptions. First year students experienced regularly sluggish and sporadic residential internet connections in the first weeks of term that interrupted networked activity. A sentiment was echoed across residential interviews:

The internet at university is so much slower than home.  
(Roy)

The internet's so rubbish in Hall.  
(Gemma)

One remote interview was conducted entirely by phone, without remote view, as the participant was unable to sustain an internet connection at any point during that hour:

It's quite frustrating at the beginning, because I had quite a few problems. I couldn't get onto the network to begin with, and then, when I could, it wouldn't let me onto websites.  
(Adele)

Disrupted interviews provided an important insight into realities of network provision for residential students. In terms of disability however, for students using specialised *and* generalised technologies for assistance, disruption to home internet infrastructure meant disruption to many of the 'reasonable adjustments' that constituted an equitable student experience. This was particularly true for students with mobility and visual impairments, for whom physical barriers in the university's built environment precluded easy travel and/or transport of personal technologies around a campus over the course of a day<sup>34</sup>.

---

<sup>34</sup> Many disabled students and the vast majority of non-disabled students at University A use centrally provided communal computing facilities. These number over 45, with residential and departmental computer rooms add to this tally. However, for students who depend upon ATs – particularly those specialised technologies which disclose impairment, or require privacy in use (for example, voice recognition), centralised provision is provided via AT Suites. The primary research site offers AT Suites at libraries on two of its campuses. These require advance booking (online) or face-to-face disclosure for the collection of a key. Two of the 18 students interviewed had used the AT Suites very intermittently.

Participants dependent on specialised or static generalised assistive technologies were observed to be more reliant on residential internet provision. For example, although Roy had a laptop, he relied upon a monitor to make onscreen information visible:

I got this one [laptop] because it's portable. It's kind of like, portable – and not see it, or not-portable, but then it is *not* portable, I've got this [desktop] anyway. So it's kind of a no-win situation.

(Roy)

In this respect, disabled students were un-duly disadvantaged by breaks in residential connectivity, their experiences are extra-ordinary. However, since all students faced this disruption, these participants did not recognise this disruption as a dis/ability difference. In this respect, students who do not perceive themselves to be disadvantaged on the grounds of impairment, do not experience the associated disabled subjectivity. Since this disadvantage cannot be perceived, it cannot be resisted. This exposes two facets of disability, that the experience of disability is predicated upon normalcy, rather than impairment. In addition, where impairment represents extra-ordinary experience, disabled students may enjoy a 'normal' experience that is not inclusive.

### **Student Culture**

The use and non-use of assistive technologies with social networks was also seen to be structured by student culture. For example, Pierce described how a screen filter might be useful, but would also imply unwelcome visibility as a marker of difference:

it does actually help with the reading cause like the words stop moving about as much but it makes you look a bit Special.

(Pierce)

Indeed, Roy, Liam, Pierce and David all identified how their assistive technologies, amongst other 'reasonable adjustments' created extra-visibility amongst their peers. All four participants valued the support they received, however, the extra-visibility that it entailed created difficult circumstances, verging on uncontrolled disclosure and creating circumstances in which participants found it difficult to maintain a

'normal' student identity and simultaneously assert the validity of the support they required.

In this respect, ATs were distinct from the other ICTs used by participants to access the network, as they were observed to be markers of difference amongst the peer group. As Ravneberg (2009) and Wielandt et al (2006) observe, this expresses a contradiction at the heart of disabled students' use of ICTs. The SNS and its supporting technologies represent belonging, competence and independence, whilst specialised assistive technologies are seen to represent 'restriction, difference and dependency' (Söderström & Ytterhus, 2010: 304). In this respect, the use and non-use of specialised assistive technologies is seen to precipitate experiences of difference both online and offline.

### **An Uneven Playing Field**

Taken together, breaks in network connectivity, delays in the arrival of ATs, a lack of training and student culture, all played a part in the non-use of ATs within SNSs, impacting disproportionately on some disabled students' confidence in self expression, the time it takes them to contribute to the network, and the efficacy of their interactions. In these circumstances, seven students proceeded to use the network without ATs. For this group, a functional misfit had to be managed. These management strategies are discussed in chapter seven. Not all students could subsist in the network without specialised ATs, however. Facebook's lack of interoperability had significant implications for two students, Claire and Elizabeth. This inaccessibility is discussed in the next section.

## Accessibility and the Social Networking Site

Facebook's lack of accessibility to specialised assistive technologies had significant implications for Claire and Elizabeth, the two students most reliant on specialised ATs for their digital lives. Both faced substantial barriers at the very threshold of the network. From this point, only Claire would progress into the networked public, where she faced continuing obstacles to her use of the SNS.

### Threshold Barriers

For Claire, CAPTCHA presented a significant barrier. To enter any 'networked public' CAPTCHA requires the user to recognise and reproduce a distorted image of letters that appear on screen. This image is designed to be invisible to machines – specifically spamming robots - however, this fact also renders the image contained in the text invisible to screen readers. As a result, Claire cannot complete registration. Claire does not find the audio equivalents featured on more progressive websites much easier, as the 'sound' of the word is also distorted to thwart computers:

There's a CAPTCHA to sign in, so I struggle with that. I can see if I have to, but obviously, the screen reader is not going to get anywhere with that and the audio ones - Facebook has an audio one - but the audio ones have to be distorted, so that a computer can't pick it up, and they're so distorted that you can't hear them anyway. And what happens sometimes, is, I don't know if you can see here with the log-in [See figure 6.1]. It gets cut off. So on a site I tried to sign up to the other day you had only half the CAPTCHA, so you couldn't read it, so there's absolutely no hope.

(Claire)

In figure 6-1, Claire demonstrates how important labels are compromised as she gestures with the mouse to where the 'Log-in' button has become partly hidden. As a result, Claire must leverage support to overcome this barrier. Thus, as an AT user, Claire is required to engage a further level of support. In this way, Facebook's interface reasserts a narrative of 'restriction, difference and dependency' (Söderström and Ytterhus, 2010: 304).



Figure 6-1: Claire's Facebook homepage: detail (02.02.09)

For Elizabeth, passwords constitute a significant barrier. In recent years Elizabeth's social internet use has rapidly declined. This has been due to structural and social factors, but the foremost issue for Elizabeth is the increasing demand for user profiles and the passwords they entail. The memory work involved turns Elizabeth's memory impairments into a disability:

There's always a bloody password! I've got better things to do with my time than remembering the bloody password! [...] I'm sorry, my brain ain't geared for that, and I'm just not interested.  
(Elizabeth)

The drop-in discussion groups characterised by Web 1.0 have now been largely supplanted by blogs, social networks and hosted platforms. These new controlled spaces proffer more regulated discussions that are reliant on user profiles for identification and easier marshaling of rogue content by owners. User profiles also frequently function as an economic currency with advertisers. The walled garden of a social network requires a Profile, as this in turn generates income. Within these terms,

Elizabeth's aversion to passwords and the memory work involved are not worth the aggravation. She has withdrawn her voice from the networked public.

Both Elizabeth and Claire encountered significant structural barriers when trying to access Facebook services. Whilst in other situations they might find the web enabling and a great tool for pursuing their interests, some of the mundane rituals of Web 2.0 constitute barriers to access that are disabling; creating dis/ability difference. With alternatives to passwords, Elizabeth's experiences are equitable to others. With alternatives to CAPTCHA, Claire can enter the networked public. These threshold barriers expose 'networked publics' to be, instead, walled gardens. AbilityNet argue that SNSs impose 'a technological lock-out' on those who have most to gain from social networking, arguably the most socially excluded members of the community' (AbilityNet, 2008).

### **Lack of interoperability**

The W3C identifies four core tenants of web accessibility. Interfaces must be perceivable, operable, usable and robust (Caldwell et al., 2008). Claire's experiences of the SNS show the interior of Facebook to be none of these things. As the only student in this study deploying a combination of specialised and generalised technologies with the network, Claire's experiences bear close consideration. This discussion is not provided to supply an accessibility audit of Facebook. It is provided to highlight the close link between functionality and social affordance and design as a discursive determinant of disability.

Claire's screen view was characterised by missing labels, over-lapping field inputs and content (figure 6-2, 6-3. See also figure 6-1 above and figure 5-23). As a result, key activities regularly used by other participants – for example the Status Update Field, Wall and Chat - were hidden from view, unlabelled, or partially visible leading to confusion. As a result, Claire experiences Facebook as a 'blur'. Invisible functionality results in a loss of affordance that impedes many of Facebook's core functions. Moreover, it restricted her navigation of the wider network and interfered with parts of her NewsFeed.

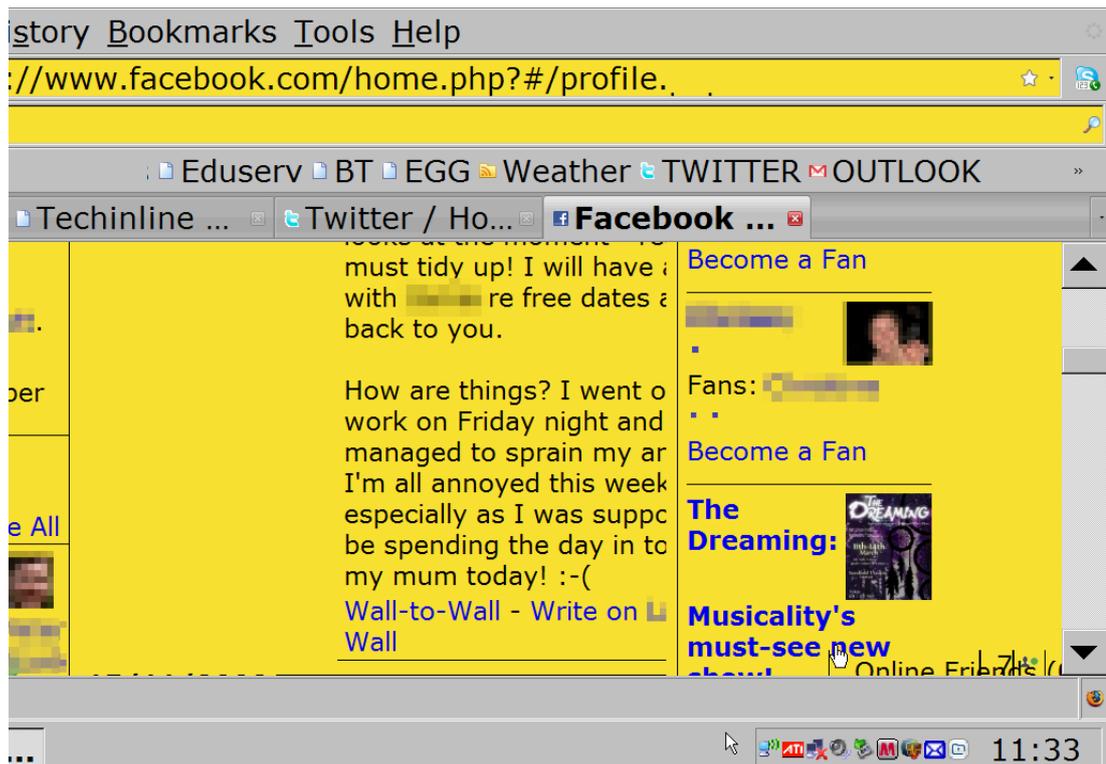
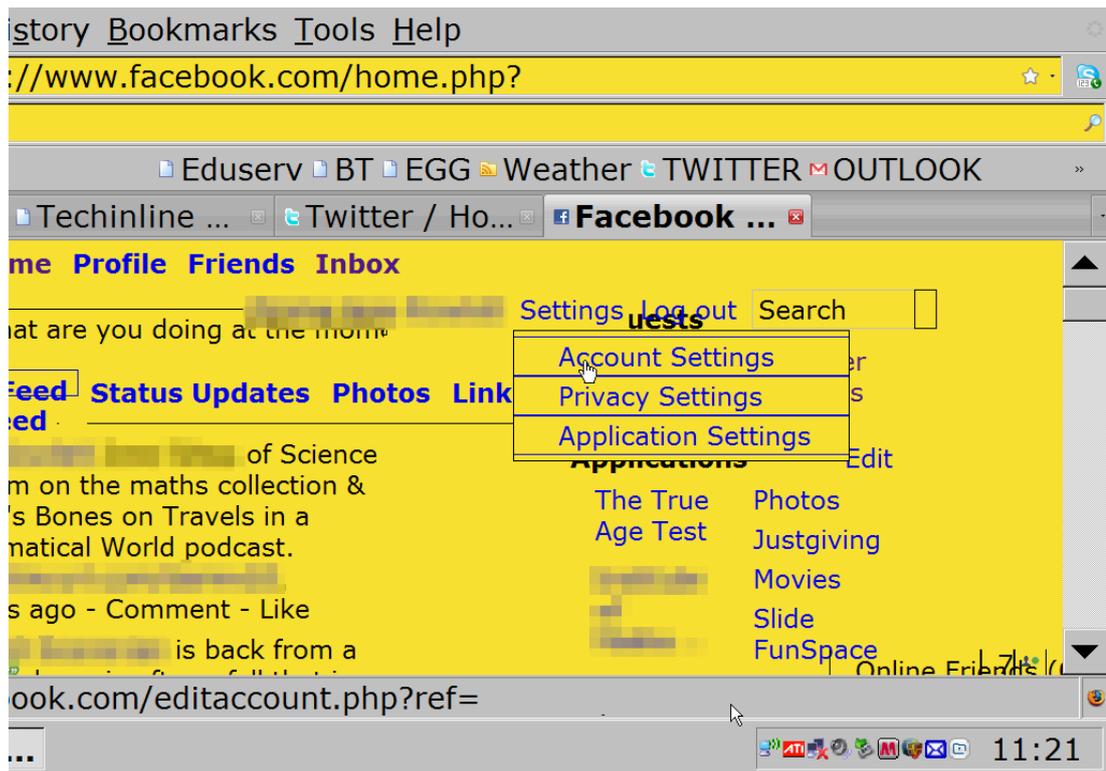


Figure 6-2: Claire's Facebook Wall (23.02.09).

In figure 6-2 we see that Claire's Friend's Wall comment is only half visible, as a result parts of the message are lost. Key menu functions relating to the comment (including 'delete') have been lost to the right of the text. The reply function 'write on Friends' Wall' is also partly hidden.

As a result, Claire experienced the network negatively as confusing and frustrating. She was aware of her marginalised status in the network and alienated as a result. However, it was difficult for Claire to perceive even the extent to which she was marginalised – since core aspects of the networked public were hidden from view. Importantly, however, Claire's profile and activity was visible to the wider network. In this sense, the technology conveyed a deeply unequal power relation between the disabled user and the broader networked public. In this respect, Claire's structural exclusion is material, however, it is also a social marginalisation that iterates beyond the individual, potentially affecting how they are perceived and interpreted in networked spaces.



**Figure 6-3: Claire’s News Feed (23.02.09)**

In figure 6-3 Claire demonstrates a drop menu. We see various functions overlap. In the bottom right of the screen, the Chat function is confused, the ‘chat’ label is invisible. The Status Update field (top right) is covered by an incomplete label.

### **Peer Interventions in Accessibility**

Importantly, the social aspect of SNSs allowed Claire’s peers to break this deadlock. Claire demonstrated her first Wall-to-Wall conversation with her Friend Jane<sup>35</sup>, illustrating a powerful social intervention in technical dynamics.

Jane Smith (City) wrote at 10.52 on 25 June 2008:

Nothing on your wall!!! Outrageous!

How are you?

[Write on Jane’s Wall – Delete.]

<sup>35</sup> Friend’s details have been anonymised.

Claire Williams wrote at 12.43 on 25 June 2008:

Thanks for writing on the wall I didn't even know I had! Can't wait to see your kitten. [...]

This exchange demonstrates several facets of Claire's experience and use of Facebook. Firstly, she was not aware of her Wall until an email notification alerted her to the fact a friend had posted on her Wall. Until this point the Wall (like the Status Update) was imperceptible. As a result, Claire must be reactive rather than a protagonist within her own Profile. The lack of Wall activity is perceived and interpreted by Jane who acts. Jane's Comment achieves several ends; she scaffolds Claire into more 'usual' Facebook behaviours by humorously highlighting a Facebook convention (Wall activity) and eliciting a Wall-to-Wall conversation with a question. Jane's comment evokes norms and deviance, but with comic overstatement that challenges such norms. In this respect she uses humour, a usual Facebook practice, to subvert the interpretation of a silence that may be perceived as deviant or anti-social behaviour. Jane also breaks this silence. This remediates Claire's lack of Wall activity to a wider public, refuting any negative interpretation a visitor to Claire's profile might make by highlighting the ridiculousness of such judgements and offering evidence of connection.

In this way, Jane's actions allow Claire to traverse a significant accessibility barrier and break into mainstream patterns of activity. Jane scaffolds Claire across disabling barriers and into the network.

### **6.3.3 The Social Networking Site Ascribes Dis/Ability**

In summation, at the level of the technology we see that Facebook ascribes two groups through the design of its systems, disabled and non-disabled. The system conveys normalcy, a certain expectation about the attributes of the user and their preferred modes of interaction. This normalcy includes those who use minor adaptations and generalised assistive technologies but disbars key aspects of functionality from those who depend upon specialised assistive technologies. The precise nature of in/accessibility will shift with new technological developments, however, this analysis suggests that, whilst disability is conceived as the exception,

rather than a normal aspect of diversity, Facebook and other social networks will continue to (re)produce dis/ability, and with it the ruptures in user subjectivities that characterise an axis of disabled experience.

For disabled students who can get by without assistive technologies, entry is possible, but an inferior user experience can be inducted. In this sense, inaccessibility reveals the ways in which developers strive to ‘configure the user’ (Grint and Woolgar, 1997), ‘doing production’ (Goggin and Newell, 2003) and thereby implicitly demanding certain modes of interaction and access. As a result, the relationship between the user and the system is ruptured. This rupture frequently results in the participant understanding themselves to be outside the system, identifying against the technology, rather than with it. Within Claire’s activity, we begin to see how resistance to this configuration manifests itself, leading us to a consideration of the network in use. In the next section I focus on experiences of the SNS in communal use: the networked public, to discover its social affects.

#### ***6.4 Dialogic Experiences of Dis/Ability: The Networked Public***

In the wake of didactic experiences of disability and ability at the level of tool, the socio-technical affects of the networked public are now elaborated. This section focuses upon the social experiences conveyed through the network. These are almost exclusively student-to-student interactions. Here I highlight how the network, as a networked public, constitutes and challenges dis/ability difference.

The combination of technology and mass use by a networked public will be shown to be highly normative, constructing and enforcing dis/ability difference – this time predicated upon the visibility of impairment and impairment effects. In the networked public, disabled students’ reflections gain an intensely dialogic and personal aspect, becoming a matter of visibility, identity management and performance. Here I examine how students experience the dis/ability difference that was seen to propagate within the norms of social networks. I also examine how didactic network properties work to amplify and convey this dis/ability difference. This discussion returns to the experiences of David, Gemma and Naomi to explore

student experiences. These students' perspectives illustrate the breadth of experience of disability in the research and reveals an 'atunement to the atunement of the other' (Rommetveit, 1992). Linnell (1998) defines these *dialogic* relations in the following terms:

1. Any communicative act (utterance) is interdependent with other acts, it responds to what has gone before and anticipates future responses;
2. Acts are similarly 'in dialogue' with other aspects of context such as cultural traditions and social settings and,
3. Meaning does not exist 'ready-made' before dialogues but is constructed in dialogues

(Linnell, 1998: 48)

Consequently, this section deals with the most explicitly social aspects of student interactions – focussing on how dis/ability occurs as a social construct and discursive product. Disabled students' accounts of their network activity demonstrate profoundly dialogic approaches to interaction. These are not necessarily revealed onscreen – being instead characterised by 'intersubjective orientations' and reflexivity in the interview. These issues are discussed in two parts.

The first part considers how students perceive the network as a social space, examining the nature of the networked public and observing the powerful norms that regulate student experiences based on visibility and the social constitution of the network as a public space. These constitute the networked public, the pre-conditions that dis/ability is then constructed within.

The second part identifies participants for whom this networked public represents a social misfit and explores this misfit to discover the juncture between social identity and disability. This section also identifies how peers can mediate and remediate experiences of disability in the networked public.

### 6.4.1 Participant Conceptions of the Networked Public

The importance ascribed to Facebook flows largely from the communities involved in its use. This critical mass is an essential part of its popularity and power and a key determinant of Facebook's Web 2.0 status. In short, Facebook's users are its content.

Participant networks were constituted by 'Friends' from several distinct groups. These included proximal subjects: connections made at university within the university network ascribed by Facebook, and distance groups including friends from home, siblings, family and other social interest groups (for example, gap year travelling companions or church groups). An early rule emerged that was rarely broken. Online contact and befriending was based upon a face-to-face connection, however tenuous. 'Friend' invites from strangers were frowned upon. These 'randomers' were regarded with suspicion and mistrust (Gemma, Sally, Howie) bearing out the assertions of Boyd and Ellison (2007). In the first of many unwritten rules, such invitations were to be ignored.

The development of new undergraduate networks was surveyed collaboratively using the FriendWheel application. It offered an insight into the extent and mode of ties developing within undergraduate networks, between close and remote friends, family and social groups. However, visible groups did not constitute the totality of person 'present' in the participant's networks. Implied and hidden groups cited by participants included:

1. 'Friends of Friends': persons in the participant's extended network
2. General public: over the course of the research Facebook changed its privacy settings to allow profiles to be listed by search engines (see appendix three), participants demonstrated varying awareness of this.
3. Proxy viewers: persons accessing Facebook via a participant. 'Over the shoulder' examples included parents and the researcher.

In student talk, participants were seen to make a distinction within their networks between 'friends' and 'people'. Friends are frequently best friends, mates and confidants. People constitute looser connections, a wider public who are less well

known. In terms of disability, this is a vital distinction. Bogdan and Taylor in Ferguson et al., (1992) argue that many disabled people are seen as ‘normal’ by those with whom they have intimate relationships, a fact obscured by an exclusive focus on norms and deviance, fit and misfit. Low (1996, 2009) concurs. Her research exploring disabled students’ negotiations of university environments, establishes an important divide between ‘intimates’ and ‘non intimates’. In Low’s analysis, intimate relationships can be enabling, but the wider context of the university is problematic:

‘where relationships with non-intimates are concerned, students with disabilities are often labelled deviant’(Low, 1996: 236)

As such, a disabled student’s network of ‘friends’ and ‘people’ may be enabling or disabling, depending on its constitution and relation to other networks, or perhaps more importantly, dependent on how students conceive that network. In general participants expressed concern regarding the scrutiny of non-intimates and connections with a wider public. They attended to what Boyd calls ‘context collapse’, an experience of social convergence that occurs as ‘disparate social **contexts** are **collapsed** into one’ (Boyd, 2008). In this way, the distinction between intimate and non-intimate may be lost.

This disabling experience hinged on the visibility of personal information and network interactions, and the normative conditions that characterise Facebook in use. It is this exposure and visibility that I consider next.

#### **6.4.2 Notions of Visibility**

Social networks function to allow communication, but also to allow that communication to be observed by a wider community. Feeds and updates bring information to the user. Users may also browse profiles and conversations. Many students identified the benefits of this process, however, others also identified its negative effects; the potential to ‘Facebook stalk’ (raised by Howie, Pierce, James, Gemma). As James states:

There’s the whole thing, Facebook stalking. It’s more than just a joke.

A heightened sense of surveillance was seen to be exacerbated by the wider social milieu, conditions in which Facebook is near ubiquitous, deemed to be a network of necessity, where participants experience ‘network creep’ and a reduction in degrees of separation. All these factors represent ‘ordinary’ student concerns. For the disabled student, however, these issues affect an ‘extra-ordinary’ experience of disability difference.

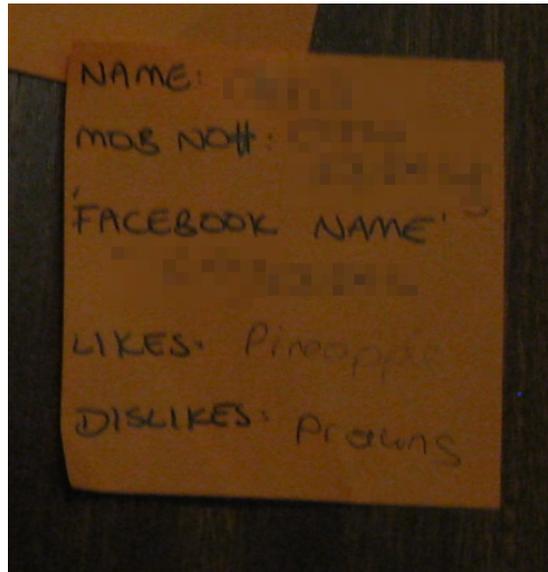
### **6.4.3 Networks of Necessity**

Facebook has been engineered to augment student culture. However, in interviews it became clear that synergy between Facebook and student life is by no means unidirectional. As Facebook has modelled itself to meet student demands, so undergraduate culture is now bending to better accommodate Facebook. Facebook has become a network of necessity, with many students (disabled and non-disabled) identifying their Facebook profile as a necessary milestone in the achievement of full student status.

Participants reported various pressures and compulsions to join Facebook. Liam reported missing parties and outings prior to joining as his friends had conveyed invites through Facebook’s events facility. Roy, Sally and Rory reported how Student Union societies required that all their members joined Facebook to receive club updates on events, fixtures and discussion:

A lot of people have literally got Facebook just because they were forced through Uni.  
(Sally)

Edward cited an instance of ‘conversion’ where an unsuspecting friend was press-ganged into membership. Jack reported the communal surprise elicited when a friend revealed their lack of profile. Pierce, who was observed to have the greatest number of intimate friends outside the network, described his circumstances as exceptional. In Roy’s Hall, the door to every student room was embellished with a post-it note notice containing the following key information: name, mobile phone number, Facebook name, likes and dislikes (figure 6-4).



**Figure 6-4: Ad-hoc door label from Roy's Hall of Residence (09.12.08)**

In Sally's Hall, posters for social and charity events listed Facebook as the sole point of contact for further information and interaction. These markers demonstrate how Facebook has become deeply enmeshed in local student cultures. Upon arrival at university, students reported that new acquaintances' surnames were newly privileged in conversation (along with current course and A-levels), to allow connections to be later cemented on Facebook. In this way Facebook registration and online group integration has become an important part of initiation into UK student culture. This is not peculiar to the 2008-2009 in-take, second year David (2007-2008 intake) corroborated this pattern:

when we first joined [Facebook] in the first couple of weeks, everyone was asking for, you'd like meet someone and they'd take your full name so they could look you up on Facebook. Very formal. 'How do you spell your surname?' and all this.

(David)

This notion of Facebook's role in the integration of a student into undergraduate life was vividly and repeatedly articulated:

If you haven't got Facebook, you don't exist.

(Edward)

All undergraduates echoed the assertion that, for better or worse, Facebook was mandatory. These narratives underline the conditions of ubiquity mobilised by campus/network synergy. Facebook is a network of necessity.

#### **6.4.4 Consolidated Identity**

In the past, the text based properties of Computer Mediated Communication and the potential for anonymity in online spaces has been valued by disabled people (Bowker and Tuffin, 2002). Gemma echoed this principle:

When I was younger, I think I was, because I was being bullied, and these things, I was kind of more confident online. I used to talk, like go to chat rooms and stuff and I wouldn't disclose that side of me because I didn't see it as relevant, but I did feel more comfortable to talk to people because they didn't know that element about me.

(Gemma)

On campus, however, the predominance of Web 2.0 profile-based social networks means that anonymity has been lost as online identity is increasingly consolidated. With the advent of the social web, identity and representation are an increasingly complex business, particular within a social network such as Facebook. Prior research exploring disclosure in social environments online has tended to focus on text-based, anonymous spaces (for example: Bowker and Tuffin, 2003). Another approach has been to target members of a community of practice, or community of interest, where members congregate around a disability issue or topic (for example: Thoreau, 2006, Seymour and Lupton, 2004). As an environment for interaction, Facebook is more complicated. Facebook is not a site for anonymous or disembodied identity play. Students are immersed in local networks, constituted in both strong-ties and typically large number of weak-ties. Moreover, the success of Facebook has, to a large extent, been based on its capacity for sharing photos, and an image enabled profile/homepage featuring a photo, proto-typically of the profile owner happily engaged in a dynamic pursuit or social activity. As a result of these recent shifts, some of the claims that the internet represents a medium outside a visual ontology (Bowker and Tuffin, 2002), must be reassessed. As Söderström and Ytterhus observe:

The online interactions of contemporary young people are highly graphic in their orientation – they play interactive games, exchange movies and pictures and create decorated home pages to express their identity and sense of belonging. (Söderström and Ytterhus, 2010: 312).

These cues amongst others combine with the extent of the network and the physical proximity of neighbours, work to identify the profile owner, creating an atmosphere of norms and ‘usual’ practices that amplifies peer-pressure and stigmatises difference. The consolidation of identity means the benefits of ‘anonymity’ resource (Bowker and Tuffin, 2002) are lost, a fact James illustrated lucidly. James valued the option to articulate a disabled perspective; however, he also prized the control over disclosure of disability that anonymity presents for allowing different emphasis of the self in different circumstances:

I’m almost postmodern on this concept [...] If I’m commenting on a political blog, if it’s an American website, it’s as an Obama supporter. If I’ve commenting on a British site it’s as a disaffected left winger. If I’m commenting on something on disability it’s as someone who has, you know, as a disabled person [...] I think that’s the wonderful thing about the anonymity of the internet, that you can just be... you’re whoever you want to be. [...] I think it can add, can be very useful because you can, you can emphasis your own, a singular element of your personality.  
(James)

For James, Facebook represents ‘the very opposite of anonymity’. In this sense, disability or impairment may cease to be singular elements of personality and experience threaten to become extra-visible, a sole determinant of social identity. The visibility of social misfit based on impairment was expressed by a wide range of participants, including those with visible impairments and unseen impairments. These cut across participants with mental health issues, cognitive impairments, sensory impairments and mobility impairments. In the case studies, attention to perceived difference was widely reflected.

In summary, the network conditions combining context collapse, a consolidated identity, visibility and the necessity of involvement create circumstances that enforce powerful norms. In the next section, I turn to the experiences of David, Gemma and Naomi to illustrate the occurrence of dis/ability difference based upon extra-visibility.

These three students highlight issues of surveillance and an unequal gaze, which resonate across participants' experiences, evoking social misfit with the networked public.

### ***6.5 Extra Visibility: David's Experiences of Dyslexia and the Networked Public***

Like many students with dyslexia who participated in the research, David was sensitive to how his identity would be constructed by others based upon text within social networks:

everything is text, you know, and when you're talking to someone there's no like sort of tone in your voice. It's all about how you write it is how you come across really.

(David)

This focus on text created a new pressure for dyslexic students, for whom dyslexia was usually conceived as an educational category, a 'learning difficulty'. With the advent of Facebook and ubiquitous networks, text has become a central part of student social display, in this sense, dyslexia as a 'disability' rather than a 'learning difficulty' had presented itself as a factor within their social world for the first time. This led to feelings of exposure:

the thing I've noticed is I'm not like a self-conscious person at all. I don't have any problem sort of socially I don't think. But it's, sort of, it's weird how I think about that sort of thing more when I'm on Facebook and I sort of almost feel a bit more self-conscious.

(David)

David observed that he was more likely than his peers to make mistakes. In an effort to control external perceptions, care and diligence was required.

I'm conscious that I'm more likely to do it [make mistakes] and I don't want people to sort of notice it every time I write a message.

(David)

By stating he is ‘more likely’, David inducts a notion of normality into his talk, accepting a position outside the mainstream. From this position, he can control how he is perceived. At the same time, David stated in clear terms that he felt it was important that dyslexia did not confuse what he was trying to say. This cast David’s impairment in very functional terms:

I don’t want it [dyslexia] to get in the way and for people to sort of think about that when they’re reading the message, rather than what I’m saying.  
(David)

This dialogic position was not straightforward.

### **6.5.1 Dyslexia and the Unequal Gaze**

David noted that his actions were ‘self-conscious’ and anticipated a critical reception; however, he positions this critical reception as being a projection – rather than a fact of the real world. He states (underline added):

I just don’t like the thought of people sort of, it’s, obviously this would never happen, but it’s, basically people sort of concentrating more on my dyslexia than on what I have to say and that sort of thing.  
(David)

This is a complex statement that tentatively plays out an anticipation of social stigma that is laden with caveats:

I mean, the thing is, if, you know, I mean, I, it is like, in my sort of perception of what people would think rather than what they would actually think. It’s because, if someone spells a word wrong on my page, I don’t think they’re, like, if Pierce wrote to me and spelled a word wrong, I wouldn’t think ‘Oh, he’s dyslexic’, do you know what I mean? But when I’m writing, I don’t know why, I just sort of feel that.  
(David)

David positions his anticipation of stigma as irrational, but also as an individual perspective that is part of the social experience of being dyslexic. This perspective is within him. In other interviews with dyslexic participants, this feeling was seen to extend beyond spelling to wider issues of textual representation. Dennis identified this most precisely. For him, it was not simply a matter of spelling – it was a matter

of conducting 'usual', 'common practices', of 'bringing ideas along in a particular fashion':

There is an element of, you know, should I say 'fear'? I don't know whether it should be seen as fear, or element of unrest, an element of insecurity in that sense. That, er, you may then to think as an dyslexic person that, you know, whatever you might fill [out] may not be seen as a common practice, which usually people do. So I think that's why there is an element of reluctance involved.

(David)

This sense of otherness and difference was identified by David as self-contained.

I think it's more my problem than, I think if I did end up spelling a load of words wrong they (friends) probably wouldn't, you know, even notice it, but it's just my sort of – I'm lost for the word. It's just, it's more in my head than, you know, than an actual thing they'd think about, I guess.

(David)

Here David reflexively acknowledges a factor incurred by network size, implied visibility and context collapse (Boyd, 2008). Namely, what Foucault (1975) identifies as the 'unequal gaze'. In this sense, David appears to have internalised this unequal gaze, resulting in self-surveillance. Whilst he can resist this gaze rationally, and does not wish to project this antagonism on to his personal networks, this sense of otherness is retained, continuing to inform his approaches to self presentation.

## **6.5.2 Social Constructions of Dyslexia**

Importantly, this ambiguous state is not related to disclosure, per se. David highlights that many of his friends know he is dyslexic:

I think it's ridic-, like, it's really silly, but I think it's more the fact that I don't want people to read the message because it's quite, everyone knows who's dyslexic and it's not really a, and I don't want, it's sort of like, I don't mind people knowing that I'm dyslexic, I just don't really want it to sort of come across when I'm writing messages and stuff, like so blatantly, but, you know.

(David)

Much of David's talk worked to assert his dyslexia. However, David clearly felt uncomfortable conflating dyslexia with wider notions of disability. Riddell et al. (2005) observe what they define as an 'equivocal identity' amongst dyslexic students they interviewed. They note that, whilst dyslexic students voluntarily placed themselves within the category of disability, 'many continued to express uncertainty about the adequacy of the label' (Riddell et al., 2005: 133). In this way, a dyslexic student described a 'struggle for recognition whilst at the same time questioning the congruence between dyslexia and disability' (Riddell et al., 2005: 133). David's account placed him at the centre of this definition; he draws on the term 'learning disability' to qualify his position:

It's labelled as a disability, obviously it's not like a very serious disability, it's just a learning disability, but I think it's, sort of, you don't really want to emphasise, you know, by spelling a load of words wrong it's sort of almost like highlighting you're disabled. I just want to sort of keep it as my own sort of thing to sort out. Do you know what I mean? And I feel like, it's almost like people alter their opinion. It's silly, because of the way you're writing. It's just sort of I don't want them to think of dyslexia when they think of me, do you know what I mean?  
(David)

Outside the network, David expressed experiences of the 'struggle for recognition' in clear terms. In the past, David's DLA provisions attracted unwelcome attention:

when we came to Uni when I had my test and then got a grant for like a laptop and all this, everyone all of a sudden was like 'Oh well, you know, I'm dyslexic, I could fake the test' and it sort of became a bit of like a ridicule topic. So I think I've become a little bit more sensitive since that just because I don't really want to have to keep bringing up the topic of dyslexia. And it doesn't bother me that much, like doesn't affect me all the time, but it's just slightly annoying when people keep assuming. I don't know.  
(David)

This experience highlights the challenge of substantiating disability. David does not feel able to claim 'disabled identity' – to do so would require acknowledging it as a 'serious disability' - however, the reality of his condition has been challenged by his peers. Whilst his friends understand that David has dyslexia, this knowledge may be relatively cosmetic. As a result, disability discourse is not empowering within this

sphere. David's quandary appears to be, that discursively, he is operating between abled and disabled – however, there is no space inbetween. As Campbell observes:

The disabled self and its separation as a given [...] can be traversed, but never transgressed. [...] One can never be *between* abled and disabled, or *outside* of it. (Campbell, 2005: 119, my emphasis)

Moreover, interrogation of how his dyslexia is perceived threatens to rupture the intimacy of David's relationship with his friends. In terms of dyslexia, David's non-disabled peers are non-intimates. They do not understand the reality of the impairment. After his peers' response to his ATs, the network represents the next moment in which disability might be evoked. In this event, to maintain control of how he is perceived, David works to control the signifiers of his impairment in text. By controlling evidence of his impairment, David mitigates any risk (whether real or imaginary), removing and trace of dis/ability difference and allowing self-definition.

Ultimately, David stated that his use of the network had declined. He related this directly to his accumulation of Friends. As his network grew – so the work to control impairment affects became more necessary. Rather than undertake this work, David uses the network less regularly.

David's account highlights the way in which dyslexia as a print impairment has the potential to become a social disability in the networked public; moving from unseen to seen. The discomfort that many dyslexic students feel in claiming a disabled identity appears counter-productive in the network. In short, the network has the potential to create dyslexia as a disability, rather than a 'learning difficulty'. The liminal position of dyslexia between disabled and non-disabled only emphasises this Othered status. In this respect, the network offers a misfit for students with print impairments, creating dis/ability.

## **6.6 Extra Visibility: Gemma's Experience of Life-Misfit in the Networked Public**

Davis argues that 'disabilities appear or are highlighted in environments that produce disability' (1995: 29). However, in this research, this 'appearance' is not necessarily a matter of visibility in interactions; it is conspicuous in its absence. Disability is demonstrated to be an often hidden facet, rendered invisible. Disability may also be evident in gaps in the network. In this section I discuss network absence and how this is interpreted. This discussion focuses on Gemma and later Naomi, two students who withdrew from their respective networks to protect socio-emotional wellbeing. Both found network norms to be untenable. However, this retreat was noticed by intimate peers, who then intervened in an attempt to reintegrate Gemma and Naomi. This peer intervention was delivered and experienced in markedly different ways. For Gemma, the intervention was a matter of peer-pressure, a disciplinary force; For Naomi, intervention represented a social life-line, a positive and supportive force.

These contrary examples of anticipation, surveillance and intervention highlight the iterative nature of networked experience as ongoing, works in progress. These cases also emphasise the nature of social norms within the network, and the interplay between social norms and the didactic, technological and normative fundament they are built upon.

### **6.6.1 Unseen Impairments and the Unequal Gaze**

In terms of didactic experience, Gemma expressed a positive experience of fit between the technological surfaces of Facebook and her impairments. However, despite this apparent fit and a profile demonstrating hundreds of Friends, Gemma's experiences of Facebook were deeply fraught, highlighting a social misfit. As a student who is not seen to have an impairment, Gemma was sensitive to the relationship between perceivable cues, stigma and prejudice both online and offline. She recounted several examples of the social scrutiny she receives in her day to day activities relating to disability. For example, when using a disabled parking bay Gemma is given 'dirty looks' and verbal abuse by the general public and other disabled people, all of whom assume she is a 'bad person'. She states:

...the automatic assumption that that person is bad rather than ‘oh, they’ve got an unseen disability and look how well they’re coping’, you know, it’s always a negative rather than a positive.  
(Gemma)

This conflicted experience of visibility extended to networked spaces evoking a strong concern for risk management, privacy and ‘answering’ archetypical behaviours.

### **6.6.2 Risk and the Extent of the Network**

Prior to university, Gemma had been bullied at school because of her impairments and had only recently ‘come-out’ as disabled. Forging this new identity in the face of an antagonistic public was vital. However Gemma found the extent of Facebook’s networks threatened this process. Some of Gemma’s Friends were linked to former aggressors from back home. As a result, the protection usually afforded by University life as a fresh start in a new location had been thoroughly compromised:

*SL: Do you feel that your impairments play any role in what you actually do on Facebook?*

Gemma: I think not what I do, but how I come across because, as I say, a lot of people, well, a lot of people I know from school are on here and also some people, those horrible people are at this university and were in my Hall and they know a lot of people I know.

*SL: So university hasn’t necessarily been a fresh start?*

Gemma: Not in the slightest. [...] like a friend of a friend, you know – literally every party I go to, any social event, if I actually get talking to someone, nine times out of ten we know a lot of the same people from home, not just here and I do feel I can’t really escape in a way.

Gemma was not alone in citing this acute contraction in degrees of separation, a contraction exacerbated by the extent of Facebook’s networks. For example, David also stated how he discovered a newly reduced degree of separation between and across the groups he associated with:

I have found recently that a lot of friends I've made at Uni do know people I know back home, which is quite interesting. There's often people that I would never have thought would have known each other.  
(David)

In this respect, Gemma's experience highlights how the extent of the social network provokes new and unwelcome experiences of visibility for marginalised and dis/abled students. Prior to the advent of Facebook, students could leave their old life behind and begin afresh at University. Anonymous networked spaces also offered a place of refuge. As Gemma knows herself to be only one step removed from her former antagonists, she reasons that she is vulnerable, aware that her information could be visible through Feeds despite applying privacy settings. This is not Gemma's only concern however. The visibility of her impairment affects and invisibility of her impairment made her aware of the ways she could be socially discredited in the network. Gemma anticipated stigma.

### **6.6.3 Misfit, Prejudice and Stigma**

The following quote is repeated verbatim at length as it highlights how the didactic properties of the network and its social use converge to amplify real-world experiences of dis/ability difference within the network. Here Gemma explains how an anticipatory dialogue of stigma, victimisation and experience shaped both her network experiences and network activity:

*SL: So could you show me your profile page?*

Gemma: Yeah. I hate it. I really, I worry about it all the time. I just, I just hate the thought of being judged so much, so...

*SL: And where do you think the feeling, where do you think the anxiety comes from?*

Gemma: People misjudging my relationships with people based on, like, how many friends I have. I mean, I'm not one to use the Wall much so does that look like I'm not really friends with people? Or is it... Because if people don't know me, it looks like, I don't know, am I uncool? Rather than I just can't be bothered to log onto my computer and I just get my phone out of my bag when I'm actually sat on a train, and I'm bored, rather than coming home and having all these things to do, why would I want to log on? Because it's not

very instant, either. Usually when I talk to people it's because I have something I actually need to ask them. I'm not very good at just sitting there going 'ooh, what shall I do with my time? Let's write on like 15 people's Walls and just ask how they are for the sake of it'. I mean, some people's profiles, you look at and they'll say 'blah blah's written on whoever's Wall', and there's like a list of 10 people. I'm not really one to do that. So, I mean, I don't feel, I haven't put my political views, my religious views. I don't, like that's quite personal to me. I don't think my groups... My Groups, here, I don't think people can look at them because I feel, that's a lot to do with me still being in Halls. I don't want people to misjudge me. I'm in Hall not because I don't have friends, it's kind of a lot to do with my disability. I didn't manage being in a house. I kept getting burgled; it was quite an unpleasant experience. I kept getting ripped off, but I got on well with my friends. I've had plenty of different groups of friends beg me to live with them and I just again don't, I just, I feel really insecure about being misjudged, I guess, which seems a bit silly.

(Gemma)

Here, Gemma graphically illustrates the relationship between the didactic properties of the network and resulting social affect and social effect. Her statement moves across several technical functions, from the Wall to Profile information. At each point, Gemma establishes how her practices can be misconceived socially, identifying her as misfit. For example, in the first instance, Gemma identifies how her commitment to managing her time results in low Wall activity: 'having all these things to do, why would I want to log on?'. She then extrapolates that this factor, in conjunction with the high number of friends on her profile may lead people to question the strength of her friendships: 'I'm not one to use the Wall much, so does that look like I'm not really friends with people?'. In her second example, Gemma's account identifies how the display of her group membership, as a member of a residential Hall, in conjunction with her student status as a third year, may be interpreted by others as a social failure, emblematic of a lack of friends to live with. In the event, Gemma's residence is a matter of 'reasonable adjustment', an affordance relating to her impairments as Gemma's university offers guaranteed accessible accommodation to disabled students for the duration of their studies. Within the network however, Gemma is clearly concerned that cues relating to impairment and the particular personal and social arrangements in which she lives are outside the range of a generalized student experience. As the Facebook profile demands this information, the bald fact of her location is available to be mis-

interpreted.

Gemma's concerns highlight the ways in which students anticipate and extrapolate nuanced social information by reading-between-the-lines onscreen. Importantly, this symbolic interpretation instigates robust norms, norms that are enforced by the peer group.

#### **6.6.4 Normative Pressure and Peer Intervention**

Gemma's anticipation of risk in the wider network led her to protect her personal information and caused her to be highly sensitive to nuance and norms onscreen. However, this status quo was a shifting one, as her peers observed her activity and strove to intervene. In their response, wider network norms were expressed directly in peer pressure:

Gemma: in terms of like information people are like: 'ahhhh you don't have anything on there, it looks like weird'. [...]

SL: *Can you tell me of an instance when that's happened?*

Gemma: Well, just people just comment on [gestures with mouse] my profile's really boring because I don't have anything about me on here. I literally, I just have, like, who I'm friends with and I even had my Wall off at one point and there's usually not much going on in my MiniFeed and my Pages, I didn't really have that until recently. So I was really private with it.

Despite this prior resistance to disclosing personal information, Gemma cited how this social censure had influenced her activity:

... just my friends that say it to me. Oh, and going back a while, I hate looking at my face and so I put a Mini sign up because my car's a Mini, because it's just something. [...] I do get comments on my Wall [...] just going "Why have you got the sign from your car? You're such a loser!" [...] It's... they're good friends of mine, it wasn't like some Randomer. But it made me feel like a bit of an idiot. I was like, 'fine, I'll put my face up'.

(Gemma)

In each of these instances, Gemma's anticipatory actions have been taken up by her peers who have then applied peer pressure to encourage more typical activity. In this

respect, Gemma's friends have striven to include her in more usual forms of student identity practice and disclosure, knitting the community together. In this way, Gemma's agency is contested as her practices are eroded by norms that are far from abstract. This conflict remained unresolved. Despite her friends call for her to use her own photo in her profile, Gemma withdrew all other photographs from Facebook.

### **6.6.5 Network Creep**

When asked why she persisted with the network, Gemma cited many of the socio-technical affordances of the network, her close friends, important events and social news. She surmised:

I don't know. I feel like I'm kind of exiting such a fundamental and big social way of communicating. It's kind of like locking yourself in your bedroom and not talking to anybody for a week. It seems quite an antisocial thing to do.  
(Gemma)

Gemma identifies the nub of the problem for many students. Once again, Facebook represents a network of necessity for students in higher education. Whilst social experiences within the network may be fraught and disabling; to wholly withdraw would be to cut away swathes of student sociality. For this, network presence is necessary. Another participant, Howie, cited for this paradox graphically:

I'm not really a big fan of Facebook because I kind of feel like it's kept under constant watch and constant tabs, like nothing you can do can kind of escape it.  
(Howie)

There's no escape, if you understand me? Like, no matter what you do, like if you go out like one night, like no matter what you do, whether you want to be sort of publicised or not, it's going to be.  
(Howie)

What Howie and Gemma identify is not only a matter of network pull – an impetus to join Facebook, it is a matter of 'Network Creep'; Identity is connected, whether this is desired or not. The network permeates every aspect of the student social world, whether an individual has a profile or not.

### **6.6.6 Unseen Experiences**

Perhaps most importantly, Gemma's complex and difficult experiences were not evidenced in either her profile, or amongst her friendship group. When asked whether any of her friends felt the same way, Gemma replied 'I haven't really spoken to anybody about it, to be honest'. In this sense, both Gemma's impairments *and* experiences of disability are unseen and unheard, rendered invisible online. Nonetheless, her testament reverberated across many interviews, expressing a general concern with accounting for, and anticipating external perspectives. As with David, Gemma's narrative highlights how unseen impairments can become extra-visible in the networked public. Whilst university friends may be 'intimates' in many respects, a lack of understanding of the lived experience of impairment results in disability difference being constituted even within these close relationships.

## ***6.7 Extra Visibility: Naomi's Experiences of Depression in the Networked Public***

Naomi predominately uses Facebook for her social networking. As with Gemma, she found that the social network offered a close functional fit with her physical impairments. However, Naomi's experiences of sociality and peer intervention are almost diametrically opposed to Gemma's.

### **6.7.1 Depression as Deviance**

In her second year, Naomi faced significant challenges to her sense of self at University, resulting in a severe depression; it is this experience that most informed Naomi's views of the network. Naomi was on the verge of quitting her course. At university she had lost herself amongst people who didn't know who she really was. This left her in a state of identity crisis:

I thought I had to fit in, with the group that I'd met, and this is why I got so ill last year, because it just wasn't me, and I was pretending to be somebody who wasn't me.

(Naomi)

During this difficult time, Naomi's online activities changed significantly. She began to withdraw from the network. Onscreen, Naomi's usual chirpy, pro-social behaviours and Facebook status updates ceased. She could not perform the usual student practices of self-performance and display through humour and interaction:

Yeah, I mean during the, the time that I was not very well, my Status didn't show that at all. You know, it was 'Naomi is.' I never put 'is so depressed she wants to go home and never come back to uni'. It was just left blank, it wasn't, I never put anything, it was just dot dot dot.

(Naomi)

Naomi's withdrawal is not surprising. Across the participant group it was agreed that Facebook represented a space characterised by conformity in positive display, humour and interaction. In this space, a spectrum of negative feelings must be suppressed:

Today, as you can see there [gestures to Status], I've put 'thinks there should be another day in the week'. And that's just because I have so much stuff, or I've got so many things to do this week, an extra day would be very helpful. But it tends to be more in that kind of thing rather than saying 'is having a terrible day and wants to curl up in a big hole'. I don't know why that is, I just wouldn't put it, and I suppose that's because it, you know, it's more upbeat and showing people what you have done as opposed to what you haven't done.

(Naomi)

### **6.7.2 Social Surveillance and Peer Intervention**

As with Gemma, Naomi's withdrawal was noticed. Prior friends from outside the university setting observed Naomi's change in behaviour, her absence, and interpreted her disconnection symbolically. In response to this change, Naomi's friends also altered their mode of communication, setting aside publically scrutinised spaces in favour of personal and private contacts. Naomi identifies the support she received as closely related to the didactic affordances of the network:

[...] the privacy of the inbox is quite useful, that you know, you could write things on people's walls, but at the same time someone could say, you know, 'I know you're not right, what's up?' and not have that publicised everywhere. And so it was quite supportive to have random messages from people I've not

seen in years, saying ‘You never have nothing on your status’, what’s going on? Er, which was quite nice in a way, that I hadn’t seen friends from school for five or six years, yet they obviously still looked at my profile to know that I wasn’t me, if that makes sense.

(Naomi)

The privacy of this process underlines the importance of non-public communications. Networked email provided an essential tool for Naomi and her friends, allowing her friends to circumnavigate spaces in which depression is created as a stigmatised identity. Private, authentic networks offered a safe space free from social performance. From this point Naomi’s friends were able to support her emotional wellbeing and scaffold her back into her usual interactions. As Naomi re-entered the public spaces of the network – updating her profile and interacting with friends, this positive experience informed a lasting perspective newly sensitised to her visibility in the network and the care and support she felt:

then when those, had gone off and [...] and I’d not seen in as long as I’d not spoken to them, they were still almost, not ‘keeping an eye on me’, cause that sounds wrong, but you know... Making sure that I was still on their radar. Which is quite nice actually, especially at the time that I needed people to know that, who knew me. For me to know that they were there if I needed them.

(Naomi)

This instance of peer intervention throws new light on the notion of the Unequal Gaze. The networked public at its most authentic represents care, rather than scrutiny. In this way, the unequal gaze affirms the individual and their place in the network.

### **6.7.3 Network Affirmation**

The contact and support Naomi received provided important affirmation of her social identity, allowing her to relate to remote friendship groups outside her University. This was an affordance that several new students cited as vital to their wellbeing:

I feel, I feel more comfortable maybe than I would if it [Facebook] wasn’t there, because it does make you feel closer to everyone. So it’s kind of comforting to have it there. [...] Like some days, if, especially at weekends it gets quiet, like a lot of people go home. So it’s nice because you don’t feel as

lonely. You've always got someone to talk to on here and things.  
(Adele)

This affirmation was maintained and supported by the didactic properties of the network. Naomi cites the anytime/anywhere nature of the network as particularly advantageous:

And knowing that one of my friends who knew me as me was there to speak to at any time day or night, you're guaranteed someone was online, kind of helped me an awful lot.  
(Naomi)

Significantly, Naomi used these connections with distance friends and remote networks to substantiate an authentic identity irrespective of impairment. This highlights how the network allows disabled students to access intimates; enabling communities in which impairments are normal. Roy and Adele also cited the benefits of network access to these close friends. Whilst all students might benefit from maintaining such links with old friends, the particular benefits for disabled students are potent. As a result, contrary to her University and student experiences, Naomi defines Facebook as 'more me than Uni'. From this position Naomi was then able to build and perform a positive, authentic and visible self. Significantly, she also conceived her Facebook profile as place of refuge.

## **6.8 Conclusion**

This chapter has explored experiences of networked dis/ability at the socio-structural level of the SNS and at the social level of the networked public. Within these spaces, disability is shown to be multi-dimensional, however, across each of these dimensions, disability is observed to be resolutely tied to a discursive norm.

For students who do not experience a misfit with the SNS, its supporting technologies, or the networked public, disability was broadly deemed to be irrelevant. These students frequently conceive their networked activity as non-disabled. However, within this group, a lack of mobility in assistive, supporting technologies meant that some of the ordinary barriers faced by the majority of students took on an

extra-ordinary significance. These students did not perceive themselves to be unduly disadvantaged amongst their peers, however, as a researcher I observed that these students (Roy and Adele) faced barriers to the network predicated upon impairment and a lack of 'reasonable adjustment'. To reiterate: this suggests to me that the experience of disability is discursively constituted, predicated upon normalcy, rather than impairment; in addition, this suggests that, when impairment represents extra-ordinary experience, disabled students may enjoy a 'normal' experience that is not inclusive.

Three further classes of experience are seen to be configured by the network:

- Students experiencing a dis/ability difference ascribed by the technical surfaces of the SNS
- Students experiencing a dis/ability difference ascribed by the socio-technical practices of the networked public
- Students experiencing dis/ability differences ascribed by both the SNS *and* the networked public.

In each instance, disabled students are marginalised. Students experiencing both technical and socially ascribed ability difference are the most marginalised. Across all of these categories, a continuum of experience is expressed, from those who identify with the network to those whose dis/abled status leads them to identify against it. In this respect, experience of dis/ability is seen to be a rupture that occurs implicitly and explicitly across different facets of the network. At times, disability adds an extra-ordinary dimension to a known concern, in other circumstances, disability difference represents a wholly Othered way of being.

As we have seen, the necessity and extent of the network, the visibility of interactions and the pro-social nature of engagement create circumstances in which conservative norms of performance and identity are observed; these norms articulate a proto-typical student. For new undergraduates and other students expanding their friendship groups, the attention to the norms of network is vital. However, as Davis observes, when a norm is evoked, so too is deviance (Davis, 1995). For some, their impairment affects represent deviance and a tension with the wider network that

highlights disability's ongoing status in wider culture as a repository for what Goodley and Lawthom call the 'ideology of the normative and able body' (Goodley and Lawthom, 2006), and the disabled person as the 'archetypal outsider' (Garland-Thomson, 1996: xiii). Difference in these cases encounters a 'hegemony of normalcy'. This hegemony marginalises particular identities, identifying them as deviant (Davis, 1995:44).

Over the course of this chapter, I suggest that through technological fit and misfit, alongside issues of inaccessibility, social network developers have implicitly configured their users as 'normate', conveying an expectation of normalcy. Any disjuncture between the interface and the individual relating to impairment thus becomes a disability. In this sense disability is received by the disabled student. However, it is important to recognise that the relationship between the individual and the technology is only enacted in a circumstance where network membership is mandatory. In this chapter I have asserted that Facebook has become a network of necessity to students in higher education. Its extent and related network creep have together created a circumstance in which Facebook is near ubiquitous. As such, issues of fit and misfit have become issues of social inclusion and exclusion.

Nevertheless, such a deterministic position fails to recognise the disabled student as protagonist. Participant reception of social and technical ascription is by no means passive or accepting. We have already seen how peers and the wider community can mediate and remediate experiences of disability. In the next chapter I consider how participants themselves manage and negotiate disabled identity online, considering the techniques, strategies and identity moves with which students resist ascriptions of disability. In this way, misfit is seen to engender critical engagement with technology and community resulting in new practices of resistance.

## Chapter 7. Managing Disability in the Network

---

In chapter six, I discussed multiple indices of disability; how experiences of disability are reconfigured by the social networking site (SNS) and the networked public. Just as networked activity is mediated by multiple actors, so too is disability. In this chapter, I examine how participants who experience disability manage such experiences. As this analysis proceeds, it becomes clear that the experiences of disability are ‘so situated, so complex’ (Shakespeare and Watson, 2002) that diverse management strategies may represent contrary activities within one individual.

The network represents multiple communities and multiple functions, different times and different places, however, all are given the same weight in a SNS and are experienced simultaneously by the individual, resulting in context collapse, a state in which communities and contexts converge (Boyd, 2008). In this collapsed context, management of disability becomes a priority, as, despite the multiplicity of selves that a student may articulate or experience, the personal profile that is demanded by Facebook’s design is the pivot around which all aspects of social interaction turn. One consolidated view of the individual is thus presented across wider contexts and communities. In these conditions, issues of stigma and risk are fore-grounded. As Garland-Thomson asserts, disability is the ‘ultimate outsider’ status (Garland-Thomson, 1996). Experiences of disability alert participants to the fact that any sign of impairment in collapsed context of the network has the potential to nullify all other aspects of personality. This sign of difference may ‘spoil’ identity (Goffman, 1963). As a result, participants demonstrated numerous approaches to impairment, disability and identity management in networked publics.

Management practices shape both external and internal interactions. Strategies, tactics and techniques for identity management may be formally learned, adopted, or may develop organically. These approaches to self-determination are multi-faceted, and vary from participant to participant. Importantly, individual participants could rarely be tied to one perspective. As we have seen, many participants expressed a profoundly dialogic understanding of the networked public. In this respect, they

bring to bear their own perspective amongst others to find their place within or without the network. For some this process results in a marginalising experience, for others the experience is one of inclusion. More often, participants expressed aspects of both these positions concurrently; or sought ambiguity, actively exploring different positions.

Within this shifting and complex environment, four approaches are seen to be deployed and reflected by disabled students to manage dis/ability difference in the network. These methods are:

**Self-Surveillance:** Disabled students recognise disability as ‘Other’; a socially marginalised identity. As a result, disabled students undertake self-surveillance, working to manage and control the appearance of impairment and impairment affects within the network. Networking is characterised by the management of different forms of disclosure and emotional work on behalf of others.

**Self-Discipline:** Disabled students work to manage impairment affects by focussing on pragmatic courses of action. Self-discipline is frequently used to resist self-surveillance. Whilst self-surveillance privileges and manages an external gaze, moderating behaviour to fit extant norms, self-discipline prioritises the self. Networking is characterised by time-limited, utilitarian approaches (including disconnection), the management of privacy and the management of reflexivity.

**Self-Advocacy:** Disabled students resist network social and/or technical norms by calling on wider social and technical resources. Self-advocacy describes the ways in which disabled students look to influence their networked experiences beyond self-surveillance and self-discipline. Networking is characterised by a critical, proactive and evaluative engagement with technology, the networked public and external resources that seek to influence and challenge the status quo.

Management strategies, techniques and tactics are observed within each of these overarching themes.

Finally I report a further aspect of networked disability management. This management purports to activities undertaken within the network that affect dis/ability difference outside the network. This is identified as ‘self-affect’:

**Self-Affect:** Disabled students use the network to positively affect themselves. In a few instances, the network is successfully used to challenge impairment and disability both inside and outside the network. Networking is characterised by positive spaces and interactions, and the use of Apps and tools that affirm and display the individual, affecting an enabled identity.

Participants drew on these multiple perspectives and approaches, sometime simultaneously. In chapter eight, I proceed to discuss disabled student activity in terms of wider discourse and identity moves that underscore management and experience, examining all participant perspectives on disability and the network to establish Facebook as both a technology of power and a technology of the self.

## **7.1 Self-Surveillance**

Self-surveillance is usually conceived as the attention a subject pays to their own behaviour when facing the ‘actuality or virtuality’ of an immediate or mediated observation by others whose opinion matters (Vaz and Bruno, 2003). Self-surveillance activity was characterised by several distinct methods of identity management within the network, each relating to the unequal gaze. The network was seen to inculcate this sensitivity to visibility, creating a space for reflexivity. Roy states:

I think people manage their identities and I think people do it in different ways [...] you’ve got time to think about the way you can phrase things, voice things, whether or not to reply to something or whether to... you don’t have to respond instantaneously, so therefore you’ve got that extra level of reflection, a chance to think ‘well, is it the best way to do it?’ and I think there’s a lot of people sort of subconsciously think about that. More so than in a conversation. (Roy)

In terms of disability, reflexive intervals create a space in which students were cognisant of impairment as difference. Participants were aware of norms of behaviour and the ways in which their impairments might be perceived as deviant. As a result, self-surveillance activities clustered around issues of controlled disclosure of disability, mitigating indirect and uncontrolled disclosure.

Disclosure of disability has been highlighted as a complex part of disability in higher education, as it 'acts as a symbol of and repository for a complex nexus of issues and social relations' (Goode, 2007:42). In online environments, disclosure has also been researched as a central facet of disabled people's experiences of disability online. Some online environments remove the visual cues which divulge impairment in face to face interactions, thus disclosure may be controlled:

Disabled people can operate within an inter-subjective space where impairment is inaccessible to others' perceptual fields. Impairment no longer necessarily affects social exchange (Bowker and Tuffin, 2003:328).

However, within social media the management of perceptual cues is an increasingly complex business, particular within networks such as Facebook. Facebook is not a site for anonymous or disembodied identity play. Cues have the potential to divulge a disabled identity individually or in combination. Students' networks are also imbricated in physical local networks, in which disability may be known or visible. Participant James observed Facebook as the very opposite of 'anonymity'. Thus disclosure retains its status as a 'complex nexus' within the networked public.

For disclosure to be managed, self-surveillance must first be in place, participants must be aware of perceived difference to exercise control. In this respect, disclosure is highly inter-subjective. Strategies for negotiating disclosure varied across participants, dependent on impairment, the social networking function in question and anticipated audience. The management of direct disclosure and indirect disclosure are considered in turn.

### **7.1.1 Managing Direct Disclosure**

Participants raised three key circumstances in which active strategies for the management of direct disclosure of disability were deployed. These circumstances are predicated upon participants' conceptual division of the networked public into intimate groups, in which disability is known and 'normal' (Bogdan and Taylor in Ferguson et al., 1992), and non-intimate groups in which disability represents difference (Low, 2009). Direct disclosure is managed:

- In relation to non-disabled audiences already aware of disability (intimates)
- In relation to non-disabled audiences unaware of disability (non-intimates)
- In relation to disabled audiences (either intimates or non-intimates)

In this respect, participants explicitly undertook audience segregation (Goffman, 1959). In general, participants did not disclose disability within the public spaces of Facebook. This space was generally deemed too impersonal. However, participants developed private channels, locations within and beneath the public that could be used for such interactions. This bifurcation resonates with Goffman's notion of front-stage and back-stage presentation of the self, with accompanying 'role segregation' (Goffman, 1959). In this section I elaborate all instances of direct disclosure of disability; each instance anticipates the unequal, non-intimate gaze.

#### **Private Communications: Communicating beneath the networked public**

Context collapse (Boyd, 2008) results in a networked public that conflates intimate and non-intimate groups. As a result, the disclosure of disability with intimates was frequently moved from public to private spheres to maintain control and manage the spread of social information. For example, Naomi described how she disclosed her depression to close friends via Facebook's private email function, rather than through public announcements.

#### **Encryption: Hiding Disability in Plain Sight**

Roy identified cryptic interactions as a strategy he employed with his close friends:

It's very, very kind of restricted what people write on Facebook usually. It's *never* the whole truth. It's always, maybe there's a few in jokes, and maybe a few digs and stuff like that, they could even be disability related. But they have to be decrypted as such by the people who read them, they, kind of have to be in the know to get it; otherwise it would just appear to just ... a throwaway comment.

(Roy)

In these instances disability or any other personal information might be used for humour or in esoteric conversation, however, such discussion is characterised by in-jokes and other forms of encryption that only those 'in the know' will understand. In this way, the group affects a private space within the public that demonstrates close friendship and resists scrutiny. Boyd (2010) defines such behaviours as 'social steganography', where a specific cultural awareness is necessary to decode messages left in plain sight. In this way, Roy and his peers obfuscate disability under the non-intimate gaze.

### **Emotional Work**

Claire was the only participant to describe issues of disclosure to a network including both non-disabled and disabled peers. In these circumstances important conflicts arose between a desire to disclose authentic experience of impairment affects (for example, pain) and the importance of recognising and anticipating others' impairments. Negotiating a path between these groups required emotional work and specific management strategies. Notably, Claire sought to manage her own emotions as well as undertaking emotional work on behalf of others (Cahill & Eggleston, 1994). Importantly this work takes place across both disabled and non-disabled aspects of her network. Management focussed on the use of the network as a buffer, and strategies for explicit self-censorship.

### **Network Buffering: Using the Network as an Emotional Buffer**

Claire cited the difficulties involved in responding appropriately to greetings from old friends who are unaware of a new or unstable disability. Such greetings invariably query health:

...people will send to me things like saying 'how are you? I hope you're well', because I've not heard from them in years and I just say 'well, health not great, but happy' or something. I haven't really gone into details about it with any of them, because I'm not sure how they'll react.

In these circumstances, Claire is able to stagger her disclosure, controlling the amount of information and type of information conveyed. Claire cited how the network buffered these reconnections from the emotional work involved in disclosing or discussing disability:

And like, with talking to her [online], I don't, she doesn't have to have my disabilities pushed in her face and have to deal with them. I don't have to mention it when I talk to her.

In this sense Claire may negotiate a gradual disclosure, allowing her to scaffold friends from non-intimate to intimate knowledge of her impairments. The network also allows her to deploy stock answers (for example 'health not great, but happy') which allow her to maintain some emotional distance within a difficult encounter. Claire was the only student to describe this process with the research, however, her account directly mirrors Franklin's biographical narrative of disability and emotional work in Facebook (Franklin, 2009), suggesting this kind of emotional work on behalf of others is now a networked issue for disabled people.

### **Self-Censorship: Suppressing Disclosure of Disability**

No students were seen to declare impairment-related experiences overtly within networked publics. Indeed, many students actively censored their experiences of disability. Naomi withheld authentic expressions of depression to maintain a regular profile. Importantly, such self-censorship was seen to extend from interactions with non-intimates across into interactions with disabled intimate and non-intimate peers.

Claire cited the difficulties involved in airing frustrations relating to impairment to a disabled and non-disabled network:

Thinking however you phrase something, you've got to be a bit careful. So, I don't want to say 'I'm sick of not being able to see' because some of my friends are totally blind, and I'd feel really awful about that. Because they

*know* I think that, you know? And they do too, but I haven't really got that much to complain about [...] I've got a fair bit of vision. So I'm not going to say some of the things I think about being disabled, if you see what I mean.

In this instance, Claire's attunement to a disabled co-presence regulates content, leading to self-censorship. Importantly, whilst Claire was the only student to refer to sensitivity to hierarchies of impairments within her network, a number of the participants interviewed cited themselves as being less disabled than other disabled students (Sally, Ana, Howie, Ben, Jack, Pierce, David, James). This brief snapshot suggests that self-imposed limits on the acceptability of expressing certain aspects of impairment could exist between and across disabled/non-disabled networks.

### **7.1.2 Managing Indirect Disclosure**

Aside from direct disclosure, participants reported multiple strategies for negotiating indirect disclosure. These focused on particular cues that indicate impairment affects, or the particular ways of being that are produced between the technology and impairment, and marked by the networked public as deviant. Here I discuss participants' attention to the management of paralinguistic cues and symbolic cues that may in-directly reveal disability.

#### **Managing Paralinguistic Cues**

Participants identified varied paralinguistic cues that may disclose a print impairment, denote the use of an assistive technology, or reveal dexterity impairments.

Participants related paralinguistic disclosure to forms of orthography, false word choice, grammar or sentence structure that may identify the producer as disabled. Orthography specifies the 'rules' of language use and covers spelling, hyphenation, capitalisation, word breaks, emphasis and punctuation. For dyslexic students in particular, paralinguistic cues were often seen to be stigmatising, inviting associations with stupidity rather than impairment, concurring with the findings of Woodfine et al. (2005). As a result, pre-emptive and correctional strategies for mitigating the appearance of such cues were undertaken.

## **Drafting and Proofing, Correcting and Deleting**

Three students with dyslexia, Naomi, Pierce and David, cited specific instances of drafting and proofing their comments and status updates before posting to Facebook, particularly in cases where a large amount of text was required. Pierce also cited an instance of deletion. This form of self-surveillance and disability management was termed ‘double think’ by Naomi. In each case, participants utilised Microsoft Word’s spellchecking facility, copying and pasting between Word and Facebook to support their text production:

If it’s a large body of text that I know I’m going to put on somebody’s Wall, I tend to cheat and copy it into Word and check it for spelling [laughs].

(Naomi)

I do that quite a lot, use the spell-check.

(David)

I have actually written something in Microsoft Word, used the spell check and the copied and pasted it over.

(Pierce)

Each drew on this adjacent tool in an assistive capacity, prior to posting a comment. These actions were not undertaken simply as a matter of accuracy. The spell-checker offered a mechanical assistance to self-surveillance. Each participant noted that this activity anticipated forms of external surveillance that were not evidenced in their networks. All three stated that if they themselves saw a Friend make a spelling error, they would not necessarily judge them to be dyslexic, or even notice. Nonetheless, David, Naomi and Pierce maintained this attention to paralinguistic cues:

It’s more in my head than, you know, than an actual thing they’d [Friends] think about, I guess.

(David)

Yeah, so, like, they [Friends] don’t care about ... for me, like, I changed that.

(Pierce)

[Friends] really don't mind if I spell things wrong [...] it gives me the peace of mind.  
(Naomi)

The actions of all three anticipated a stigmatising, unequal gaze, even though Naomi, Gemma and Pierce acknowledged that this perspective was not a reality amongst their friends. Nonetheless, each had, to some extent internalised dyslexia as 'Other' and sought to realign themselves with a perceived norm and external perspective.

### **Disclosing Impairment / Deviance Disavowel**

Jack deployed a contrasting approach to disability management. He identified how he had directly disclosed his impairment on Facebook to offset orthographic and communicative errors:

I think there's been a couple of times, maybe I've done, said: 'Ooh, sorry, you know, that's just me being, you know, a bit dyslexic there. That's maybe not what I meant to imply'.  
(Jack)

Jack's disclosure is designed to mitigate the impact of his impairment and any additional, more negative implications, such as confusion, or a more discrediting stigma of 'stupidity'. In this respect, Jack appeals to his Friends knowledge of dyslexia, to position himself more favourably. This resonates with a strategy identified by Davis as 'deviance disavowel', whereby disabled people orchestrate social encounters to present themselves as physically difference 'but not socially deviant' (1961: 122). Notably, Davis' analysis pertains to people who are visibly disabled. The adoption of such strategies by students with dyslexia, an otherwise unseen impairment, once again emphasises the impact of digital visibility on action.

Notably, this approach was not desirable for all since it requires a positive association with the status of the impairment and confidence in the audience being addressed. Claire considered this tactic for mitigating errors made by her Speech Recognition programme, but identified this as requiring 'bravery':

Dragon does make silly mistakes sometimes. So it'll be things like the typing error, and I noticed someone had put at the bottom of their e-mail message: 'This has been produced using voice recognition, so please excuse any errors', and I thought 'that's sort of interesting'. I don't know. I don't know if I would be brave enough to say that.

(Claire)

In this sense, Claire finds the stigma of using assistive technologies and tactically disclosing her impairments less desirable than the risk associated with mistakes or orthographic errors.

### **Managing Symbolic Cues**

Symbolic disclosure was seen to relate to visual cues that might allow impairment to be inferred. This issue collated over the Profile image. Only one student, Claire, related how choosing a Profile photo raised the matter of disclosure. For Claire and other disabled students she knew, in-direct disclosure was attended to by editing visual cues:

I tried to choose photos where I had my eyes open, because I have problems with keeping my eyes open, with the flash because I'm sensitive to the light. And I just sort of think my photo, I don't look like I've got a visual problem, and there's a bit of a thing because obviously if you can't see a thing, for a start you're not going to know what your photo looks like.

(Claire)

Claire reported this issue as a common concern:

But some people do talk about, you know, wanting not to look too disabled in their photo or whatever. And there's someone on the list, who is visually impaired, and I don't think you'd know.

(Claire)

Other students (Ben and Roy) admitted digitally enhancing photos to improve their appearance in the network, but identified this within a trajectory of usual networked behaviour that their non-disabled peers also undertook, according with the networked 'self-reification' (promoting impressions of the self that are perceived as 'desirable') observed by Manago et al., (2008). Claire established an extra-ordinary perspective

on self-reification; she explicitly referred to a choice of image in terms of visible impairment, resulting in unwelcome reflections:

I think being able to say different things and I want my picture to look 'normal', which is just horrible. Why can't I just accept myself how I am? But other people don't always. And I used to be one of them, so I can understand that there are probably, I probably still have my prejudices, and everyone does.

(Claire)

This highlights a core issue for some disabled students within networked publics. To manage negative perceptions of impairment, the perceptions become, to some extent, internalised. For students who have become disabled due to injury or unstable impairments, the shift from one perspective to another creates conflict. External scrutiny has become self-surveillance.

### **Disability Interest Cues**

Symbolic disclosure also relates to the visibility of interests and expertise. For example, SNS Profiles allow the owner to express themselves by curating particular group memberships and Apps. Peers may then browse these to gain a more detailed understanding of the subject. Groups may acknowledge disability related topics, from which an audience may extrapolate that the profile owner is, themselves, disabled.

Elizabeth, James, Claire, Freya, Howie and Ana all cited interactions with impairment, health and disability related communities. Disability Interests included, for example, cancer support, disability politics and charity discussion fora, disability fashion blogs, and Ouch!<sup>36</sup>, the BBC Disability Lifestyle website. Each can be conceived as a Community of Interest. Disability expertise can also be demonstrated through Communities of Practice. In these instances the expert knowledge associated with specific impairments is traded, for example in Accessibility networks on Twitter.

Students as a whole located these interactions outside Facebook, with only subtle exceptions; two students, Freya and Naomi, had befriended Disability Studies

---

<sup>36</sup> <http://www.bbc.co.uk/ouch>

academic Tom Shakespeare. In this respect, participants maintained disability interests outside the bounds of the network.

In summary, self-surveillance strategies are diverse and are mobilised across a variety of network functions to control disclosure and the perceptions of impairment in the network public. Diverse management approaches are divested, with further experiences, some unwelcome, iterating out of this process. In the next section I consider the second significant approach to disability management, self-discipline.

## ***7.2 Self-Discipline***

Students frequently governed their behaviour using self-discipline to resist self-surveillance. Whilst self-surveillance privileges and manages an external gaze, moderating behaviour to fit extant norms, self-discipline prioritises the self. In this respect, self-discipline manifests as a form of self-care that subjugates external views and the network according to an independently determined hierarchy of need. In this way, participants seek to modify their own behaviours and actions for purposes of self-efficacy rather than social integration.

When considering the efficacy of the network, students were seen to tacitly deploy ad hoc cost/benefit analyses, to judge the salience of the network tool, particularly in light of inaccessibility to assistive technologies. Seale, et al. (2008) identified that many disabled students engage in a complex 'cost/benefit analysis' to determine their use and non-use of technology. This is borne out in disciplined approaches to the network. Disciplinary actions were seen to focus on several areas: management of time resources, management of reflexivity and the management of privacy.

### **7.2.1 Managing Time Resource**

The majority of students identified time management as a central determinant of their social networking activity. This accords with the findings of Seale et al., (2008) who observe that time was seen to be particularly important to disabled students 'particularly in relation to decisions made regarding the use of assistive technologies and social networking applications' (Seale et al., 2008: 72).

Importantly, concerns relating to time were not always experienced as relating exclusively to dis/ability difference. Students frequently evoked a wider discourse of deviance relating to excessive use and Facebook 'addiction'. In this sense, participant experiences of time resource were observed to relate to a disciplinary ordering in which a social identity was relegated beneath an academic identity for the sake of self efficacy. Since this perspective segues into a mainstream student discourse of deviance through overuse, participants did not always distinguish their attention to time management as being extra-ordinary. Seemingly, all students must either manage their time, or manage how their time is perceived to be spent within the network:

I wouldn't want people to know I'm on Facebook all day necessarily, cause I'm not, I don't really think it's an efficient use of time as such. And I think a lot of people agree like 'Oh, I've just spent that last hour on Facebook, I've wasted the time' and stuff, but if you...so you don't necessarily want to show the world that you've been every waking hour on Facebook – even though a lot of people do it, and I mean I, I do it quite a lot. And *you know* that other people do it, so you don't, there's no real reason, there's no real logic behind it. Just the perception thing.

(Roy)

Amongst undergraduates, Sally, Jack, David and Gemma established an explicit connection between network time management and their impairments:

Work for me takes longer. I can get quite stressed if I haven't done my work and if I spent time on Facebook it feels like I've done something naughty or something, spending time on Facebook rather than working productively.

(Sally)

Amongst postgraduates time pressures were more explicit. Ana, Claire, Elizabeth and Dennis all identified lack of time connected directly to their impairments in conjunction with work and family commitments:

I wanted to write something [on Facebook] but I think due to time constraints I couldn't do that.

(Dennis)

In addition, it was observed more widely that, within student reflections on the network, many participants with print impairments noted that the process of managing network contributions took longer. Academic commitments and reading are also seen to command more time. In accord with Elliot and Wilson's findings, during transition into University, first year participants were also seen to devote time to informing and negotiating with departments (Elliott and Wilson, 2008).

Importantly, it is possible that time is a larger issue for disabled students than presents within this research. One first year research respondent rescheduled and then withdrew from the interview phase, based on work pressure and lack of time. It is reasonable to speculate that others may have been deterred from engaging with the network and this research for the same reason.

### **Non Use of Network**

Ana and Elizabeth were the only students interviewed who did not use Facebook. For Ana, the time-consuming nature of her treatment and the impact it has had on her energy levels have meant that she has to focus her available, functional time on work commitments rather than social foibles. Time is conceived as a very precious resource. For Elizabeth, networks represented a false economy 'in terms of time', she doesn't have time to read 'everything and anything' that was sent her way. Again, she stated work commitments as a priority, disbarring online social networking.

### **Utilitarian Networking**

Many students characterised their networking habits as utilitarian and strictly regulated. These students frequently disavowed Apps, seeing them as frivolous and distracting. Likewise, networking was not undertaken for show or display. Usage was characterised by communication, responding to contacts, invitations, friend requests and so forth, rather than profile browsing or wider social research activity. Participants were also seen to enforce their own sets of rules about when, where and for how long networking should take place. For example, Jack, Adele and Sally amongst others, marshalled their access to the network. The network would only be accessed in the evening, from their own laptop or PC, for up to half an hour. These

rules might relax at weekends, but this strategy was deemed necessary to maintain productivity. Importantly, this time-bound approach is in opposition to the findings of Golder et al. (2007). Their analysis of Facebook interactions of 4.2 million US students show that Facebook is used whilst students are at their computers studying, rather than at evenings and weekends. Utilitarian strategies suggest that academic time pressures shape disabled student practices.

The strategies of Utilitarian networkers and Non-Users highlight the role of the university in structuring (non) use of networks amongst disabled students. These strategies echo Selwyn's (2006) citation of Niece (1998). Both studies cite the 'technical intermediation' of institutions such as the workplace, school or home on computer use. These constitute 'structural circumstances which prevented respondents from otherwise making use of technology which could be considered relevant and useful to their lives' (Selwyn, 2006: 288). The cases of Elizabeth and Ana appear to parallel this finding. University pressures together with impairment affects incur a circumstance in which networking is not viable. For Elizabeth this situation is compounded by Facebook's inaccessible systems. For other students, a pragmatic solution is limited access.

Goode observes that a 'prevalent discourse of personal responsibility for learning' can subvert efforts within the University for creating an inclusive environment (Goode, 2007: 46). Indeed, emphasis on self-sufficiency in academia installs a self-disciplinary culture in which some disabled students cannot undertake networking equivalent with their peers, due to the extra-ordinary pressures of managing disabling barriers to learning resources, or time taken up managing issues such as ill health, treatment and so forth. Since social time is not covered by 'reasonable adjustment', disabled students may cope with their educational task load, but simultaneously become socially disadvantaged amongst their peers. As a result, any subsequent social disparity is arguably caused by the University.

### **Reduced and Alternative Participation**

Amongst the participant group, students who experienced misfit with the network frequently cited the use of other modes of communication as ultimately preferable to

Facebook. Some, who had depended heavily on the network in their first year to build their network of friends, sought alternative modes of communication once their network was established. For example, James, David, Pierce, Gemma and others cited a strong, or increasing preference for face to face or phone communication, finding this a more satisfying arena for interaction. Even Claire, who was most dependent on social networks for social contact, asserted the benefits of face to face contact ‘after all, we’re not robots’. In this respect, the network represented an important option for disabled students, but it was conceived as an adjunct to social life, not a replacement. A significant proportion of students privileged other modes of communication and structured their networked presence accordingly.

### **Non Use of Specialised Assistive Technologies**

Participants who could get by without specialised assistive technologies, were frequently seen to manage without, trading the convenience of broader access around campus or at home for a less functional experience. Without assistive technologies, these students broadly judged their experiences to be within the range of acceptability, but reducing the need for available skills and technical resource, and risk of stigma attached to the use of ATs in public spaces. Notably, some students did not have assistive technologies available to them; these students pragmatically asserted that compromised network use was far preferable to disconnection.

### **7.2.2 Managing Reflexivity**

Several participants were seen to actively think about *how* they think about their impairments in the network, and acted to self-regulate on this basis. Students used this meta-cognitive self regulation, to inform their network activity. This internal strategy was frequently deployed to resist excessive self-surveillance. This was particularly true for a group of dyslexic students. Pierce, Naomi, Sally, Jack and Liam all expressed a commitment to managing self perception to ensure that self-surveillance did not get out of hand and adversely affect network interactions:

... if I look at things too much, I see errors that aren't there [laughs] so I've got to be very careful that I don't over critical, criticise myself.  
(Naomi)

Meta-cognitive self regulation was expressed in choices to *not* reflect on disability, by exercising resilience and emotional detachment, by seeking to be consciously assertive, and by using social comparison and social affirmation to validate a networked identity.

## **Resilience and Emotional Detachment**

Several students asserted the necessity of a resilient attitude to maintain regular networked activity. Coping with impairment affects and any inadvertent disclosures had to be overcome. These participants expressed a need to ‘get on with it’, ‘get over it’ and so forth. Sally states:

Commenting is not so bad [...] You do like learn to cope with it [...] I’ve actually managed to conquer quite a lot of stuff.  
(Sally)

This resilience was frequently evoked in relation to a necessary level of emotional detachment from the networked public:

If I really cared then I would like never go on it, like I’d be too scared, so I get over it [dyslexia].  
(Pierce)

When you’re going something on Facebook you can’t really think about how 252 different people are going to react in the same way as if you’re with me [...] that degree, that degree of thought isn’t possible.  
(Ben)

For this group, the unequal gaze was present, but actively refuted on pragmatic grounds.

An additional self-regulation strategy prioritised assertiveness. Dennis also recognised that his anxieties relating to how his dyslexia is perceived were counter-productive. He reported working on becoming more assertive as his primary mode for overcoming this barrier:

I've been working around it, trying to become more assertive in things which I write.  
(Dennis)

In this sense, disability was purposefully unreflected within the network to allow other aspects of self to be prioritised, locating the subject within the norms of regular network activity. This robust pragmatism is also seen in other aspects of student behaviour, as we have seen, particularly structuring the use and non-use of assistive technologies and other cost/benefit judgements.

## **Comparison**

Allied to meta-cognitive regulation, many students used onscreen comparative evidence to locate their own activity within a wider sphere of 'normal' interactions. Several students observed how their interactions matched the genre of interactions onscreen, using onscreen evidence within the interview to establish a range of regular behaviour within which they positioned themselves. For example, amongst dyslexic students, some cited Facebook as an informal sphere in which formal and academic orthographical rules do not apply. In this respect the transparency of interactions was beneficial:

I've had messages that made even less sense than messages I've sent  
(Liam)

Because things like Facebook [...] are so informal that you don't have to think about, you know, being grammatically correct, or spelling everything perfectly.  
(Jack)

In this way, students observe diversity within the network to substantiate their position. Liam and Jack note that in this sphere, textual differences do not matter. Their approach resonates with the assertions of LexDis participants who conceive

Facebook as informal application that ‘allows for a more relaxed mode of writing’ in which ATs are unnecessary (Draffan, 2009: 235).

### **7.2.3 Managing Privacy**

Some participants seek to create distance between their authentic and networked selves, to mitigate risk and create spaces in which some anonymity resource is re-affected. To do this, several participants sought to disrupt the referent power of particular combinations of cues. This was not a matter of self-surveillance, strategic ambiguity or crucial omission. These students actively managed privacy to ensure self-determination of disability and identity.

Referent cues are those cues that are interpreted in combination. In this way, information may be triangulated to establish an impression of the individual. Several students referred to this triangulation, when seeking authentic social information:

But I think Facebook gives you a, it’s almost like a photograph. It sort of gives you a snapshot of someone’s identity and life. You use these different ideas to correlate a sense about someone. So, no, I mean, it’s a bit like judging a book by its cover.

(Ben)

Despite the partial nature of display, these students did not seek to present a ‘normal’ front to the network. These students strove to extricate themselves from the tyranny of norms and surveillance. Gemma related her desire to disconnect to protect a disabled identity against stigma and other discredit; Howie wished to disconnect for other reasons. James sought space to express singular aspects of his identity, rather than bow to a consolidated norm. Despite their diverse motivations, this group’s tactics for disengagement broadly concur.

### **Withholding Information**

Gemma created space between her authentic self and her profile by actively withholding personal profile information. Gemma recognises that cues relating to the particular personal and social arrangements in which she lives as a disabled student are outside the range of a generalized student experience; as a result she seeks to

disrupt this triangulation to maintain control over disclosure. Gemma's anticipation of risk in the wider network led her to protect her personal information:

I even had my Wall off at one point and there's usually not much going on in my MiniFeed and my Pages, I didn't really have that until recently. So I was really private with it.

(Gemma)

James adopted a more passive approach to subverting network norms. He allowed his profile to date. In this way, James appeared within the network, but established himself against it. Since his profile information was evidently out of date, those seeking authentic information must contact him directly. From this point James may dictate the nature of interaction, moving conversations to offline arenas as required.

### **Enforcing Privacy**

Many participants used privacy settings to express strict limits on who could and who couldn't access their network. To stop the network becoming unwieldy with a view to intimate and non-intimate audiences, many students enforce privacy protocols and were strict about granting Friend Requests. Four participants reported 'unfriending' activity to retain control of privacy and prevent their network from becoming unwieldy. Indirect tactics include actions such as the use of an abstract or pictorial profile image to obfuscate identity. These actions reflect wider public and actions with regard to network privacy (Boyd, 2008), however, this is another instance in which disability offers an extraordinary intersect with a popular concern. This is most graphically illustrated in Gemma's case. She had experienced bullying from peers at school 'because of my disabilities'. The extent of Facebook's network meant that the presence of former aggressors in the network represented a security crisis for Gemma, a security crisis founded upon disablism.

### **Profile 'Cleaning'**

For those enmeshed in networks but wishing to leave, extricating oneself proved difficult. If a student attempts to disconnect, they may still be represented in photographic content uploaded by peers. A profile could not be meaningfully deleted

in these circumstances. Digital identity must be guarded. As a result, Gemma and Howie cite ‘cleaning’, deleting and de-tagging strategies undertaken to maintain maximum privacy:

I just try and kind of keep it but monitor it quite a lot and keep it quite clean.  
(Gemma)

It’s just a case of going through and like, de-tagging pictures and deleting messages, stuff like that.  
(Howie)

To manage perceptions, identity must be closely marshalled online. Deleting a profile does not solve the problem of a connected self.

In summary, self-discipline is characterised by individual acts to fit the network to the self, rather than the self to the SNS or networked public. In the next section I consider self-advocacy, management approaches that participants use to draw upon diverse resources outside the individual, to challenge the given properties of the network.

### **7.3 Self-Advocacy**

Self-advocacy is frequently cited within the disability movement as a key constituent for self-determination. Indeed, self-advocacy has been a movement in its own right for disabled people (for example, Williams and Shoultz, 1982), particularly for those with learning disabilities. In this research, self-advocacy is used to describe the ways in which participants looked to influence their networked experiences beyond self-surveillance and self-discipline. Self-advocacy describes the approaches of students who mobilised external social and technical resources, explicitly widening focus from the individual micro level to the meso and macro level. In this way, participants refuse to simply ‘cope’ by using individual strategies for self-monitoring. These participants looked outwards to gain expertise, support and leverage in their networked lives. Akin to wider notions of self-advocacy, this approach is seen to be founded upon constituent knowledge about the self, knowledge about rights, in tandem with communication skills and assertiveness (Test et al., 2005).

### 7.3.1 Digital Agility

Across many approaches to self determination, students demonstrate ‘digital agility’ (Seale et al., 2008, 2010), using ‘sophisticated awareness’ to ‘adapt activities, environments and technologies to suit their own circumstances’ (Seale et al., 2010:451). For a smaller group, this approach moves from a matter of subject-object relations between the user and any given interface, and becomes a matter of subject-object-subject relations. In this way, participants related to the developers and persons behind the technology, understanding the interface as man-made. Facebook has been criticised as being particularly hierarchical and resistant to user voice (Boyd, 2008, Ellis and Kent, 2011), in this respect, advocacy is limited. However, these students challenged the ‘given’ properties of the system by utilising entrepreneurial tactics, ‘work-arounds’, hacks, ‘cheats’ and new routes through the technology, indicative of bricolage.

In this way, digital agility constituted a magpie approach to achieving the best and most personal networked experience. For example, in response to Facebook’s inaccessibility, Claire used the email notifications as her exclusive route into the networked public. Whilst this limited the interactions available, it made the system practicable; allowing Claire to responsively maintain social presence in what was otherwise an inaccessible domain. Likewise, in 7.2.2, we see how three students use Microsoft Word to spell-check contributions, drawing on adjacent tools to augment Facebook’s systems. All participants demonstrated other steps to improve their individual experiences, for example, using distinct browser settings, shortcuts, favourites, setting their homepage for productivity, deploying Mozilla Firefox rather than Internet Explorer, the university’s default service, using ‘password remember’ options and so forth.

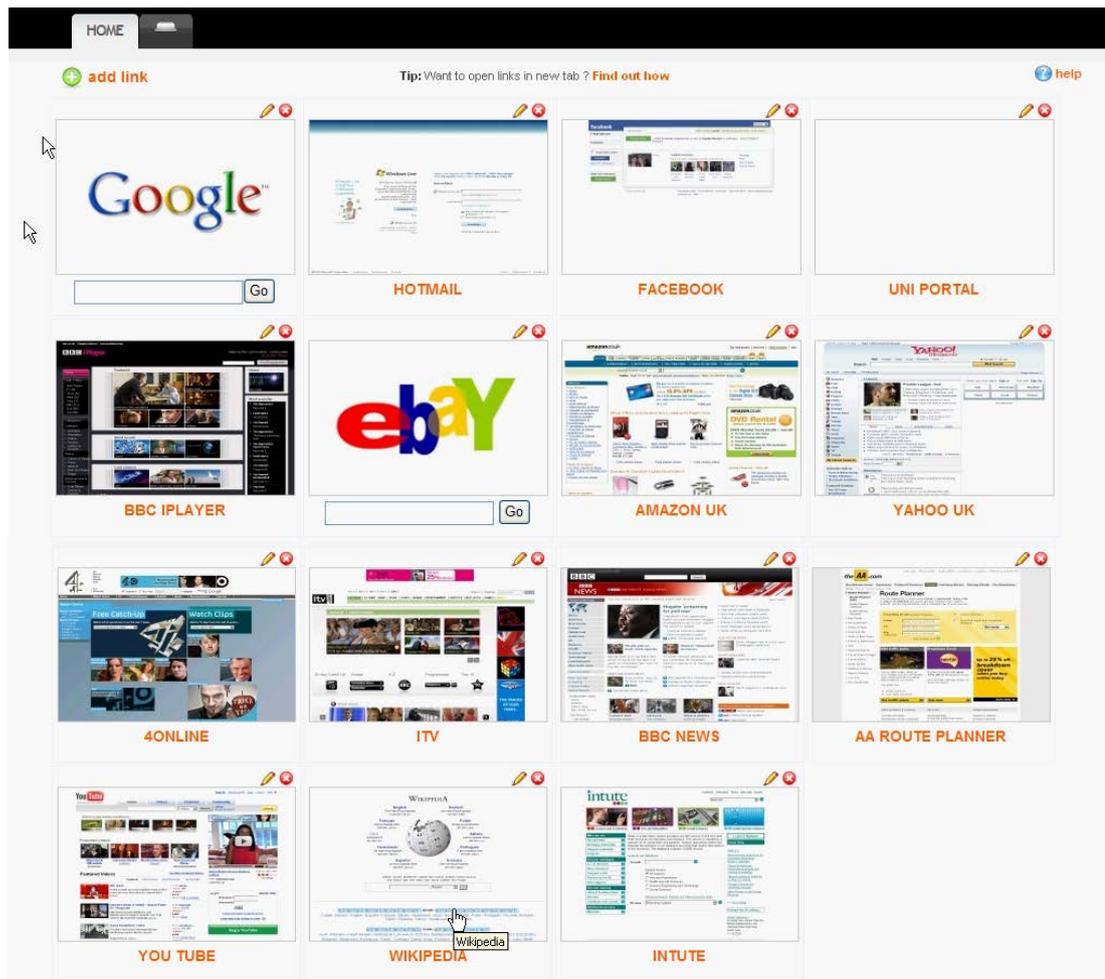


Figure 7-1: Sally's browser homepage (03.10.08).

For example, Sally's homepage (figure 7-1) features her favourite websites displayed for easy access. Facebook is positioned between Google, Hotmail and her University Portal. She describes it in the following way:

I've got Google, obviously. E-mail there. Facebook. The Uni portal which I've just added. I've got BBC i-Player, Channel 4, ITV there, for your instant access TV. Um, eBay and Amazon to sell stuff. And then these three [gestures with mouse to Yahoo, BBC News and AA Route Planner] I very rarely use but they're there anyway, they're just some more use, stuff. YouTube, and then Wikipedia is already on here. And Intute, I can't remember what it is, but it is something. [Laughs] I don't really use the bottom ones. It's mainly those top, sort of, six that are my main usage.  
(Sally)



**Figure 7-2: Jacks' desktop (12.12.08).**

Jack's desktop (figure 7-2) features a photo from a recent trip to Hong Kong. Many students used their backdrop as a photo-frame for pictures of family or holidays. Productivity Apps are visible on the right of the screen. These include a diary, calculator, news feeds and laptop status for battery life and memory.

Such bespoke conditions personalise interaction and represents a streamlining of the technological surfaces the network is embedded within. Self-advocacy expands from this individual resource focus, to utilise wider social resources.

Facebook has represented a glass-ceiling, immune to user advocacy. As such, proactive engagement with the network was frequently delimited to working around Facebook's systems. Self-advocacy in this context proved problematic. Many students<sup>37</sup> reported pro-actively working to engage with Information Services, teaching staff and Academic Support to acquire access to resources they needed for an equitable university experience. However, few lobbied with relation to the digital

---

<sup>37</sup> James, Gemma, Edward and Sally all worked to represent and improve the experiences of disadvantaged groups more broadly, through political and personal routes.

surfaces upon which their networked lives were built. Roy and Adele made direct contact with Information Services to demand better connectivity for their Halls; however, they did so under the auspices of ‘regular’ student need. Roy was one of the few students to directly advocate for timely delivery of his assistive technologies. Claire sought formal assistance and collaboration to affect the best networked experience, for example contacting PC manufacturers and Assistive Technology providers. As an accessibility advocate, she mobilised both a discourse of disability expertise to affect a dialogue with those responsible for her assistive technologies. This was not always straightforward however, leading Claire to explicit reflections on the performance of her impairment:

So, someone, I came across a forum that said, ‘contact this address, and they will remove that if you tell them you can't see’. So that's when I had my thing, because often I say. I'm visually impaired, because that could be anything. If I want to sound like I can see a lot I say I'm partially sighted, if I want somebody to just go 'Ok we'll help' I'll go 'I'm blind', because I am on the borderline and partially sighted at the moment. I'm probably being registered blind. [...] because it's just how you present yourself? And I've got these three different things that I use, three different terms I would use depending on how I want to sound.

(Claire)

In this respect, advocacy presented unanticipated outcomes for identity.

### **7.3.2 Building Digital Capital**

Several students drew upon and contributed to their peers’ digital social capital by sharing expertise, tools and knowledge. Information about Facebook’s systems and capabilities was traded around the network. Sally, Edward and Claire cited instances of sharing information with friends. For Claire, many of her conceptions and experiences of Facebook drew upon wider knowledge networks and immediate family:

My husband does a lot of web design, and he sort of says it can be difficult depending on what you're trying to do.

(Claire)

I came across a forum that said ‘contact this address and they will remove that if you tell them you can't see’.  
(Claire)

They've updated Facebook haven't they? Could it was quite a while ago I remember someone saying they've updated Facebook because they were whingeing about not being able to use it with a screen reader.  
(Claire)

Each of these instances identifies a different social resource which Claire draws upon to expand her expertise and achieve her aims, mitigating the impact of dis/ability difference.

### **7.3.3 Research Participation**

Some participants communicated their views powerfully in the research. For those experiencing highly negative or conflicted, inaccessible experiences of Facebook, the research interview presented a channel through which this could be expressed and heard for the first time. Amongst some students there was some relief that Facebook was being attended to:

That's why I wanted to speak to you, I think a lot of software is overrated.  
(Elizabeth)

I think it's a really important platform to be researching.  
(Jack)

I feel like a grain of sand in creating knowledge [...] my experience counts towards something.  
(Ana)

In this sense, participation in the research represented a form of advocacy for some, those who wished to increase their understanding of Facebook's powerful presence in their lives, and those who wished to present views that are otherwise unheard and unrepresented within the network, pro-Facebook student culture or an ambivalent academia.

It is notably that amongst the research participant group, Elizabeth, Claire, Edward, Gemma and James demonstrated politically active conceptions of disabwere politically active at the student level.

This is an important reminder of the researcher's duty to disseminate research and answer the participants' agenda as well as their own.

This section has recounted the ways in which participants leveraged digital agility, building and drawing upon digital capital and the research to self-advocate challenging dis/abling constraints in network circumstances. Finally, I consider self-affect, this represents the use of the network to manage impairment itself.

## **7.4 Self-Affect**

Here I report disabled identity management strategies that students undertook within the network to affect self determination outside the network. Many non-disabled students use services such as Facebook for social display, to evidence a successful social self, begin and sustain friendships and build social capital. It is important to reiterate that many disabled participants also benefited from such affordances and activities, however, in a few instances, students have been able to deploy the network in ways that actively reduce impairment and challenge disability difference. Naomi, in collaboration with her friends, was able to use her network and profile to re-establish an authentic, pro-social self that helped her to overcome her depression. Likewise, Edward used Facebook to augment his entry into student life. These actions are seen to coalesce in two interrelated dynamics, the creation of a safe space and the affirmation of the self.

### **7.4.1 Creating a Safe Space**

Naomi reported using Facebook tools for escapism; she described creating a 'safe haven'. Naomi's use of the Go Pokey! App [described in 5.4.9 and figures 5-20 and 5-21] allowed her to engineer a 'surreal world' that acted as a buffer to her immediate situation. In this sense, Naomi was able to use the network to break out of a disabling situation.

## 7.4.2 Affirming the Self

With her network, Naomi engaged in positive interactions and decorated her profile with Apps such as 'bumper stickers' (figure 7-3) that express an positive enabled self that is socially verified in the networked public, making the subjective objective. To reiterate:

Yeah, my Facebook profile, erm, has, you know all 'me' things, like if I go onto boxes somewhere down here, erm, oh... it's like they're my friends back home would class me as those, and further down we've got like the bumper stickers.



Figure 7-3: Two of Naomi's 'bumper stickers' (11.11.08).

In this respect, Naomi was able to 'declare' and affirm aspects of self that were not available in her immediate student, or university environment. This representation of self she described as 'more me than Uni' allowing her to 'not evidence... that sounds horrible' but to publically express and record her values, in socially accepted modes, with positive self-affect.

Edward's enthusiasm for Facebook demonstrated it to be a significant part of a wider university experience which he noted had a profoundly positive impact on his sense of self, reducing some the stress related symptoms of his impairment, resulting in a less disabled experience. Edward's use of authentic modes of self expression and apps to visualise his network also resulted in an experience of social acceptance and self-affect. These are two instances in which Facebook is deployed to beneficial and inclusive ends. In this way, some disabled students have been able to use the network to challenge disability and impairment directly.

## **7.5 Summary**

Management of disability within and without the network is a complex task. Students are seen to deploy a raft of measures to ensure self-determination in the networked public. Measures range from self-monitoring and self regulation, to pragmatic issues of time management and technical access. The management tools that are deployed are physical, psychological, digital, and socially distributed. Across these spheres ambivalence about the role and nature of disability, and the ubiquity and heightened visibility of networked space are seen to affect often cautious and risk-averse behaviours.

Of the four approaches deployed, self-surveillance, self-discipline, self-advocacy and self-affect, a distinct split between individual and social approaches are observed. The majority of management strategies are seen to be deployed at the individual, rather than group or social level. At the time of data collection, modes of communication or feedback between the disabled student user and those responsible for user experience at Facebook were unknown. Whilst this may change, for the students interviewed self-advocacy takes place largely outside the network, with students recruiting help and acquiring information to inform and shape their network experiences entering from adjacent networks.

Positive experiences of the network are possible. Some students are included – allowing disability to become a matter of relevance. Others work to engineer a positive network, carving out intimate network spaces in which disability is normal;

known, but not stigmatised. Others strive to maintain a locus of control where they ensure that disability is irrelevant, but also suppressed.

In the next chapter, I proceed to discuss experiences and management of disability in terms of wider discourse and identity moves. I examine participant perspectives on disability and the network to establish Facebook as both a technology of power and a technology of the self.

## Chapter 8. Discussion

---

In chapters six and seven, I have reported students' experiences and management of disability within social networks. In this chapter I consider these experiences and activities in light of discursive notions of power to widen the lens of concern from a comparative meso-level to address super-ordinate issues of domination, resistance and the constitution of disability through the social use of technology. In short, I seek to explain how student practices relate to wider issues of networking and university life.

This discussion begins by introducing Foucault's *technologies of power* and *technologies of the self*. Social networks have previously been considered as a digital technology of the self (for example, O'Regan, 2009), mobilising new opportunities for self determination. However, within this research, participants expressed various ways in which the network constituted disability, leading to disability management in the network, self-surveillance, self-discipline and self-advocacy. Each of these positions is considered in terms of the discursive identity-moves that it expresses and its relation to the SNS as a tool and 'technology' in the Foucauldian sense. In this opening discussion, a split is observed between those students who identify with the network and those who seek to create a distance between their authentic selves and their network representation. Here I argue that the campus conditions of network usage create the social network as a technology of the self for some, and a technology of power and domination for others.

As a technology of the self, the network helps disabled students build social capital and write themselves into being. The network is also recognised as a mode of integration or assimilation in student culture. These affordances are seen to challenge the social isolation that has previously characterised disabled students' experiences of student life in higher education. However, as will be seen, these affordances can also be understood to promote certain ontologies that continue to marginalise disability.

From this point, discussion shifts to the implicit affects of the network as a technology of power, or domination. For those who identify with the network, attention is paid to important questions concerning the concealment of impairment and impairment effects within the network. Is this attention to non-disclosure a symptom of ‘internalised oppression’? Are disabled students who identify with the network simply ‘passing’ online? The conflicted nature of self-surveillance is considered alongside a review of student conceptions of disability. This highlights the fine line between self-determination *within* the network and determination-of-self *by* the network.

Some participants experienced the network explicitly as a technology of power. The network conveyed an oppressive unequal gaze, or created dis/ability difference through inaccessible systems and public spaces configured to non-disabled norms. Participants did not experience these social and structural barriers passively. Resistance to these challenges was mobilised through external technologies of the self; these are established to be identity associations with ‘activist’, ‘expert’ and ‘academic’ identities. Importantly, each of these positions is seen to subsist within a wider framework of values governed by the university. It will be shown that the university has an instrumental role in structuring disabled students’ network experiences, determining the grounds in which marginalisation and validation are constructed. I begin by introducing Foucault’s *technologies* as the keystone to this discussion of agency and power in the disabled students’ network.

### **8.1 Technologies of the Self, Technologies of Power**

In this investigation disabled students have identified both positive and negative experiences of dis/ability in the networked public. Networked participants have benefitted from the affordances of the SNS as well as experiencing social limits, risks and costs, sometime simultaneously. In each case, students have expressed attention to self-determination. This has been particularly evident amongst new undergraduates, for whom the move to university represents a critical juncture in the development of an independent personal and social identity (Goode, 2007: 40). The performance of social self is the objective of the network.

Some participants are found to experience disability as a difference determined by the SNS and the networked public. This difference is not always reflected, particularly in instances where students do not recognise their experiences as extraordinary. In this respect, networked identity and disabled identity are socially dependent.

Experiences relate to certain management strategies within the network: self-surveillance, self-discipline, self-advocacy and self-affect. In analysis, it becomes clear that each of these approaches represents a certain type of technique, or instrumental practice. These are ‘technologies’ in the Foucauldian sense (Foucault et al., 1988), deployed either in resistance to the network, or affect through the network. Foucault defines four ‘technologies’ extant in human action:

(1) technologies of production, which permit us to produce, transform, manipulate things; (2) technologies of sign systems, which permit us to use signs, meanings, symbols, or signification; (3) technologies of power, which determine the conduct of individuals and submit them to certain ends or domination, an objectivising of the subject; (4) technologies of the self, which permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (Foucault et al., 1988:18).

Amongst these, much of Foucault’s work focuses on power. Only in later life does he consider technologies of the self<sup>38</sup> to explore how people resist objectification and assert themselves as subjects. His expositions on technologies of the self chart the different self-practices that bookend particular eras in history. Amongst these practices, material tools are referenced. In particular, the advent of the notebook and its use for reflexive self-mastery, memory support and self-inspection are identified in the Hellenistic period as *hyponemata*. Foucault subsequently states:

---

<sup>38</sup> Foucault uses ‘technique’, ‘techniques of the self’ and ‘technologies of the self’ synonymously.

This new technology was as disrupting as the introduction of the computer into private life today. It seems to me the question of writing and the self must be posed in terms of the technical and material framework in which it arose. (Foucault, 1984: 363-5)

In this instance, Foucault asserts the impact of the tool as it is discursively realised. Writing alone is not the 'technology of the self' however; it is the particular practices of self-care and self-knowledge that writing answered for Hellenistic society that marks it as a technology. In comparison, Foucault identifies how writing, as a self-practice, changes, becoming an early Christian confessional practice. As we move into the digital age, Web 2.0 marks another determined shift in such technologies. Writing is not simply reflexive; it is social, visible and idealized (Turkle, 1984). In this respect, writing, 'audience' and 'self-identity' enter into a precarious new dynamic (Boyd, 2008). Technologies of the self have been previously evoked in relation to analogue and digital technologies by Abbas and Dervin, (2009) and others. Technologies have also been proposed with relation to critical practices of disabled identity (Reeve, 2002). I now turn to apply Foucault's critique of discourse, via technologies and power, to elucidate my analysis at the juncture of these fields.

## ***8.2 The Network as a Technology of the Self***

Facebook is found to be an essential aspect of student experience. It shadows the ebb and flow of the academic year, mapping the daily social activity of hundreds of thousands of students every day. The authenticity of this mirror on student life is to be questioned. Nonetheless, amongst those participants registering a non-disabled experience, a social and technical fit with the network, Facebook offers a portal through which students may enter and observe a proto-typical student experience and fashion themselves amongst their peers. In terms of disability, this process is significant. Disabled students recognise network affordances in terms of integrating with new connections, building social ties, increasing presence and keeping up to date with social information. These are all 'normal' affordances, but for some disabled students, an interaction between impairment and network affordances has specific, enabling effects. The network represents an assistive technology that connects disabled students with wider student life; these effects are enabling and

represent an extra-ordinary affordance. Prior to the advent of Facebook, research shows disabled students' experiences at university to be characterised by social isolation (Shevlin et al., 2004) and 'difficulties in accessing 'normal' student experiences (Riddell et al., 2005). As a result, disabled students lacked the wider networks that typify social capital:

Disabled students may have strong links with a disabled student's advisor, a personal assistant, a mental health support tutor or a small group of friends, but they often lack the myriad loose connections which are a vital part of the higher education experience for many students. The full benefits of higher education may therefore be elusive. (Riddell et al., 2005: 153)

For the participants who fit and associate closely with the network, it appears Facebook offers a means to overcome isolation and barriers to sociality. In this way, Facebook represents a technology of the self that enables activities such as building social capital, writing identity into being and assimilating into student culture. I discuss each of these three affordances in turn and describe the particular benefits these represent for disabled students.

### **8.2.1 Building Social Capital**

Disabled students can accrue valuable social capital through Facebook. Riddell et al., (2005) express a concern specifically with a dearth of 'bridging' social capital possessed by disabled students in their research. Bridging capital denotes connections between tight networks, exceeding an immediate circle of friends to incorporate links to new groups brokering information and opportunities. Bridging capital expresses the value of 'weak ties' (Granovetter, 1983) that cross into new networks and have the potential to mobilise new resources. In this sense, Facebook offers a means for 'getting on' rather than subsisting within a close knit group.

Many students valued the bridging affect of Facebook in terms of establishing friendships, but also in terms of access to social campus resources. Such resources were frequently reported as the core determinant of membership. The availability of social information about friends, student union society and club updates, the sharing of interests, media and current affairs gave participants a sense of connectedness and control, offsetting the physical requirements that such news gathering might

previously have incurred. Indeed, Ellison et al., (2007) suggest a strong association between intensity of Facebook usage and resulting formation of bridging social capital. Ellison et al., also establish that intensity of use predicts the maintenance of social capital. In terms of participant moves to determine themselves, the value of maintaining and extending their networks are clearly demonstrated.

For students such as Naomi and Adele, social networks have represented an important, if not vital, way of maintaining the social capital they have built up prior to university. Indeed all networked participants demonstrated communities within their networks representing friends and family from home. This maintained social capital (Ellison et al., 2007) is a particular boon for disabled students. It reduces loneliness and continues connections with intimates amongst whom impairment is known and normal. Thus, social networks offer a means to carry established emotional support networks into higher education. Again, this particular affordance, whilst available to all students, has particular resonance for disabled students. In research conducted in 2006, Goode outlines the diverse experiences of disability produced by transitions into higher education, identifying how breaks with home can mean losing sources of support, that whilst anticipated, ‘could nevertheless make life far more complicated than it had been whilst living at home ’ (Goode, 2007: 41). Prior to the advent of Web 2.0, students used other communication technologies, however Facebook allows students to not only maintain these networks asynchronously, but also render such networks visible with powerful self-affect.

### **8.2.2 Writing Identity**

Through the SNS, students can evidence their friendships, share photos and so forth, allowing their social networks to materialise. In this way, they may curate friendships, associations and past events. All such activities were evidenced amongst networked participants. All networked participants were aware that such evidence constituted a performance, some thrived on this opportunity to demonstrate themselves, and others considered it a necessary by-product of functionality. However, Naomi shows how this performance can act powerfully for positive self-affect. As a technology of the self, Naomi is able to write herself into being, in new ways that break with external and prior modes of thinking, allowing her to answer and negate external discourse. Naomi lucidly describes building a social environment

that speaks to her of her own competence, independence and belonging. In this way, the network can be used by disabled students to challenge limits placed upon them by external structures and power relations. For Naomi, the network is ‘more me than Uni’, re-affecting an authentic self. In these circumstances the formation of individual identity was seen to alleviate symptoms – for example stress and depression, not only mitigating disability as a power relation, but mitigating impairment at the same time.

### **8.2.3 Assimilating into Student Culture**

For new students beginning at university, Facebook represents a rite of passage that parallels the educational transition into the academy. Many undergraduate participants described a trajectory through networks, from Bebo to Myspace culminating in Facebook, the quintessence of student social life. Student practices have been seen to bend to better accommodate Facebook, just as Facebook’s functionality has been designed to reflect the requirements of its student populous. Many participants spoke of the network as a social necessity, reflecting their friendship groups, interests and actions. Amongst these networked participants, Facebook is a route to regular student experience and activities. In this space, disability is irrelevant; other aspects of the self are prioritised as disabled students work upon a pro-social student self and identify with (non-disabled) peers according to usual practices of interaction. Within the network these ‘usual practices’ are made visible, evidencing and rehearsing norms that disabled and non-disabled students may then appropriate. As a practice of the self, the network offers a transparent space where actions may be reflected, edited and perfected.

In summary, SNSs and networked publics can reduce disabled students’ social isolation, increase bridging social capital, and maintain home support structures over the course of a student’s university career. Networks can be used to write the self into being, in a mode that is socially validated, with effects that can remediate experiences of impairment and challenge disability as a socially ascribed identity. Finally, and significantly, networks can give disabled students access to ‘regular’ student activities and experiences, allowing them to integrate with peers and control aspects of disability and impairment. In these ways, disabled students deploy the

network as a technology of the self, to achieve self-affect. For many students however, such affordances were also accompanied by costs. In the next section I consider the loss of agency that the network represents for disabled students and an implicit impact on the ontological status of ‘disability’ amongst students created as non-disabled. In short, I discuss social networks as technologies of power.

### ***8.3 Social Networks as Technologies of Power***

Power is a fraught issue. Facebook is a network of necessity. It is nearly ubiquitous amongst undergraduates and is known to convey important social information unavailable through other sources. This creates excluding conditions for some. Furthermore, ‘network creep’ means that non-users and low-users may still be represented by peers within network spaces, whether or not they are active and registered, or consent. As a result, the networked public represents an unequal gaze (Foucault, 1977).

For some disabled students, this gaze represented an often unwelcome intrusion. The conflation of different peer groups and wider circles in the network meant students felt exposed. Visible impairments and unstable impairments might be discerned by an unknown audience, non-intimate friends, friends of friends, acquaintances, and the general public. Amongst students with unseen and cognitive impairments, the varied cues of the network also threatened to expose impairment socially for the first time. In each instance, participants reported anxieties relating to extra-visibility and concern with disability intruding on their self-representations, objectifying them as Other.

The social network is a technology of power because it is a technology of surveillance. The surveillance of disabled students differs from the surveillance of non-disabled students, as many disabled students have experienced forms of discrimination, stigma and marginalisation predicated entirely upon their impairments. As a result, disabled students recognise that disability remains widely conceived as deviant and discredited within society, and that to be perceived as disabled involves risk. Alongside disability, religion, sexuality and ethnicity were

also raised by participants, suggesting that the unequal gaze may be amplified across multiple indices of oppression for some disabled students.

These experiences of extra-visibility highlight the way in which the network interrupts and refracts the usual operations of surveillance, power and knowledge on campus. The social network ruptures the ways of seeing and observing that have previously ascribed disability as a discredited identity on campus. This rupture results in a re-arrangement of power and knowledge; as the visible 'evidence' of impairment and impairment effects are mediated by the network. This results in a re-ordering of the hierarchies of impairment that have been traditionally expressed in student's social lives. Some disabled students move to a *seemingly* enabled status. Others find themselves disabled. Between these binary conditions of disabled and non-disabled, students are seen to negotiate hybridic self-determinations.

In addition to issues of surveillance, Facebook also represents a structural expression of the marginal status of disabled students. Its systems are not accessible to all, and, in use, the networked public creates social conditions in which impairment is *invisible*, since the expectations of the system anticipate in use is that users are non-disabled, both in terms of the interface, and the normalisation of social information represented. On campus, Facebook is a place without patterns of living involving 'reasonable adjustment', treatment, pain, mental illness, physical or cognitive diversity. Modes of resistance are discussed in turn. However, I begin by observing an exercise of power upon and through those for whom the technology represents a close 'fit'.

### **8.3.1 Morphing Ablism**

Despite the affordances of the SNS, power can be seen to operate upon those for whom the technology represented a 'fit' resulting in a non-disabled experience of the network. These students (Howie, Adele, Ben, Freya) did not identify with disability in their social or technical interaction with the network, conceiving their impairment as having no practical impact in the use of the tool. In this respect, the SNS represented a technology of the self, enhancing 'normal' practices. Commentators (Campbell, 2005; Goggin and Newell, 2005) have observed that new technologies

are regularly touted in terms of their capacity to remediate disability, however for Campbell, this remediation is not unproblematic, it represents a “morphing ablism”:

Recent technological “advancements” hold out the possibilities of “elevating” the bodies (and minds) of individuals designated as disabled to the level of “nearly able”. Thus, we could argue that “enhancing” and “perfecting” technologies are really a means with which to assimilate by way of illusion (that is, an appearance) that the “disabled” body transmogrifies into the “normal” body, effecting a corporeal recomposition and re-formation of subjectivity. (Campbell, 2005: 119)

Campbell argues that this reformation constitutes a ‘fantastic reimaging’ that has consequences at an ontological level. As the subjectivity of ‘ability’ is produced, disability is ontologically confirmed as a deficit. In this way, disability continues to be subjugated to a non-disabled norm. Campbell observes that the object of this technological intervention, the disabled person, may not require an inducement towards this re-imaging:

An inducement to cooperate ... may not be necessary due to the enduring hegemonic compulsion towards ablest normativity. (Campbell, 2005: 119)

In this respect, disability is seen to be reconfigured only in a cosmetic sense. Static, medical and embodied notions of disability are reinforced, not challenged by this refraction.

### **8.3.2 Resistance**

For those students who experienced disabled subjectivities within the network, resistance to the unequal gaze was complex. Management strategies included self-surveillance, self-discipline and self-advocacy. However, within and amongst these strategies, participants’ motivations for their actions varied. The motivations are linked closely to conceptions of disability and identity, and represent a challenge for analysis, as, for many students, this construct was emergent, multifaceted and interwoven with conceptions of the wider activity system, the network and the university. Next, I briefly review student’s conceptions of disability, to elucidate the particular actions undertaken in the network as a result of underlying identity moves, or self-positioning.

### 8.3.3 Participant Perspectives on Disability

Participants demonstrated a variety of views on disability. Perspectives related to life experience, background, disciplines and intersections with other identities. In this sense, disability remains relational, imbricated with the social and material world. Many students were deeply ambivalent about the term ‘disability’. Indeed, the majority of student perspectives accord with Watson’s (2002) assertion that disabled people do not prioritise disability in self identity. Even amongst those pro-active in disability politics, none founded their assertions of self solely on disability. Amongst the participant group, Gemma, James, Elizabeth and Claire recognised themselves as ‘disabled people’ in terms of advocacy and a positive political identity. However, this association was made as an assertion of agency on behalf of the self and others, to resist the denigration of people on account of impairment, rather than the acceptance of ‘disability’ overarching descriptor or total signifier of experience.

Many other students also rejected disability as an externally ascribed label. For example, amongst undergraduates, many questioned the congruence of disability as a category, noting that the diversity of experience that it supposedly encapsulates renders it meaningless. Importantly, these views did not negate impairment as an experience, but that experience was not necessarily ‘Other’. Edward observes ‘it’s my “normal”’, Ben echoes this determination ‘if you’ve never experienced something else, you’re not going to see the distinction’. Other students recognised a functional limitation, but rejected negative social implications. Some evoked disability’s relational qualities directly. These reflections on the relation between disability and the self were complicated by students’ awareness of external views of disability, the impositions of stereotypes and experiences of disadvantage and prejudice. Many participants referred to students with more significant impairments than themselves, often whilst simultaneously critiquing their own stereotyping of disability as physical, or wheelchair based. For example Pierce cites his notion of disability as ‘so stereotypical... when it can mean, oh, a thousand different things’. Claire, who experienced some of the most disabling circumstances, also referred to those in more difficult situations at several points.

In sum, students expressed various perspectives and modes of talk about dis/ability. These demonstrate what Bakhtin calls 'heteroglossia' (Bakhtin, 1981); students participated in multiple discursive practices, in each instance positioning themselves differently in relation to perceived knowledge and power. In this respect, disabled students actively shifted between discourses to position themselves more powerfully (Henriques et al., 1984). From this position, two inferences become possible. One interpretation asserts that disability is an undesirable category and that the majority of students reject disability to associate more closely with the perceived norm. This expresses 'internalised oppression' or 'false consciousness' (Shakespeare and Watson, 2001) as disabled students seek to distance themselves from an oppressed group and refuse to recognise disability authentically. By evoking those who are 'more' disabled, students position themselves against an 'other' to secure their position.

A second interpretation observes that disabled students are rejecting external labels to expand the category of 'normal' (Watson, 2002). The disabled student asserts their experiences as normal, challenging social ascriptions. Impairment may or may not affect function, but it is not socially relevant and does not determine identity. In this case, student references to more significant impairments is not a matter of 'Othering', it is a recognition of the diversity of the category and a move to highlight a hierarchy of impairment (Deal, 2003) and those who may be more disadvantaged within the context of the university. It may also be an acknowledgement that their knowledge of disability is partial and that they speak only for themselves. As Watson notes:

Even though this acts at an individual level, the agency exhibited in this action is a very political action, in that they reject identities others may wish to enforce on them. (Watson, 2002: 524).

Riddell et al.'s findings have resonance with this position. They found that amongst disabled students disability 'Is experienced as something which others wish to impose, rather than a lived experience' (Riddell et al., 2005: 147). These two stances are important, as the majority of students actively removed cues to impairment from their networks. This editing and its motivation are essential to understanding whether Facebook represents domination or self-affect in the lives of disabled students.

## **8.4 Self-Surveillance**

A foremost technique in resisting the unequal gaze was self-surveillance. Participants monitored their actions to render impairment invisible and irrelevant. Self-surveillance is complex. In a Foucauldian sense, self-surveillance recognises and privileges external perspectives to act accordingly. Where disabled students experience surveillance as a form of oppression, proscribing certain ways of being; the resulting self-surveillance can represent a form of internalised oppression. This issue is a political one since it implies a denial and rejection of disabled identity.

Self-surveillance was used by participants to mask and neutralise disability and impairment, reflecting the findings of Bowker and Tuffin (2002) who report established repertoires of 'relevance' and 'normality' as essential to disabled people's self-representations online. These activities demonstrate diverse motivations, in circumstances that amplified the significance of disclosure due to the breadth of student networks and their close integration with local, residential communities.

Students accounted for their lack of disclosure, revealing complex motivations:

**Discredited Identity:** Many recognised that disability continues to represent a discreditable identity and is stigmatised in wider society. As a result, they strove to manage this external ascription. Disability was strictly controlled to mitigate risk to the self.

**Consolidated Identity:** Relating to this, many students were concerned that disability should not dominate others' conceptions of them, for students with print impairments there was also a concern that disability should not disrupt what they are trying to convey in communication.

**Network Norms:** Facebook was seen to be an upbeat and frequently inauthentic space that is edited to represent a student's pro-social self. In these circumstances,

disability and impairment do not fit the genre of public Facebook interactions. Students did not consider it the correct space to disclose disability.

Importantly, none of the above approaches was considered absolute as participants' relationships with their networks changed over time. For some students, self-surveillance was undertaken as part of a wider strategy to scaffold new friends into more intimate knowledge of disability. For others, non-disclosure represented a mode of 'keeping options open', in all cases, student perceptions are marked by a self that is conceived as an ongoing project, demonstrating 'mobility' that is seen as characteristic of identity practices in high modernity society (for example, Giddens 1999), but often conceived as a project unavailable to disabled people (Hughes et al., 2005).

Söderström notes that, within the use of ICTs:

Disabled youth often have to overcompensate to prove themselves in doing 'being ordinary', and to achieve the liquidity and mobility anticipated of youth. (Söderström, 2009: 142)

Indeed, such behaviour was observed most keenly amongst some dyslexic students. For example, David, Naomi and Pierce noted their non-disabled peers did not attend to orthographic rules within Facebook, but despite this, and the fact their networks *knew* about their impairments, all felt compelled to conduct perfect interactions.

#### **8.4.1 Passing**

The masking of disability is a concern within disability studies. Writers such as Corbin (1994), Shakespeare (1996) and Morris (1991) have argued that this apparent struggle to attain normality and eliminate impairment amplifies the oppression of disabled people (Watson, 2002). Bowker and Tuffin extend these arguments explicitly into the digital sphere:

By eliminating disability from the social sphere in order to pass as non-disabled, differences are denied and already marginalised voices are silenced even further.  
(Bowker and Tuffin, 2003:330)

These arguments suggest students are ‘passing’ as non-disabled, reinforcing norms in the network and reinforcing a stigmatised image of disability through denial. However, such judgements devalue participant perspectives. As Watson (2002) finds, those who deny disability ‘are not reinforcing oppression, but trying to make difference *not* matter’ (2002: 522). It is important to iterate that *all* students, including non-disabled students undertake presentation strategies to position themselves within the norms of their network, striving to assimilate into student culture. Moreover, motivations for self-surveillance reveal this action not simply to be a matter of denial or ‘internalised oppression’, it is in fact an expanded understanding of self-surveillance that conveys a purposeful attention to self care (Vaz and Bruno, 2003).

#### **8.4.2 Self Care**

In view of the lived realities of university life, stigma and the identity transitions that the move to university represents, it is not surprising that some participants sought to render their impairment invisible to the network (see also Bowker and Tuffin, 2003). Undoubtedly, non-disclosure, like ‘morphing ablism’ leaves the homogenous network unchecked, potentially incurring norms that create greater barriers for those who are unable or unwilling to ‘pass’ as non-disabled. Non-disclosure also requires effort that can be difficult to sustain and leads to a (perhaps unnecessary) dissonance between authentic experience and a ‘front stage’ profile. Nonetheless, it is important to recognise the validity of these students self-determination. As Dewsbury et al., (2004) note, disability research has the potential to ‘ironicise ‘ordinary experience, leading to unhelpful abstractions that consider disabled people’s experiences as ‘somehow partial and flawed in its ignorance of what is really going on and thus in need of sociological remedy’ (Dewsbury et al., 2004: 146). Alternatively, research can privilege versions of ‘experience’, which equally attend to socio-political matters, but which leave the ordinary practical business of getting on with one’s life unattended to:

In the former, the ordinary activities of disabled people are described from a stance where social life exists in order to permit the sociologist to solve theoretical problems and argue about who has the ‘best’ theory of inequality

and in the latter allows disabled people to express disquiet, rage etc. About the silencing of their voices. (Dewsbury et al., 2004: 146)

These purposes answer important political purposes, but do not necessary solve the local power issues that disabled students must subsist within.

In summary, the majority of disabled students do not represent their impairments or a disabled identity within the social network. Due to the complex nature of network cues and effects, this omission requires effort; self-surveillance. Self-surveillance within the network represents a spectrum of activity, between assimilation on the one hand, to the rejection of external ascriptions and dis/ability difference on the other. The outputs of self-surveillance are also diverse, gesturing to internalised oppression and the necessity of self-care.

Self-surveillance is seen to be evoked by network conditions that amplify norms and position the dis/abled self as Other. In this respect, self-surveillance is used to protect the individual from the risk of discrediting stigma and to allow disclosure to be negotiated. However, as a result, the norms of the network remain unchallenged and its apparent homogeneity is arguably re-enforced. Nonetheless, as Watson (2002) attests, this action *is* a form of resistance to external ascription.

Further to this finding, I note that, whilst disabled student self-surveillance may be built upon experiences of impairment, a strong convergence between ordinary and extra-ordinary self-presentation strategies within the network is also apparent. All networked students, both disabled students and their non-disabled peers, are seen to use pro-social presentation strategies that emphasise similarity and relegate difference. In this sense, student strategies to manage dis/ability difference may highlight a greater tension of marginalisation and discredited identity across other disadvantaged groups and the networked public as a whole. In the next section, I consider self-discipline as an alternative response to the network as a technology of power.

## **8.5 Self-Discipline**

Disabled students used self-discipline to resist self-surveillance, the unequal gaze and those aspects of the SNS that represented a life-misfit with impairment at university. In this way, many participants identified against both the SNS and the networked public, creating distance to position themselves more powerfully. The management of time resources, privacy and the psycho-emotional dimensions of disability were key within this approach. Disabled students strove to resist network norms rather than neutralise them.

Modes of self-discipline were found to be diverse, but were frequently associated with underlying identity moves that align the disabled student within the governance of the university. In this sense, resistance to the misfit ascribed by the SNS and the networked public as a 'technology of power' involved 'technologies of the self' that are in turn governed, shaped by the wider context of the university. This activity distinguishes an academic, student identity as the keystone of participant identities.

### **8.5.1 Governance**

Foucault defines government as conduct, or, more precisely, as "the conduct of conduct". It links technologies of the self with technologies of domination and helps to differentiate between power and domination (Lemke, 2002). In this sense, self-disciplining participants subjectivise themselves, resisting objectification by the network by operating 'student' identities. Governance is an indirect action upon action. The rationale is clear: In coming to university, the participant seeks a student identity, undertaking higher education to develop, transform and expand aspects of self. As a result, an academic self is privileged over and above a networked, social self. Disabled students make themselves governable. In this instance, Government is 'the regulation of conduct by the more or less rational application of the appropriate technical means' (Hindess, 1996: 106). In the context of the university, student identity is the quintessential technology of the self, the 'appropriate technical means' within the campus context:

The concealment of these practices, these *limits* of possible conduct, allows the discursive formation in which they circulate to be naturalised and

legitimised. That is to say, the production of these seeming acts of choice (these *limits* of possible conduct on the everyday level of the subject) makes possible the consolidation of more hegemonic structures. (Tremain, 2006: 8)

In this sense, the university impacts on all aspects of the student's life. It is:

... a total structure of actions brought to bear upon possible actions; it incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutes; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action, (Foucault: 1982: 220).

This governance may be observed in wider student cohorts, but for disabled students, the result of institutional governance and self-discipline exposes the ways in which the university itself structures participant experiences of disability.

Disability researchers have repeatedly asserted the ways in which universities' institutional culture impacts on student experiences of disability:

Institutional culture plays a major role in determining the backcloth against which disabled students and other non-traditional groups experience a sense of either validation or marginalised. (Riddell, et al., 2005: 58)

Riddell et al., note that institutions convey clear message about the types of disabled student that they wish to recruit:

Those who are able to adopt the existing institutional ethos are most readily absorbed, whilst those who reject these norms are marginalised and are likely to be excluded. There is thus considerable pressure on disabled students to conform to the institutional habitus, defining themselves as the same as, rather than different from others. (Riddell, et al., 2005: 77)

In this respect, disabled students are under greater pressure than non-disabled students to discipline themselves:

Disciplinary technology is designed to produce a body which is 'docile' that is, one which can be subjected, used, transformed and improved. (Hughes and Patterson, 1997) in (Tremain, 2001: 36)

This returns us to the idea of ‘normality’, to perform as a student, disabled students must overcompensate to do ‘normal’ (Söderström, 2009):

‘the great complex idea of normality’ has become the means through which to identify subjects and make them identify themselves in ways that make them governable. (Rajchman, 1991: 104) in (Tremain, 2001: 37).

In Foucauldian language, the proto-student, visible in the social formation of Facebook or the disciplined formations borne by the University, represent a “regime of truth” about what constitutes *proper* studentship. In this way, students are not simply ‘doing normal’ they have developed a sense of ‘responsibilization’: a group of judgements about the ‘correct’ way in which to conduct oneself. Foucault identifies this responsibilization as being affected in response to antagonistic external forces:

Shaped by, (or despite) one’s awareness of the ontological, epistemological, and political effects of resistance or transgression against such prescriptions (Foucault, 1988, 1997: in Campbell, 2005).

Indeed, various studies exploring the experiences of disabled subgroups within higher education (for example, Boxall et al., 2004, Farrar, 2004, Fuller et al., 2004) assert that a culture of independent learning in higher education has a disproportionate and negative impact on disabled students. Despite legislative duties towards ‘reasonable adjustment’ many disabled students strive to cope alone. In this way, the university may be seen to inculcate circumstances in which students become socially disadvantaged through excessive discipline. The university culture of independent learning may also inculcate a desire to independently manage circumstances that discourages disability as a politicised, group identity, reducing self-advocacy both within the institution and within the social networks as its social shadow.

Ultimately, the network is cited by many participants as threatening academic efficacy, most explicitly in its demand on time. Within interviews, impairment was seen to command time resource – inside and outside the network, resulting in less leisure time. The time required for networking, and any extra resource that it required

due to impairment and extra-ordinary identity management, thus placed an excessive burden on disabled students.

In conclusion, self-discipline is a necessary survival strategy for some participants. Disciplined disabled students do not participate in the same level of networking as non-disabled peers on the basis of (for example) the time commitments incurred by impairment affects such as treatment, energy levels or the extra time they require completing coursework. In the case of complete disconnection, there is a risk that ‘the rich get richer’ and the ‘poor get poorer’. Connected students have repeatedly described the social necessity of their networks. As a result, we may speculate that disabled students who are disconnected or excluded may become more socially isolated and disadvantaged through the loss of bridging capital afforded by network integration. Further research is needed. However, evidence shows, that for connected students, discipline offers an expedient and realistic way to manage presence in the network. In this sense, discipline is exerted to assert a ‘student’, rather than ‘disabled’ network identity. A concern remains that institutions still lack forms of ‘reasonable adjustment’ that afford disabled students the same leisure time as their non-disabled peers. As a result, disconnection, which may result in digital and social exclusion, is structured by the institution.

## **8.6 Self-Advocacy**

Over the course of data collection, Facebook has been found to be built upon conceptions of embodiment and cognition that are highly normative. It is accessible and inaccessible by degrees, but particularly inaccessible to a distinct group of disabled users; those dependent on specialised assistive technologies, and those with cognitive impairments. In this way, Facebook engenders a hierarchy of impairment. Facebook has a history of resistance to user input<sup>39</sup>. In this sense the network is

---

<sup>39</sup> As Ellis and Kent (2010) state “Despite being targeted by dissatisfied users as early as 2006, Facebook did not adequately respond to the issue of accessibility until 2008”.

Subsequent to the data collection, Facebook have been cited as undertaking a concerted effort to address the networks’ accessibility failings. In October 2009, Cahill and Hollier name Facebook as the ‘most accessible social network’, describing it as ‘a good choice for people with disabilities’ (2009: 11). The authors did not state that Facebook was wholly accessible, however, they observed improvements in Facebook’s systems following redesigns completed in consultation with the

individualising. As a result, the disabled student who meets these pre-social barriers to the network is itemised. They experience this as an individual, disability is pushed onto them. For students who can get by without assistive technologies, this individualisation represents a key aspect of Facebook's normalizing administrative apparatus – for some this is unquestioned, neutral and a matter of fact. However, amongst some participants, such barriers mobilise self-advocacy.

Those students who have been able to pro-actively engage with this flow of cost and affordance have been those students who are able to leverage technical knowledge, technical communities and academic disciplinary identities with the most politically and technically engaged students (for whom advocacy and equality make up a substantial aspect of self). This suggests a subtle relation between disability, technology and a kind of 'hacking'<sup>40</sup> for accessibility; that is, that students who most successfully and reflexively engaged with the limits of the technology were those drawing on critical faculties in combination with digital expertise.

Self-advocacy highlights the discursive and social resources that disabled students require to support their position within or without the network. These discourses were varied and distinctive, ranging from identification with particular ethical systems, institutions or political movements. Students' experiences of disability were situated amongst other perspectives, such as feminism, religion and class. Those students seeking to engage the system most explicitly on their own terms were those observed to be those mobilising:

- technical, expert 'geek' identities (Claire, Edward, Ben, Roy, Sally)

---

American Foundation for the Blind to make the network more accessible to users with visual impairments. In particular, the introduction of an HTML based (rather than dynamic) mobile interface may be used by screenreader users, suggesting that the technology is better accounting for specialised assistive technology users. Such steps suggest some adjustment to a more inclusive norm, however, despite this 'adequate' response concerns continue to be expressed (for example: Cahill and Hollier (2009), Ellis and Kent (2011) Web2Access (2009). As a result, accessibility in terms of equal access, networking experience, or the foregrounding of disabled users in the design process has yet to be fully evidenced at time of writing.

<sup>40</sup> 'Hacking' culture has shown how technology can be reconfigured to subvert expected outcomes (Jordan, 2008).

- politicised disability ‘activist’ identities (Gemma, James, Claire, Elizabeth) and
- ethical and moral frameworks (Sally, Edward, Liam)

Many students’ disciplinary and academic identities were also seen to positively characterise diversity and/or critical approaches to technology, supporting student assertions of agency and difference online. Roy, (Law), Edward (Computer Science), Ben (Engineering), Gemma (Social Sciences) and Jack (English) all asserted their disciplinary experiences and identities that supported positive disabled identities, a reminder of the universities’ governance of disability.

This is not to say that the students highlighted were the only students with technical expertise and ethics, it is only to highlight that these students reported these wider resources within interviews and related them explicitly to active strategies of advocacy in networked experiences.

Participants facing the most disabling barriers called upon the strongest identification with disability politics and displayed the most complex understanding of the social costs and affordances of technology. In these instances critical engagement with technology has been a matter of survival in education. In this sub-group, participants experiencing and reflecting most strongly upon dialogic experiences of network surfaces were demonstrated to be advanced in their university careers; third years Gemma and James, and post-graduates Elizabeth and Claire, who each demonstrated experience advocating on their own and others’ behalf.

Critical identities are posited as a ‘technology of the self’ by Reeve (2002), who asserts how the critical consciousness or ‘conscientization’ (Freire, 2000) characterised by the social model of disability can be used to resist the psycho-emotional aspects of disability, the disabling gaze and internalised oppression. This identity was seen to be expressed in impairment language explicitly by Gemma, James, Claire and Elizabeth. Each denied the negative connotations of the network and to persist online on their own terms, but did not refer specifically to a critical perspective as a tool to this end. At the time of data collection, the network did not

represent a politicised space in which disabled students could meaningfully affect change. Thus, whilst activist identities were leveraged outside the network to promote disability rights and accessibility, and in terms of the network, to deny the negative psycho-emotional dimensions of network experience and sustain battles for ‘reasonable adjustment’<sup>41</sup>, with regard to the network, political expression was manifest in resistance only.

Whilst ‘Otherness’ is seen to be ascribed with misfit in the network, the migration of identity to more critical positions is not guaranteed. As Shakespeare states, evoking Weeks:

There is nothing inevitable or determined about the process, and there are major difficulties with successfully and positively identifying as disabled. As Weeks says in the context of sexuality: ‘Oppression does not produce an automatic response, but it does provide the conditions with which the oppressed can begin to develop their own consciousness and identity’ (Weeks, 1977: 33) in Shakespeare (1996: 103).

Foucault (1980) claims that individuals can always resist, responding ‘to every advance of power by a movement of disengagement’ (Foucault, 1980: 138), and for some students, disengagement was literally manifested in disconnection.

### **8.6.1 Empowered Disconnections?**

In chapter six [6.3] I observe that participants’ experiences of ability and disability at the level of the network can be seen to represent a move from an unreflected understanding of the technology as ‘neutral’ through to a reflexive and critical (dis)engagement based upon inaccessibility and other ruptures between the system and the disabled user. Elizabeth’s’ disconnection is a move of resistance, rather than an acquiescence to a system that excludes her.

In this respect, non-participation can be conceived as an empowered act, reflecting the observations of Selwyn (2006) who argues that removing oneself from participation can be conceived as an empowering move given the conditions available.

---

<sup>41</sup> For example, Claire’s direct negotiations with diverse technologists [detailed in 5.4.14].

However, for students excluded from, or resistant to the network, opportunities for the development of social capital are more limited. In particular, the affordances for developing bridging capital, characterised by information and opportunities outside an immediate circle, are lost. In this respect, the convergence of student services, societies, universities and peer support on Facebook constitutes a worrying development. This has the potential to significantly exacerbate a social and digital divide, further marginalising and disenfranchising disabled students who are disconnected. Nonetheless, disengagement as empowerment bears close consideration. All participants demonstrated digital capability. Seale et al., (2010) emphasise the skills and digital agility extant amongst disabled students, refuting the characterisation of disabled students as passive or victims. This active characterisation is borne out in this study. In some cases where students strove to disconnect, they did so within a wider context that was seen to draw on alternative forms of communication, social and digital capital. For example, Claire represented an early adopter of Twitter, supplementing the failings of Facebook with external resources. Elizabeth, who refused the network, employed alternative and varied strategies to remain engaged with peers and education. In this respect, disengagement amongst critically aware disabled students may represent a leading-edge practice. Disabling barriers necessitate work-arounds. With positive discursive identity resources available and a wider platform of social and digital capital in place, disabled students can effectively challenge the network as a technology of power. Moreover, this challenge may represent powerful possibilities for non-disabled students who are also alienated and marginalised by the norms of the network.

In summary, Facebook's inaccessibility and high levels of use creates a digital divide. Disabled students may disconnect to maintain agency and self-determination, nonetheless, on campus, this disconnection can result in a loss of affordance and 'voice'. Disabled students' self-advocacy strategies within and around the network were found to draw upon an intersection between critical faculties: social justice and 'geek' identities. Furthermore, disabled students are seen to deploy social and discursive resources to resist network domination. However, this resistance can be counter-productive unless pre-existing bridging social capital, critical 'conscientization' and digital expertise are available to the disabled student.

## **8.7 Summary**

In this chapter I have argued that dis/abled identities are produced in social networks. The network as a technology of the self promotes self-affect, with enabling consequences within the network and beyond. However, the interplay between the network as a technology of norms, power and domination also conveys an ontology of deficit, creating student resistance and constructing a disabled subjectivity.

I find that some participants were afforded extra-ordinary benefits in their use of the network, deploying it as a technology of the self to renegotiate the boundaries of both impairment and disability. Further attention to the locus of self-determination reveals the ways in which some participants negotiate discreditable identity to care for the self, whilst identifying with the network through self-surveillance. Attention to participants' self-discipline reveals how the university governs student action. Finally, attention to critical subjectivities mobilised in the network points to ways in which political and technical discursive resources might offer students meaningful opportunities for self-advocacy in the future.

In either event, the network affected a disjuncture, individualising experiences of impairment whilst promoting and scaffolding a highly normative student identities. This is seen to offer assimilation into student culture, rather than the opportunity to represent diversity in a meaningful way.

## Chapter 9. Concluding Remarks

---

In this final chapter I review the research and outline my key findings. From this point I discern the implications for digital disability research and practice, using an evaluation of my methods to supply insight into potential ways forward.

### **9.1 Research Overview**

The aim of this study has been to assess and understand how disability/ability difference is constructed and mediated by SNSs and networked publics at university. This research was instigated to forefront the perspectives of disabled students at a frontier of social media, to challenge practices that situate disability as a secondary, minority interest and accessibility as an afterthought. I hoped to ascertain what equity issues might arise in education's appropriation of Web 2.0 technologies. I sought to answer three core research questions:

RQ1: How and where does disability occur within disabled students' networks?

RQ2: How do disabled students experience disability in the network?

RQ3: How do disabled students manage disability in the network?

These research questions were exploratory. With these concerns I sought to illuminate the interpersonal facets of social networks, to understand how dis/ability as a social construct is negotiated within these spaces.

Disabled students' networked activities are found to converge on Facebook. Facebook has reached a near ubiquitous presence on campus, and in this respect, undergraduate life is no longer wholly online, or wholly offline. This ubiquity and the social necessity of membership for cementing friendships, gaining information about events and controlling digital identity means the network has a powerful influence in the lives of students. It has become an undergraduate rite of passage into

student social life. Within this context disabled students' experiences of the network are found to be complex and diverse.

For a proportion of disabled students, the network shifts the boundaries of disability, affording a non-disabled experience. For these students, the network represents the opportunity to mobilise new ways of being, building social capital, mitigating the ascription of disabled identity and allowing students to integrate in mainstream student social practices. In some instances, the network was used to mitigate impairment itself, with outcomes beyond the network in the real world. These findings suggest that the social barriers disabled students have previously faced in their university careers (for example, Riddell et al., 2005) may be eroded by this new form of co-located connectivity. In short, the network represents a technology of the self (Foucault, 1980), allowing some disabled students to self-affect through the network as a powerful tool for self-determination.

Other students with impairments are disabled by the network. Disability was ascribed in two forms; by the technical interface of the SNS and its supporting technologies, and by a socio-technical misfit with the norms of the networked public. For students experiencing misfit in both these spheres a particularly disabling encounter is inducted, often leading to restricted network interactions, and disconnection.

At the technical level, student experiences of Facebook's inaccessibility to specialised assistive technologies and a design predicated upon inflexible cognitive and embodied norms meant the SNS creates disability by presenting barriers to particular user groups. Barriers were particularly evident at the threshold of the network. At the social level, disability is also evident as a social construction. This construction occurs through a combination of factors that characterise the network in use. The network trades in social information through multiple cues; it consolidates identity and blurs the boundaries between intimate and non-intimate peer groups. As a result, the network inducts an unequal gaze that in turn institutes powerful conservative norms. Students must observe and traverse 'normal' and 'deviant' ways of being. In this context, impairment and impairment effects are extra-visible and risk associations with discrediting stigma. In these terms, students encountered disability that was mediated by the network. As the network places new emphasis on

select cues and actions, impairments and impairment effects are perceived in new ways. In the co-located physical environment of the university campus, this inducts a new hierarchy of impairment (Deal, 2003). Some disabled students move to, or maintain enabled subjectivities, for example Freya, Adele, Howie and Ben. Others are disabled. Some students with print impairments were found to experience disability in their social lives for the first time. Students with unseen and cognitive impairments were also aware that their impairments could be newly exposed to their networks. As such, the network represents a technology of power (Foucault, 1980) objectivising and dominating the disabled student. Students disabled by the networked public sought to resist such external ascriptions. To do so, they drew on external technologies of the self.

Participants asserted themselves. All refused to be determined by impairment alone. Management and resistance strategies highlight disabled students' agency, political motivations and technical expertise. Indeed, disabled students are seen to deploy a raft of measures to ensure self-determination in the networked public. Measures range from self-surveillance and self-discipline to self-advocacy. Tools deployed to self-determine are physical, psychological, digital, and socially distributed. Across these spheres ambivalence about the role and nature of disability, and the ubiquity and heightened visibility of networked space were seen to affect often cautious and risk-averse behaviours. Impairment was rarely disclosed online. Where disclosures did take place they were controlled, often private or encoded.

This management of identity represents an extra-ordinary effort on the part of disabled students; an effort exerted on top of an already complex transition into higher education, relating to the negotiation of disabled identity (Riddell et al., 2005), and the issues for 'managing disability' identified by Goode (2007) and others.

As previously stated, positive experiences of the network are possible. Some students are included – allowing disability to become a matter of relevance. Others work to engineer a positive network, carving out intimate network spaces in which disability is normal; known, but not stigmatised. Others strive to maintain a locus of control where they ensure that disability is irrelevant, but also suppressed.

The complexity of student experience and strategies for resistance are indicative of wider complexities in disabled students' experiences: revealing how the university itself governs disabled students' network activity, structuring divisions between pro-social and anti-social network behaviours as students seek to minimise risk and perform *student* identity.

Ultimately, networks are shown to have the potential to reposition disabled students within taxonomies of identity. Two interrelated conclusions are drawn; firstly, networks are perceived to be essential to student life, yet not all students may access them on an equal basis. Consequently, the network introduces a digital divide with material social outcomes. Secondly, the networks represent a redefinition of dis/ability, where some students with impairments experience non-disabled subjectivities, or may adopt non-disabled interactions. As a result, however, diversity remains suppressed, arguably leading to a situation where an exclusionary divide is maintained and those who are unable or unwilling to access the networked public are further marginalised. In this respect, students disabled by the network are doubly disadvantaged as disability is rendered invisible and the digital and social divide of the network is reinforced.

## **9.2 Implications for Research and Practice**

My analysis has highlighted the ways in which disabled and non-disabled subjectivities are produced by and through social networks on campus. This suggests an array of outcomes for diverse stakeholder groups. Whilst positive findings are important in terms new affordances of action, the expression of agency and new subjectivities, the effects of power and domination offer the most significant implications for disabled students, educators and technologists. In this respect, I align myself with Foucault's concern with 'danger' to discern key implications for research and practice. As Foucault states:

My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a

hyper- or pessimistic activism. [...] I think that the ethico-political choice we have to make every day is to determine which is the main danger. (Foucault, 1983: 343)

Within the network disability is re-orientated. Some students may adopt non-disabled subjectivities. Disabled students may opt-in, assimilate, edit impairment effects and pass as non-disabled. Students may judge disability to be irrelevant or be subject to a morphing ablism. Such actions may reflect diverse motives and experiences – actively political, or governed by the system. However, in each instance, disability is rendered invisible, difference is suppressed, and the norms of the network are more powerfully applied. In this way, the network functions as an oppressive technology of power that acts both on disabled students and through them. The apparent paradox of the application of social media in disabled student's lives is that social networks are at once facilitative and empowering and at the same time, stringent and punitive.

As a result, the question remains, what happens to those disabled students who cannot, or will not, engage with the network? As disability is rendered invisible, in the technology and the networked publics, what happens to those who are ascribed as disabled within this increasingly normative state?

I contend that the main 'danger' emerging in this research is that students who cannot or will not use social networks disappear. Social networks are perceived as networks of necessity. As Edward states, in a comment that echoes in other social media research "If you haven't got Facebook, you don't exist."<sup>42</sup> Those students who are not networked are, in a sense, missing or erased. They may become invisible according to the networked culture of the campus. Since the network produces disability it pre-empts this disappearance; as the technology itself enacts normative principles of action and ability. For some students (such as Gemma) this creates a double bind. One cannot risk leaving the network; however, staying requires attending to the norms of the networked public, norms that evince a condition in which all physical or cognitive difference must be denied or maintained within strict discursive limits. In this way both disability and the *possibility* of disability are

---

<sup>42</sup> See also Boyd, (2007:170) who quotes an 18 yr old from Colorado "If you're not on MySpace, you don't exist".

rendered invisible. As the physical campus becomes increasingly enmeshed within the digital campus, there is a danger that dis-connected disabled students lose access to a significant swathe of the public life of the physical campus, however, maintaining a presence in a network where disability is rendered less-than-normal involves a risk to socio-emotional well-being.

These arguments reflect a wider concern with disability and the ascendance of social networks as a primary mode of online engagement in the public sphere. Ellis and Kent (2011) observe:

As the value for those who are already part of the network grows, so too does the cost of exclusion for those who are prevented for joining. (Ellis and Kent, 2011: 100-101).

When considering the internet more broadly, Goggin and Newell extend this ‘danger’:

...contemporary notions of citizenship, including those associated with governmentality, assume ability to access and use a range of communications technologies, as visions of e-government suggest. What, then of many people with disabilities who are excluded from the communications that they may require in order to be admitted to the ranks of cyber-citizens; as defined by dominant norms? These people are of course active citizens; but do their activities count? (Goggin and Newell, 2005: 274)

Here Goggin and Newell identify the importance of digital self-representation in terms of citizenship; and it is here, once again, that the work of Foucault suggests useful modes of ethico-political theorisation. The most effective exercise of power, according to Foucault (1983) consists in guiding the possibilities of conduct and putting in order the possible outcomes. This ‘governance’ is an action upon an individual that determines their possible actions. Writing on the liberal state, Hindess advances the ideas of Foucault with respect to those on the margins of governance. He identifies three approaches extant in the governing of the ‘remainder’. These are:

1. A clearing away;

2. A compulsion towards disciplinary techniques (such as the normalisation principle); and

3. Targeting external causes (for example, by creating welfare safety nets). (Hindess, 2000:11, reformulation by Campbell, 2005:113)

When the findings of this research are viewed through this optic of governance, it appears that, for those disabled students who are most marginalised by the technological barriers and normative surveillance of the social network, disappearance is the effect of this *clearing away*. The disabled student as Other, is governed by socio-technical effects that propel them towards a non-disabled norm, or render them invisible. As those that cease to use the system disappear, or fail to engage (appear) in the first place; they cease to be a ‘problem’.

The second of Hindess’ aspects of governance; *the compulsion toward disciplinary techniques* has constituted the main focus of this thesis. These are the normalisation principles expressed through the networks social and technical spaces that have engaged the majority of disabled students. Disabled users have been found to experience non-disabled subjectivities; they may also opt in and become assimilated to network norms. Some pass or become ‘nearly able-bodied’ via morphed ablism. Alternately, disabled students feel a pressure to modify or reformulate themselves and their technologies to manage the appearance of disability and attend to, if not bend, to approach the norm.

For those who cannot or will not participate, the *targeting of external causes* suggests a project of barrier removal, attention to assistive technologies, accessibility protocols and legislation. Amongst participants, such support has been valued, however, where such support fails, or when the application of assistive technologies or other reasonable adjustment has threatened notions of ‘independence’, disappearance and the surveillance of the self to fit external norms are activated.

The provision of more adequate technological support action allows disabled students to engage with the network. However, there remains a danger, that, in this last ‘inclusive’ option, disability continues to be constituted as Other, or what Goggin and Newell term an ‘add-on’ (2005: 272). In this respect, all three practices

of governance upon disabled individuals are of a piece insofar as each conveys a normative ontology of disability that defines disability as a material minority deficit.

As Goggin and Newell state:

Well-intentioned efforts to understand and address the needs of people with disabilities have created a complex apparatus of practices to manage and govern disability: special equipment funds, special modifications to technology, specific entitlements for people with disabilities, or certain groups of people with disabilities, and separate consultative bodies. (Goggin and Newell: 2005, 272)

These actions are brought about to support and integrate disabled people as ‘active participants’. However, within a framework of governance, Goggin and Newell observe that disabled people ‘linger on the margins of the governable’ (2005: 272). To move forward, a project of barrier removal and attendance to the social construction of disability is salient, and progresses equal access and creating non-disabled subjectivities for some students. However, such projects do not address the persistent issue of normalcy in the network.

If we apply Campbell’s (2005) critique of normalcy and welfare to assistive technologies, we perceive that the application of assistive technologies to disabled students might constitute a reappraisal through which the student is ‘fabricated as rehabilitated’, or becomes ‘*nearly* able-bodied’, or non-disabled. In this way, the disabled student is be ‘benevolently transfigured’ (Campbell, 2005: 113) and the normative demands of the network are met, rather than challenged. To fundamentally challenge normalcy, Davis argues, we must recognise that problem ‘is not the person with disabilities; the problem is the way that normalcy is constructed to create the “problem” of the disabled person’ (1995: 24). This approach acknowledges the sense of power implicit in being ‘normal’ that requires deconstruction (Davis, 1995: 24). Whilst the network retains its highly normative technical and social conditions, disability is confirmed as a deficit; a transgressive and abnormal condition, that remains unchallenged, discursively and resolutely embedded in the network.

It is this relation, between normalcy and deviance, non-disabled and disabled, which I perceive to be the ‘danger’ to which a research, accessibility and education agenda must orientate.

In light of attention to the disappearance of disability under the auspices of governing superstructures highlighted by this doctoral research I propose two potential ways forward. The first requires a re-envisioning of disabled students and a commitment to bringing marginalised perspectives into view. The second attends to normalcy, examining the ways in which technologies, universities and students produce and (re)produce normalcy. It within these topographies that I suggest the most valuable lines of research and critical practice could convene. I discuss each in turn, highlighting both gaps and insights from my research to suggest ways forward.

### **9.2.1 Re-Envisioning Disability**

Post-structuralism, informed by Foucauldian thought, with reference to Derrida’s notions of ‘undecidability’ has offered a powerful lens with which explore and expand the subterranean discourses of disability. However, my initial attempts to map these discourses using activity theory and phenomenology underestimated the issues of power implicit within my research questions. In practice I found these methods lacked the nuance necessary to analyse and report the complexity of student experiences of disability as a marginal discourse. In retrospect, I concur with the sentiments of Goggin and Newell (2005):

People with disabilities experience a remaining oppression that calls out for a theory of power recognising the enduring, if shifting, power blocs of dominant and marginal groups. [...] we are yet to come across some manifestation of disability that does not involve some forms of oppression by virtue of the power relations that constitute that very disability. (Goggin and Newell, 2005: 273)

To this end, I continue to propose a Foucauldian commitment to agitate on behalf of marginalised groups (Boyne, 1999), seeking to recognise difference and instate marginalised identities. As previously stated in chapter three [3.1.4] this represents the simultaneous recognition of difference and identity, and recasts educators, researchers and technologists as supporters rather than leaders (Boyne, 1999: 133).

Ultimately, I have used discourse analysis as my lens on my data. Given the opportunity to repeat my research, I would begin with this more critical and discursively orientated approach.

To reinstate those students rendered invisible by the norms of the network it is necessary for researchers, educator and technologists to actively seek the perspectives of those who are silenced and bring them back into view. As a result, I support Söderström's (2009) assertion that disabled people should be recognised within mainstream ICT research, rather than niche areas of rehabilitative, therapeutic or educational research.

This is a challenge, as disabled students represent a marginalised community and social networks represent a liminal space: outside formal university protocols, but fundamentally integrated in the social campus. As a result, social networks have not been scrutinised to the extent warranted. This is an ongoing concern as in the academic year 2008-9 it was estimated 95% of the 744, 000 undergraduate students in the UK regularly use SNSs (Mori, 2007, Mage et al., 2009). Approximately 55,000 disabled students (7.4% of the total cohort) are implied amongst these networks. Further to this social use, the NUS (2009) report that 40% of student respondents (406/1,003) used SNSs 'such as Facebook' as part of their studies. A crowd-sourced and expanding directory of universities lists 36 UK Universities amongst 957 HEIs with an official Facebook presence (4ICU, 2010). This number is rising. In this way, it is not prescient to argue that universities are engaging social networks to educational ends. However, whilst Universities recognise that Facebook is a central part of student experience, there is a concern that they do not support or *perceive* disabled students' use of SNSs. Practical concerns are raised in education as a result of this 'danger'. For example, to deploy Facebook as a learning technology in its present guise could be construed as a neglect of 'reasonable adjustment' for disabled students. In terms of the experiences of students for whom life-misfit results in network alienation; seeking to deploy the network for classroom purposes forces connection and a myriad of social affects with potentially detrimental *and invisible*, outcomes. In this respect, for mainstream educational technologies, the experiences of disabled students constitute an unknown which cannot then inform learning design. Even amongst those students who enjoy Facebook, Selwyn's (2009)

assertions that academia's appropriation of Facebook disrupts a valued 'backstage' arena for students' social life. As such, teaching with Facebook is exposed as a precarious practice.

With regard to research, to challenge the existing status quo and re-envision disabled students, I suggest an attention to modes of online data collection and direct attention to the benefits of seeking marginal voices.

### **Perceiving Marginal Discourse Onscreen**

New media create both new opportunities and new restrictions in terms of accessibility, but also in terms of self-identity and action; facets of disabled students' experiences that remain hidden in the majority of technology enhanced learning research. Over the course of interviews, it became clear that the narrative of interaction is not contained onscreen. In the past, SNS research has tended to prioritise the accounts of (usually non-disabled) students whose recorded and visible online interactions supply rich data for analysis. In this sense, evidence of online interactions can lead research.

This project has sought to convey disabled students accounts of social networking, giving voice to perspectives that have not previously been recognised in mainstream technology discourse. These students offer an alternative account. A focus on experience has allowed students to demonstrate the backstage strategies and meanings that they attribute to their actions in context. These have been frequently at odds with the front presented onscreen, demonstrating how meaning is discursively enacted. In these terms, results show that evidence of abundant and sophisticated online interaction does not necessarily evidence the most engaged student understandings of social presence and social networking. Where participation is required and mandatory, the need to maintain 'face' must be recognised as having a negative impact on both the number of interactions, and the authenticity of interactions.

In this way many 'roles' depicted in non-disabled research are turned on their head, as a highly reflexive understanding of social networks is shown to exist for students

who choose to disconnect and limit their online life. In this sense, disconnection must be considered as a potentially empowered act in limited circumstances (Selwyn, 2006, Selwyn, 2003).

In terms of ongoing research, I therefore recommend that onscreen information is used by researchers only when subject to the wider context of participant reflection and meaning-making. This attention to the disjuncture between onscreen activity and off-screen meaning-making has resulted in findings that gesture to wider invisible populations and marginalised discourses with important intersections in the lives of disabled and non-disabled students.

### **Intersectionality**

Disability is complex, it is one amongst multiple and inter-related identities and indices of disadvantage. Intersectionality (Söderström, 2009) proposes that merely recognising such multiplicity is not sufficient. Indeed, on these grounds, mobilising an analytic framework on the basis of a single facet of identity, ‘disability’ is questionable, and fails to represent the multi-faceted nature of participants’ identities. In this research I have used case study as an approach to reporting to alleviate this concern; however, it has not been possible within the constraints of the research to fully investigate arising issues of class, religion, gender, ethnicity, nationality, sexuality and so forth. All such indices of identity are objectified by norms and subject to scrutiny within the networked public.

In addition, whilst the research has involved participants from groups commonly under-represented in disability and technology research (for example, students with mental health conditions, those labelled with learning disabilities), there are groups who were not represented in the research sample, including wheelchair users, student who use Augmentative and Alternative Communication technologies, Deaf students<sup>43</sup> and students who utilise Personal Assistants. No respondent was turned away, or disbarred from participating on grounds of impairment or accessibility<sup>44</sup>. Nonetheless, this research cannot be considered wholly representative of ‘disabled’

---

<sup>43</sup> Whilst Claire was hearing impaired, and Sally had experienced periods of deafness, no participants identified as culturally Deaf, and/or used British Sign Language as their first language.

<sup>44</sup> For example, financial contingency was maintained throughout the research to ensure British Sign Language interpreters could be provided to support interviews with Deaf students.

experience and the engaged participant group will certainly have shaped my findings. As Anderberg and Jonsson (2005) state, the absence of specific groups means that research will lack insight into the particular experiences of these students, and the particular costs and affordances that social networks might bring in terms of interaction (for example interaction unmediated by a PA) and the experiences of autonomy that that might afford. In this sense, this research marks an exploratory beginning in understanding the breadth of disabled students' experiences of networked publics, not a totalising conclusion.

A note of caution here is that, in seeking to bring unseen perspectives to light, I have found that any attempt to deliver a 'universal' account of disability is also problematic, returning us to the critiques of post-structuralism outlined in chapter three. Any 'universal' account presupposes a position of authority that is somehow free of discourse, suggesting a pre-discursive reality that is available to us. This research shows that disabled subjectivities are not stable, they are discursively constituted and partially situated. As Derrida observes, an acknowledgement of this partiality is vital to securing an ethical stance (Derrida, 1990). This ensures that those perspectives that are gleaned in any account of disability do not foreclose on others' voices.

### **Disaggregation**

In light of issues of intersectionality and the complexity of disability, the question arises: should researchers disaggregate disability and focus on particular impairment groups? In view of my research experience, I do not feel this 'solves' the issue of complexity. Participants have shown to have hugely diverse experiences, which, under scrutiny, quickly deconstruct categorical definitions. Some students have accounted for similar experiences, but not always along the lines expected. In this sense, experiences of exclusion and disadvantage present social commonalities that could be lost through disaggregation. Disaggregation may also potentially privilege clinical diagnosis above social identification. Importantly, this returns us to the epistemic assumptions of the research. Research grounded upon an identity model of disability is vulnerable: As Tremain (2006) observes:

A disability movement that grounds its claims to entitlement in the identity of its subject can expect to face similar criticisms from an ever-increasing number of constituencies that feel excluded from, and refuse to identify with, those demands for rights and recognition. (Tremain, 2001: 44).

Tremain argues on this basis that disability activists and writers ‘must develop strategies for advancing claims that make no appeal to the very identity upon which that subjection relies’ (2006: 44). Disaggregating disability may be unhelpful, leading to ever increasing fractions and sub-groups, disappearing down a rabbit-hole of division. As such, intersectionality and disaggregation represent two competing research concerns that I have attempted to negotiate. Tremain’s observations return us to the ‘blank spot’ (Wagner, 1993) represented by non-disabled students’ conceptions of disability and the wider issue of normalcy.

### **9.2.2 Deconstructing Normalcy**

Davis (1995) and Snyder and Mitchell (2006) observe an apparent axiomatic, seemingly self-evident relationship that exists between non-disabled and ‘normal’. This has constituted the majority discourse that disabled students have sought to resist in their negotiation of disability in the network. To progress a deconstruction of this normalcy, Snyder and Mitchell (2006) propose a research rationale that thereby seeks to ‘unmark’ normalcy – without essentialising disability. This is achieved by attending to both disabled and non-disabled students.

To engage with the pragmatics of disability, I have attended to the division between participants’ disabled and non-disabled identities and how they relate to socio-structural disadvantage predicated upon impairment. Frequently this investigation has brought up the role of the public and the social constitution of stigma, risk and so forth. However, this research has directly not investigated the perspectives of non-disabled students, their constructions of disability and perspectives on the discursive reality of disability in networked publics.

In addition to a continuing re-envisioning of disabled students, a broader challenge is to seek the roots of stigma, prejudice and oppression based on embodied and cognitive difference that remain hardwired into the social network and networked

public. The oppression of normalcy is not monolithic, it is seen to take different forms and is articulated at through both the network and the public. It is expressed in different communities, across tools, and manifesting in different ways as a complex interaction between the student and their socio-technical environment. And yet this interaction hinges on what is seen and unseen.

Although disablist language was not apparent onscreen in the interactions of the students, it punctuates the language and culture of Facebook. In this sense, the discourse of disablism was unspoken, but present outside interviews. It would be desirable to extend a research focus on the disabled/non-disabled dichotomy to consider wider discourse surrounding social networks more fully, including non-disabled students. For example exploring the normate identity mechanics of language and action: MySpace's pejorative nickname 'MySpaz', Facebook's 'How Mental are You?' quizzes (Das-Gupta,2007), and the deeply disablist Facebook Groups that target particular impairment groups (Shakespeare, 2009). Such phenomena represent a fundament of normalcy. Attention to the development of technology, and the discursive cultural production, use and application of social information, what is gleaned and how it is shared in the conveyance of norms will also shed important light on the construction of normativities.

### ***9.3 Lasting Impressions***

When focussing on normalcy amongst the student populations, wider structures of governance are called into question. This may require a broader consideration of the ways in which universities and media implicitly configure and produce disabled subjectivities. This wider emphasis is necessary to examine the overarching institutional and network practices that govern student/user behaviours, examining the 'regimes of truth' that 'responsibilize' students into 'doing normal'. Such a project is not a small one, it engages diverse actors and disembodied structures. The fields of education, technology and disability studies are called into play. The development of a digital disability studies sufficient to the task is emergent, but overdue.

In sum, I find that, once again, attention to normalcy evokes the critical ‘watching brief’ commended by Foucault, Derrida and other philosophers of difference. By attending to the mediation of student experience and the developments of new technologies, we may ‘keep an interventionalist eye open for the other’ (Derrida, in Caputo, 1997: 131), an Other that cannot be otherwise perceived by the structures that enact it. Research attention to a re-envisioning of disability and a watching brief on the ways in which socio-technical systems produce and mediate disability may begin a deconstruction through which we might seek the ‘formation of new, better adjusted forms of social subjects’ (Boyne, 1993: 134). This acknowledges that, whilst ‘norms’ cannot necessarily be dissolved, they can be made to be more inclusive and generous.

This research has shown that norms are powerfully re-orientated online, and with them the defining discursive characteristics of disability on campus. The challenge then, for myself and other lies in re-envisioning. I hope to continue to research and re-envision disability and deconstruct the punitive norms that govern student sociality. To this end, in conjunction with technologists, education and support it is hoped we might meaningfully deliver on the promise of the ‘networked public’.

## References

---

- 4 INTERNATIONAL COLLEGES & UNIVERSITIES (2010) *Colleges and Universities on Facebook*. [Accessed 18.8.2010] <http://www.4icu.org/facebook/>.
- ABBAS, Y. & DERVIN, F. (Eds.) (2009) *Digital Technologies of the Self*, Newcastle Upon Tyne, Cambridge Scholars.
- ABBERLEY, P. (1992) Counting us out: a discussion of the OPCS Disability Surveys. *Disability, Handicap and Society*, 7, 2, 139-155.
- ABILITYNET (2008) Social networking sites lock out disabled users. *State of the e-Nation Report*. [Accessed 10.05.2009] <http://www.abilitynet.org.uk/enation85>.
- AHRC (2009) *Improved rights protection for people with disability. Commentary on the 2009 changes to the Disability Discrimination Act 1992 and related measures*. Australian Human Rights Commission. [Accessed 12.11. 2009] [http://www.hreoc.gov.au/legal/publications/improved\\_dda2009.pdf](http://www.hreoc.gov.au/legal/publications/improved_dda2009.pdf).
- ALBRECHT, G. L. (1992) *The Disability Business: Rehabilitation in America*, London, Sage.
- ALTMAN, B. (2001) Disability Definitions, Models, Classification Schemes, and Applications. IN ALBRECHT, G., SEELMAN, K. D. & BURY, M. (Eds.) *Handbook of Disability Studies*. Thousand Oaks, CA, Sage.
- ALLEN, J. (2008) *Rethinking Inclusive Education: The Philosophers of Difference in Practice*. Dordrecht, Springer.
- AMUNDSEN, R. (1992) Disability, handicap and the environment. *Journal of Social Philosophy*, 23, 1, 105-118.
- ANDERBERG, P. & JONSSON, B. (2005) Being there. *Disability & Society*, 20, 7, 719-733.
- ATRAN, S. (1990) *Cognitive Foundations of natural History: Towards an Anthropology of Science*, Cambridge, UK, Cambridge University Press.
- AVIS, J. (2007) Engeström's version of activity theory: a conservative praxis? *Journal of Education and Work*, 20, 3, 161-177.
- BAILEY, S. (2009) *Producing ADHD: An ethnographic study of behavioural discourses of early childhood*. PhD Thesis, University of Nottingham.
- BARAB, S., SCHATZ, S. & R, S. (2004) Using Activity Theory to conceptualise online community and using online community to conceptualise Activity Theory. *Mind, Culture and Activity*, 11, 1, 24-47.
- BARNES, C. (2005) Reflections on Doing Emancipatory Disability Research. IN SWAIN, J. (Ed.) *Disabling Barriers, Enabling Environments*. 2nd ed. London, Sage in association with the Open University Press.
- BARNES, C. and MERCER, G. (1997) *Doing Disability Research*. Leeds: The Disability Press.

- BARNES, C. and MERCER, G. (2010) *Exploring Disability*. Cambridge: Polity.
- BARNES, C. & TYNAN, B. (2007) The adventures of Miranda in the brave new world: learning in a Web 2.0 millennium. *ALT-J*, 15, 3, 189-200.
- BASSEY, M. (2008) *Case Study Research in Educational Settings*, Glasgow, Open University Press.
- BERA (2004) *Revised Ethical Guidelines: Educational Research*, British Educational Research Association, [Accessed 10.01.2006] <http://www.bera.ac.uk/files/guidelines/ethical1.pdf>.
- BERGLUND, A. (2005) Learning computer systems in a distributed project course: The what, why, how and where. *Faculty of Science and Technology*. Uppsala, Acta Universitatis.
- BERNSTEIN (1990) *The structuring of pedagogic discourse volume IV: Class, codes and control*. London: Routledge.
- BERR & DCMS (2009) Digital Britain: The Interim Report. London, TSO.
- BLASIOTTI, E. L., WESTBROOK, J. D. & KOBAYASHI, I. (2001) Disability Studies and Electronic Networking. IN ALBRECHT, G., SEELMAN, K. D. & BURY, M. (Eds.) *Handbook of Disability Studies*. Thousand Oaks, Sage.
- BRAUN, V. and Clarke, V. (2006) Using thematic coding in psychology. *Qualitative research in Psychology*. 3, 2, 77-101.
- BOGDAN, R. (1988) *Freakshow: presenting human oddities for amusement and profit*, London, University of Chicago Press.
- BOWKER, G. C. & STAR, S. L. (1999) *Sorting Things Out: Classification and Its Consequences*, London, The MIT Press.
- BOWKER, N. (2003) What it means to be online for people with disabilities. *Psychology*. Palmerston North, Massey University.
- BOWKER, N. (2009) Understanding barriers to online experience for people with physical and sensory disabilities using discursive social psychology. *Universal Access in the Information Society* 9, 2, 121-136.
- BOWKER, N. & TUFFIN, K. (2002) Disability Discourses for Online Identities. *Disability & Society*, 17, 3, 327-344.
- BOWKER, N. & TUFFIN, K. (2003) Dicing with deception: people with disabilities' strategies for managing safety and identity online. *Journal of Computer-Mediated Communication*, 8: 2, article 6, [Accessed 10.01.2008] <http://jcmc.indiana.edu/vol8/issue2/bowker.html>.
- BOXALL, K., CARSON, I. & DOCHERTY, D. (2004) Room at the academy? People with learning difficulties and higher education. *Disability & Society*, 19, 2, 99-112.
- BOYD, D. (2008) Facebook's Privacy Trainwreck: Exposure, Invasion, and Social Convergence. *Convergence: The International Journal of Research into New Media Technologies*, 14, 1, 13-20.
- BOYD, D. (2010) *Social Steganography: Learning to Hide in Plain Sight*, danah boyd: apophenia [Accessed 23.08.10] <http://www.zephoros.org/thoughts/archives/2010/08/23/social-steganography-learning-to-hide-in-plain-sight.html>.

- BOYD, D. (2011) *Bibliography of Research of Social Network Sites* [Accessed 12 .04.2011] <http://www.danah.org/researchBibs/sns.php>
- BOYD, D. M. & ELLISSON, N. B. (2007) Social network sites: Definition, history, and scholarship. *Journal of Computer-Mediated Communication*, 13, 1, [Accessed 10.04.2009] <http://jcmc.indiana.edu/vol13/issue1/boyd.ellison.html>.
- BRADWELL, P. (2009) *The Edgeless University: Why higher education must embrace technology*. London, DEMOS.
- BRETT, M. (2006) *Live Remote Captioning*, Disability Liaison Unit, University of Melbourne. [Accessed 5.9.2008] <http://www.services.unimelb.edu.au/disability/development/lrc.html>.
- BURGSTAHLER, S. (2002) Distance Learning: the library's role in ensuring access to everyone. *Library Hi Tech*, 20, 4, 420-432.
- BURGSTAHLER, S., ANDERSON, A., SLATIN, J. & LEWIS, K. (2008) Accessible IT: Lessons Learned from Three Universities. *Information Technology and Disabilities*, 12, 1, [Accessed 20.04.2010] <http://www.thefreelibrary.com/Accessible+it%3A+lessons+learned+from+three+universities.-a0198354433>.
- CAHILL M. and HOLLIER, S. (2009) "Social Media Accessibility Review – Version 1.0" *Media Access Australia*. [Accessed 20.04.11] <http://mediaaccess.org.au/online-media/social-media>
- CAHILL, S. A. & EGGLESTON, R. (1994) Managing emotions in public: the case of wheelchair users. *Social Psychology Quarterly*, 57, 300-312.
- CALDWELL, B., COOPER, M., REID, L. G. & VANDERHEIDEN, G. (2008) Web Content Accessibility Guidelines (WCAG) 2.0. [Accessed 10.04.2009] <http://www.w3.org/TR/WCAG20/>, W3C.
- CAMPBELL, F., K. (2005) 'Legislating Disability: Negative Ontologies and the Government of Legal Identities' IN TREMAIN, S., *Foucault and the Government of Disability*. Michigan. University of Michigan Press. pp. 108-130.
- CARR, D. (2010) Constructing disability in online worlds: conceptualising disability in online research. *London Review of Education*, 8, 1, 51-61.
- CHISHOLM, W., VANDERHEIDEN, G. & JACOBS, I. (1999) *Web Content Accessibility Guidelines 1.0. W3C Recommendation 5-May-1999*, W3C [Accessed 20.07.10] <http://www.w3.org/TR/WAI-WEBCONTENT/>
- COHEN, L., MANION, L. & MORRISON, K. (Eds.) (2000) *Research Methods in Education*, London, Routledge.
- COOPER, M., COLWELL, C. & JELFS, A. (2007) Embedding accessibility and usability: considerations for e-learning research and development projects. *Association for Learning Technology Journal*, 15, 3, 231-246.
- CORBIN, J. (1994) A proud label: exploring the relationship between disability and Gay Pride. *Disability and Society*, 9, 343-357.
- CORKER, M. & FRENCH, S. (1999) *Disability discourse*, Buckingham ; Philadelphia, Pa., Open University Press.

- CROOK, C. & LEWTHWAITE, S. (2009) The Networked Student, a socio-cultural perspective. IN LITTLETON, K., WOOD, C. & KLEINE STAARMAN, J. (Eds.) *The Handbook of Education: The Psychology of Learning and Teaching*. Bingley, Emerald.
- CROW, L. (1992) Renewing the Social Model of Disability. *Coalition*, July, 5-9.
- CUBAN, L. (1986) *Teachers and Machines: The classroom use of technology since 1920*, New York, Teachers' College Press.
- DALE, M. (2003) *Ethical Conduct and Data Protection Guidelines*, Nottingham, University of Nottingham [Accessed 06.12.05] <http://www.nottingham.ac.uk/quality-manual/research-student/students/role-supervisor.phtml>.
- DANIELS, H. (2007) Discourse and Identity in Cultural-Historical Activity Theory: A response. *International Journal of Educational Research* . 46, 94-99.
- DAS-GUPTA, I. (2007) *Facebook quiz 'trivialises mental health problems*, Third Sector Online, [Accessed 3.8.2010] <http://www.thirdsector.co.uk/news/Article/773356/facebook-quiz-trivialises-mental-health-problems/>.
- DATA PROTECTION ACT (1998) London, TSO. [Accessed 12.10.07] <http://www.hmso.gov.uk/acts/acts1998/19980029.htm>.
- DAVIS, F. (1961) Deviance disavowal: the management of strained interaction by the visibly handicapped. *Social Problems*. 9.2: 120-32.
- DAVIS, L. J. (1995) *Enforcing Normalcy: disability, deafness and the body*, London, Verso.
- DDA (1995) *Disability Discrimination Act*, London, TSO.
- DDA (2005) *Disability Discrimination Act part VI*, London, TSO.
- DEAL, M. (2003) Disabled people's attitudes toward other impairment groups: a hierarchy of impairments. *Disability & Society*, 18, 7, 897-910.
- DEAL, M. (2007) Aversive disablism: subtle prejudice toward disabled people. *Disability & Society*, 22, 1, 93-107.
- DEAN, M. (1999). *Governmentality: Power and Rule in Modern Society*. London: Sage.
- DENZIN, N. K. & LINCOLN, Y. S. (2005) Introduction: The discipline and practice of qualitative research. IN DENZIN, N. K. & LINCOLN, Y. S. (Eds.) *Handbook of Qualitative Research*. London, Sage.
- DERRIDA, J. (1978) *Writing and Difference*, London, Routledge.
- DERRIDA, J. (1990) The Force of Law: The 'Mystical Foundations of Authority'. (M. QUANINTANCE, trans.) *Cardozo Law Review* 11: 919-1045.
- DERRIDA, J. (1997) *Of Grammatology*, London, John Hopkins University Press.
- DEWSBURY, G., CLARKE, K., RANDALL, D., ROUNCFIELD, M. & SOMMERVILLE, I. (2004) The anti-social model of disability. *Disability & Society*, 19, 2, 145-158.
- DFES (2003a) *The Future of Higher Education* London, TSO.

- DFES (2003b) *Widening Participation in Higher Education*, London, TSO.
- DICKERT, N. and GRADY, C., (1999) What's the price of a research subject? Approaches to payment for research participation, *New England Journal of Medicine*, 341, 198–203.
- DISABILITY RIGHTS COMMISSION (2003) Facts and Figures: Disability Rights Commission Educating for Equality Campaign. [Accessed 27.10.2005] <http://www.drc-gb.org/campaign/about/facts.asp>.
- DIUS (2009) *Disabled Students and Higher Education*, London, TSO.
- DUNN, S. (2003) Return to SENDA? Implementing accessibility for disabled students in virtual learning environments in UK further and higher education. [Accessed 01.06.06] [http://www.saradunn-associates.net/uploads/tx\\_policyreports/CityEU\\_VLEreport.pdf](http://www.saradunn-associates.net/uploads/tx_policyreports/CityEU_VLEreport.pdf).
- DUNN, S. (2007) *Accessible e-learning in Higher Education: The Distributed e-Learning Accessibility (DelAcc) Project*. York. TechDis
- ELLIOTT, T. & WILSON, C. (2008) *The perceptions of students with hidden disabilities of their experiences during transition to higher education*, Ipswich Aim Higher East of England, Aim Higher East of England. [Accessed 25.10.2009] [http://www.impact-associates.co.uk/docs/transition\\_to\\_he-feb08.pdf](http://www.impact-associates.co.uk/docs/transition_to_he-feb08.pdf)
- ELLIS, K. and KENT, M. (2011) *Disability and New Media*. Abingdon: Routledge.
- ELLISON, N. B., STEINGFIELD, C. & LAMPE, C. (2007) The benefits of Facebook "friends": Social capital and college students' use of online social network sites. *Journal of Computer-Mediated Communication*, 12, 4, Article 1.
- ENGESTRÖM, Y. (1996) Developmental studies of work as a testbench of activity theory; The case of primary care medical practice. IN CHAIKLIN, S. & LAVE, J. (Eds.) *Understanding Practice: Perspectives on activity and context*. Cambridge, Cambridge University Press.
- ENGESTRÖM, Y. & MIETTINEN, R. (1999) Introduction. IN ENGESTRÖM, Y., MIETTINEN, R. & PUNAMÄKI, R.-L. (Eds.) *Perspectives on Activity Theory*. Cambridge, Cambridge University Press.
- ENGESTRÖM, Y. (2001) Expansive learning at work: towards a theoretical reconceptualization. *Journal of Education and Work*. 14. 1. 133-156
- EQUALITIES ACT (2010) London, TSO. [Accessed 10.08.2010] [http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)
- FARRAR, V. (2004) *Access to research. Institutional issues for disabled postgraduate research students*, Newcastle upon Tyne, University of Newcastle upon Tyne. [Accessed 20.05.2010] <http://vitae.ac.uk/CMS/files/upload/Premia-Access-to-research-institutional-issues-for-disabled-postgraduate-research-students-March-2004.pdf>
- FERGUSON, P. M., FERGUSON, D. & TAYLOR, S. J. (1992) *Interpreting Disability: A qualitative reader*. New York, Teachers College Press.
- FINKELSTEIN, V. (1996) Outside, 'inside out'. *Coalition*, April: 30-36.
- FLORIAN, L. (2009) Inclusive Pedagogy and Assistive Technology. *ESRC seminar series: Theoretical frameworks for research the use of assistive technologies*. King's College London, Economic and Social Research Council.

- FLYVBJERG, B. (2008) *Making Social Science Matter: Why social inquiry fails and how it can succeed again*, Cambridge, Cambridge University Press.
- FOUCAULT, M. (1970) *The Order of Things: An Archaeology of the Human Sciences*, London, Tavistock Publications.
- FOUCAULT, M. (1973) *The Birth of the Clinic: An Archaeology of Medical Perception*, London, Tavistock Publications.
- FOUCAULT, M. (1977) *Discipline and Punish: The Birth of the Prison*, London, Penguin Books.
- FOUCAULT, M. (1978) *History of Sexuality. Vol. 1. An Introduction*. Translated by Robert Hurley. New York: Random House.
- FOUCAULT, M. (1980) Power and Strategies. IN GORDON, C. (Ed.) *Power/knowledge: Selected interviews and other writings 1972-1977*. Brighton, Harvester Press.
- FOUCAULT, M (1983) 'On the Genealogy of Ethics: An Overview of Work in Progress' in DREYFUS, H., L. and RABINOW, P. *Michel Foucault: Beyond Structuralism and Hermeneutics*. Chicago: The University of Chicago Press.
- FOUCAULT, M. (1984) Hypomnemata. IN RABINOW, P. (Ed.) *The Foucault Reader*. New York, Pantheon.
- FOUCAULT, M. (1999) *Abnormal: Lectures at the Colledge De France 1974-1975*, New York, Picador.
- FOUCAULT, M. (2002) *Archeology of Knowledge*, London and New York, Routledge.
- FOUCAULT, M., MARTIN, L. H., GUTMAN, H. & HUTTON, P. H. (1988) *Technologies of the self: a seminar with Michel Foucault*, University of Massachusetts Press.
- FOX, N. J. (1993) *Postmodernism, Sociology and Health*, Buckingham: Open University Press.
- FRANKLIN, K. (2009) *Face to Facebook*, BBC Ouch! [Accessed 12.05.2009] [http://www.bbc.co.uk/ouch/opinion/face\\_to\\_facebook.shtml](http://www.bbc.co.uk/ouch/opinion/face_to_facebook.shtml).
- FRASER, N. & NICHOLSON, L. (1990) Social criticism without philosophy: an encounter between feminism and postmodernism. IN NICHOLSON, L. (Ed.) *Feminism/Postmodernism*. London, Routledge.
- FREIRE, A. P., RUSSO, C. M. & FORTES, R. P. M. (2010) The perception of accessibility in Web development by academy, industry and government: a survey of the Brazilian scenario. *New Review of Hypermedia and Multimedia*, 14, 2, 149-175.
- FREIRE, A. P., FORTES, R. P. M., PAIVA, D. M. B. & TURINE, M. A. S. (2007) Using Screen Readers to Reinforce Web Accessibility Education. *Proceedings of the 12th ACM Annual SIGCSE Conference on Innovation and Technology in Computer Science Education (Dundee, Scotland, June 25-27, 2007)*, ITiCSE 2007. ACM Press, New York, NY, 82-86.
- FREIRE, P. (1970) *Pedagogy of the Oppressed*, New York, Continuum.
- FUIJURA, G. T. & RUTKOWSKI-KMITTA, V. (2001) Counting Disability. IN ALBRECHT, G. L., SEELMAN, K. D. & BURY, M. (Eds.) *Handbook of Disability Studies*. Thousand Oaks, CA, Sage.
- FULCHER, G. (1989) *Disabling Policies?* London: Falmer Press.

- FULLER, M., BRADLEY, A. & HEALEY, M. (2004) Incorporating disabled students within an inclusive higher education environment. *Disability and Society*, 19, 5, 455-468.
- FULLER, M., GEORGESON, J., HEALEY, M., HURST, A., KELLY, K., RIDDELL, S., ROBERTS, H. & WEEDON, E. (2008) Disabled students in higher education: experiences and outcomes. *TLRP Research Briefing 46*, [Accessed 28.05.2010]  
<http://www.tlrp.org/pub/documents/Fuller%20RB%2046%20FINAL.pdf>.
- FULLER, M., GEORGESON, J., HEALEY, M., HURST, A., KELLY, K., RIDDELL, S., ROBERTS, H. & WEEDON, E. (2009) *Improving disabled students' learning: experiences and outcomes*, London, Routledge.
- GARLAND-THOMAS, R. (1997) *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, New York, Columbia University Press.
- GARLAND-THOMSON, R. (Ed.) (1996) *Freakery. Cultural Spectacles of the Extraordinary Body*, New York, New York University Press.
- GARLAND-THOMSON, R. (2007) *Public perceptions of disability images*, Radio Nederland Wereldomroep, [Accessed 12.06.2010]  
<http://static.rnw.nl/migratie/www.radionetherlands.nl/thestatewerein/otherstates/tswi070719garland-redirected>.
- GIDDENS, A. (1991) *Modernity and Self-Identity: Self and Society in the Late Modern Age*, Palo Alto, Stanford University Press.
- GILL, C. J. (2001) The social experience of disability, in: G. L. Albrecht, K. D. Seelman & M. Bury (Eds) *Handbook of disability studies*. London, Sage.
- GLEESON, B. J. (1999) *Geographies of Disability*, London, Routledge.
- GOFFMAN, E. (1959) *The Presentation of Self in Everyday Life*, London, Penguin Books.
- GOFFMAN, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*, New York, Prentice-Hall.
- GOGGIN, G. & NEWELL, C. (2003) *Digital disability: the social construction of disability in new media*, Oxford, Rowman & Littlefield.
- GOGGIN, G & NEWELL, C. (2005) Foucault on the Phone: Disability and The Mobility of Government. IN TREMAIN, S. (Ed.) *Foucault and the Government of Disability*. Michigan, University of Michigan Press.
- GOODE, J. (2007) 'Managing' disability: early experiences of university students with disabilities. *Disability and Society*, 22, 1, 35-48.
- GOODLEY, D. & LAWTHOM, R. (2006) *Disability and Psychology: Critical introductions and reflections*, Basingstoke, Palgrave MacMillan.
- GOSLING, S. (2009) Supporting student learning. IN HEATHER, F., KETTERIDGE, S. & MARSHALL, S. (Eds.) *A Handbook for Teaching and Learning in Higher Education*. Abingdon, Routledge.
- GRADY, C. (2005) Payment of clinical research subjects, *Journal of Clinical Investigation*. **115**, 1681-1687.

- GRANOVETTER, M. (1983) The strength of weak ties: a network theory revised. *Sociological Theory*, 1, 201-233.
- GRINT, K. & WOOLGAR, S. (1997) Configuring the User: Inventing New Technologies. IN GRINT, K. & WOOLGAR, S. (Eds.) *The Machine at Work: Technology, Work and Organization*. Cambridge, Polity Press.
- GWERNAN-JONES, R. (2008) *Identity and disability: a review of the current state and developing trends*, Bristol, Future Lab.
- HAHN, H. (1985) Towards a politics of disability: definitions, disciplines and policies. *Social Science Journal*, 22, 4, 88-105.
- HALL, S. (2001) Foucault: Power, Knowledge and Discourse. IN WETHERELL, M., TAYLOR, S. and YATES, S. (Eds.) *Discourse Theory and Practice: A reader*. London, Sage.
- HACKING, I. (1986). Making up people. In T. C. Heller, M. Sosna & D. E. Wellbery (Eds.), *Reconstructing individualism: Autonomy, individuality & the self in western thought* (pp. 222-236): Stanford University Press.
- HACKING, I. (1995). The looping effects of human kinds. In D. Sperber, D. Premack & A. Premack (Eds.), *Causal cognition: A multi-disciplinary approach* (pp. 351-383). Oxford: Clarendon Press.
- HALL, K. & BUCHOLTZ, M. (Eds.) (1995) *Gender articulated: Language and the socially constructed self*, New York, Routledge.
- HARAWAY, D. (1988) Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*, 14, 3, 575-599.
- HARAWAY, D. J. (1991) *Simians, cyborgs and women: the reinvention of nature*, London, Free Association.
- HARAWAY, D. J. (1997) A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s. IN KEMP, S. & SQUIRES, J. (Eds.) *Feminisms*. Oxford, Oxford University Press.
- HARDING, S. G. (1986) *The science question in feminism*, Ithaca, Cornell University Press.
- HARGITTAI, E. (2007) Whose space? Differences among users and non-users of social network sites. *Journal of Computer-Mediated Communication*. *Journal of Computer-Mediated Communication*, 13, 1, article 14. [Accessed 25.10.2009] <http://jcmc.indiana.edu/vol13/issue1/hargittai.html>
- HAYLES, N. K. (1999) *How we became posthuman : virtual bodies in cybernetics, literature, and informatics*, Chicago, Ill. ; London, University of Chicago Press.
- HEASLEY, S. (2010) *Social Networks Opening Doors For People With Disabilities*, Yahoo News. [Accessed 07. 09.2010] [http://news.yahoo.com/s/afp/20100905/tc\\_afp/usitinternetdisabledyahooapplegoogle](http://news.yahoo.com/s/afp/20100905/tc_afp/usitinternetdisabledyahooapplegoogle).
- HEFCE (2005) *Strategy for e-learning*, Bristol, Higher Education Funding Council for England.
- HENRIQUES, J., HOLLWAY, W., URWIN, C., VENN, C. & WALKERDINE, V. (1984) Theorizing subjectivity. IN HENRIQUES, J., HOLLWAY, W., URWIN, C., VENN, C. & WALKERDINE, V. (Eds.) *Changing the Subject. Psychology, Social Regulation and Subjectivity*. London, Methuen.
- HERON, J. & REASON, P. (1997) A Participative Inquiry Paradigm. *Qualitative Inquiry*, 3, 3, 274-294.

HESA (2008) *Collection viewer - Student record 2007/08: HESA Student Record 2007/08*. [Accessed 29.09.2009]  
[http://www.hesa.ac.uk/index.php/component/option,com\\_studrec/task,show\\_file/Itemid,233/mnl,07051/href,a%5E\\_%5EDISABLE.html/](http://www.hesa.ac.uk/index.php/component/option,com_studrec/task,show_file/Itemid,233/mnl,07051/href,a%5E_%5EDISABLE.html/).

HESA (2008b) *Table 11b - First year UK domiciled HE students by qualification aim, mode of study, gender and disability 2007/08* [Accessed 29.09.2009]  
[http://www.hesa.ac.uk/index.php/component/option,com\\_datatables/Itemid,121/task,show\\_category/c atdex,3/](http://www.hesa.ac.uk/index.php/component/option,com_datatables/Itemid,121/task,show_category/c atdex,3/).

HESA (2009a) *Collection viewer - Staff Person Table 2008/09: 08025: Disability 1*. [Accessed 29.09.2009]  
[http://www.hesa.ac.uk/index.php?option=com\\_collns&task=show\\_manu als&Itemid=233&r=08025&f =024](http://www.hesa.ac.uk/index.php?option=com_collns&task=show_manu als&Itemid=233&r=08025&f =024).

HESA (2009b) *Collection viewer - Staff Person Table 2008/09: 08025: Disability 2*. [Accessed 29.09.2009]  
[http://www.hesa.ac.uk/index.php?option=com\\_collns&task=show\\_manu als&Itemid=233&r=08025&f =025](http://www.hesa.ac.uk/index.php?option=com_collns&task=show_manu als&Itemid=233&r=08025&f =025).

HOCHSCHILD, A. R. (1983) *The managed heart: commercialization of human feeling*, Berkeley, CA, University of California Press.

HREOC (2002) *World Wide Web Access: Disability Discrimination Act Advisory Notes*. Human Rights and Equal Opportunity Commission [Accessed 10.07.2010]  
[http://www.hreoc.gov.au/disability\\_rights/standards/www\\_3/www\\_3.html](http://www.hreoc.gov.au/disability_rights/standards/www_3/www_3.html).

HUGHES, B. & PATTERSON, K. (1997) The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment. *Disability and Society*, 12, 3, 325-340.

HUGHES, B., RUSSELL, R. & PATERSON, K. (2005) Nothing to be had 'off the peg': Consumption, identity and the immobilization of young disabled people. *Disability and Society*, 20, 1, 3-17.

HUNT, P. (Ed.) (1996) *Stigma: The experience of disability*, London, Geoffrey Chapman.

HURST, A. (1999) The Dearing Report and Students with Disabilities and Learning Difficulties. *Disability & Society*, 14, 1, 65-83.

INGBER, J. (2009) Untangling the Web: A New Way to Find Old Friends: A Review of the Accessibility of Facebook. *AccessWorld*, 10, 2, [Accessed 08.02.2010]  
<http://www.afb.org/afbpress/pub.asp?DocID=aw100204>.

INNOVATION UNIVERSITIES SCIENCE AND SKILLS COMMITTEE (2009) *Students and Universities: Eleventh Report of Session 2008-09*, London, TSO.

JACKLIN, A., ROBINSON, C., O'MEARA, L. & HARRIS, A. (2007) *Improving the experiences of disabled students in higher education*, York, Higher Education Academy. [Accessed 25.02.2009]  
<http://www.heacademy.ac.uk/assets/York/documents/ourwork/research/jacklin.pdf> .

JAGER, S. & MAIER, F. (2009) Theoretical and Methodological Aspects of Foucauldian Critical Discourse Analysis and Dispositive Analysis. IN WODAK, R. & MEYER, M. (Eds.) *Methods of Critical Discourse Analysis*. 2 ed. London, Sage.

JELLINEK, D. (2010) E-Access '10 Conference Report: Digital Lifeline. *E-Access Bulletin Live*, [Accessed 12.08.2010] <http://headstar.com/eablive/?p=468>.

- JOHNSON, D. G. (2001) Ethics Online. IN SPINELLO, R. A. & TAVANI, H. T. (Eds.) *Readings in Cyber Ethics*. London, Jones and Bartlett.
- JORDAN, T. (2008) *Hacking: Digital Media and Technological Determinism*, Cambridge, Polity Press.
- KALDOUDI, E., BAMIDIS, P., PAPAIOAKEIM, M. & VARGEMEZIS, V. (2008) *Problem-Based Learning via Web 2.0 Technologies*, 21st IEEE International Symposium on Computer-Based Medical Systems, [Accessed 10.10.2007] [http://ieeexplore.ieee.org/xpls/abs\\_all.jsp?arnumber=4562023](http://ieeexplore.ieee.org/xpls/abs_all.jsp?arnumber=4562023).
- KELLY, B., LEWTHWAITE, S. & SLOAN, D. (2010) *Developing Countries; Developing Experiences: Approaches to Accessibility for the Real World*, New York, Association for Computing Machinery.
- KELLY, B., NEVILE, L., SLOAN, D., FANOUE, S., ELLISON, R. & HERROD, L. (2009) From Web Accessibility to Web Adaptability. *Disability and Rehabilitation: Assistive Technology*, 4, 4, 212-226.
- KELLY, B., PHIPPS, L. & SWIFT, E. (2004) Developing A Holistic Approach For E-Learning Accessibility. *Canadian Journal of Learning and Technology*, 30, 3. [Accessed 05.05.2008] [www.cjlt.ca/index.php/cjlt/article/view/138/131](http://www.cjlt.ca/index.php/cjlt/article/view/138/131).
- KELLY, B., SLOAN, D., BROWN, S., SEALE, J., PETRIE, H., LAUKE, P. & BALL, S. (2007) Accessibility 2.0: people, policies and processes. *W4A 2007: International Cross-Disciplinary Conference on Web Accessibility*. Banff, Canada, 7-8 May 2007, W4A. [Accessed 20.05.2008] <http://www.w4a.info/2007/prog/15-kelly.pdf>.
- KINCHELOE, J. L. (2001) Describing the bricolage: Conceptualizing a new rigor in qualitative research. *Qualitative Inquiry*, 7, 679-692.
- KINCHELOE, J. L. (2008) *Knowledge and Critical Pedagogy: An Introduction*, New York, Springer.
- KINCHELOE, J. L. & MCLAREN, P. (2005) Rethinking critical theory and qualitative research. IN DENZIN, N. K. & LINCOLN, Y. S. (Eds.) *Qualitative Research* 3ed. London, Sage.
- KNOBEL, M. (2005) Rants, ratings and representation: ethical issues in researching online social practices IN SHEEHY, K., NIND, M., RIX, J and SIMMONS, K (Eds.) *Ethics and Research in Inclusive Education; Values into Practice*. London: Routledge Farmer.
- KROKSMARK, T. (1987) *Phenomenographic Didactics*, Goteburg, Acta Univeristatis.
- KUTCHINS, H. & KIRK, S. (1997) *Making Us Crazy: DSM: The Psychiatric Bible and the Creation of Mental Disorders*, New York, Free Press.
- KUZEL, A. J. (1992) Sampling in Qualitative Enquiry. In B. F. Crabtree & W. L. Miller (Eds.) *Doing Qualitative Research* (pp. 31-44). Newbury Park, CA: Sage.
- LABOUR PARTY MANIFESTO (1997) [Accessed 05.01.2006] <http://www.labour-party.org.uk/manifestos/>
- LATOUR, B. (1993) *We have never been modern*, New York ; London, Harvester Wheatsheaf.
- LEE, R., M. (1993) *Doing Research on Sensitive Topics*. Thousand Oaks: Sage.
- LEMKE, T. (2002) Foucault, Governmentality and Critique. *Rethinking Marxism: A Journal of Economics, Culture and Society*, 14, 3, 49-64.

- LICCARDI, I., OUNNAS, A., PAU, R., MASSEY, E., KINNUMEN, P., LEWTHWAITE, S., MIDY, M. A. & SAKAR, C. (2007) The role of social networks in students' learning experiences. *ACM SIGCSE Bulletin*, December Issue, 224-237.
- LINELL, P. (1998) *Approaching Dialogue: Talk, interaction and contexts in dialogical perspective*, Amsterdam, John Benjamins.
- LOW, J. (1996) Negotiating Identities, Negotiating Environments: An interpretation of the experiences of students with disabilities. *Disability and Society*, 11, 2, 235-248.
- LOW, J. (2009) Negotiating Identities, Negotiating Environments: An Interpretation of the Experiences of Students with Disabilities. IN TITCHKOSKY, T. & MICHALKO, R. (Eds.) *Rethinking Normalcy: A Disability Studies Reader*. Toronto, Canadian Scholars' Press.
- MACKLIN, R., (1981) On paying money to research subjects: 'due' and 'undue' inducements, *IRB: Ethics and Human Research*, 3,1-6.
- MADRIAGA, M., HANSON, K, HEATON, C., KAY, H., NEWITT, S. and WALKER, A. (2010) Confronting similar challenges? Disabled and non-disabled students' learning and assessment experiences, *Studies in Higher Education*, 35: 6, 647 — 658.
- MAGE, C., MEEK, J., WELLENS, J. & HOOLEY, T. (2009) Facebook, social integration and informal learning at university: 'It is more for socialising and talking to friends about work than for actually doing work'. *Learning, Media and Technology*, 34, 2, 141-155.
- MALLETT, R. (2007) *Critical Correctness: Exploring the Capacities of Contemporary Disability Criticism*, Unpublished Thesis. Department of Geography. Sheffield, University of Sheffield.
- MANAGO, A. M., GRAHAM, M. B., GREENFIELD, P. M. & SALIMKHAN, G. (2008) Self-presentation and gender on MySpace. *Journal of Applied Developmental Psychology*, 29, 446-458.
- MARTON, F. (1994) Phenomenography. IN HUSÉN, T. & POSTLETHWAITE, T. N. (Eds.) *The International Encyclopedia of Education*. London, Pergamon.
- MARX, K., & ENGLES, F. (1968). In C.J. Arthur (Ed.), *The German ideology*. New York: International Publishers (original work published in 1846).
- MASON, J. (2002) *Qualitative Researching*, London, Sage.
- McGEE, G., (1997) A piece of my mind. Subject to payment? *Journal of the American Medical Association*. 278:199-200.
- McKEON, M. (2010) *The Evolution of Privacy on Facebook: Changes in default profile settings over time*, [Accessed 20.08.2010] <http://mattmckeon.com/facebook-privacy/>.
- McLOUGHLIN, C. & LEE, M. J. W. (2007) *Social software and participatory learning: Extending pedagogical choices with technology affordances in the Web 2.0 era.*, Proceedings ASCILITE Singapore 2007, [Accessed 25.10.2008] <http://www.ascilite.org.au/conferences/singapore07/procs/mcloughlin.pdf>.
- MERLEAU-PONTY, M. (2002) *Phenomenology of perception*, London, Routledge Classics.
- MERRIAM, S. B. (1998) *Qualitative Research and Case Study Applications in Education*, San Francisco, Jossey-Bass.

- MINOCHA, S. (2009) *A Study on the Effective Use of Social Software by Further and Higher Education in the UK to Support Student Learning and Engagement (Final Report)*, Coventry, Joint Information Systems Committee.
- MITCHELL, D. (2003) 'Research methodologies and the quandary of over analysed populations', *Using Emancipatory Methodologies in Disability Research*, proceedings of the first NDA Disability Research Conference. Dublin: NDA.
- MORI, I. (2007) *Student Expectations Study*, Coventry, Joint Information Systems Committee.
- MORRIS, J. (1991) *Pride against prejudice: a personal politics of disability*, London, Women's Press.
- MWANZA, D. (2002) Towards an activity-oriented design method for HCI research and practice. United Kingdom, The Open University.
- NARDI, B. A. (1996) Studying context: A comparison of activity theory, situated action models, and distributed cognition. In NARDI, B. A. (Ed.) *Context and Consciousness: Activity Theory and human-computer interaction*. Cambridge, MA: MIT Press.
- NUS (2009) *NUS/ HSBC Students Experience Research Report: Teaching and Learning* [Accessed 20.02.2010] <http://www.nusconnect.org.uk/pageassets/campaigns/highereducation/student-engagement-hub/resources/articles/NUS20HSBC20Teaching20and20Learning.pdf>.
- OLIVER, M. (1996) *Understanding Disability: From Theory to Practice*, Basingstoke, Macmillan.
- OLIVER, M. (2005) If I had a hammer: the social model in action. IN SWAIN, J., FRENCH, S., BARNES, C. & THOMAS, C. (Eds.) *Disabling Barriers - Enabling Environments*. London, Sage.
- O'REGAN, M. (2009) New Technologies of the Self and Social Networking Sites: Hospitality Exchange Clubs and the Changing Nature of Tourism and Identity. IN ABBAS, Y. & DERVIN, F. (Eds.) *Digital Technologies of the Self*. Newcastle upon Tyne, Cambridge Scholars Publishing.
- O'REILLY, T. (2005) *What is Web 2.0?*, [Accessed 20.05.2007] <http://www.oreilly.com/go/web2>
- PATTON, M. Q. (1990) *Qualitative evaluation and research methods*. Beverly Hills, CA: Sage.
- PAYNE, G. (2000) *Social divisions*, Basingstoke, Macmillan.
- PEARSHOUSE, I., BLIGH, B., BROWN, E., LEWTHWAITE, S., GRABER, R., HARTNELL-YOUNG, E., (2009) *A Study of Effective Evaluation Models and Practices for Technology Supported Physical Learning Spaces*. Bristol, JISC.
- PEARSON, E. J. & KOPPI, T. (2001) Inclusion for online learning opportunities: designing for accessibility. *Association for Learning Technology Journal*, 10, 2, 17-28.
- PEIM, N (2009) Activity theory and ontology. *Educational Review*, 61, 2, 167-180.
- PERMUTH-WEY, J. and BORENSTEIN, A. R., (2009) Financial Remuneration for Clinical and Behavioural Research Participation: Ethical and Practical Considerations. *Annals of Epidemiology*, 19:4, 280-285.
- PHIPPS, L. & KELLY, B. (2006) Holistic approaches to e-learning accessibility. *Association for Learning Technology Journal*, 14, 1, 69-78.
- PLANT, S. (1996) On the matrix: Cyberfeminist simulations. IN SHIELDS, R. (Ed.) *Cultures of the Internet: Virtual spaces, real histories, living bodies*. London, Sage.

- POPHAM, J. and PHILLIPS, B. (April, 2008) *Disadvantaged Learners: Report: Evidence review to support the harnessing technology strategy development*. Coventry, Becta.
- PRENSKY, M. (2001) Digital natives, digital immigrants. *On the Horizon*, 9, 5, 1-6.
- PRICE, J. & SHILDRICK, M. (2002) Bodies Together: Touch, Ethics and Disability. IN SHAKESPEARE, T. & CORKER, M. (Eds.) *Disability / Postmodernity: embodying disability theory*. London, Continuum.
- PRIESTLY, M. (1997) Who's Research? A personal Audit. IN BARNES, C. and MERCER, G. (Eds.) *Doing Disability Research*. Leeds, The Disability Press. 88-107.
- RADERMACHER, H., L (2006) Participatory Action Research with People with Disabilities: Exploring Experiences of Participation. PhD Thesis. Victoria University.
- RAJCHMAN, J. (1991) *Truth and Eros: Foucault, Lacan, and the Question of Ethics*, New York, Routledge.
- RAMSDEN, B. (2005) *Participation in Higher Education: A Study to Determine Whether the Higher Education Initial Participation Rate Should be Disaggregated*, Department for Education and Skills Research Report RR676, [Accessed 20.10. 2009]  
<http://www.dfes.gov.uk/research/data/uploadfiles/RR676.pdf>.
- RANGANATHAN, S. R. (1931) *The Five Laws of Library Science*, Madras, Madras Library Association.
- REEVE, D. (2002) Negotiating Psycho-emotional Dimensions of Disability and their Influence on Identity Constructions. *Disability & Society*, 17, 5, 493-508.
- RESNIK, D.B. (2001) Research participation and financial inducements, *American Journal of Bioethics* 1, pp. 54-56.
- RICKINSON, M. (2010) *Disability equality in higher education: a synthesis of research*, York, Higher Education Authority.
- RIDDELL, S., TINKLIN, T. & WILSON, A. (2005) *Disabled students in higher education : perspectives on widening access and changing policy*, London, Routledge.
- RIOUX, M. & BACH, M. (Eds.) (1994) *Disability is not Measles: new research paradigms in disability*, New York, L'Institut Roehar Institute.
- ROBINSON, J. & JENSEMA, C. (Eds.) (1996) *Computer Speech Recognition as an Assistive Device for Deaf and Hard of Hearing People*, [Accessed 1.11. 2005]  
<http://sunsite.utk.edu/cod/pec/1996/robison.pdf>
- ROMMETVEIT, R. (1992) Outlines of a dialogically based social-cognitive approach to human cognition and communication. IN WOLD, A. (Ed.) *The dialogical alternative: towards a theory of language and mind* (pp. 19- 45). Oslo, Scandinavian Press.
- ROSMAITA, B. J., DEIBEL, K., COHEN, R. F. & EGAN, M. A. L. Accessibility and computer science education. *SIGCSE '06: Proceedings of the 37th SIGCSE technical symposium on Computer Science education*, pp. 63-64, New York, ACM Press.
- ROTH, W.-M. (2007). The ethico-moral nature of identity: Prolegomena to the development of third generation Cultural-Historical Activity Theory. *International Journal of Educational Research*, 46: 1-2. 83-93.

- ROULSTONE, A. (1998) *Enabling Technology: Disabled people, work and new technology*, Buckingham, Open University Press.
- SÄLJÖ, R. (1988) Learning in educational settings: methods of inquiry. IN RAMSDEN, P. (Ed.) *Improving Learning: New Perspectives*. London, Kogan Page.
- SEALE, J. (2003) *Learning technology in transition : from individual enthusiasm to institutional implementation*, Lisse ; Abingdon, Swets & Zeitlinger.
- SEALE, J. (2006) *E-learning and disability in higher education : accessibility research and practice*, London, Routledge.
- SEALE, J., DRAFFAN, E. A. & WALD, M. (2008) Exploring disabled learners' experiences of e-learning. LEXDIS Project Report. University of Southampton, [Accessed 13.08.2009] [http://www.lexdis.org/project/media/LEXDIS\\_ProjectReport\\_Dec08final.doc](http://www.lexdis.org/project/media/LEXDIS_ProjectReport_Dec08final.doc).
- SEALE, J., DRAFFAN, E. A. & WALD, M. (2010) Digital agility and digital decision-making: conceptualising digital inclusion in the context of disabled learners in higher education. *Studies in Higher Education*, 35, 4, 445-461.
- SELWYN, N. (2003) Apart from technology: understanding people's non-use of information and communication technologies in everyday life. *Technology in Society*, 25, 1, 99-116.
- SELWYN, N. (2006) Digital division or digital decision? A study of non-users and low users of computers. *Poetics: Journal of Empirical Research in Culture, Media and the Arts*, 34, 4-5, 273-292.
- SELWYN, N. (2009) Faceworking: exploring students' education-related use of *Facebook*. *Learning, Media and Technology*, 34, 157-174.
- SELWYN, N. & GORARD, S. (2003) Reality bytes: examining the rhetoric of widening participation via ICT. *British Journal of Educational Technology*, 34, 2, 169-181.
- SENDA (2001) *Special Educational Needs and Disabilities Act*, TSO, [Accessed 27.08.2006] <http://www.hmso.gov.uk/acts/acts2001/20010010.htm>
- SEYMOUR, W. & LUPTON, D. (2004) Holding the line online: exploring wired relationships for people with disabilities. *Disability & Society*, 19, 4, 291-305.
- SHAKESPEARE, T. (1996) Disability, Identity and Difference. IN BARNES, C. & MERCER, G. (Eds.) *Exploring the Divide: illness and disability*. Leeds, Disability Press.
- SHAKESPEARE, T. (2006) *Disability Rights and Wrongs*, London, Routledge.
- SHAKESPEARE, T. (2009) Not Just a Pretty Facebook. BBC Ouch! [Accessed 28.08.2009] [http://www.bbc.co.uk/ouch/opinion/not\\_just\\_a\\_pretty\\_facebook.shtml](http://www.bbc.co.uk/ouch/opinion/not_just_a_pretty_facebook.shtml).
- SHAKESPEARE, T. & WATSON, N. (2001) The social model of disability: an outdated ideology? IN BARNARTT, S. & ALTMAN, B. M. (Eds.) *Exploring theories and expanding methodologies: where we are and where we need to go*. Oxford, Elsevier Science.
- SHAKESPEARE, T. & WATSON, N. (2002) The Social Model of Disability: an outmoded ideology? *Research in Social Science and Disability*, 69, 32-36.
- SHEFFIELD HALLAM UNIVERSITY, D. S. S. (2009) UCAS Classification Codes. [Accessed 29.09.2009] <http://students.shu.ac.uk/services/disability/ucas.html>.

- SHEVLIN, M., KENNY, M. & MCNEELA, E. (2004) Participation in higher education for students with disabilities: an Irish perspective. *Disability & Society*, 19, 1, 15-30.
- SIEBER, J., E. (1992) *Planning Ethically Responsible Research*. London, Sage.
- SIGNORINI, P. (2011) *The dynamics of mixed group work in British Higher Education*. PhD Thesis, University of Nottingham.
- SILVERMAN, D. (1998) Research and Social Theory. IN SEALE, C. (Ed.) *Researching Society and Culture*. London, Sage.
- SIMONS, H. and USHER, R. (2000) *Situated Ethics in Educational Research*. London, RoutledgeFalmer.
- SKILL (2011) *The future of higher education; evidence submission*. [Accessed 12.03.2011] <http://www.publications.parliament.uk/pa/cm201011/cmselect/cmbis/writev/885/m30.htm>
- SLOAN, D., STRATFORD, J. & GREGOR, P. (2006) Using multimedia to enhance the accessibility of the learning environment for disabled students: reflections from the Skills for Access project. *ALT-J Research in Learning Technology*, 14, 1, 39-54.
- SÖDERSTRÖM, S. & YTTERHUS, B. (2010) The use and non-use of assistive technologies from the world of information and communication technology by visually impaired young people: a walk on the tightrope of peer inclusion. *Disability & Society*, 25, 3, 303-315.
- STAKE, R. E. (2000) *The Art of Case Study Research*, Thousand Oaks, Sage.
- STANLEY, L. and WISE, S. (1983) *Breaking Out: Feminist Consciousness and Feminist Research*. London: Routledge
- STONE, E. and Priestly, M. (1996) Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers. *The British Journal of Sociology*, 47, 4, 699-716.
- TEST, D. W., FOWLER, C. H., WOOD, W. M., BREWER, D. M. & EDDY, S. (2005) A Conceptual Framework for Self-Advocacy for Students with Disabilities. *Remedial and Special Education*, 26, 1, 43-54.
- THOMAS, C. (2002) Disability Theory: Key Ideas, Issues and Thinkers. IN BARNES, C. & BARTON, L. (Eds.) *Disability Studies Today*. Cambridge, Polity Press.
- THOMAS, C. & CORKER, M. (2002) A Journey around the Social Model. IN CORKER, M. & SHAKESPEARE, T. (Eds.) *Disability/Postmodernity: Embodying disability theory*. London, Continuum.
- THOMAS, C. (1982) *The Experiences of Handicap*, London and New York, Methuen.
- THOREAU, E. (2006) Ouch!: An examination of the self-representation of disabled people on the internet. *Journal of Computer-Mediated Communication*, 11: 2. article 3, [Accessed 02.01.2007] <http://jcmc.indiana.edu/vol11/issue2/thoreau.html>
- TISHLER, C. L. and BARTHOLOMAE, S., (2002) The recruitment of normal healthy volunteers: a review of the literature on the use of financial incentives. *Journal of Clinical Pharmacology*. 42: 356-375.
- TREMAIN, S. (2001) On the subject of impairment. IN CORKER, M. & SHAKESPEARE, T. (Eds.) *Disability/Postmodernity*. London, Continuum.

- TREMAIN, S. (2005) *Foucault and the Government of Disability*. Michigan, University of Michigan Press.
- TREMAIN, S. (2006) Foucault and the Government of Disability. *Scandinavian Journal of Disability Studies*, 8, 1, 75-77.
- TRUEMAN C. et al. (2010) *Vulnerable People and Groups*. University of Lancaster. [Accessed 18.12.10] <http://www.lancs.ac.uk/researchethics/4-1-intro.html>
- TURKLE, S. (1984) *The second self : computers and the human spirit*, London, Granada.
- UCAS (2010) *Decade ends with record student numbers*, Universities and Colleges Admissions Service [Accessed 02.02.2010] [http://www.ucas.ac.uk/about\\_us/media\\_enquiries/media\\_releases/2010/210110](http://www.ucas.ac.uk/about_us/media_enquiries/media_releases/2010/210110).
- ULJENS, M. (1991) Phenomenography - a qualitative approach in educational research IN MERENHEIMO, S. (Ed.) *Qualitative approaches to educational research* Oulu, University of Oulu.
- UNITED NATIONS (2008) *Convention on the Rights of Persons with Disabilities*. [Accessed 12.02.2009] <http://www.un.org/disabilities/default.asp?id=259>.
- UNITED NATIONS (2008b) *Frequently Asked Questions on the Rights of Persons with Disabilities*. [Accessed 12.02.2009] <http://www.un.org/disabilities/default.asp?id=151>.
- UPIAS (1976) *Fundamental principles of disability*, London, Union of the Physically Impaired Against Segregation.
- VALENTINE, G. & SKELTON, T. (2008) Changing Spaces: the role of the internet in shaping Deaf geographies. *Social and Cultural Geography*, 9, 5, 469-485.
- VAUCELLE, C. (2009) Collect to Connect in the Mobile Age. IN ABBAS, Y. & DERVIN, F. (Eds.) *Digital Technologies of the Self*. Newcastle upon Tyne, Cambridge Scholars Publishing.
- VAZ, P. & BRUNO, F. (2003) Types of Self-Surveillance: from abnormality to individuals 'at risk'. *Surveillance and Society*, 3, 1, 272-291.
- VERNON, A. & SWAIN, J. (2002) Theorizing Divisions and Hierarchies: Towards a Commonality or Diversity? IN BARNES, C., OLIVER, M. & BARTON, L. (Eds.) *Disability Studies Today*. Cambridge, Polity Press.
- VYGOTSKY, L. (1978) *Mind and Society: the development of higher psychological processes*. Cambridge, MA, Harvard University Press.
- WAGNER, J. (1993) Ignorance in educational research or, how can you not know that? *Educational Researcher* 22, 5, 15-23.
- WALD, M. (2006) An exploration of the potential of Automatic Speech Recognition to assist and enable receptive communication in higher education. *Association for Learning Technology Journal*, 14, 1, 9-20.
- WATSON, N. (2002) Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: identity and disability. *Disability & Society*, 17, 5, 509-529.
- WATSON, N. & WOODS, B. (2005) No Wheelchairs Beyond this Point: A Historical Examination of Wheelchair Access in the Twentieth Century in Britain and America. *Social Policy & Society*, 4, 1, 97-105.

- WEGERIF, R. (2007) *Dialogic education and technology: Expanding the space of learning*, New York, Springer.
- WEINSTEIN, D. & WEINSTEIN, M. A. (1991) Goerg Simmel: Sociological flaneur bricoleur. *Theory, Culture and Society* 8, 3, 151-168.
- WENDELL, S. (1996) *The Rejected Body: feminist philosophical reflections on disability*, New York, Routledge.
- WESCH, M. (2009) Youtube and you: experiences of self-awareness in the context collapse of the recording Webcam. *Explorations in Media Ecology*. 8(2):19-3
- WILKINSON, M. and MOORE, A., (1999) Inducements revisited, *Bioethics* 13: 114-130.
- WILLIAMS, G. H. (1996) Representing Disability: Some Questions of Phenomenology and Politics. IN BARNES, C. & MERCER, G. (Eds.) *Exploring the Divide: Illness and Disability*. Leeds, The Disability Press.
- WILLIAMS, P. & SHOULTZ, B. (1982) *We can speak for ourselves: Self-advocacy by mentally handicapped people*. Bloomington, Indiana University Press.
- WOODFINE, B. P., NUNES, M. & WRIGHT, D. J. (2005) Constructivist eLearning and Dyslexia: Problems of Social Negotiation in Text Based Synchronous Environments. *Proceedings of the 3rd International Conference on Multimedia and Information and Communication Technologies in Education*. [Accessed 20.01.2008] <http://www.formatex.org/micte2005/97.pdf>.
- YIN, R. K. (2009) *Case study research : design and methods*, London, Sage.
- ZAPPONE, K. Ed (2003) *Re-Thinking Identity: the challenge of diversity*. Dublin, Equality Authority.
- ZOLA, I. K. (1993) Self, Identity and the Naming Question: Reflections on the Language of Disability. *Social Science and Medicine*, 36, 167-73.

## Appendix 1: Glossary of Terms

---

This glossary provides an overview of some of the technical terminology used in this thesis. Terms are organised alphabetically into two areas: assistive technologies and Web 2.0 technologies. The latter includes an introduction to the social networking sites that are the focus of this thesis. In the case of Facebook, a guide to terms and functionality is provided. A timeline establishing the availability of Facebook functions over the course of the research period follows as appendix three.

### ***Assistive Technologies***

**Dragon Naturally Speaking** – Speech recognition (speech-to-text). Can also be used to control computer by voice command.

**Inspiration** – Mind mapping software.

**Mind Mapping** – Diagrammatic organisational method of visualising, structuring and linking ideas, words or tasks, arranged into groupings. A mind map typically consists of a central idea or word with related concepts branching from this and arranged in order of importance.

**Read and Write Gold** – Assistive software, aiding literacy skills such as reading and text composition. Scanned text can be read aloud using a digital voice (text-to-speech). Other features include phonetic spell checker and word prediction.

**Screen Reader** – Software application used for the identification and interpretation of what is displayed on a computer screen or monitor. This information is then described or re-presented in another modality, such as text-to-speech, sound icons or Braille output.

**Specialised Assistive Technology** – Specific adaptive devices or software aiding interaction with technology in response to the user's needs.

## ***Web 2.0 and Related Technologies***

**Blackboard** – A leading e-learning and study management system or online learning environment incorporating teaching materials, discussion boards, calendars and contacts. Blackboard can also be used to set and track study tasks.

**Blog** – A website or part of a website used as a record of events or ideas in the form of an online journal. Usually updated by an individual, a typical blog consists of opinions, descriptions of events, links to other blogs or websites, photographs and videos. Blogs may be subject specific and interactive, allowing comments to be left by other users. Entries generally appear in reverse chronological order.

**Twitter** – Social networking and microblogging service that allows users to send and read publicly visible text based messages, or tweets, limited to 140 characters. Users can ‘Follow’ tweets by specific individuals. In doing so, the user becomes a ‘Follower’ of that individual.

**iGoogle** – Service provided by Google. iGoogle allows a user to personalise their internet home page, adding dynamic content such as news, photographs, weather and games. These features are usually added in the form of Google Gadgets and feeds.

**Instant Messenger** – Web based service enabling real time text based communication between individuals over the internet.

**Internet TV** – Television service distributed on the internet. Television programmes can be selected from an archive or channel list. The programmes are either viewed by the information being streamed directly to a media player, or downloaded.

**BBC iPlayer** – BBC specific Internet Television and Radio service available in the UK, enabling users to view or listen to streaming content from the BBC. BBC programmes are usually accessible for seven days after original transmission. iPlayer can be linked to SNSs allowing users to recommend programmes.

**MSN - MicroSoft Network, MSN Messenger, now Windows Live Messenger,** is a service enabling real time text based communication between individuals.

**Second Life** –Virtual World and SNS. Software called a Viewer enables users to enter a virtual world based on 3D modelling. The user, or Resident, creates an Avatar which is seen by other users and becomes the visual identity of the resident. Residents can interact, communicate, and play games such as role playing games in specific themed areas. Objects can be created such as items of clothing, vehicles and buildings which can be sold or bought from virtual stores.

**Skype** – An application that allows telephone type voice calls over the internet. Calls to other users on the Skype service are free. Calls to landline telephones or mobile phone networks are charged. Skype can also be used for instant text messaging, electronic information transfer and video conferencing.

**Social Bookmarking** – A method of organising, storing and searching for references or Bookmarks to internet resources. Users collect and organise links to websites which can then be searched and viewed by other users. Links are tagged with descriptive keywords or phrases which can then be grouped by category and used as search terms. Social Bookmarking provides a way of sharing references to resources rather than the resources themselves.

**Delicious** – A social Bookmarking service allowing users to save bookmarks online and see what other people are Bookmarking. The service also shows the most popular Bookmarks on a range of different subjects.

## **Social Networking Sites**

**Bebo** - Developed in 2005, Bebo is network popular amongst teenagers. A user has a personal Profile page and can post information such as blogs, photographs, video, music and questionnaires. Bebo users can link to other users, or Friends, and can exchange messages with them as well keeping up to date with personal news and information by updating their own profile page. A typical profile page will include

an interactive comments section, a list of the users Friends and other selected additions.

**Facebook** – Student SNS launched in 2004, now open to anybody over the age of 13. Users have a personal Profile which can be constantly updated with news and information such as Photos and links to other websites. Users can link to Friends, who they can then share information with and send messages to, and join different Groups and Networks associated with a particular interest or organisation. A user can elect to hide most of the information on the Profile page to all but their list of Friends. A users Profile can be enhanced with Applications. Functions include:

**Application / App** – Add-on software used to enhance a users profile and experience. This may include cooperative games or utility applications such as specialised calendars. Apps cited by participants include:

**Aquarium App** – Adds a virtual aquarium to the profile page. Aquatic pets can be purchase with virtual coins. Pets have to be replaced regularly using more coins, earned daily.

**Bumper Stickers App** – Adds a bumper sticker style graphic to the profile.

**FriendWheel App** – Enables the generation of a circular diagram showing all of the user’s Friends and how they are interlinked with one another.

**GoPokey App** – Virtual pet puppy application allowing interaction with an animated graphic of a puppy. Now replaced with FooPets App.

**Word Challenge App** – Word game using random six letters. The object of the game is to create as many three to six letter words as possible in a given time period. Rankings or Vocabulary Types are given in response to scores, with the highest ranking being Poet. This adds a competitive element between Friends.

**Commenting** – Adding a message or other response to a Friend’s Wall, Status or media such as Photos.

**Chat** – An information bar on the Profile page allows a user to see who of their Friend's are using Facebook online at that moment. This then allows for a real-time text based conversation, with one or more users.

**Friends** – Facebook users who create links to each other's profiles. Information can be shared and viewed by other Friends. Friends can add comments, media and website links to this information.

**Group** – A user created page that is dedicated to a particular interest or associated with a subject, place, person or thing. Other users can join the group to form a community, discussing relevant issues, or to promote related events or ideas. A typical University group may consist of a social society, sports team, fan club, or political group motivated by a current affairs issue.

**Invite** – To make another Facebook user a **Friend**, an invite has to be sent to their profile. This invite has to be accepted for them to become a Friend. Invites can be rejected.

**News feed** – Highlights changes to Friends' profiles such as added Comments, website links and Photos in a constantly updating list of Friends' Facebook activities. Events such as Birthdays and the joining of Groups or making of new Friends are included.

**Network** - An overarching network to which users must join upon registration. Maybe based on a location or organisation. For example, 'London' or 'University of York'.

**Page** – The addition of Pages to a Profile allows users to customise the presentation of information such as interests. The page can be static, showing the same content each time it is viewed, or dynamic, with changing content on each viewing.

**Poke** – A feature that attracts attention of another user without a specific

message being sent. It functions as a type of virtual nudge and can be interpreted in various ways from a simple hello to a more flirtatious act.

**Photos** – Photographs can be uploaded to the profile page and placed in albums. Comments can be added to these Photos and individuals included in the image can be Tagged, which identifies them within the photograph. A user will also usually have a Profile Photo of themselves which can be seen on the user's Profile Page and when creating a Status Update or comment. A user will often have more than one Profile Photo which can be swapped around. Some users choose to have a related image other than their own photographic portrait, to use as their Profile Photo.

**Profile** – Webpage that displays the user's personal information, Profile Photo, contact details and Status Updates. Friends' comments and messages directed to the user can also be seen on the Profile. Private messages sent directly to individuals do not appear on the Profile Page. The profile page can be edited and various privacy settings can control who sees the Profile information.

**Status** – The Status or Status Update is the feature which allows a user to post a message that can be read by Friends. This function is privileged at the top of the users profile and News Feed. Friends can, in turn, comment on the Status update or simply add a Like showing that they enjoyed the comment or link. The most recent Status Update appears at the top of the user's Profile Page and on their Friends' Recently Updated section.

**Tagging** – A user can Tag a photograph with the name of a person or persons who are included within the image. The Tag creates a link from a Tagged Friend's Profile to the photograph. The Friend is notified that they have been Tagged and has the option of deleting the Tag which removes their name and link from the photograph.

**Wall** – A section in a user's Profile where Friends can leave messages. Other Friends who can see a user's profile can also see what has been written on the

Wall. Friends can also leave Gifts on a Wall, which are small humorous image icons.

**Friendster** – SNS based around social the sharing of online content and media such as photographs and videos. Members can send messages to each other and add comments to Profiles. Friendster is also used for dating and sharing information about interests and hobbies. Founded in California in 2003, the majority of users are based in South East Asian, the USA, the Middle East and India.

**Habbo Hotel** – Now known as Habbo. SNS aimed at teenagers. It consists of a cartoon-like virtual world where users can access Hotels via a screen known as Hotel View. Using a created avatar, or ‘Habbo’, users then interact with other users, chat, send messages and play games.

**Hi-5** – Profile based SNS, where users can post comments, photographs and other media. Other users can be invited to be Friends and share comments, view photographs, play games and listen to music.

**MySpace** – A website for the sharing of information and meeting people. Users can email other users, take part in discussion forums and keep blogs. Due to an emphasis on multimedia, MySpace has become a source for music groups to profile their songs and videos.

**Ning** – Enables members to create their own mini-social networks, giving names to the networks and customising elements. Members can also choose to join other user-created networks. Networks can be created as groups relating to workplaces or schools. In 2010 Ning became a paid service.

**YouGoFurther** The UCAS, Universities and Colleges Admission Service, student social network. Enables students to meet other students studying the same courses and interested in studying at the same universities and colleges. Through a Profile page, users can also contact UCAS, and other educational institutions, directly.

**Voice Over Internet Protocol (VOIP)** – Technology that allows the user to make telephone type calls over broadband internet without the use of a standard phone line.

Services may restrict calls to other users on the same service, or allow calls to landline telephones and mobile phones.

**Wiki** – A website that allows users to collaboratively edit, update and add content to web pages using their internet browser. Content is created using simplified text editing software rather than complex website editing codes.

**Wikipedia** – A web based encyclopaedia-style reference service. Users can add to and edit content within articles. The collaborative project is multilingual and constantly expanding.

**Yahoo Messenger** – An internet service allowing real time text based communication.

**YouTube** – A video sharing website allowing members to upload and share videos. Video media can then be viewed by anybody on the internet accessing the website.

## Appendix 2: Participant Profiles

---

**Adele** (18) is a 1<sup>st</sup> year full-time American and Russian Studies undergraduate. She is an amputee with some mobility and fine motor impairments.

SNS: Facebook (242-261 Friends) ~~MySpace, Bebo.~~

**Ana** (37) is a full-time Social Science Masters postgraduate. She has been treated for Cancer during her MA.

SNS: Ning (22), ~~Hi5~~

**Ben** (20) is a 1<sup>st</sup> year MEng student with ADHD and dyspraxia.

SNS: Facebook (252 Friends), YouTube, ~~MySpace, Hi-5, Bebo, Friendster, Habbo Hotel.~~

**Claire** (28) is a 3<sup>rd</sup> year full-time Social Science postgraduate. She has multiple impairments including visual and hearing impairments, mobility impairments, and cognitive impairments including depression, OCD and anxiety.

SNS: Facebook (57 Friends) Twitter (Following: 14, Followers: 9) Bebo (unused).

**David** (20) is a 2<sup>nd</sup> year full-time Management and French undergraduate who has dyslexia.

SNS: Facebook (588 Friends), ~~MySpace, Bebo.~~

**Dennis** (40) is a 3<sup>rd</sup> year full-time Social Science doctoral postgraduate. He has dyslexia.

SNS: Facebook (2 Friends).

**Edward** (18) is a 1<sup>st</sup> year full-time Computer Science undergraduate who has Asperger's Syndrome, dyspraxia and a fine motor impairment.

SNS: Facebook (88-175 Friends) ~~YouGoFurther.~~

**Elizabeth** (37) is a 1<sup>st</sup> year part-time Education doctoral postgraduate. She has dyslexia and has been 'categorised by the standard IQ tests' as having learning disabilities.

SNS: N/A.

**Freya** (20) is a 2<sup>nd</sup> year full-time Education undergraduate. She has visual impairments.

SNS: Facebook (177 Friends). ~~MySpace, Bebo.~~

**Gemma** (22) is a 3<sup>rd</sup> year full-time Sociology undergraduate. She has Spina Bifida and dyslexia, these are unseen.  
SNS: Facebook (662 Friends).

**Howie** (23) is a 2<sup>nd</sup> year full-time Business Studies undergraduate who has an injury and variant of Repetitive Strain Injury.  
SNS: Facebook (303 Friends).

**Jack** (19) is a 1<sup>st</sup> year full-time English Studies undergraduate with dyslexia.  
SNS: Facebook (360-377 Friends).

**James** (20) is a 3<sup>rd</sup> year History undergraduate. He has mobility impairments, visual and hearing impairments and cognitive impairments.  
SNS: Facebook (355 Friends).

**Liam** (19) is a 1<sup>st</sup> year full-time Theology undergraduate. He has 'dyslexia slash dyspraxia' and a heart condition that restricts some sports activities.  
SNS: Facebook (31-90 Friends).

**Naomi** (20) is a 3<sup>rd</sup> year full-time Sociology undergraduate. She has dyslexia and a scotopic sensitivity that leads to migraine. She has experienced depression.  
SNS: Facebook (248 Friends).

**Pierce** (19) is a 2<sup>nd</sup> year full-time Management undergraduate. He has dyslexia.  
SNS: Facebook (391 Friends).

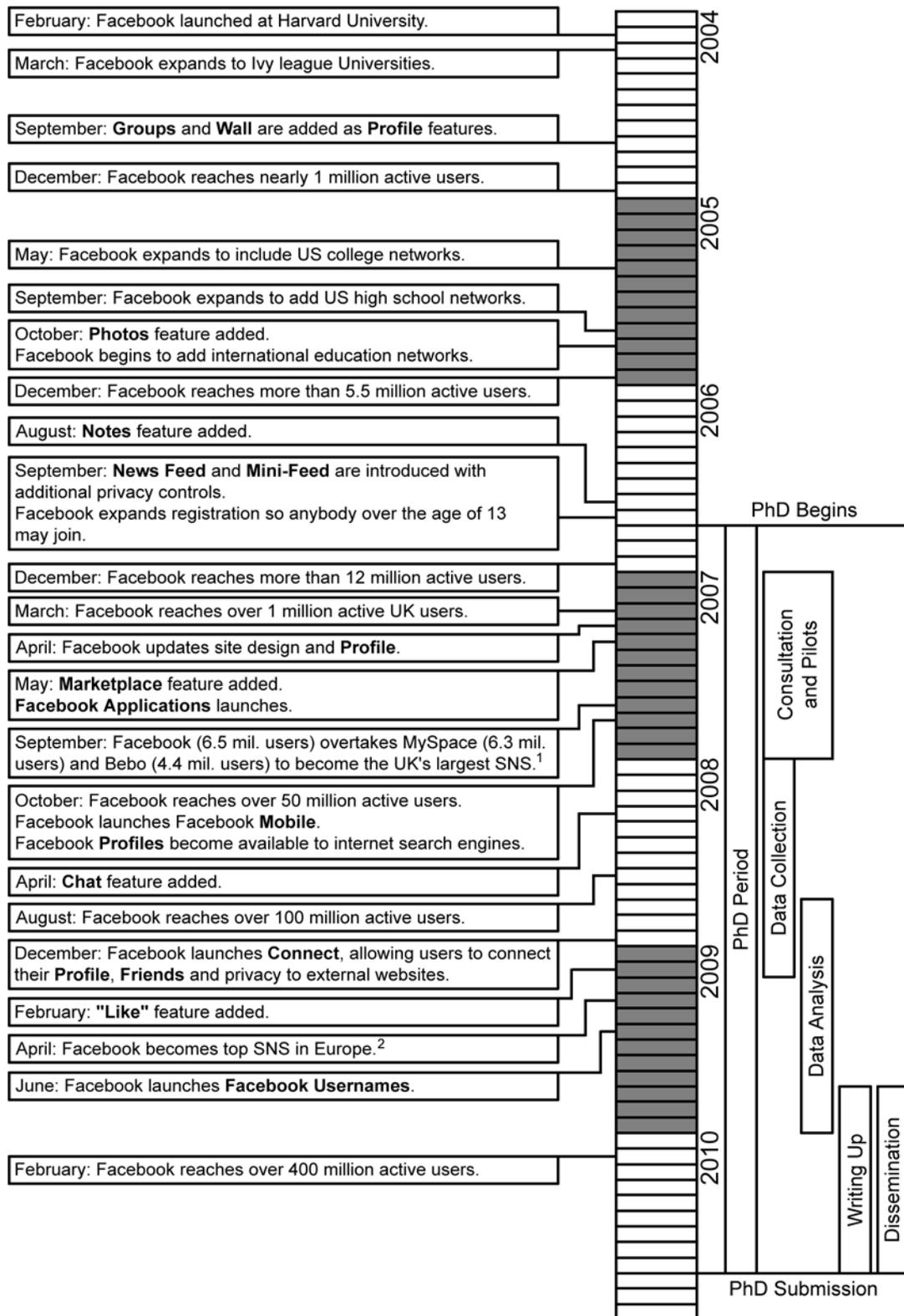
**Roy** (18) is a 1<sup>st</sup> year full-time Law undergraduate who has a visual impairment.  
SNS: Facebook (417-443 Friends) ~~YouGoFurther~~, MySpace, ~~Bebo~~.

**Sally** (18) is a 1<sup>st</sup> year full-time Economics undergraduate. She has dyslexia, as a child she had hearing impairments.  
SNS: Facebook (241-273 Friends) ~~Bebo~~.

## **Appendix 3: Timeline of Facebook Developments**

---

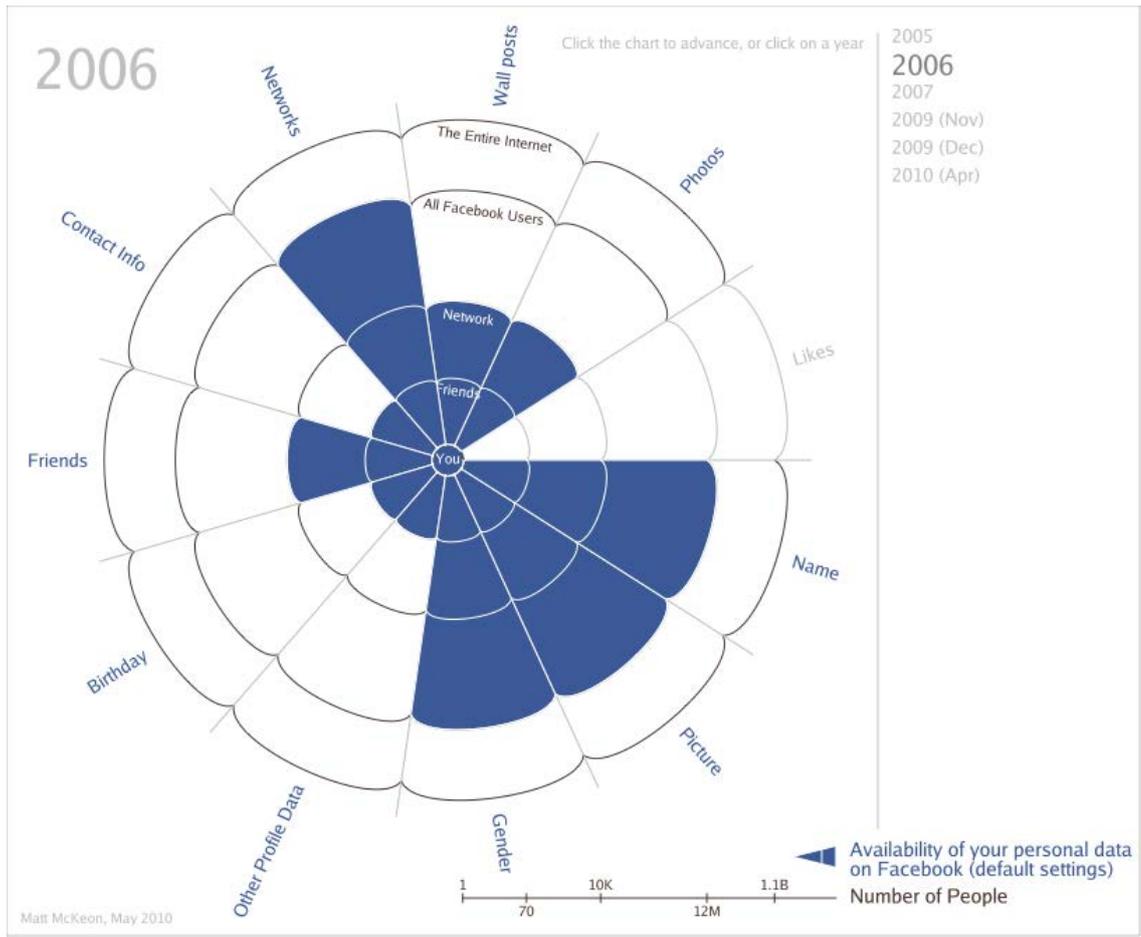
This appendix provides a timeline of Facebook's developments in functionality, scale and significance mapped against my PhD research period. Graphic visualisations relating to changes in Facebook's default privacy settings are also presented.



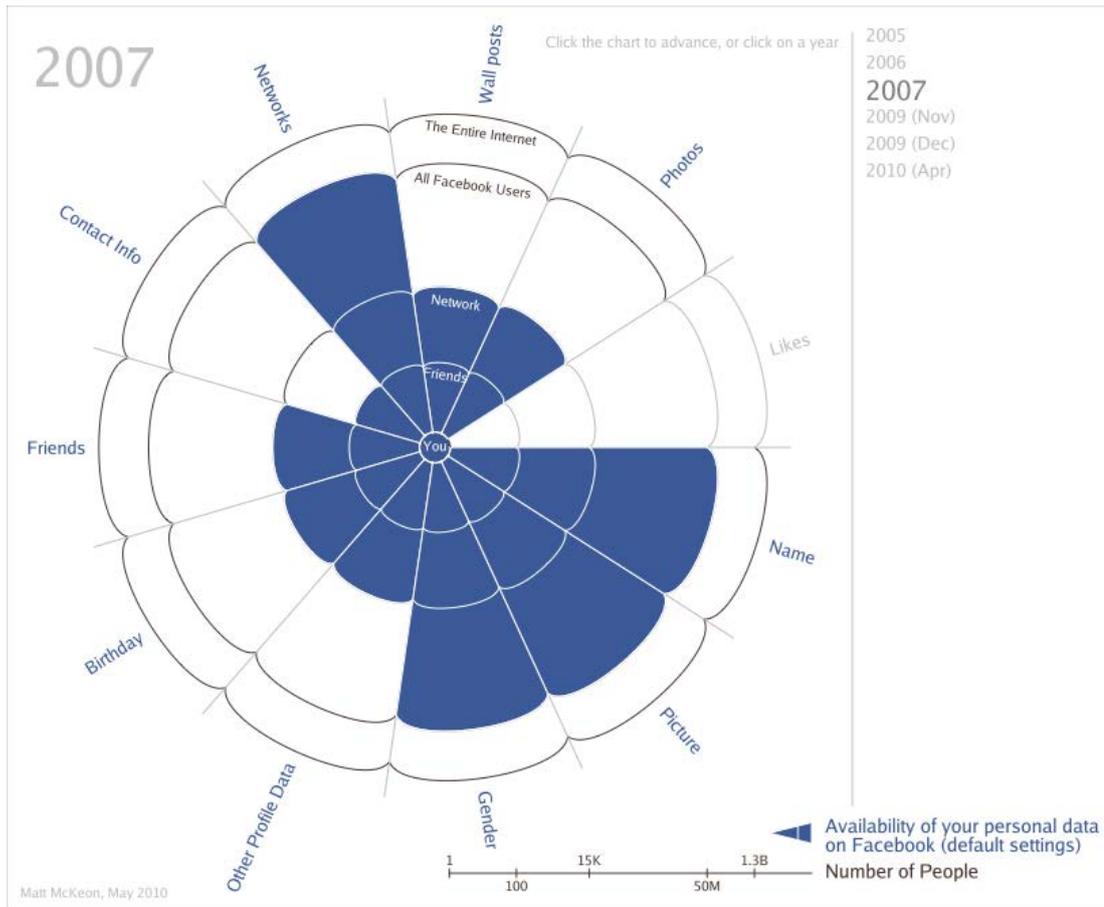
Appendix 3 Figure 1: Timeline of Facebook Developments and Research Period

<sup>1</sup> Based upon Nielsen/NetRatings statistics (measures website traffic based on a panel of UK users at home and work - it does not cover usage in schools, universities and internet cafes, meaning that younger internet users are under-reported). Supplementary trend information drawn from Comscore (excludes traffic from public computers).

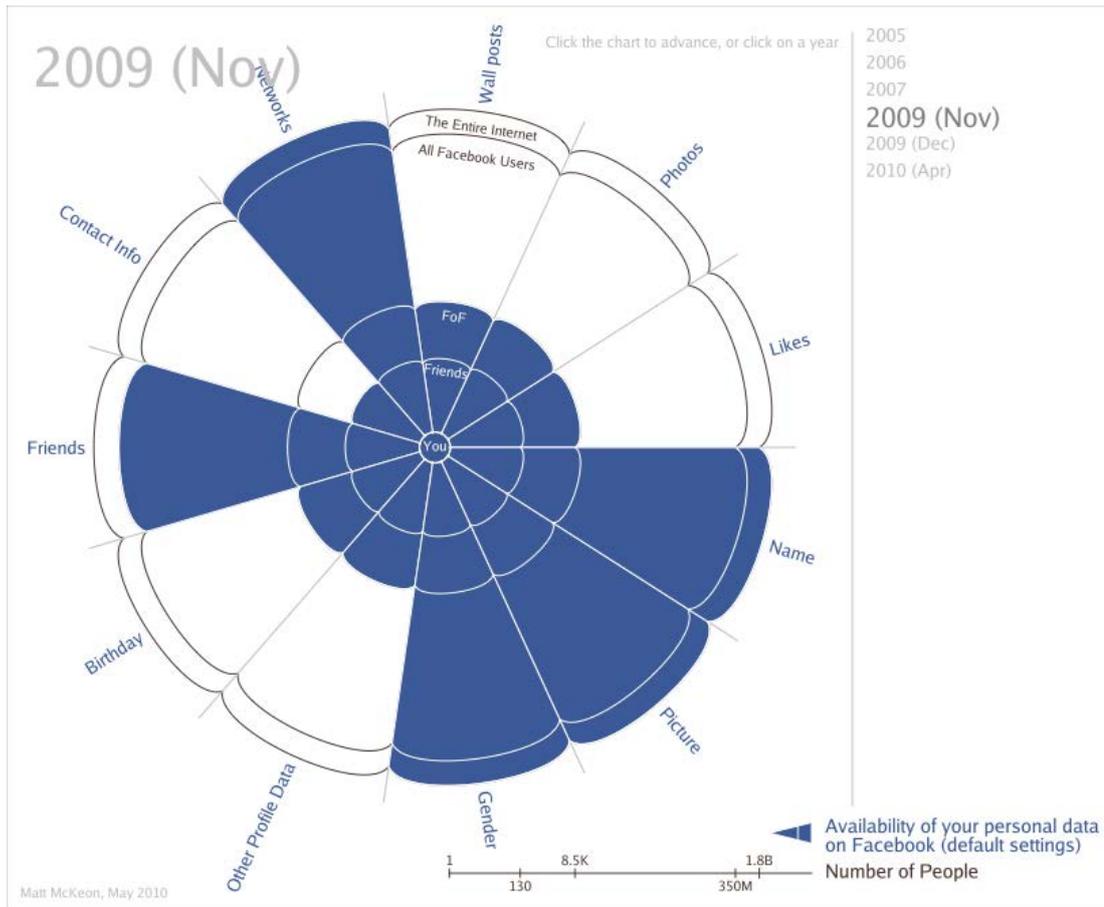
<sup>2</sup> <http://eu.techcrunch.com/2007/09/25/facebook-overtakes-myspace-as-perfspot-accelerates/>



**Appendix 3 Figure 2: Visualisation of Default Privacy Settings: 2006 (McKeon, 2010)**



**Appendix 3 Figure 3: Visualisation of Default Privacy Settings: 2007 (McKeon, 2010)**



**Appendix3 Figure 4: Visualisation of Default Privacy Settings: Nov 2009 (McKeon, 2010)**

## Appendix 4: Research Materials

---

### Example of Recruitment Materials

#### **Email: Research participants wanted**

Hi

I'm a PhD researcher looking for students to take part in a study exploring student's social experiences of disability online, looking in particular at social networks like Facebook, MySpace and Bebo.

The results of the study will examine how social networks transform or recreate (dis)ability difference, and help improve e-learning for all students.

As a participant you will be paid £10 for an interview lasting up to an hour. The interview is conversational, and can be at a time and place to suit you, either face to face, or by phone. Interviews are completely confidential and any extra travel expenses are refunded.

If you are interested in taking part, or would like to know more, please get in touch with me by email at [ttxsem@nottingham.ac.uk](mailto:ttxsem@nottingham.ac.uk) or by text or phone on 07903 590121.

Best wishes

Sarah

Sarah Lewthwaite

Learning Sciences Research Institute  
School of Education, University of Nottingham

## Example of Participant Consent Form

**Project title:** The Networked Student: Social experiences of disability online.

**Researcher's name(s):** Sarah Lewthwaite

**Supervisor's name:** Dr Charles Crook

- I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me. I understand and agree to take part.
- I understand the purpose of the research project and my involvement in it.
- I understand that I may withdraw from the research project at any stage and that this will not affect my status now or in the future.
- I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
- I understand that I may be audio-taped during the interview.
- I understand that data in electronic and paper formats (including transcripts, audio and screen recordings) will be stored securely by the researcher, solely for the research purposes stated above, at the School of Education, Jubilee Campus, University of Nottingham.
- I understand that I may contact the researcher or supervisor if I require further information about the research, and that I may contact the Research Ethics Coordinator of the School of Education, University of Nottingham, if I wish to make a complaint relating to my involvement in the research.

**Signed** ..... (research participant)

**Print name** ..... **Date** .....

### Contact details

Researcher: Sarah Lewthwaite  
Tel/txt: 07903590121  
Email: [txsem@nottingham.ac.uk](mailto:txsem@nottingham.ac.uk),  
School of Education (Room C8), The University of Nottingham,  
Jubilee Campus, Wollaton Road, Nottingham, NG8 1BB

Supervisor: Dr Charles Crook  
[Charles.crook@nottingham.ac.uk](mailto:Charles.crook@nottingham.ac.uk)  
Tel: 0115 8466453

Education Research Ethics Coordinator: [andrew.hobson@nottingham.ac.uk](mailto:andrew.hobson@nottingham.ac.uk)

## Example of Interview Schedule

### Informant Interview Schedule

Following initial introductions describe aims of research and research design. Outline length and nature of interview (approximately 1 hour including comfort break) and any remuneration of costs. Set up laptop and wifi for remote desktop. Answer any initial questions from interviewee.

- 1) Obtain consent, get full details, check appropriate form of contact.

#### BACKGROUND

- 2) Consider demographic. Age, nationality, course, year group, computer literacy, ask respondent to describe disability in their own words.
- 3) Does the participant use any assistive technologies to support their computer use?
- 4) Ask about computer literacy. General feelings.
- 5) What social software do they currently use? Listserv, newsgroup, social network, blog, chat, instant messaging, forums etc. wiki, social bookmarking.
- 6) Discuss access issues. How do they physically access social networks? When? How? What most recently? What pattern of access? Why?

#### ONSCREEN

- 7) Discuss usual network activity
- 8) Discuss reasons for using, reasons for joining.
- 9) Discuss an instance of composition (e.g. wall post, comment or status update)
- 10) Discuss content of social networks
  - a. Discussion – typical content of interactions.
  - b. Structure - community
  - c. Interaction
  - d. Student roles – rules
- 11) Discuss advantages and disadvantages of social networks.
- 12) Comparison with other social techs?
- 13) Discuss impact on Real Life. Specify an instance.
- 14) Time permitting, return to any question for clarification.

#### DEBRIEF

- 15) Thank participant, advise of regular contact, supply participant with researcher contact details in suitable format.
- 16) Accountability: arrange further communication to review interview material, transcripts and findings.

17) Debrief. Any questions or comments on the methods?

---Note: In discussion elaborate on/attend to:

1. *Activity* of interest, Social Networking
2. *object* or objective of activity, networking, socialising, other?
3. *subjects* engaged in the activity, participant
4. *tools* mediating the activity, interface, software, hardware etc. affordances of web 2.0
5. *rules and regulations* mediating the activity: norms, netiquette, regulations, university?
6. *division of labour* mediating the activity: any specialist support/advocacy/hosts/peers?
7. *community* in which the activity is conducted, tutors, students, peers, strangers, professionals
8. *outcome* toward which the activity is directed

## Appendix 5: Sample Data

---

### ***Example of Participant Transcript***

**Interviewer (Sarah Lewthwaite)**

**Respondant (Claire)**

*I: Well I'll ask you a few questions about the kind of things you get up to online, and then I'll set the screen capture going and we'll connect our computers and have a look. So, can I ask you how old you are Claire?*

R: 28.

*I: And your nationality?*

R: British.

*I: And you're studying?*

R: [\*\*\*] Ph.D.

*I: Right. And what year of the PhD are you in?*

R: Oh four, I got funding an extra year

*I: Right*

R: So, I'm sort of second/third year, I'm still funded. I'm not, it is not my writing up year or anything. I still have a writing up year. Next year, if I want to, but I'm funded, but I'm funded this year and I probably can't afford a writing up year! You know what it's like, I may need to.

*I: And computer literacy, do you consider yourself...?*

R: I think reasonable. You're probably tell me not, but I think so, reasonable (laughs).

*I: And could I ask you to describe your disabilities or impairments?*

R: I've got a visual impairment, it's all right when I'm at home, because I know my way around and stuff. But when I go outside, I use a long cane because I sort of, I can't ... I navigate *mostly* by seeing, sort of. Sort of workout where the hedge ends 'I turn up here'. It's different to, you know, how you do things when you can see properly. But daylight, unless it's really bright or at night, when it's dark, I don't use my stick, swinging it about and stuff. I just have it down on the floor, to feel for curb or drops because I can't tell, because only one eye works. So I don't have depth perception and I've got tunnel vision in the eye that works and is, you know, the acuity is lower in that, so visual impairment. I've got a hearing impairment, which is fairly mild. I think if I could see alright. I would probably manage without hearing aids, and as I said to you earlier, just us one-to-one. I probably would have been fine, if I couldn't find them in the morning, but it's just that bit more tiring because you fill in the gaps all the time. And that just makes it that little bit more tired. Yes, I can't really manage that. So, they help with in that sort of way. It's more when I, when there's more people or I'm out and I've got to pay attention to traffic, and all sorts of things again, because one eye, one ear is weaker than the other. My hearing is sort of compensating for that, so that I do get the, I can't remember the word, it's stereo but not that. It's multi directional hearing thing, being able to pinpoint things a bit more. Which doesn't really

work when I've not got them in. So one-to-one conversations, I can manage, but other things. It's sort of harder. And then I've got a... nerve problem, which they haven't quite worked out what it is. It might be what's caused my eyes and ears to be bad, it's certainly involved. And it affects my hands and stuff. So I can't feel my fingers very well and I have a special mouse, like on its side, because I get sort of like RSI carpal tunnel-ey type thing. It has got a bit better, but it's still a bit of a problem. So I've got this funny mouse. I've got a back problem, but that doesn't really cause too much problem now. I was on crutches for a long time, but I can walk again now. Um, and I said before you put the tape on. I've got quite severe depression, and I take a lot of medication for that and stress and anxiety and stuff, I've come off the medication for. So if I seem a bit hyper, sorry! And I have a bit of, it's not as bad now, but I get a bit of OCD. Sometimes, if you notice me tapping patterns or something. I try not to, I think that's everything.

*I: Thank you for telling me about that. Can you tell me about the, about the assistive technologies, you might use? You mentioned the mouse as being sideways on.*

R: This is where we had a problem today. Most of the time, the main thing I do with the computer is, you can see here. I've got a 32 inch monitor, which is actually a TV. So if you try to display small text you wouldn't be able to see it properly because it can't do the resolution, but it works fine, because I want everything large. So I going to the window settings firstly and change all the settings to make them I think they're 17 font on this Verdana, because I prefer Verdana to other fonts. I think it's Tahoma normally, which is a bit narrower, and then I change the DPI, as well that if you know about that. I change it to 126 large, rather, instead of 96 normal. So that makes everything quite a big bit bigger than on a normal screen, which is my main sort of thing that I do and that causes problems when you try to use the web, because I also use Mozilla, and I enlarge that. And that means that websites don't display, how they thought they were going to display, so things go missing and bits aren't there that they think are going to be there sometimes they don't enlarge because of the settings or its JavaScript or something and it doesn't enlarge and stuff so that causes problems. But I have SpeakMagnify<sup>47</sup>, which isn't working.

*I: So what is SpeakMagnify?*

R: It is, it's a screen reader and screen magnifier combined. I could put my laptop on and show you briefly, but on this computer I don't use it so much. I tend to try and manage by looking at things. I can't use a screen magnifier very well, because my eyes. It's something I had before my vision impairment started, is that trying to focus, well my, I should say my eye, because only one really works. If I try to focus from something close to something further away that takes longer than it normally would for people, and if I try to focus on a moving object my eyes, sort of go a bit swirly on the way and then focus, they don't focus straight away. So if I try and use a screen magnifier and then use a mouse, everything moves, and I've got to try and focus again. I can't do it. Whereas this is static, I can move my eye, and it stays at the same distance, so I can focus. So screen magnifiers don't really work for me very well. It is, it's not working but they're trying to fix it for me. It was until yesterday, and I've tried to get it fixed, but it's not working on this machine, but it will work on the laptop. But as I don't use it so much on my main machine. Perhaps showing you, you know, just with large settings are better. I do like having the speech option, because my eyes get tired towards the end of the day. Or if I've got a long document or something, I'd rather have it read to me. I like to be able to follow and SpeakMagnify will highlight the word. So I can follow it. So I can highlight of the line, ah, I can't show you, highlight in yellow or put a pink box around something and it will jump from each word, which helps me focus. And I find it takes, I take it in much better if I can hear it and see it. And I don't know, I think a lot of people do really, it just reinforces that a bit and you pay more attention. If I just listened to get to the end and think 'I've no idea what it's just said...er'. I remember some words...um... . Post-modernism!' (laughs) I just think that sort of thing, take it in so well... I sometimes use Dragon. Do you know, Dragon speech, you talk to it and it takes it and do stuff. You can control your computer with it but I'm not very good at that. I mainly use it just to dictation. That's the main thing is that sort of relates to what you're doing.

---

<sup>47</sup> For anonymity purposes, the name of this assistive technology has been changed.

*I: And can I ask about, your actual desk space here?*

R: Oh, I've got a large print keyboard as well... This is a normal keyboard with stickers on, I've got some on sheets of them [stickers] over there. You just stick the stickers on and they don't always fit. This one hangs off the edge so when you press shift it sometimes sticks down because the sticker falls off. So this is one that I've made myself.

*I: You're describing a dialogue with manufacturers and providers. How do you feel about this dialogue?*

R: Well I'm sick of it, because I contacted [PC manufacturers], and they do remote desktop, which would have been fine, but instead of saying "Everything is large. Do you have a vision impairment or something?". He went. 'It's not displaying right' and took all my display drivers off my computer and completely ruined it. It just wouldn't display. So my husband - so we had to give up on that - so my husband had to put all the display drivers back on, because this guy, you know, wherever he was, didn't understand and just wrecked everything. And I phoned up about the USB ports not about the monitor. So it's none of his business what my monitor looks like, and he could've asked, he just mumbled something. I didn't know what he was talking about, and he just went and changed everything. And I was sat trying to watch what he was doing and thought 'how is this relating to USB ports?' But you don't want to say anything because you think 'this is a computer expert', so-called, and he took all my display drivers off and staff and completely messed it all up.

*I: So it sounds like there's quite a lot of extra time...*

R: Loads, loads and loads and loads, and trying to get things working. But there's just so much you have to do, get in touch with them to tell them this doesn't work. You have a conversation with this computer guy and he sort of came to me and said 'it hasn't updated properly', and I thought 'fine'. And after I thought about it, I didn't update this computer. I did update my Uni computer, and I did update my laptop. I did them all in different ways, one from the CD one from the website. So how come none of these three computers have updated properly. How can that be my fault? I got back in touch with them and said 'what?', you're just screaming at them the whole time! Sorry, I'm having a bit of a rant! It's been a really awful week for trying to get my computer working!

*I: Now I'm just going to give you a list of social technologies to find out if you use them. And then we'll zoom in a little bit and focus on networks. I can see Skype on your desktop.*

R: Yes.

*I: Do you use any other voice over internet services?*

R: No.

*I: Do you use any SMS, like Windows Messenger?*

R: No.

*I: So social networks. Are you a member of any social networks presently?*

R: Facebook. What's the other one? Bebo. Although I don't remember ever signing up for Bebo, but every now and then I get an e-mail saying such and such has added you as a friend on Bebo. So I must be on Bebo, but I didn't know. And then Twitter, which is that sort of thing.

*I: I've heard that described as a micro-blogging software, network.*

R: Yeah. Yeah. You sort of send a short like text message sized message to people, and you sort of linkup, where everyone can see your page and you send messages to different people and stuff. So that's quite interesting. And I've got a blog, a maths blog, which I don't. I don't update anymore. Well, I would if I had anything to say about maths, but I'm not doing much of maths

stuff at the moment. And I have like a website that I update and stuff. And that's got a news page, which is a vague sort of thing.

*I: Are you a member of any forums or e-mail lists? (30.12)*

R: Yes, I quite like mailing lists.

*I: Other any sort of forums, just online that you use?*

R: Yes, I don't. I don't often leave messages. Sometimes I do. There's BBC Ouch! has like stuff, I use that sometimes and I have left messages there. There's the [advocacy charity] one. I can't remember, something like ... there's all sorts I've been to over the years and I used to go to... I won't give its name... That I used to go a visual impairment forum. A lot. But it got so scary. I don't know if you know? Different disability groups, and you've got like the people who have been blind or visually impaired since birth versus those who gained it later. And you've got those who are totally blind, versus those that are registered blind versus those that are registered partially sighted and it was horrible! People were just so mean and it's just like "What? What are you doing? People are here for support" Or something, but yes, if you're feeling aggressive. I guess its got to vent it somewhere...

*I: So was that a, an anonymous space?*

R: No, it was anonymous... yeah. I don't know it was horrible. But the trouble was, it was addictive, because you just have to go back and see what someone said, and I tried a bit careful with how I use forums, because I was getting so. I mean, I try not to do it now. But I was like as soon as I get up. Check my e-mail, everything is open Twitter. I've only been on Twitter for a few days and I can't keep off the bloody thing. And it's just, I know!

*I: Do you use Wikis at all?*

R: Yeah, a little bit. I have always... not on here anymore, I have my own wiki thing for my research, but it didn't work.

*I: Okay.*

But it was sort of a Private thing that I was using, it wasn't like... And I use, what do you call that? Wikipedia, quite a bit. I'm often looking for things, and I struggle with it a bit because it was, everything in a little column, and it's quite hard to read, but I was here with someone the other day, and they were saying 'it's awful there aren't any Alt tags', and I was saying 'yes, but it is user contributed'. And he said 'it should make them. It gives you a data field.' You don't get all the tags and things that you really need, the headings and everything. So it can be slightly difficult. Something like that. And people don't know. I mean, I didn't used to know about it.

*I: We'll talk about those in more depth. When we had our e-mail conversation setting this up, you mentioned that you work quite a lot at home. [Yes] Do you also use any other computers regularly?*

R: Four hours a week I've got Uni computer, but it's not working properly, surprise, surprise. So, I do go in, and I have a, an assistant who comes in, but, so I go in. So normally one day a week for about four hours.

*I: So, if you think about where you regularly access your computer, and for how long in the average week, what would you generally do?*

R: Mostly use my one at home. Normally I've got turned on by about nine, and it stays on till I go to bed. So you shouldn't do, probably burning electricity, but then I work for maybe 9, eight or nine hours, sometimes longer. I'm a bit awful for that.

*I: So when you think about something like Twitter and Facebook, how often do you check them?*

R: My e-mail has this notifier, so it will pop up when I got an e-mail. So I don't need to check that too often. Is it blue? Yes, it's blue, I've got an e-mail. Then I'll stop working for some reason. But Twitter, I have it open all the time, and it doesn't refresh automatically so you have to press F5 or whatever to refresh it, so every time I notice it's still there I refresh because it only takes a second to check. It's new, so I'm a bit awful, but I don't see a lot of people other than my assistant and I don't really see people in the department. I have got couple of people that in the last couple of months I've got to know some, I pop-in and see them, but generally I don't see anyone. I'm at home, I just tend to, you know, I speak to the woman in the corner shop that's about it. So I find that these sorts of things are way of speaking to people and getting in touch with people and stuff. So, I'm sort of a bit desperate for human contact. I am awful for it. I really am.

*I: So, would you mind if we have a look at your social networks? If you could open a browser? So now this is where I hope my mobile broadband keeps up... So I've literally got your screen on my screen. I don't know if you can see that.*

R: You're losing a bit with widescreen.

*I: This follows the mouse, so wherever you point the mouse I can see.*

R: Ah, that's okay then.

*I: I notice you've got bookmarks across the top. Could you show me Twitter? [referring to laptop] I'm just catching up with you. Now, I've never used Twitter. I've got a vague understanding of what it is and what it does. How you find out about it?*

My husband told me about it because he's away quite a lot, especially this month. So he's travelling all over the place, and as I said, I don't really see people and I get really desperate for conversation! So, he said he'd heard of Twitter, now he's a bit of a tech geek, and apparently that's sort of how it started. It's quite geeky, and so, yes! I'm a lady geek!

*I: Could you show me around what's on screen here?*

R: So you've got the people you're following. So these are the people that I can get messages from that I've said, 'I know you exist, I want to follow what you're doing'. So, that includes [advocacy charity] and SpeakMagnify and all sorts they are all down here the people you're following, you know. That's the SpeakMagnify people. And that must be [\*\*\*]. I don't know who some of the others are. And then you've got follow-ers which are people that, they're the people that, oh, no. I'm confused, they're people you get messages from, the people who are following who... No! I'm confused! One a lot of people is the people who are looking at your messages and other people are the ones whose messages you're looking at. These seem to be the people whose messages, these followers. They must be people following me and I'm following some of them as well so... I've got [advocacy charity] are following me. Why do the [advocacy charity] want to know what my messages are? I put them first and then they must have clicked me back. That's weird. It's a bit weird!

*I: What do you mean when you say weird?*

R: I don't know, they've probably never heard of me, they might have done. But it might just be that they've gone 'Someone is interested in us, we'll follow them back'. I don't really know. And then there's some other people on here. My husband and things. Oh, has he gone? There's someone else who's like a tech person and I happen to mention SpeakMagnify on here and you can send direct messages which don't appear on the page. It's sort of like sending a little e-mail and I don't really know why you don't just send an e-mail, and these are direct messages. And he sent me a direct message saying 'get a proper screen reader like [\*\*\*], 'SpeakMagnify's rubbish', but he sells [\*\*\*], so... you know, but it's interesting to see that. So it's quite interesting that it's sort of pops up with a short message that you can ignore rather than having to open the e-mail and all that. So it's quite useful for that, really.

*I: So what do you gain, what are you getting, exactly?*

R: Some like [advocacy charity] have told me that they have a radio controlled talking clock, which is like a new thing and you can put you, your link to it and things. And you can, there's all sorts of things you can add in that aren't actually part of Twitter. There's Twitpics, which is a site that allows you to put a picture there and then like send a link to Twitter. So if you want, you can't, Twitter won't let you update, upload photos or something, but if you've got a link that will take you to the photo, but it's not actually part of Twitter. And there's loads of them apparently. All these things that aren't really part of it, but will react, interact with it.

*I: Have you felt like you're on a steep learning curve? Or has it been straightforward?*

R: No, I've learned quite a lot on the first day really and it wasn't too hard. It's just sort of, you notice that someone is.... Oh, here's Twitpic. So... I don't know what that is. I'll have a look... But you click on that and it brings this up, and I sort of found out about that. Just because it was there, and I wondered what happened if you clicked on it. Actually, I shouldn't have clicked on that... Hang on I've clicked on the wrong thing. I think I've gone to the main site, rather than to the actual photo. But, but this thing is a sort of open to everyone so. Anyone's photo can pop up here.

*I: Right. So these are photos people are taking somewhere in the world, and they, and it goes on to Twitter.*

R: Yeah.

*I: So has this been direct or is it indirect messaging?*

R: This is indirect. It tells you... Direct messages go to this second separate thing. You click on direct messages, and it takes you there, and then all of these are sent to everyone. These are just general things she's posted, and if it says, are... I don't think there is one here now. If it says at, if there's an @ symbol in front of that, then it's a reply to me to something I've said, but still everyone can see it. It's only direct messages that not everyone can see. But then if there's one here, it can be a little bit confusing, because you've got to work out which message they've replied to.

*I: I'm interested [yeah] you've mentioned Twittering about screen readers [yeah] which sort of implies you use a screen reader [yeah, yeah] Were you conscious of 'disability' when you were posting to the group?*

R: Well, not so much that. It's just that, it is a bit of a weird thing, because what you say... And, I'm not sure how it works. I *think* that if someone decides to follow me tomorrow they can get my back messages. So... and you can block yourself so that you have to approve someone before they follow you. And one of the people I want to follow, who is like a tech accessibility person, has done that. But I'm a bit nervous and saying 'I'm interested in what you're doing' and I don't know, he might say, 'No. I'm not going to let you follow me', and that'll be embarrassing. So I'm not following him. I'm not blocked, so anyone can follow me. And everything you're saying you're thinking 'my brother might look into this tomorrow, so don't slag off so and so'. You know, more that sort of thing. Thinking, however you phrase something you've got to be a bit careful. So, I don't want to say 'I'm sick of not being able to see', because some of my friends are totally blind. And I'd feel really awful about that. Because they *know* I think that, you know, and they do to, but I haven't really got that much to complain about. You know, I can tell you're there, I can see you got dark hair. I can't really see your features very well, but I've got a fair bit of vision. So I'm not going to say some of the things I think about being disabled, if you see what I mean. But most of the people on here know I am. I mean, [advocacy charity] don't know, but they'll assume I am because I'm following them, but I could just be interested. And then most of the other people are people I've selected, but there are a few of like friends that [\*\*\*] and I have got that are following me and stuff. And then there are some people I've never even heard of, but then I don't really care what they think of me. So I'm not sort of too bothered, but I did find myself sort of thinking 'what am I saying?'. I don't know if I can find the e-mails I did send in the end. ... It's this scrolling thing that is a bit tricky for me. (49.45) . I'm not sure if it does update every now

and again, because sometimes it suddenly jumps to the top of the page. So I think it might be set to refresh every now and again. There have been loads of messages since I sent mine. So again. Its people think, perhaps you, you've got something to do with that. So I sort of mention what I'm wanting to do eventually. Where is that it must be the next page, I think. I love [onscreen] that allows travel on any permitted route. If it's not allowed, how can I be permitted route? It can only be a permitted route if it's allowed. Where is it? There's been so many [messages] and it's only been 10 minutes.

*I: If you just scroll up a bit I've just spotted, there's a message you sent to [\*\*\*] directly there.*

R: It's not direct, it's a reply to her message. So anyone can see it, but it's telling her 'I'm replying to something you've said', if you see what I mean. Saying 'AAAh! PhD, it's hard!'. But she's got kids and all sorts. I don't know how she does it. [To computer] Come on! I don't think you can search through your messages, which would be good if you could because this scrolling is really doing my head in. Um.

*I: So, does sensitivity to it - do you think that heightens your awareness of...?*

R: Yes, and like weird things happen. He put that he's going to watch madmen on i-player and the next day someone in the persona of a character from Madmen started following him, because somehow you must be able to search it because they must have searched madmen and got him. Some weird things happen with it, it's interesting, I don't know. I have said something, I was thinking about throwing my computer out of the window and it seems you can't have large text on screen and working screen reader program and that was when this other guy got in touch with me directly and said 'yes you can, get a proper screen reader.

*I: So was that a reply to you?*

R: His was a reply. This was what..um, I said, so I said this. So I said yes, I'm doing this. Then I sent the two [\*\*\*], he said, I must have said somewhere, oh, it's on the next page. I said, 'Twitter's addictive', and he sent a message saying 'have you say that out loud?', which I did and I typed it and 'you seem to have cured yourself', because I didn't send a message for hours. And I said no, I was at a meeting, and it was, because this can be seen -I didn't really think because here I was trying to be a bit careful about mentioning which screen reader. I don't want them to see this and I don't think they are following me, but they could do. And it's me whingeing, which I didn't really intend to do. I wish you could sort of .... I mean, yeah, you can block certain people, but you don't want to block someone because that's a bit rude, you know, because they'll go, Oh, I've been blocked and presumably they'll be told, or they'll. You know... they'll know. And certainly if nothing else they'll not get any messages. So you don't want that. But...

*I: Do you think your awareness of this it typical?*

R: I don't know. I wish I could have two Twitter that has [advocacy charity] and SpeakMagnify and then me on this. But I don't know if you can have two accounts, and they'll have to have different email addresses, because it's based on your e-mail address and it would be difficult. But I wish I could have separate bits. So it's just a worry when I say things, because I think, you know, you're just aware. When you say things that, that's been taken. But then... are people going to think, if someone. I haven't put it on my website but I might put on my blog. I might put on it that I got a Twitter feed if people are interested, but I don't know if I want to because I don't really want talk about professional things on it. I'm happy to keep updating on, what the [advocacy charity] are doing, but I just want a place for talking to friends really, and it's sort of become a bit of both.

*I: That's really interesting. Could we have a look at Facebook?*

R: Now, this will be rather telling in that I have Twitter up here and I don't even have Facebook in my drop-down list, because what happens is the only time I ever really go to Facebook. I've been there because of coming out, and the only time I really go is when I have an e-mail saying somebody's left you a message or whatever.

*I: This is the first time I've seen Facebook through your personal settings. How do you, you find it?*

R: ...SpeakMagnify has added some stuff to make Facebook work a bit better, but there are a lot of problems with Facebook. I have problems...

*I: How do you find it when you first came across it?*

R: I could be wrong, because I sign up for so many things but I think Facebook... I'm fairly sure it was Facebook. There's a CAPTCHA to sign in, so I struggle with that. I can see if I have to, but obviously, the screen reader is not going to get anywhere with that and the audio ones. I don't know if Facebook has an audio one but the older ones have to be distorted, so that a computer can't pick it up, and they're so distorted that you can't hear them up anyway. And what happens sometimes, is, I don't know if you can see here with log in. It's get cut off so on a site I try to sign up to the other day you had only half the capture, so you couldn't read it, so there's absolutely no hope. So, we tried the audio one because my husband was here. We tried the audio one he couldn't get it and he can hear perfectly and he couldn't work out what it was asking him to put in. So they're just, those things are really hard. And once you've got in every now and again it would ask you to verify who you are by reading the CAPTCHA. I think it's Facebook, I can't think what else it would have been. I think it must have been Facebook. So, someone, I came across a forum that said, contact this address, and they will remove that if you tell them you can't see. So that's when I had my thing, because often I say. I'm visually impaired, because that could be anything. If I want to sound like I can see a lot I say I'm partially sighted, if I want somebody to just go 'Ok we'll help' I'll go 'I'm blind', because I am on the borderline and partially sighted at the moment. I'm probably being registered blind. And there, you know, so there's these three... It's something that I want to look at more in my next lot of research actually, because it's just how you present yourself? And I've got these three different things that I use, three different terms I would use depending on how I want to sound. If that makes sense...which I find interesting, because I know I do it and who else does it? I want to go into user mobility aids, you know, because if you carry a long cane, that's *kind of* saying 'I'm blind or have virtually no vision', which isn't quite true for me so people tend to assume that. But I'd rather someone assumed I couldn't see anything work back then, that than assume I can see a lot, think I'm drunk, and I know people who got the same vision as me, maybe slightly worse, that don't use any mobility aids, and I think that's really interesting, because they would find it easier if they did, and they admit 'yeah, it would probably be easier, but I don't want people to identify me as blind'. So it's interesting, and I think that sort of feeds back into the these sorts of things, because I tried to choose photos, where I had my eyes open, because I have problems with keeping my eyes open, with the, I'm sensitive to the light. And I just sort of think my photo. I don't look like I've got a visual problem, and there's because obviously if you can't see it being for a start you're not going to know what your photo looks like. But some people do talk about, you know, one thing not to look too disabled in their photo or whatever. And there's someone on the list, who is visually impaired, and I don't think you'd know. But another thing I wanted to do was only have my head, you know, there's a lot going on, and there's like people who potentially might sign up, who haven't seen me in years, and I'd rather they could only see my face! And on one of them, I think it's on Facebook, I've actually got quite... I'll sign in and find out [typing].

*I: Yes. Let's have a look.*

R: I don't normally come to this page, because as I had the same. The only time I log onto Facebook is when I've had an e-mail that says, 'someone's added to you' or someone's done something, so I don't *remember* otherwise. I don't, I mean, Twitter, I find really interesting but Facebook's just a bit blurgh to me really. And I'd I click on the link and go there then. So, I think if I click... See again the thing is, my Twitter and stuff automatically signs me in, but here, I haven't even entered my password, but I'm going to put 'remember me' this time, and I might actually logged in, I might add it because I, I don't know, the I might use it more but I haven't. Let's see if this is going to work. What happened there?

*I: We're just catching up on this side [reference to screen capture]. Could you scroll the mouse across to the left of the screen, because my screen capture will just capture this.*

R: This is quite an old photo. This is from 2003. You can't see all of it. I don't know if I've got it here anywhere, but is a photo I really like, I've got a pink top on that I really liked. And all this and it was like my favourite photo of myself and it was, this was a bit dodgy, it's a doctored picture of me, and it was the one I always used. But now I've lost the electronic file, so Twitter has a different photo, which I don't like at all. I don't like this picture at all. And if I could find this one again and go back to this one because it's much nicer picture, but I know people who got professional photos they've had done, a bit like professional photos done a bit like their passport or whatever, but they use those. (Laughs)

*I: So... this is your newsfeed, your livefeed. Can you show me around the page? Would you only go to see what activity you've been e-mailed [received an email notification] about?*

R: Normally I have problems with it, because as you can see there's these things, and you can't, you can't, you can sometimes get to them but if you're not careful it'll go missing. This is better than it used to be [gestures with mouse] in previous versions of Firefox this was transparent, the background. I don't know if you know about this. So these, behind, would show up, so you didn't use to be able to use these things at all, if you had enlarged settings and stuff. It just wouldn't work. But now, Firefox has done something that means that works and that is one of the biggest changes for me. I mean, that is really, really good for me.

*I: So you think Firefox [yeah] is trying to improve [yeah] rather than Facebook?*

R: Because as I say, it's only on a few sites. As far as I'm aware it's the only change is with Firefox 3 has fixed this problem of it becoming transparent, because that was a big problem. But the thing is for something like the screen reader these drop downs are virtually impossible, and the thing is, is finding this here. I happen to know it's there. I can see, you can't quite find it. Getting to that is quite hard. And there's.. I don't know what this is, is this a box?... Oh lord, what have I done now?!

*I: That's your status box, which is where you would...*

R: I don't think I've done anything.

*I: ...it's essentially the same as Twitter. It says 'Claire', and you could say 'is doing an interview' or 'is out and about'...*

R: Oh right. I might, I might have done once. They've updated Facebook haven't they? Could it was quite a while ago I remember someone saying they've updated Facebook because they were whingeing about not being able to use it with a screen reader. The way they were, because things have moved because she could set up to tell it. So you always go say, you always go to that edit box. You can tell the screen reader and put a new something, you know, you can tell your screen reader 'when you get this page always do this action'. So you can put in a command that will always say like 'Search and label this' even if it's not properly labelled as a search box. So some people would set up things to say, go to the first edit box to put the status then. Maybe that was what the search so these settings don't work. So that's been a problem for a lot of people. I've not really used SpeakMagnify much with Facebook, because as I said, a lot of the time I'm enlarging stuff, but similar things in that I know to send my eyes to a part of the page, and that is in the same part anymore. So I have to work around, so there were words there and then I clicked on them and nothing happened. And then I clicked on, again, I looked at my name is crossed out. I don't know if it'll show up, of it does show up. Sometimes these things, quite often when you've got an edit area, you don't get the full word. You get half a word. So you just have to hope that you've typed in right and there's a button here I think [gestures with mouse].

*I: It's gone, as you've scrolled onto it.*

R: So I can get that often these buttons overlap, see this might be interesting. Just quickly to sign back in again. And this is tabs, and this is often what I have to do. You've got IE tabs set up, which means I can any page am looking at. I can look at in Internet Explorer instead, but Internet Explorer, I have big problems with bulk, I thought that's how you did it so well.

*I: You're in the right box. It says e-mail.*

R: ...and this is when I really need speech, because then I can tell what I've typed...

*I: It says Claire @ gmail.com. So this is Facebook in Internet Explorer.*

R: What I really should've done is open it in a separate tab fees, these at the top... I do want to zoom, but I was going to try and change the ... I don't really use this, it's very much worse, text. Normally I change text size somewhere. Is it at the top? Is it not in this version? I'll just zoom in. Control, that's what I was pressing, wasn't I? Ah, control shift plus? No? Weird. That's a problem, not everything appears.

*I: These spaces aren't actually spaces, that's part of the problem.*

R: Weird. It told me it was Control Plus. I think it's Control Plus Plus, which I'm pressing it should be control shift plus, I don't know why that isn't enlarging.

*I: That might be to do with Facebook and not to do with the browser.*

R: It might be. Anyway, I'll go back and I might have to log back in again. Anyway, come on go back to where I was, there we are. So I've got these things, they are there.

*I: So, can you show me the kinds of things you've done on Facebook?*

R: Not a lot, I get people saying ... that was what was popping up before, wasn't it?

*I: That's to do with editing a message that goes on your feed is if you get too many messages from [\*\*\*]. You can just ask to see not so much, things like that.*

R: So I've got some applications, because people have said to me do this. This is [\*\*\*]'s. one and I don't know what these are. I'll just giving. I have Just Giving website. And then something down here, I don't know what's going on.

*I: You've been poked there.*

R: That's interesting, I haven't heard from her in years.

*I: So some of these things, you don't receive notifications about?*

R: That's interesting, I remember him. See that's a sort of quite. You know, so yeah, I don't go here very often. I added him by mistake. He was someone I sort of vaguely, but I didn't mean to add him because I don't really know him enough and he said 'yes alright', which is weird.

*I: So have you seen your profile page? It's at the top.*

R: That one. It's the only sort of thing I'd really edited. I don't know how to get to like my wall. I sometimes come across it because someone is added, see, this is my pink T-shirt and stuff. And I don't know if you can zoom in on that picture. Hee-hee. But yeah, it's quite an old photo. I really should have a newer one.

*I: The wall, if you just scroll down, is just this area here, where it says you are now friends with Ben. So that was 19 February, four days ago, at about the time.*

R: I had an e-mail [\*\*\*], something like "[\*\*\*] thinks you might know this person" and I clicked on that. I didn't know he'd accepted it.

*I: And then before that Sarah has written something on your wall, which has disappeared, and that's direct to you. Did that come in e-mail?*

R: Ahhh. Oh. Yeah. Yeah. I did send something, I don't know, I don't remember.

*I: It says 'you invited us for dinner' So this is a conversation that almost happened over months?*

R: I don't speak to Sarah, very often. I saw her loads [...] and hardly since. I mean this is 2007 'thanks for writing on the wall. I didn't even know I had it'. So that was the first time I discovered it, I got an e-mail saying someone has written on your wall. What's that? I didn't know what the Wall was! So I went there to try to find out, and I guess I've been there and, like, replied to her, because I don't think I know how to get to this. I don't know how to initiate a message without having replied to someone. I mean, this is ages ago. Yeah, that's what she must first, there's nothing on your wall.

*I: That was in June. So when did you join Facebook?*

R: I think in the May 2007.

*I: Why did you join?*

R: Because [\*\*\*] told me to again, no it wasn't, no it wasn't. Facebook was actually weird, because [\*\*\*] had signed up, but hadn't changed his profile and hadn't told anyone he'd signed up. I think he, so I signed up, and I can't actually remember who suggested I sign up, but someone said to me "sign up to Facebook" so I did, and I think he did to, I think where it goes to your e-mail contacts, and that's so Sarah came up. So I suspect it was Sarah that told me to sign up, and then if it says exactly when I signed up. I think it was the May of that year, and Jane found out I was on and she's said "you've put nothing on your Wall", because I said "I didn't know I had one". And I didn't really have anyone signed up at the time, and then I replied to that. I guess it was the same day, because I would've got an e-mail about it. Yeah that went out for my birthday. And thing is, so there's not many, I haven't done anything in quite a while, because I sort of forgotten about it and things seem to come up and I don't really know what they are. This is quite good, I must go... yes that types ok, that's quite good. I wasn't sure of that. But then this is... God, weird.

*I: So if you click on your profile again at the top. I suppose I'm aware, Facebook can be so social in the sense that people spend a lot of time on it.*

R: I don't really know what happens because it sometimes says there's no one there, but I've never. I don't know what you do, do you talk like on a messaging board or just on the Wall?

*I: They have introduced an instant messaging thing which you can do it and if you can see down in the bottom right-hand corner.*

R: Things seem to pop up. I do know someone with that name, I can't tell from the picture of her not do know why she's there. Does that mean she's trying to mail me?

*I: If you just scroll up a bit. It's not very clear, but basically, there is a thing, which recommends potential friends.*

R: Because that says we both went to [\*\*\*]. Yes I know him.

*I: So it may just be recommending people, you may know, because it's a where you've got three friends who were also friends with this person. So, there are these recommended things.*

R: What does 'become a fan' mean?

*I: If you like something, it's a way of stating you like it on your Profile. So, how does this compare to Twitter?*

R: For me, if you look at how different this is displaying properly, you can see everything about Twitter and other quite good things about it with the screen reader as well. It's then you can see, it is displaying properly, and everything and then you go somewhere like, like Facebook, and there's so much. It just hurts my head being there, because there's all these columns, and I'm trying, I just really struggle with it visually. And I did have a bit of a go. I can't show you 'cause

this is not working and trying to sort out whether there are headings and all the things you need to work the screen reader, and it wasn't very well done.

*I: So, with regards to interacting with your friends here, would you do you treat this as a social space? How does Facebook influence your life?*

R: It's quite interesting going here now. There's just loads of people that have it. I vaguely remember him. I've been trying to get in touch with this person. Twitter is just great, everything displays properly. It's really good. Facebook Argh! there's too much going on. It just feels cluttered, I don't know.

*I: Does it make you feel a certain way about a certain. What's the word? Does this clutter change how you feel?*

R: Yeah well, I get cross, I try not to. My husband says it can be difficult depending on what you're trying to do. Something like Twitter, I guess there's not a lot you need to do it's fairly straightforward. So I guess it's fairly easy. Whereas this they're trying to do so much with it. You almost need a cutdown version to be able to just look at some things at a time. And just find there's a bit much going on. So I don't know what I'm doing with it. I can't follow it. Whereas Twitter I just picked up, because it's much simpler and simpler and yeah, that's just done and things. Yeah, most of it, I deal with it through my e-mail really.

*I: Does Facebook change how you view and interact with friends?*

R: There's an awful lot going on, but I don't know, I've just gone and there're loads of people with thousands of friends and I'm like, 'wow, I didn't know they were there'. So, I'm sort of like I'll maybe have another look at it, but I don't know. I don't really I just don't find it very easy. I did, I went away, doing my research, and I don't know. I was sort of feeling a bit. You know at things a bit and I don't how I did it. I guess I must have gone to like Alton College. Or something, where I went and selected people who went there on my school. I don't know how it works. I don't remember now that I got in touch with quite a lot of people may be about 20 people I knew. And maybe 10 of them added me as a friend and as a few people have been talking to, that I hadn't spoken to in sort of 12 years. So it's quite interesting, but we don't ...

*I: So you're having a conversation through Facebook?*

R: Yeah, but not regularly. That's the first time I've spoken them to them in years so it was quite interesting. And there are a few people I may be sort of fell out with a little bit. And now we're speaking, because I guess it's, you only have to be a little bit, you only have to be civil, you don't have to be whatever.saying. But there is one person who was obviously quite interested so I sent her a couple of direct messages saying 'when I'm in Alton do you want to meet up?' but I've never heard back, so maybe she's not getting the messages . Or maybe she's ignoring them something to draw back a bit, because perhaps ...

*We also talked about how the computer helps you to get out outside the house in a way. [Yeah] and get that social interaction. How does social media, like Facebook, Twitter, how does that change your day-to-day experiences of disability?*

Well, it's so important to me, because it's much easier for me to communicate through the computer. There's a number of issues. There's the visually getting somewhere, to see friends or whatever. There's the holding a conversation sometimes, I don't know I'm a bit worried about the impression I give to people sometimes, because when I hold a conversation I have to really listen to what's being said. Like when I did my interviews, I find that I'm concentrating so much on what's being said, that I can't work out what my next question is. And I often end up interrupting people and things. When I don't mean to, but I'm still processing what they've just said, and in my head they've only just finished saying that thing and I'm not even listening to the next thing they're saying. And [\*\*\*] always having a go at me for interrupting people but it's because I'm not hearing it in the same time span that everyone else is, and I'm trying quite hard today, would you not to do it but I probably am making. It can get quite hard. If you're concentrating its alright,

but you know, when you just want a conversation. It can be difficult. It sounds like a silly thing, but it does worry me quite a bit. So I'm a bit nervous when I go and speak to people. I'm so busy listening to and what have you, I, someone asked me how I am, and I'll tell them. And then think 'I haven't asked you, gh God that's really bad social manners'. You know where it's, when you're on something like this. It takes time, you ask a question you get a response or whatever. Or it's just, you know, instant messaging, so you've got the time and things is so much easier because you can sit there and you can think and are not expected to respond straight away. So that's easier. So in both those respects is easier if my back setting, and I can't walk today, I can send messages. It does interrupt my work a bit, especially something like Twitter, because all the time. What's that and my e-mail, because I feel really starved of social interaction, I guess. And it's weird...

Although so many people I lost touch with, and part of it I think is that when I'm walking around, you need. Sometimes I think "that shape, is that someone I know? It might be?" I'm not sure so I don't say anything. Sometimes I do there someone I know who uses an electric wheelchair, and I feel really bad. It's like discrimination, because there aren't that many people who use electric wheelchairs on campus. So that an electric wheelchair wearing, particularly in the Law and social sciences building, which is where he is also based on that person also seems to have sandy brown hair, I'll ask if it's this person, and it is, it has been everytime, but then when we were in town, I didn't realise, he went past me and I didn't realise. So most of the time, I don't notice people are about, so they probably think I'm ignoring them and I just want to say 'I'm not ignoring you. I don't know if you're there, say hello to me. Perhaps tell me who you are if you don't mind'. I always do and I've got a lot of totally blind friends who say 'Hello. It's such and such', and they perhaps know. But I say, just in case they're not sure because it's really hard and tons of people say hello to me and I don't know who that was. Something like this is set to a name. It's just, I don't know, it's easier, but, I don't know if I want that because it's a bit of a sad state of affairs in a way. You know this only dealing with people, electronically, I mean, we're not robots. We, and it is different is very different meeting up with someone. It's a very different experience, and that's why as I said, through Facebook. I tried to contact his old friend of mine, we were best friends all through school, and we fell out. [...] That's when I sent her a message actually in a jokey way. So we're talking again, so. It's so different, but I really need it. But then often I will try and arrange to meet physically. There's someone I e-mail a lot. I don't see him very often but e-mail a lot and we've arranged hopefully to meet next Thursday evening and stuff. And it's just like that's a way of getting into it and stuff. You know?

*Are you conscious of the ways you might put yourself into text? When you're contacting people?*

I don't know, I just try to. I think it depends on things, because like I've got my blog, and that's it was supposed to be personal, but it is a sort of professional type thing. Then I go to Twitter, and I'm trying to be aware to be a bit professional in case the professional people are looking out, so I'm careful what I'm trying to say and I'm not always myself. Whereas with Facebook, it's only friends. I've got this as a professional blog. I've got Twitter, which is a bit of both and then I got Facebook, which is just friends. I'm not. I don't think there's anyone else there, although I don't know how Facebook works as to what appears and stuff. I don't really know how your status appears, doesn't it? So I'm not sure if people, if what I put appears on their page, but I'm more myself with Facebook. Like I said, I feel like [home town]'s home, so I'll say what I feel a bit more and tell people stuff. But then.

*You get a sense of people being same way of people being in some way more authentic on Facebook?*

I think maybe, I think e-mail is the best form, because you know who's going to see it and you know the right people are going to see it. So that's okay. But now I think about it. I'm not sure if I've told these people from school that I'm disabled now, because, I had a friend. All the way to secondary school and she just couldn't really cope with the fact that I couldn't see, because to her. That was, she didn't like it when I started using a cane, because you should be doing the best you can do about it and it was just the way she was brought up. And I was weak and sort of a second class citizen to her and that was horrible because we were friends for so long. She is on Facebook,

and I sent her a message, a direct message, well, it's not a direct message on Facebook, but like an e-mail or whatever to her, because it was National friendship week and I just thought 'well go for it' and I said 'its National friendship week, so it's time I told you that I really miss your friendship, and I'm sorry that you know, something that happened, I'm sorry for that', because we were friends. [...] And I just didn't have so much time for her. And you know, it was really horrible stuff, and I just wanted to say "look I'm really sorry and that like to get in touch and she sent a message back saying 'I'll reply to you when I've got more time' and that was in November and I never heard again. That's the last time I heard from her and that is really sad, and it feels like a way of getting in touch with people... And like, with talking to her, I don't, she doesn't have to have my disabilities pushed in her face and have to deal with them. I don't have to mention it when I talk to her, and people will send to me things like saying 'how are you? I hope you're well', because I've not heard from them in years and I just say 'well, health not great but happy' or something. I haven't really gone into details about it with any of them, because I'm not sure how they'll react. And I don't know, I just feel a bit uncomfortable and I know I've lost friends because of it. ... and when I started going bad I got upset about it and the depression kicked in. Really badly and I probably wasn't a nice person to be around and that didn't help with everything. This really annoying, miserable now-disabled person, who carries a white stick and she didn't like being there. So it was difficult, where as this, I don't have to mention it. I can just keep... Obviously with the maths thing I do because it's part of my authentication from being able to say: 'This is an authentic experience. I'm visually impaired.' But for most of the other things, I just sort of keep a bit quiet about it, and it felt a bit weird sending a message saying 'you can't have large text and a screen reader', because I did think there might be some people who don't know that. And one person who I didn't know who was following me suddenly wasn't following me anymore. And I thought 'it's probably not because of that', but you do think 'Well, maybe I've put them off' because I think ...

But I was using e-mail and some things, you know, something like 98 or whenever when I first really became aware of the Internet, and I can't remember. It was on some forum or something, and if someone said they were disabled at that point I felt weird about them. Not necessary that there was something wrong with them. But what if I say something wrong. You know, like I know now that, that visually impaired people say 'see you tomorrow', even if they can't see, and that's fine. But when you don't know that think was, if you say. I'll see you another noted, get a vision impairment. I got involved in a forum, and one thing that happened was we were talking about being visually impaired, I have a name, it might be obvious. Like, (I can't think of an example) that they might have the word in their name. Some sites I've been to there are vision impairment sites have like "blind girl" or something as their name. And you're just thinking 'that person, probably yes', but maybe they're using it for another reason. And you're not sure. So sometimes people do state it but I never would, I just use my name, and I'm really nervous about what you put because some of the sites are a bit like the [\*\*\*] site. I was on, the just sort of them abusing your initials and unthinkable, God, that people might still know who I am don't want to use my name, I want to hide, but to explain yourself. Sometimes, you have to, sometimes you don't want to, sometimes you sort of had to defend yourself and lay out who you were.

*So, are you aware of, of disability when presenting yourself on Facebook?*

I certainly changed how I am, very aware when I say something. I thought that today, I think being able to say different things and I want my picture to look 'normal', which is just horrible. Why can't I just accept myself how I am? Other people don't always. And I used to be one of them, so I can understand that there are probably a proper still have my prejudices, and everyone does. So, you just when you meet someone face-to-face, you still don't know everything. Do not necessarily going to know their sexuality or whatever, which some think you might put across that you can often tell. You can't always tell somebody is visually impaired, but for me personally, if I go out is quite obvious that I'm visually impaired and my hearing aids are in, it's quite obvious I'm hearing impaired and stuff, but you don't get that and. I notice that some people e-mail, and this is an aside really, but I sometimes use Dragon, and it does make silly mistakes sometimes. So it'll be things like the typing error, and I noticed someone had put at the bottom of their e-mail message: 'This has been produced using voice recognition, so please excuse any errors', and I thought that's sort of interesting. I don't know. I don't know if I would be brave

enough to say that and someone else sent from a company sense to me and said at the end of her e-mail 'my access with speech', which isn't quite how I'd put it. I think she's English isn't her first language, so it's a bit. It sounded a bit formal ' my access the speech', so text not website or something, which again is weird, because really, you should be able to use most websites. So she's saying basically, don't send me a link to some where copy the text that which seemed to be what she was asking, that again is putting forward when you don't know someone. It's a bit weird. So I don't know. It's a weird thing.

*I: I'm aware time has passed, so we should probably be drawing things to a close.*

End of Recording

## Sample Extract of Coding Process

### Excerpt from coded transcript (Roy Interview 2)

¶347: R: Well hopefully you might have got the indication from me that I try to be as normal, using the word 'normal' loosely, as possible. I'm not trying to suggest that people with disabilities aren't normal and that's very politically correctness kind of thing, can we forget the political correctness? I don't like the fact, I don't like people knowing... well I suppose that's not really true. I don't like being labelled, myself, as being disabled, because I think I'm just as capable in every respect to do with everyday life as everybody else. And it really used to frustrate me, like, it would be, like, going to a new college or school or parents evening and my mum would be like 'mind the steps' or talking to the teacher and would say things like 'and are you making sure the work's enlarged' because the nature of my disability is just a visual impairment, both and long and short sighted, and I would always push away as far as possible from any suggestion that I couldn't really see as well. And I cannot see as well as a lot of people, I struggle, especially with the reading here. I got a lot of things produced in large font but I never take them to lectures. And that's more of an insecurity to do with me. Back home everybody knows that I have sort of a sight problem and nobody cares. But when I came to university for some reason I didn't want to, kind of, go through all that again having to explain it all. I'm pretty confident that I could talk to anybody, sort of the flatmates, the people I'm with in the hall and you say you're, 'I've got this, this isn't an issue I can't see very well', and like they went 'oh well'. In fact there's people here who have got their own sort of issues - everybody's got something. But for some reason I never really wanted to bring that to the front here. I don't really know why that is. So here, nobody knows I've got a disability. And that meant it's been quite interesting to see if people could tell. So, I've been trying to push to be as normal as possible and it's pretty much been working, I'd say. It just means that when I can't catch the Frisbee, I attribute it to being rubbish at catching, not because I can't see it coming as easily and stuff like that. But that's one way of dealing with it for me.

¶348:

¶349: I: *So the term 'disability' is that the negative connotations of difference?*

¶350:

¶351: Yes. Also the word disability implies a range of difficulties, and there's definitely stigma attached to all kinds of disabilities which is totally prejudiced and I don't agree with it, I mean I did the induction program here and I did that with the people that were deemed to be disabled here and there was not a single person in the room I can get on with it can have a laugh with, some other people like... there was one particular guy who was in a wheelchair and he was fantastic at Pool and he beat me every single time and there's absolutely nothing... there's no reason why are people with disabilities aren't the same, it's just society's sort of stigma...

¶352:

¶353: \*knock at the door\*

¶354:

¶355: Hello.

¶356:

¶357: (Inaudible)

¶358:

¶359: I'll be down at in a bit.

¶360:

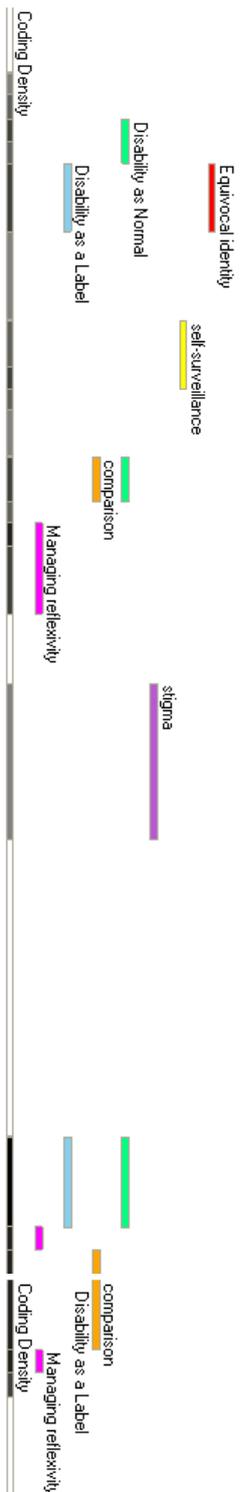
¶361: [I'll see you in a bit]

¶362:

¶363: *You were just saying. I suppose, about society's role in creating disability?*

¶364:

¶365: Yes, it sort of, the fact that there is they have this term 'disability' instantly makes it seem different to if they, kind of, just, sort of grouped everybody in terms of their strengths for example then disability would just be seen as a weakness and you would look at everybody else's weaknesses and it would be something and it wouldn't necessarily have to be a category. But, it's, I don't know, I think ... I think I make more of a deal of it than it actually is. From the outside. I think if people looking inwards, being a, get on with their own business. Because I wouldn't prejudice people and if I get on with them it's because I like them. their personality I can't see that being a reason why somebody wouldn't want to hang around with someone or make friends with someone. I'm just that extra difficulties it's a mobility disability, and mine can be classed as that because I walked into lamposts a lot, but, you know, you just have to deal with it.



## **Sample of Coding Output**

### **Surveillance (Negative) / Child Code: Exposure**

[<Internals\Interviews\David\David interview 1>](#) - § 5 references coded [2.89% Coverage]

Reference 1 - 0.65% Coverage

Also I don't really, I mean, I've always been a bit suspect about who can look at your page. I've got the full privacy on mine. But also I just, I didn't want like the big picture of me, where people search your name and they can see it, because, you know, if you know me then if you add me I'll be able to tell anyway.

Reference 2 - 0.86% Coverage

I just found, because on the homepage whenever anyone does anything it just pops up and I mean you used to be able to delete it when you'd written on someone's wall so that not everyone can see it, but I'm not quite sure how to do it on the new one. I don't, I mean, I don't really like the fact that everyone on my Facebook can see when I write a message to someone, like a friend at uni or a friend at home or anything.

Reference 3 - 0.52% Coverage

Even still if they all know each other it's, if you're [\*] from writing on someone's wall just, it's almost like a conversation you're having, you wouldn't want someone listening, standing right next to you listening in while you're talking to someone.

Reference 4 - 0.42% Coverage

It's just when I saw people's like private conversations popping up on my homepage. And often it's with people like I'm friends with and their friends who I don't know and I feel a bit sort of intrusive.

Reference 5 - 0.44% Coverage

More people who are going to see what I'm writing and stuff. I mean, that might be part of the reason I don't use it as much any more as well. I just, I definitely don't write on people's walls as much as I used to.

[<Internals\Interviews\Gemma\Gemma Interview 1>](#) - § 8 references coded [10.14% Coverage]

Reference 1 - 1.65% Coverage

I have kind of been tempted to get rid of my account, because I feel quite insecure about it in a way that people can know about me and my life and without them not really being in it and that people who were at school who used to bully me and they can like judge how I've grown up, because you've got your relationship status, how many friends you've got, who's written on your wall, how often they write on your wall. It seems a bit of a, like a popularity thing. And like the photographs, it's, you know, I'm not very photogenic, and I look like maybe I've grown up into somebody who I'm not, you know. And I am quite, I'm really self-conscious of that, kind of

people misjudging, misunderstanding. I don't know if that kind of stems from the childhood experiences. I don't know. So I've taken my pictures off there and I'm quite kind of strict on the security of who can access it and I'm kind of contemplating, shall I get rid of it altogether? Or keep it because then I do have contact with people and it's free, unlike phoning people, that kind of thing, so...

Reference 2 - 2.97% Coverage

Yeah. I hate it. I really, I worry about it all the time. I just, I just hate the thought of being judged so much, so...

*And where do you think the feeling, where do you think the anxiety comes from?*

People misjudging my relationships with people based on like how many friends I have. I mean, I'm not one to use the Wall much so does that look like I'm not really friends with people? Or is it... Because if people don't know me, it looks like, I don't know, am I uncool? Rather than I just can't be bothered to log onto my computer and I just get my phone out of my bag when I'm actually sat on a train, and I'm bored, rather than coming home and having all these things to do, why would I want to log on? Because it's not very instant, either. Usually when I talk to people it's because I have something I actually need to ask them. I'm not very good at just sitting there going ooh, what shall I do with my time? Let's write on like 15 people's Walls and just ask how they are for the sake of it. I mean, some people's profiles, you look at and they'll say blah blah's written on whoever's Wall, and there's like a list of 10 people. I'm not really one to do that. So, I mean, I don't feel, I haven't put my political views, my religious views. I don't, like that's quite personal to me. I don't think my groups... My groups, here, I don't think people can look at them because I feel, that's a lot to do with me still being in halls. I don't want people to misjudge me. I'm in hall not because I don't have friends, it's kind of a lot to do with my disability. I didn't manage being in a house. I kept getting burgled, it was quite an unpleasant experience. I kept getting ripped off, but I got on well with my friends. I've had plenty of different groups of friends beg me to live with them and I just again don't, I just, I feel really insecure about being misjudged, I guess, which seems a bit silly.

Reference 3 - 0.94% Coverage

I think not what I do but how I come across because, as I say, a lot of people, well, a lot of people I know from school are on here and also some people, those horrible people are at this university and were in my hall and they know a lot of people I know. And it's kind of, I know they viewed me as this kind of uncool loser, ugly idiot and I'm just kind of, I'm not and I don't want to carry that childhood thing with me. I feel like I've grown up, I've grown beyond these things. I just don't, I'm just really self-conscious that that doesn't, I haven't, I look like I haven't changed or that kind of thing.

Reference 4 - 1.56% Coverage

And then the weird thing, again, like the whole Facebook stalking thing. A friend of mine's ex-boyfriend was, she thought he was cheating on her with somebody so I checked his profile. She's like, the messages has been on her Wall so I looked at her and she's like telling me to like, I was trying to reassure her that it was fine,

everything's OK, and then it turns out that my boyfriend's housemate knows this girl. You know, this whole ridiculous chain. In a way it's interesting to note. But then at the same time I don't want to know kind of thing. Ignorance is bliss in a way, isn't it? I feel uncomfortable that everybody seems to know everything about everyone else and this ability to just sort of Facebook stalk people and make these judgements. I mean, I don't know this girl, but I was kind of having to judge her to my friend: 'oh yes, she's really ugly, she's really uncool', and all these things. And I think, I think it's just a really unnatural way of communicating, really.

Reference 5 - 0.20% Coverage

I think another public, ridiculous public thing is now on your homepage the mini-feed comes up, so you can see that, you know.

Reference 6 - 1.90% Coverage

And then at the same time sometimes, you know, people do stalk and then say 'Oh, it was on my mini feed' and you kind of think 'Well, I deleted it off my mini feed, it can't be.' And it's that kind of trust in people, are they weird people that are stalking you or, because I found out some people do sort of stalk me and that may, I think that's where this comes from. I did find out people were like stalking me on Facebook and making judgements and therefore making comments on my Wall and they made me feel really uncomfortable. Because I just didn't really understand why they would because they were sort of friends of mine, they sort of should know me anyway. It's not like someone who's curious who's suddenly discovered me on Facebook ten years later and like 'Oh what's she doing with her life?' That's kind of understandable, doing that, but somebody who's like still in my hall and everything... And to the extent where she clicked on my boyfriend and looked down through his profile and looked through his pictures, looked like at his life and I just thought that was a really weird thing to do and I felt uncomfortable that somebody was doing that because they did it surely with the intention of making judgements.

Reference 7 - 0.49% Coverage

And the only reason she would have known that is if she had clicked on like the, like view, because with somebody else you can see like view the Wall to Wall. It's like she'd done that and checked up on me and checked his profile and I'm thinking 'Why are you looking at the profile of a complete and utter stranger?'

Reference 8 - 0.44% Coverage

So I think because of the sureness of the negativity about that, I kind of thought 'Ooh, God, who else is like looking at my profile? What else are they thinking? Are they just not kind of being quite this bolshy enough to show they've stalked me and my new boyfriend?' I've no idea.

[<Internals\Interviews\Howie\Howie Interview 1>](#) - § 1 reference coded [1.11% Coverage]

Reference 1 - 1.11% Coverage

People like writing something on your wall and then you don't check like you don't get the email for a couple of days or something because you're not around the

computer and then you have to think 'Oh God, people have actually seen that' like whether it be true or not true. That's another thing as well, like. I've got a quite strange comic relationship with a lot of my friends, especially my close friends, so they might post something on my wall which I find completely funny but the other 250 people like that could possibly look at my profile, it would come across as considerably weird, if you get me.

[<Internals\Interviews\Pierce\Pierce Interview 1 Part 2>](#) - § 2 references coded [3.44% Coverage]

Reference 1 - 1.41% Coverage

Yeah I feel like sometimes a lot of the people I have on Facebook like I don't... like this sounds harsh as well but sometimes you'll have people who like ...like there are people that Facebook Stalk basically, I mean do you know about this? Do you know about this?

*Tell me your thoughts on this.*

This is the worst thing in the world. There will be people like...I don't want to sound sexist but it is girls. Girls Facebook Stalk 'cause I've had like 3 or 4 girls that have told me...like when I went to Uni like from back home and things like that.

Reference 2 - 2.03% Coverage

Like one of my friends [\*] went to [\*] she was sitting on a beach with a computer and she wasn't bored but she says things like basically 'I went through all your friends, all your pictures' like, 'everyone does it'. But like sometime I get a bit paranoid cause like some of the people that I like am friends with aren't like my real friends. So like for instance there are the ones without the computers at home, like, if I was to say...if I was to show someone - these are my friends these are the people I trust ,the people who always look out for me and I would show you them in like real life but you couldn't do that by Facebook stalking me you couldn't see who my real friends are so sometimes I think, I do, people think I'm friends with the wrong people or something like that.

## **Surveillance (Negative) / Child Code: 'No Escape'**

[<Internals\Interviews\Gemma\Gemma Interview 1>](#) - § 4 references coded [2.36% Coverage]

Reference 1 - 0.15% Coverage

I think at university as well, you can't really survive without it, because everything's on there.

Reference 2 - 0.50% Coverage

I don't know, I feel like I'm kind of exiting such a fundamental and big social way of communicating. It's kind of like locking yourself in your bedroom and not talking

to anybody for a week. It seems quite an antisocial thing to do. So I just try and kind of keep it but monitor it quite a lot and keep it quite clean.

Reference 3 - 1.04% Coverage

I mean, the other night I went out with a friend who's living with somebody she met through somebody else and I ended up in a corner chatting to this girl. Turned out she went to school down the road from me, you know, knew all the same people, people I knew from when I was six, you know, and to me she's just some random girl in [\*] that does a computing course, wasn't even in a Hall with, like a friend of a friend of a friend, you know, and for me literally every party I go to, any social event, if I actually get talking to anybody, nine times out of ten we know a lot of the same people from home, not just here and I do feel that I can't really escape in a way.

[<Internals\\Interviews\\Howie\\Howie Interview 1>](#) - § 2 references coded [1.17% Coverage]

Reference 1 - 0.52% Coverage

Like I said, I'm not really a big fan of Facebook because I kind of feel like it's kept under constant watch and constant tabs, like nothing you can do can kind of escape it and things like that. So I tend to like, I don't really like using it. I only do it because I kind of have to.

Reference 2 - 0.65% Coverage

It's kind of like, kind of feel like there's no escape, if you understand me? Like no matter what you do, like if you go out like one night, like no matter what you do, whether you want there to be sort of publicised or not, it's going to be.

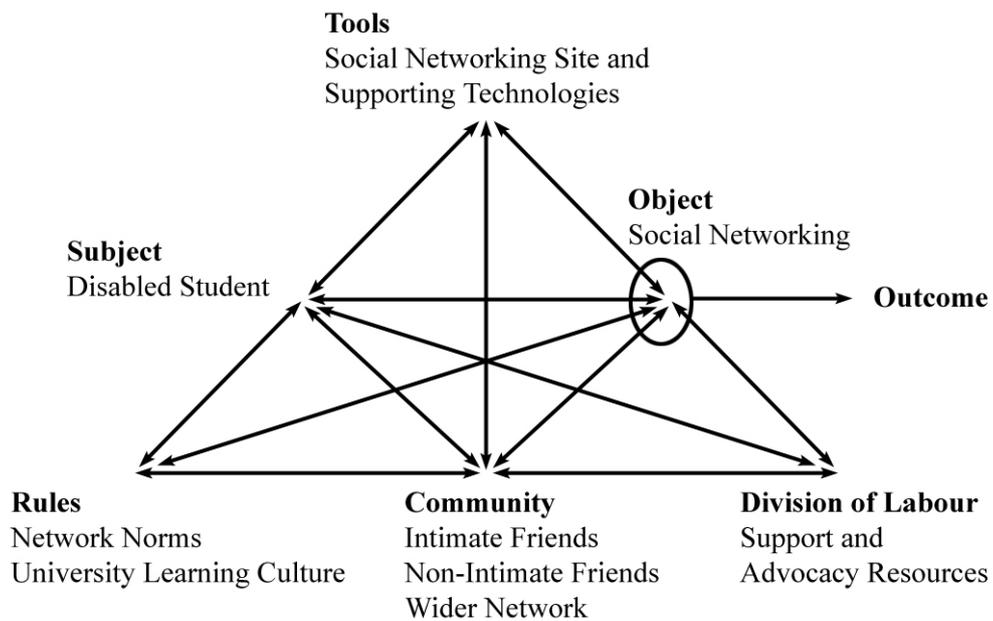
[<Internals\\Interviews\\Roy\\Roy Interview 4>](#) - § 1 reference coded [0.66% Coverage]

Reference 1 - 0.66% Coverage

Yes. I still don't like Facebook really. But I think that you can't really get by at university without it. And I don't like it because I think of all the privacy issues. And it can be so easily misused. And maybe only at the moment it's harmless but Skynet takes over the world.

## Dis/ability Coding Structures

### Coding Framework [RQ1] Locating disability in disabled students' networks



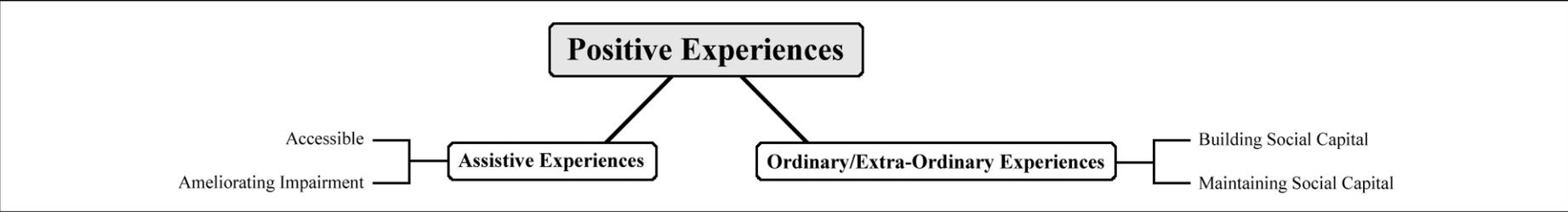
Appendix 5 Figure 1: Example of Student Activity System

### Additional Dis/abled Identity Codes: student perspectives

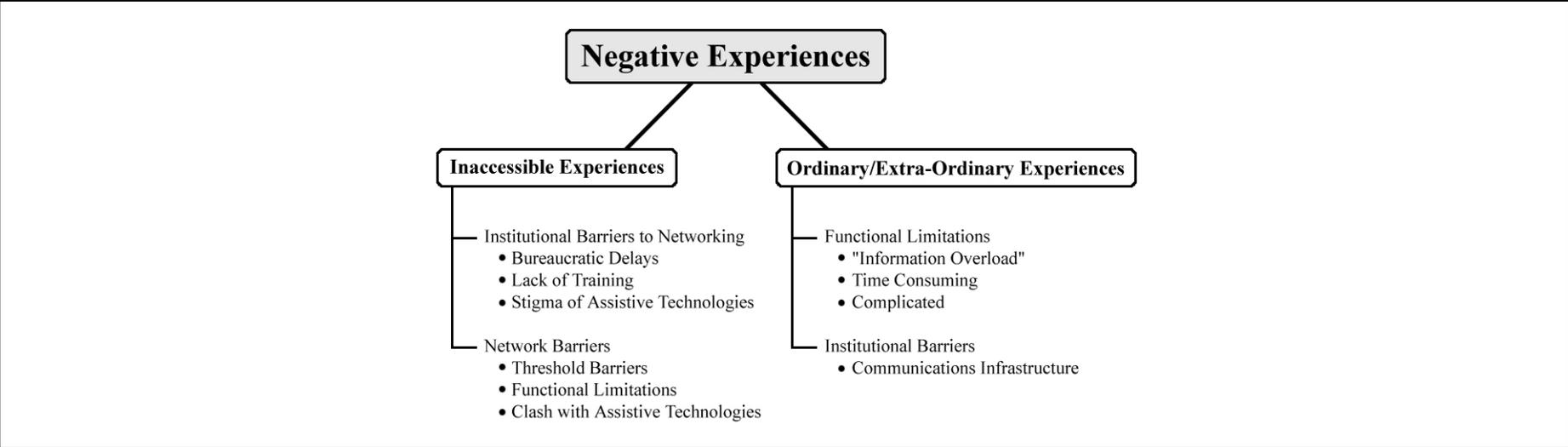
- Equivocal Identity<sup>48</sup>
  - Disability is an unsuitable label ('it can mean a million different things')
  - Disability is normal ('everyone has something about them')
  - Disability is relative ('dependent on who you're with')
  - Disability is contingent
- Rejected / Conflicted Identity
  - 'a temporary thing'
- Political Identity
  - 'coming out as disabled'
  - 'I'm almost postmodern about it'

<sup>48</sup> These codes broadly concur with disabled student identities outlined by Riddell, Tinklin and Wilson (2006), with the exception of 'misplaced' identity, which did not present in the sample.

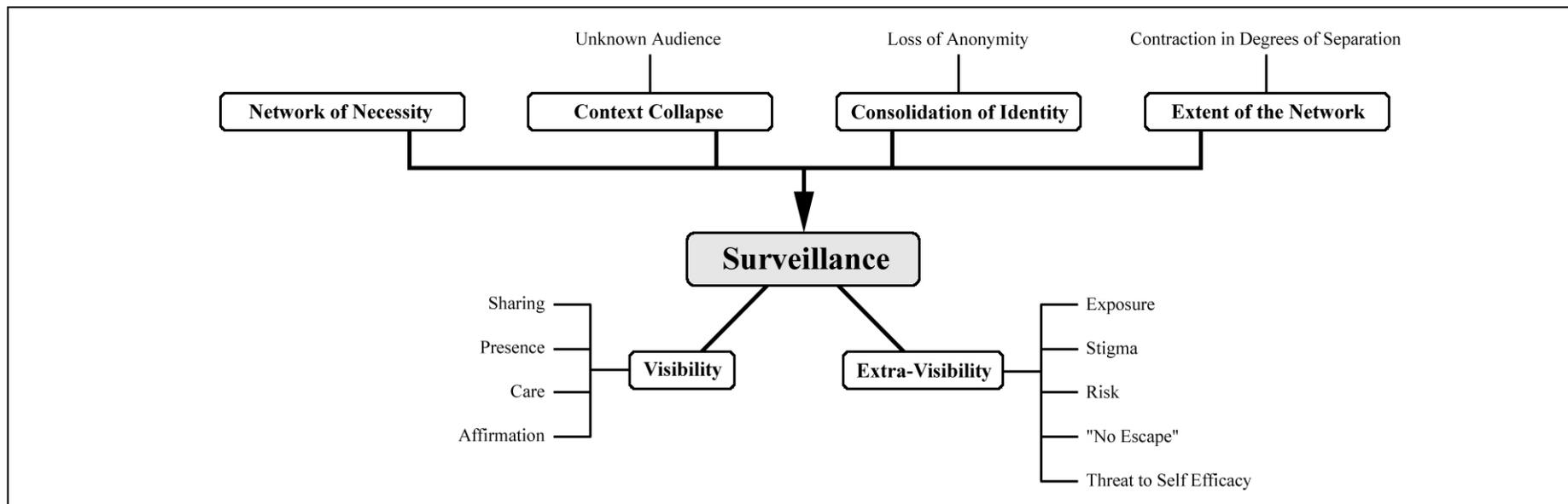
**Coding Framework [RQ2] How do disabled students experience disability in the network?**



**Appendix 5 Figure 2: Coding framework: Positive Experiences at the level of the technology**

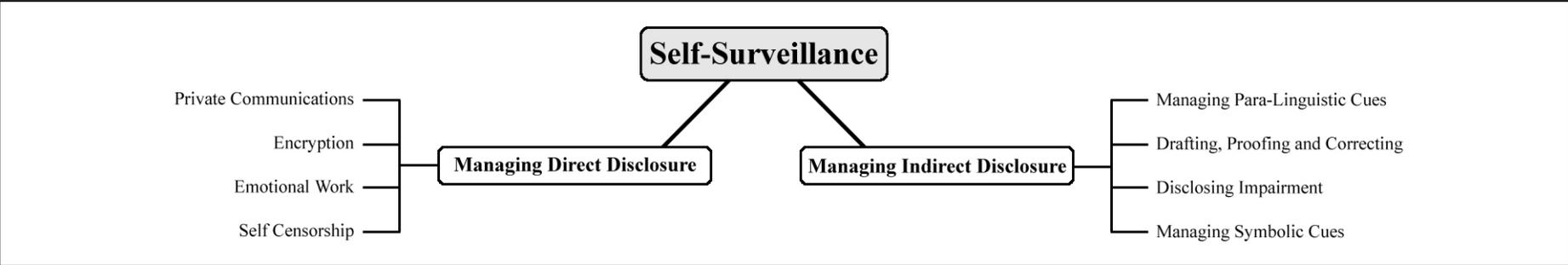


**Appendix 5 Figure 3: Negative Experiences at the level of the technology**

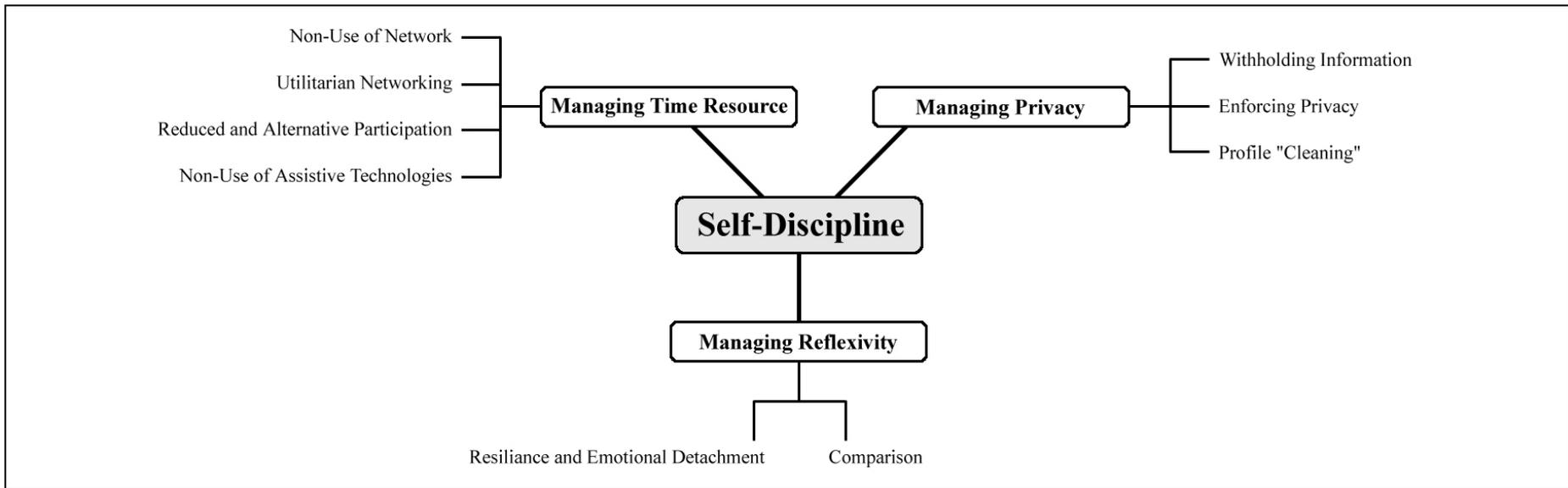


**Appendix 5 Figure 4: Positive and Negative Experiences in the Networked Public**

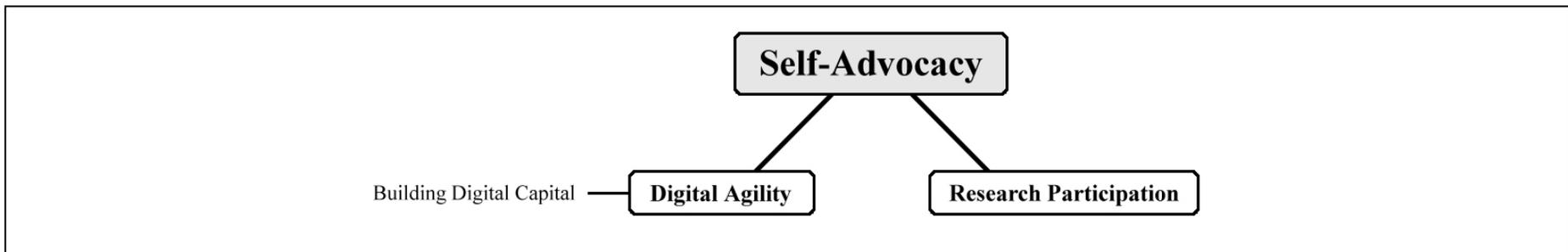
**Coding Framework [RQ3] How do disabled students manage disability in the network?**



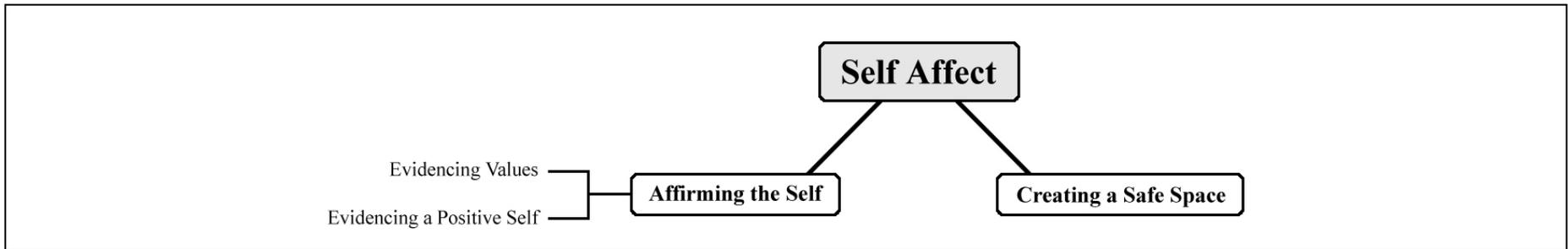
**Appendix 5 Figure 5: Management Strategies: Self Surveillance**



**Appendix 5 Figure 6: Management Strategies: Self-Discipline.**



**Appendix 5 Figure 7: Management Strategies: Self-Advocacy**



**Appendix 5 Figure 8: Management Strategies: Self-Affect**