

**PARENTAL ACCOUNTS OF SHARING AN AUTISM SPECTRUM
DIAGNOSIS WITH THEIR CHILD – A THEMATIC ANALYSIS**

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Thesis Abstract

The aim of the systematic literature review was to gain an in-depth understanding of how parents of children with an autism spectrum diagnosis experience stigma and in what ways they might manage this. Electronic databases and reference lists of published articles were systematically searched and six qualitative articles were selected for inclusion in the review. Findings from the studies formed the data for a thematic synthesis. Four interconnected themes were identified which capture parents experience of stigma: parent blame/responsibility; hidden disability; diagnosis/label and social isolation/avoidance. A further four themes were identified to highlight ways in which parents may manage this: diagnosis as a weapon; celebrating; increased resilience over time and planning and avoidance. The review suggests that negotiating public spaces may continue to be a challenge for some parents who experience both felt and enacted stigma.

The aim of the study was to explore how parents share an autism spectrum diagnosis with their child and the processes which may be involved in this. Literature regarding parental experiences of autism assessment and diagnosis indicate that this is a highly emotive time for both parent and child and highlights multiple factors which may impact on the sharing process. There is also an indication in the literature that there is often a delay between the autism diagnosis being confirmed and this being shared with the child. In the absence of autism specific research, literature pertaining to diagnosis disclosure in developmental disabilities and in paediatric chronic illness is examined, outlining a range of emotional and social factors which may shape parental decisions of whether to share their child's diagnosis with them.

The researcher adopted a critical realist position and employed a qualitative approach to explore this under-researched area. A total of 10 parents were recruited to the study and participated in a semi-structured interview. Transcribed interviews were analysed using thematic analysis. A secondary thematic analysis was undertaken to produce a leaflet reflecting the accounts shared by the group of parents in the study. It is hoped that this may be useful

to other parents who are contemplating sharing an autism spectrum diagnosis with their child and the professionals who support them.

Three inter-connected themes were identified, each with further sub-themes: (1) Sharing is a process: *naming autism, exploring and meaning-making and acceptance and integration*; (2) Parental motivation to share: *providing an explanation and protection* and (3) Parental management of sharing: *parental preparedness, perceived child preparedness and approach and strategies*. Sharing is a process and its related sub-themes are discussed in the journal paper, whilst the remaining themes and sub-themes are presented in the extended paper.

The findings illustrate that sharing an autism diagnosis with one's child is a complex and dynamic process involving the balancing of many parent, child and social factors. Commonalities with previous literature are discussed alongside some alternative insights gained. The thesis concludes with personal reflections of aspects of the research process including the nature of autism as a diagnosis and the potential ethical issues raised when considering whether this is shared with children or not.

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Statement of contribution

1. Project design:

Emma Ward (with supervision from Roshan das Nair)

2. Applying for ethical approval:

Emma Ward (with supervision from Roshan das Nair)

3. Systematic literature review:

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4. Recruiting participants:

Emma Ward, Claire Millward

5. Data collection:

Emma Ward

6. Transcription:

Interviews 1, 2 and 6 - Emma Ward

Interviews 3, 4, 5, 7, 8, 9 - Helen Smith (transcription service)

7. Analysis:

Emma Ward (with supervision from Roshan das Nair)

8. Write-up:

Emma Ward (with supervision from Roshan das Nair and comments on journal article from Claire Millward)

Contents

Thesis Abstract.....	1
Statement of contribution	4
Systematic Literature Review	10
Abstract.....	11
Introduction	12
Method	14
<i>Searching</i>	14
<i>Selection</i>	15
<i>Data Abstraction</i>	16
<i>Critical Appraisal</i>	16
<i>Synthesising qualitative data</i>	17
Critical appraisal of included studies	17
<i>Aims</i>	17
<i>Country</i>	18
<i>Samples</i>	18
<i>Data Collection</i>	25
<i>Data Analysis</i>	26
<i>Ethical Considerations</i>	26
<i>Findings</i>	28
Synthesis of findings	28
<i>Sources of stigma</i>	28
<i>How parents experience stigma</i>	29
<i>Responding to and managing stigma</i>	32
Discussion.....	35
References.....	37
Journal Paper	41
Abstract.....	42
Introduction	43
Methodology	47
Findings	50
Discussion.....	61
References.....	66

Appendix: Parent information leaflet	70
Extended Paper.....	78
1. Extended Background.....	79
1.1 <i>The autism spectrum</i>	79
1.2 <i>Neurodiversity – an alternative perspective</i>	80
1.3 <i>The prevalence of autism</i>	80
1.4 <i>Parental experiences of the diagnosis of autism</i>	81
1.5 <i>Children’s perceptions of the autism spectrum</i>	83
1.6 <i>Diagnostic disclosure in paediatric illness</i>	85
1.7 <i>Disclosing a stigmatised identity – A proposed model</i>	87
1.8 <i>Study Aims</i>	91
2. Extended Methodology	91
2.1 <i>Qualitative Methodology</i>	91
2.2 <i>Epistemology</i>	92
2.3 <i>Qualitative approaches considered</i>	95
2.4 <i>Participants and Recruitment Strategy</i>	98
2.5 <i>Data Collection</i>	100
2.6 <i>Ethical Considerations</i>	103
2.7 <i>Analysis</i>	105
2.8 <i>Secondary Analysis</i>	107
2.9 <i>Quality Assurance</i>	108
3. Extended Findings	110
3.1 <i>Summary of themes</i>	110
3.2 <i>Sharing is a process – further exemplar quotes</i>	111
3.2.1 <i>Naming autism – further exemplar quotes</i> :	112
3.2.2 <i>Exploring and meaning-making – further exemplar quotes</i>	114
3.2.3 <i>Acceptance and integration- further exemplar quotes</i>	116
3.3 <i>Parental motivation to share the autism spectrum diagnosis</i>	118
3.3.1 <i>Providing an explanation</i>	120
3.3.2 <i>Protection</i>	122
3.4 <i>Parental management of diagnosis sharing</i>	125
3.4.1 <i>Parental preparedness</i>	127
3.4.2 <i>Perceived child preparedness</i>	130

3.4.3 <i>Approach and strategies</i>	132
4. Extended Discussion.....	136
4.1 Discussion of findings in relation to past literature	136
4.2 The application of the disclosure decision-making model.....	137
4.3 Limitations of the study	140
4.4 Future Research	141
4.5 Clinical Implications	142
5. Critical Reflection	143
5.1 Reflections post viva voce examination	145
References	148
Appendices.....	157

List of Figures and Tables

	Page Number
Figure 1: Meta-synthesis inclusion flowchart.....	16
Figure 2: The process of sharing an autism diagnosis	53
Figure 3: The health disclosure decision-making model.....	89
Table 1: General characteristics of the included studies	19
Table 2: Critical appraisal of the included studies	27
Table 3: Themes contained within the studies.....	30
Table 4: Details of participants, children and timeline to sharing of diagnosis..	51
Table 5: Phases of thematic analysis	106

List of Appendices

	Page Number
Appendix A: Initial letter of ethical approval (University).....	158
Appendix B: Request for amendments (University).....	159
Appendix C: Approval of amendments (University).....	161
Appendix D: Initial letter from REC Committee.....	162
Appendix E: Researcher's response to the REC Committee.....	169
Appendix F: REC confirmation of ethical approval.....	170
Appendix G: Participant Information Sheet.....	172
Appendix H: Newsletter advertisement.....	178
Appendix I: Poster advertisement.....	179
Appendix J: Consent form.....	180
Appendix K: Demographic Questionnaire.....	181
Appendix L: Interview schedule.....	182
Appendix M: Confidentiality Agreement for Transcriber.....	183
Appendix N: Excerpt from a worked transcript.....	184
Appendix O: Mind-map for worked transcript.....	196
Appendix P: Coding frame grouped according to theme and sub-theme.....	197
Appendix Q: Provisional thematic map.....	200
Appendix R: Working diagram of final thematic map.....	201
Appendix S: Final thematic map.....	202
Appendix T: Table of data extracts for parent information leaflet.....	203
Appendix U: Parent information leaflet.....	214

Systematic Literature Review

How do parents of children on the autism spectrum experience stigma and in what ways do they manage this? A meta-synthesis of qualitative research *

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Abstract

The purpose of this literature review was to gain an in-depth understanding of how parents of children with an autism spectrum diagnosis experience stigma and in what ways they manage this. Electronic databases and reference lists of published articles were systematically searched; six qualitative articles were selected for inclusion. Findings from these primary research studies were analysed using thematic synthesis. Four interconnected themes were identified which capture parents experience of stigma namely parent blame/responsibility, hidden disability, diagnosis/label and social isolation/avoidance. A further four themes were identified to highlight ways in which parents may manage this - diagnosis as a weapon, celebrating, increased resilience over time and planning and avoidance. The review suggests that there is perhaps still a limited understanding of autism and that negotiating public spaces may continue to be a challenge for some parents.

* Article prepared for submission to Focus on Autism and Other Developmental Disabilities.

Introduction

The ‘autism spectrum’ is an umbrella term used to describe developmental disorders including autism, Asperger syndrome, high functioning autism and pervasive developmental disorder – not otherwise specified (PDD-NOS). Within this review the word ‘autism’ will be used as an umbrella term unless it is pertinent to refer to a specific label.

It is estimated that over one million people in the UK have an autism diagnosis (Baird et al., 2006). Those with an autism diagnosis will experience difficulties in communicating with and relating to others and may display restricted or stereotyped behaviours and sensitivity to sensory stimuli. As a spectrum disorder, how these difficulties are experienced, and the impact that they have on daily life is unique to each individual.

As a diagnostic label, autism has not escaped controversy. The past forty years have seen many shifts in the discourse of autism from a condition *caused* by cold and inattentive mothers to one linked with environmental toxins and vaccinations and more recently, cognitive and biogenetic explanations (Farrugia, 2009, Lagan, 2011). There is also a growing movement to promote a discourse which accepts and respects autistic difference (Langan, 2011).

Lay perspectives of autism construct a person who violates developmental and societal norms; is comparable to a person with a learning disability or mental illness; is unlikely to reach independence and may possess savant abilities (Huws & Jones, 2010). It appears then, that within the professional and wider community, autism continues to be a phenomenon which is poorly understood. Within this context it is unsurprising that parents of children with an autism diagnosis may experience challenges when negotiating professional and public spaces.

The challenges faced by parents of children with autism are multiple and may include excessive stress; having to advocate and fight for their child; managing behavioural problems; strained family relationships; a lack of understanding from others and social isolation (Altiere & von Kluge, 2009; Myers, Mackintosh & Goin-Kochel, 2009). Furthermore, parents have reported that the child with autism becomes the centre of family life where activities and home and daily routines are driven by their needs,

leading to a sense of loss of a 'normal' life (Woodgate, Ateah & Secco, 2008). Despite these challenges, parents frequently report positive aspects of their experience including the emergence of new understandings of and empathy for disabilities, an enriched life, enhanced spirituality and a renewed appreciation for the small things in life (Myers et al., 2009). It is possible that such factors mediate how parents of children with an autism diagnosis negotiate the social world.

This review focuses specifically on the stigma experienced by parents of children with an autism diagnosis. Goffman (1963) described stigma as a discrediting attribute that demarcates a person from social norms, leading others to view the person as a tainted, discounted one. He further posited that individuals can be subject to stigma through their association with a 'tainted' person rather than due to an attribute of their own - courtesy stigma. As such, parents of children with an autism diagnosis may experience stigma due to their affiliation with their child. Francis (2012) further suggests that the blame and criticism experienced by parents constitutes stigma in itself as poor parenting is being labelled as the discrediting attribute.

Stigma may be *felt*, for example where parents experience embarrassment or social isolation because they predict that they will (or have) been negatively labelled; or *enacted* which can be observed during interactions via stares, comments, rejection and discrimination (Francis, 2012; Gray, 2002).

Green, Davis, Karshmer, Marsh and Straight (2005) reported that having a disability that is not visible to others can enhance the stigma experienced. This is particularly pertinent to parents of children with an autism diagnosis as others cannot detect that their child is different unless they engage in behaviours which violate social norms (Francis, 2012; Gray, 1993). However, it may not be the case that all parents perceive that either they or their family members are stigmatised due to their child's autism diagnosis (Gray, 1993).

A number of qualitative studies have emerged that explore the stigma experiences of parents of children with autism. Although individual qualitative studies allow for a detailed understanding of lived experience, the often small sample sizes limit the possibility to generalise findings (Kramer, Olsen, Mermelstein, Balcells & Liljenquist, 2012). Meta-synthesis, or a review of qualitative studies, offers a solution to this. Amalgamating the studies enables the nuances and textures in varying accounts of the

stigma experience to be described and interpreted in such a way as to develop new insights and a richer understanding (Walsh & Downe, 2005).

This review aims to synthesise the findings from a number of qualitative studies to gain an in-depth understanding of how parents of children with autism experience stigma and to identify the strategies which are employed to mitigate this experience. In doing so, the review asks '*What experiences of stigma do parents of children with autism face and how do parents deal with or manage this?*'

Method

Meta-synthesis is an approach used to systematically integrate findings from multiple qualitative studies (Kramer et al., 2012). This section outlines the process of the review including how papers were searched for, selected and appraised.

Searching

A systematic literature search was conducted using four databases: EMBASE (1980-2012), PsycINFO (1906 – 2012), Cumulative Index of Nursing and Allied Health Literature (CINAHL 1981-2012) and Applied Social Science Abstract Index (ASSAI 1987 – present) during July and August 2012. These databases were chosen as they incorporate a variety of disciplines including medicine, nursing and applied social sciences. As such, they were considered to represent the professionals and researchers who would come into contact with the parents of children with an autism diagnosis. Alerts were set up on the databases to enable further relevant studies to be considered up to the point of analysis.

Databases were searched using a combination of terms linked to the autism spectrum; to parents / perspectives of parents; to stigma / social behaviour and to qualitative methodology. Subject headings and thesaurus terms were checked on all databases to enhance the search strategy. Where available, subject headings were exploded to incorporate narrower terms into the search to maximise the relevant studies identified. If subject headings were not available free-text search terms were used. This meant that the search strategy was tailored to each database. Duplicate studies were excluded.

The reference lists of the relevant studies located through databases were searched, but only duplicate studies were identified. Google Scholar was used to search the citing articles of each of the studies and also to conduct a key-word search. The key-words autism AND parents AND stigma, limited to the years 2002-2012 were used and the first 150 results were screened. Duplicated studies were excluded.

The located studies were firstly screened based on their title. If the title did not provide enough information to decide on inclusion in the review, the abstract was considered. Finally, where abstracts did not contain enough information to decide on inclusion, full text versions were obtained and examined. The majority of articles were rejected at this stage as they did not meet inclusion / exclusion criteria.

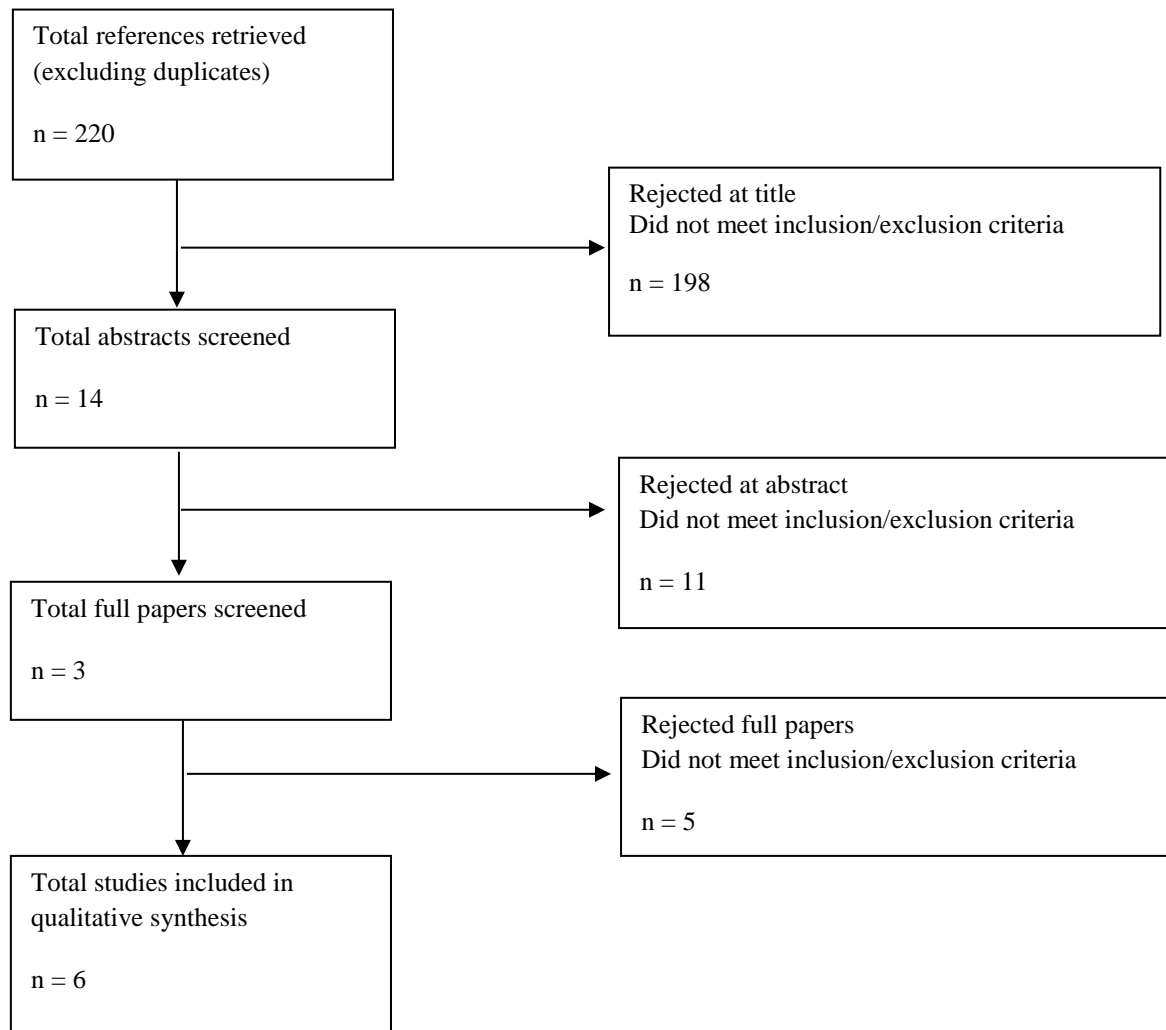
Database searches identified five potential studies to be included; citation searches one possible study and Google Scholar, two possible studies. Full text review of these articles led to further exclusions because - articles were not directly related to parental experiences of stigma (Calzada, Pistrang & Mandy, 2012; Myers et al., 2009; Woodgate et al., 2008); included parents of children with a diagnosis outside of the inclusion criteria (Francis, 2012) or were thought to be largely descriptive with minimal participant voice (Wnoroski, 2008). A total of six studies were therefore included in the review. This process is outlined in Figure 1.

Selection

The following a priori inclusion/exclusion criteria were used to select articles. Studies were included in the review if they:

- Included parents of children on the autism spectrum as direct participants or captured parents' voice.
- Included parents of children with a diagnosis on the Autism spectrum, including autism, Asperger syndrome, high functioning autism, atypical autism or pervasive-developmental disorder - not otherwise specified (PDD-NOS);
- Explored parents' experiences of stigma and/or how this is managed;
- Used qualitative data collection and analysis methodology;
- Were primary research studies and not systematic reviews or opinion pieces;
- Were published within the last 10 years (2002-2012)
- Were published in the English language

Figure 1: Meta-synthesis inclusion flowchart



Data Abstraction

The general characteristics drawn from the articles included: country, study aims, sample size, data collection, methodology, data analysis and key findings. The coding frame was adapted from those used in previous qualitative syntheses (Dyer & das Nair, 2012; Morton, Tong, Howard, Snelling & Webster, 2010).

Critical Appraisal

Critical appraisal is the process of carefully and systematically examining research for its trustworthiness, value and relevance in a given context (Burls, 2009). Assessing quality in qualitative research is a contested area with limited consensus on how or even if this should be done (Thomas & Harden, 2008). Furthermore, the use of appraisal criteria is subject to bias and as such, the application of criteria to the same research, by different reviewers can yield different results (Sandelowski & Barroso, 2002).

Nevertheless, critical appraisal remains important as it allows a reader to judge the usefulness and application of research. This synthesis used the Critical Appraisal Programme Tool (CASP) Qualitative Checklist (CASP, 2010). The CASP contains 13 questions with additional prompts to guide appraisal. Areas of quality that are reviewed include the appropriateness of the study design; the consideration of ethical issues; the rigour of analysis and the value of the research. As mentioned, the appraisal of quality is largely subjective and in the case of this review was completed by just one author.

Synthesising qualitative data

A number of methods have been developed to synthesise the findings of qualitative research. In this review, a thematic synthesis was conducted based on the methods used in previous qualitative reviews (Morton et al., 2010; Thomas & Harden, 2008). This method was chosen as it can be used to abstract both overlapping and divergent themes across the studies to inform an interpretation that goes beyond the original analysis. The data used in the synthesis consisted of the ‘findings’ or ‘results’ sections of the original studies. To conduct the synthesis, firstly, each article was read and re-read with salient topics being concurrently noted. Overlapping topics were then identified and grouped to form themes and a phrase was developed which best captured the essence of the theme.

Critical appraisal of included studies

The data abstracted from the reviewed studies and the critical appraisal can be found in Tables 1 and 2 respectively.

Aims

All studies provided a clear statement of the aims of the research. It was felt that the methods used and reported findings in each of the studies demonstrated that the original aims had been met. This is perhaps because many of the studies were exploratory and endeavoured to develop an account of the subjective experiences of parents, albeit with a different focus. Although the aims across the studies were diverse and not directly linked to stigma per se, (Chell, 2006; Russell & Norwich, 2012; Ryan, 2010) it was felt that together, they portray different aspects of the stigma experience across time and setting.

Country

The studies were conducted in Australia (Gill & Liamputtong, 2011; Gray, 2002; Farrugia, 2009) or the UK (Chell, 2006, Russell & Norwich, 2012, Ryan, 2010) although do not appear to have been conducted within the same locality, or to have used the same sample. There may be an over-representation of data drawn from Australia and the UK; nevertheless, it is possible that wider inferences can be made from the findings, albeit restricted to Westernised countries.

Samples

Together, the data reported in the articles represent 162 parents of children with an autism spectrum diagnosis, consisting of 112 mothers, 36 fathers and 7 couples whose gender was not stated. Sample descriptions varied across studies with some providing more detailed accounts of gender, ethnicity, age of children and socioeconomic status (Ryan, 2010, Gill & Liamputtong, 2011, Gray, 2002) than others (Chell, 2006, Farrugia, 2009, Russell & Norwich, 2012).

One author indicated that purposeful sampling had been used (Chell, 2006) and although not stated, a further two studies appeared to have used the same method (Farrugia; 2009; Gray, 2002). One study reported that sampling methods had been purposeful and triangulated with snowballing and the use of personal networks (Gill & Liamputtong, 2011). One author indicated that a maximum variation approach had been used to enhance the demographics of the sample (Ryan, 2010). Russell & Norwich (2012) reported that snowball sampling had been used for parents of undiagnosed children and a newsletter and word of mouth had been used to recruit parents of diagnosed children.

Two studies accounted for participants who had withdrawn or were excluded from the analysis (Gray, 2002; Ryan, 2010). One author commented on the implications a small sample recruited from one source may have had on the data collected and cited that individual interviews had been offered (but declined) following focus groups to compensate for this (Chell, 2006). However, the accounts provided by these parents are largely consistent with those provided across the other studies.

Table 1: General characteristics of the included studies

Study	Country	Sample	Diagnostic label	Aims	Data collection	Data analysis method	Key findings
Chell 2006	UK	10 mothers 3 fathers n = 13	Asperger syndrome	To gain an understanding of the experience of parenting a child with Asperger syndrome. To identify parents perspectives on what helps to inform service development.	Focus Groups (using guide questions)	Thematic approach (Miles & Huberman, 1994)	Parents related stigma with a lack of recognition and understanding. Sources of stigma reported were professionals and the wider community. Parents suggested that diagnosis can be helpful in managing this, although diagnosis itself is not enough on its own.

Table 1. General characteristics of the included studies

Study	Country	Sample	Diagnostic label	Aims	Data collection	Data analysis method	Key findings
Farrugia 2009	Australia	11 mothers 5 fathers n=16	ASD	To reconstruct the concept of stigma as a socio-cultural process in order to better understand the stigmatisation of parents of children diagnosed with an ASD.	Semi-structured Interviews	Discourse analysis Constant comparative method Deviant case analysis	Parents' experiences of perceived and enacted stigma were often mediated by social context. Sources of stigma reported included friends, the public and institutions. Strategies deployed in managing and resisting stigma were subtly different across contexts, often involving complex discursive strategies to preserve or reconstruct identities of self parent), child and family.

Table 1. General characteristics of the included studies

Study	Country	Sample	Diagnostic label	Aims	Data collection	Data analysis method	Key findings
Gill & Liamputtong 2011	Australia	15 mothers n=15	Asperger syndrome	To explore whether mothers of children with Asperger syndrome perceive themselves to be stigmatised due to their child's disability and how they deal with perceived stigma. (Part of a larger study into the experience of being a mother of a child with Asperger syndrome)	In-depth interviews Solicited diaries (optional)	Thematic analysis	Mothers felt more stigmatised than parents of children with visible disabilities. Stigma often experienced as having parenting skills judged. Single mothers felt they were more stigmatised. Sources of stigma included the school and the public. Diagnosis experienced as vindicating, was shared to reduce stigma, although not always successfully. Certain situations avoided to avoid stigma.

Table 1. General characteristics of the included studies

Study	Country	Sample	Diagnostic label	Aims	Data collection	Data analysis method	Key findings
Gray 2002	Australia	32 mothers 21 fathers n=53	High functioning autism Asperger syndrome	To explore the stigma experienced by parents of children with high functioning autism. (Part of a larger Brisbane based study exploring the social experiences of families of children with autism)	In-depth, semi-structured interviews	Interactive, naturalistic research method (Erlandson et al. 1993)	Parents reported both felt and enacted stigma, although reports were more frequent in mothers. Stigma was linked to the presentation of autism (e.g., more likely if a child behaved inappropriately) and the ‘invisibility’ of autism. Sources of stigma included the community and school.

Table 1. General characteristics of the included studies

Study	Country	Sample	Diagnostic label	Aims	Data collection	Data analysis method	Key findings
Russell & Norwich 2012	UK	15 mothers 2 fathers n=17	ASD Undiagnosed ASD	To examine parental influence in pursuing or avoiding a diagnosis of an ASD for their child; to explore the function of the ASD diagnosis and how this may affect how ASD is conceptualised.	Semi-structured in-depth interviews	Constant thematic and comparative analysis (modified from Braun & Clarke, 2006 and Strauss & Corbin, 1998)	Parents reported dilemmas relating to diagnosis e.g., balancing potential (perceived) stigma against benefits. Parents of children with a diagnosis positively re-framed autism and engaged in strategies to de-stigmatise this. Parents uncertain about diagnosis enlisted anti-labelling discourses to justify their position / resist diagnosis.

Table 1. General characteristics of the included studies

Study	Country	Sample	Diagnostic label	Aims	Data collection	Data analysis method	Key findings
Ryan 2010	UK	29 mothers 5 fathers 7 couples n=48	ASD	To explore the emotion work parents engage in to manage public places when out with their child. (Part of a larger study exploring the experiences of, support and information for children and their parents)	In-depth interviews semi-structured interviews	Thematic approach assisted by Nvivo and constant comparative method (Seale, 1999)	Parents shared the emotional complexity of managing social situations where they often felt stigmatised for their child's behaviour. They reported feeling responsible for their own emotions, the emotions of their child and the 'other' in social situations. Stigma linked to the lack of visible signs of disability .Strategies used included planning ahead, diagnostic disclosure and avoidance of social situations.

Note. ASD = Autism Spectrum Disorder

Other authors commented on their sample of parents of diagnosed and undiagnosed children, stating that they may have been a proportion of the whole population who wanted to share their experiences (Russell & Norwich, 2012). In all studies, the recruitment strategy seemed appropriate to the research aims.

Data Collection

Four of the studies indicated that face-to-face, semi-structured or in-depth interviews had been conducted (Farrugia, 2009; Gill & Liamputtong, 2011; Gray, 2002; Russell & Norwich, 2012). One study used focus groups and offered subsequent interviews (Chell, 2006). One study used an in-depth open interview and a semi-structured interview (Ryan, 2010). Gill & Liamputtong (2011) included the option of solicited diaries which were kept by 6 of the 15 participants. It was felt that four of the studies provided some justification for the use of the data collection method (Chell, 2006; Gill & Liamputtong, 2011; Russell & Norwich, 2012; Ryan, 2011).

Three of the studied reported that data collection was audio-recorded and fully transcribed (Chell, 2006; Farrugia, 2009; Ryan, 2010). One study indicated that interviews had been audio-recorded and selectively transcribed (Gray, 2002). The remaining studies did not indicate how interview data had been recorded and participant narratives preserved (Gill & Liamputtong, 2011; Russell & Norwich, 2012). Four of the studies included the topic list or an indication of the questions asked (Farrugia, 2009; Gray, 2002; Russell & Norwich, 2012; Ryan, 2011) which provided clarity between data collection and analysis. Only two of the studies referred to data saturation (Chell, 2006; Gill & Liamputtong, 2011). The former referred to conducting enough groups to demonstrate a trustworthy answer to the research question as opposed to data saturation. The latter indicated that data saturation was not possible given the time constraints of the study, although reported that the data was sufficient in developing an understanding of parental experiences.

Two studies used field notes (Chell, 2009; Russell & Norwich, 2012) with the former also reporting that a reflective diary was kept, although it was not clear how these had been incorporated into the analysis beyond being 'examined'.

Data Analysis

The majority of the articles reported the theoretical framework used for analysis. Three of the studies indicated that a form of thematic analysis was used, the latter two stating that this was supplemented with the constant comparative method drawn from Grounded Theory (Gill & Liamputtong, 2011; Russell & Norwich, 2012; Ryan, 2010). One author indicated that an interactive process used in Naturalistic Research was utilised (Gray, 2002) and another referred to qualitative coding and grouping of data, referencing the authors of the model they had adapted (Chell, 2009). One study reported that Discourse Analysis and qualitative data coding techniques were used (Farrugia, 2009). No authors explicitly reported that coding was conducted by further analysts or that member checking had been conducted, although one author reported that transcripts were reviewed by participants prior to analysis (Chell, 2006). One study referred to the use of constant comparative and deviant case analysis to improve the rigour of the analysis and to ensure that all data was accounted for (Farrugia, 2009). No author reflected on their relationship with participants and how this may have influenced data collection and analysis.

The majority of the authors described the processes involved in analysis, although only two were thought to adequately justify why the approach was taken (Farrugia, 2009; Russell & Norwich, 2012). Few of the studies described the analysis process in enough depth to understand how themes had been identified. One study reported that software had been used to organise data into open codes under named headings which were further refined to identify key themes (Ryan, 2010). One author reported that broad categories consistent with the topic list were initially used to organise data and subsequent interviews were grouped according to thematic links which emerged (Farrugia, 2009). These descriptions were helpful when interpreting findings.

Ethical Considerations

Only two of the studies refer to ethical considerations. One author indicated that ethical approval was granted, that participants received a full copy of the proposal prior to the study and also reported that informed consent, confidentiality and anonymity were respected (Chell, 2006). Another study indicated that ethical approval was granted, referred to informed consent and stated that transcription and analysis was anonymised (Russell & Norwich, 2012). No authors reported on how findings were shared with participants.

Table 2: Critical appraisal of the included studies

Appraisal question	Study reference					
	Chell (2006)	Farrugia (2009)	Gill & Liamputtong (2011)	Gray (2002)	Russell & Norwich (2012)	Ryan (2010)
Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the	Y	Y	Y	Y	Y	Y
Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y
Were the data collected in a way that addressed the research question?	Y	Y	Y	Y	Y	Y
Has the relationship between researcher and participants been adequately considered?	N	N	N	N	N	N
Have ethical issues been taken into consideration?	Y	N	N	N	Y	N
Was the data analysis sufficiently rigorous?	-	-	-	-	-	-
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y
Does the research demonstrate value?	Y	Y	Y	Y	Y	Y

Findings

The majority of authors reported findings in relation to the study aims and wider research. Furthermore, the articles include direct quotations from the data, which allowed for differentiation between author interpretation and the subjective experiences described by participants. Two authors reported on potential bias in their findings as parents in the studies were actively involved in support groups (Chell, 2006; Farrugia, 2009). A further study suggested that their sample could reflect a proportion of the populations of parents of undiagnosed and diagnosed children who were willing to talk (Russell & Norwich, 2012). Service contact and involvement in support groups or online communities was also evidenced in other studies (Gray, 2002; Ryan, 2010). The possibility that these samples may represent a particular group of parents of children with autism diagnoses (i.e. those willing to talk, those who are supported by services etc.) cannot be overlooked. Parents who do not engage in these activities may provide an alternative perspective on the stigma experience that has not been captured within these studies.

Synthesis of findings

The review found that parents in all studies experienced both felt and enacted stigma due to their position as a parent of a child on the autism spectrum (Chell, 2006; Farrugia, 2009; Gill & Liamputtong, 2011; Gray, 2002; Russell & Norwich, 2012; Ryan, 2010). Table 3 indicates the themes identified across studies and those in which the theme was present.

Sources of stigma

The sources of stigma identified were: public places, friends/extended family and professionals. In three of the studies, school was experienced as a place of heightened stigma, received from both staff and other parents (Farrugia, 2009; Gill & Liamputtong, 2011; Gray, 2002). A striking example of this was shared by separate parents in one study who reported that school staff had made suggestions like “...well we know he’s got a diagnosis but, can’t you just talk to him? ...” and “...we’ve got to lift the autism off the boy” (Farrugia, 2009, p. 1023). This perhaps reflects a poor understanding of the challenges faced by both children with autism and their families. The words used also

suggest that parents ultimately bear responsibility for their child's behaviour and indeed the label attached to them.

How parents experience stigma

A number of themes were identified which capture parents experience of stigma. Parental blame or responsibility was a theme common to all studies (Chell, 2006; Farrugia, 2009; Gill & Liamputtong, 2011; Gray, 2002; Russell & Norwich, 2012, Ryan, 2011). This theme incorporated both felt and enacted stigma where parents felt "... It was myself that had the problem because I hadn't done it right" (Chell, 2006, p.1351) [following an interaction with a professional]. Parents in many of the studies also reported receiving stares, glares, and rude comments in public places: "...what sort of mother are you? How can you not discipline him?! ..." (Gill & Liamputtong, 2011, p.715). Interestingly, a number of the studies indicated that mothers were more likely to experience felt or enacted stigma (Chell, 2006; Farrugia, 2009; Gray, 2002):

"... If you are home with the children all the time ... That is your job and you're planning the children's day. You're responsible'. (Gray, 2002, p.744)

When making sense of this, one mother stated "... Maybe the roles have changed, but the opinions haven't" (Gray, 2002, p.744). These extracts demonstrate that the public respond negatively when a child with an autism diagnosis violates societal norms, often blaming parents. Mothers appear to experience stigma from the public more frequently, perhaps because they are in public spaces more often with their child and perhaps because of society's concept of the mother role.

Associated with the above theme is the issue of the invisibility of autism:

"... I mean, you can't blame them, he looks completely normal. There is nothing different about the way he looks...." (Ryan, 2010, p.872)

Autism was conceptualised as a hidden disability in four of the studies (Chell, 2006; Gill & Liamputtong, 2011; Gray, 2002; Ryan, 2010). There was a perception that mothers of children with profound disabilities receive more sympathy and were not stigmatised by the community in the same way (Gill & Liamputtong).

Table 3: Themes contained within the studies

Theme	Study reference					
	Chell (2006)	Farrugia (2009)	Gill & Liamputtong (2011)	Gray (2009)	Russell & Norwich (2012)	Ryan (2010)
Experience of stigma						
Parent blame/responsibility	+	+	+	+	+	+
Hidden disability	+	-	+	+	-	+
Diagnosis / label	+	-	+	-	+	+
Social isolation/avoidance	+	+	+	+	-	+
Coping						
Diagnosis as a weapon	+	+	+	+	+	+
Celebrating	+	+	-	-	-	+
Increased resilience over time	-	-	+	+	-	+
Planning & Avoidance	-	+	+	+	-	+

Note. ‘+’ = theme present, ‘-’ = theme not present

Two Papers articulated that having a disability such as Down's syndrome would perhaps lessen stigma (Chell, 2006; Gray, 2002) as it would be visible to the public:

“... Actually, there were times when I thought, ‘God! I wish he were Down’s syndrome’, because people would leave me alone. They would see the Down’s syndrome [and] know there was a problem”. (Gray, 2002, p.743)

It appears that ‘hidden’ difference is perceived to be implicated in the stigma experienced by parents and perhaps contributes to a sense of parent blame and responsibility.

Diagnosis was something which some parents felt had the potential to be stigmatising (Chell, 2006; Gill & Liamputtong, 2011; Russell & Norwich 2012; Ryan, 2010).

Parents in one study, who were resisting diagnosis, often drew on anti-labelling discourses to defend their position:

“And we just, you know, we just live in this world where people have stigmas about things and views about things and the way people are treated, I’m worried that he’ll be discriminated against, or that it’ll be seen as like a weakness or something”. (Russell & Norwich, 2012, p.234)

This suggests that perceived stigma mediated whether parents sought or accepted a diagnosis, wanting to protect their child from potential stigma. Furthermore, some parents noted that professionals were reluctant to diagnose: “The problem we have is a lot of professionals who deal with our daughter believe she would be handicapped by having a label ...” (Chell, 2006, p.1352)

Social isolation was also a theme which emerged across studies (Chell, 2006; Farrugia, 2009; Gill & Liamputtong, 2011; Gray, 2002; Ryan, 2010). This theme was reflected in changing social circles and interactions with friends.

“Like uh we discovered really who your friends are and that ... So you go to their place and you know it’ll be a case rather than where you can tell the child well look you can’t touch anything, you can’t tell them that, they do. So a lot of the people will be ‘oh yes you can *come* around but can you not bring the boys they’re a bit loud’ ...” (Farrugia, 2009, p.1018)

This suggests that having a child with autism impacts not just on how parents are perceived in the *world out there* but also within existing social networks, contributing further to a feeling of difference and isolation.

Responding to and managing stigma

A secondary aim of this review was to identify how parents manage stigma. Themes of coping and resilience were identified across all studies (Chell, 2006; Farrugia, 2009; Gill & Liamputtong, 2011; Gray, 2002; Russell & Norwich, 2012; Ryan, 2010). The themes and studies they were present in can be viewed in Table 3.

Despite some parents fearing that diagnosis could be stigmatising, an overwhelming proportion of parents referred to the usefulness of diagnosis which is captured in the theme *diagnosis as a weapon*. Diagnosis was described as a means of accessing support and services, and was referred to as “a ticket” (Chell, 2006), “a key”, “a passport” and a “lever” (Russell & Norwich, 2012). There was also a sense that diagnosis reduced parental blame and validated their concerns for their child:

“I feel alleviated by the fact that I can now explain his behaviour, provide an explanation, and so now people, those who know and those who understand it – because there is a difference between knowing and understanding, so those who understand it ... They are now willing to help support us rather than sit back and judge us”. (Gill & Liamputtong, 2011, p.716)

This demonstrates that a diagnosis can be powerful in changing attitudes towards parents, yet a subtle distinction is made between *knowing* and *understanding*, suggesting that knowing a child’s diagnosis is not always sufficient in challenging stigma and changing attitudes. This account also reflects the relief felt upon receiving a diagnosis, which was echoed in other studies where parents felt validated in their concerns for their child.

Communicating the autism diagnosis in public spaces also helped parents cope and alleviated stigma. How the diagnosis was communicated took different forms. It was often verbal e.g. “... have a quiet word with someone, say, ‘I’m sorry he’s got Asperger’s, he’s just finding this situation a bit difficult ...” (Russell & Norwich, 2012, p.237). Sometimes it involved handing out cards produced by the National Autistic Society (Ryan, 2010) and perhaps more strikingly:

“ ... because I got sick of people sort of like I say looking at us and gawping and sort of pointing the finger you know ... I had some t-shirts printed ... And it just simply said on it. ‘I am not naughty. I am autistic’ ...” (Ryan, 2010, p.872)

Perhaps disclosing a diagnosis makes the hidden difference visible and may help some parents feel more confident in public spaces. However, sharing the autism diagnosis was not always successful and some parents were reluctant to do this because of the impact it may have on their child:

“There is one thing I do find quite difficult [um]... the decision whether or not to say to a stranger ... [er] this youngish man with me has autism ... But a big part of the problem is a feeling of some sort of embarrassment in front of Geoff sort of labelling him in his presence [um] as being autistic.” (Ryan, 2010, p.872)

There were also examples when sharing the diagnosis did not have the desired effect:

“... I only bring it up if people ... start talking about him ... And ... straight away I’ll get ... a sympathetic response ... [However] I get people [who] will turn around and say, ‘Oh there’s nothing wrong with him ... He just needs a good kick in the backside’ ...”. (Gray, 2002, p.741)

Negotiating public places is clearly difficult for some parents and sharing the diagnosis may help them to manage these situations. However, a lack of understanding, the hidden difference and unpredictable reactions of others mean that public spaces continue to be a challenge.

Parents also carefully plan activities and distance themselves from particular setting in order to resist stigma. This theme was identified in four of the studies (Farrugia, 2009; Gill & Liamputtong, 2011; Gray, 2002; Ryan, 2010). One parent reported:

“... I must say I am quite bad because, in a way, because it is very hard, with family and going to other people’s houses and that. So Tom and I do, we do keep to ourselves a lot”. (Ryan, 2010, p.870)

This reflected the feeling that it is easier to lessen contact with people and places where there was potential for stigma. This is also associated with the theme of social isolation found in the stigma experience and may suggest that social isolation in part, stems from parents lessening contact with others to resist feeling stigmatised.

Other parents suggested that being actively involved in support groups gave them a new social network and support system: "... associating with autism families is just so much more comfortable because nothing fazes them ..." (Farrugia, 2009, p.1017).

The strategies adopted by parents to manage stigma are likely to be interwoven with how much support they have, how autism affects their child and perhaps for how long they have negotiated the challenges and stigma of public spaces.

This leads on to a further theme identified in three of the papers (Gill & Liamputtong, 2011; Gray, 2002; Ryan, 2010) *increased resilience over time*:

"I am now able to deal with it, ... you grow a very thick skin and there are sometimes when you turn around and tell them what you really think and other times when you are able just to walk away because you know that it is basically ignorance and you are not going to get anywhere with them. So that has become easier". (Ryan, 2010, p.873)

Increased resilience over time was also reflected in the following extract: "It used to upset me, but now I just take it on the chin ..." (Gill & Liamputtong, 2011, p.718). What emerges from these accounts is a sense that parents do not *perceive* lessened stigma over time, but perhaps that repeated negative experience have reduced the emotional impact.

The final theme identified in relation to coping was *celebrating* which was present in four of the studies (Chell, 2006; Farrugia, 2009; Russell & Norwich, 2012; Ryan, 2010):

"... and he's going to be fantastic, and you just think that the way his mind works completely compensates for every other, almost to every other behaviour, and just that he's got so much to give, and I don't know that I could see that before." (Russell & Norwich, 2012, p.239)

In this theme parents reconstructed autism and celebrated their children as "... a precious gift" (Chell, 2006, p.1352), beginning to recognise the positives of the autism diagnosis.

Discussion

This meta-synthesis identifies how stigma is experienced by parents of children with autism, in addition to the strategies which help parents manage this. As anticipated, the review suggests that parents experience both felt and enacted stigma when in public spaces, during interactions with professionals and within their existing support networks.

The themes identified in the review are interwoven and suggest a lack of understanding and perhaps tolerance of autism and of the challenges faced by families, within both the professional and wider community. Stigma often arises in public spaces when children become overwhelmed or distressed and express this behaviourally. Parents experience felt stigma (where they think others are judging them) and enacted stigma (where others stare, point or make rude comments) at these times, perceiving that their parenting abilities are being scrutinised. This echoes the findings in similar studies and suggests that although parents may experience courtesy stigma, they may too be stigmatised themselves by being discredited as parents (Francis, 2012).

The stigma experience was perhaps underpinned by the hidden difference of autism in that others cannot observe the difference and may therefore be reluctant to take on the explanation offered by parents. Indeed, subtle differences have emerged relating to the nature of the child's difficulties. Parents in two of the studies (Gill & Liamputtong, 2011; Gray, 2002) reported that either they had not been, or could not identify if, they had been stigmatised because of their child's condition. Both authors suggest that the stigma experience may be more pronounced in parents of children who experience greater difficulties and violate social norms more frequently.

The review identified a number of themes relating to how parents respond to and manage experiences of stigma. Diagnosis was often used as a tool to deflect stigma and parent blame, although with varying degrees of success. It is also possible that having the diagnosis increases parents' confidence in negotiating public spaces as they know they are not the cause of the problem. Sharing a diagnosis may also serve to combat the hidden difference of autism. However, not all parents felt that they should have to offer an explanation, or were concerned about the implications of labelling their child in their presence. Increased resilience over time was also identified as a factor which

contributed to coping. Sadly, increased resilience appears to reflect adaptation and having a ‘thicker skin’ rather than a reduction in perceived stigma.

In order to consider the usefulness of this review it is necessary to consider the limitations. Firstly, the review was relatively small, including just six articles. It is possible that by expanding the inclusion criteria to include all developmental disabilities a greater number of articles would have been found and would therefore have provided a richer data source. Also, given the small sample of articles, perhaps a mixed-method review would have been appropriate. Additionally, although thematic meta-synthesis was useful in identifying consistent and divergent themes, this method of analysis is subject to interpretation bias. The themes were developed by one author meaning that themes could have been missed. The utility of the synthesis would perhaps be increased if the data was collated and coded by multiple reviewers.

In relation to the included articles, they potentially represent a biased sample as many of the participants were recruited through support groups or services. As such, the review may represent a particular population of parents who are a) willing to talk about their experiences and b) may experience stigma differently by virtue of having social support networks. This of course limits the generalizability of the synthesis.

In terms of the usefulness of the synthesis, an over-arching concept appears to be that the autism spectrum continues to be poorly understood within some professional and community contexts. Indeed, a number of papers cited that more has to be done to raise awareness of autism (Gill & Liamputtong, 2011; Russell & Norwich, 2012). In terms of professional interaction, the review suggests that the questions and language used by some professionals may lead parents to feel stigmatised and that some reflection upon how assessments are conducted may be beneficial (Chell, 2006). Finally, with the number of children diagnosed with autism increasing (and the potential confusion which will be created by medical re-classification) it seems that post-diagnosis support is perhaps needed by some parents, not only to help them understand their child’s diagnosis but also to be supported themselves for the challenges and stigma they may experience. Perhaps some collaborative work between healthcare providers and support groups would fill a gap in services and mean that more parents can experience the benefits of these groups and develop their own resilience to stigma.

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Journal Paper

Parental accounts of sharing an autism spectrum diagnosis with their child - A thematic analysis*

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Abstract

This is the first study to explore how parents share an autism spectrum diagnosis with their child. Research into diagnostic disclosure in the context of intellectual and developmental disabilities provides insight into the complexity of this issue and the challenges faced by parents during this time. Parents' retrospective accounts were explored to develop an understanding of diagnosis sharing specifically in the context of autism. 10 parents of children with an autism diagnosis, consisting of eight mothers and two fathers participated. Semi-structured interviews were conducted, including one couple interview and eight individual interviews. Interviews were transcribed verbatim and analysed using thematic analysis. The analysis identified that sharing an autism diagnosis is a complex and dynamic process which evolves over time. Parents negotiate a range of self and child factors to inform them of when and in what way to discuss autism with their child.

Keywords

Autism Spectrum Disorder, diagnosis disclosure, parent-child communication, thematic analysis

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Introduction

It is widely accepted that people who have an autism spectrum diagnosis possess a unique profile of strengths and needs, and have different ways of understanding and interacting with others and the wider environment. Given the complexity of autism and the challenging journey that parents traverse in getting their child diagnosed, it is likely that sharing a diagnosis with one's child would be challenging and highly emotive for parent and child alike. Clinical guidelines (e.g., National Institute for Health and Care Excellence, 2011) provide recommendations for communicating the diagnosis to a family, although a child's inclusion in this process is dependent on negotiations between parents and professionals. Clinical observations suggest that the outcome of such negotiations is often that parents proceed to share the diagnosis with their child independently, which is perhaps associated with the child's ability to understand (Nissenbaum, Tollefson, & Reece, 2002). Yet anecdotal clinical reports suggest that parents rarely feel well equipped to deliver this information, and there appears to be minimal support in helping them through this process. It is therefore important to explore *how* parents inform children of an autism spectrum diagnosis and the issues and processes that may arise.

Communicating about autism is perhaps further complicated by competing conceptualisations, undetermined causation and the contested nature of autism as a valid diagnosis (Timimi, 2007; 2011). It could be conceived that available explanations fall across a disability versus difference continuum. The former confers with medicalised notions of patterns of social communication, social interaction and restricted repetitive behaviours and interests (American Psychiatric Association, 2013) that fall outside normative expectations and which may be problematic. This contrasts with proponents of the Neurodiversity movement who contend that autism should be viewed as an alternative way of thinking and acting that should be accepted, respected and celebrated (Langan, 2011). Such conflicting descriptions may create challenges for parents in the sharing process and could influence how they understand and talk about autism with their child.

Literature pertaining to the communication of an autism diagnosis has predominately focused on the initial disclosure between professional and parent. There is some indication that parents may feel overwhelmed at this time and struggle to understand written information provided and apply this to their child (Abbott, Bernard & Forge, 2012; Braiden, Bothwell & Duffy, 2010). Nissenbaum and colleagues (2002) reported that parents need time to understand autism themselves and to process their emotional reactions to the diagnosis before sharing. This warrants consideration of how parents proceed from a position of not only understanding their child in the context of autism, but also to sharing this knowledge with their child.

Huws and Jones (2008) interviewed young people (aged 16 - 21 years) with autism about their perception of the diagnosis and its disclosure highlighting that there was often a delay in sharing the diagnosis with the young person. The disclosure was met with a range of responses including acceptance, dislike of having the diagnosis and concerns relating to stigma. However, there was no reference to the disclosure itself – who shared the diagnosis and how this was done for example. The authors suggest that the experience of parents and professionals who have shared a diagnosis of autism with a child is an area in need of exploration. Other authors (Jones, 2001) stress the importance of sharing an autism spectrum diagnosis with children, particularly those considered high functioning, as it may help them make sense of their experiences and provide an explanation of *being* different that is not *being crazy*. Such studies suggest that disclosing an autism diagnosis may be pivotal in the lives of some people with autism.

The absence of autism-specific research led to a broader consideration of literature regarding the disclosure of developmental conditions and intellectual disabilities. It was considered that the similarities between these groups (e.g., diverse cognitive and communication abilities and the potential for social exclusion) meant that insights could be gained from which parallels could be drawn to autism.

Research with parents of adult offspring with learning disabilities (Todd & Shearn, 1997) suggests that parents may avoid disclosing this to their child and some may actively attempt to keep this information secret in order to protect their child from emotional distress. Many of these parents worried that disclosing the diagnosis in adulthood would have a powerful and negative impact on their child's sense of self and perceived that it was beneficial that they did not know.

Consistent with this, research with the parents of children and adolescents with diagnoses including intellectual and developmental disabilities and Down's syndrome reported that some parents choose not to disclose their child's disability or talk about difference with them (Cunningham, Glenn & Fitzpatrick, 2000; Jones, Oseland, Morris & Larzler, 2014; Kelly, 2005). Non-disclosure was associated with parental perceptions that their child would not understand and also concern about the impact of this knowledge on their child's emotional wellbeing and self-esteem (Cunningham et al., 2000; Jones et al., 2014). Cunningham et al. (2000) reported that within the group of parents who had not spoken about diagnoses with their children, some perceived that the diagnosis was not something to be dwelt upon while others reflected that sharing the diagnosis was not something they had considered.

Furthermore, Kelly (2005) suggested that some parents perceived that the impact of their child's impairment on daily life meant they could understand without a specific explanation. Interestingly, the author reported that children may gather information from other sources to understand or describe impairment and disability despite this not being shared by parents.

These findings reflect the challenges that parents experience when negotiating what to share with their children and the emotional, social and developmental factors that may shape their decision. It is reasonable to assume that the parents of children with an autism diagnosis may face similar dilemmas when deciding if and what to share with their child and it is important to develop an understanding of this.

Within these studies however, some parents had shared diagnoses with their child (Cunningham et al., 2000; Jones et al., 2014). Jones et al. (2014), whose sample included parents of children with autism, found that parental descriptions of conversations they had with their children were more likely to reflect discussions about difference (e.g., from peers or siblings) rather than disability per se. The authors suggested that disclosure was usually reactive (e.g., in response to their child having a negative social experience) rather proactively planned. Some parents felt uncertain if their child understood the diagnosis, whilst others spoke about the sense of loss their child expressed following the disclosure. The authors further reported finding no significant differences between the groups of parents who had, and had not communicated about difference with their child in relation to the child's verbal mental age, chronological age and demographic variables such as parental education.

Interestingly, some parents described diagnosis sharing as an ongoing process whereby they would focus on what was important to a child at a given point in their life, providing more detailed explanations as they perceived their child to be more able (Cunningham et al., 2000). Consistent with Jones et al. (2004), these authors found that disclosure may be reactive. In their study it was often triggered by a child's recognition that they shared facial features with others who had Down's syndrome or asking why they could not do things that their siblings and peers could. Although children with autism do not have physical characteristics which differentiate them from others, it is possible that they may recognise that there are social differences between them and their peers.

This, albeit modest, body of literature offers some insight into the complex emotional, relational and social factors which may influence parental choice regarding sharing developmental or intellectual disability diagnoses with their child. However, the focus of existing research and the methods employed preclude a detailed and nuanced understanding of such processes in the context of sharing autism spectrum diagnoses. The current researchers aimed to address this by exploring parents' retrospective accounts of sharing an autism diagnosis with their child. Broadly speaking, the question '*How do parents share an autism spectrum diagnosis with their child?*' was asked to

develop an understanding of the processes, methods, techniques, and outcomes of this disclosure.

Methodology

Given the paucity of literature, utilising a qualitative methodology was deemed appropriate. Thematic analysis (Braun & Clarke, 2006) was employed to explore parents' retrospective accounts of sharing an autism spectrum diagnosis with their child. Thematic analysis was chosen for its flexibility and atheoretical stance, meaning that it could accommodate the critical realist epistemology adopted (Braun & Clarke, 2006). Furthermore, it provided a systematic framework to identify, analyse and report patterns of meaning in the data which in the current study, was performed at a semantic level to facilitate broad interpretations of meaning at an explicit rather than latent level (Braun & Clarke, 2006).

Using a critical realist lens, the researchers adopted the position that knowledge production is inherently subjective in the context of expectations, beliefs and external social forces (Madill, Jordan & Shirley, 2000). The experience and meaning of sharing an autism diagnosis was understood as an interaction shaped by external factors such as access to services, other social contexts, and the child's developmental level and response to the diagnosis. The accounts articulated were viewed as being embedded in the interactional context of the interview and beliefs and expectations of each party. Consistent with this, the first author (EW) acknowledges that their clinical experience in specialist autism services may have shaped their position in relation to the research aims and interpretations made.

This experience, and the motivation to conduct the research were made clear in the participant information sheet and EW also kept a reflexive diary throughout data collection and analysis. The second author (RdN) had no experience in working in autism services, so acted as a foil to appraise the interpretations made by EW to ensure that they remained true to the data collected. This is one way in which the integrity of the data is maintained. Similarly, one transcript was

coded by an independent researcher to offer a forum to discuss areas of commonality and divergence from EWs coding to assure that developing codes were data-driven rather than directed by previous clinical experience. In accordance with Elliott, Fischer & Rennie, (1999) further quality assurance measures taken include outlining the position held in relation to the research, contextualising the sample and, providing data extracts to support the analysis.

Ethical approval

Ethical approval was conferred by The Institute of Work, Health and Organisations, University of Nottingham in July 2012 with subsequent alterations approved in March 2013. Further ethical approval was granted by a local NHS Research Ethics Committee in November 2012.

Participants and recruitment

Inclusion criteria were intentionally kept broad to recruit a range of participants. These were: 1) a parent/carer of a child with a diagnosis on the autism spectrum (e.g. autism, high functioning autism, Asperger syndrome), 2) to have shared, or to have begun to talk about autism with their child, 3) that the child was aged 18 years or younger at the time of interview, 4) to have the ability to provide informed consent and 5) to be English speaking in order to promote consistency in the understanding of the language and concepts used between participants and interviewer.

A purposive sample of ten parents of children with an autism spectrum diagnosis were recruited to the study (eight mothers, two fathers), two of whom were a married couple. The sample was homogenous in that all participants shared the experience of communicating an autism diagnosis with their child. However, the children whom they spoke about varied in terms of reported cognitive ability, educational placement and additional diagnoses. All participants identified as White British. Diagnostic labels were reported by parents and were not formally verified.

All participants self-selected to participate in the study. Two participants responded to an advert placed in the newsletter of a charitable organisation, a

further two responded to a poster displayed in a specialist school. The remaining participants were recruited when they contacted the first author directly after being informed of the study by clinicians at a local National Health Service (NHS) Trust.

Data collection

All participants were sent information about the study, and all data was collected at the time of the interview after written informed consent was provided.

Participants completed a brief questionnaire to capture their child's diagnosis, wait for diagnosis, age at diagnosis, age diagnosis was shared, and the length of time for which the child had known of the diagnosis. This information was used to contextualise the data collected through semi-structured interviews.

Based on knowledge of the area and initial reading of the literature, an interview schedule was designed and amended on the basis of feedback from a parent governor of a specialist school for autism. The schedule consisted of 11 questions intended to explore parents' recollections and was used flexibly during interviews alongside prompts, reflective statements and summaries to clarify and/or elaborate descriptions. At the end of the interview participants were asked if there were any pertinent issues which had not been covered that they wished to share.

Eight interviews were conducted by EW with individual parents and one with a parent couple. Interviews ranging in duration from 37- 96 minutes were digitally recorded. One interview was conducted at a University base and the remainder in participants' homes. The recorded interviews were transcribed verbatim by EW or a professional transcription service (to which participants had consented) who signed a confidentiality agreement prior to receiving audio files. All transcripts were checked against audio recordings for accuracy by EW and were amended accordingly. All transcripts were anonymised and identifiable information was removed.

Analysis

The six phases of thematic analysis as described by Braun & Clarke (2006) were used to conduct the analysis. An inductive approach was taken whereby codes and themes were generated from the data rather than from the application of a pre-defined coding frame. Analysis was completed manually and began with the repeated reading of each interview transcript, with notes of initial ideas recorded in the margin along with any potential patterns which related to the study aims. A list of codes was developed which captured the initial ideas and interesting patterns that had been noted. Interview transcripts were re-read, and data extracts were further coded. Connected codes were then grouped into potential themes which were checked against coded extracts and across the data set to establish if these themes worked. Further definition of themes was achieved in collaboration with the second author (RdN) whereby the overall story captured by the analysis was discussed and some themes were collapsed into broader themes which were then clearly defined and organised into a thematic map.

Secondary analysis

It was considered that it may be useful to develop a leaflet to reflect the experiences shared by the participants that could be offered to other parents who are deliberating about sharing the diagnosis. A secondary analysis was therefore conducted to create a leaflet based on the data. A coding frame was developed and each transcript was re-read and extracts which demonstrated the use of a strategy or pertinent process were coded accordingly. Data extracts were collated in a word document, forming the final framework for the leaflet which is appended to the journal paper.

Findings

Sample characteristics

10 participants (eight mothers, two fathers) were interviewed, all of whom reported that they welcomed the opportunity to share their experiences hoping that it would be helpful to other parents and professionals. All participants were

a biological parent of the child. Table 4 describes some of the key features of the sample and their children.

Table 4: Details of participants, children and timeline to sharing of diagnosis

Participant (a)	Age of child (years)	Gender	Diagnosis	Wait for diagnosis (months)	Age at diagnosis (years)	Age diagnosis shared (years)	Approx. time child known (years)
Steven	12	Male	ASD Dyspraxia Severe LD	30	4y,7m	11	11m
Dawn	12	Male	ASD Dyspraxia Severe LD	30	4y,7m	11	11m
Rebecca	15	Male	Asperger syndrome	12	3y,6m	4	12
Jenny	17	Male	Classic Autism LD	9	2y,5m	9	9
Erica	14	Male	Asperger syndrome	96	11	11	3
Susan	13	Female	ASD, ADD Sensory problems Dyslexia	6	2y,11m	9	4
	12	Male	Asperger syndrome Sensory problems	36	4	8	4
Laura	12	Male	ASD Sleep Disorder	18	3y,6m	9	3
John	16	Male	ASD	6	10	10	6
Kirsty	16	Male	Asperger syndrome	120	11	11	5
Anne	11	Male	ASD LD	48	7	7y,6m	3

Notes. ^(a) Pseudonym used; ASD: Autism Spectrum Disorder; LD: Learning Disability; ADD: Attention Deficit Disorder; m months; y years

The majority of the children (nine) were male and ranged in age from 11 to 17 years. One participant (Susan) discussed informing both her son and daughter of their autism diagnoses during the same interview. One couple (Dawn and Steven) were interviewed together about disclosing the autism diagnosis to their son. Over half of the parents (seven) reported that their child had additional diagnoses. The average waiting time to receive a diagnosis was three years, although this may be somewhat misleading as the parents who reported the longest wait for diagnosis (96 months and 120 months) had not been seeking an autism diagnosis for this entire duration, although had some concerns about their child's development.

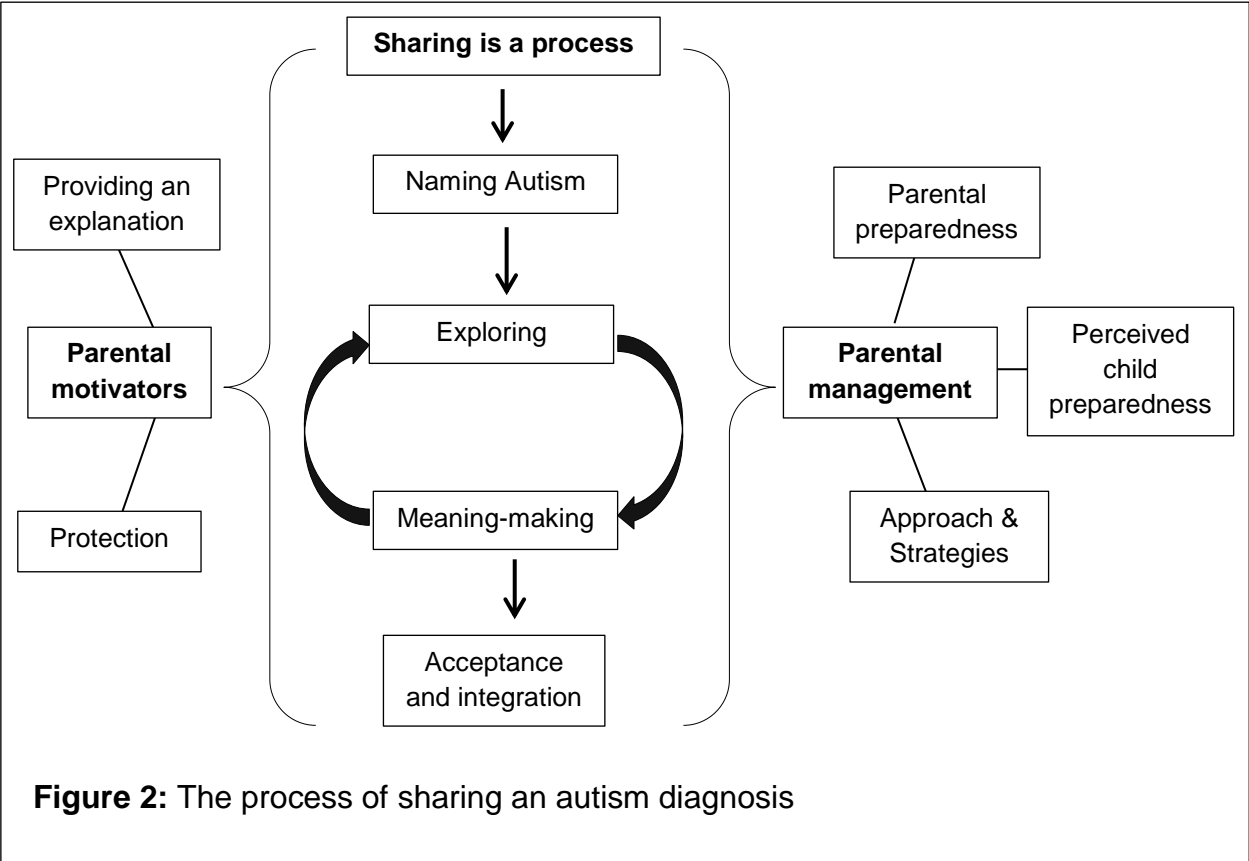
The average time between a child receiving a diagnosis and this being shared with them was 2 years and 6 months. This ranged from there being no delay (when the diagnostic process with professionals was open) to a period of 6 years and 5 months. For children diagnosed at a younger age there was typically a longer period during which parents knew about the diagnosis whilst their child did not. The mean age at the time the diagnosis was shared was 8.95 years, ranging from 4 to 11 years. The average time for which a child was aware of the diagnosis was 4 years and 6 months.

Overview of themes

The analysis identified three overarching themes, each with corresponding sub-themes. The thematic map (see Figure 2) has been constructed as a process diagram to capture a dominant description in the data – that sharing an autism diagnosis with one's child is an ongoing process and not an 'event'. Three 'phases' (or sub-themes) were identified in this process: 'naming autism'; 'exploring and meaning-making', and 'acceptance and integration'.

Analysis further identified that the sharing process was mediated by parental motivation to share (or not) and ongoing parental management of the sharing. The former describes parents motivation to provide their child with an explanation (e.g., of difficult social experiences) and to protect often the self and child (e.g., from the perceived negative responses of others). The latter relates to parental preparedness (e.g., understanding their child in the context of

autism); perceived child preparedness (e.g., their ability to cope and understand) and approach and strategies (e.g. drawing on the positives).



These themes and sub-themes are presented separately to represent the different foci of the data and therefore the alternate aspects of the process of sharing an autism diagnosis with one's child. However, they are inherently linked and the sense of parents' motivation and management of the sharing process is inflected throughout discussions of all sub-themes. Although the diagram provides a good overall framework from which to understand the process of sharing, an inherent criticism of any process model is that it fosters the assumption that parent and child move through the phases sequentially and it is acknowledged that this is unlikely to be the case.

Due to space restrictions, one theme will be described in detail, alongside a brief overview of the others. The central theme of 'sharing is a process', is the focus of the current paper.

Sharing is a process

Perhaps unsurprisingly, parents consistently reported that sharing the autism spectrum diagnosis with their child was an ongoing process, and not a one-off event. This was often described as being unplanned and initiated by the child. Parents often referred to ongoing conversations as “coming out of the blue”, requiring them to “think on their feet” in order to respond to their child. It also suggests that the child’s motivation to explore autism is unclear to parents until any given interaction.

“I don’t think we’ll ever *really* have explained what autism is to him for quite a long time, we’re working through it slowly, at his pace.” (Steven)

Here, Steven reflects the prolonged nature of the sharing process, further suggesting that a child *knowing* they have an autism diagnosis and constructing an *understanding* or *meaning* of this are quite distinct. Steven also draws attention to the perceived importance of pacing sharing in accordance to the child (“his pace”). Therefore, parents appear to monitor and reflect on interactions with their child to assess their understanding and responses to information about autism.

“[...]”² I thought it was positive. I was glad he asked and, I was glad I had the opportunity to just start the ball rolling, but like I said it was, it was gradual, so it wasn’t like, you know ‘oh my god I’ve told him’ and ‘this is all really upsetting’ or anything. It wasn’t like that at all. [...] so no, I think that, that the actual telling him was ... not a problem.” (Rebecca)

Rebecca’s account demonstrates a positive outcome to her son asking if he had autism. Her being “glad” of the opportunity implies that knowing when or how to approach sharing the diagnosis with one’s child may be troublesome for parents and this is made easier by being invited into the interaction by the child. It may also be interpreted that parents have an expectation that sharing the diagnosis will be upsetting for both them and their child which influences the withholding of this decision to share.

² In providing extracts of data, some text has been removed to make extracts more manageable as indicated by [...]; this was only done when removing text did not alter participants’ meanings.

Susan, however, offers an alternative experience compared to the rest of the sample as she planned her approach to sharing autism spectrum diagnoses with both her daughter and son.

“And even when I did tell them [children], I didn’t, you know, I knew it would be a gradual thing as to what it would actually mean to them. So I didn’t have high expectations in them being able to grasp it ... greatly, and that will still change as they get older as well.” (Susan)

Susan presents her expectation that sharing would be gradual but also indicates that the child’s ability to attach meaning to the diagnosis did not prevent sharing. Susan also infers that the meaning attached to an autism diagnosis by a child is changeable, which is perhaps based on experiences and transitions as they move through the life span.

Naming autism

Naming autism reflects the distinct time when (usually) parents’ explicitly shared the autism spectrum label with their child. This signifies the beginning of the child’s involvement in the sharing process which, for most families, had previously been restricted to parents. Some³ parents described the word autism being “in the ether”, whereby they openly discussed autism within the home; and reflected that the word being familiar to the child made naming autism easier. Retrospectively, other parents considered that having “the word out there” may have made naming autism easier.

“We’re, just trying to sow the seeds aren’t we I think more than anything to ... you know, let him get used to the idea and, and then um, we, like I say, we have to drip stuff to him.” (Dawn)

“Sowing the seeds” captures the essence of naming autism whereby parents name and share just enough information consistent with their perception of their

³ General ‘quantifiers’ (e.g., ‘some’, ‘many’, etc.) are used for descriptive purposes and do not relate to specific frequencies or ‘significance’ of endorsements. Frequency and prevalence alone did not quantify saliency of themes. Our judgement in relation to extracts capturing meaning or patterned responses defined the saliency of themes (Braun & Clarke, 2006).

child's cognitive and emotional position in relation to this. However, parents' tentativeness also illuminates the emotionality of such interactions, and a possible need to reconcile that what was once private knowledge has become shared. This tentativeness is further reflected in Rebecca's recollection of when her son asked if he had autism:

"A little bit, but he was so young then, I mean he was only four. So I just said 'Yeah, I think you've got a little bit and I think I've got a little bit as well and you know, it's just, it's just about being a bit different'. It's nothing, you know, I didn't say too much ... and he didn't ask too much at the time. It was really just a passing question; it's like "do you think I've got a bit?" (Rebecca)

To provide some context, Rebecca also has an older son who she described as severely autistic which provides an understanding of the surprisingly young age when the 'have I got autism?' question was asked. Rebecca indicates that Asperger syndrome was referred to, but does not appear to have been considered essential. Rebecca's account also encapsulates how parents may minimise autism and gate-keep the amount of information they share during this phase; perhaps with the intention of protecting their child (and themselves) from distress. Additionally, Asperger syndrome has been positioned as a difference rather than a disability, which is a tension shared by other parents, and is perhaps related to personal constructions of autism and disability. During this phase, and indeed throughout the sharing process, parents normalise autism during interactions with their child as has been demonstrated here by Rebecca describing herself as "having a little bit *as well*".

Like Rebecca, Jenny's account again demonstrates that naming autism often occurred in response to a child's question.

"But um, he was about nine and, um, I thought, I decided I would talk about autism or mention it. So I said something about autism and Aidan said, 'Am I autistic?' And I said, 'Yes you are', you know, and it was so kind of *liberating*. And er, he smiled kind of thing because, you know, he said, 'Alright Mum, I'm autistic'. Um, because he knew and I think he'd known for, for years and he must have been quite ... mystified." (Jenny)

Jenny also highlights that prior to naming autism parents may ‘test the water’ to get a sense of how talking about autism feels and, how their child will respond. Parents frequently reported relief and for Jenny, liberation, suggesting that prior to this, parents are waiting for a time to tell. Jenny also indicates the possibility that children will construct an understanding of themselves in relation to autism prior to parents explicitly making this connection with them. For Jenny’s son this understanding was probably constructed in the context of attending a specialist school.

However, not all parents experienced relief directly addressing autism with their children, particularly when they were not prepared for it. Laura, for instance, provides a divergent account of naming autism, and indicates that being able to control, or manage, the disclosure is important to parents.

“[...] I think it was taken out of our hands. I think there was some discussion at school about it ... And we *had* to tell him, I don’t think we were ready. I think it was an assembly [...], that they pulled him out of. So Robert realised he was the, odd one out [...] And then he found out from all his friends the assembly was about autism ‘so that must be you Robert’.” (Laura)

Such public *outing* of children with autism was not considered to be helpful as the child’s difference was amplified to him, his peers and parents before the family felt ready to address the issue of diagnosis sharing. However, in the following extract, Laura goes on to reflect that despite this having been upsetting, there was a positive in that it opened up a space for questions and conversations about autism, which were perhaps previously avoided.

“It was, it was horrible and certainly not the way to do it. But I think we found our feet with it quite quickly. And actually then it was all out in the open and he was able to ask questions.” (Laura)

Exploring and meaning-making

Exploring and meaning-making was conceptualised as occurring in a recursive fashion, reflecting interactions between parent and child that promote an

understanding of what autism is. 'Exploring' captures interactions and exchanges that occur between parent and child, when autism is related to the child's past and present experiences to promote connections and understanding. Meaning-making refers to the child's evolving understanding of autism as they begin to view day-to-day experiences *with the knowledge of their autism diagnosis* and have an emerging sense of how autism may impact on them, and then seek verification from parents.

"I always say, 'You're 95% normal boy and 5% autism' and that's kind of how we deal with it. It's 'No, you're just like us, but you've got this little bit that makes you love Mario [Nintendo game] a bit more or worry a bit more'. I try and normalise it all down really [...] and he seems very comfortable with the 95% ... rule. If he gets down I say 'Don't forget you're 95% just like us'. That's how we deal with it, he kind of likes that."

(Laura)

Some aspects of this quote relate to the minimisation and normalisation ("you're just like us") that was seen in the previous sub-theme (e.g., Rebecca's quote above). However, Laura's account here also demonstrates how parents understand their child's experiences and difficulties within the context of autism and share this knowledge to enable the child to make connections ("...that makes you love Mario..."). The importance of describing autism in a way which preserves the child's concept of themselves prior to sharing the diagnosis also seems important, as does aiming to prevent the child from developing a sense of themselves that is disconnected from the family.

Such discussions also appeared to allow parents to explain autism or an experience better to their child or to pre-empt problems:

"Well I just sat down with him and I explained to him, there's going to be various times when he's not going to be able to understand what's going off, or people might get angry with him and he won't understand why. Because he struggles with understanding people that are angry err, or, I suppose, facial expressions. He can't pick up on things sometimes."

(John)

In talking about autism in this way, John communicates the permanence of autism to his son, providing also, reasoning for the negative and confusing social encounters he has experienced. Such explanations also reflect how parents may support their children to relate better to others. Dawn describes how an emerging understanding of autism may lead a child to be curious about whether peers share their diagnosis, perhaps seeking containment in knowing that they are not the only one.

“And he has asked sort of like, ‘Well so and so, have they got autism?’ hasn’t he? ... There’s been a few children that he’s sort of said, ‘Have they?’ And most of them have actually haven’t they? [...] for the most part, the children that he has sort of asked about, well yes, they’re autistic too.” (Dawn)

This awareness that others too can have similar problems arguably encourages acceptance of the diagnosis and integration within daily life.

Acceptance and integration

Parents described interactions with their child that suggested the diagnosis had begun to be accepted and integrated into daily life which, arguably, is interwoven with parents own acceptance of autism and the meaning they hold. Parents’ accounts reflected a sense that autism was *part* of the child’s personality or identity and communicated with them in a way to promote this positively:

“He’s like any child who’s diagnosed or not diagnosed, they are what they are, you know, they’ve got their own personalities. He’s you know, he’s been brilliant with it, you know, he’s just taken it on board. ‘Okay, I’ve got that’, you know, ‘That’s fine ... really’.” (Erica)

Erica describes how children may positively accept and integrate the autism diagnosis, which perhaps links with how the child connects with this and the understanding it provides. She also hints that the normalising practices parents engage in with their children may be under-pinned by an intention to nurture acceptance and to maintain the child’s sense of themselves. John also

suggests that understanding and incorporation of the autism diagnosis may foster self-acceptance in the child, even if tension remains with the diagnosis itself:

“[...] I think he has. I mean, I mean given a choice, I don’t think he would want it, but I think um, I think it’s helped him to accept himself a bit more, you know.” (John)

The importance of the child’s acceptance of the autism diagnosis to parents was overwhelming within their accounts. There was a sense that this would be pivotal throughout life, perhaps suggesting that for these parents, sharing the diagnosis in childhood was crucial to enable them to support the child in negotiating the boundaries of autism positively and in a manner that was not all-encompassing:

“So we wanted him to just be able to be who he is first, you know, loved, part of our family. We’re all different; we’ve got our good points and our bad points, our strengths and our weaknesses. And this is just part of who you are and, um, and it’s not going to limit you, you know. I mean, obviously, there are limitations for him, but for him, we want him to know that, you know, there’s a future and it’s a happy future.” (Anne)

Here, Anne further captures how parents encourage the integration of autism as ‘part’ rather than ‘whole self’ and continues to communicate the message that the autism diagnosis does not disconnect the child from the family. Interestingly, this ‘part’ versus ‘whole’ discourse also relates to Laura’s quote above (“You’re 95% normal boy and 5% autism”), suggesting that communicating about autism in this way is an approach which many parents may choose to adopt.

Normalising practices are again evident in the promotion of strengths and weaknesses as a reality for everyone.

Anne also highlights parents’ attempts to protect their child, and to help maintain a positive self-image and view of the future by carefully selecting the information shared. In some circumstances, the normalising practices referred to appear to reflect a critical stance to the position of autism within society:

“Um, we can discuss that and we can talk about, it is important to socialise, but just as your critics will think that you’re being antisocial by not doing the norms, they’re actually being very stereotypical about what they think is socialisation. So you could actually, they have some jokes about flipping it round and people that think they’re neurotypical, actually they’re being quite rigid in their thinking.” (Susan)

Susan shares how her children engage in interactions which challenge normative assumptions about their social preferences, suggesting a level of integration and acceptance of the autism diagnosis which is rooted in the communication between Susan and her children. Interestingly though, acceptance and integration of the autism diagnosis as a both process and outcome of the disclosure was viewed as potentially changeable as Susan goes on to capture here:

“I’m pretty, *I’m* pretty sure that they are happy, they’re comfortable with their diagnosis And, they don’t have, certainly don’t appear so far, to have an emotional hang-up about, and they’re not fighting it, their diagnosis. Um, I’m not saying things can’t change in the future ... I’m aware of that.” (Susan)

Susan illustrates parental perceptions that acceptance of the diagnosis could change as the child becomes aware of their potential limitations. This is perhaps related to the range of experiences and challenges the child may traverse as they develop and move through life transitions. Given that the trajectory of autism is uncertain, parents are unable to prepare their child (and themselves) for every eventuality or to provide definitive answers about what will be. This of course could mirror the experience of parents, whose feelings and perceptions of autism may fluctuate across the life course as they become aware of normative rituals and transitions which are absent from their child’s life.

Discussion

This was the first study to explore how parents share an autism spectrum diagnosis with their child. Thematic analysis of parents’ retrospective accounts

identified that sharing an autism diagnosis with one's child is a gradual and ongoing process, mirroring parental reports of sharing a diagnosis of Down's syndrome with their child (Cunningham et al., 2004). The evolving and ongoing nature of diagnosis sharing with children has also been reported in literature relating to paediatric HIV (Ledlie, 1999; Weiner et al., 2007), genetic conditions (Gallo, Angst, Knafl, Hadley & Smith, 2005; Faux, Schoch, Eubanks, Hooper & Shashir, 2012) and paediatric oncology (Claiflin & Barbarin, 1999). This suggests some commonality in sharing diagnoses with children at a broader level, despite differences in causation and prognosis of condition.

Furthermore, parents within the current and related studies appeared to use their understanding of their child's emotional, cognitive and social development to gauge what was appropriate to share. There is also an overwhelming sense of parents wanting to protect their child from emotional distress and responding in ways which are congruent with this.

Compared with existing literature, the analysis presented here provides greater detail of the processes which occur between parent and child in the sharing process. Whilst studies relating to sharing information about intellectual disabilities, Down's syndrome or developmental disabilities offer an understanding of the factors which may influence decision making, the current study enriches an understanding of the methods, techniques and relational knowledge that parents employ to facilitate communication with their child.

The findings also demonstrate that parents work hard to understand their child within the context of autism and use this knowledge to explain autism by providing examples which are rooted in their child's day-to-day experiences which, they believe their child will relate to. This experiential framework does not appear in other literature, which tends to focus on explaining the condition, (Faux et al. [2012] for example, explaining a genetic condition). This perhaps reflects there being no answer to the 'why' question in the case of autism. Although parents may say "Your brain works a bit differently" or, "You just think a bit differently" they appear to support their child's exploration in a way that establishing meaning and connections with daily life.

Also evident in parents' accounts were attempts to discuss autism with their child at a pace perceived to be suitable, in a way which normalised autism and maintained connection with the family, and perhaps 'the world out there'. These processes are also evident in existing literature where information is shared in a way that will not scare the child or make them feel different (Faux et al., 2012) and is safe and in a way which they can process (Gallo et al., 2005). This resembles the findings of Cunningham et al. (2004) who noted that parents often structure explanations within the context of what is relevant to the child at a particular point in time.

Indeed, parents often presented a developmental framework in their approach, managing information sharing in-line with their perceptions of child preparedness and acknowledging that this would vary across the life span. This is consistent with literature pertaining to paediatric HIV and oncology where parents engage in 'selective sharing' according to the perceived ability of the child to understand and cope with what is shared (Lester et al., 2002; Young, Dixon-Woods, Windridge & Heney, 2003). Such perceptions mediated when parents shared the autism diagnosis. Parents often waited for the 'right time' to tell which has been consistently reported across the paediatric diagnosis sharing literature. Extending this further, the developmental framework could be understood as a reciprocal process which encapsulates how ready a parent is to consider, accept and discuss the pervasive nature of an autism spectrum diagnosis.

The findings of course need to be understood in relation to the study limitations. Firstly, the sample was self-selected and participants openly expressed their desire to share their experiences. This may reflect a perceived positive outcome of sharing an autism diagnosis with a child. Parents who experience greater challenge in this process, or who choose not to share an autism diagnosis with their child may not have selected to participate in the study, meaning that their account is absent from the analysis. Secondly, although exploring retrospective accounts has provided some indication of the factors which mediate when and what parents share with their child, it is possible that prospective accounts of this would differ. Future studies could employ a longitudinal design to record prospective experiences and perhaps track changes in the sharing process

over-time to enrich our understanding of the role of transitions across the life span.

Furthermore, it would be pertinent to seek the views and experience of parents who have chosen not to share the diagnosis or who have experienced this more negatively than the parents in this sample. This may enrich the understanding of factors which shape parental decisions and to indicate if support may be needed during this time.

A further limitation of the study is the over-representation of mothers in the sample. The recruitment strategy may have biased the sample in this way if, mothers are more likely to be the primary contact with services. Future research would benefit from increasing the representation of fathers and other caregivers. The application of the findings may also be limited to children who are able to communicate verbally. Indeed, during recruitment some parents chose not to participate, indicating that they had not shared the autism diagnosis with their child and are unlikely to do so due to their level of cognitive impairment and the 'severity' of autism.

Expanding on this study and that of Huws and Jones (2008), curiosity remains about children's views of the 'disclosure' process. Further qualitative research with children could help discern if the presented process model is apparent in their accounts to broaden the understanding of this. Such research also affords the opportunity to develop an understanding of what impact (if any) knowledge of diagnosis has and may also contribute to an understanding of how exploration, meaning making and integration may alter through childhood and adolescence.

We hope that our findings prove useful to clinicians supporting families who are considering, or who have begun to discuss autism with their child. Reflecting upon conversations with parents - sharing an autism diagnosis with a child is unique to both the child and their family. Parents also propose that "there is no right way" and to tell parents how to share is "wrong". In-keeping with the wisdom of those who have shared their experiences, we hope that providing insights into the process of sharing, alongside some suggestions of approaches

that have been considered helpful, will support parents who are debating the 'ifs', 'when's' and 'how's' of sharing.

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Sharing an autism spectrum diagnosis with a child

Parents' stories

What is this leaflet is for?

This leaflet is based on our research with parents who had shared their child's autism diagnosis with them. This included autism and Asperger syndrome. Some of the children also had a learning disability or other diagnoses. All of the children could communicate verbally.

We asked parents about how they shared autism with their child. We know that this will be different for every family. Some families decide not to talk about autism with their child and some do. We know that this is not an easy decision to make. It is important to think about what feels right for your family.

This leaflet is not a plan of how to share a diagnosis. It offers some ideas based on what the parents we spoke to found useful when they shared the diagnosis with their child.

Autism means something different for each family. People have different ways of understanding and talking about autism so some of these ideas may not seem relevant. They may help you to think about how to talk about autism in a way that fits with you and your child.

Before sharing the diagnosis

Parents had some worries about telling their child that they had autism. They worried about upsetting them. They sometimes worried that they were not ready to tell. They said it was important for them to process news of the diagnosis before they shared it with their child.

Most parents said that they were waiting for the right time to tell their child. Some children were older when they were diagnosed and were told about the diagnosis at this time. Some parents did not make a plan to share the diagnosis with their child. Others wrote a list of things to talk about.

Working out when to tell your child

*"Oh, if I was to do it again I would share the diagnosis, if I felt my child was ready and, if I am ready... I think sometimes after diagnosis, parent's need a bit of time just to get their head round it." (Jenny)**

The parents we spoke to shared autism with their child when:

- Their child had started to recognise that they were different from others
- They were experiencing emotional distress or struggling at school
- Their child asked them directly about their difference or diagnosis
- Parents thought they were at a stage when they needed to know

The children were between 4 and 11 years old when they were told about the diagnosis. Parents told their child about autism hoping it would:

- Help their child understand their emotional and social experiences
- Provide a reason for the difficulties they experienced
- Let them know that they were okay and that they were not a 'weirdo' or 'crazy' like other children had said

What did parents do?

Parents said that sharing the diagnosis with their child was an ongoing process. This involved having conversations and answering questions over time. Some parents said that their child asked questions to understand autism and how it affected them. Although the process of sharing is individual to each child, there were some similarities in how the parents we spoke to approached this. These are outlined below.

Preparation

Parents thought it was important to learn about autism before they shared it with their child. They said that reading books, going on courses and speaking to other parents helped them:

"It's about confidence, knowing, understanding autism and trying to apply that to your child and trying to understand your child to help you explain it; that's really important." (Steven)

It seemed to be helpful for parents to understand how autism affected their child so they could share the diagnosis in a meaningful way. Parents talked about autism in a way that suited their child's needs and preferences. They spoke about autism in a way to help their child understand what it meant.

Approaches to sharing

Parents thought that it was important for them to have some understanding of their child's abilities to help them during the sharing process. They used this to shape how they shared information about autism. The parents we spoke to felt that knowing their child and how they liked to interact and communicate helped them too.

"You have to take things at their pace. And ... because my son's got learning difficulties as well ... at the moment ... although he hasn't got a great understanding, just the awareness that this is what makes him different, I think is really sufficient for him. And then as and when he wants to know more then we'll have to start ... trying to find more answers." (Dawn)

For some children, this meant sharing in 'bite size' chunks and waiting to see when they were ready for more information. For others, it seemed okay to have longer conversations and to give them time to ask questions.

Parents seemed very good at answering questions based on their child's ability even though they said that they didn't feel like they always got it right. Sometimes they were unsure if they had shared too much or confused their child. Parents used this experience to adapt what they said next time.

Parents said that they 'took their child's lead.' They often waited for them to ask more questions. Parents used examples from the child's day-to-day experience to help explain autism:

"We didn't get all technical, like say "you have impairments in the following areas". I think we may have said, for example, if there was something that he found difficult, like if something was cancelled at the last minute; I'd say that "you find that hard because you have autism", and "people with autism like the same thing to happen at the same time."(Jenny)

Sharing over time

After initially sharing the diagnosis parents said they took opportunities to continue discussing autism when they saw that their child was struggling. They thought that this helped their child understand why they found certain things so hard, or got upset easily.

"Autism means that you find it difficult to do things like learning and understanding, you get anxious and you get upset easily'. And we'd pick out whichever problem we were discussing then, so if it was that he was scared of something, we'd say, 'autism can make you scared and that's fine and we can do things to help you. So it's not your fault and it's just something that you have'." (Anne)

It seemed important to the parents we spoke to that their child understood and accepted the diagnosis. Some parents said that they didn't think the diagnosis changed who their child was, and spoke about it as another part of their personality.

"Sometimes you've got to let them know; sometimes it's good to be different. You don't want to all be the same, that's what makes us up." (Erica)

Parents often shared their child's strengths to help their child to feel positive about themselves and about autism:

'A lot of the time I say to him "Well that's your Asperger's, that's good isn't it?" and ... "You're ability at maths, your politeness, your ability to work out computers and to fix computers; that is definitely from your Asperger's." (Rebecca)

Drawing on the positives

As well as highlighting their child's strengths, the parents in our study shared the positives of autism with their child. They also said that they thought it was important to be balanced and spoke about the challenges their child experienced and that these could be explained by autism too.

"Most of us are fairly average - you recognise your strengths and you use these, but when it comes to careers for example, they can't do something which requires a lot of social ability."(Susan)

Summary

The parents we spoke to felt that sharing the autism diagnosis with their child was not always easy. Even when sharing the diagnosis did not quite go to plan, in time, parents said that they saw the positives for them and their child. We know that this experience will be different for all families and that for many different reasons some families may choose not to talk about autism with their child.

To echo the stories shared by the parents we spoke to – there are no right or wrong answers when it comes to sharing an autism diagnosis with your child. The important thing seems to be doing what feels right for you and your family. We hope that this leaflet offers some ideas to parents who decide to share the diagnosis with their child.

Resources

Some parents found these resources useful:

- A CBBC programme called '*My Autism and Me*' in which children talk about their experience of autism. You can find this online using this address:
<http://www.bbc.co.uk/newsround/15655232>
- Books written by people with autism like:
 - *Freaks, Geeks and Asperger syndrome: A User Guide to Adolescence* written by Luke Jackson
 - *Martian in the playground* written by Clare Sainsbury
- Books explaining about autism:
 - Doherty, K., McNally, P. & Sherrard, E. (2000) '*I Have Autism, What's That?*'
- Books about famous people with autism:
 - Elder, J.(2005) *Different Like Me; my book of autism heroes*
- The National Autistic Society also has a resource section of books about autism spectrum disorders. You can find this using this address:
<http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/reading-lists/autism-books-for-children-and-young-people.aspx>

Extended Paper

1. Extended Background

1.1 *The autism spectrum*

Medically speaking, autism is defined as a complex and lifelong developmental disability which affects an individual's ability to communicate with and relate to others. Autism is traditionally understood as a spectrum which includes diagnoses such as high functioning autism and Asperger syndrome (National Autistic Society [NAS], 2012). Broadly speaking, people diagnosed with autism share difficulties in social communication, social interaction and social imagination; displaying repetitive behaviours and restricted interests (NAS, 2012). Although still conceptualised as a 'spectrum disorder,' the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders ([DSM-V], American Psychiatric Association, 2013b) has collapsed previously separate disorders⁴ into one category – autism spectrum disorder. This decision is said to reflect scientific agreement that these previously separate categories are in fact a single condition (American Psychiatric Association, 2013a). DSM-V presents diagnostic criteria under two domains: 1) deficits in social communication and social interaction and 2) restricted repetitive behaviours, interests, and activities to encapsulate people with varying levels of symptom severity (American Psychiatric Association, 2013a). It is beyond the scope of this paper to consider the polemics or possible ramifications of such changes, although, it is pertinent to briefly consider the contested nature of autism as a diagnostic label.

Ironically, current changes in the diagnostic classification of autism amplify many of the criticisms and doubts surrounding the 'true' existence of autism spectrum disorders. Broadly speaking, criticisms highlight that a medical basis for autism has been identified in just a minority of cases with suggestions of a genetic vulnerability or core underlying pathology being as yet, unfounded (Moloney, 2010; Timimi, 2007). The disproportionate number of males diagnosed over females has also led to dispute in light of there being no association to the X or Y chromosome; with further suggestion that historical, political and social forces have been foreshadowed by a quest for the discovery

⁴ Previous diagnostic categories were Autism, Asperger syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder-Not Otherwise Specified.

of a biological foundation (Timimi, 2007; 2011). Others have pointed to the variability in diagnosis, whereby decisions reached by clinicians based on behavioural observation and parental report are arbitrary, with the line between normal variation and disorder being largely determined by culturally defined norms and expectations (Norbury & Sparks, 2012).

1.2 Neurodiversity – an alternative perspective

Neurodiversity describes an activist movement which opposes the medicalization of autism and its predominant conception as a disability.

Advocates of Neurodiversity propose a model based on natural human variation (difference) as opposed to deficit, highlighting the strengths of individuals and valued contribution that they make to society (Jaarsma & Welin, 2012; Langan, 2011). The movement overlaps with social models of disability which distinguish between *impairment* (i.e. biological impairment) and *disability* which results from lack of accommodation of the impairment within society (Brownlow, 2010).

Consequently, the Neurodiversity movement places autism in a historical, social and cultural context which supposes a disabling environment and largely rejects the notion of a cure.

1.3 The prevalence of autism

It is widely considered in both academic and health communities that the rate of autism had increased exponentially over the past few decades. However, Fombonne (2005) cautions against this increase being interpreted as a true increase in the incidence of autism spectrum conditions. The author suggests that this apparent increase needs to be understood in the context of changes in concepts and definitions of autism and autism spectrum conditions; changes in the availability of services and heightened awareness of autism within both lay and professional communities. Fombonne (2005) further argues that methodological differences such as case identification in such studies may further obscure the true increase of autism prevalence over time. However, similarly to other authors (Baird et al., 2006; Baron-Cohen et al., 2009) he supports the notion that existing prevalence rates are likely to be an under-estimation. In the child population of the United Kingdom, estimated prevalence is 1 per cent (Baird et al., 2006; Baron-Cohen et al., 2009) with autism spectrum conditions considered to be three to four times more common in males than

females (Timimi, 2007), probably accounting for the majority representation of males in autism related research.

1.4 Parental experiences of the diagnosis of autism

Autism is usually recognised in childhood and it is well documented that the diagnostic pathway is diverse, lengthy and often involves families seeing multiple professionals over a number of years (Braiden, Bothwell & Duffy, 2010; Brogan & Knussen, 2003; Howlin & Asgharian, 1999; Midence & O'Neill, 1999). Prior to receiving a diagnosis for their child, parents often report feelings of despair, guilt, confusion and concern that they were to blame for their child's difficulties (Midence & O'Neill, 1999; Nissenbaum, Tollefson & Reese, 2002).

Parental satisfaction with the diagnostic process and diagnosis disclosure is multifaceted. The timeliness of the assessment process and effective parent-professional communication has been cited as important to parents (Abbott, Bernard & Forge, 2012). Some studies have indicated that parents believed that they did not received enough support in understanding what autism is or, information related to their child's prognosis at the point of disclosure; although, the desire for detailed information may be associated with a child's younger age at the point of diagnosis (Nissenbaum et al., 2002; Osborne & Reed, 2008). This proves a dilemma for professionals providing the diagnosis, as the trajectory of autism is diverse and although assumptions can be made about potential prognosis, no definitive answer can be given. Conversely, other studies warn against information over-load, indicating that parent's emotional responses may impact on their ability to absorb information (Abbott et al., 2012).

Upon receiving an autism diagnosis for their child, parents report mixed responses ranging from a sense of relief (Midence & O'Neill, 1999; Osborne & Reed, 2008) to anger, denial, grief and upset (Nissenbaum et al., 2002; Russell & Norwich, 2012). Nissenbaum and colleagues (2002) suggested that parents who had not suspected autism (or the possibility of disability) react more angrily and resist the diagnosis. Nevertheless, it is acknowledged that receiving an autism diagnosis is a challenging experience for any parent and child (Abbott et al., 2013). The literature also highlights positive parental responses to an autism

diagnosis. These include the label providing an understanding and explanation of the child's difficulties and behaviours which can then be offered to others (Midence & O'Neill, 1999; Osborne & Reed, 2008); providing access to support and, legitimising that parents were not to blame for the child's difficulties (Calzada, Pistrang & Mandy, 2012; Midence & O'Neill, 1999; Osborne & Reed, 2008). Russell & Norwich (2012) further suggested that post-diagnosis, parents restructured their concept of autism in a positive light, highlighting the strengths and benefits of the diagnosis in their descriptions.

Interestingly, few of these studies provide an account of the child's involvement in the diagnosis disclosure. Nissenbaum and colleagues (2012) suggested that for professional and parent alike, the perception that the child would not understand the information discussed would likely exclude them from this process. Calzada et al. (2012) further highlighted that even when children were aware of their diagnosis, parents avoided discussing this, fearing that it would make their child feel abnormal. It is therefore important to develop an understanding of the factors which may mediate parents' decision to include children in this process or not.

Although together, the literature provides a good insight into parental perceptions of autism and the diagnosis pathway, some methodological issues warrant consideration. Noteworthy is the variation in how autism was conceptualised across studies, with some citing broad definitions like 'autism spectrum disorder' (e.g. Russell & Norwich, 2012) or autism, Asperger syndrome and PDD-NOS (Nissenbaum et al., 2002) whilst others focussed on part of the spectrum (e.g. high functioning autism / Asperger syndrome in Calzada et al., 2012). Although prima facie this appears problematic, it is thought that taken together a broad picture of the experiences of parents is achieved which are largely consistent. Furthermore, a broad conception of autism was adopted in the current study as it was not anticipated, or desired that children would have the same diagnosis.

In terms of sample composition, in all studies mothers formed the majority; if not, entire sample meaning that the views of fathers are under-represented which, largely obfuscates an insight into potential gender differences. This

however is a common criticism of child research. Furthermore, the samples do not reflect the heterogeneity that would be expected in the general population, typically comprising of White British or White American participants albeit with some variation in socio-economic status. This of course precludes from an understanding of cultural variations that may emerge in parents' responses to autism. That said, the majority of studies were qualitative and would therefore have been unlikely to have aimed for representativeness in their sample. Given that participants self-selected into most studies, it is necessary to be mindful that the views reflected represent parents who were willing to participate and motivated to share their experiences. Such views may conflict with those who chose not to participate; which arguably, obscures a comprehensive understanding.

Given the arduous process of obtaining an autism spectrum diagnosis and the emotional context of this for parents, it is understandable that feeling ready to disclose autism to their child may be a challenging prospect, which to date, no research sheds light on. The literature provides some indication of the range of experiences at this time and, unsurprisingly, hints that the raw emotions experienced by parents are processed over time. It is therefore important to consider how these issues may contribute to parents' decision of whether to share the diagnosis and how they may shape the approach taken.

1.5 Children's perceptions of the autism spectrum

There is at best, a modest body of literature pertaining to the perceptions of children and young people diagnosed with autism. Calzada et al. (2012) employed framework analysis to investigate the perceptions of young people (n = 10; mean age 11.7 years) regarding the usefulness of high functioning autism or Asperger syndrome diagnoses. There were limited accounts which reflected the utility of the diagnosis in providing understanding of experiences or making others more tolerant of behaviours. Interestingly, although concerns were expressed regarding perceived negative consequences of others knowing the diagnosis, the young people rarely reported feeling different to others. Furthermore, the young people were interpreted to be indifferent about their diagnosis, making no attempts to explore its meaning. Parents (also interviewed in the study) reflected that although they hoped knowledge of the diagnosis

would improve their child's understanding of their difficulties, they were doubtful that it had. As noted by the authors, these findings may be limited in their application to the broader autism spectrum, especially for individuals with co-morbid learning disabilities, as the intellectual functioning of the majority of participants was within the average range.

More recently, in a mixed-methods study, Drummond (2013) found that adolescents with ASD (n= 27; mean age 14 years, 11 months) self-reported lower ratings of social acceptance compared to attention deficit hyperactivity disorder (ADHD) and typically developing adolescent groups. They also reported lower ratings of close friendships and global self-worth than the ADHD group. Drummond also indicates that adolescents with ASD had some awareness of their behaviours and characteristics associated with autism (e.g. difficulties in social communication, having fixed interests, lack of friendships and problems with change) although these self-reports were significantly lower than those of parents. Arguably, this relates to the construction of 'problems' whereby individuals may not rate characteristics and behaviours to the same degree as others if they do not experience them as a problematic. It is also unclear whether the young people's awareness developed through a 'true' recognition of their difficulties and differences from others or if this was externally imposed by others informing them of this within an ASD framework. The pictorial measure (adapted specifically for the study) had the advantage of enabling those with autism to share their understanding of the diagnosis, yet being based on DSM criteria perhaps precludes a richer exploration. It is also noteworthy that the internal consistency of measures varied considerably, suggesting a need for cautionary interpretation. Interestingly, lower perceived social acceptance was associated with increased awareness of ASD symptomology and perhaps understandably, such awareness was related to a longer duration since diagnosis disclosure.

The author concurrently thematically analysed interviews with a sub-set of participants (n= 13; mean age 14.83 years), relating to their understanding and experience of ASD. Findings indicated that the participants became increasingly aware of their diagnosis with age, although maintained a sense of their personhood prior to the disclosure. In contrast to the findings of Calzada et al.

(2012), participants had self-learned about autism via books and the internet although the initial disclosure was made by a parent or professional. Many of the participants identified strengths associated with ASD (e.g. having a special interest, good memory abilities, intelligence) and all perceived weaknesses (e.g. making friends, a need for routine and sameness, difficulties managing emotions). Drummond reported that the children described psycho-social difficulties associated with not fitting in and stigma and, that the majority saw benefits in developing a network of ASD peers to counter this. The author notes that Caucasian ethnicity was over-represented in the sample which was also skewed toward the higher functioning end of the autism spectrum. Additionally, the author reported that not all participants were able to engage in the interview process which raises the question of whether nuanced information may not have been captured in the study. Nevertheless, this provides an insight into how adolescents may understand their diagnosis. The divergent findings between studies perhaps reflects that as children age and move through the life span they may become more aware of and interested in making sense of their experiences in relation to ASD.

Alongside this, accounts of the experience of autism in adulthood (MacLeod, Lewis & Robertson, 2013) and the positive consequences of eventually receiving an autism diagnosis later in life (Punshon, Skirrow & Murphy, 2009) lead to the assumption that knowledge of autism can be beneficial to many people with such a diagnosis. MacLeod et al. (2013) further concluded that the manner in which individuals acquire knowledge (e.g. its personal relevance and applicability) relating to autism is crucial in how and if autism is incorporated into personal identity. In this vein, it is essential to explore the possible factors involved in parents' decisions to inform their child of their autism spectrum diagnosis and to develop an understanding of how this may be done.

1.6 Diagnostic disclosure in paediatric illness

Pinzón-Iregui, Beck-Sagué & Malow (2013) conducted a review of world literature pertaining to disclosure of HIV status to infected children and adolescents (n=2977), which included 31 articles referring to those infected by all routes of transmission and, from multiple countries of origin. The mean age of disclosure was between 7.0 to 13.7 years. The authors reported that the most

frequent reasons for withholding the diagnosis were a fear that the child would experience emotional trauma, that the child would share the diagnosis with others and risk stigmatised responses and, that the child was too young to be informed. Conversely, reasons for disclosure included a hope for better adherence to medication regimens, the child being old enough to know, that the child may engage in better self-care and that the child had begun to ask illness-related questions. With regards to children's responses to the disclosure, the authors cited one prospective study which reported that six months following disclosure 70% of participants reported normalcy, a further 2.5% reported a preference that they had not been informed of their diagnosis and the remainder expressed that they were glad they were told. A small number of papers reported that earlier disclosure was associated with improved psychological functioning. Importantly, the reviewers concluded that reasons for the non-disclosure and disclosure of health status were comparable across time and multiple world regions. This stability suggests that parental experiences of diagnosis sharing with children may be remarkably similar across diverse contexts. This reflects a strength of the review as the sample contained papers from different countries with varying levels of economic status. However, the cognitive abilities of the children were not reported and it is possible that this would add further complexity to the decisions made by parents of children with autism.

The impetus of much of the literature pertaining to disclosure of HIV to children has been on identifying factors which mediate when a disclosure is made and suggests that a child's age and increasing ability to cope and understanding is closely associated with when, and how much is shared. However, it is also important to consider the procedural aspects of disclosure in this context. In her grounded theory study of the disclosure of perinatally acquired HIV, Ledlie (1999) conceptualised disclosure as an ongoing and dynamic process which may consist of total secrecy (where the child is told nothing), selective telling (where some information is shared) and full disclosure (where the diagnosis is named). The author identified nine intervening conditions of the sharing process including the child's response to the diagnosis, their age, their understanding of the diagnosis, their growing disease awareness and the responses of others to

the child's diagnosis. Caregivers also indicated that they used cues from the child to decide if they were ready to know more about the diagnosis. A strength of the study is that the diverse sample included caregivers of different ethnicity, with varying educational attainment and of different social-economic contexts. Furthermore, the sample comprised of caregivers who had and had not disclosed the HIV diagnosis to the child, meaning that the substantive theory incorporates both prospective and retrospective accounts.

Consistent with Ledlie's account, literature asserts that diagnosis sharing is an ongoing process mediated by parent factors such as emotional readiness to tell, child factors including age and cognitive abilities and social factors such as concern about potential stigma (Dematteo et al., 2002; Gerson et al., 2001; Lesch et al., 2007). As such, it is recognised that diagnosis disclosure (specific to paediatric HIV) is likely to involve multiple conversations, guided by the child's cognitive development to assist a gradual and richer understanding (Gerson et al., 2001; Lesch et al., 2007). It is possible that this process will be further complicated in the context of an autism spectrum condition given the cognitive differences within this population, meaning that any aged-based advice may not be applicable. Undoubtedly, the experience and prognosis of HIV and autism differ significantly, yet drawing on this literature offers some insight into the complexity of diagnosis sharing that extends beyond deciding when to disclose further supporting the need to explore diagnosis sharing from the perspective of parents of children with an autism diagnosis.

1.7 Disclosing a stigmatised identity – A proposed model

Although literature relating to diagnosis disclosure illuminates the factors which may be implicated in the decision to share the diagnosis with a child, it is further necessary to consider how these factors may be integrated in decision-making. The disclosure decision-making model ([DD-MM], Green, 2009) provides a potential framework within which to do so. Qiao, Li & Stanton (2013) indicate that the model is theoretically informed by social influence theory (i.e., decisions are contextualised relative to societal norms, cultural beliefs and experiences of discrimination); disease progression theory (i.e., decisions to inform others relate to illness status / visibility of symptoms) and consequence theory (that disclosure is dependent on perceived outcomes).

The DD-MM describes health information decision-making disclosure processes within the context of personal relationships (Greene, 2009). The model is traditionally applied to instances when the decision-maker is the diagnosed person or 'bearer' of the stigmatised identity. The DD-MM divides the process of disclosure decision-making into a number of parts, from the perspective of the discloser (see figure 3). There are three core components to the disclosure decision process within the model and a person may exit at any stage if they reach the decision not to disclose.

The model proposes that in any given disclosure, a person firstly evaluates information relating to the diagnosis, assessing the potential risk of the disclosure (1). This involves balancing five interrelated components - stigma, preparation, prognosis, symptoms and relevance to others. If the level of risk is deemed acceptable, the person will proceed to assess the potential receiver (2) in terms of the quality of the relationship (e.g., relational proximity and level of contact) and, the perceived response to the information shared (Greene, 2009). The model further proposes that the receiver assessment may be mediated by questions being asked by the potential receiver which demonstrate concern or, by demonstrations of reciprocity in information disclosure (Greene, Derlega & Mathews, 2006).

If the assessment of the receiver is also approving of the disclosure, the person will then move on to judge their personal disclosure efficacy (3). This refers to a person's perception of their ability to share the information to produce the desired outcome. If a person judges themselves to possess the efficacy to share and all other components have been satisfied, the person is considered to have reached a decision to share and will then enact message strategies. Alternatively, a person may not consider that they are able to achieve their desired outcome of sharing independently, and may enlist the support of a third party (Greene, 2009).

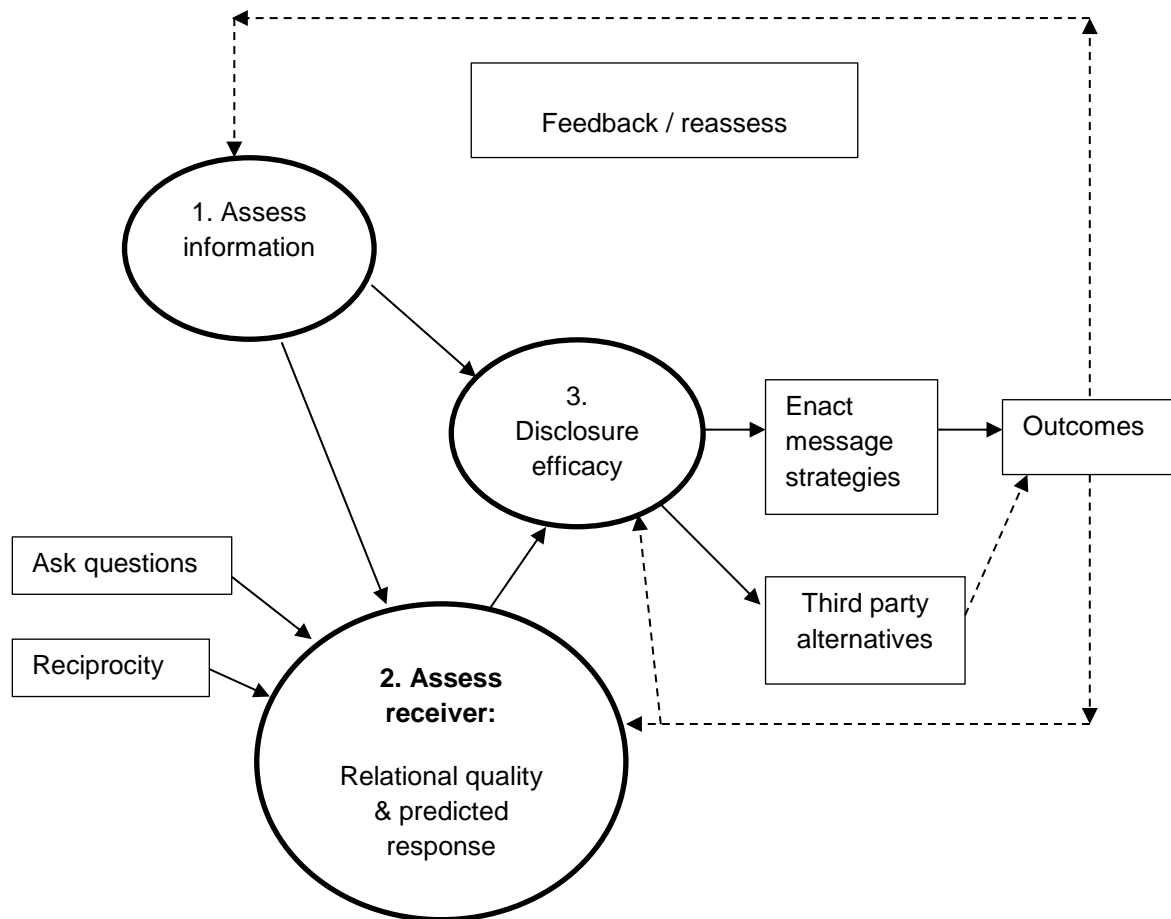


Figure 3: The health disclosure decision-making model. (Greene, 2009, p. 228)

The enactment of message strategies consists of negotiating how, when and where to disclose. Greene et al., (2006) consider message enactment in terms of mode, context and content. The mode pertinent to the current study is face-to-face interactions whereby a discloser may use non-verbal cues to guide the disclosure and may also be asked follow-up questions which could broaden or limit the information shared. The DD-MM relates the context of the disclosure to factors such as place and time. A prospective discloser may carefully plan the location of the disclosure in relation to maintaining privacy or attempting to manage how the person in receipt of information may respond (e.g., at home versus in a public space). Greene et al. (2006) also consider that diagnosis sharing may be deliberate and planned or spontaneous whereby the disclosure results from the asking of a question. Planning may involve consideration of the timing of the disclosure in terms of when during the course of a relationship, or specific interaction the disclosure is made. Features of the enacted message

strategies include directness, length and content of the disclosure, all of which may place different demands on the recipient or be a means of managing responses. For example a person may provide 'being ill' as the reason for missing a social engagement but may not divulge that their illness was related to HIV symptomology. Outcomes are conceived in relation to the self, other, the relationship which are reassessed to inform subsequent disclosures (Greene, 2009).

Consideration of the support for the DD-MM feels rather circular as the model itself was based on existing literature in an attempt to integrate the alternate aspects of disclosing a health diagnosis. Green (2006) cites a body of evidence in support of the assessment of information and assessment of the receiver and concedes that assessing disclosure efficacy does not have the same empirical support. Qiao et al. (2013) consider the utility of the DD-MM in the context of parental disclosure of their own HIV status to their child. They concluded that there is empirical support for the notion that parents weigh-up perceived benefits and risks of the disclosure (e.g., potential catharsis and the potential emotional response of the child); that they make assessments of their child as the receiver (e.g. age and the likelihood of secondary disclosure) and there is limited evidence to suggest that the disclosure itself may be shaped by these assessments (e.g. explicitly stating that the child should not share the information with others as a message enactment strategy). The current researcher could not identify any literature to date that has empirically evaluated the proposed model in its entirety.

An obvious divergence between the DD-MM and the current study is that the parent is not the 'possessor' of the potentially stigmatised identity. However, it remains a possibility that the factors described in the DD-MM may also be relevant to how parents share an autism diagnosis with their child. Indeed the literature suggests that potential stigma and discrimination is a concern for both parent and child, and that the child's age and understanding is factored into their inclusion or exclusion at the point of initial diagnosis. Research pertaining to diagnosis disclosure in the context of paediatric HIV enriches this idea, as parents are reported to make assessment of their child based on age, cognitive ability and potential harmful effects of the disclosure. Message enactment

strategies are also evident in parent's approach to disclosure which often spans non- to full-disclosure. On this basis, the utility of the DD-MM warrants consideration as it may assist in the conceptualisation of the processes involved in parents' decisions of whether to inform their child of the autism diagnosis.

1.8 Study Aims

Although accepted as a socially constructed label, the 'autism spectrum' nevertheless *exists* within today's society, with health and educational services designed to provide specialist support for those considered to warrant the diagnosis, and their families. In turn, some parent's reality involves the deliberation of 'if', at what time, and in what way to inform their child of an autism diagnosis.

Literature relating to paediatric chronic illness suggests that diagnosis sharing is a complex and dynamic process, yet one which remains unexplored within the context of autism. Furthermore it has been argued that how an autism diagnosis is shared with a child could impact on whether and, in what way this is incorporated into their personal identity (MacLeaod, 2013). It is therefore crucial to obtain the perspectives of parents who have experienced sharing autism with their child in order to gain an insight into the challenges faced and approaches employed; which in turn, will support parents and professionals who may be posed with similar deliberations in the future.

The current study aimed to explore, retrospectively, how parents share an autism diagnosis with their child. In doing so, the study aimed to develop an understanding of the issues which impact upon parents' decision to tell; how parents communicate the diagnosis to their child and what the outcomes of this were.

2. Extended Methodology

2.1 Qualitative Methodology

Qualitative methodology can be conceptualised as exploratory in nature, employing methods (e.g. interviews, focus groups, solicited diaries) which garner detailed accounts of personal experience and processes (Thompson &

Harper, 2012). The collection and analysis of often textual data, aims to explore phenomena in the context in which they occur, focussing on meaning and interpretation as opposed to testing a priori hypotheses, establishing causality or, quantifying that which is studied (Carter & Little, 2007; Thompson & Harper, 2012). At a basic level, this encapsulates the difference between qualitative and quantitative approaches. That said; there is also considerable overlap and divergence in the procedures and techniques used in different qualitative methodologies, in addition to their philosophical underpinnings. Although, such methodologies do tend to be unified in their critical stance towards positivist approaches and search for meaning in participants accounts (Holloway & Todres, 2003).

Despite ongoing debate, qualitative methodology is increasingly accepted as a legitimate means of inquiry (Lincoln & Guba, 2000). Within this context it seems pertinent to consider methodology in terms of its appropriateness in meeting the aims of the study and indeed, answering the research question (Howitt, 2010). Given that an understanding of how parents share an autism diagnosis with their child is absent in the literature and the researchers aim to develop an account of this from parents' experiences, adopting a qualitative methodology was considered to be justified.

2.2 Epistemology

The divergence between quantitative and qualitative approaches in addition to the variation within qualitative methodologies can be further understood in the context of their philosophical standpoint, which relates to concepts of epistemology and ontology. Epistemology concerns the nature of knowledge and considers 'How, and what, can we know?' the bounds of knowledge and indeed, the claims that can be made about the legitimacy of knowledge (Willig, 2008, pp. 2). Further epistemological considerations relate to the relationship between the researcher and research participants (Ponterotto, 2005) which primarily concerns whether the pre-existing experiences, beliefs and knowledge of the researcher are independent of or intrinsic to the research process; and as such should be reflected upon (i.e., a subjectivist epistemology). A closely linked concept is ontology which asks 'What kinds of things are there in the world?' the answer to which reflects assumptions about what reality is and in

turn, influences the claims which can, and are made by researchers (Benton & Craib, 2001, p.4).

Epistemological aspects of research methodologies can be conceptualised on a positivist to constructivist spectrum largely shaped by historical, social and cultural changes (Lincoln & Guba, 2000). Positivism is most commonly associated with quantitative methodology which is underpinned by beliefs that there is a knowable and true reality and that this truth can be uncovered by an objective researcher through measurement and hypothesis testing, to produce reliable knowledge (Lincoln & Guba, 2000). From a positivist perspective the researcher is seen as separate to the participants and there is a belief that bias can be controlled – an objectivist epistemology (Howitt, 2010).

Postpositivists conceive that although there is one true reality, this can only be imperfectly known; further acknowledging that the researcher impacts on the research process, although should aim for objectivity (Lincoln & Guba, 2000). Critical realists may be positioned within the postpositivist paradigm. However, critical realists can also be positioned within a more subjectivist epistemology whereby 'a reality' independent of the knower is accepted to exist (realist ontology), but that knowledge of this reality is dependent on (and shaped by) context including interactions between researcher and participant, beliefs, culture and social factors (DeForge & Shore, 2012; Madill, Jordan & Shirley, 2000). This conceptualisation of critical realism aligns it partly with Critical Theory.

Critical Theory asserts historical realism which is crystallised over time by social, political, cultural, economic, ethnic and, gender values (Lincoln & Guba, 2000). It is thus positioned in a subjectivist epistemology whereby knowledge is not value-free and develops between a researcher and the researched (Lincoln & Guba, 2000). Constructivists move away from realist ontology and assume that there are multiple realities (i.e. a relativist ontology) and that knowledge is subjective, context dependent and co-constructed by the researcher and participant (Denzin & Lincoln, 2000). Social constructionism is also situated within a relativist ontology, asserting that there are 'knowledge's' as opposed to 'knowledge' which, are historically, socially and linguistically bound (Willig,

2008). Social constructionism gives primacy to the role of language in the construction of social realities and dominant discourses within society (Willig, 2008).

Clarifying such epistemological and ontological assertions within research are therefore important to enable an understanding of the methods of inquiry employed, the role of the researcher and, the claims made about the knowledge produced through the research (Braun & Clark, 2006, Carter & Little, 2007).

Epistemological position of the researcher

In the current study, the researcher adopted a critical realist position and as such, understood diagnoses on the autism spectrum as constructs that are historically, socially and culturally situated. However, this was believed to hold *real* implications for those diagnosed with such conditions and their families and carers. The experience and meaning of sharing an autism diagnosis was viewed as an interaction shaped by external factors such as access to services, the media, social support, educational placement, the child's developmental level and responses to diagnosis.

Consistent with a critical realist position, the researcher acknowledged that experiences of working with adults and children with autism and their families shaped their position in relation to the conception of the study, research aims and the interpretations made. From this experience, the researcher held the assumption that parents were often confused and anxious about sharing an autism spectrum diagnosis with their child and as such, thought that there may be a delay between 'receiving' the diagnosis and this being shared. Additionally, the researcher assumed that conscious and active planning would contribute to the sharing of the autism diagnosis, giving that this was considered to be a worrisome issue for parents. Interactions with parents in a clinical setting also made the researcher curious about the support, particularly from health services that parents had or, which they believed would have been helpful. In turn, a reflexive diary was kept during the research process to assist the interpretation and reporting of data.

Finally, subjectivity was further acknowledged in that the account of the experience of diagnosis disclosure was considered to be embedded in the interactional context between researcher and participants. However, in providing a description of the group of participants and the children whom they refer to, the sample can be situated within a context from which to interpret the findings.

2.3 Qualitative approaches considered

Thematic Analysis

Thematic analysis is a method used to identify and analyse patterns of meaning within a data set (Braun & Clarke, 2006); the end product of which should illuminate “the most salient constellations of meaning present in the data set” (Joffe, 2012, p. 209). In common with other modes of qualitative inquiry, thematic analysis often uses textual data collected through interviews or focus groups. ‘Phases’ of thematic analysis have been described which involve the researcher increasing familiarity with textual data, coding this and, grouping these codes to identify themes (Howitt, 2010). This proceeds in an iterative manner whereby the researcher moves back and forth between the phases during analysis (Howitt, 2010). The active role of the researcher in the identification of codes and themes is acknowledged, with authors being dubious about claims that themes simply emerge from the data (Braun & Clarke, 2006).

Thematic analysis is not tied to a particular theoretical framework which is considered to be advantageous as it can be employed from a range of epistemological positions (Braun & Clarke, 2006). However, it is recognised that a good thematic analysis should contain a description of the epistemological or theoretical stance adopted by the researcher and demonstrate reflexivity in how this may have interacted with analysis and interpretation (Braun & Clarke, 2006). Although the flexibility afforded by the absence of a theoretical framework is often cited as an advantage, it is also a target for criticism with the assumption being that thematic analysis is a process contained within many qualitative methodologies, rather than being an approach in its own right.

However, the guidelines for conducting thematic analysis produced by Braun & Clarke (2006) do go some way to establishing thematic analysis as a distinct approach and outline ways in which this can be done systematically, and to a good standard. Some authors also claim that the findings generated by thematic analysis are more accessible to both the general public and policy makers which is beneficial in the current study considering the dearth of literature available to inform practice (Braun & Clarke, 2006; Howitt, 2010).

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is epistemologically bound to theories of phenomenology (pertaining to 'being' and experience); hermeneutics (interpretation) and, symbolic-interactionism (relating to how individuals construct meaning socially and personally) (Biggerstaff & Thompson, 2008; Larkin & Thompson, 2012). The purpose of IPA is to conduct a detailed exploration of how participants make sense of their personal and social world, emphasising the meanings of lived experience (Smith, 2008). The interpretive role of the researcher has centrality and a double hermeneutic is acknowledged whereby the researcher attempts to make sense of participants attempts to make sense of their experience (Smith, 2008). IPA differs from thematic analysis in that it aims for an in-depth idiographic representation of a person's account (Larkin & Thompson, 2012). Although parallels can be drawn between the analysis involved in both approaches (i.e. the identification of themes), IPA gives primacy to the meaning of experiences to individual participants and conducts in-depth analysis of data for one participant before progressing to the interpretation of patterns of meaning for the entire data set (Howitt, 2010). The focus on meaning-making led the researcher to consider that the processes involved in 'how' parents share an autism spectrum diagnosis with their child may have been fore-grounded by the 'meanings' parents developed during this time which, would not have been consistent with the aims of the study; and IPA was therefore not the approach adopted.

Grounded Theory

There are different forms of grounded theory which span positivist to constructivist epistemological positions (Tweed & Charmaz, 2012). What these approaches have in common is the aim to inductively develop a theory of social or psychological phenomena from the data collected over the course of the research (Tweed & Charmaz, 2012). Theory building is an ongoing and recursive process which involves the researcher staying 'close' to the data, developing an in-depth understanding and moving backwards and forwards between different aspects of data collection and analysis, constantly checking between the data and emergent categories (Howitt, 2010). Although the current study aimed to conduct a detailed exploration of parents' recollections of sharing an autism spectrum diagnosis with their child, the intention was to illustrate shared patterns of this experience across participants and not to construct a theory of diagnosis sharing. On this basis, Grounded Theory was not used in the current study.

Discourse Analysis

Discourse Analysis is epistemologically rooted in social constructionism with a particular focus on the use of, or productive potential of language (Willig, 2008). Language is viewed as a way of constructing, rather than being a direct reflection of reality which functions to attain interpersonal goals in a given interactional context (Georgaca & Avdi, 2012). Rather than asking questions about the reality of participants' experiences, discourse analysis focuses on the construction of reality and experience through social and interpersonal processes (Georgaca & Avdi, 2012). The aim of the current study was to develop an understanding of the experiential aspects of how parents share an autism spectrum diagnosis with their child rather than how language was used to construct this account. Discourse analysis was therefore not considered to be consistent with the aim of the current study.

Methodology adopted in the present study

Although thematic analysis is not without criticism, the aim of the current study was to develop a detailed and meaningful account of how parents share an autism diagnosis with their child. Thematic analysis afforded the possibility to

inductively achieve this understanding in a way that could maintain the sense of 'how' this was done without given primacy to how parents *made sense* of this which would be the case if IPA had been used. Furthermore, although the researcher planned to go beyond description and make interpretations relating to the diagnosis disclosure, there was no intention to construct a theory. The researcher concluded that thematic analysis could be used to explore parental accounts of diagnosis sharing in a way that would appropriately address the aims of the study and would be consistent with a critical realist epistemological stance. In light of the criticisms of 'badly done' or undefined thematic analysis, the guidance offered by Braun & Clarke (2006) was used to offer a systematic and transparent approach to data collection, analysis and interpretation.

2.4 Participants and Recruitment Strategy

Consistent with qualitative assumptions, purposive sampling was employed in order to recruit participants who had experienced sharing an autism spectrum diagnosis with their child, rather than aiming to recruit a sample which was statistically representative of the population (Carter & Little, 2007).

Inclusion criteria

The inclusion criteria are detailed in the journal paper, although it is necessary to expand upon parents being considered eligible to participate in the study if their child was 18 years of age or younger. This decision was based on the premise that below the age of 18, a person may still be considered a child and were likely to be more homogenous in their life stage and normative transitions, albeit chronologically rather than developmentally. For example it was assumed that such children were more likely to still be in the education system and to be living at home. It was also assumed that childhood may be a time when parents share an autism diagnosis. Although the time since diagnosis sharing could not be predicted, it was considered that focusing on this group may have meant that the sharing of the diagnosis would have been closer in time to the interview and as such would facilitate recollections of this.

Sample size

A total of 10 participants were recruited to the study which is consistent with the range of the number of participants recruited in other doctoral and published research using thematic analysis. Although there is no clear indication of the number of participants necessary to conduct thematic analysis samples used range from seven (Hughes, 2010) to recommendations of 32, 48 or 60 (Joffe, 2012), depending on the aims of the study. Larger samples tend to be used when there are multiple researchers or when analysis is performed using qualitative computer software packages, resources which were not available to this project. The sample in the current study was ultimately defined pragmatically based on the time limits of completing the research and the number of parents who self-selected to participate within this time.

Recruitment

Stage 1: During the planning of the study, the Academic Research Supervisor (RdN) was a representative on the Board of Governors of a local specialist school. He introduced the project to the Head Teacher who provisionally agreed to facilitate recruitment. Following receipt of ethical approval from the Institute of Work, Health and Organisations, University of Nottingham the researcher met with the Head Teacher to further discuss the details of the project. After verbal agreement to facilitate recruitment had been obtained, posters advertising the study were placed on notice boards in the school and an advertisement was placed in the school newsletter (see appendix H & I). Parents self-selected to participate by contacting the researcher via an email address or telephone number used specifically for the research. The researcher was also invited to attend a transition day at the school when parents were informed of the study by the Head Teacher who invited them to approach the researcher for further information if interested. A small number of parents approached the researcher although, declined the invitation to participate as they had not, and were not planning to, inform their children of the autism spectrum diagnosis.

Concurrently, the researcher contacted local charitable organisations and parent support groups via telephone and email, sending an electronic copy of

the participant information sheet and research proposal (if requested) for review. One organisation declined to facilitate recruitment as they were regularly engaged in research and could not support another project. A further two organisations placed the study advertisement in their newsletters. Participants self-selected to the study as described above.

Stage 2: To maximise recruitment, ethical approval was also sought from a local National Research Ethics Committee to enable recruitment via the National Health Service (NHS). Once approval had been conferred, posters were placed in two related services which specialise in the assessment of autism spectrum conditions. Recruitment was further supported by Dr Claire Millward who informed parents of the study and provided them with an information sheet containing the researcher's contact details. Parents who contacted the researcher were sent a further copy of the participant information sheet via email (with their permission) which was followed-up within two weeks by the researcher if the parent had not replied.

Stage 3: A final attempt to promote recruitment involved the researcher contacting further parent support groups and charitable organisations to establish interest for focus groups. It was considered that an established group may demonstrate greater interest in this. Support groups and organisations were identified using the National Autistic Society's online directory. Initially, fathers groups were contacted due to the sample composition, and shortly after, mixed groups were contacted. No further organisations or groups agreed to facilitate recruitment.

Six participants who demonstrated initial interest in the project did not respond to subsequent attempts made by the researcher to contact them. It was therefore assumed that they had chosen not to participate.

2.5 Data Collection

Combining methods of data collection

Given that the experience of parents informing their child of an autism spectrum diagnosis is largely neglected in the literature, the researcher proposed to collect interview data followed by focus group data with the aim of exploring any

divergent themes and to develop a richer understanding of this phenomenon. It was also considered that this would have pragmatic benefits to participants, offering greater choice in how they contributed to the study. The iterative use of these methods is advocated by Lambert and Loiselle (2008). No data was collected via focus groups in the current study as sufficient numbers of participants did not choose this option.

Demographic Information

Demographic information was collected to aid researcher interpretation and analysis, and also to enable the reader to situate the sample within a context from which the findings could be interpreted. The following information was collected using a brief questionnaire (see appendix K) which was completed immediately before the interview.

Gender (parent)	To provide an indication of the composition of the parents in the sample and highlight any differences in diagnosis sharing between mothers and fathers.
Ethnic origin	To provide an indication of the composition of the sample and highlight any variation in diagnosis sharing across ethnic origin.
Child's diagnosis	To indicate the autism spectrum diagnoses which children had received to situate the sample and, to aid interpretation about any interaction of this with diagnosis sharing.
Other diagnoses	To provide an indication of any further diagnoses to situate the sample and aid interpretation about any interaction of this with diagnosis sharing.
Wait for diagnosis	To provide an indication of the elapsed time between parental concerns and when the

	autism spectrum diagnosis was confirmed by a professional.
Age when diagnosed	To provide an indication of the child's age when the autism spectrum diagnosis was given and to aid interpretation of any interaction of this with diagnosis sharing.
Age at diagnosis sharing	To provide an indication of the child's age when parents shared the autism diagnosis to situate the sample and to aid interpretation of any interaction this had with diagnosis sharing.
Time since sharing	To illustrate the time for which children had been aware of the autism spectrum diagnosis in order to situate the sample and aid interpretation.

Semi-structured Interviews

Participants were given the option of a face-to-face or telephone interview and all chose the former. Semi-structured interviews are accepted as an appropriate method to collect data for thematic analysis (Braun & Clark, 2006; Joffe, 2012). Interviews were conducted between January and August 2013. Questions were designed to guide parents in their recollections of sharing an autism diagnosis with their child (see appendix L for interview schedule). The schedule was used flexibly during interviews and was not followed sequentially. However, the researcher acknowledged that following each participant too closely through the interview may have achieved idiosyncratic detail which in turn, may have impacted on the ability to look across the data set to identify commonalities and divergence in parents' accounts which is what the study aimed to do (Frith & Gleeson, 2012).

2.6 Ethical Considerations

Informed consent

The participant information sheet informed participants of the nature and purpose of the study and the researchers experience and motivations for conducting the study. Participants recruited via the NHS were also informed that the researcher had previously worked in the services they were in contact with and that their choice of whether to participate would not affect this. All participants had the opportunity to ask questions before signing the consent form and were informed that their participation was voluntary. Participants were made aware that audio data collected would still be used in the final analysis if they withdrew from the study beyond two weeks from when the interview was conducted. Two copies of the consent form were signed and dated by both the participant and the researcher; one copy was kept by the participant and the second was retained in the study records.

Interviewing

All participants were given a choice about how and where the interview was conducted and this was arranged at a time and place most convenient to them. Participants consented to interviews being digitally recorded. Participants were informed that they could refuse to answer questions and could stop the interview at any time. All participants consented to an external transcription service being used and were informed that a confidentiality agreement would be signed prior to this.

Confidentiality and anonymity

Participants were informed of the limits to confidentiality in relation to any safeguarding concerns for themselves or others. Pseudonyms were used in transcripts and the final write up. Other identifiable information such as the names of third parties was omitted or pseudonyms were used. Names of locations and services were also omitted from transcripts. Anonymisation of transcripts completed by the transcription service was completed as above, when the researcher was checking their accuracy. Participants consented to

quotes being used and were aware that these would be anonymised in any report or publication.

Storage of information

All data was securely stored in a locked filing cabinet at the Institute of Work, Health and Organisations, University of Nottingham. Only the researcher and academic research supervisors had access to the interview data. All participant identifiable data was stored separately to interview transcripts. This information will remain securely stored at the University of Nottingham for seven years in accordance with University protocol, after which time it will be securely destroyed.

Participant distress

The researcher was alert to any indication of participant distress throughout the interviews. On the occasions when participants became distressed the researcher offered to end the interview or to have a break. Participants declined this offer and expressed that they wished to continue. Following all interviews the researcher asked how the participant felt and if they were caused any undue distress as a result of the conversations. No participants reported feeling distressed at the end of the interview and all shared that they had partners, friends and broader networks that they could seek support from.

Power dynamics

Unanticipated power issues between researcher and participant emerged in relation to the presence of children during interviews. Due to child care issues, one participant enquired if their child could attend the interview. The researcher explained that ethical approval did not allow for this and also that there was no appropriate space available where the child could wait. The researcher had to negotiate an alternative date and ways of managing this with the participant within the parameters of ethical approval. There were also instances when the researcher arrived at a participant's home and their child was present. Within this context the power imbalance was amplified as the researcher had to

negotiate with participants about how the interview was structured within their own home. Participants were highly accepting of the ethical limits within which the researcher had to work. Participants accommodated the pragmatic decisions made by the researcher in line with the ethical approval granted and safeguarding issues (e.g. the age of the child, supervision needs) so that interviews could continue safely.

2.7 Analysis

Braun and Clarke's (2006) guidelines were used to conduct a systematic analysis of the data. The authors outline six phases of this process (see table 5). An inductive approach to analysing the data was taken whereby codes were identified within the data as opposed to being pre-determined theoretically or by an a priori coding frame. However, the researcher acknowledges the difficulty in a truly inductive approach given that the aim of the analysis was to answer the research question.

Phases of analysis

Phase 1 and 2: Familiarisation began through the process of transcribing and when checking the accuracy of transcripts completed by the researcher and external transcriber. Each transcript was read and re-read to further promote familiarity. The researcher noted initial ideas and patterns relating to the research question on the transcripts. A mind-map capturing salient features of the data in relation to the research question was completed for each transcript (see appendix N for an excerpt of a worked transcript and appendix O for the corresponding mind-map). Following this, mind-maps were reviewed to develop a coding frame which was applied to each transcript by noting the code number in the margin. Consequently, data was not coded if it did not capture an aspect of diagnosis sharing.

Phase 3 and 4: As outlined by Braun and Clarke (2006), a theme encapsulates an important, patterned aspect of the data in relation to the research question. In developing themes, the researcher hand-wrote the codes on a separate sheet of paper which were then cut out and grouped and re-grouped according to whether they were saying 1) something pertinent about the data and 2) were not reflecting an idiosyncratic experience of parents' recollections of diagnosis

sharing. Codes were discarded if they were not deemed to meet the aforementioned criteria (see appendix P for a table of codes grouped according to final themes).

A provisional thematic map of the data was developed (see appendix Q) and discussed in supervision when it was agreed that themes could be collapsed into broader categories to describe the data (see appendix R). The researcher colour coded each theme and sub-theme and reviewed transcripts, marking relevant data (see appendix N). Data extracts were copied and pasted into word documents consistent with theme and sub-theme.

Table 5: Phases of thematic analysis

Phase	Description of the process
1 Familiarising yourself with your data:	Transcribe data, read and re-read the data, note any initial ideas.
2 Generating initial data codes:	Systematically code interesting features across the data set, collating data relevant to each code.
3 Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4 Reviewing themes:	Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic map of the analysis.
5 Defining and naming the themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6 Producing the report:	Final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing scholarly report of the analysis.

(From Braun & Clarke, 2006, p. 87)

The thematic map was checked against the transcripts and data extracts to review how well it captured the story told in the data (see appendix S for final thematic map).

Phase 5: In this phase the researcher reviewed the themes to define them further in terms of what was interesting about them and the relationships that existed between themes and sub-themes. A theme was not reduced to the frequency of which it occurred in the data, but rather the contribution it made to the researchers understanding of parents' experiences of diagnosis sharing. In this way the themes differed in terms of the amount of data extracts which support them. The researcher was open to divergent reports throughout analysis. Some accounts were initially thought to be thematically divergent to the general 'story' which had been identified in the data. However, when themes were reviewed and refined, these accounts were considered to represent alternative perspectives and experiences within the existing thematic description. An example of this was the perception that *not sharing* a diagnosis functions to protect from the responses of others versus *sharing* the diagnosis functioning to protect the child from ongoing suffering. Although these were initially considered to be divergent when refining themes the researcher interpreted that these were both indications of parental motivation and more specifically, that they reflected motivation to protect the child.

Phase 6: Interpretation of the themes continued during the writing of the report, with reference to transcript notes and the researcher's reflexive diary. Although thematic analysis does not traditionally reflect on the preconceptions and knowledge of the researcher (Joffe, 2012) this was considered a useful method which was consistent with the researcher's critical realist stance.

2.8 Secondary Analysis

It was considered that developing an information sheet for parents would be a beneficial output of the study. Secondary analysis was performed to achieve this. The researcher re-read all transcripts and coded extracts where parents expressed a strategy they used or an approach which they found useful. After each transcript was coded extracts were compiled in a word document and formed the basis of a provisional information sheet (see appendix T and U). Readability was assessed using the Gunning Fox Index, achieving a score of

10.46. It is suggested that for a wide audience the Index score should be below 12 but for universal understanding should be less than eight. The researcher considers that this score to be acceptable but will review the supporting data extracts to try and improve on this. The information sheet will also be reviewed by participants prior to publication which will offer further indication of its utility.

2.9 Quality Assurance

The increase in the use and publication of qualitative research within health settings has led to scrutiny regarding the quality of and claims made by proponents of such methods (Mays & Pope, 2000). Assessing quality in qualitative research is not without contention due to concerns with the misapplication of established quantitative standards, and also due to the diverse approaches and epistemological positions adopted within qualitative research (Madill, Jordan & Shirley, 2000; Parker, 2004). Even so, there is some consensus that consideration of quality assurance is necessary. Quality of analysis was monitored using the checklist provided by Braun and Clarke, (2006). Additional methods used to promote integrity in the current study were as follows (based on Elliott, Fischer & Rennie, 1999):

Clarifying the researcher's perspective - The researcher has clearly outlined the critical realist epistemological position that was adopted in relation to 1) how the autism spectrum was understood, 2) how the sharing of this was understood and 3) the researcher's active role in collecting, analysing and interpreting the data. Furthermore, the researcher has considered how experience of working with individuals and their families has shaped the conception of the research study and interacted with data collection, analysis and interpretation.

Situating the sample – The researcher has detailed the gender and ethnicity of the participants. Importance was given to providing an indication of the time span between parents 'receiving' the diagnosis and proceeding to share this with their child, and the child's age at these time points. The researcher has indicated the autism spectrum diagnosis and additional diagnoses which were reported by parents.

Grounding in examples – The researcher has aimed to include sufficient excerpts of data in the findings to illustrate the analysis and interpretations that

have been made so that the reader can assess if the findings fit the data and to allow for independent interpretations.

Credibility checks – The researcher discussed the analysis during a number of supervision sessions and received feedback on the findings presented in the journal paper from a professional with extensive knowledge and experience in the field of autism. Although member checking has not been completed, the researcher plans to share the information leaflet that has been developed and a summary of the findings with participants, prior to submission for publication. The researcher acknowledges that the integration of feedback will be need to be negotiated with the context within which the original data was situated, considering that participants positions in relation to the analysis may have altered since this time.

Cross-checking of coding – One transcript was independently coded by a Trainee Clinical Psychologist who was not involved in the study and who discussed areas of convergence and divergence with the researcher. The independent coder identified data extracts within two broad categories – social and family factors. Within the former, data extracts relating to parental shame and child exclusion were coded and in the latter extracts relating to the readiness of both parent and child were identified. It was agreed that these were consistent with codes relating to parental motivation to share and parental and child preparedness. The independent coder also made interpretations about possible ‘false positivity’ within the transcript and was curious about why the parent so strongly pushed a positive narrative rather maintaining a neutral position. The coder linked this with an underlying internal sense of shame and questioned the participant’s positivity in the context of describing the initial disclosure as stressful and “not positive at all”.

The coder reflected upon their therapeutic orientation to Compassion Focused Therapy, suggesting that this may have biased their interpretation. It was also considered that this constituted latent level analysis as interpretations were being made about the participants underlying psychological state which was not consistent with the semantic coding undertaken by the researcher. The researcher also considered that at a broader level this was consistent with a

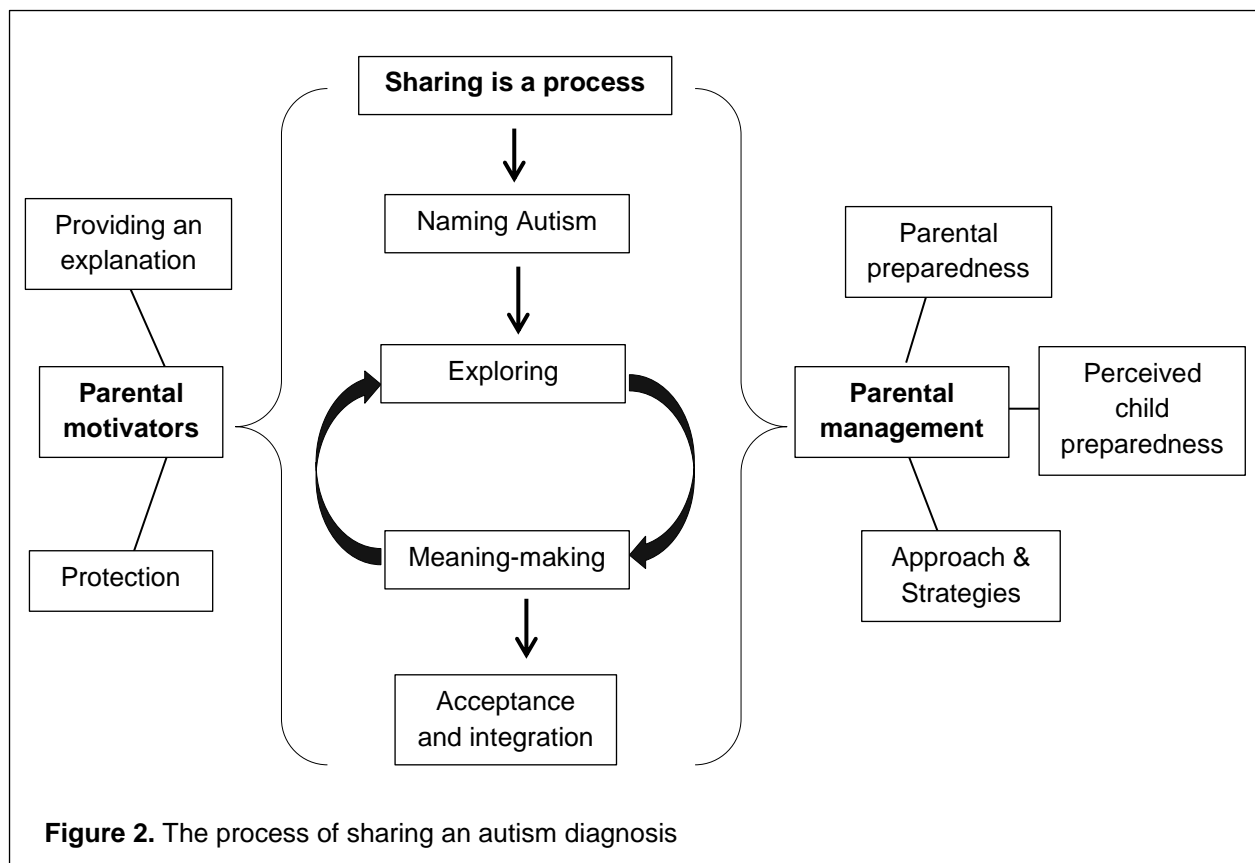
thread in the data. Namely, parents speaking positively about autism in order to enhance their child's self-concept and perhaps due to fears of stigmatisation. The researcher remained mindful of the independent coders interpretation for the remainder of the analysis although did not identify codes or themes specific to personal shame. Although the cross-checking of data in this way provided some assurance of the credibility of the codes developed, this would have been further enhanced by including more data and therefore has limitations as an assurance of quality.

3. Extended Findings

3.1 Summary of themes

Parents consistently reported that sharing an autism spectrum diagnosis is a process not confined to a single event or moment in time. It is likely that for parents, this process begins before they name autism with the child as can be seen in their approach to managing diagnosis sharing and the need for self-preparation. Parents often vividly recalled when their child became involved in this process and the evolution of this over time through *exploring and meaning-making* and *integration and acceptance*. 'Parental motivation to share' outlines factors which may inhibit or encourage parents to broach the subject of autism with their child whilst 'Parental management of sharing' provides an understanding of parents' executive role in the sharing process and the multiple factors which inform their approach. Although the themes and sub-themes convey alternate aspects of how parents share an autism diagnosis with their child, they are also inherently connected and it is anticipated that parental motivation and management will adapt over time as parent and child move back and forth through the phases of sharing.

In this way it can be understood that parental motivation and management both mediate and are mediated by this progressive sharing in addition to broader child development and social factors (see figure 2).



3.2 Sharing is a process – further exemplar quotes:

“And like most things, you know, it will come out at a later date ... I don’t think he really understood to start with. I think it’s that drip feed, so it’s just a bit at a time. It’s just a word and a, you know, it didn’t seem to actually change anything for him really. [...] So there was no big reaction, no big change, nothing really, but just the start of a journey to, to understanding it, which has been, is coming along nicely I’d say. You know, [...], he uses the word now, he’s not ashamed of it, he’s quite happy with that and he seems to be okay with it.” (Anne)

Anne denotes a positive experience of the process of sharing which was not undermined by the uncertainty of her son’s comprehension. She illustrates that sharing is a process (“it’s that drip feed”) and connects this with other day-to-day exchanges of information with her child (“it’s like most things”). The

expectation that diagnosis sharing will be ongoing is also contained in Susan's recollection:

"Well that was, well yes, you expect to have things that come at you, you know, drip fed over time and they might come back, ask more questions, as they understand things better." (Susan)

Susan further highlights how parents associate the sharing process with the child's evolving understanding of autism and also, their cognitive and emotional development. This may also suggest that diagnosis sharing requires patience from parents and a recognition that questions could arise at any time. In the extract below, Steven reflects that the uncertainty in diagnosis sharing may be broader than the child's grasp of what autism means:

"To be honest I don't think he understands now, um. I mean I don't think anybody really understands autism, to be honest, but I think ... James, he knows he has this condition called autism but, what does it actually mean for him ... I, I er don't know ..." (Steven)

Here, Steven raises the possibility that the uncertainty inherent in sharing autism with a child is socially and historically bound and will perhaps be shaped further as new knowledge or understandings of autism emerge within society.

3.2.1 Naming autism – further exemplar quotes

Prior to naming autism some parents spoke openly with their child about their difficulties and difference from others. This could be conceived as parents 'doing the groundwork', predicting that they would share in the future and so preparing both themselves and their child for this eventuality, as is illustrated by Anne:

"So I think he, we'd sort of already, with, without the word autism, been saying, because he'd got a learning disability, we'd been saying, 'Craig you just find it harder than some people do'. And, you know, 'I know you're struggling with your work but you're doing really well'. And so we'd already had, without the word, so it was almost easier then." (Anne)

Anne's account also demonstrates that parents name autism in a manner which they hope will resonate with their child, often drawing on the child's experiences or difficulties to support this which is further denoted by Susan:

"Yeah, I, I don't remember thinking, 'Oh I'm going to do that in a week's time'. It's again, a gradual process. And when it came near to the time, I wrote down ... a list, [...] of things that we'd cover. Because it was both of them together, I deliberately put a list of things, you know, I explained roughly about autism and what it was. And then I'd got on my list things, which would ... both of them had maybe different difficulties, and made sure there was some for both of them on there um, when I was talking about autism. And things, which I knew they would recognise was them."
(Susan)

Susan's planned approach was not the typical account provided by parents in the sample, indeed, the extract below captures how naming autism may occur in response to a child's questions and curiosity. Although in such circumstances parents proceeded to explain autism in the context of the child's experiences:

"So usually it would be things like, 'Why do I find it so hard?' So I think the first time was, we, we would talk back, because he'd had some assessments and we'd say, 'Well you remember we went to do some tests and things' and, you know, we'd just talk about, you know, things that he found difficult. And then just that 'There's something called, autism. And that that *means* that you find it difficult to do things like your learning and understanding, you get anxious and you get upset easily'."
(Anne)

Unsurprisingly, the communication of the diagnosis and the amount of information shared varied according to parental judgements of the child's readiness and, knowledge of how the child typically processes and understands information. In naming autism to their child parents referred not only to relational and social difficulties, but also the emotional experiences of the child.

3.2.2 Exploring and meaning-making – further exemplar quotes

Now that autism has been named, parents take opportunities to increase the child's understanding of autism by offering the child an explanation of experiences as they occur:

“[...] I mean I'm sure we didn't get all technical, like say, you know, 'You have impairments in the following areas', kind of thing (laughs). Err, I think we may have said, for example, um, if there was something that he found difficult, for example, if something was cancelled at the last minute. I'd say that, you know, you, 'You find that hard because you have autism', you know, and um, 'People with autism like the same thing to happen at the same time', you know, and, and things like that.” (Jenny)

Jenny's laughter suggests that speaking about autism in “technical” terms may not be appropriate for children and parents may rework their knowledge in order to facilitate communication with their child. Parents also negotiate the kinds of understanding autism can offer both them and their child as is indicated by Rebecca:

“[...] And I don't, I think he, I don't think he really does question it now. Except, something, the way he might be feeling, you know he'll say to me 'Is that my Aspergers?' and sometimes I say 'I, I don't know, yeah it could be, it may not be, it may just be you and your personality'. But, yeah, I, he certainly doesn't ... dwell on it or ponder over it at all, it's just, it's just how, what he knows he is and he's very proud of it.” (Rebecca)

Rebecca's account highlights parents' construction of autism as part of the child which is distinct from their personality and may indicate attempts to negotiate the boundaries of autism with their child in such a way that it is not all encompassing. Her account provides further indication that exploring autism includes the child's emotional experiences.

Parents often described questions as “coming out of the blue” and indeed, the emotive nature of discussing autism. Some parents had to contend with their child's rejection or upset relating to the diagnosis and at these times strived to

re-focus autism in a positive light, emphasising the strengths and positive qualities of the child which, were perceived as not necessarily divisible from autism.

P1: He does ask doesn't he? [...] He says, '*Why, why?*' 'Why have I got it?' He asks that a lot.

P2: Why have I got it ... and when he's *really* anxious 'It's my autism, I want you to cure it'.

R: Okay.

P1: Yeah, did ask if he could go to hospital didn't he? To have it made better; which was *absolutely heart-breaking* (laughs).

R: I can imagine.

P1: I mean (laughs) because he's absolutely terrified of hospitals apart from anything else isn't he? [...] But he wanted to go to be made better. And that was ... oh, it was awful. Wasn't it?

P2: And he was in a right state at the time as well 'Take me to hospital and cure it, I want to be cured.' And he's, and you know, and then you try to explain that actually ... his autism, makes him who he is. You know, and there's a lot of traits about James that ... you know ... hmff, are just wonderful, they're lovely.'

(Dawn (P1) and Steven, (P2))

Some divergence in how parents construct autism in relation to their child becomes apparent although it is equally possible that parents draw on multiple understandings depending on the social and emotional context in which they are discussing autism. Steven and Dawn also touch upon there being no definitive explanation regarding 'why' a person develops autism. It is perhaps from this absence of causal knowledge that parents focus on meaning and the understanding of autism in the here-and-now.

3.2.3 Acceptance and integration- further exemplar quotes

There was a continuing sense that autism is communicated about in a manner to promote the child's acceptance; hinting at parental fears of the potential consequences if this was not so:

“Um, I'd sort of explained to him, he'll always be Scott, because he's been diagnosed with something, it's just a, it's just a label. It's not changing him or who he is, he's the same as what he was the day before. So I was worried that he might think that he might get worse or, you know, so explaining to him that by knowing this you'll be able to understand it. And you won't get any worse, you are just what you are, it's just a different personality really.” (Erica)

Talking about autism in this way may further suggest a parental need to maintain part of the child which is unaffected by autism or, to retain positivity in the challenges of raising a child with an autism spectrum diagnosis.

Alternatively, it may simply reflect parental acceptance and a belief that disability does not define a person. Perhaps then, how parents conceive of and communicate about autism with their child will impact on how the child integrates autism into their self-concept and daily life.

Interestingly, parents recalled times when their child had tried to “use” the diagnosis to avoid going somewhere or to excuse ‘bad behaviour,’ thus suggesting a level of integration:

“[...] Um, occasionally, he, he would say something like, ‘Oh, um I can't do that because I have autism’. And sometimes he used it to get out of doing things that he didn't want to do (laughs). [...], which made us laugh kind of thing. So he'd say, ‘I find that a bit difficult because I have autism’, kind of thing, and we knew that it was because he didn't want to do it. So, you know, we didn't, um, you know, kind of give into that (laughs).” (Jenny)

Parents considered this to be cheekiness or the child testing the boundaries of the diagnosis; viewing it as something to “reign in”, perhaps reflecting

discomfort with children enlisting autism to negotiate in this way. Conversely, such interactions could reflect the child's emerging sense of agency and empowerment as a person with autism and, their attempts to impact on their social worlds. Below, Erica demonstrates further, the potentially empowering value of autism knowledge:

“Because he's had comments like, ‘You're mental!’ and things like that, you know, children are very cruel in the playground, as we all know. And so that he knows himself that he's not mental and he knows himself why he does these things. So, you know, it did really help him see. [...], on, on another hand, he's quite intelligent, so if his behaviour is a little bit naughty sometimes, he'll use it as an excuse. ‘Oh it's that, it's because I've got that’, [...]. So you've got to rein him in a bit, no, (laughs) you know. So he's very clever in that way, so it's helped him.” (Erica)

It seems then that autism knowledge may also be used to buffer derogatory comments made by others, albeit in private rather than public contexts in this case, which in turn, could have positive connotations for a child's self-esteem.

Linked with this, parents perceptions of their child's sense of group affiliation within a network of autistic peers and the normalisation this provided was frequently reported as being beneficial to the child:

“I think to see that not everybody's a weirdo with autism, because I think that's what normal children at that school said ‘Oh you're all weirdos’. And he moved to [names school] and they're not all weirdos, and they were bright and clever and funny. And he could see that they were bright and clever and funny and so is he. So, instead of all negative vibes he got positive role models, and other children who he really enjoyed being with and he wasn't on his own, it wasn't just him anymore. It was much better for him. And now he really likes the autistic kids at [names school]. He really enjoys their company (laughs).” (Laura)

This suggests that knowing or meeting others with an autism diagnosis may be helpful to children in understanding, accepting and integrating the diagnosis which is perhaps facilitated by a sense of being accepted by others.

3.3 Parental motivation to share the autism spectrum diagnosis

Perhaps unsurprisingly, parental motivation to share the autism diagnosis with their child was crucial in when and how this was done. Parents' accounts illustrated factors which both motivated and inhibited them in approaching the subject of autism with their child or, in providing autism as the answer to their child's questions. This offers some indication of the challenges inherent in making this decision. The sub-themes *providing an explanation* and *protection* illustrate the tensions parents experience when considering what is best for their child. As Susan describes in the below extract, a child's emerging awareness of difference from others and their developmental level were factors which encouraged sharing.

“Um, understanding themselves and ... understanding, because I felt they'd got to, I suppose, a stage in their development, where they could maybe see some differences. And then understanding *why* you find certain things difficult. So it's really to be a help for, for themselves.”

(Susan)

Taking this further, for some parents, motivation to share appeared to be tied to a moral obligation to the child, reflecting the importance of truth in the context of a child's recognition of their difference.

“[...] knowing ... what he was going through, it would have been wrong to not tell him. Erm ... because he is quite, you know, he is able to do things for himself. He's not the, you know, to the extent where, you know, he's not, he does know the difference between him and others and, you know, it is quite, is visible is the proper word, between him and others.”

(Kirsty)

Here Kirsty draws focus to autism being publicised as an 'invisible disability' which perhaps, enables the possibility that sharing can be delayed. Indeed, some parents drew comparisons with diabetes and physical disability, suggesting that in these circumstances professionals may be more involved in

discussions about diagnosis or, that parents would have to share this knowledge with their child sooner, as Jenny demonstrates:

“Um, it wasn’t that I wasn’t going to tell him but I hadn’t *thought* about *how* I was going to tell him ... at all, I don’t think. Thankfully, his question could have initiated it. I was just able to say, ‘Yes you are autistic’ (laughs) and it was really made really easy for me. [...] I think, obviously, if it had been something like, you know, a physical ... disability or a, you know, a diagnosis of a ... medical condition, um, I would have *had* to tell him I think, or [...], we would have probably told him *earlier*. But maybe we thought that because he had autism, and when we had the diagnosis he was actually not verbal, either. Um, we thought for a long time that he wouldn’t understand ... anyway what it meant.” (Jenny)

This invisibility is perhaps challenged as children become curious about the difficulties they experience and sense that they are different to their peers; prompting parents to share. There is also an indication that to not affirm or name autism when a child expresses curiosity would constitute deception. This is interesting given the delay often present between the parents having knowledge of the diagnosis and proceeding to share this with their child. Perhaps parents feel more comfortable withholding the diagnosis when their child is not actively seeking understanding.

The sense of importance of sharing the diagnosis during childhood was also communicated by parents who hoped that the benefits of doing so would extend across the life span.

“And this isn’t an easy one but I think it’s something, that if he’s going to grow up to be, you know, comfortable in his skin as a man, I don’t want him to start this process when he’s a man, when he’s not known all this time. I want him to start this now, that it’s something he’s always grown up with, that he knows he’s loved, that he’s knows, and then it’s a bright future for him, you know.” (Anne)

There is an inference here that children need to know about their diagnosis to understand themselves and to support their self-acceptance. Although

diagnosis sharing is challenging for parents there is a perception that the subsequent benefits of doing so for both parent and child, make this challenge worthwhile:

“I’d jump in and do it as soon as you can, ‘cause it, the longer you leave it, I think the worse it would get, the worse you would feel in yourself. I think it would be hard to tell the child to begin with, but would be a relief to the child after a while. Because they, then they can understand and know what their behaviours are, they have reasoning for them. So instead of them wondering why, or thinking they’re being naughty, they’ll know they’re not actually, it’s just because they’re a bit stressed about something.” (Erica)

Erica also alludes to perceived drawbacks of not sharing the autism diagnosis in that a child may struggle to make sense of their experiences or may do so in a negative way. Whilst accepting the challenge inherent in diagnosis sharing, Erica also reflects that avoidance will exacerbate this and may become an emotional drain on parents.

For some parents, motivation to share extended beyond the family context. Anne’s account demonstrates that for her, embracing and being open about an autism diagnosis constitutes a form of social action in challenging stereotyped views which permeate society.

“And I think that’s why I wanted to see you because I’m really passionate about not making it taboo. And that we, if we as parents of Autistic children aren’t going, ‘He’s got Autism and I’m really proud of him’, then how do we expect everybody else?” (Anne)

3.3.1 Providing an explanation

Providing an explanation is the first sub-theme of ‘Parental motivation to share the diagnosis’. Parents drew on multiple factors including their own experience of feeling different in the past, conversations with adults with autism spectrum diagnoses and the reading of autobiographical accounts to conclude that naming autism had explanatory power.

“Urm, it was um, after we got it sort of confirmed that he had got that, to, to let him have some understanding of the problems he’d been experiencing and the problems, it wasn’t him, it was the fact that he’d got a disorder called autism spectrum disorder. And that the reasons he was experiencing the problems he was experiencing was because of this condition. And in a way, hoping that it may ... help in some way, by letting him know that he has got a condition”. (John)

John’s account illustrates that parents wanted to offer their child reasoning for their difficulties and difference from peers and siblings. Autism as an explanation may resonate with parents experience in that it may have offered a framework within which to understand their child which, may have been accompanied by a sense of vindication from blame which is mirrored here by John (“it wasn’t him, it was the fact that he’d got a disorder”).

In providing an explanation, parents further hoped to contain their child’s distress and foster an understanding of their emotional experiences:

“Mainly I think because he started to realise, that, well, he was getting ... other issues, a lot of anxiety issues, a lot of worries ... aand, he wanted to know why he was getting all these worries [...] there was no plan ... It’s just he was starting to get in that way and he wanted an answer, and truthfully that is the only answer that we could give him.” (Steven)

Steven’s account further suggests that prior to naming autism; parents may offer their child alternative reasons but that in time, these become exhausted. Such interactions may contribute to parents’ judgement of it being time to tell. In the extract below, Rebecca outlines how parents extend the concept of providing an explanation by connecting it to a child’s ability to cope.

“And I think, I’m glad that, you know I haven’t waited to tell him now, ‘cause I sort of think ... all these things that he’s brought up with me, how would he have dealt with them if he didn’t know? Yeah, I don’t regret it; I think it was the right decision.” (Rebecca)

Here Rebecca draws attention to the potential struggles of a child trying to make sense of their world if they are unaware of the diagnosis. This was seen

also in parents hope that knowledge of autism would support children's sense-making in a manner which maintained self-esteem and a positive self-concept:

"Because ... I felt, at that age, he needed to understand why he was different. And, and he actually said to me, it felt like ... relief. He knew why he was different from all the other kids and why he acted differently and it was like a weight off his shoulders." (Kirsty)

The relief experienced by Kirsty's son may reflect the possibility that children may develop negative alternative accounts of their difference which diagnosis sharing could mitigate. For some parents, alertness to the potentially damaging nature of these self-constructed accounts may be based on personal reflection:

"And I, I can remember thinking that I was a bit weird and I didn't want Billy to think like that. I wanted him to have a reason why he was, like that. So I think, I based it a bit on myself as well and, and just reading about other people and people that have been diagnosed in their 40s that, you know, spent all their lives thinking there's something not quite right but I don't know what it is." (Rebecca)

In this sense autism is perceived to offer an explanation which may challenge stigmatised identities espoused by others or, which the child may self-construct in the absence of knowledge of autism. Thus suggesting that having the conversation about autism is crucial for some children; even if it takes time for them to attach meaning to or accept the diagnosis.

3.3.2 Protection

Protection is the final sub-theme associated with parental motivation to share, (or not) the autism diagnosis. Parents were explicit in their perception that concealing the diagnosis served to protect the child, often relating this to perceptions that autism is a stigmatised condition, that their child would be unable to cope or, that the knowledge would damage their child in some way.

"Um, well I mean it was quite a long time after he was diagnosed, um, and I think the *attitude* was, I mean people like my mum would say, 'Oh you shouldn't mention the 'A' word in front of Aidan', you know, because

he shouldn't, he shouldn't feel *labelled*. And a lot of people sort of were very concerned that a child with autism shouldn't feel labelled." (Jenny)

Jenny's account captures the complexities of sharing an autism spectrum diagnosis which extend beyond the parent-child relationship, as parents contend with the perceived views and attitudes of others when deliberating whether to tell. Although, upon reflection, parents considered that concealment may not have held the protective function they had once perceived it to:

"Yeah, but it was misguided I think. I don't think it was really protecting him. Um, and at school, they certainly weren't, um, you know, being careful about not using the 'A' word, they were using it all the time and uh, and I think ... it would have been helpful um, if at home we'd also been using it, you know, just, we'd been just as open as they were at school." (Jenny)

This leads to consideration of who is being protected by keeping the autism diagnosis hidden within the home, when the child may access knowledge of autism in alternative settings such as school. Perhaps parents are protecting themselves from underlying fears and uncertainty of the outcome of diagnosis sharing or perhaps are just not ready to have the conversation with their child. In the extract below Laura is more explicit in recognising that parents delay the diagnosis sharing as a means of self-protection.

R: So, it maybe had quite a positive impact on the whole family then?

P: Yes, I think it did actually. Yeah, maybe, if we were burying our heads and avoiding it ... because it might have gone away (laughs).

R: And I, I think that avoidance though is, is really important, and I guess, well, trying to understand, well, what was that avoidance about? What was so scary about *this* moment?

P: I think it's that protection from outside people actually, who don't understand. I think it's easier to, for nobody to ask you about it. Or if you're not quite there yourself. I haven't got to explain to

anybody, and just hide from them. But, err yes, you soon learn whose accepting and who's not. And that's how it will always be and some people want to know, and you find a whole lot of new friends and some people just really don't want to know. But that's life (laughs). (Laura)

Parents' motivation to share then may be entwined with their own position in relation to the diagnosis. Although parents are explicit in communicating their motivation to protect their child, "burying our heads and avoiding it" perhaps encapsulates the underlying need for self-protection. However, fears about 'coming-out autism' were not completely unfounded with some parents reporting shifts in friendships groups and social networks as knowledge of autism moved beyond the family. This may further contribute to an understanding of delayed diagnosis sharing in that parents who are not ready for public 'outing' may fear who the child will share the diagnosis with.

Conversely, for some parents, offering protection underpinned the decision to share the autism diagnosis with their child:

"It's for a specific reason, it's not, you know, so it's partly to protect them, to help them for their, err, self-esteem, you know. 'It's not your fault that you find difficulty in this area', for example. 'Don't give yourself a hard time about it, that's the way it is, but this is what we do about it'." (Susan)

Susan also infers that knowledge of autism could exonerate the child from self-blame for the day-to-day difficulties they experience and further portrays how once autism is named, parents can include their child in developing coping strategies. John takes this further in his reflection that continued concealment of the diagnosis may in itself be harmful to the child in the long-term.

"It may have a, a, feeling for the child that's got the condition that it's something bad ... something maybe to be ashamed of. Maybe their development will be hindered by the fact that they think that, and they may end up with behavioural problems ... Because you see it's a, you know, it's a hidden thing, and it's not a hidden thing, it's a condition that we have to deal with." (John)

Although a bold assertion, one may intuitively understand how parental communication and behaviour will be influential in how their child understands and relates to autism. Attention is again drawn to the hidden nature of autism which enables parents to delay sharing although the reasoning for this is likely to be multifaceted.

3.4 Parental management of diagnosis sharing

Parental accounts reflected that being able to manage the process of diagnosis sharing was important to them. Management of diagnosis sharing involved weighing-up how ready parents felt to share (*parental preparedness*) and also how ready they perceived their child to be (*perceived child preparedness*). Commonalities in parents approach to diagnosis sharing were also identified in the data and will be discussed under the sub-theme *approach and strategies*.

Parents frequently described that it was the ‘how’s’ and ‘when’s’ of sharing the diagnosis which posed a challenge, and had considered that they would do so “when the need occurred”.

“I think we always planned to tell him, we were always going to tell him he had autism I think it was trying to find the right time and the right way of doing it [...]” (Steven)

Like Steven, other parents reported that there was no plan per se to withhold the autism diagnosis, and some reflected that it had become such a part of everyday life, that this obscured the idea of sharing. Indeed upon reflection, many parents agreed that there was no ‘right time’ or ‘right way’ and appeared far more relaxed about this after autism had been named, re-focussing instead on the continued approach that would best suit them and their child.

P1: I don’t think we felt we needed to actively, look at well, well how are we going to do this?

P2: No

P1: I think we just played it by ear just to see what works for James and try and pitch it. (Steven (P1), Dawn (P2))

Interestingly, when asked to consider the advice they would offer other parents, the participants referred back to this illusive 'right time' and 'right way'; thus underlining the complexity of sharing autism and the nuances between children diagnosed with such a condition and their families:

"If I was speaking to someone else about, you know, if they didn't know what to do, I would just, say know, know your child; and I think you get feelings and ... What's, when's the right time. But I'd never not, not tell them until they were adults. I'd never ... yeah, I don't know really. Just I think, just, you have to do what you feel is right, for your child."
(Rebecca)

In this sense it may be considered that sharing the diagnosis not only requires knowledge of autism but also an in-depth understanding of the child, which, perhaps only parents possess. This is supported by Anne who reflected that having a professional disclose the diagnosis to her son would not have appealed to her:

"So I never wanted him to be sat at a table and I never wanted anybody else to do that. I think, you know, some people might um, but me personally, I knew that I was the person, I didn't want him to be taken into an office and this is what it is, because I think he would have been overwhelmed." (Anne)

The possibility of the child being "overwhelmed" by the news of autism was shared by other parents and is telling of a need to have the time to discuss the diagnosis with a child, in a manner which parents feel is appropriate.

"Well they were together for one, so the three of us, it was a time where ... I knew we'd got plenty of time, it wouldn't be rushed, or we could do it in, you know, in several chunks, because it was an afternoon, in the afternoon. So it was a, feel for where they were at, do they need a break? Do we come back to it? So yes, I knew we weren't having to rush out, plenty of time." (Susan)

Susan planned her approach to sharing autism diagnoses with her children and in doing highlights the importance of parents being able to monitor the process and be responsive to how they perceived their child is coping. The importance of managing communication about autism is also reflected in Anne's account below:

"[...] and sometimes I've done it and it's not gone well and so I think, well okay, we'll leave that and we'll come back, or he looked worried when I said that, so I'm going to try and steer away from that bit. But certainly, I, um, you know, try and just follow their lead. So if they're asking you questions, they want to know. And I think that, in all things in life, if people are asking you questions, they want to know. And they might not want to know it all though, so just follow their lead and your instinct for it, would be my advice." (Anne)

The involvement of the child in this process is introduced here with parents often referring to 'following the child's lead' when communicating about autism. The sense of a parents understanding of their child is again outlined, further suggesting that parents use their wisdom and intuition to manage what and when they share. However, Anne's account also indicates that rather than having disastrous effects, parents may use such interactions to inform them how to approach future communication about autism.

3.4.1 Parental preparedness

As previously discussed, how prepared parents feel in relation to the initial disclosure and continuing discussion about autism seemed important in the process of sharing. It was interpreted that to share the diagnosis, parents needed to have first accepted the diagnosis and processed their emotional response to this.

"And err, I don't know what would have happened if he'd asked that question two years earlier or three years earlier, when I was still in the sort of, 'Don't mention the 'A' word' frame of mind ... Um, hopefully, I mean I wouldn't have ever said *no* or lied to him. So it was important to have integrity. So, so I'm hoping I would have said yes but I think it would

have forced something on that I might not have been quite ready for ... myself. Aidan would have been ready for it but, I don't think I would."
(Jenny)

Jenny indicates that parental preparedness may outweigh parents' perceptions of how ready their child is to know. This perhaps relates to an underlying assumption that parents will be able to offer greater containment and responsiveness to the child when they have resolved their own emotional response to autism. That is not to say interactions with a child about autism are not still emotive for parents, but rather outlines the possible need for them to be in a position, psychologically, where their primary focus can be on the child and not on managing their own upset. This is echoed by Laura in the extract below.

"[...] We'd had a long time I think ... but, while I didn't speak to him about it I could just feel that it was naughty behaviour or something in my head, I don't know. Maybe I could just think, 'Oh, he's acting out'. But yeah, it was certainly all of us coming to terms with it properly really. We couldn't hide (laughs) anymore." (Laura)

Laura's account also raises curiosity regarding whether some parents may be in denial about, overwhelmed by or, disagree with the autism diagnosis. Some parents may experience challenge in response to the diagnosis and perhaps hold onto or promote alternative explanations for their child's difficulties and withhold 'the truth' from their child. A crucial factor in the sharing process then maybe that parents assimilate autism themselves in order to proceed to a position when they can share this with their child.

Beyond feeling emotionally prepared to talk about autism with their child, parents also described the importance to them of being knowledgeable about autism:

"[...] I don't think anybody could come in and tell you how to do it. Because I don't think that would be right. I think ... how do you approach it? And these are the pointers, and for, for us, it's understanding the child, it's understanding, you know, do we understand enough about it first. And, and then when's the right time and how do you do it? In an, in

a sort of environment you do it in. You know it's, so we do these things together, we're here to support you ... and, and like, you know, deal with it like that... Yeah so, these are the things you need to consider when you're doing it and take into account and then, then you have to find ... the way." (Steven)

Steven also illustrates that parents' idiosyncratic understanding of autism in relation to their child also seemed vital in them feeling prepared to share this with them. Parents described promoting their knowledge of autism in a number of ways including reading and attending courses and groups. Concurrently, parents begin to apply this knowledge to their child, thus building a representation of their child in the context of autism which they then use to explain autism to their child.

For Kirsty however, having just enough knowledge about autism was acceptable at the time of diagnosis sharing, although she still thought it important to increase her own knowledge to ensure that she could support her son.

"Um, well I was still learning myself because, you know, there was a lot of differences out there. And, you know, I started going on these courses that the NAS [National Autistic Society] run and, you know, to find out more. Erm, so, I wanted to make sure that I had the information if he [son] did need to know anything." (Kirsty)

The 'knowing autism' and 'knowing autism and your child' are perhaps superseded by other factors such as concerns for the child's wellbeing or their insight into how they differ from peers. This again demonstrates the balancing act that parents are presented with when deciding whether to share the diagnosis with their child and that understandably, such negotiations will differ according to the multiple contexts of parent and child.

Relating this back to diagnosis sharing, if it is accepted that a parent's conceptualisation of autism will impact on the understanding developed by a child and also their relationship with the diagnosis, then it is understandable that

this process will benefit from parents feeling emotionally and practically prepared.

3.4.2 Perceived child preparedness

Another factor which mediated parents management of the sharing process was how prepared they believed their child was to learn about autism. Parents often based judgements of their child's preparedness on factors such as age, cognitive ability and the child's ability to cope.

“Yeah, definitely age as well, when they can cope with bad news better and they're at an age where you can tell them things and they can deal with it better. But I think when he needed to know as well. I think I would have kept him just like everybody else for as long as I could have. For me, maybe, for him, I'm not sure.” (Laura)

Laura's account again reflects that parental preparedness may be given primacy when balancing the decision of when and what to tell children about autism. Laura's experience of diagnosis sharing was not initially a positive one as her son discovered his diagnosis outside the family, which hints at parental need to have some control in diagnosis sharing. She usefully alludes to the perceived importance of the child's age, ability to cope and 'need to know' as mediating parents approach to the sharing process. Typically, the child asking questions about their social or emotional experiences was considered to signify their readiness to know about autism, but even at this time, parents would gauge how much to share:

“It, yeah, you can't over-load him with information ... I mean that's just who James is, whether other children would, take more in, but with James it's just ... little and often really if he needs it isn't it or, just give him ... something to work with and, you, he'll go away and digest it and you might move on to the next bit.” (Steven)

Cognitive abilities such as information processing then may also have pragmatic implications for parents' management of diagnosis sharing, and reflect how the process will need to be tailored to each child:

“So you make it ... age appropriate and also cognitively as well for what they would understand, and the way they think about things. It’s not just their own ... you know, academic or cognitive ability, but it’s the way they see things, what would be meaningful to them? So it’s no good talking to them about, well this is going to affect you in relationships when you’re older because ... you know, it’s just totally inappropriate at that age. It would have been emotionally unfair as well, to talk about that, you know, how they’re going to get on in an adult relationship. But it’s very relevant to how that affected them with their peers at school.” (Susan)

“Not pushing it, no. It’s there [a book on autism], I never said, you’ve got to read this or anything, I’ve just left it there, knowing Christopher and knowing what he would do with a book. He’d probably secretly read it ... it was up to him. If he wanted to know about it, it’s up to him.” (John)

The extracts again highlight that possessing an in-depth understanding of their child (“the way they see things, what would be meaningful to them”) and their preferences (“knowing Christopher and knowing what he would do with a book”) enables parents to shape how, in what medium and the pace at which information is shared with children in order to support their understanding. Susan also introduces the perceived importance of sharing in the here-and-now to ensure that the child can connect with explanations that would otherwise be too abstract if spoken about in future terms.

The assumption of future talk being ‘emotionally unfair’ was often captured in parents’ accounts. Parents were interpreted to act as gate-keepers of information generally, and more specifically, about the possible negative future implications associated with autism. The emotional underpinnings of which are summarised by Dawn and Steven:

P1: Yeah, and he’s got no awareness, like, it’s going to impact on his future has he? It’s, it’s very much a, a now thing for him I think he doesn’t, he, he can’t see you know well, actually, you know you probably won’t get married and have children and, but you can’t say that to a child, um, so that.

P2: No, so at the end of the day, that might not actually be true, because he might well do, [...] which is obviously why it's important to focus on the now, rather than what might be. Because if you, if you told him, no you're not going to get married James and have children ... he'd probably be well, quite upset about that.

P1: Yes, you can't squash all of his dreams. (Dawn (P1) & Steven (P2))

In this way it could be understood that parents use the life stage of a child to inform them about what is and is not okay for them to share, not just in terms of whether the child can meaningfully connect to the information shared, but also in terms of potentially adverse emotional consequences. Parents may feel that talking about driving tests or moving away from the family home for example, are more appropriately addressed as they arise. Thinking back to the process of sharing, the child's increasing awareness of the limitations autism may pose may underlie parental perceptions that acceptance of the diagnosis is changeable.

3.4.3 Approach and strategies

"I think that well, what I did do was, get lots of books. Um, um, I can't remember what they're called but we've still, still refer to them now. Err, 'my brother has autism' and books describing autism . . . and, and we showed him a lot of that, and showed him a lot of um, clever people with autism. Um, on the internet, so, 'Okay here's a musician, he's amazing, he's got autism'. So, so we just planned to tell him about it and all the *positive* things about it." (Laura)

All parents verbally communicated about autism with their child in the first instance and after this supported learning and exploration with the use of television programmes⁵, books⁶, and/or the internet. It appeared that parents packaged their responses and approach to discussing autism with the aim of enhancing communication and fostering greater understanding in the child. Such processes have been peppered throughout the analysis where parents

⁵ For example Clarke & Griffiths (2011) *My autism and me*

⁶ For example Jackson (2002) *Freaks, geeks and Asperger syndrome*

have described 'sharing in the here and now,' 'taking the child's lead' and 'drawing upon everyday experiences'. Like Laura, parents used resources which detailed famous or successful people considered to be on the autism spectrum:

"One of the things that we did, erm, oh, I think I found it on Google, all the people that have supposedly got Aspergers or Autism, like Bill Gates, Einstein and all them, and I think that, that boosted Dylan's confidence, [...] it's good to show that it hasn't stopped them. I mean they said Einstein didn't speak until he was four or five or something, you know, and things like that. So it just goes to show that you can achieve, if they put their mind to it. So yes, that was, that was a positive that we did for Dylan I think." (Kirsty)

Parents also personalised talk of strengths and positive qualities to their child:

"[...] His maths ability, how good he is at that. The way that he looks at different things, you know, certain things differently. He can solve a problem much quicker than some other people, certain things, you know, see things differently. He's very quick on the mark. Also with comments, he's got quite a dry sense of humour, you know, which is really, really good, he makes me chuckle." (Erica)

Consistent with the thread running through the analysis, Kirsty and Erica demonstrate how interactions about autism were overwhelmingly positive, perhaps with the aim of instilling hope and retaining positivity in the child's current and future self-concept. Parents appeared to have greater difficulty talking about the 'negatives' associated with autism:

"Err ... I think mostly, um, mostly, it's, it's, it's hard when it came to, the kind of the negatives of autism or kind of having learning difficulty, um, especially if you had to say something, something negative or something that, um, that he couldn't do as well as other people." (Jenny)

Jenny alludes to "the facts" of autism which has been interpreted to mean everyday difficulties such as disliking change or experiencing intense emotional responses. Such difficulties may be part of the shared understanding of autism

which has developed between parent and child and which is openly communicated about. Conversely, parents appeared to filter out information about the vulnerabilities associated with autism, understanding this to protect the child. Jenny went on to suggest that other systems may also support a minimising approach:

“[...] he had a personal review last November. When he’s present, you know, everybody’s very careful to talk about strengths and positives and things like that. And it’s only really when he’s gone out of the room that we can talk about how *vulnerable* he is, how he *struggles* with this and that, you know. So, you know, I think it’s the same at home, [...], if it came to, to the negatives, then it’s finding the right way to, to phrase it, so as not to upset him or hurt him because he’s actually quite sensitive, so, you know.” (Jenny)

Parents (and perhaps broader systems) tend to take a balanced approach to communication about autism, whereby they draw on strengths, positives and, day-to-day challenges in supporting their child to understand autism. However, it is perceived that parents need to gate-keep information relating to autism and the future, the assumed reasons for which have been captured in the broader analysis (e.g. *parental preparedness*, *perceived child preparedness*).

Interestingly, there appeared to be a tension in parental accounts regarding the autism spectrum as a difference versus a disability, which of course is also observed in professional and Neurodiverse communities. At times parents appeared uncomfortable describing autism as a disability and often adjusted their narrative; appearing to be in a conflicted position of “well, it is, and it isn’t” (a disability).

Perhaps parents’ descriptions reflect the conflicting discourses available in society, and importantly, suggest that parents do not communicate about the autism spectrum with their children as a disability, although may do so privately. Arguably, parents may use the language which best fits their intention for example, talking about ‘disability’ may be useful and indeed required when accessing support for a child, whereas ‘difference’ may be used in context where parents want to cushion others and their response to autism.

“[...] I don’t think it has to be a negative thing really. I don’t think it’s, it’s not like a disease is it? It’s just a different way of thinking. [...] Wendy Lawson⁷, [...] you know her? (R: yeah) She calls it “diff -ability, differently abled”. You know, [...], as soon as you start saying disability, it’s like something wrong and ... it’s only wrong if, you know, you’re told its wrong. But, it, it’s not wrong is it? It’s, you know, why, why are they wrong and we’re right? I ... and when, and a lot of it when you think of how we are, how we talk and how we, don’t finish our sentences, and presume things and don’t say what we mean, you think ‘God, no wonder they’re confused and think we’re the weird ones’ (both laugh) So no, you know I’m very positive about autism.” (Rebecca)

Rebecca’s is clearly aligned to autism being a difference and also draws upon social notions of disability and disabling environments; which contrasts greatly with Susan’s account below:

“And also, I ensured that ... um, it’s not my personality to sort of say, ‘Oh it’s just a difference’, you know, we’ve all got a, you know, we’ve all got a right to be who we are. It was, it was explained, ‘Yes it is a disability’ ... some people take the extreme attitude of; it’s not a disability it’s just a difference. Um, I don’t ... go with that. I will say; it’s a disability.” (Susan)

Susan infers that a person being aware of their disability allows them to adapt in ways to accommodate life’s challenges. These divergent accounts perhaps encapsulate how a parent’s position in relation to autism will be likely to shape the shared understanding they construct with their child.

That is not to make a value judgement on either position, but rather to reflect on the broader social and cultural factors which may impact on diagnosis sharing. This further raises curiosity about the difference-disability conflict and the range of descriptions available to parents when sharing an autism diagnosis with their child and indeed whether or not they decide to share.

⁷ Dr Wendy Lawson is a renowned speaker and professional in the field of autism; she has a diagnosis of High Functioning Autism.

4. Extended Discussion

4.1 Discussion of findings in relation to past literature

This is the first study to explore how parents share an autism spectrum diagnosis with their child and as such, provides a unique insight into the complexity of this experience. Sharing an autism diagnosis with one's child is a process that evolves over time, which for parents, begins when their child is first diagnosed when (for multifaceted reasons) the diagnosis is often withheld. Parents balanced their own feelings of emotional preparedness, potential benefits and consequences and, their perception of how ready the child is to inform their initial disclosure decision and, the information shared thereafter. Interestingly, parents did not tend to strategically plan when and how they shared the diagnosis with their child with it being more common for naming autism to be intrinsically bound to a given interactional context; this challenged the researcher's pre-existing assumptions.

Consistent with literature pertaining to paediatric chronic illness, the current study found that diagnosis disclosure to children was often delayed (Ledlie, 1999; Pinzón-Iregui et al., 2013). Furthermore, the conceptualisation of diagnosis sharing with children as a dynamic and multifaceted process is echoed in similar studies (Gerson et al., 2012; Ledlie, 1999; Lesch et al., 2007; Lester et al., 2002). Additionally, these studies view the sharing of a diagnosis as a developmental process which evolves according to a child's age, social, emotional and cognitive development. However, there is some divergence in the mechanisms of withholding or sharing. Ledlie (1999) for example produced a substantive theory which conceptualised diagnosis sharing as a spectrum between total secrecy, selective telling and full disclosure (i.e., when HIV is named). The same model does not appear to apply in the context of parents sharing an autism diagnosis. Parents did engage in all of these processes, however, after a period of total secrecy, parents named autism and then proceeded to manage the process in a way akin to selective sharing.

The current study differs also in relation to the interpretations made regarding the importance of sense-making and the development of meaning in the sharing process, perhaps offering a richer understanding of sharing diagnoses with children, or perhaps reflecting a nuance of this process in the context of autism.

4.2 The application of the disclosure decision-making model

The disclosure decision-making model (DD-MM) was proposed as a framework to conceptualise how parents decided when and how to share an autism diagnosis with their child. Each component will be considered in turn to consider the utility of its application. In decisions relating to health diagnosis disclosure, Greene (2009) proposes that individuals first assess information relating to the diagnosis in order to judge the potential risks of disclosure. This involves four factors – stigma, preparation, prognosis, symptoms and relevance to others.

Perceived stigma was certainly interpreted as something that inhibited parents from sharing the diagnosis, serving a dual function of protecting both themselves and their child. Perceived stigma has also been identified as a mediating factor in literature pertaining to paediatric HIV (Weiner et al., 2007; Pinzón-Iregui, 2013). Greene (2009) proposed that the perceived risk of stigma inhibits a disclosure decision, but, this may be moderated by relational quality and anticipated response. For parents of children with autism it is possible that that the inhibitory nature of perceived stigma lessens as they sense a child's increasing need to know.

Preparation relates back to the time of initial diagnosis and parental expectations at this time. Greene (2009) suggests that having an expectation of the outcome of the assessment may mean that decisions relating to disclosure have already begun. As Nissenbaum et al. (2002) indicated; expectations are important in parents initial response to diagnosis as autism being unexpected news could lead to parents feeling angry. Parents' accommodation of the autism diagnosis therefore seems important in their decision of whether to tell. However, caution is needed in attributing this as a singular reason for non-disclosure, as parents simultaneously assess their child rather than moving through the model in a linear fashion. Furthermore, the model does not account for the role of health care professionals in this. For example, how does the manner in which the diagnosis was given and any support that was provided at that time influence this preparatory process?

Prognosis is also asserted to mediate the initial step of disclosure decision-making. This is perhaps where the model becomes less applicable in the case

of autism, as prognosis is largely defined in medical terms (i.e., is the illness terminal, what are the treatment options and potential outcomes). Perhaps the uncertainty of prognosis and outcomes in autism or, that it is a lifelong condition inhibits parents from sharing.

Interestingly, 'symptoms' form part of this initial assessment, with the assumption being that increased symptomology leads to increased likelihood of disclosure. The invisibility of autism was interpreted as making the withholding of the diagnosis possible and coupled with the cognitive and social-emotional development of the child means that a diagnosis could be withheld for a significant period of time. However, parents frequently referred to the child's emerging sense of awareness of their difficulties and difference from others as mediating factors in deciding whether to share the autism diagnosis. The final part of this first step is assessing relevance to others. It can be argued that being informed of one's diagnosis is highly relevant to that person. However, accounts often reflected that parents were motivated to share when they perceived that the 'time was right', that their child would understand and, that self and child were ready. In the context of sharing an autism diagnosis with one's child then, issues such as protection may supersede the relevance of the diagnosis.

If the perception of risk is deemed acceptable, the person will continue to the second phase - assessing the proposed receiver (i.e., the child). Parental assessments of their child are reflected throughout the findings, particularly in the sub-theme *perceived child preparedness* and also in 'Parental motivation to share'. Parental assessment of their child's possible response, and also their own fears of upsetting or harming their child often mediated parents' intention to share. Greene (2009) argues that intention to disclose would increase in a better quality relationship. This perhaps over-simplifies the issue. In the case of a parent-child relationship 'quality' may hold less relevance than parents' intentions of protection or offering an explanation of their child's difficulties. Furthermore the researcher is hesitant to apply the notion of relational quality in this context as it cannot be assumed that a better or poorer quality of relationship would lead to a heightened or decreased intention to tell.

This criticism perhaps stems from the original conception of the model relating to personal disclosure of health information whereby the person may be seeking comfort or emotional support via disclosure which would make relational quality more important. In this sense, applying the model to an alternative relational dynamic may not be appropriate. Greene (2009) proposes that assessing the potential receiver could be interrupted by the asking of questions. Indeed, a child asking questions about their difference or directly about diagnosis was often a catalyst in parents naming autism. It was considered that the asking of questions indicated to parents that their child was ready or needed to know, which is supported in broader paediatric diagnosis disclosure literature (Ledlie, 1999; Madiba, 2012).

The final stage in the diagnosis decision- making model involves an individual judging their personal efficacy in disclosing the diagnosis and achieving a desired outcome. Elements of disclosure efficacy are seen in the sub-theme *parental preparedness* whereby parents negotiate 1) whether they are emotionally ready to share, 2) knowledgeable (enough) about autism and 3) feel confident that they can rework their knowledge to meaningfully share it with their child. However, being rooted in retrospective accounts, this may present a misleading picture as parents often spontaneously decided to share or were responding to their child's questions. Arguably, parents who spontaneously shared the diagnosis may have held pre-existing judgements about their disclosure efficacy, although, this is of course speculative. Importantly, the researcher considers that the potential benefit of sharing for the child (e.g., containing emotional distress or providing an explanation) outweighed parental judgements of their efficacy in achieving that outcome. However, there was some indication that the emotional readiness of parents may surpass their perceptions of the child's readiness to know; and this could link with their view that they could be effective in providing the support required at this sensitive time.

The DD-MM proposes that if all of the above stages are satisfactorily met then a discloser will proceed to enact message strategies. There was a general sense amongst participants that they should be the one to share the diagnosis with their child and not a third party. However, this is likely to be unique to each

family depending on how prepared parent's feel to share. Laura for example expressed her view that they were "dumped" by services after the diagnostic assessment and that having professional input may be helpful in explaining about autism factually, by somebody who does not have the same emotional investment in the process.

There was a level of consistency in the enactment of message strategies including drawing on the positives; gate-keeping information; using every day experiences to promote understanding and packaging the response to suit the child. Parents used the outcomes of such interactions to inform their future approach by actively monitoring their child's responses and attempting to assess their comprehension of the information shared.

The DD-MM has some utility in integrating the multifaceted nature of parents' decision to share an autism diagnosis with their child. However, the model asserts that diagnostic disclosure is the product of a rational examination of predicted costs and benefits. In this way, the model assumes a cognitive and individualistic framework which does not capture the relational nature of this process and the social and cultural factors which may mediate this (Qiao et al., 2013). Furthermore, the often unplanned and spontaneous nature of the initial disclosure and subsequent sharing of information is not fully appreciated by the model. Although ultimately parents hold power in what is shared, the child becomes an active participant in this process which may mean that many of the decisional processes relating to parental intent become redundant.

Finally, the model does not account for the importance of meaning that was identified in the study. The model focuses on the enactment of messages and outcomes in terms of whether they inhibit or enhance the likelihood of future disclosures. What appeared important to the parents in this study was how a child made sense of the diagnosis, the meaning they attached to this and, the potential consequences on self-acceptance and well-being.

4.3 Limitations of the study

Although the current study offers new insights into an under-researched area, the benefits of this must be considered within the context of methodological limitations and unanswered questions. Firstly, although the study offers an

account of how parents share a diagnosis of autism with their child to establish meaning, it is limited by the exclusion of the views of children and young people. Parental perceptions of such processes may reflect a hope that diagnosis sharing will be beneficial for example, whilst available children's accounts are inconsistent (Calzada et al., 2012; Drummond, 2013; Huws & Jones, 2008). Furthermore, although parents referred to the child's emerging sense of difference as a motivation to share the diagnosis with them, it is unclear how this sense of difference emerges. Is this achieved independently or is it externally imposed by the actions and comments of others?

Although thematic analysis was considered to be an appropriate method to use in addressing the aims of the current study, it has raised some points of interest which thematic analysis could not address. The range of narratives available to parents to talk about autism was evident throughout the analysis. For example, the researcher considers that parents' narratives contain elements of both the medical and Neurodiversity conceptions of autism. Building upon the current study, it would be interesting to use a discursive methodology to explore this further and to consider in what settings such discourses are likely to be enacted.

4.4 Future Research

1. There remains a gap in understanding the negotiations that take place between parents and professionals in relation to disclosure at the point of diagnosis. Although age and ability have been cited as factors which may exclude a child from initial diagnosis disclosure, it will be beneficial to explore the perceptions of professionals at this time to ascertain their views on when and how a diagnosis 'should' be shared in addition to the potential role services could play in this.
2. Given that parental acceptance of the autism diagnosis was considered to be important in deciding when to share this with their child future studies could measure parental responses to and level of acceptance of the diagnosis to explore if this relates to intention to disclose the diagnosis to their child.
3. Although an emerging body of literature has considered the meaning of autism for children (Drummond, 2013; Huws & Jones, 2008); there still remains

uncertainty about how diagnosis sharing relates to the child's conception of autism and their response to the diagnosis. Further qualitative exploration of this issue is warranted to discover the range of factors which contribute to how children with autism make-sense of their diagnosis that goes beyond the disclosure itself.

4. Employing a narrative approach may be an interesting way of considering how a child's autism narrative links to that of their parents. In this way, the interactional context in which meaning-making and the development of multiple identities are constructed can be better understood.

5. The current study captures the experience of a proportion of parents who decided to share their child's autism diagnosis with them and experienced this (or were able to reflect on this) positively. There is a need to explore the views and understanding of parents whose positions and experience differ to those in the current sample so that factors and processes involved in decision-making and which influence the progress and outcome of the sharing process can be better understood. This may prove challenging as such parents may wish not to talk about experiences which have distressed them and their child or may feel criticised for decisions they have made or approaches taken. It is possible that collecting data using online parent forums or discussion groups may overcome this barrier, as it may adjust power issues and create a safe distance between researcher and participant. It would be important in this context to demonstrate genuine interest in wanting to understand decision-making processes or the challenges that parents have experienced without a sense of judgement.

4.5 Clinical Implications

Parental responses to and acceptance of the autism diagnosis were considered crucial in diagnosis sharing. Clinicians working in diagnostic assessment services should be alert to this and perhaps make links with agencies and services that could support parents through this challenging time. The recommended post-diagnosis follow-up session is ideally placed for clinicians to assess this need (NICE, 2011).

A gap exists in current clinical guidelines whereby the role of the clinician in supporting parents in sharing an autism diagnosis with their child is undefined.

This research goes part-way to offering some suggestions; particularly, the importance of clinicians discussing diagnosis sharing with parents if their child is absent from the initial disclosure. It is possible that not all parents will be ready to, or indeed, need to have this discussion and clinicians should be mindful of this in their practice.

Finally, given that parents perceived benefits to the development of peer networks for both self and child, this is a further consideration for service development. For example, there may be benefits to brief post-diagnosis support groups for children and young people to enrich their understanding of the diagnosis within a context where this is being normalised in the presence of peers.

5. Critical Reflection

Constructing the research proposal for this study feels like a very long time ago and I will use this opportunity here to reflect on the process of the study and further questions that it has raised for me.

Perhaps unsurprisingly, I encountered problems with recruitment. I was glad that I fore-planned to recruit from the NHS, as that is where the majority of participants self-selected from. The process of obtaining approval from the Trust Research and Development team (R&D) was arduous and I felt frustrated with the misinformation provided which lengthened this process. Upon reflection though, this raises an ethical question – did more people participate because the means of advertising the study was more successful, or, did participants feel more obliged to participate because of their relationship with the service? I'm confident that all of the parents took part because they wanted to share their experiences, however, I will continue to be mindful of the power issues inherent in research. In future research I will strive to be more assertive when communicating with R&D to speed up this process but, I think in any project will have to contend with the uncertainty and relative lack of control one has during the recruitment phase.

During the planning of the project I was terrified of the 'up to 40 participants' stipulation in my proposal. This number was negotiated in supervision and I think it reflects the pressures faced by qualitative researchers when

communicating research findings in academic and clinical settings where traditionally, numbers equate to impact. Although I was disappointed not to have completed any focus groups, I think that the detailed accounts of the sharing process contained in the data collected enabled me to meet the study aims. That said I am still left wondering whether divergent accounts may have been shared and elaborated in focus groups which would have enriched the analysis and overall account of this phenomena. Furthermore, I felt overwhelmed by the amount of data that I had collected in nine interviews and think that the analysis would have suffered if I'd had more data to contend with. Even so, I was extremely disappointed to have a number of fathers email me about the project shortly before the submission deadline. I think it would have been beneficial to hear from more fathers to see if any divergence from the thematic description emerged in their accounts.

As someone who is new to qualitative research (and indeed someone who has not conducted a study independently since undergraduate days) I think that thematic analysis was an appropriate choice. Aside from believing that it was appropriate for the study, I also think that its atheoretical stance meant that I had less to contend with! Although demarcated as a simple method, I did not find that analysis was easy. I had to constantly refer to my aims throughout analysis and supervision was really useful in distinguishing what I found interesting about parents accounts and what was relevant to the study. At times I did feel like I was not accounting for the 'whole story.' This is captured in the following extract from my reflexive diary following a supervision session:

I can't help thinking that I've missed something or should have something grander to say about the data. I wonder if this is something all qualitative researchers experience and if this tension reduces over time, with more experience. Roshan said (probably rightly so) that I need to let go of some of the themes and my ideas in order to produce a coherent description. I was really glad that we reviewed the themes together and thought about 'the overall story' in the data. It really helped me to see that the final thematic map is an accurate reflection of parents' experiences. I'm not sure I would have achieved this on my own! (8th August 2013)

During the analysis phase I began to consider the ethical connotations of withholding a diagnosis from a child. My clinical experience and indeed, my conversations with parents over the course of the project suggest that this is common practice, and I understand the complexity surrounding this. As a child becomes an adolescent and young adult should they have a right to know that they have a diagnosis which has the potential to divert their life course from what is considered 'typical'? Furthermore, clinically, how does this impact on consent? If one works therapeutically with a child with an autism diagnosis and concurrent anxiety issues, the clinician is likely to include 'autism' in a formulation of this anxiety and adapt interventions upon this basis. However, if the child is in the dark about diagnosis how can they truly be consenting to the work? These are issues which I think extend beyond autism and I think such reflections have sharpened my attention to times in clinical settings when consent may be 'assumed' for well-intentioned and pragmatic purposes, perhaps in-keeping with the remnants of paternalism which still remain in healthcare services.

So now I am left with the question 'so what?' I do think that the project offers something unique to the field of autism research and maintain my assertion that it was an important topic for consideration. I like the idea of having an 'output' of the study, and thank Roshan for suggesting this in a supervision session. Part of me can't help thinking that the findings are 'common sense' but I do think they shed light on the processes and tension that exists for parents when making decisions about what and how much to share. The impact and utility of the findings may well be limited to clinicians and researchers who are interested in autism and to parents who are deliberating sharing the diagnosis with their child.

5.1 Reflections post viva voce examination

My viva voce examination provided the opportunity to reflect more broadly on my position in relation to autism as a diagnosis and diagnosis more generally. I realise that autism is a really tricky point for me, possibly in the same way that intellectual disabilities are. Do they exist or are such differences not accommodated successfully in individualistic and capitalist society?

I think that I was drawn to a critical realist position because of this tension. I feel able to adopt a pragmatic position in clinical practice when working with those already diagnosed with autism when the importance of the true existence of autism often lessens. This is often replaced often by acceptance (albeit critical) of the label and wondering what will be beneficial and meaningful to the person, those who care for them and networks which support them.

Autism diagnosis though is entrenched in politics whereby a diagnosis may enable access to funding, be a preferred alternative to an intellectual disability label or more cynically, sustain disconnection from the distress that a child is experiencing which emerges from and within their attachment experiences and relationships. Although accepting of the potential utility of an autism diagnosis for some individuals and families, I still maintain a critical stance in practice and feel very uncomfortable about the pathologising of childhood. Nevertheless, we exist in professional, cultural and social systems where diagnosis is used and relied upon and I believe that it is important to understand the challenges and unique experiences that people who have been given the label autism can share.

Indeed, my interest in this area was based upon my interactions with parents in clinical practice and the worries and questions they had about how to inform their child. Although I do not hold the position that children should be told about their diagnosis, by virtue of asking the questions that I did and advertising the project in the way which I did may have inadvertently communicated this.

Conducting this research has made me think of the broader implications of diagnosis sharing. The power imbalance is amplified when a child is given a label, often without their knowledge and often based on parental consent for assessment. I'm now pondering on the ethics of this. If a child is never told about their diagnosis then are they being denied the ability to question this or to interact with society in ways which challenges such concepts as existing within them? I'm also really interested in how children who are attributed a label (be that autism, depression, ADHD) make sense of themselves and their experiences in the presence or absence of knowledge of this label. I think that these are issues that will revisit me throughout my career and I believe that I will

be more thoughtful in how I communicate with children and will be aware of and careful about practicing within taken for granted assumptions.

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Appendices

Appendix A: Initial letter of ethical approval (University)

Institute of Work, Health & Organisations

<http://www.nottingham.ac.uk/iwho>



**The University of
Nottingham**

UNITED KINGDOM • CHINA • MALAYSIA

Emma Louise Ward

Faculty of Medicine & Health Sciences

School of Community Health Sciences
Institute of Work, Health & Organisations

The University of Nottingham
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19/07/2012

Dear Emma

I-WHO Ethics Committee Review

Thank you for submitting your proposal on "Informing Children of Their Autism Diagnosis: Parents' Perspectives". This proposal has now been reviewed by I-WHO's Ethics Committee to the extent that it is described in your submission.

I am happy to tell you that the Committee has found no problems with your proposal. If there are any significant changes or developments in the methods, treatment of data or debriefing of participants, then you are obliged to seek further ethical approval for these changes.

We would remind all researchers of their ethical responsibilities to research participants. The Codes of Practice setting out these responsibilities have been published by the British Psychological Society. If you have any concerns whatsoever during the conduct of your research then you should consult those Codes of Practice and contact the Ethics Committee.

You should also take note of issues relating to safety. Some information can be found in the Safety Office pages of the University web site. Particularly relevant may be:

The *Safety Handbook*, which deal with working away from the University.

<http://www.nottingham.ac.uk/safety/>

Safety circulars: Fieldwork P5/99A on <http://www.nottingham.ac.uk/safety/fieldwork.htm>

Overseas travel/work P4/97A on <http://www.nottingham.ac.uk/safety/overseas.htm>

Risk assessment on <http://www.nottingham.ac.uk/safety/risk-assessment.htm>

Responsibility for compliance with the University Data Protection Policy and Guidance lies with all researchers.

Ethics Committee approval does not alter, replace or remove those responsibilities, nor does it certify that they have been met.

We would remind all researchers of their responsibilities:

- to provide feedback to participants and participant organisations whenever appropriate, and
- to publish research for which ethical approval is given in appropriate academic and professional journals.

Yours sincerely

Professor Nadina Lincoln
Chair IWHO Ethics Committee

Appendix B: Request for amendments (University)



Campus

Emma Ward, Trainee Clinical
Psychologist
Trent Doctorate in Clinical Psychology
IWHO, International House
University of Nottingham, Jubilee
Wollaton Road
NG8 1BB

Professor Nadina Lincoln
IWHO Ethics Review Committee

Dear Nadina,

AMENDMENTS TO STUDY PROTOCOL

Study title: Informing children of their autism diagnosis; parent's perspectives

Student: Emma Ward

Course: DClinPsy

The following amendments are being made to the protocol for the above study. These amendments reflect changes in advertisement of the study including the addition of organisations in this process. These changes have been made to promote recruitment to the study. Additionally, telephonic interviews will be offered to increase the choice participants have in how they engage in the study. All amendments have been included in the study protocol, version 2.0 (pages 9, 10 and 11).

Recruitment

- The specialist school will be advertising the study on their school website.

- The XXXX branch of the XXXX have agreed to advertise the study via their newsletter.
- XXXX has agreed to advertise the study via their newsletter.
- XXXX has agreed to advertise the study via their website. To advertise the study, they require a copy of the protocol which they will share with participants who request to see it. I will provide XXXX with a PDF copy of both the participant information sheet and protocol.

N.B. The advert used will be the same as the advertisement placed in the school newsletter submitted with the original protocol.

Method/Process

- Telephonic interviews will also be offered to participants.
- The original protocol stated that participants could withdraw from the study any point up to two weeks after the interview / focus groups. This has now been amended so that participants are free to withdraw at any time although specifies that information collected cannot be erased and may still be used in the project analysis.
- Participants will be asked to if they wish to participate in feedback sessions/receive a summary of the research via the consent form.

Materials

- The participant information sheet and consent form have been amended to reflect changes.
- Separate consent forms have been created for interviews and focus groups to improve clarity and accessibility.

Yours sincerely,

Emma Ward
Trainee Clinical Psychologist

Appendix C: Approval of amendments (University)

Institute of Work, Health & Organisations
<http://www.nottingham.ac.uk/iwho>



**The University of
Nottingham**

UNITED KINGDOM • CHINA • MALAYSIA

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14/01/2013

Dear Emma

I-WHO Ethics Committee Review

Thank you for submitting your amendment to your study entitled "Informing Children of Their Autism Diagnosis: Parents' Perspectives". This amendment has now been reviewed by I-WHO's Ethics Committee to the extent that it is described in your submission.

The Committee has accepted your proposed changes. If there are any further significant changes or developments in the methods, treatment of data or debriefing of participants, then you are obliged to seek further ethical approval for these changes.

We would remind all researchers of their ethical responsibilities to research participants. The Codes of Practice setting out these responsibilities have been published by the British Psychological Society. If you have any concerns whatsoever during the conduct of your research then you should consult those Codes of Practice and contact the Ethics Committee.

Responsibility for compliance with the University Data Protection Policy and Guidance lies with all researchers.

Ethics Committee approval does not alter, replace or remove those responsibilities, nor does it certify that they have been met.

Yours sincerely

Professor Nadina Lincoln
Chair IWHO Ethics Committee

Appendix D: Initial letter from REC Committee

NRES Committee East Midlands - Nottingham 2

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839437

05 November 2012

Dr Thomas Schroder
DClinPsy Course Director
University of Nottingham
Institute of Work, Health & Organisations, International House
Jubilee Campus
Wollaton Road
Nottingham NG8 1BB

Dear Dr Schroder

Study title:	Informing children of their autism diagnosis: parents' perspectives
REC reference:	12/EM/0374
Protocol number:	12081
IRAS ID:	109540

The Research Ethics Committee reviewed the above application at the meeting held on 29 October 2012. Thank you for attending to discuss the study.

The committee queried whether the Participant Information Sheet has been reviewed by a Parent Governor. You confirmed this has not yet happened but will be submitted as an amendment once it has been reviewed.

The committee asked why the student researcher had not been listed as Chief Investigator. Dr Schroeder replied that this is due to the limitations of University of Nottingham Indemnity Policies.

The committee asked how the audio tapes would be stored securely for seven years. You confirmed that the data would be in the form of digital recordings and thus would be encrypted and stored securely at the University of Nottingham.

The committee requested that you use a different system for the anonymisation of participant data as using initials and date of birth may not maintain confidentiality.

The committee also requested that you include a section in the Informed Consent form to enable parents to indicate whether or not they would like to receive feedback relating to the outcomes of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The committee requested that you use a different system for the anonymisation of participant data as using initials and date of birth may not maintain confidentiality.
2. The committee also requested that you include a section in the Informed Consent form to enable parents to indicate whether or not they would like to receive feedback relating to the outcomes of the study.
3. The committee also requested assurance from you that the audio recordings will be encrypted and stored securely at the University of Nottingham and that this be included in the Participant Information Sheet.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

The committee requested that the researchers use a different system for the anonymisation of participant data as using initials and date of birth may not maintain confidentiality. The committee also requested that the researchers include a section in the Informed Consent form to enable parents to indicate whether or not they would like to receive feedback relating to the outcomes of the study. The committee also requested assurance from the researchers that the audio recordings will be encrypted and stored securely at the University of Nottingham and that this be included in the Participant Information Sheet.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>	
Advertisement	1.0	03 September 2012	
Evidence of insurance or indemnity	Henderson Corporate	25 July 2012	
Investigator CV	Thomas Schroeder	20 September 2012	
Letter from Sponsor	Signed by Paul Cartledge	20 September 2012	
Other: CV	Emma Louise Ward	03 September 2012	
Other: CV	Roshan Das Nair	28 June 2012	
Other: Interview Schedule	1.0	03 September 2012	
Other: Focus Group Schedule	1.0	03 September 2012	
Other: Recruitment Advertisement (School Newsletter)	1.0	03 September 2012	
Participant Consent Form: Consent Form - Interview	1.0	03 September 2012	
Participant Consent Form: Consent Form - Focus Groups	1.0	03 September 2012	
Participant Information Sheet	1.0	03 September	

		2012	
Protocol	1.0	03 September 2012	
Questionnaire: Demographic Questionnaire	1.0	03 September 2012	
REC application	109540/365131/1/376	20 September 2012	

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/EM/0374

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Simon Roe

Vice-Chair

Email: Tracy.Leavesley@nottspct.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: Sponsor - Mr Paul Cartledge, University of Nottingham

Lead NHS R&D contact - Teresa Grieve, Derby Hospitals NHS Foundation Trust

NRES Committee East Midlands - Nottingham 2

Attendance at Committee meeting on 29 October 2012

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>	
Ms Gill Bumphrey	Clinical Trials Pharmacist	Yes		
Miss Shamim Byrne	Consultant Gynaecologist/Obstetrician	No		
Dr Frances Game	Consultant Physician	Yes		

Miss Heather Harrison	Committee co-ordinator	No		
Dr Martin Hewitt	Consultant Paediatric Oncologist	No		
Dr Asam Latif	Research Pharmacist	Yes		
Mrs Linda Reynolds	Occupational Therapist	Yes		
Dr Simon Roe (Vice-Chair)	Consultant Nephrologist	Yes		
Dr John Shaw	Lay Member	Yes		
Miss Catherine Shenton	Lay Member	Yes		
Mrs Sally Ann Smith	Retired Audit Manager	No		
Mr Glen Swanwick	Lay Member	No		
Dr Alison Thorpe	Research Management and Governance Facilitator	Yes		
Ms Margret Vince	Translator	Yes		

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>	
Ms Bejal Gosai	Research Project Manager	
Miss Tracy Leavesley	Assistant Committee Coordinator	

Appendix E: Researcher's response to the REC Committee



Emma Ward, Trainee Clinical Psychologist
Trent Doctorate in Clinical Psychology
Institute of Work, Health & Organisations
International House
University of Nottingham, Jubilee Campus
Wollaton Road
NG8 1BB

30th November 2012

NRES Committee East Midlands – Nottingham 2
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Study title: Informing children of their autism diagnosis: parents' perspectives
REC reference: 12/EM/0374
Protocol number: 112081
IRAS ID: 109540

Based on the conditions set out for favourable opinion from the above REC, the following minor amendments have been made.

1. A different system will be used for the anonymisation of participation data to ensure participant confidentiality. The system will use the first three letters of mothers' maiden name, month and year of birth. For example, if the maiden name was Williams and the participant was born on the 18/11/1983 the code would be WIL1183. These instructions have been added to the demographic questionnaire.
2. The Informed Consent form for both interviews and focus groups include sections to enable participants to indicate if they would a) Like to be involved in a member checking session of the results and b) like to receive a written summary relating to the outcomes of the research.
3. I confirm that audio recordings will be encrypted, saved on a disc, and stored securely at the University of Nottingham. This information has been added to the Participation Information Sheet.

All amended documents have been sent electronically.

Yours sincerely,

Emma Ward (Student Researcher)

Appendix F: REC confirmation of ethical approval



NRES Committee East Midlands - Nottingham 2

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839437

30 November 2012

Miss Emma Ward
Trainee Clinical Psychologist
Trent Doctorate in Clinical Psychology
Institute of Work, Health and Organisations
International House
University of Nottingham
Jubilee Campus
Nottingham NG8 1BB

Dear Miss Ward

Study title: Informing children of their autism diagnosis: parents' perspectives
REC reference: 12/EM/0374
Protocol number: 12081
IRAS ID: 109540

Thank you for your letter of 30th November 2012. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 31 October 2012

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter	Letter from Emma Ward	30 November 2012
Participant Consent Form: Focus Groups	2.0	30 November 2012
Participant Consent Form: Interview	2.0	30 November 2012
Participant Information Sheet	2.0	30 November 2012
Questionnaire: Demographic questionnaire	2.0	30 November 2012

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Advertisement	1.0	03 September 2012
Covering Letter	Letter from Emma Ward	30 November 2012

Evidence of insurance or indemnity	Henderson Corporate	25 July 2012
Investigator CV	Thomas Schroeder	20 September 2012
Letter from Sponsor	Signed by Paul Cartledge	20 September 2012
Other: CV	Emma Louise Ward	03 September 2012
Other: CV	Roshan Das Nair	28 June 2012
Other: Interview Schedule	1.0	03 September 2012
Other: Focus Group Schedule	1.0	03 September 2012
Other: Recruitment Advertisement (School Newsletter)	1.0	03 September 2012
Participant Consent Form: Focus Groups	2.0	30 November 2012
Participant Consent Form: Interview	2.0	30 November 2012
Participant Information Sheet	2.0	30 November 2012
Protocol	1.0	03 September 2012
Questionnaire: Demographic questionnaire	2.0	30 November 2012
REC application	109540/365131/1/376	20 September 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

12/EM/0374	Please quote this number on all correspondence
-------------------	---

Yours sincerely



Miss Tracy Leavesley
Assistant Committee Coordinator

E-mail: NRESCommittee.EastMidlands-Nottingham2@nhs.net

Copy to: CI - Dr Thomas Schroder, University of Nottingham

Sponsor - Mr Paul Cartledge, University of Nottingham

Lead NHS R&D contact - Ms Teresa Grieve, Derby Hospitals NHS Foundation

Appendix G: Participant Information Sheet



Participant Information Sheet (Final Version 2.0 /30.11.2012)

Title of Study: Informing children of their autism diagnosis: parents' perspectives

Name of Researcher(s): Emma Ward

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear. You can contact me if you have any questions or would like more information about the study, my contact details are provided at the end of the information sheet.

What is the purpose of the study?

Before I began training to be a Clinical Psychologist, I worked with individuals with autism and their families. For some of this time I was involved in autism assessments. In my experience, professionals often disclose the autism diagnosis to parents but it is parents who go on to share the diagnosis with their child. This made me interested in how parents inform their children of their autism diagnosis.

Much of the research within this area has focussed on the disclosure of an autism diagnosis from professionals to parents. There is also some research about the experience of being told you have autism. To date, no research has considered *how* parents tell their child about an autism diagnosis and the processes which are involved in this. There are books available which offer advice to parents. However, I think that having first person accounts of parents will be invaluable for future parents who will go through the same process. I think the research will also be useful for professionals who work with children with autism and their families.

I am completing this research in partial fulfilment of my Doctorate in Clinical Psychology.

Why have I been invited?

You are being asked to participate because you are the parent or carer of a child with autism and you have begun to talk to your child about their diagnosis. We are inviting up to 40 participants like you to take part

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

I will contact you two weeks after you receive this information sheet to see if you would like to participate. If you wish to participate I will ask you to decide if you would like to take part in a focus group or an interview. You will not be asked to participate in both.

If you want to take part in a focus group, a meeting will be arranged with you and other group members to talk about the research, to give you an opportunity to ask questions and to sign a written consent form. We will then arrange a time for the focus group.

If you choose to participate in an interview, I will accept this as informal consent and we will arrange a date for the interview. Before we start the interview we will talk about the purpose of the study, you can ask any questions you may have, and I will ask you to sign a written consent form.

What will happen to me if I take part?

Participating in the project will be different depending on whether you choose to take part in a focus group or an interview. There are some things that all participants will be asked to do.

It is expected that interviews and focus groups will be conducted between January – July 2013.

i) All participants will be asked to:

Complete a short questionnaire. This contains questions like 'What is your child's diagnosis?' and 'For how long has your child known they have autism?' The information you provide will be used to describe the participants of the research group as a whole. The questionnaire takes about five minutes to complete.

ii) Focus groups:

A focus group will involve you discussing the process of telling your child they have autism with other parents who share this experience. It is likely that your experiences could be similar or different to other group members and it is this sharing of unique experiences that is an advantage of being part of a focus group. I will be present during the discussion and we will set ground rules and remind ourselves of the aims of the research before the discussion begins. The ground rules will include an agreement to keep the information shared in the group confidential. The group will consist of four to six parents of individual children. *Both parents of a child will not be invited to the focus group, although they can choose to participate in an interview together.* The group will take place in a room at the University of Nottingham or another suitable location and will last for between 1 ½ - 2 hours. It is possible that you may know some of the parents in the group. The discussion will be audio-recorded and I will also make written notes

ii) Interviews

I understand that not all parents will want to participate in a group but may still want to share their experiences. For this reason, participating in an interview is also an option. You can choose whether to participate in a face-to-face or telephone interview. If you prefer a telephone interview, I will arrange a brief meeting with you before this in order to answer any questions you have, to obtain consent and for you to complete the demographic questionnaire. In the interview, I will ask you (or you and your partner) about the process of telling your child they have autism. The interview will last for up to 1 ½ hours and can be arranged at a time that is convenient for you. Face-to-face interviews can take place at your home or at the University of Nottingham if you prefer. The interview will be audio-recorded and I may also make written notes.

The researcher will ask participants if they want to take part in feedback session when the analysis is complete. This will give participants an opportunity to comment on whether the analysis is a good reflection of the research. You can indicate whether or not you would like to be invited to this session on the consent form.

You will also be asked if you want to receive a summary of the research when it is completed. You can indicate whether you would like to receive a written summary on the consent form.

Expenses and payments

Participants will not be paid to participate in the study. You can request reimbursement of travel expenses for any visits incurred as a result of participation.

What are the possible disadvantages and risks of taking part?

There is a possibility that sharing your experiences with a researcher and with others in a group may be an emotional experience. From the outset I wish to acknowledge that I don't believe that there is a 'right' or 'wrong' way to share an autism diagnosis with a child. I am conducting this research to explore the ways in which parents' have done this as well as the experience of doing so. If you do find the experience emotional I will be available to talk to after the interview or focus group. I do not expect that participating in the research will cause participants any inconvenience, although I am sensitive to the possible difficulties in arranging childcare in order to participate.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help future parents who embark on the journey of sharing their child's autism diagnosis with them. It may also be helpful to professionals who work with children with autism and their families.

What happens when the research study stops?

When the research study stops there will be a timeframe within which the named researcher will analyse the data. When analysis is completed you will have the option of attending a session to provide feedback on the analysis. After this, any changes will be made and the study will be written-up. The research will be submitted in October 2013 when you will receive a summary of the research. You will not be contacted again after this time.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the organisation who introduced you to the study, the Chief Investigator or Academic Supervisor (see contacts at the end of the information sheet).

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. This means that anything we discuss will be treated as confidential, unless, however you were to disclose something that raised concerns about your own safety or the safety of another person. If this were to happen, firstly I would talk to you about my concerns and would seek advice from my supervisors to see how to proceed. You will be kept informed throughout this process.

All audio-recordings of interviews and focus groups will be transcribed. All identifiable information will be removed so that you will not be recognised. Although I will transcribe most of the audio-recordings, a professional transcription service will also be used. The transcription service will sign a confidentiality agreement before they are given any information. No personal identifiable information will be given to the transcription service.

Confidentiality in focus groups may be limited. This is because I cannot control what information is shared by group members and who this information is shared with after the focus group. All participants in focus groups will be asked to respect the confidentiality of all participants and will have to sign a confidentiality agreement on the written consent form.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a

password protected database. This includes audio-recordings which will be saved to a password protected disc and will be stored in a secure, locked office.

Your personal data (address, telephone number) will be kept for 6 months after the end of the study so that we are able to contact you about the findings of the study. All research data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis. The services received by you and your child will not be affected if you decide to withdraw from the study.

Involvement of the General Practitioner/Family doctor (GP)

The researcher will not inform your GP of your involvement in the study.

What will happen to the results of the research study

The named researcher will submit the research to the University of Nottingham towards completion of her Doctorate in Clinical Psychology. The research will also be submitted to a suitable journal for publication. The results will be anonymous and it will not be possible to identify participants. I will also ask for your permission to send you a summary of the research when it has been submitted.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the National Research Ethics Committee East Midlands.

Further information and contact details

For further information please contact:

Emma Ward, Trainee Clinical Psychologist
Trent Doctorate in Clinical Psychology
Institute of Work, Health & Organisations
International House

University of Nottingham
Jubilee Campus
Wollaton Road
NG8 1BB

Tel: 07934101718 Email: autismresearch2013@hotmail.co.uk

(This number and email address will be used only for the duration of the study)

Roshan das Nair (Academic supervisor)
Research Tutor, Trent Doctorate in Clinical Psychology
Institute of Work, Health & Organisations
International House
NG8 1BB Email: Roshan.Nair@nottingham.ac.uk

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Appendix H: Newsletter advertisement

RECRUITMENT ADVERTISEMENT

(Draft Version 1.0: 20/07/2012)

Name of Researcher: Emma Ward

[HAVE YOU STARTED TO DISCUSS YOUR CHILD'S AUTISM SPECTRUM DIAGNOSIS WITH THEM?](#)

If so, I would be very interested in hearing from you. I am training to be a Clinical Psychologist and as part of this I will be completing some research. I would like to interview parents who have **started to discuss** their child's autism diagnosis with them. The aim of the research is to understand what prompted you to share the diagnosis with your child, your experience of sharing the diagnosis and the processes that were involved. Having first-hand accounts will be beneficial to future parents considering telling their child they have autism and also to professionals who work with children with autism and their families.

If you would like more information or have any questions please contact me:

Emma Ward Tel: 07934101718 Email: autismresearch2013@hotmail.co.uk

Appendix I: Poster advertisement

HOW DO PARENTS SHARE A DIAGNOSIS WITH THEIR CHILD?

I am looking for parents of children with a diagnosis of:

- *Autism*
- *High functioning autism*
- *ASD*
- *Asperger syndrome*

Who have begun to talk to their child about their diagnosis.

I want to invite you to take part in a research project which is considering *how* parents shared an autism diagnosis with their child and what processes were involved in this.

The research will involve being interviewed in a group OR as a couple OR as an individual. This will be your choice.

For more information please contact:

Emma Ward

email:autismresearch@hotmail.co.uk

Trainee Clinical Psychologist

Tel: 07934 101 718



Appendix J: Consent form

CONSENT FORM - INTERVIEW (Final Version 2.0: 14.06.2013)

Study: Informing children of their autism diagnosis: parents' perspectives

REC ref: (12/EM/0347)

Name of Researcher: Emma Ward

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version numberdated..... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports and publication. ☐
5. I would / would not like (delete as appropriate) to be contacted about participating in a feedback session. ☐
6. I would / would not like (delete as appropriate) to receive a written summary relating to the outcomes of the study. ☐
7. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

2 copies: 1 for participant, 1 for the project notes

Appendix K: Demographic questionnaire

DEMOGRAPHIC QUESTIONNAIRE

“Informing children of their autism diagnosis: parents’ perspectives”

Name of researcher: Emma Ward

Date: __ / __ / __

This questionnaire asks for some information about you and your child. The answers given by all participants will be put together so that I can describe you as a group. The questionnaire will take about five minutes to complete. Please answer the following questions:

I am female / male (delete as appropriate).

What is your ethnic origin?

What is your child’s diagnosis?

Does your child have any other disability or impairment?

Roughly how long after you first had concerns about your child was the diagnosis made?

How old was your child when they were diagnosed?

How old was your child when you shared their diagnosis with them?

For how long has your child known they have autism?

Thank you for completing this questionnaire

Appendix L: Interview schedule

INTERVIEW SCHEDULE

“Informing children of their autism diagnosis: parents’ perspectives”

Questions

1. What prompted you to discuss the autism diagnosis with your child?
2. How did you plan this?
3. Did you seek any support?
4. How confident were you in telling your child they have autism?
5. What were your hopes about telling your child they have autism?
6. What were your fears about telling your child they have autism?
7. How did you communicate your child’s diagnosis with them?
8. What was your experience of sharing your child’s autism diagnosis with them?
9. What happened after you shared the diagnosis?
10. Can you offer any reflections on the disclosure process?
11. What advice would you offer to parents embarking on the same journey?

Appendix M: Confidentiality agreement for transcriber



Data Protection Act 1998 Confidentiality Agreement for Transcribers

This Agreement is made as of **25.07.2013**, by and between the University of Lincoln, with principal offices at Brayford Pool Lincoln LN6 7TS (the University) and **Helen Smith** with principal offices at [REDACTED], (the Transcriber).

The Transcriber has been appointed by the University of Lincoln to transcribe audiotapes/audio files and documentation resulting from research undertaken by **Emma Ward** which will involve the disclosure to the Transcriber of personal data held by the University. Accordingly the Transcriber is required to deal with any such information in accordance with the terms of this Agreement and the Data Protection Act 1998.

The Transcriber undertakes to respect and preserve the confidentiality of personal data. Accordingly, for an indefinite period after the date of this Agreement the Contractor shall:

- maintain the personal data in strict confidence and shall not disclose any of the personal data to any third party;
- restrict access to employees, agents or sub-contractors who need such access for the purposes of the contract (and then only if the employee, agent or subcontractor is bound by conditions of confidentiality no less strict than those set out in this agreement, which the Transcriber shall enforce at the University's request);
- ensure that its employees, agents or sub-contractors are aware of and comply with the Data Protection Act 1998; and
- not authorise any sub-contractor to have access to the personal data without obtaining the University's prior written consent to the appointment of such sub-contractor and entering into a written agreement with the subcontractor including conditions of confidentiality no less strict than those set out in this agreement, which the Transcriber shall enforce at the University's request.

The Transcriber agrees to indemnify and keep indemnified and defend at its own expense the University against all costs, claims, damages or expenses incurred by the University or for which the University may become liable due to any failure by the Transcriber, its employees, agents or sub-contractors to comply with any of its obligations under this Agreement.

For the avoidance of doubt, the confidentiality imposed on the Transcriber by this Agreement shall continue in full force and effect after the expiry or termination of any contract to supply services.

The restrictions contained in this Agreement shall cease to apply to any information which may come into the public domain otherwise than through unauthorised disclosure by the Transcriber.

This Agreement shall be governed by and construed in accordance with the laws of England and the parties hereby submit to the exclusive jurisdiction of the English courts.

Signed for and on behalf of

Signed: [Signature] Name: Helen Smith.....
Title: Miss Date: 25.07.2013.....

Signed for and on behalf of the University of Lincoln

Signed: [Signature] Name: Emma Ward.....
Title: Miss..... Date: 25.07.2013.....

Appendix N: Excerpt from a worked transcript (participant three)

- 1 **Research Interview 2**
- 2 **Participant: 3**
- 3 **Location: Participants' home (22.2.13)**
- 4 With the mother of a 13 year old boy with a diagnosis of
- 5 Asperger syndrome (Billy) and an 17 year old boy with
- 6 severe autism (Adam). Interview based on sharing the
- 7 diagnosis with the former. Diagnosed at 3 years and 6
- 8 months. Shared when child age 4. At time of interview had
- 9 known of diagnosis for ~~12~~ ^{nine} years.
-
- 10 **R (R):** Um, so... Is it Adam that you've shared the diagnosis
- 11 with?
- 12 **P (P):** No, Billy
- 13 **R:** Billy, okay. **[P: yeah]**
- 14 **R:** Um, and what prompted you to discuss the autism
- 15 diagnosis with Billy? *initiated by child*
- 16 **P:** Um, he asked me ... **[R: Oh, okay].** (Laughs) First, yeah,
- 17 'cause there'd been so much going on with Adam and he
- 18 knew Adam was autistic and err, he just said to me "Am I
- 19 autistic?" (Laughs) and I, at the time I knew he'd got a - *mother knows before child*
- 20 diagnosis of Asperger's. So I err sort of said err I think you've
- 21 got a little bit. **[R: mmhmm]...** Um ... yeah, and then it, it just *sharing develops over time ongoing → process*
- 22 developed from there really. He, some, he alw, (still now he'll
- 23 say to me ... something "I feel like this, is that my
- 24 Asperger's?" *child making connection between feeling + Δ seeks verification of link*
- 25 **R:** Oh, Okay... So he tries to make sense of his experiences
- 26 **[P: yeah]** in terms of having Asperger's? **[P: yeah]** Can you
- 27 think of any examples of that? *Provides eg. of social situation when child makes sense of ↑ anxiety / sensory issues + autism*
- 28 **P:** Umm ... Like ... If we go somewhere and there's lots of
- 29 children like squealing, making noises and he gets really
- 30 anxious and he'll get really quite emotional about it and he'll
- 31 say "I've got to get out of here, it's really bothering me" and *making connections*
- 32 then he might say then, "Is that my Asperger's?". **[R: Ah,**
- 33 okay]. And its, he's so upset with like all the noise. *seeks verification establishing meaning of Δ*
- 34 **R:** Okay, so having a high level of anxiety **[P: yeah]** while
- 35 there's lots of people or children and lots of noise in public
- 36 places?

37 P: Yeah, yeah, and socially at school, you know he'll ... he's
 38 quite different to his peers. He, he's very much black and
 39 white with his ... if, if there's a rule it should be obeyed and
 40 that's it um, and so, so he can't really understand it, how his
 41 mates go to the park and have a fag (laughs). And, you
 42 know, or go behind the sheds at school and do something
 43 they shouldn't be doing, that sort of thing. [R: yeah] So, he
 44 just thinks "Why would you do it when it's wrong?" you know?

*child aware
of this?*

*example of how
Δ relates to
child, not
about sharing*

45 R: And he's at mainstream school?

46 P: Yeah, he is yeah. Um I mean I think the more I notice his
 47 ... it's like he copes really well at school, but when he comes
 48 home, he can't, I can't ask him any questions, I can't have a
 49 discussion with him when he first gets home from school. He
 50 literally has to go upstairs and have a couple of hours just to
 51 ... I don't know, get, get ... get over the day I think. [R: okay].
 52 I think he holds, holds in a lot at school. [R: mmm] You
 53 know, he tries to fit in and then [R: yeah] and when he comes
 54 home he, he can often go a bit hyperactive and like he's
 55 getting it out of his system. [R: yeah] ... And then he's alright,
 56 yeah. And sleeping that's another thing, he doesn't sleep well
 57 at all. Um, and it, he like, I can remember him saying to me
 58 "How, how do you close your eyes?" So I used to say to him
 59 "Just close your eyes and go to sleep" "How do I close my
 60 eyes?" And when you think about it literally, it's like yeah,
 61 "How do you close your eyes?" how do you explain to
 62 someone how to close their eyes? [R: yeah] ... You know [R:
 63 yeah] ... So, yeah, it's sort of lots of little things that come up.
 64 But he's really proud of it, he's not, there's nothing ...
 65 negative or no embarrassment over it. - *child has accepted Δ*

*indication
that child
recognises difference
from others.*

*continued
exploring in
relation to
experience*

66 R: Okay ...

① 67 P: I mean that's now, you know I suppose he doesn't
 ② 68 understand how much it's gonna affect him. And I mean no
 ③ 69 one does really, I don't know how it's gonna affect him. [R:
 70 yeah] ... You know, I, 'cause he's just become a teenager
 71 now so, [R: mhmm] with hormones and everything and I
 72 don't know how much more it's gonna ... (trouble him but, [R:
 73 Mmhmm] he's yeah, he's it feels like, we had to fill out an
 74 application form for school the other day and it said um, any
 75 medical problems. And I said, well, it's, well 'cause obviously
 76 it's not a medical problem. I said "Do you want me to put your
 ④ 77 Asperger's in or not?" and he said "yeah, why? I'm not

*AS
- process*

*mother has
pessimistic outlook?
limiting what is
shared*

*But has some
ideas?*

*Sharing in
uncertainty
child's acceptance
may change
mother doesn't
conceptualise AS
medically*

negotiate sharing to others

- 78 embarrassed about it." [R: Okay]. And I think it helps as well
 79 because there's quite a few children ... at sch ... it's more
 80 open now isn't it so he knows people at school that have got
 81 a bit of Asperger's and ... [R: okay] they'll have a chat about
 82 it and he'll say, "Yeah! I'm like that. I have to have my door
 83 shut, and I can bear this and I can't bear that." So, yeah ...

84 R: Does he ...

85 P: It's not new, it's not sort of a really alien thing to him.

86 R: And so he's got um, so it sounds like he has quite a
 87 positive experience then in school in terms of having other
 88 people [P: yeah] recognising, and shared experiences

- 89 P: Yes, since secondary school [R: mmhmm] ... and he's
 90 always been really embarrassed about his brother, but
 91 recently, he's spoken to kids at school that have got a
 92 brother, or a niece, or a nephew that's severely autistic and
 93 ... I think that's helped him a lot. Because he hasn't wanted
 94 to access any sibling groups or anything like that. ... [R:
 95 mmhmm] Umm and I think just that natural, having chats with
 96 people at school has, has made him realise he's not the only
 97 one in the world who's got a severely autistic brother, you
 98 know ... [R: yeah, yeah] 'cause he did struggle with that a lot.

99 R: I suppose being, I wonder if being quite rigid, when you
 100 say about black and white thinking, and [P: mmm] ... And,
 101 umm, maybe it's harder for him to understand the differences
 102 and the behaviours and things like that?

103 P: Yeah, definitely. Yeah, and the emotional. I mean Adam's
 104 gone now and he's got no intention of wanting to see him or
 105 ... you know they're, they're encouraging, they're trying to
 106 encourage me to encourage him to go and visit his brother
 107 'cause, it's what he should do. You know in a real world, but
 108 ... to Billy, he's, he's gone. [R: yeah] And that, and that's it
 109 and he never got anything out of Adam, he never, there was
 110 no, no, because he was so severe ...

111 R: Yeah, there was no ...

112 P: There was no brotherly sort of connection there ... umm.
 113 Yeah.

114 R: And, you, you mentioned earlier about like um, filling out
 115 application forms and things for school [P: mmm] Um ... and

social factors important

identifies others + it enhances understanding

sharing experiences & peers normalises AS?

increasing acceptance of brothers & acc time

responds to child's preferences not formalised, no big deal.

nuances of ASD

- 116 it seems like then you're at a point now where you actually
 117 negotiate about sharing the diagnosis and you speak [P:
 118 Yeah] ... Quite openly about that.
- ① 119 P: Yeah, 'cause I think a few years ago he wouldn't have
 ⑤8 120 wanted me to put it down on anything but um, yeah ... now, I
 121 don't know how much he's looked up himself [R: mmm] I
 ①5 122 don't, I think with Billy, he if he doesn't feel the need then he -
 ⑨1 123 won't. So ... I think he just, he's just accepted it and yeah,
 124 and no problem with it now at all
- 125 R: And has that been a gradual process?
- 126 P: Yeah, definitely ... and he'll ... he'll often ask me things
 127 like ... he feels very like injustice at school. You know like if a
 128 few weeks ago they were all coming out of a classroom and
 129 they're all pushing and Billy got ... pushed into the
 130 headmaster's office which was next door and he got told off;
 131 and he was absolutely mortified. He was more angry than
 132 anything because. [R: yeah] It wasn't his fault ... you know,
 133 he couldn't help the fact that someone had pushed him. And,
 134 the headmaster obviously just reacted to that situation
 135 "What's your name?" and "What class are you in?" and
 136 "You're gonna to get into trouble" and he, he was so
 137 distraught about it. We went into school about it that
 138 afternoon and fortunately, 'cause the t, his form tutor knows
 139 him and ... he know he's got Asperger's and I mean, they, I,
 140 sometimes, I a lot of the time I don't think they really believe
 141 that's he's got Asperger's because they don't see it. But, they
 142 know that he, he obeys the rules and so they know that that's
 143 out of character for Billy. So, it was all sorted very quick and
 144 you know, he didn't get into trouble for that. So...
- 145 R: But, those occurrences that happen in school, well, that
 146 seems quite important as well. Not having ... people believe
- 147 P: It drives me mad you know when he knows he's right and
 148 you cannot argue, you cannot win an argument with him. You
 149 know, if he's upset on something, that's right and that's it,
 150 there's no, there's no grey area, it's black or white with Billy.
- 151 R: And, and how does it feel for you and, and for Billy as well
 152 in terms of teachers, if you get the sense that teachers don't
 153 believe that he has Asperger's.

— timing comparing past + present

— unsure if seeks knowledge independently
 ↑ knowledge of Δ led by child

— acceptance over time?
 timing/process

instances when wants to be 'out' or not?

— affirms process

— asks questions about daily experiences?
 (relates to AS?)

Δ shared & others

invisibility of Δ
 invisibility @ school
 'hyperinvisibility' @ home

154 P: We've had that all his life. It used to wind me up. But now
 155 ... mmm, I don't know, I just. You just accept that that's the
 156 way the world is really at the moment. It's frustrating but,
 157 unless there's an issue, if there's an issue then I'll deal with it
 158 straight away. Umm, but you can't really, you can't really
 159 explain, if people don't understand much about Asperger's
 160 you can't explain to them, err, how it affects Billy. You just
 161 can't "Ooh, he's alright when he's here" you know, "He's
 162 good as gold" ... there's, just, you know, just sort of think "I'll
 163 leave that one" mmm.

- could this impact on a parent's decision to tell?

164 R: And it's funny that they, I guess they use the "he's good
 165 as gold" and that makes it seem to me that maybe then ...
 166 [P: oh yeah, yeah] Asperger's is something about behaviour?

167 P: Yeah, yeah ... Yeah, and because he is very polite he's
 168 very um, he's above his age really for, you know if he met
 169 you he's shake your hand and say 'How d'you do?' which is
 170 quite unusually (laughs) for a 13 year old. You know, they
 171 normally just mumble don't they? Umm, but that's you know
 172 it's like he's learnt how to be polite and that's what he'll do for
 173 everybody. So yeah, he does well at school. He's very
 174 intelligent ... but, err, I think more the social aspect and like
 175 in the playground and in free time. Which, I think perhaps the
 176 teachers don't really pick up on. That's the time when he has,
 177 you know, difficulties understanding ... I mean he used to go
 178 down to the park after school with everybody but ... he just
 179 said "I don't understand the point of it all, all they do is hang
 180 around chatting, they don't do anything, it's all just boring".

181 R: Yeah

⑫ 182 P: (laughs) ... I'm quite glad he, you know, I quite like his
 183 Asperger's 'cause it makes him, I don't know. I never worry
 184 where he is or if he's on the streets smoking or stealing like
 185 half the kids in his year are and you know [R: mmm]. (laughs)
 186 Billy's just on his computer in his room.

mother sees benefits in Δ

Does parents perception / acceptance of Δ impact on sharing?

187 R: Yeah, so there are lots of positives for you then?

⑧ 188 P: Mmm, an I've been on loads of talks with people with
 189 autism that, that are able to talk about it and you know, they
 190 say "Don't, don't worry that they're on their own" you know,
 191 "They're happy, it's, it's us that's got the problem more"...
 192 And I think that's true. I think, I don't know ... He does spend
 193 a lot of time in his room, but, I think there's a lot because

mother well informed about Δ

194 Adam's only just recently gone as well and so he's adjusting
 195 to life without him being around and ... I think if he's happy
 196 and as long as he's ... learning, you know rules and a you,
 197 and how, you know little tasks. We do little tasks together,
 198 but you, it's like he can't, he can't make a cup of coffee, no
 199 he's 13 and yet the teachers wouldn't believe that [R: yeah].
 200 But I've, you know. We've gone through the stages step-by-
 201 step several times and every time I say right, make me a cup
 202 of coffee. He'll just look at the kettle and he won't know which
 203 comes first. You know, does he get a mug out, does he pour
 204 the water in the kettle, does he get the spoon out, he just ...
 205 he can't do it. [R: mmm, so ...]

(58) 206 P: So in a lot of ways, he, he struggles and I think that's
 (25) 207 gonna come more apparent 1. now he's getting older, but
 208 then ... I always think that ... if for example if he gets a
 209 girlfriend or if he's got some reason to do something he'll do
 210 it. If it's a good enough reason for him [R: Mhmm]. You
 211 know [R: yeah]. Bet if his girlfriend wants a cup of coffee
 212 (laughs) he'll learn how to make it (laughs)

213 R: So it's about having that reason then?

214 P: Yeah, it's a reason for them isn't it?

215 R: So it's almost like he's got his own sort of developmental
 216 pathway and he'll learn things and he'll pick up skills? [P:
 217 yeah] And I guess what those might be and might not be will
 218 kind of become clearer in time?

(16) 219 P: Yeah, yeah. I mean the thought of him ever going to live
 220 on his own I can't imagine that. Because he is, he is very
 221 much a daydreamer, you know. He's not there half the time
 222 bless him (laughs). But err, I think he'll get there. Just like
 223 they all say "they'll get there, just takes them longer" and if
 224 you, I think if you try and put too much pressure on when
 225 they're not able to do it, then it's gonna cause problems. [R:
 226 mmhmm, yes] Mmmm.

227 R: It sounds like it's almost being patient in a way and
 228 waiting for them.

229 P: Yeah, definitely.

230 R: Yeah.

*believes
difficulties
will become
more visible.
How will this
relate to child's
view of Δ?
and themselves?*

*indicates assumption
about future*

*Shares this
with child?
or unshared?*

*→ could this imply that sharing too much
would ↑ pressure + be problematic for
mother + son?*

231 P: Definitely, and I think if, if we've got, 'cause I, I want to
 232 keep our relationship good and I think if I put too much
 233 pressure on him, then you kn, it'll affect our relationship and
 234 I, you know I don't want that to happen 'cause he ... I think
 235 he does know that I understand. You know how he feels
 236 sometimes [R: mmm] As much as I can and I think there's a
 237 lot of people that ... don't understand. And like, his Dad will
 238 sort of, reacts in a totally different way to me. And I can see
 239 Billy struggles with that, but he accepts it 'cause that's the
 240 way his Dad is [R: mmm] But, I think he needs one person in
 241 his life to, that he can just open up to and ... you know be
 242 accepted for that.

*Broadly,
but also
underlying
concerns re.
Sharing Δ?*

243 R: And, and when you, um shared the um Asperger's ... did
 244 you talk about Asperger's when ...?

245 P: A little bit, but he was so young then, I mean he was only
 246 4 [R: okay]. So I just said yeah, I think you've got a little bit
 247 and I think I've got a little bit as well and you know, it's just,
 248 it's just about being a bit different. It's nothing, you know, I
 249 didn't say too much ... and he didn't ask too much at the
 250 time. It was really just a passing question; it's like "do you
 251 think I've got a bit?" [R: mmm] ... I don't know whether he
 252 thought about it at all to ask that or ... whether it was just
 253 because he'd seen so much of Adam, but he doesn't like, he
 254 always had a problem ... that Asperger's is autism, you know
 255 'cause his brother's severely autistic he, he doesn't like
 256 people to say you're autistic because that just makes him
 257 think about Adam. And when he was younger we did try
 258 putting a few symbols up. Like for him to get dressed in the
 259 morning, he could never ... do it in the right order. It, you
 260 know his vest and his shirt and he, didn't. So we, we made a
 261 chart and he was really into cars at the time and we had
 262 these little cars that he drove along the track when he'd done
 263 his vest and his top and everything. But, he just, he did it for
 264 a couple of days and then he just, he just didn't want it at all
 265 and I, I, and I sort of think it, he was relating it too much to
 266 Adam, That Adam needed a lot of support in that and .. [R:
 267 mmm] I think with him he'll just need sort of like written lists,
 268 you know, just the main points of certain things, so yeah.

normalises Δ
*mother dampens
the affect of what
she has to say
lots of cushioning*
*perceived as
fleeting query
= no big deal?*
*Also some avoidance?
mother wasn't
expecting question
child motivation
unclear*

*AS as a distinct
identity*

*persisting
possible Δ?
mother believes
that relating
Δ to Adam
caused
resistance*

269 R: So it sounds like for him then, Asperger's is err, kind of,
 270 it's something that's separate [P: yeah] to autism and ... [P:
 271 definitely, yeah]. So within your conversations do you just
 272 talk about Asperger's, or do you ...

- 273 P: I have explained that it's all on one sort of line and then
 274 he's at one end and Adam's at the other and [R: mmm].
 275 Umm ... but yeah, we don't sort of go into the autism side of
 276 things too much. *exp. AS is on spectrum*
mother recognised 'autism' wasn't okay for child
packages' response to knowledge of son + his preferences
- 277 R: Okay... [P: hmmm] And, did you, like, how did you go,
 278 well it sounds like he was obviously very young and small [P:
 279 mmm]. And it was not something that was planned [P:
 280 mmm]. So in that sense I'm guessing that you never, you
 281 know, you didn't make a decision to tell? Um, which means
 282 you wouldn't have planned what you were going to say, but,
 283 [P: nooo] But, as times gone on have you, um, have you
 284 used any resources or have you, like how have you
 285 approached sharing more information about Asperger's?
unplanned affirm
no resources used
- 286 P: I haven't really, and I did, I know when he asked me,
 287 because I can remember we were sitting, we were in the car
 288 and Adam was in the and they were both in the back and
 289 Adam was a bit, we'd had a difficult day and, and that's when
 290 he asked me and, and I know before that I had been thinking
 291 about "Do I say anything to him yet or not?" Umm.
lots of detail suggests sig. event
had been contemplating when to tell = always going to?
difficult deciding on the right time.
timing important
- 292 R: And, and what was prompting that? What, what do you
 293 think was important in that? *mother well-informed about Δ*
- 294 P: I just, I really feel that ... I, I think because that I've
 295 researched it so much over the years. Ever since Adam was
 296 diagnosed and I always, when you talk, when you read about
 297 people with Asperger's it's always, most of the time it's, it's
 298 like they wished they'd known earlier or, it was a good thing
 299 that they were told. Umm ... and I do think a bit of that myself
 300 because, I, I wouldn't say I've got a diagnosis of Asperger's
 301 but you know when I look back to when I was at school and
 302 then when I was, I err, I trained to be a nurse and I ... I was
 303 very much like Billy in that when I'd done my shift at work, I
 304 just needed to be on my own. I didn't want to go round and
 305 see a mate or anything. I just needed that time on my own
 306 and And I, I can remember thinking that I was a bit weird
 307 and I didn't want Billy to think like that. I wanted him to have
 308 a reason why he was, like that [R: mmm]. So I think, I based
 309 it a bit on myself as well and, and just reading about other
 310 people and people that have been diagnosed in their 40s
 311 that, you know, spent all their lives thinking there's something
 312 not quite right but I don't know what it is. [R: mmm] I suppose
 313 I didn't want him to feel like that and, I have asked him if he's
motivation to tell? does this knowledge mediate decision?
positive perception of sharing not if but when
protecting child from developing -ve view of self? informed by personal reflection
sharing has explanatory power?
wanted to protect child

- 314 got, if he's looked anything up on Asperger's on the internet
 315 and he said "No, why would I do that?" So it's obviously, it's
 316 not really an issue to him at the moment. [R: Mmm] But, it will
 317 be interesting to see whether that becomes more of an issue
 318 [R: mmhmm]. You know, as he goes through his teenage
 319 years [R: yeah]. But yeah, I just think that, I just think that you
 320 have to be open and ... yeah
- 321 R: And have you shared, 'cause you said obviously about
 322 identifying similarities between yourself, [P: yeah] between
 323 both of you [P: yeah]. And, have you shared those when
 324 you've been talking about Asperger's?
- 325 P: Yeah, I've said I think I've got a little bit, but he says "Ooh,
 326 you think everybody's got autism", he said "you diagnose
 327 everyone, everyone you see you think, ooh, they're a bit on
 328 the spectrum" (P and R laugh). (So I am a bit obsessed)
 329 (laughs), I do, I always like assess people when I talk to them
 330 and think "hmm, there's another one" (laughs)
- 331 R: So, it sounds like, I suppose, even just on a day-to-day
 332 basis you're very open about Asperger's [P: yeah]. And
 333 actually there's some humour there and there's some [P:
 334 yeah, yeah, definitely]. Yeah
- 335 P: Yeah, and I, I've always worked around, I mean, Adam's
 336 gone now and I'm looking to do befriending with autistic
 337 people and, and Billy said to me "well, why, why would you
 338 want to do that? You've had Adam for 15 years, you've been
 339 through hell Mum and now you want to do it again" ... So
 340 yeah, but that's, that's what I know and that's, you know, I
 341 need to put my, my experiences to use you know. So, it's, it
 342 was all just very much in his face with Adam, you know, there
 343 were social workers and [R: mmm] ... And just constantly,
 344 and I was doing the course and it was just autism, autism,
 345 autism, so ... he couldn't really get away from it really. [R:
 346 mmm] Bless him, but now, you know, he's, he's a lot happier
 347 now Adam's gone and I think he's got time to ... sort of learn
 348 about himself a bit more now. [R: mmm] He did go through a
 349 difficult, I mean he used to have to hide in his room, you
 350 know, when Adam's kicking off and, so yeah, I think
 351 compared to what he lived, how his life was, you know, a few
 352 years ago; to now, he's able to get to know himself a bit more
 353 now [R: mmm] and his, his Asperger's.

Not an issue or
not wanting to
know more?

Process
acceptance not
stable
transitions?

mother tells - hedging → encourages
self-exploration

self-disclosure normalises
+ offers protection?
or related to
mother's discomfort

1- Normalising
2- child spots
strategy
3- Mum
confessed

→ normalising to self also?

child happier
for knowing
about self
+ AS
self-concept
that includes
AS?
learning this
seems important

354 R: Yeah, so all part of that, knowing himself then is, I guess
355 integrating that Asperger's ...

356 P: Mmm, yeah, definitely *- I affirm integration important*

357 R: Okay, umm ... Did you seek any support? When, it
358 sounds like you, read, or you, you were quite knowledgeable
359 anyway about autism and about the spectrum, from, from
360 Adam?

361 P: From Adam, yeah *mother knowledgeable about Autism*

362 R: Did you, did you seek any support about sharing the
363 diagnosis, or, talk to ... I suppose when I say support that
364 could be services, or that could be other parents or friends,
365 or ...

366 P: Yeah, I used to go to a parents group, um, when Adam
367 was first diagnosed and there was a lot, there was quite a lot
368 of input with Adam because he was so young and so severe
369 and ... [R: yeah] and you know, there was lots of access to
370 different groups and play therapies and all that but, because
371 Billy was so different, [R: mmm] I had trouble ... convincing
372 people that he was, and I got a really bad reaction from his
373 nursery; and, you know, people used to say to me, "just
374 because you've got one child with autism doesn't mean
375 you're gonna have another one" ...and, it was, it, he,
376 because Billy was so different, he didn't do the same things
377 as Adam, but there was still, there, rang alarm bells with me.
378 [R: yeah] To be honest I felt all, err professionals, no, I learnt
379 very early on to do it on my own, 'cause they don't
380 understand (laughs). *lacks faith in professionals?*

381 R: And what sort of professionals do you mean?

382 P: Social workers. [R: okay] (laughs) Umm, I mean when
383 Adam was diagnosed they, they gave, it was just, "yeah, we
384 think he's..." No actually, I brought it up. I said I'm paranoid
385 he's autistic and thinking they'd say no and they said "no, I
386 think you, I think you're right". Um, but there was no, support
387 in you know, this is what you need to do or you can speak to
388 somebody about how to approach it with them. There was
389 nothing, absolutely nothing. *Absence of professional advice / support*

390 R: Would that have been helpful do you think, on reflection?

/ - conditional

391 P: ... Yeah, but it would have had to have been right,
 392 because I think so many professionals think that they know
 393 autism and don't (laughs). Or they don't know your child. Um

knowing/
 understanding Δ
 + child
 important in
 sharing

394 R: So there's something about if support was offered, it
 395 would have to come from people who not only understood
 396 autism and Asperger's quite well, [P: mmm] but somebody
 397 who knew your child [P: yeah] and your family?

398 P: Definitely, because ... you see, social, I mean I have had
 399 social workers since, you know Adam was diagnosed and
 400 they're just social workers for the disabled children's team.
 401 They're not, you know, they see all different disability.
 402 They've got no understanding of autism, they really haven't,
 403 they've no idea what it's like to live with it day-in-day-out. [R:
 404 mmm] Um, and it's all very much, I think nowadays with
 405 social services it's very much, looking to make sure the
 406 children are safe and ... missing out really, what struggles
 407 you're having. [R: mmm] Just, you know it's all about, you
 408 know about doing their job and their paperwork and ... you
 409 know, covering themselves. [R: mmm] But not actually, you
 410 know what you're dealing with day-in-day-out [R: mmm] So
 411 yeah ... and I think having one person ... from the start as
 412 well. Not chopping and changing different people every five
 413 minutes. Yeah

experiential
 knowledge
 important

414 R: So is that just in terms of social care?

415 P: Um ... well see, we moved, we were in [names location]
 416 when Adam was diagnosed then we moved down here, so
 417 we had a whole new load of professionals and ... um ... I
 418 think, I think, really, it should be ... a, like a multidisciplinary
 419 approach, but there should be a lead person that the, is the
 420 one that comes to see you and ... you know, takes all the
 421 information from their team, but that follows through with you,
 422 because you can't, you know. You tell the whole story to one
 423 person and then the next time it's somebody else working for
 424 them coming in. [R: mmm] And then they say, ooh, sorry
 425 you'll have to go through it all again and just ... and there's
 426 far too much talking about it and not enough, um, you know
 427 "what are we going to do then?" [R: mmm] "What can we do
 428 to help you?" It's all just lets write notes and talk about it.

About
 broad level
 support,
 not relating
 it to
 sharing

429 R: So more practical, you feel like more practical support?

430 P: Yeah.

431 R: Is that true for Billy as well?

432 P: Yeah, yeah. There's just far too much talking. But I think,
433 really, I think parents just, I've always said that parents need
434 to know their rights, they need to know their child inside out,
435 and they need to be fighters, because ... it's, there's not
436 enough knowledge of it, at the moment so parents, they do.
437 And they need to be able to speak out and I think that's the
438 trouble, a lot of the time that, parents can't. They haven't got
439 that knowledge or you know, that confidence to do it and they
440 don't get what they should, you know, what they should
441 have.

Accessing
support
generally

442 R: So there's something then about, knowing about autism,
443 the diagnosis, and your child and be, and almost having all of
444 that knowledge is important not only in sharing it with your
445 child, but also when communicating with professionals [P:
446 mmm] and trying to put thing in place [P: yeah] and access to
447 services or supports for your child as well.

448 P: Yeah, yeah, 'cause you have these big meetings, you
449 know someone from school, someone from social services,
450 someone from somewhere else and the educational
451 psychologist that you might see once every five years, you
452 know (laughs). And they all come together, and they all talk,
453 and you come out of the meeting and you think, "yeah,
454 what's actually gonna come out of that meeting?" [R: mmm]
455 And normally it's nothing (laughs).

456 R: Okay ... So, sharing, the, I guess the label of Asperger's
457 with Billy was something which you did independently then?
458 [P: yeah] Okay.

31 459 P: But there was no advice, or no ... suggestion of it from
460 any professional and I think probably back then they would
33 461 have said "No, he's too young". That, I think he's, because
39 462 he's very intelligent, you know, I felt that I knew him well
40 463 enough to know that he would be okay with that. [R: yeah]
464 And I think, I'm glad that, you know I haven't waited to tell
61 465 him now 'cause I sort of think ... all these things that he's
47 466 brought up with me, how would he have dealt with them if he
467 didn't know? [R: yeah] Yeah, [R: so] I don't regret it, I think it
51 468 was the right decision.

no advice/
support

Age mediates

parent - prof.
views may
have conflicted

individual
assessment
important
- could labilify /
coping

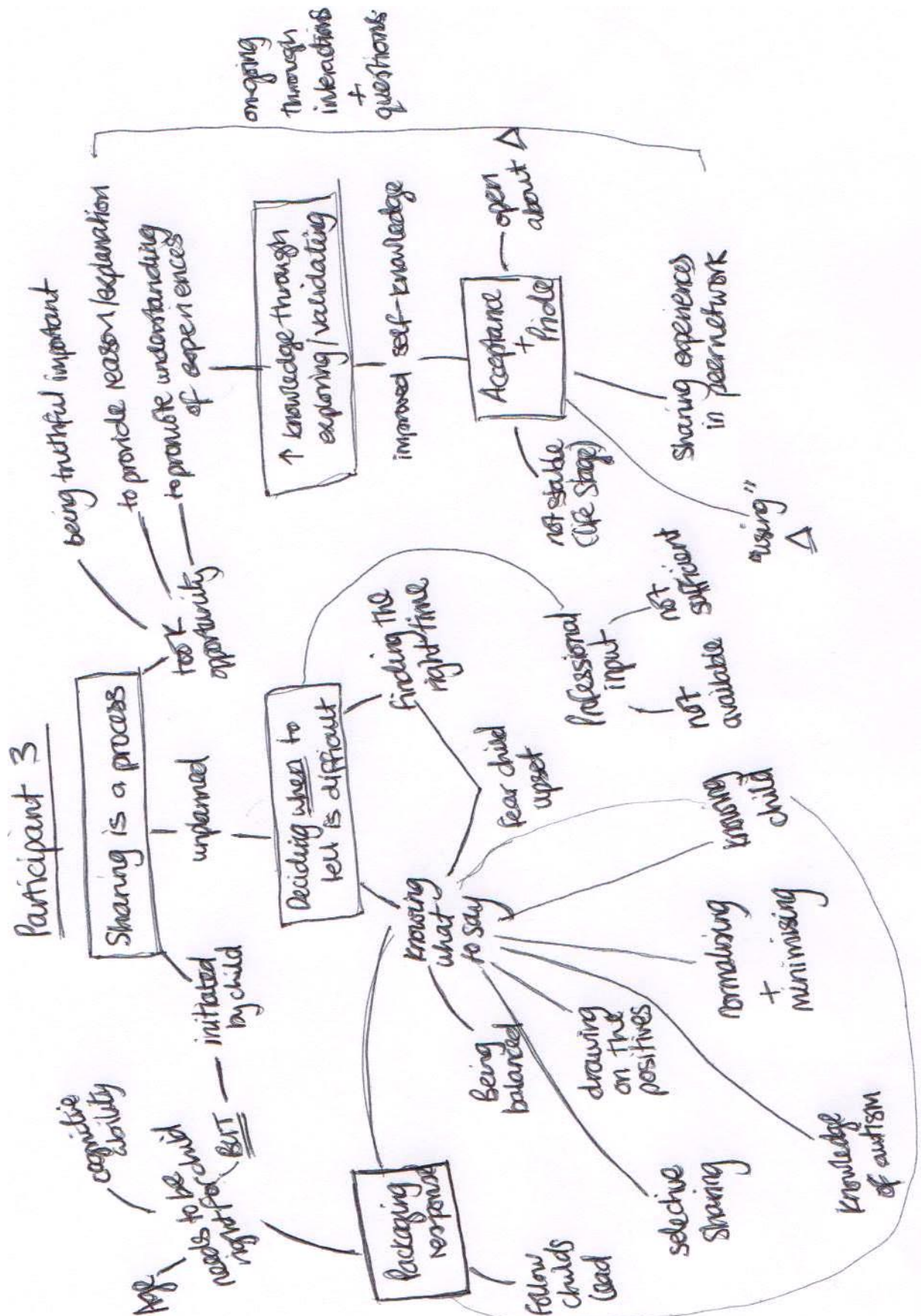
→ mother made
judgement
about whether
to / how to respond
to question based
on knowledge of
child

no knowledge of A could have
meant child would have been confused.

469 R: So going through, I suppose as he's growing up when
470 there have been, err, when he's had experiences that he's

→ may have tried to make sense of experiences
without support + help = crucial to have discussion.

Appendix O: Mind-map for worked transcript



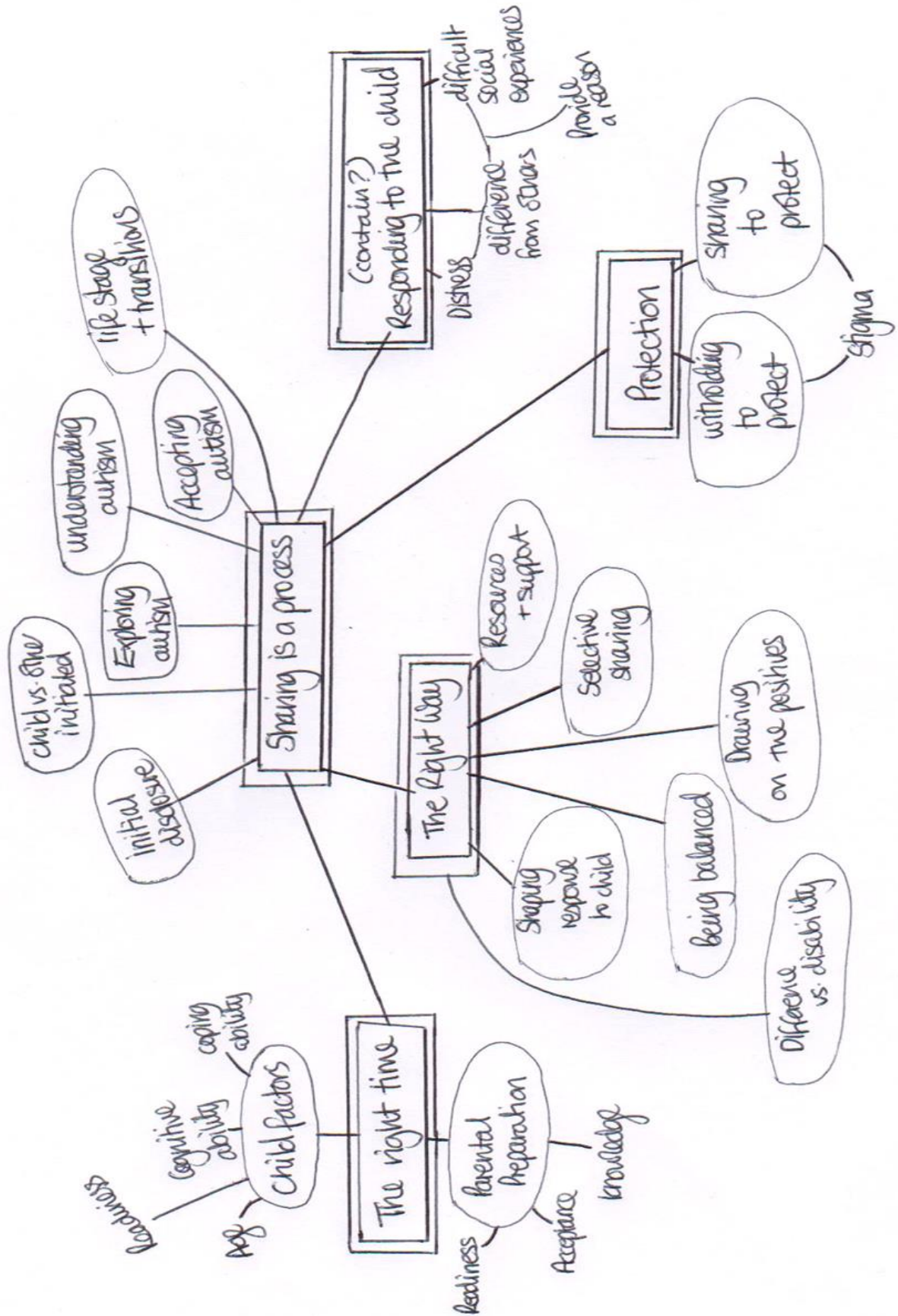
Appendix P: Coding frame grouped according to theme and sub-theme

Theme: Sharing is a process		
1. Sharing is a process 30. Sharing is emotional 51. Parents happy to have shared 79. Sharing in the context of uncertainty		
Naming autism	Exploring & meaning-making	Acceptance & integration
17. Initiated by child 18. Open diagnosis 26. Shared sense of relief 34. Child better for knowing 36. Unplanned event 37. Taken out of parents' hands (public 'outing') 31. No support/advice 49. Uncertain if child understands 52. Child upset / angry (rejects autism) 53. Parents upset 60. Word out there makes sharing easier 63. Sharing opens up conversations 72. Sharing initiated externally [parental permission / control] 79. Sharing in the context of uncertainty 84. Liberating 87. Not difficult (reflection)	19. Using every day experiences to promote understanding 20. Child asks questions to construct meaning / validate understanding 21. Sharing in the here-and-now 29. Difficult to explain 49. Uncertain if child understands 52. Child upset / angry (rejects autism) 59. Autism becomes part of everyday life 53. Parents upset 75. Seeking knowledge independently (child) 79. Sharing in the context of uncertainty	20. Child asks questions to construct meaning / validate understanding 24. Autism as a self-identity 35. Making sense of diagnosis / developing acceptance in peer network 44. Using diagnosis as an excuse (testing boundaries?) 48. Child shares with others 57. Self-acceptance – acceptance by others 58. Acceptance as process and outcome-impacts on life 74. Knowing promotes self-acceptance 77. Knowing/meeting others with autism helpful 91. Accepts diagnosis (child)

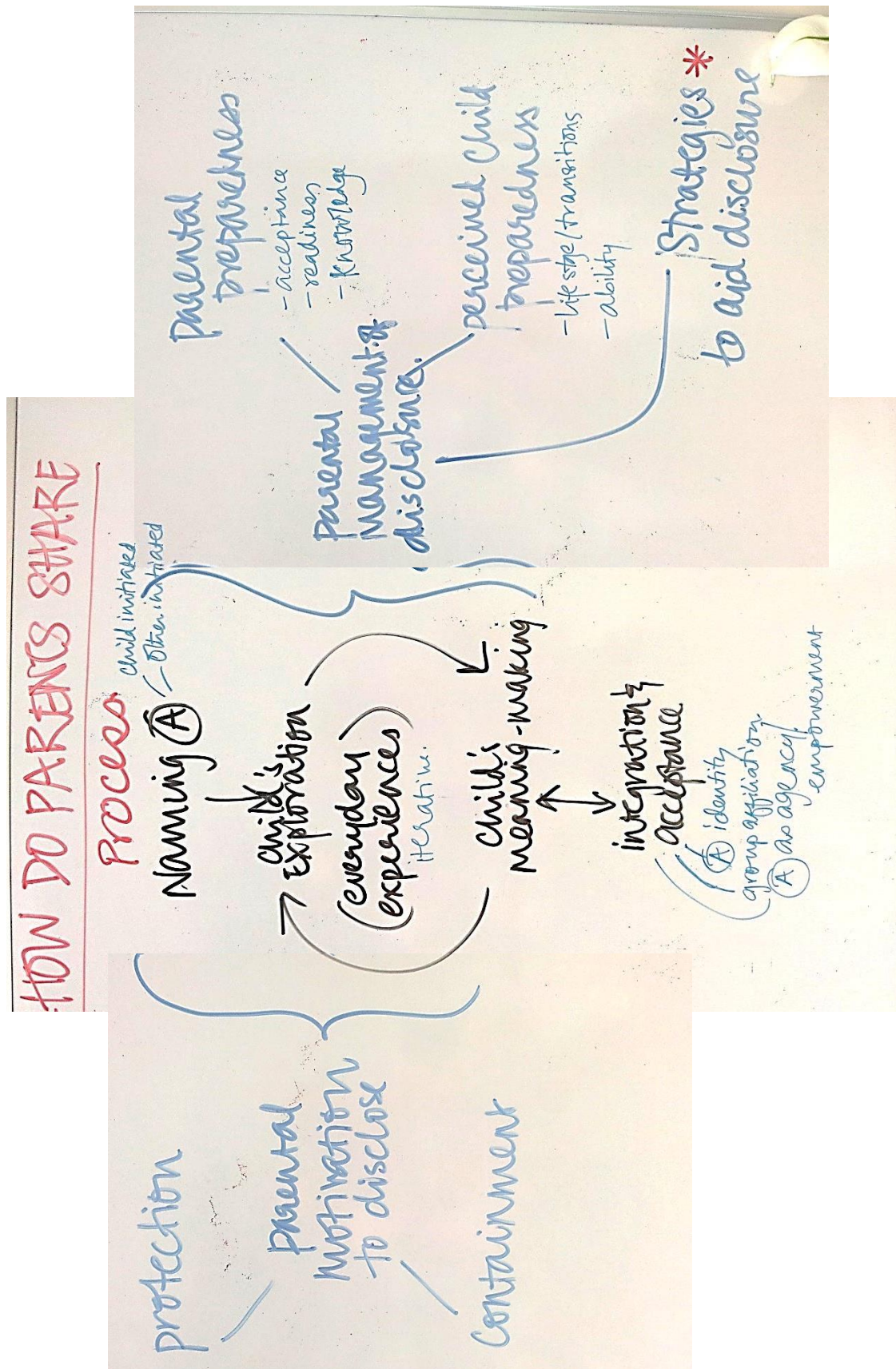
Theme: Parental motivation to share	
2. Responding to child's distress 3. Responding to child's recognition of difference 17. Initiated by child 46. Helpful for child (hope) 61. Child needs to know to cope through life 73. Child needed to know 78. Withholding perpetuates child's suffering	
Protection	Providing an explanation
32. Perceived stigma / protecting from responses of others 33. Sharing is protecting 41. Withholding to protect child and self 43. Fears of negative consequences (rejection/upset/limiting) 45. Concerns about labelling 50. Withholding suggests something to be ashamed of 54. Negative social consequences – the odd one out/ isolation/exclusion 55. Negative social consequences – parents 56. Family secret – shame/acceptance 62. Social negotiation of sharing 78. Withholding perpetuates child's suffering 81. Avoidance/protection 82. A big weight to carry	4. Sharing to explain difficult social experiences 6. Providing a reason 28. Hope sharing helps child understand experiences 47. Provide an understanding of problems 83. Promotes understanding in family

Theme: Parental management of sharing		
7. The right time vs. no right time 16. Sharing just enough / gate-keeping 27. Not if but when and how to tell 66. Fear of doing it wrong (can be repaired) 67. Asked clinician when – no answer 68. Testing the water 71. No right or wrong way		
Parental preparedness	Perceived child preparedness	Approach & strategies
8. Parents need to know/understand autism 9. Parents need to know how autism affects child 10. Parents need to know their child 12. Parents acceptance of diagnosis 14. Parents need to be ready 56. Family secret – shame/acceptance 70. Autism and the future 88. Reflecting on experiences of self / others	13. Child needs to be ready 25. Life stage and transitions 38. Mediated by age of child 39. Mediated by child's ability to understand 40. Mediated by child's ability to cope 70. Autism and the future 82. A big weight to carry	5. Shaping responses to the child 11. Drawing on the positives/child's strengths 15. Taking child's lead / pacing 21. Sharing in the here-and-now 22. Normalising autism / not the only one 23. Difference vs. disability 42. Professional input – conditional 31 No support/advice 64. Being balanced 65. Minimising 69. No cure, but ways to help 70. Autism and the future 76. Individual to the child 90. Resources

Appendix Q: Provisional thematic map

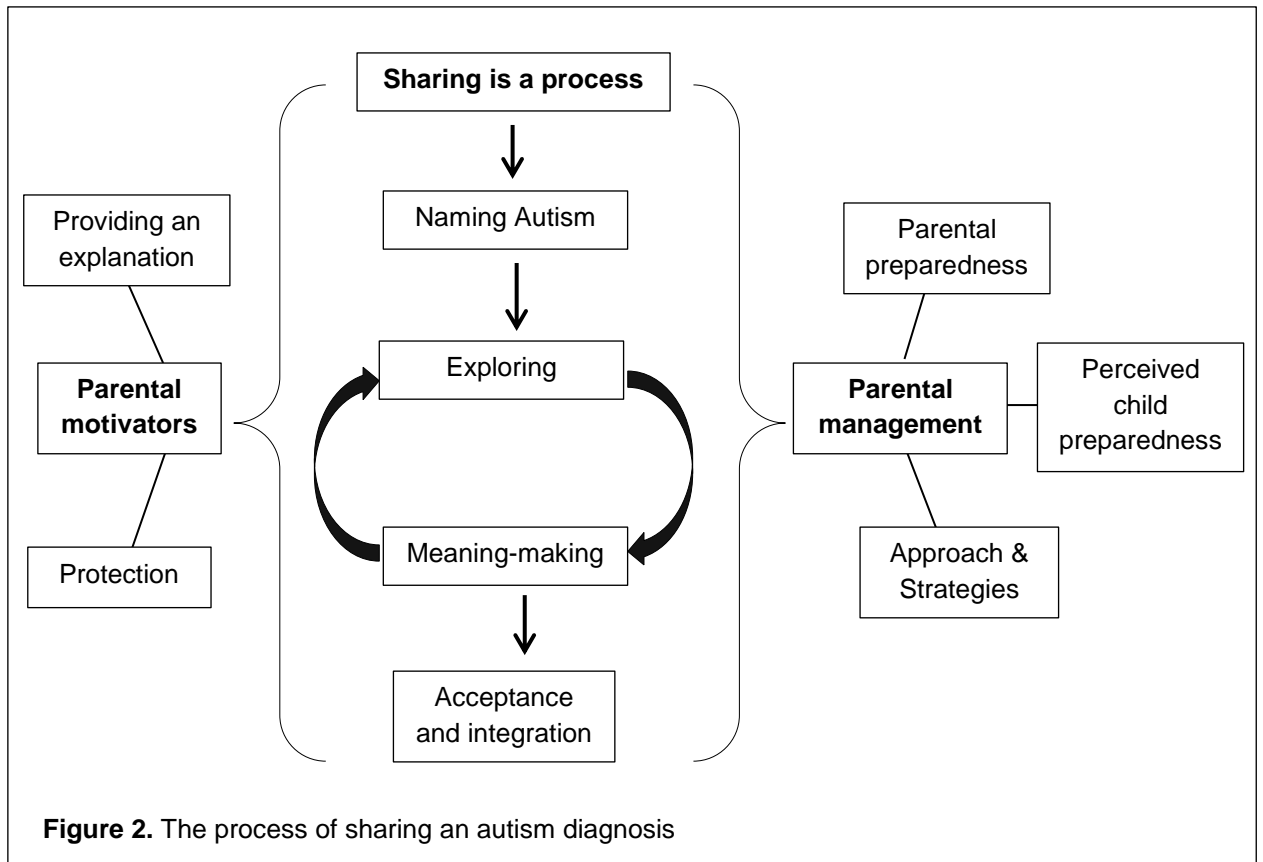


Appendix R: Working diagram of final thematic map



Photographs of thematic map developed in supervision when reviewing themes

Appendix S: Final thematic map



Appendix T: Data extracts for parent information leaflet

Participant	Data extract
	Preparation
1 856-62	And ... because autism is so different, [R: mmhmm] <i>by child</i> , I don't think you can pick up a book and it'll tell you how to do it. Because I don't think there's a right or a wrong way of doing it to be honest, [R: mmhmm] I think, I think you have to ... you know, know what autism is and what it's about. You've got to know how it affects your child, and know how your child responds to, <i>whatever</i> , in your; sort of when you're trying to pitch it, if you like, to ... at what level,
1 846-51	I mean, we'd done, obviously quite a lot of ... <i>research</i> into autism and things [R: mmhmm] and things and trying it understand it our, so we could understand it, so we could do the right thing as, as <i>parents</i> [R: mm hmm] and I think we try and you know, we use that as, what <i>we</i> know and then, try and put it in a way that James would <i>understand</i>
1 1032	but I think it's about confidence, knowing, kn, understanding autism and trying to apply that to your child [R: yeah] and trying to understand your child to help you explain it [R: mm hmm] that's really important
5 394-400	And so when he was diagnosed, I was given a sheet with websites and book titles and things like that on, which I did use and I found them useful. And I could take bits out at a time that I wanted to find out, and not bombard myself with all the information at once. You know, so I could relax and associate certain things, pull certain things out, when I was ready to really, and research that way. So I wasn't prepared, I knew a little bit.
6 1120-22	And that's how I approached the children. So it wasn't rushed, it was ... you know, you try and think things through, write down examples of those, how am I going to do it?
1 846-48	I mean, we'd done, obviously quite a lot of ... <i>research</i> into autism and things [...] and trying it understand it our, so we could understand it, so we could do the right thing as, as <i>parents</i> . And I think we try and you know, we use that as, what <i>we</i> know and then, try and put it in a way that James would <i>understand</i> .
2 1052-54	I think you've got, you've got to sort of have that knowledge and understanding yourself before you can begin to sort of try and pass it on.
4 978-81	Oh, oh I would definitely say, if I, if I was to do it again I would share the diagnosis, if I felt my child was ready and, and, you know, if I am ready. I think it really just sort of depends. I think sometimes after diagnosis, parents need a bit of time just to get their head round it.

5 394-410	And I could take bits out at a time that I wanted to find out, and not bombard myself with all the information at once. You know, so I could relax and associate certain things, pull certain things out, when I was ready to really, and research that way. So I wasn't prepared, I knew a little bit [...]But, you know, as he got older and looking at his behaviours, and also television programmes, that's helped, yeah.
7 185-88	Yeah, I quickly got my act together, I thought, I don't want this to be negative forever, we'll turn this around. And got books, got the research and never gave in to his negativity. Always pushed through the positives ... for him.
7 227-29	Yes, yes, I think so. We just went through, looked on the internet for clues, positive role models. Looked for books about autism. Went through it that way.
9 280-84	Um, well I was still learning myself because, you know, there was a lot of differences out there. And, you know, I started going on these courses that the NAS run and, you know, to find out more. Erm, so, I wanted to make sure that I had the information if he did need to know anything.
9 488-95	Yes, yes I think it depends on their ability to understand. But if it's Asperger's, where they do have more of an understanding, I think having lots of information that is <i>child friendly</i> . It's alright having lots of information but if children aren't into reading lots and lots, its pictures as well, err, social stories. A lot of people have found social stories help ... I think you've got to understand it yourself as well because I think, and accept it. Because if you don't accept that your child's got it yourself, then you're going to cause more grief for your child.
10 1370-75	Yes, it's more, yes absolutely. With regards this, I didn't need, me personally, and if she'd said to me, do you want me to tell Craig, I'd have said no, I will tell him. And so no, it was absolutely fine that. Um, and I think you know your own child and I think you've just got to go with that yourself really.
	Approach to sharing (i) Drawing on positives / child's strengths
1 165-71	Well you've got to, 'cause you've got to turn it around, in a, in a way, anything where James' is concerned, especially with his anxiety and his worries. Is trying to look for a positive ... because if you can focus on a positive it stops his anxiety and his worries, doesn't it? And it's really hard with the autism ones, and it's really hard with a lot of them to turn them into a positive. Erm, but that's what we try to do in this case, and it makes him who he is.
3 459-60	Yeah, I've always said you know, yeah it's cool to be different and um, you know, he's grown up with that
3 637-49	Yeah, I think people think it's you know, I don't think it has to be a negative thing really. I don't think it's, it's not like a disease is it? It's just a different way of thinking. And I always, you know, I, Wendy Lawson, you know, you know

	<p>her? (R: yeah, yeah) She calls it diff -ability, differently abled. You know, you sort of, as soon as you start saying disability, it's like something wrong and ... it's only wrong if, you know, you're told it's wrong. But, it, it's not wrong is it? It's, you know, why, why are they wrong and we're right? I ... and when, and a lot of it when you think of how we are, how we talk and how we, don't finish our sentences, and presume things and don't say what we mean, you think 'God, no wonder they're confused and think we're the weird ones' (Researcher and participant laugh) So no, you know I'm very positive about autism.</p> <p>R: Yeah, so have you avoided using words like disability and ...</p> <p>P: Yeah, definitely, yeah.</p>
3 786-800	<p>P: Um ... it's hard to think now. Um, but yeah well, a lot of the time I say to him well that's your Asperger's, that's good isn't it and ... I mean, he's intelligent, he's, he's his interests and his, he's not going to get into the wrong thing, because of his need for rules and, um. His ability at maths is, is um, his politeness. I don't know, it's hard really, but ... I'm trying to think of a situation when I've said it... I mean his ability to do, to work out computers and to fix computers and things like that is definitely from his Asperger's. And, if he's interested in something ... you know, he, he can put to such good use because if he's got the interest there he will ... learn everything about it. Which can be, yeah, like become an obsession and a problem but if it's, if it's dealt with the right way, then, it can be a really positive thing can't it?</p>
4 142-50	<p>Yes, or, or sort of afraid that people might write him off, you know, if he was, autistic, or at least that's what people thought. Whereas, actually, and also there's, what you said about, there actually are positives about being autistic, it's just <i>different</i>, rather than, you know. Um, and it's fascinating and it's been really, really funny sometimes, you know, the, the way Aidan, you know, he's had some of the classic family, lines that have gone down in, you know, the family history. And, and it's because he's autistic partly that, you know, it, some of the things he's said are so funny and also so <i>perceptive</i>, you know, and he's a real character.</p>
5 802-5	<p>Yeah, exactly. Yeah sometimes you've got to let them know, sometimes it's good to be different. You don't want to all be the same, that's what makes us up. It's not a bad thing to be different, you know, it's, it's quite a good thing sometimes.</p>
5 822-29	<p>And then I point out as well, positives, I think there's a list of famous people that often gets drawn up at meetings and social events, and, you know, what they do. And if it wasn't for people with Asperger's and things, there would probably be no such thing as space rockets. And, you know, or this, that and the other, because they like things like that. They look at things differently, they solve things differently, that is a massive positive, you know. So then that</p>

	in himself he's thinking, oh yes, you know, yes these are different and they have got that and it's only them that's done it. You know, somebody without Asperger's or whatever, so again another positive for him really.
5 762-67	Like I say, his maths, his ability really, another thing is is, he will push his self and push his self with his football and things. You can see he's in pain; he's limping when he's running. But because his passion is that thing, he pushes his self much more than anybody else possibly would, you know, to accomplish what he wants.
6 142-49	And I was able to talk about, you get your normal kind of Einstein or Bill Gates, which are extreme examples of people that have done very well. Most of us are fairly average but, you know, it's, you recognise your strengths and you use those, but you may not have as many options as other people. You know, when it comes to careers, for example, you can't do something, which is highly, which requires a lot of social ability.
4 365-68	So, you know, we did also sort of like try and stress the positives of autism, as well as, you know. If we tell him things like that, you know, that he was really good as a baby at doing this, he, he loves that kind of story, you know, so.
	Approach to sharing (ii) Packaging the response
2 183 - 89	You have to take things at his own pace. And ... you know let the moment, because he's got the learning difficulties as well ... I think ... at the moment ... although he hasn't got a very great understanding, just the <i>awareness</i> that <i>this</i> is what makes him different and things, I think that is such a really sufficient for him isn't it and then as and when he wants to know more then we'll have to start ... trying to find more answers; but I don't know what that will be.
1 & 2 298 -304	But with Ja, with James we don't <i>push</i> the issue, sort of well 'do you want to talk about it?' 'Would you like to talk about it?' ... and if he doesn't, that's, that's the end. (P2: mmm) There's no point in forcing it upon him. Aand ... he does sometimes go away and sort of think about it, doesn't he? (P2: mmm) And he'll perhaps come back ... you know, an hour or so, a day or so, a <i>week</i> or so later and will ask, will then ask a couple of questions won't he? So ...
2 327 – 32 338-41	You do have to <i>really try</i> and get something that's going to be ... <i>at his level</i> . At the moment we're sort of, doing about sex education stuff and it's ... it's trying to find out what he actually <i>really</i> knows about something isn't it? And then pitching the rest of it ... at the level he's at. And you do have to think about it quite hard don't you and ... and you have to sort of <i>drip it</i> as well, and, and keep re-visiting and re-visiting. And, then, ultimately ... hopefully he'll sort of <i>get it</i> , but you, we, you never expect him to sort of, take something in on the first, the first <i>go</i> particularly would we

1 632-43	It, yeah, you can't over-load him with information ... I mean that's just who James is, whether other children would, take more in, but with James it's just ... little and often really if he needs it isn't it (P2: mmm) or, just give him ... something to work with and, you, he'll go away and digest it and you might move on to the next bit. So, yeah, yes it's quite important, but I that is very much ... down to the individual. Down to the individual, down to the child and how much you feel that they would er, would take on I think. So we, we just gauge it for James really...
1 & 2 647 - 56	You know and that's one of James' things is processing the information. It's got to be ... you can't use big words, you can't use long sentences, it's got to be ... short and, snappy really hasn't it? (P2: mmm) just to try and get the point across and then see if he comes back with a question, or whether he seems to be, you know, is that alright, do, do you understand? But even when you've asked him that he'll sometimes just say "yes" and he might not have done. So it's quite hard to gauge, but he does sort of ... you can see when he's had enough can't you (P2: mmm) when you're trying to tell him something.
2 1340-45	No, I, er, I think, I think it was just a case of well, I did it. Because, we did it in parts I suppose. The actual 'well you have autism, that's what makes you like this' and that was it then. And then it was only then when we'd when, watching. You know, we sort of said well tomorrow we need to sit down and we need to watch this with him again (R: yeah) and ... say this is about autism.
2 1531-34	And, and don't, like, like with giving any information don't try and <i>over-load</i> them. Just ... just, give them a little bit and let them come back and do the asking and the wanting more information, and if they do, so it's a little bite size.
3 445-47	Yeah, it did, definitely, and I didn't say too much at the time, I just thought, well, I've, given him that bit and now it's if he wants to, you know, question it any more, he can.
3 734-40	No, you can't really. They have to be in that situation as well I think to be able to, discuss it with them. It's like Adam, you know, he, he, he's just in his moment. He doesn't know about yesterday or tomorrow. He's just, he's just there at that time and what's happening at that time, and I think there's a lot of that with Billy. Until, you know, until he finds he's saying the wrong thing to his girlfriend or, upsetting her, or not being sympathetic, or, you know. I think until these things arise, you can really discuss them with him.
6 657-67	Yes, it was quite a ... several hours discussion type thing. It was, but equally recognising, although I'd got things written down, you know, at any point in the conversation, if after five minutes that was it, you know, they weren't able to take it on, too emotionally upset, then it wasn't, well here's my agenda, we're going to get through it come what may, that wasn't the issue. But they were

	<p>very much, you know, it was a two way thing, they were very much participating in the conversation. So we, you know, we sort of continued, continued beyond what I'd got, you know, you sort of adlib a bit whilst you're thinking.</p>
6 692- 702	<p>So you make it ... age appropriate and also cognitively as well for what they would understand, and the way they think about things. It's not just their own ... you know, academic or cognitive ability, but it's the way they see things, what would be meaningful to them? So it's no good talking to them about, well this is going to affect you in relationships when you're older because ... you know, it's just totally inappropriate at that age. It would have been emotionally unfair as well, to talk about that, you know, how they're going to get on in an adult relationship. But it's very relevant to how that affected them with their peers at school.</p>
8 396-02	<p>Yes and we've got books on it and I left the books lying about.</p> <p>R: OK, so you did a ... kind of relaxed approach?</p> <p>P: So if, if, if he secretly wanted to pick up a book, which he very often, he does read a lot, he could have picked it up and had a read of it if he wanted to. He may have done and he may have done it when I've not been there say. But I left the paperwork and books and things lying about.</p>
8 408-10	<p>Not pushing it, no. It's there, I never said, you've got to read this or anything, I've just left it there, <i>knowing</i> Christopher and <i>knowing</i> what he would do with a book. He'd probably secretly read it.</p>
9 247-49	<p>Yeah, yeah, because he is an avid reader, he takes after me that way. He's always, er, if he's not on his games, which he normally is, err, he's got his head stuck in a book.</p>
9 404-6	<p>Yeah I think, because I did get a couple of books for him, because he wanted to absorb, he wanted to read about it and find out things and what, you know.</p>
10 26-34	<p>And then just that there's something called, Autism. And that that <i>means</i> that you find it difficult to do things like your learning and understanding, you get anxious and you get upset easily. And we'd pick out whichever problem we were discussing then, so if it was that he was scared of something, we'd say, you know, Autism can make you scared and that's fine and we can do things to help you. But that's why, so it's not your fault and it's just something that you have.</p>
10 11-19	<p>It would be things like, um, he has quite low self-esteem, so he would say, I'm rubbish, why can't I do that, you know, or he'd say, um, everybody else does this, why can't I? So that just, so often the conversation was never sat at a table, it was just often when he's in the bath or, you know, as we're putting him to bed or, or driving in the car. He likes a lot of conversations there because I can't look at him, the eye contact's not there, and I can't touch him because</p>

	I'm quite a tactile person.
10 42-46	I tried to let him lead it and if he asked more questions then, then I would, you know, try and answer them. But we, you can sort of tell when he's had enough because often he'll just flick on to his favourite subject, which is circus'.
10 67-76	We talk, and we're still taking through it now. But because of his learning disability, his language is very good but his understanding is very limited. So it's been, that's been difficult. So sometimes it might only be a couple of sentences, well because you have Autism, that makes you feel scared sometimes. And then try and give some reassurance at the end, but I'm here to help you, or, you know, your TA's going to help you with it or, you know, and so some ways around it, to try and make it a positive thing, not a negative thing.
10 1319-24	Verbal yeah and, yes that was it really, just little chats and as he gets older, I think I might use some books. But I don't think he's quite ready for it yet, I think we're just getting to a transition. But as we get a bit older I think, you know, we might get a few more because he does respond well with pictures and things like that.
	Approach to sharing (iii) Rooting in experience
4 334-41	Yeah, I think, Um ... I'm just trying to think. I mean I'm sure we didn't get all technical, like say, you know, you have impairments in the following areas, kind of thing (laughs). Err, I think we may have said, for example, um, if there was something that he found difficult, for example, if something was cancelled at the last minute. I'd say that, you know, you, you find that hard because you have autism, you know, and um, people with autism like the same thing to happen at the same time, you know, and, and things like that. So ...
10 391-97	Um, and well Daddy's got freckles and Mummy hasn't and [names sister] got straight hair and look, I've got curly hair. And, you know, this person's tall and this person's small. And so, you know, you've got Autism and I've got, and we've both got glasses, but [names daughter] and Dad don't have glasses. And we've just, but just very simple, you know, just a couple of things we pick out and, you know.
10 26-34	And then just that there's something called, Autism. And that that <i>means</i> that you find it difficult to do things like your learning and understanding, you get anxious and you get upset easily. And we'd pick out whichever problem we were discussing then, so if it was that he was scared of something, we'd say, you know, Autism can make you scared and that's fine and we can do things to help you. But that's why, so it's not your fault and it's just something that you have.
5 728-42	'[...] you have this thing called Asperger's and your brain works slightly

	<p>differently to other peoples. That's the way you like it and if it's not that way, then it upsets you. And that's all it is really, it's just this thing, it's just a name really, you know. So, like you say, drawing on what he knew himself, what frustrated himself and when he said things like, why do I feel like that, why doesn't this happen, why is that, you know, the questions. I can say, that's because ... that's because ...</p>
7 490-92	<p>Yeah, and I think maybe he just thought he was really naughty. When he was always acting out. Whereas now we can talk it through and say 'autism is making you worry too much'</p>
6 50-56	<p>Because it was both of them together, I deliberately put a list of things, you know, I explained roughly about Autism and what it was. And then I'd got on my list things, which would, both of them had maybe different difficulties, and made sure there was some for both of them on there [Researcher: okay], um when I was talking about Autism. And things, which I knew they would recognise was them.</p>
10 29-29	<p>And we'd pick out whichever problem we were discussing then, so if it was that he was scared of something, we'd say, you know, Autism can make you scared and that's fine and we can do things to help you. But that's why, so it's not your fault and it's just something that you have. And then we'd often discuss other things like I have glasses because I can't see very well, or so and so, they have a hearing aid or, you know. Um, we'd talk about people we knew, who he, he knew had got something different, and we'd just say, it just makes you special, it's who you are, but that's why it's hard</p>
	<p style="text-align: center;">Approach to sharing (iv) Resources</p>
1 & 2 42 – 57	<p>Yeah, I mean we had, we had actually ... previously ... um shown him a programme. The Cbee ... What was it, CBeebies? (P1: CBeebies programme) Umm, in November 2011 ... they did, I don't know if you ever saw it? [...] Umm, they did a programme called 'Autism and Me' wasn't it? (P1: And it ...) Umm, and it was, it was a child who been, they did a, BBC 2 did a series about autism. And she was one of the, children that was featured on it, and sh ... and she, she's got Asperger's hasn't she. But her brother is <i>profoundly</i> autistic. Um, and so she, she did this little 10 minute thing ... umm ... (P1: Trying to explain autism to children).</p>
242-244	<p>But I think the fact that we've got this programme recorded, did make it, a lot easier didn't it? Because it was, it was aimed for children. Um ...</p>
P1 & 2 647 - 656	<p>You know and that's one of James' things is processing the information. It's got to be ... you can't use big words, you can't use long sentences, it's got to be ... short and, snappy really hasn't it? (P2: mmm) just to try and get the point across and then see if he comes back with a question, or whether he</p>

	seems to be, you know, is that alright, do, do you understand? But even when you've asked him that he'll sometimes just say "yes" and he might not have done. So it's quite hard to gauge, but he does sort of ... you can see when he's had enough can't you (P2 : mmm) when you're trying to tell him something.
3 612-14	Yeah, yeah, we had a couple of books like that. I do, I think that helped. I think it helped him to understand that, that it's not about being naughty, and there's a reason behind it. So I think that helped him with that. But, I still don't think that he really pro, I think, doing that with him early was the right thing, but I don't think he really was able to process it or make, attach meaning to it. Until he was more mature.
5 284-93	Yeah, I think it helped quite a lot in that way and understanding that it's not just him that behaves that way. And also, he was given err a book, err, I can't remember which one it was now, which he read. R : There's a Luke Jackson one isn't there, the Freaks, Geeks and Asperger's? P : That's right, that's the one yes and he read that. So, was it written by a person with Asperger's? R : Yes. P : Yes and he read that
6 1041-48	And immediately er ... afterwards, what did I do next, would be I gave them a book each. Um, so one was, Asperger's, for Andrew, and one was high functioning Autism for Elizabeth. So, you know, they each had their books, where again, they could read the book, it would have some things there that would ring true with them. [Researcher : mmhmm] Something that they could maybe feel was theirs as well ... I speak too much, I've probably covered a lot of your proper questions.
6 1147-53	Yeah and sort of making sure they're comfortable at the time. It's things, you, you're giving them time to talk about ... specific things that maybe you, examples that they're bringing into it and er, yeah, yeah. I mean that's so, that's worked for me but that's my children and um, yeah, I was fortunate as well that I had these books as well, which I was able, you know, to give them.
7 227-29	Yes, yes, I think so. We just went through, looked on the internet for clues, positive role models. Looked for books about autism. Went through it that way.
7 238-44	Yeah, with Robert. To talk it through, give some literature that he can, because he still refers to those books now. They're still always under his pillow ... about his autism, why he's different. He still goes back to them. I think anything like that in a positive light would be what he needed. And some professionals to ask questions about it who <i>really knows</i> the subject.
7 368-73	Yes, I had a book ready to hand and told him about how he was just the same as everybody, but, he had an extra bit. That's how we described it, and extra

	bit to him, which was his autism. Which is the reason he got so stressed, the reason he found school extra hard [researcher: mmm] and the reason he shouts. We described it as an extra bit.
7 386-90	Yeah, and left it with him, and just left it in his bedroom so he could pick it up any time he wanted ... and just answer his questions as you go along, but always pushing him positively (laughs). I didn't want him to be sad and depressed 'cause he was different.
8 396-402	Yes and we've got books on it and I left the books lying about. R: OK, so you did a ... kind of relaxed approach? P: So if, if, if he secretly wanted to pick up a book, which he very often, he does read a lot, he could have picked it up and had a read of it if he wanted to. He may have done and he may have done it when I've not been there say. But I left the paperwork and books and things lying about.
	Approach to sharing (v) Being balanced
3 654-60	I just always say it's cool to be different, and, you know, different is good; and, doesn't mean there's anything wrong and. But, obviously that doesn't, you know, it, he, you also need to explain, you know that, the reason why, you know, if kids are noisy it hurts his ears, it's because he's you know, he hears louder than people that don't have Asperger's. So, but I think once he knows that, he sees. 'Cause otherwise, he'd be thinking 'well why does it hurt me and not them?' So, I mean he's got a reason.
3 775-82	I'd say, um, know your child. Um, I'd say don't, don't take on board too much textbook information, go with your feelings. Um, I'd say, be, be positive, but I think you've also got to, you can't make out it's, you can't make out its fantastic having Asperger's, because that's, they might not see it like that, so I think. I think just be, I think kids need honesty and I think more honest you can be the better. I think that's with or without Asperger's.
3 846-51	But I think yeah, it has to be a gradual process, because you can't, you can't explain Asperger's or autism in just, in one conversation can you? It's, um, so yeah. But I do think positive, but also make them aware that there will be difficulties, but then, there's difficulties with not being autistic isn't there? So, it's just different difficulties they're gonna face.
4 152-58	But, you know, I'm not saying that, um ... I'm not saying that I, you know, I don't think we should sort of <i>glorify</i> a, a disability like autism and it makes life difficult for people. But there is, you know, it's an <i>identity</i> in itself and <i>they're still them</i> , they're, they're a person with a personality. And in some ways, the autism can enhance it, as well as cause, causing difficulties, kind of thing.
6 129-40	And also, I ensured that ... um, it's not my personality to sort of say, oh it's just a difference, you know, we've all got a, you know, we've all got a right to be

	<p>who we are. It was, it was explained, yes it is a disability [Researcher: okay] it isn't how we're meant to be or how we're created to be. Um, but, um, so I wasn't trying to say, it's just different, because I'm aware as well, because I'm registered blind, you know, some people take the extreme attitude of, it's not a disability it's just a difference. Um, I don't ... go with that. I will say, it's a disability. But equally so, you can throw lots of positives into there, say, well yes it's not good in many respects but you can manage.</p>
6 164-66	<p>Huh, yeah, I and it's, I'm very much a person that if you understand your disabilities and you understand your weaknesses, then you're going to get on a lot better</p>
6 297-302	<p>It's more of a disability than a plus; although you have to look for your pluses and make sure you look at what you're good at and grow that. It's trying to find a plus in a negative situation I think, rather than, hey ho, it doesn't matter, you know, and everything's swimmingly wonderful.</p>
10 156-63	<p>There's no point going, 'oh yeah, you can be a brain surgeon Craig and it's going to be fine and it's going to go away'. It's got to be a reality, you know, this is hard and yeah, your friends can do that better but that doesn't make them better people, it doesn't make them, you know. It just means we're working hard to find the right things to help you. So, and it seems to be working, he's quite sort of, you know, and he tells people and he chats.</p>
10 1089-94	<p>And so, I sort of think, that is just so much part of me, that no matter if there were big barriers, the fact of the matter is, Craig has Autism, it's a life-long condition and he <i>has got</i> to cope with that. And he <i>has got</i> to realise that if he says to me, I want to be a brain surgeon, that that isn't going to happen</p>



Sharing an autism spectrum diagnosis with a child

Parents' stories

What is this leaflet is for?

This leaflet is based on our research with parents who had shared their child's autism diagnosis with them. This included autism and Asperger syndrome. Some of the children also had a learning disability or other diagnoses. All of the children could communicate verbally.

We asked parents about how they shared autism with their child. We know that this will be different for every family. Some families decide not to talk about autism with their child and some do. We know that this is not an easy decision to make. It is important to think about what feels right for your family.

This leaflet is not a plan of how to share a diagnosis. It offers some ideas based on what the parents we spoke to found useful when they shared the diagnosis with their child.

Autism means something different for each family. People have different ways of understanding and talking about autism so some of these ideas may not seem relevant. They may help you to think about how to talk about autism in a way that fits with you and your child.

Before sharing the diagnosis

Parents had some worries about telling their child that they had autism. They worried about upsetting them. They sometimes worried that they were not ready to tell. They said it was important for them to process news of the diagnosis before they shared it with their child.

Most parents said that they were waiting for the right time to tell their child. Some children were older when they were diagnosed and were told about the diagnosis at this time. Some parents did not make a plan to share the diagnosis with their child. Others wrote a list of things to talk about.

Working out when to tell your child

*"Oh, if I was to do it again I would share the diagnosis, if I felt my child was ready and, if I am ready... I think sometimes after diagnosis, parent's need a bit of time just to get their head round it." (Jenny)**

The parents we spoke to shared autism with their child when:

- Their child had started to recognise that they were different from others
- They were experiencing emotional distress or struggling at school
- Their child asked them directly about their difference or diagnosis
- Parents thought they were at a stage when they needed to know

The children were between 4 and 11 years old when they were told about the diagnosis. Parents told their child about autism hoping it would:

- Help their child understand their emotional and social experiences
- Provide a reason for the difficulties they experienced
- Let them know that they were okay and that they were not a 'weirdo' or 'crazy' like other children had said

What did parents do?

Parents said that sharing the diagnosis with their child was an ongoing process. This involved having conversations and answering questions over time. Some parents said that their child asked questions to understand autism and how it affected them. Although the process of sharing is individual to each child, there were some similarities in how the parents we spoke to approached this. These are outlined below.

Preparation

Parents thought it was important to learn about autism before they shared it with their child. They said that reading books, going on courses and speaking to other parents helped them:

"It's about confidence, knowing, understanding autism and trying to apply that to your child and trying to understand your child to help you explain it; that's really important." (Steven)

It seemed to be helpful for parents to understand how autism affected their child so they could share the diagnosis in a meaningful way. Parents talked about autism in a way that suited their child's needs and preferences. They spoke about autism in a way that helped their child understand what it meant.

Approaches to sharing

Parents thought that it was important for them to have some understanding of their child's abilities to help them during the sharing process. They used this to shape how they shared information about autism. The parents we spoke to felt that knowing their child and how they liked to interact and communicate helped them too.

"You have to take things at their pace. And ... because my son's got learning difficulties as well ... at the moment ... although he hasn't got a great understanding, just the awareness that this is what makes him different, I think is really sufficient for him. And then as and when he wants to know more then we'll have to start ... trying to find more answers." (Dawn)

For some children, this meant sharing in 'bite size' chunks and waiting to see when they were ready for more information. For others, it seemed okay to have longer conversations and to give them time to ask questions.

Parents seemed very good at answering questions based on their child's ability even though they said that they didn't feel like they always got it right. Sometimes they were unsure if they had shared too much or confused their child. Parents used this experience to adapt what they said next time.

Parents said that they 'took their child's lead.' They often waited for them to ask more questions. Parents used examples from their child's day-to-day experience to help explain autism:

"We didn't get all technical, like say 'you have impairments in the following areas'. I think we may have said, for example, if there was something that he found difficult, like if something was cancelled at the last minute; I'd say that 'you find that hard because you have autism', and 'people with autism like the same thing to happen at the same time'".(Jenny)

Sharing over time

After initially sharing the diagnosis parents said they took opportunities to continue discussing autism when they saw that their child was struggling. They thought that this helped their child understand why they found certain things so hard, or got upset easily.

"Autism means that you find it difficult to do things like learning and understanding, you get anxious and you get upset easily". And we'd pick out whichever problem we were discussing then, so if it was that he was scared of something, we'd say, 'autism can make you scared and that's fine and we can do things to help you'. "So it's not your fault and it's just something that you have".' (Anne)

It seemed important to the parents we spoke to that their child understood and accepted the diagnosis. Some parents said that they didn't think the diagnosis changed who their child was, and spoke about it as another part of their personality.

"Sometimes you've got to let them know; sometimes it's good to be different. You don't want to all be the same, that's what makes us up." (Erica)

Parents often shared their child's strengths to help their child to feel positive about themselves and about autism:

"A lot of the time I say to him 'Well that's your Asperger's, that's good isn't it?' and ... "You're ability at maths, your politeness, your ability to work out computers and to fix computers; that is definitely from your Aspergers." (Rebecca)

Drawing on the positives

As well as highlighting their child's strengths, the parents in our study shared the positives of autism with their child. They also said that they thought it was important to be balanced and spoke about the challenges their child experienced and that these could be explained by autism too.

"Most of us are fairly average - you recognise your strengths and you use these, but when it comes to careers for example, they can't do something which requires a lot of social ability." (Susan)

Summary

The parents we spoke to felt that sharing the autism diagnosis with their child was not always easy. Even when sharing the diagnosis did not quite go to plan, in time, parents said that they saw the positives for them and their child. We know that this experience will be different for all families and that for many different reasons some families may choose not to talk about autism with their child.

To echo the stories shared by the parents we spoke to – there are no right or wrong answers when it comes to sharing an autism diagnosis with your child. The important thing seems to be doing what feels right for you and your family. We hope that this leaflet offers some ideas to parents who decide to share the diagnosis with their child.

Resources

Some parents found these resources useful:

- A CBBC programme called '*My Autism and Me*' in which children talk about their experience of autism. You can find this online using this address:
<http://www.bbc.co.uk/newsround/15655232>
- Books written by people with autism like:
 - Freaks, Geeks and Asperger syndrome: A User Guide to Adolescence written by Luke Jackson
 - Martian in the playground written by Clare Sainsbury
- Books explaining about autism:
 - Doherty, K., McNally, P. & Sherrard, E. (2000) 'I Have Autism, What's That?
- Books about famous people with autism:
 - Elder, J.(2005) Different Like Me; my book of autism heroes
- The National Autistic Society also has a resource section of books about autism spectrum disorders. You can find this using this address:
<http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/reading-lists/autism-books-for-children-and-young-people.aspx>

