

**Consensus-based good practice guidelines for Clinical Psychologists to support care staff in enabling sexual expression in people with intellectual disabilities - A Delphi study.**

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## Thesis Abstract

Increasingly, society is acknowledging that people with intellectual disabilities (PWID) have sexual needs. This shift is reflected in international policy, with sexual expression acknowledged a basic human right for PWID. Staff that care for PWID have a responsibility to ensure this right is upheld. Though they generally report accepting views of PWID's sexual expression, PWID report that their sexual expression is restricted by care staff. A lack of service-level policy regarding PWID's sexual expression and how to support them in this, leaves care staff confused, and lacking confidence to make decisions about PWID's care. Clinical Psychologists work with care staff who experience these difficulties. Though pockets of good practice are emerging, there is no guidance on how to best approach this work. This research sought to utilise the good practice already occurring.

We<sup>1</sup> used the Delphi Method to develop a set of consensus-based good practice guidelines for Clinical Psychologists working with care staff around supporting PWID's sexual expression. We conducted the Delphi across three rounds, with a panel of 17 Clinical Psychologists experienced in helping care staff support sexual expression in PWID. In Round One, the primary researcher interviewed panel members about clinical experiences and they each suggested three potential good practice guidelines. We then compiled the Round Two survey, in which all 51 suggested guidelines could be rated in terms of importance and sent it to all panel members. We developed the Round Three survey using the responses to Round Two, personalised to include information on how the 51 guidelines had been rated by the individual panel member and the panel as a whole. The Round Three survey gave panel members the option to amend their responses. Consensus that a guideline was important or essential (set at  $\geq 90\%$  agreement, a priori), meant it was included in the final set. We supplemented endorsed guidelines with vignettes based on the practice described in the Round One interviews.

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<sup>1</sup> The term 'we' is used because although I led the project, I wish to acknowledge the support and input of my supervisors.

The panel reached consensus that 12 guidelines were important or essential. These guidelines fell under four themes: 'Addressing staff attitudes', 'Addressing uncertainty about rights and responsibilities of PWID', 'Locating the problem, being part of the solution', and 'Supporting care staff to understand and reflect upon their role'.

The limitations of this study include the homogenous sample and that the effectiveness of the practice Clinical Psychologists cited as evidence was not independently corroborated. This research provided insight into the important role Clinical Psychologists play in helping care staff support PWID's sexual expression. Direct work with care staff to clarify their understanding of PWID's rights, and to normalise and encourage reflection on the values care staff hold, were both considered central to the role. In addition, the panel suggested that Clinical Psychologists must put to use their unique professional skillset to share understanding about how organisational approaches are maintaining the gap between policy and practice, and what needs to be done about it.

## Acknowledgements

I would firstly like to take this opportunity to thank Dr Anna Tickle. I could not have asked for a more supportive and compassionate mentor, not only through the course of this research, but throughout my training as a whole. As my personal tutor, research supervisor and then specialist placement supervisor, I'm sure you will have had your fill of me by the time these three years are finally up, but you have ceaselessly encouraged me, picked me up when I have been struggling, and inspired me to believe in myself. I am certain I would not be half the Psychologist I am today without your support and will be forever indebted to you for nurturing me along this challenging path.

I must also pay special thanks to Professor Roshan dasNair. Your critical eye has certainly kept me on track throughout this project and helped carve it into what I believe is an important and innovative piece of research. I was desperate for my thesis not to look like so much of the research on this topic that offers no solutions and your insightful and confident approach to the project has helped me to achieve that goal.

I would also like to thank Dr Kate Moore. After you struggled with the trials and tribulations of the Delphi Method, you were more than happy to swoop in and guide me through the process. I think a few pitfalls were avoided owing to your input, and for this I am very grateful.

A special mention to my family, who have encouraged me to keep going, even when things get tough and have never let me forget how proud they are of me. In particular, my late Gran and Grandad, who worked so very hard to be able to leave me in a position to seize opportunities such as pursuing this profession.

Finally, my partner Niki (save the best until last). Your patience and solidarity next to me has played an immeasurable part in me getting to this point. Your belief, your input and your insistence on me looking after myself (at least a little bit!), has guided me through this long process and through the many years leading up to it. Without you, I simply would have not gotten through it.

## **Statement of Contribution**

The design of the project was developed by the author in collaboration with Dr Anna Tickle and Professor Roshan dasNair, who provided research supervision and feedback throughout the execution of the research. They also corroborated on the finalising of the wording of the guidelines, and the development of the vignettes, for which the author was chiefly responsible.

Dr Katherine Moore supported in the development of the Delphi design.

The author was responsible for applying for ethical approval, recruiting participants, conducting the interviews, constructing and sending the survey, data analyses and the write up of the project.

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## **Systematic Literature Review**

**Views and experiences of people with intellectual disabilities regarding intimate relationships: A qualitative metasynthesis**

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## **Abstract**

The aims of this review were to systematically identify, critically appraise and synthesise the results of existing qualitative literature exploring the views and experiences of intimate relationships amongst people with intellectual disabilities. Fourteen peer-reviewed articles were identified through a systematic search of eight databases, reference lists, citations, and relevant journals. The identified articles were appraised for quality, then synthesised using a metaethnography approach. No study met all quality criteria and references to ethical approval were often lacking. Interpretation of the findings suggested three key themes: the meaning of intimate relationships, external constraints and facilitators, and managing external constraints. Though many people with intellectual disabilities desire and benefit from intimate relationships, they experience restrictions that others do not, which can lead to isolation and loneliness. Intimate relationships are not always necessarily linked with sexual behaviour; therefore, intimate relationships warrant their own focus in future research, as well as in education and training for people with intellectual disabilities and their caregivers. Within this, a commitment to transparency over research processes is needed, in particular with reference to how ethical approval was obtained, since this has been a shortcoming of research with this focus to date. Keywords: Intellectual disabilities, intimate relationships, romance, couples, metasynthesis

The author would like to thank Dr Jennifer Clegg (Institute of Mental Health, University of Nottingham) for her advice.

## Introduction

Historically, the sexual expression of people with intellectual disabilities (PWID) has been ignored, with PWID perceived as child-like, asexual, vulnerable to sexual abuse, or sexually deviant [1-4]. The 'normalization' principle [5,6] challenged this, asserting PWID are entitled to an 'ordinary life', including intimate relationships [7]. This became enshrined in the United Nations Convention on the Rights of Persons with Disabilities [8] and the UK government's 'Valuing People' white paper [9], both stating that PWID have the same rights to marriage and relationships as anyone else. However, in 2009 the Department of Health acknowledged that many clinicians and caregivers were still not recognising that PWID want and need personal and sexual relationships, and more enabling practice around relationships was needed [10].

Research exploring why such 'enabling practice' has not naturally flowed from the shifts at policy level has focused on caregivers' attitudes to the sexuality of PWID. In a qualitative metasynthesis, Rushbrooke, Murray and Townsend [11] found that those providing care to PWID harbour an ambivalence between enabling sexuality and protecting individuals by restricting it, believing the former leaves individuals vulnerable to abuse or unsafe practice, or themselves vulnerable to accusations of not managing risk. A potential limitation of this metasynthesis was that Rushbrooke et al. [11] included studies that elicited the views of both parents and formal carers, despite prior research suggesting that the views of each group are often different, with that of parents being more negative/protective [12,13]. However, the authors managed this well by explicating the commonalities and distinctions between the difficulties experienced by paid carers up against family members. A notable distinction perhaps offering some insight into what contributes to the differing standpoints is that while both types of caregiver often feel uncomfortable acknowledging the sexual desires of those they work with, formal caregivers often deal with this by focusing on their 'professional' role over their 'mothering' role, where informal caregivers do not have that option [11]. Caregiver ambivalence has also been described as manifest in feelings of personal responsibility when relationships are facilitated, resulting in it being done in an overly restrictive way – through monitoring and controlling, caregivers have become 'the new institutional

walls' [14, p. 197]. Therefore, there has been a shift from the sexuality of PWID being denied, to it being 'managed' [2,15], resulting in little change in the level of restriction experienced by PWID [16].

PWID appear to strive for a 'normal' identity [17] and in doing so tend to internalise the attitudes of carers [18-20], so if their genuine opinions and desires are not sought, we cannot really know their needs. The recent emergence of self-advocacy movements and inclusive research for PWID has led to an increase in research giving voice to this population [21]. Though the focus again tends to be on sexuality generally, the topic of intimate relationships consistently emerges within findings [18,22]. An intimate relationship is defined here as a relationship with another person that involves emotional and physical closeness, is consensual, and is considered romantic and/or sexual in nature by both parties. Intimate relationships are associated with enhanced mental well-being [23] and quality of life [24]. The desires and benefits of such relationships for PWID appear to generally match that of the general population [25], with enhanced quality of life [24,26-29], mental health [30], and emotional well-being [31] reported. However, a large scale UK survey of PWID found that only 4% were in an intimate (couple) relationship [32], compared to 60% of the general population reported to be either married or cohabiting in the 2011 census [33]. Furthermore, the social circles of PWID tend to be smaller than those of the general population [34], with these mainly made up of staff or family members [35]. Overall, this demonstrates that despite shifts in policy, the needs of PWID in developing intimate relationships are not being met.

PWID lack support from adequate sex education [22,36] and where it does exist it tends to focus on biology, with issues around relationships ignored [37]. Zigler [38,39] has conceptualized the impact of this and the lack of support more generally from a developmental perspective, suggesting that PWID have the same needs as others since they go through the same developmental stages, though they move through these stages more slowly and often need social and emotional support in acquiring the skills to do so. The prevailing apprehension in fully supporting relationships is leaving PWID ill-equipped to form appropriate, consensual and safe relationships [40]. This and the limited opportunities to develop intimate relationships leads to isolation and loneliness [41]. Therefore, understanding how these



relationships are developed, experienced and understood by PWID would be beneficial in informing how they can best be supported. Unfortunately, aside from a handful of quantitative surveys focused on the incidence and success rates of marriages [42-44] that pre-date policy shifts, research specifically on intimate relationships in PWID has been sparse. Until recently there has been little added to this research base, but with the importance of intimate relationships to PWID beginning to be acknowledged [1,14,45] more studies are emerging. Therefore our aim was to systematically identify, critically appraise and synthesise the results of existing qualitative literature to date, to develop a coherent and accessible understanding of the views and experiences of intimate relationships amongst PWID.

## **Method**

The metasynthesis was approached from a critical realist epistemological position, which assumes that any reality that does exist can only be understood through our own perceptions of it. While two of the authors have a background and interest in working with clinically PWID, the third has little experience working with this population, though has a clinical and research interest in the social and psychological constructions of gender, sex, and sexuality. The authors' different contexts allowed for reflexive dialogue and triangulation around interpretations made throughout the process of the metasynthesis, with potential bias (or perspectives) consistently monitored for and interrogated.

## **Searching**

A systematic search was undertaken on 20<sup>th</sup> October 2016 across Medline, Embase, CINAHL, ASSIA, AMED, PsychINFO, Web of Science and Academic Search Complete databases. Search terms were<sup>2</sup>: ((Intellectual\* or learn\* or development\*) adj2 (disabil\* or disabl\* or disord\* or dysfunct\* or impair\*)).mp.; (mental\* adj2 retard\*).mp.; ((sexual\* or intimate\* or close\* or personal\* or interpersonal\*) adj2 (relation\* or partner\* or behav\* or orientat\*)).mp.; (experien\* or attitud\* or percept\* or perceiv\*).ti,ab.. In addition, where terms mapped onto a subject heading or

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<sup>2</sup> Command line syntax and reserve words adapted to meet the requirements of each database.

thesaurus term, these items were included in the relevant database. For example, in Embase intellectual disability maps on to the term 'intellectual impairment', therefore the latter was included in the Embase search.

To identify further studies, reference list and citations searches (google scholar) were performed on studies meeting the inclusion criteria. Since qualitative research can be difficult to identify through database searching [46], the Journal of Applied Research in Intellectual Disabilities, the Journal of Intellectual Disability Research and Sexuality and Disability were hand searched, as they had appeared regularly in the search results and are key publications in this area.

### **Selection**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [47] was adhered to for the selection procedure and the results of the process are outlined in figure 1. Studies were included if they:

- were written in English language
- were published in a peer-reviewed journal
- included participants who were adults ( $\geq 18$  years) with an intellectual disability<sup>3</sup> (or previous labels for this diagnosis, e.g. learning disability, mental retardation)
- investigated first-hand experience and/or understanding of 'intimate relationships', as defined above
- used qualitative methods, which we defined as studies that used 'discursive' methods (e.g., interviews, focus groups, diaries, etc.) to collect data.

Studies were excluded if:

- they used mixed methods and the qualitative data could not be extracted separately
- they included participants without ID, such as carers, and the data from PWID could not be extracted separately
- they included participants under 18 years old, and the data from PWID  $\geq 18$  years could not be extracted separately

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<sup>3</sup> Those who appear to meet the current diagnostic criteria [48].

- intimate relationships were not the primary focus
- focus was on only a specific aspect of relationships, e.g. arranged marriage

### **Critical appraisal**

We used the Joanna Briggs Institute (JBI) [49] tool to appraise quality. This tool is more sensitive in assessing validity than others [50] and includes a check of interpretive validity, important since limited richness can occur in responses of participants with ID [51], which potentially tempts researchers into interpretative leaps. The JBI tool identifies 10 quality criteria to be applied to each article (see table 2). Although the tool uses the 'No', 'Unclear', and 'Yes' format to identify the presence or absence of criterion, it was adapted within this study to 0, 1, and 2 respectively. This allowed each paper to be given an overall quality score, and made the comparison of overall quality between studies clearer. An additional criterion was included regarding the recruitment process since caregivers often have a role in selecting potential participants in research with PWID and, as highlighted above, there are still mixed attitudes held by those in this role regarding the sexuality and relationships of PWID.

The studies were appraised by each of the authors independently, using the checklist. In spite of the anchoring guidance provided by the Joanna Briggs Institute [49] for each item of the tool, there is still some overlap between the items. However, this may be a necessary evil in order to retain the wider insights into the subject of interest that could be lost through an overly rigid formulaic approach to appraisal [52] (through the disqualifying of less rigorous studies), and has the benefit of encouraging raters to be explicit about their reasons for judgements [53]. Discrepancies that arose between authors' ratings were resolved through discussion.

### **Metasynthesis of findings**

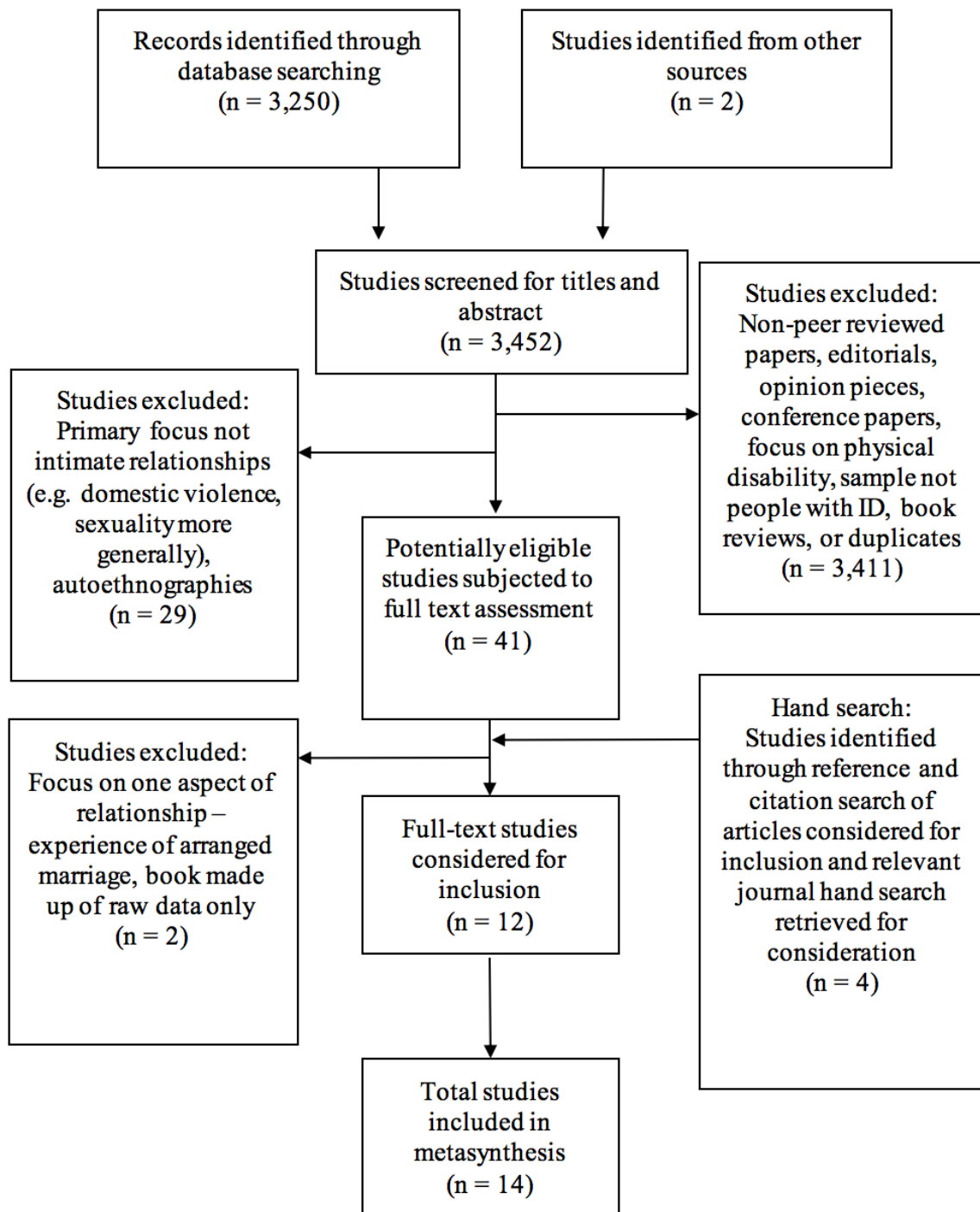
We synthesised the data using Noblit and Hare's [54] meta-ethnography approach. After reading and re-reading the studies, the findings and conclusions of each were systematically abstracted into a structured framework (self-developed data-extraction form) in terms of raw data (direct citations of participant responses – 'first-order'

constructs), author interpretations, author commentary and discussions. The themes and key concepts documented in each study ('second-order' constructs) were then identified and grouped together to form initial synthesis themes ('third-order' constructs). Common themes were then identified within the first-order constructs and author commentary across all studies through a process of 'reciprocal translation' [54] – concepts appearing across multiple studies are grouped. The third-order themes were adapted where necessary to accommodate the relevant subsets of first-order constructs, which included a process of 'refutational synthesis' [54] – contrasting findings around a singular concept are incorporated under a theme which acknowledges the disparity between findings. The process eventually resulted in a set of themes (some including subthemes) that encapsulated the findings provided by all included studies, allowing for the development of a 'line of argument' synthesis, through which new meaning is brought [54].

## **Results**

The QUOROM (QUality Of Reporting Of Meta-analysis) diagram in Figure 1 demonstrates the outcome of the search. Fourteen studies were selected for the metasynthesis [55-68], providing a total of 326 participants (167 women, 159 men), aged 18-78 years. There was a large heterosexual bias, with only five participants identifying as gay (one woman, four men), two of which described having had relationships with others of both genders. Living arrangements included the family home, supported or staffed group homes, and cohabiting with partners (visited regularly by support staff). Table 1 describes the general characteristics of the studies. One study was excluded owing to a particularly poor quality score [69]. Though it is acknowledged that a study of poor quality may still contribute valuable findings and/or data [70], this particular article presented the same data used for another included [63], therefore little was lost.

**Fig. 1** Quorum diagram – flow diagram of the search and selection process



**Table 1: General characteristics, aims, methodology and key findings of studies included in the metasynthesis**

Study No	Authors, year and country of publication	N <i>Female:</i> <i>Male</i>	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
1	Bane et al. (2012), Ireland. [55]	97 52:45	Un-specified	Learning disability service and self-advocacy groups.	Focus groups (x16).	To investigate the meaning of having a friend, boyfriend or girlfriend for PWID, and what support they need.	Thematic analysis.	Positive attitudes towards having a boyfriend/girlfriend , though some found it embarrassing to talk about or unsure what it meant. Benefits were companionship and sharing affection. Some felt sad or 'left out' not having a partner.

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						Marriage seen as their own choice. Inability to access public transport cited as an obstacle.
2	Bates, Terry, & Popple (2016), England. [56]	11 5:6	≥35	Two charities that support PWID.	Interview (flexible).	To investigate the experiences of partner selection for PWID in heterosexual relationships.	Hermeneutic Phenomenology.	Same desire for intimate relationship as general population, but valued partner traits differ – physical attractiveness and financial stability less important.

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						All met partners in segregated environments for PWID.
3	Healy, McGuire, Evans., & Carley (2009), Ireland. [57]	32 <i>12:20</i>	≥18 (three males ≥17 years; not considered for meta-synthesis)	ID service database.	Focus groups.	To gather information about knowledge, experiences and attitudes about sexuality for policy on relationships and sexuality.	Thematic analysis.	Companionship, trust and reciprocal nature of relationships were important. Positive effects of intimate relationships on self-esteem. Aspirations of marriage, parenting, and



Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						greater tolerance and privacy from carers. Endorsed masturbation.
4	Heyman (1995), England. [58]	20 <i>10:10</i>	19-35	Adult training centres. 'Theoretical sampling'; Families who were either 'danger-avoiding'; 'limited-risk taking'; exhibiting conflict about	Semi-structured interviews, and re-interview for two participants.	To explore the orientation of PWID (and their carers) to adult sexuality as a hazard.	Grounded theory.	Most participants held negative or ambivalent views towards sexuality, but some still wanted to engage in sexual behaviour. Felt deprived of adequate sex education.

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>		hazard management; or who had become more risk tolerant (since interview in previous study).				Those who did not wish for intercourse still communicated frustration over restricted privacy with partner.
5	Johnson, Frawley, Hillier, & Harrison (2002), Australia. [59]	25 <i>13:12</i>	25-60	Local advertisement s through radio, colleges and advocacy organizations.	Telling of life stories.	To identify the key issues around sexuality and relationships for PWID in	Qualitative (loosely based on thematic analysis).	Families and services posed obstacles to developing relationships. Lack of information about sexuality

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						context of their lives. and relationships available. Many experienced feelings of loneliness and isolation.
6	Kelly, Crowley, & Hamilton (2009), Ireland. [60]	15 7:8	23-41	Participants volunteering from within an ID service that was looking to develop a relationships and sexuality policy.	Focus groups (separated by gender). Additional individual interviews with two female participants.	To develop understanding about Irish PWID's views, experiences and aspirations regarding sexuality and romantic	Thematic analysis.	Wanted intimate relationships, but restrictions, monitoring, punishment and lack of information meant a disadvantage regarding sexual expression.

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						relationships, and the type of support they wanted.
7	Knox & Hickson (2001), Australia. [61]	4 2:2	26-58	Two small organizations concerned with supporting PWID.	One-to-one 'in-depth' interviews (unstructured ).	To explore the meaning of 'close' friendships held by PWID.	Grounded Theory.	Distinction made between 'good mate' and 'boyfriend/girlfriend'. Boyfriend/girlfriend relationship more changeable and would naturally

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						progress to marriage and children. Restrictions and lack of privacy precluded the development of intimate relationships.
8	Lafferty, McConkey, & Taggart (2013), Northern Ireland. [62]	16 (heterosexual couples) 8:8	26-65	Service providers for PWID throughout three Health and Social Services Board areas.	Interviews with couples and follow-up one-to-one interviews.	Uncover the experiences and nature of couples with ID in a relationship and the meanings	Grounded theory.	Many benefits of being in a couple; comradeship, sense of contentment, reciprocity and commitment.

Study No	Authors, year and country of publication	N <i>Female:</i> <i>Male</i>	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
						they ascribe to them.		
9	Lesseliers & Van Hove (2002), Belgium. [63]	34 <i>23:11</i>	20-65	Support services for PWID provided through facility-based programs (some residential, some daycare).	Semi-structured interviews.	To acquire knowledge about the social reality of people with developmental disabilities by investigating how they experience their environment	Grounded theory.	Some wanted love, a partner, a relationship, marriage, children, some did not. Some found pleasure in relationships, some felt pain (e.g. through abuse).

Study No	Authors, year and country of publication	N <i>Female:</i> <i>Male</i>	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
								and feelings in the context of their relational and sexual lives.
10	Neuman & Reiter (2016), Israel. [64]	40 (heterosexual couples)  <i>20:20</i>	23-78	Living in a framework that provides assisted to living to people with ID.	Observations and semi-structured interviews.	To explore what constitutes a couple relationship in the view of PWID, what the needs, abilities and implication are, and how this	Thematic content analysis.	Intimate couple relationship had more significant meaning than other relationships in their lives.

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						
						compares to the general population.		
11	Rushbrook e, Murray, & Townsend (2014), England. [65]	9 4:5	21-58	Community learning disability services.	Semi-structured interviews.	To explore how PWID perceive intimate relationships, what barriers they experience and what support they would want.	IPA.	Desired and valued intimate relationships like everyone else, the biggest distinction being the restrictions imposed by others. Intimate relationships enhanced mental health and well-being.



Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						Friendships don't meet same needs (e.g. physical intimacy). Secrecy and avoidance used to cope with difficult situations. Some blurred partners' role with that of a caregiver.
12	Sullivan, Bowden, McKenzie, & Quayle (2013), Scotland.	10 4:6	31-60	People First Scotland; ID advocacy network.	Semi-structured interviews.	Explore the experiences and perceptions of close and sexual	IPA.	Touch is important, though this did not always constitute sexual behaviours –

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
	[66]	<i>Female:</i> <i>Male</i>				relationships of PWID.		which many saw as wrong. Opportunities for relationships and physical intimacy were limited.
13	Turner & Crane (2016), USA [67]	5 2:3	21-54	Recruited through 'agency professionals' out of PWID receiving case management services.	Semi-structured interviews and observations.	To explore how PWID live out their social-sexual lives.	Thematic analysis.	Sexual pleasure is important to the participants; therefore, the sexuality of the participants should not be viewed solely through the lens of 'safety'. Though the participants had

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						little sexual knowledge or experience, they all had demonstrated that desire and ability to date. Some embraced their sexual identity with a sense of pride, while others denied it or felt somewhat ashamed of it.

Study No	Authors, year and country of publication	N <i>Female:</i> <i>Male</i>	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
14	White & Barnitt (2000), England. [68]	8 (two heterosexual couples, four single).  5:3	18-35	Social club for PWID.	One-to-one semi-structured interviews and two dyadic interviews with the couples.	To investigate whether PWID feel empowered or discouraged in intimate relationships.	Four-reading method.	Positive attitudes towards relationships, and marriage anticipated. Generally, felt supported by family, though felt unable to talk about sex. No particular level of independence needed for intimate relationship. Sex education limited to formal

Study No	Authors, year and country of publication	N	Age (years)	Context of recruitment	Method of data collection	Research aims	Method of data analysis	Key findings
		<i>Female:</i> <i>Male</i>						

classes and was insufficient.

## Quality appraisal

Table 2 shows the quality appraisal for each included paper. No study met all of the quality criteria. Only half of the studies [56,62,63,65-68] met at least seven of the criteria, and the unmet criteria often made it difficult to assess the research process clearly.

Congruity between philosophical perspective and methodology utilised could not be established for a number of studies owing to a failure to identify the former [55,57,59,62,65,60]. Where the methodology used was not specified in two studies [55,59], correspondence with the authors established that thematic analysis had been used in both; the accessible format of the article, and the 'participatory action research' approach used, were the respective reasons the method of analysis had been omitted from the write up. It was still unclear whether study five's methodology had been appropriate for the question, since the method of data collection had also been unconventional. With the aims of most studies to focus on experiences, the wide range of ages within samples raised questions of heterogeneity, which would pose a risk of diluting the depth and credibility findings. This was a particular issue for those adopting a phenomenological approach [56,65,66]. The interpretations made in study six appeared further reaching than was warranted for a study with 15 participants (generalising to 'PWID in Ireland'), and the extent to which the interpretation in study four [58] adhered to the inductive approach inherent in grounded theory was questionable, since the research was embedded in (and led by) the context of sexuality as hazardous for PWID.

All but four studies neglected to divulge the researchers' context in terms of beliefs and values [55,63,67,68], which leaves the reader uninformed about any potential biases/perspectives in the development of research questions and how the study is conducted. Furthermore, though some reflexivity was described, very little consideration was offered as to how the context and perspectives of each researcher may have influenced the participants and the interpretation of the findings, or evidence of how this had been managed. All but two studies [63,67] did this only partially or not at all, which is striking considering the many challenges that occur in conducting qualitative research with PWID, such as pressure to respond and inability

**Table 2: Quality appraisal of each study based on an adapted version of the JBI checklist for qualitative research**

Quality criteria	Study													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Is there congruity between the stated philosophical perspective and the research methodology?	1	2	1	2	1	1	2	1	2	1	2	2	2	2
2. Is there congruity between the research methodology and the research question or objectives?	1	2	1	2	1	2	2	2	2	2	2	2	2	2
3. Is there congruity between the research methodology and the methods used to collect data?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
4. Is there congruity between the research methodology and the representation and analysis of data?	2	2	2	2	1	2	2	2	2	2	2	2	2	2
5. Is there congruity between the research methodology and the interpretation of results?	2	2	2	1	1	1	2	2	2	2	2	2	2	2
6. Is there a statement locating the researcher culturally or theoretically?	2	0	0	0	1	1	0	0	2	0	0	0	2	2

7. Is the influence of the researcher on the research, and vice- versa, addressed?	0	0	1	0	1	0	1	0	2	0	0	0	2	0
8. Are participants, and their voices, adequately represented?	1	2	2	2	2	2	1	2	1	1	2	2	2	2
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	2	2	0	0	0	0	0	2	0	2	2	2	2	2
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	2	2	2	2	1	2	2	2	2	2	1	2	2	2
11. Did the recruitment strategy avoid biased selection processes?	1	0	1	1	1	2	0	0	0	1	0	1	1	1
<b>Overall quality score</b>	<b>16</b>	<b>16</b>	<b>14</b>	<b>14</b>	<b>12</b>	<b>15</b>	<b>14</b>	<b>15</b>	<b>17</b>	<b>15</b>	<b>15</b>	<b>17</b>	<b>21</b>	<b>19</b>

*A score of 0 indicates that either one or all elements of the criterion were not identified by the authors (e.g. for criterion one, the philosophical perspective, research methodology, or both were not identified by the authors). A score of 1 indicates that there was insufficient detail provided by the authors regarding some or all of the elements to confirm that the criterion had been met (e.g. for criterion one, though the philosophical perspective had been stated, the description of the research methodology was insufficiently specific to determine whether it was appropriate). A score of 2 indicates that there was clear evidence that the criterion had been met.*



to express feelings (Nind, 2008). A similarly alarming finding was that in nearly half of the studies there was no mention of ethical approval or consideration [57-61,63].

Participants' voices were well represented across almost all of the studies, but where this was absent or insufficient it was a result of a lack of transparency as to which participants were cited [55,63,64], less emphasis being placed on those not currently in a relationship [61], or a large sample [55] (97 participants represented through 18 citations of raw data), making it difficult for the reader to judge how closely the interpretations may fit the results.

Generally, the conclusions drawn from the research flowed logically from the interpretations of the data. However, in one study [65] there did appear to be an overgeneralisation of the more positive views, for example, the conclusion that all PWID desire intimate relationships appeared to conflict with some of their findings around some participants' ambivalence on the matter. In another [59], the focus of the conclusion was the research process itself (participatory action research) rather than the qualitative findings. That many of the studies required participants to be identified by caregivers [56,61-63,65] meant recruitment strategy was often a limitation. Recruitment will have been dependent on caregivers not only acknowledging or knowing about the relationships, but also presumably adjudging that potential participants' views would not reflect badly on them or the service. The range in quality amongst the studies appears largely down to a lack of clarity in reporting, however, all included studies can still be considered to provide findings of some value [70], especially since they provided a perspective of a population that has been severely lacking.

### **Metasynthesis**

Three key themes were identified through the synthesis of the 14 studies, which were made up of multiple sub-themes. The themes are outlined in table 3, with the studies contributing to each theme highlighted. Each theme and subtheme is expanded upon below, with the description supported by evidence from both second-order constructs and first-order constructs (raw data) cited in the individual studies.

**Table 3: Cross-comparison of the third-order themes and subthemes with the studies included in the metasynthesis**

Theme <i>Subtheme</i>	Study													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
The function and meaning of intimate relationships	*	*	*		*	*	*	*	*	*	*		*	*
<i>Boyfriends/girlfriends are different to close friends</i>	*	*	*		*	*	*	*	*	*	*			*
<i>Why I want to be in an intimate relationship</i>	*	*	*		*	*	*	*	*	*	*		*	*
<i>Physical intimacy</i>			*	*	*	*	*	*	*	*	*	*	*	*
External constraints and facilitators	*	*	*	*	*	*	*		*	*	*	*	*	*
<i>The attitudes of families</i>			*	*	*				*			*		*
<i>Formal caregiver imposed prohibition</i>	*	*	*		*	*			*	*	*	*	*	*
<i>Reprimand</i>				*		*			*		*	*		
<i>Support and facilitation</i>	*		*			*			*		*		*	*
Managing external constraints	*	*	*	*	*	*	*	*	*	*	*		*	*
<i>Operating in secret</i>			*	*	*	*	*		*		*		*	
<i>Marriage and commitment – looking to the future</i>	*	*	*	*	*		*	*	*	*	*		*	*

\*Indicates that the first and/or second order constructs within a study contributed to the corresponding third order theme or subtheme

## **Theme One: The function and meaning of intimate relationships**

### *Boyfriends/girlfriends are different to close friends*

For some, the distinction between intimate relationships and close friendship was how the former provides them with a means of physical closeness with another that the latter does not [60,61,63-65]: “A girlfriend would more suitable for me. Because I could...hold hands and...just enjoy ourselves like going to the pictures” [65, p. 534]; “being in love is healthy, it is laughing with each other, playing together, cuddling, and more of that.”

[63, p. 73]. Many alluded to the boyfriend/girlfriend relationship requiring a different sort of maintenance to others, mainly involving spending time doing activities alone together [55-57,61,64]. However, the distinction was less clear for some. The role of the boyfriend or girlfriend occasionally got blurred with that of paid carers [60,65]; two participants described a ‘special friend’, but both were referring to a member of staff whom they were attracted to [60]. Confusion over boundaries was demonstrated well by a participant speaking of a friend: “Well, I don’t know what a boyfriend is. If I went out with Sean I wouldn’t know what to do with a boyfriend” [55, p. 117].

### *Why I want to be in an intimate relationship*

Positive views about intimate relationships were evident in all but two studies [58,66]. Most participants not in a relationship expressed a desire to be [55,57,59,60,62,63,67], with the alleviation of feelings of loneliness often cited as a primary function. One participant highlighted this when she described life before finding her partner:

When you’ve a learning disability, it can be very lonely. You end up just sitting in the house and wandering about on your own and all and you ... feel as if the whole world is coming down on top of you and [you] feel like suicide ... I would have stayed in bed all day, never bothered getting up.  
[62, p. 1080]

Companionship [56,57,60,62,64,65], being supported [56,60,64,65,67], loved and cared for [55,56,64,65,67,68] also featured heavily as things that

participants perceived that intimate relationships would bring to their lives, which was conceptualised by one study [67] as coming out of individuals 'choosing to be known' by another person. A minority reported not wishing to have a partner; three having been hurt in previous relationships, adopted 'a lifestyle of transitory relationships' [59, p. 7], whilst another stated that she preferred to stay at home and was a 'mummy's pet' [60]. Not wanting to be in a relationship was generally associated with previous experience of physically [62,64,65] and emotionally [59,68] abusive relationships.

### *Physical Intimacy*

Though seen as an important part of an intimate relationship for some, it appeared that for just as many, physical affection, especially that considered overtly sexual, was not integral for an intimate relationship. Some participants, despite being in intimate relationships, rejected physical intimacy outright as 'dirty', 'yucky' [58,63], shameful, wrong or dangerous [58,60,63,65-67], or viewed it as an 'affair' (seeming to link it to secret and immoral portrayals seen depicted on television [60]). The disapproval of caregivers was the most prevalent fear about physical intimacy [58,63,65,66]: "Interviewer: Do you have a sexual relationship [with girlfriend]? Adult: No. Interviewer: Why not? Adult: I think it is wrong. I am not allowed" [58, p. 148]. However, many expressed a desire to engage in at least some form of physical contact, ranging from kissing, cuddling or caressing [55,63,64,67], to full intercourse [58,63,65,67]. The conflict between desire and the negative message provided by families, staff and sometimes peers/partners led to ambivalent views about physical intimacy for some, as encapsulated well here:

Interviewer: Would you like a sexual relationship ever?

Adult: ... It's like something inside me. One half says yes, and one half says no... When you are in love with somebody, you can have a good relationship by being friends. If you are having sex, you are taking risks.

Interviewer: Do you mean having babies?

Adult: No, AIDS or something like that. If I had sex with [girlfriend] on holiday she would come back, and her mum would say to her if she had

enjoyed herself with me, and she would say that she had sex, and she would be mad and get on the phone and play hell with me. [58, p. 150]

Direct experiences of physical intimacy with partners were referenced in all but four studies [55,56,61,68]. Some participants indicated that they do not engage in sexual intercourse, but in other behaviours that are equally important to maintaining the intimate relationship, e.g. hugging and kissing [66]:

I felt closer to William than I did, than I did to Ben [...] because he used to, he used, he used to put his two arms around me [...] instead of just one it was two [...] It made me feel more secure. [66, p. 3462]

Negative experiences of physical intimacy all related to sexualized behaviour [57,59,63,64,66]. For some this was getting 'caught red handed' having sex [57], for others, unfulfilling or upsetting experiences arose with their partners; agreeing to painful sexual acts [63], engaging for a partner's benefit, or feeling pressured by the actions of their partner [63,64]. Thirty-four participants (10% of total n) across four studies [56,59,63,66] directly reported having been the victim of sexual assault or rape, most of those participants reporting a subsequent aversion to intimacy of a sexual nature, but not more generally to intimate relationships.

All but four studies [55,56,62,64] made reference to understanding of physical intimacy and where this knowledge came from. Though some had been made aware of the mechanics of sex [59,60,63,66], ideas around pleasure and human connectedness were generally omitted [60,66,67]. Informal information from caregivers was generally delivered ad hoc and at their discretion (e.g. when risk was feared), which in some cases painted a rather negative picture:

Grace (*interviewer*): Elizabeth, have you ever had a sex education class?

Elizabeth: No I never went (. . .) only mammy told me. (. . .)

Grace: And what kind of things did she tell you about?

Elizabeth: About the development. About people touching me (. . .)  
Harassment. [60, p. 310]

Formal sex education was very rarely mentioned [58,59,63,68], with some who had experienced it describing it as ‘embarrassing’ and ‘irrelevant’ [59]. Knowledge was often limited and/or partial; understanding of masturbation [57,63], contraception [57,65,67] and consent [57,63] was rare, and rudimentary at best. Those wanting further information were forced to acquire it opportunistically through television, magazines or observations of others [57,58,60,63,67], and for some this knowledge appeared to directly influence how they engaged with partners – one participant explaining that he did “the same thing that they do in the porno – it was my first time. Like put their penis inside a vagina, and uh, put it in the mouth and, uh, put it in their butt.” [67, p. 687-8].

## **Theme Two: External constraints and facilitators**

### *The attitudes of families*

Examples were provided in six studies [57-59,63,66,68] of family members’ disapproval of participants’ intimate relationships, especially if there was a sexual element to them. For some this was overtly expressed by preventing partners staying over (or vice versa) [58,65-68]:

My friend...I said to my mother, um, I’m going to invite her to stay with at my house and she turned around and said well if you’re going to do that don’t come back to the house...I phoned her mother to say that, um, I’ll have to ask her to leave because my mother says if I’d if I have her in the house then she’s going to disown me. [66, p. 3460]

For others this was less explicit; granted permission to stay over with his partner, the sister of one participant’s partner put a single bed and a camp bed in the room to replace the double [66]. This act conveys a clear message about how the family member wishes the couple to behave. Many felt unable to talk to parents about their relationships, anticipating disapproval [58,66,68].

### *Formal caregiver imposed prohibition*

Restrictions and rules implemented by the various services accessed appeared in all but three studies [58,61,62], such as 'it's ok to have a friend but not a boyfriend/girlfriend' [55,60] and 'they don't let people stay overnight' [66]. Some agreed on a need for rules [57,63], but found those enforced excessive and neglectful of their needs: "I do really think that we don't matter because we don't have any much of a life anyway" [57, p. 910]. There was a lack of clarity over what the rules actually were [57,59,60,63,65,68]. Confusion was maintained by the inconsistent way rules were enforced, for example:

Before we shared our room, a staff member knocked on the door and found us together. She said 'Get into your own bed'. I didn't like her that much doin' that. Because we're two adults and she should have let us do it. We didn't like it, so we left one night and we had sex somewhere. When we came back they had a talk to us and they said 'You can move into a room together'. [59, p. 7]

Some resisted the restrictions being imposed on them [57,60,67,68]: "I said I'm not giving in to you . . . they have to give up because they get tired" [57, p. 908] and demonstrated a sense of pride in their right to a sexual identity. Others however, reported feeling defeated by the restrictions, and seeming reluctant to describe themselves a sexual or romantic beings, resigned themselves to being powerless to fight for the opportunity to obtain an intimate relationship, and so ceased trying [60,63,67].

### *Reprimand*

Direct reprimand was identified in five studies [58,60,63,65,66]. Examples included being told off for holding hands [65] and kissing [60], detention [66] or having it recorded on their file [58] when caught having sex, and even being punished for waiting around for a peer: "Ow, they made me remember that day, we were punished the whole day although we did nothing wrong" [63, p. 75]. This led to fear over the repercussions for being physically intimate

[58,63,65,66]. Many participants avoided speaking of their desires to staff, parents or even partners [58,63,65,66].

### *Support and facilitation*

Though caregivers supporting intimate relationships was recurrent across first order constructs in six studies [55,57,60,63,65,68], incidence was minimal. Some said caregivers had an important role to play at difficult times [55,65]: “The good times was when I was having a good patch, when like, I’d basically ignored him and stuff. And I was getting all the support I needed” [65, p. 537], and when meeting with a new partner to make sure they are ‘trustworthy’ [65]. However, refutational data highlighted that formal staff did not offer counselling at particularly confusing times [63], and that staff are ‘afraid’ to give socio-sexual advice [57]. This was associated with confusion and ‘heartache’ as participants struggled to understand and process relationship conflict [63] and breakdown [65]. Two participants in one study [60] reported staff being supportive in their relationships, however, in contrast some had been put under pressure to end relationships:

Grace (*interviewer*): You said Elizabeth that you gave a guy a kiss (. . .)

Was he your boyfriend?

Elizabeth: He was, yeah, (. . .) we broke up years ago.

Grace: Ahh (sympathetically)

Elizabeth: Yeah. And we had to be friends.

Grace: (. . .) You had to be friends?

Elizabeth: Yeah.

Grace: Why?

Elizabeth: Because it’s the rule of the staff. [60, p. 313]

Failure to support the maintenance of intimate relationships at a service level was discussed in three studies in terms of the feared, or enforced separation or move of a partner to another facility [56,63,64]: “I’m scared of you (the caregiver), afraid that you will not let us live together. Do not take him away from me” [64, p. 5].



### **Theme Three: Managing external constraints**

#### *Operating in secret*

Recurrently within seven studies [57-61,63,65] participants stated they were never alone and were constantly monitored, which was overbearing, as encapsulated by one participant:

Having support there all the time we couldn't feel like we could do things what normal people would do in a relationship. Like kiss, cuddle, hold hands...And we felt like that we didn't have space, and it felt like quite intimidating for me, having staff there all the time. [65, p. 538]

The lack of privacy afforded forced many participants into engaging in acts of physical intimacy in secret [57-60,65]. One participant explained how he achieves this secrecy: "At the centre we are not allowed to kiss and cuddle, but we still sneak one in when nobody is looking" [58, p. 148]. Surreptitious behaviour functioned to avoid the disapproval of others [58,60,65], prevent further prohibition or punishment [57,59], but also to protect others from upset such as parents [65]. Acting in secret made individuals vulnerable, since the acts tended to be carried out in public places, in a hurried manner devoid of appropriate care (e.g. unsafe sex) [59] and 'divorced from interpersonal intimacy' [58].

#### *Marriage and commitment – looking to the future*

Thoughts about the future featured in all but two of the studies [60,66], a desire to marry evident in most. Finding an intimate relationship and/or marriage was linked in a number of studies to some form of perceived control [62,63] or progression in life [56,57,61-64]. For some participants it also meant status, and acceptance that they were "just like other people and special to someone" [56, p. 7], and a means of moving towards a 'normal' identity, which for some was associated with a marked sense of pride [67]. However, an actual [58,59] or presumed [57,63] outright prohibition of marriage was described by some, which could be particularly upsetting; one participant described how her sibling

was “married you see and then I feel kind of sad cause that I can’t you see. I mean I think it’s not fair, I think I should be happy as well” [57, p. 910].

Planning for the future appeared more concrete for those already in a relationship, with some idealistic views portrayed: “Well, that’s what we want (to get married), you know, a wee house, a wee dog and Michelle wants a bird” [62, p. 1083]. However, for planning for the future to begin, and a better life worked towards, finding a relationship was seen as an integral first step.

### ***Line of argument synthesis***

Most participants expressed a desire to have an intimate relationship, citing that such relationships can function to alleviate loneliness, feel supported and cared for, and feel physically close to someone. Though a desire for physical intimacy was mentioned by some, this was not universal, and when it was present it did not necessarily constitute sexual intercourse, with other forms of physical affection such as hugging and holding hands described as important to maintaining intimate relationships.

Whether physical intimacy was desired within intimate relationships or not, participants across all studies felt that varying degrees of constraint were being put on them in terms of being able (or allowed) to engage in intimate relationships and to what extent. The prohibition of relationships experienced ranged from the implicit (e.g. disapproval) to the overtly explicit, in terms of the enforcing of sweeping rules, and ranged from a total denial of intimate relationships, to condoning intimacy up to a point, for example, hugging and kissing allowed but nudity and intercourse not. In response, two main approaches were adopted to overcoming the constraints. The first was to pursue an ambition to get married. The participants appeared to feel that by their relationships being acknowledged and accepted they would be able to progress in their life and take steps towards a ‘normal’ identity rather than one of disability. The second was to fulfil the relationship, or at least certain parts of it, in secret. This was particularly the case when some level of physical intimacy was sought. When this involved sexual behaviour it often led to PWID engaging in risky practice such as unsafe sex and/or doing so in public. Upsetting or risk-

laden romantic experiences appear to also in part be a consequence of poor sexual or relationship knowledge owing to insufficient education on the matter and an aversion to discussing such matters with family, formal caregivers or even partners, for fear of disapproval. In addition, the common absence of conceptualisations of pleasure in discourse around sex and relationships for PWID perpetuates this poor understanding and potentially leads some to engage in such behaviours as another means of pursuing the 'normal' identity, which can result in upsetting rather than enjoyable experiences. Knowledge was sought from other sources by some, such as TV, film and magazines, which in turn was associated with sex and intimate relationships being understood as dangerous and inappropriate (e.g. labelling them as 'affairs'). Though some lead a spirited individual rebellion against the constraints placed on them, sadly, many appear to not have the understanding or the fight to do so.

### **Discussion**

Varying levels of methodological and reporting quality were identified across the studies, with none meeting all criteria. The collection and analysis of data was generally appropriate, using a suitable methodology to answer the question posed. However, almost half of the studies failed to mention ethical approval, which is a major shortcoming when discussing sensitive topics with vulnerable people. It is unclear why so many studies failed to document matters of ethical approval, but this must be addressed, not only for transparency of the research process, but to set a precedent for the way in which PWID should be treated. The absence of statements regarding the researchers' context culturally or theoretically was conspicuous, especially considering high levels of interpretation needed for data that often lacked depth. Furthermore, when recruiting participants, researchers asked staff to identify participants, meaning they would have to be aware of and acknowledge the individual's intimate relationship(s), and potentially, perceive that their input would not reflect badly on the care being given. Consequently, potential biases in the development of research questions, sampling, and the interpretation meant the trustworthiness of many studies was difficult to determine.

Since previous research suggests that PWID benefit from being in intimate relationships [24,26-31], the finding that almost all participants desired one was unsurprising. Participants emphasized the loneliness of 'having nobody', and conceptualized intimate relationships as multi-dimensional, with descriptions of 'companionship' and being 'loved' and 'cared for' featuring heavily across the studies. Physical and sexual intimacy provided only one aspect of intimate relationships, and one not desired by all. This is at odds with the portrayal of intimate relationships in PWID in previous literature being inevitably associated with sexual behaviour and the perceived risk associated with it [11,14].

Across the reviewed studies, PWID experienced restricted opportunities to develop intimate relationships both on an explicit and implicit level. From a developmental perspective, these restrictions demonstrate a denial of the social and emotional support PWID require to move through 'normal' developmental stages [38,39]; a failure to equip them with the skills and understanding needed to develop intimate relationships. From a perspective of considering the rights of PWID, the restrictions seem at odds with national policy [9,10]. The level of restriction experienced varied across studies, for example, some participants were forced to end relationships, while for others the relationship was condoned but privacy together was not. The messages being delivered to PWID through these restrictions, were internalized to varying degrees, as has been exhibited in previous literature [18-20]. The extent to which the influence of others through these various channels was internalised can be conceptualised as being on a continuum. At one end, those who appeared to accept that intimate relationships were not acceptable for them, at the other, the few cases explicitly rejecting the restrictions. The majority of the participants appeared to hold the middle ground and harbour an ambivalence or cognitive dissonance [71] between wanting to have an intimate relationship, and believing that they are wrong or risky. This appears to mirror the ambivalence harboured by those supporting PWID about enabling intimate relationships and protecting them from harm [11,14].

Confusion over relationships, seemingly maintained by the partial/biased information afforded to them, saw a lack of clarity about boundaries, poor understanding of physical intimacy in the context of relationships, and numerous reports of negative relationship and sexual experiences. In spite of this, intimate relationships were generally still desired. Measures taken by PWID to fulfil their needs, most notably to act in secret, often put them at greater risk, i.e. acting in unsafe environments, with an unnecessarily poor understanding of what they are doing. This suggests that those caring for PWID limiting access to intimate relationships in an attempt to protect them from harm might inadvertently increase risk. The prevalent ambition of marriage can here possibly also be understood as PWID's attempt to exert some control over unmet developmental needs regarding relationships in the absence of sufficient support to do so. This fits with past findings that PWID strive for a 'normal' identity by trying to achieve goals that align them with this [17], as marriage was generally seen as a marker for life progression, and would equate to an intimate relationship being accepted by others, a perceived means of resolving the felt dissonance.

Intimate relationships are not inextricably linked to sexual behaviour for PWID. Our findings suggest that maintaining this purported link leads to denial of the knowledge, skills, and privacy to access the enhanced quality of life an intimate relationship could bring, presumably through the implied connection to risk. Therefore, it is important that future research and education for PWID and their carers acknowledge the distinction between sexual behaviours and intimate relationships and portray the overlap between them as possible but not inevitable. Acquisition of new information offers a means of alleviating cognitive dissonance [71]. Providing new information here, in terms of providing insight into how intimate relationships for PWID are not inextricably linked to sexual behaviour and /or risk could act to relieve some of the ambivalence carers appear to feel around the intimate relationships of those they care for – relationships that can ultimately bring much happiness, pleasure and satisfaction.

There are some limitations to the metasynthesis. As can be seen from the citations, the raw data was not overly rich, meaning that a high level of interpretation was sometimes evident in second order themes. Insufficient statements regarding researchers' context (and therefore potential biases) meant that the distance being put between first and third order constructs through the triple hermeneutic was at times difficult to determine. A prevalent inclusion criterion across the studies was the ability to clearly communicate experiences verbally, therefore the more severely disabled were absent in the primary studies. Though including those with expressive language difficulties poses an obstacle in research this is not insurmountable [72]. Their absence leaves a considerable section of the ID population whose views have not been represented and therefore little is known about their relationship needs. Future research should remedy this.

Metasynthesis as a process carries dangers of imprecision, with the aggregating of multiple equivocal qualitative findings potentially 'thinning out' the human experiences presented in the original studies [70]. Consideration of this was pertinent to the current metasynthesis, with data being collected, analysed and presented in a multitude of ways across the studies (including accessible formatting). However, the strong recurrence of themes across the studies reviewed here implies that the synthesis is valid [73], as does the fit of the findings within existing literature [74].

To conclude, the findings of the metasynthesis do not necessarily reveal things that were not already being suggested, but now that PWID have been asked, policy, practice and sex education no longer needs to be based on assumptions. A delineation of intimate relationships and sexual behaviour in future research provides an opportunity to move away from the focus on risk and highlight the benefits of the former that PWID are being denied through blanket restrictions and reprimands. It is essential that a greater emphasis is placed on quality in this research, in particular transparency regarding ethical procedures.

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## Journal Paper



**Consensus-based good practice guidelines for Clinical Psychologists to support care staff in enabling sexual expression in people with intellectual disabilities - A Delphi study.**

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**Consensus-based good practice guidelines for Clinical Psychologists to support care staff in enabling sexual expression in people with intellectual disabilities - A Delphi study.**

**Running title:** Sexual expression in intellectual disability.

**Key words:** sexual expression, intellectual disability, Clinical Psychologists, care staff, Delphi Method, clinical mindlines.

## **Abstract**

### *Background*

Care staff that support people with intellectual disabilities (PWID) report accepting views on PWID's sexual expression, but PWID report their sexual expression is restricted by care staff.

### *Method*

We recruited a panel of 17 Clinical Psychologists experienced in helping care staff support PWID's sexual expression. We used the Delphi Method to develop consensus-based practice guidelines for Clinical Psychologists supporting care staff in this way.

### *Results*

Having proposed three guidelines each in Round One, the panel reached consensus ( $\geq 90\%$  agreement) that 12 were important, falling under four themes: 'Addressing staff attitudes', 'Addressing uncertainty about rights and responsibilities of PWID', 'Locating the problem, being part of the solution', and 'Supporting care staff to understand and reflect upon their role'.

## *Conclusions*

Clinical Psychologists help care staff support PWID's sexual expression by normalising care staff concerns, encouraging reflection, clarifying PWID's rights, and prompting those at managerial and service level to support care staff.

## **1 Introduction**

Increasingly, society is acknowledging that people with intellectual disabilities (PWID) have sexual needs (Chapman, Ledger, Townson, & Docherty, 2015; Robbins, 1990), and this shift has been reflected in international policy. The World Health Organization (WHO) identifies 'sexual expression' as an important part of sexual health, defining it as the possibility of having pleasurable, safe sexual experiences that are devoid of coercion, violence, and discrimination (WHO, 2006). This is the definition used within this research, with the addition that sexual expression can include the desire to not be sexual. Since sexual expression is a basic human right that PWID have difficulty understanding and accessing (Azzopardi-Lane & Callus, 2015; Lesseliers & Van Hove, 2002), the United Nations (UN) (2006) states that governments are responsible for ensuring PWID are supported in doing so. The UK government ratified this need in 'Valuing People Now' (Department of Health (DH), 2009); placing responsibility with local systems and care services to 'enable practice' that supports PWID's choices around making and maintaining relationships, including sexual ones (DH, 2009).<sup>4</sup>

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<sup>4</sup> See extended paper 1.1.

PWID still frequently report experiencing social and environmental barriers to their sexual expression imposed by their families and care staff (Bane et al., 2012; Dinwoodie, Greenhill, & Cookson, 2016; Healy, McGuire, Evans, & Carley, 2009; Rushbrooke, Murray, & Townsend, 2014a). A recent review of this literature (English, Tickle, & dasNair, 2017) highlighted that these barriers range from the implicit, such as replacing an individual's double bed for a single (Sullivan, Bowden, McKenzie, & Quayle, 2013), to the explicit, in the form of punishment for displays of physical affection (Kelly, Crowley, & Hamilton, 2009) and not providing privacy (Hollomotz, 2009).

Care staff are individuals and teams that are employed or volunteer to support PWID in the community, in their own home, or within residential care services. Research suggests care staff hold relatively 'positive' attitudes<sup>5</sup> towards the sexual expression of PWID, though it is often viewed less favourably than that of the general population, and many advocate some level of restrictive practice (Cuskelly & Bryde, 2004; Gilmore & Chambers, 2010; Saxe & Flanagan, 2014; Yool, Langdon, & Garner, 2003).<sup>6</sup> Care staff often lack the confidence in addressing matters of sexual expression (Rushbrooke, Murray, & Townsend,

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<sup>5</sup> Though prevalent in the literature, it is questionable whether the term 'positive' should be used to describe a certain type of belief here, since it is value-laden and biased in privileging certain views over others. The terms 'liberal' and 'accepting' are more appropriate, since these appear to be the type of beliefs being favoured.

<sup>6</sup> See extended paper 1.2.

2014b), and are often not clear on what rights PWID actually have regarding relationships and privacy (Abbott & Howarth, 2007; Lyden, 2007).<sup>7</sup>

Staff attitudes influence the personal and professional care they provide (Brown & Pirtle, 2008; Evans, McGuire, Healy, & Carley, 2009; Swango-Wilson, 2004), and their attitudes are often internalised by PWID (Cuskelly & Bryde, 2004; Murphy & O'Callaghan, 2004). Furthermore, ignoring PWID's need for sexual knowledge leaves them at risk. For example, many PWID are unaware that they are protected by the law against sexual abuse (O'Callaghan & Murphy, 2007). Supporting care staff to acknowledge what influences their values, such as cultural orientation (Ditchman, Easton, Batchos, Rafajko, & Noopur, 2017), and belief system (Löfgren-Mårtenson, 2004), helps care staff to be more accepting of PWID's sexual expression (Brown & Pirtle, 2008). However, helping care staff feel more comfortable and confident in supporting sexual expression will also require change and greater support from the many organisational levels around them (Grace, Greenhill, & Withers, 2017; Rushbrooke et al., 2014b).

A service-level 'policy vacuum' (Wilson, Parmenter, Stancliffe, & Shuttleworth, 2011) exists regarding matters of sex and relationships; care providers for PWID often avoid developing policies, perturbed by the complexities around capacity, and fears of "prosecution by outmoded statutes" (Alexander & Taylor Gomez, 2017, p. 117). Perhaps this is why policies that do exist are generally vague, restrictive, and focus on sexual offending and abuse (McConkey &

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<sup>7</sup> See extended paper 1.3.

Ryan, 2001; Wings-Yanez, 2014). Care plans that make reference to sexuality tend to have a similarly narrow focus (Stoffelen et al., 2017).

Clinical Psychology services engage with many of the organisational levels involved in PWID's care – working directly with PWID, their carers, as well as consultation at service and policy-development level, and therefore have a role to play in ensuring PWID's rights are upheld.<sup>8</sup> However, not all Clinical Psychologists are particularly confident in addressing matters of sexuality (Miller & Byers, 2009; Shaw, Butler, & Marriott, 2008; Snowdon-Carr, 2005).<sup>9</sup> Overall, it is therefore possible that Clinical Psychologists feel less-equipped for utilising their professional skill-set when dealing with issues of sexual expression and PWID, though this point has been neglected within research.

More needs to be done to close the gap between national policy and support in practice. Previous research has recommended 'more staff training' (Futcher, 2011; Rushbrooke et al., 2014b), but this has led to little change. For sustainable change to occur, it must take place across multiple organisational levels (Futcher, 2011; Kramers-Olen, 2016). Good practice is emerging in Clinical Psychology services for PWID, but in isolated pockets, only showcased by special interest groups or organisations (e.g. the supported loving network - <http://www.centreforwelfarereform.org/our-work/supported-loving.html>). We sought to capture this wisdom by approaching the issue from a 'practice-based evidence' perspective (Margison et al., 2000) – examining what is already

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<sup>8</sup> See extended paper 1.4.

<sup>9</sup> See extended paper 1.5.

occurring in the field to provide insight into how the problem can be addressed.<sup>10</sup>

The research has also been informed by Gabbay and le May's (2004, 2011) 'mindlines' paradigm, a conceptual framework of how knowledge is developed through interaction between individual and groups of experts in a given field (in particular, healthcare professionals). Gabbay and le May (2004, 2011), found that when faced with gaps in their professional knowledge, rather than turning to policy and recent research, healthcare professionals have a tendency to turn to their own tacit and anecdotal knowledge, as well as to seek this from colleagues. This wisdom is subsequently assimilated as 'clinical mindlines'; "internalized, collectively-reinforced, and often tacit guidelines" (Gabbay & le May, 2011, p. 44).<sup>11</sup> Our intention was to utilise the process of knowledge creation through communication between a group of experts. We did so using the 'Delphi Method' (Linstone & Turoff, 1975) – an approach to establishing consensus between a group of experts in a given field.

By drawing upon the effective approaches Clinical Psychologists are already using, this research had two aims. To answer the research question: how do Clinical Psychologists address the difficulties of care staff in supporting the sexual expression of PWID? And, to develop a set of good practice guidelines for Clinical Psychologists helping care staff to support the sexual expression of PWID. Furthermore, by supplementing each of the guidelines with vignettes

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<sup>10</sup> See extended paper 1.6.

<sup>11</sup> See extended paper 1.7.



(based on clinical practice), we sought to ensure their usability by emulating the way in which 'mindlines' are shared.

## 2 Method

The development of clinical practice guidelines traditionally consists of gathering scientific evidence, and formal and explicit consensus judgement methods (Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999). We used the Delphi Method (Linstone & Turoff, 1975),<sup>12</sup> which has been used successfully in practice guideline development (e.g. Schilling, Wyss, Faisst, Gutzwiller, & Haller, 1999; van der Linde, Hofstad, van Limbeek, Postema, & Geertzen, 2005), and has been found to be more reliable than other consensus judgment methods such as 'Nominal Group Technique' (Hutchings, Raine, Sanderson, & Black, 2006).<sup>13</sup> There are no clear quality guidelines for using the Delphi Method, but Diamond et al. (2014) have suggested a set of Delphi research quality criteria, which were adhered to throughout the study.<sup>14</sup>

The study was approved by the University of Nottingham Faculty of Medicine & Health Sciences Research Ethics Committee (reference number: N18082016).

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<sup>12</sup> See extended paper 2.2

<sup>13</sup> See extended paper 2.3.

<sup>14</sup> See extended paper 2.7.

## **2.1 Study design.**

We conducted a ‘classical Delphi’ study (Young & Hogben, 1978), across three rounds, set a priori (generally considered sufficient to establish consensus; Stone Fish & Busby, 2005). The study consisted of an initial round of interviews, from which items were developed for two subsequent rounds of surveys.<sup>15</sup>

## **2.2 Participants and recruitment.**

We recruited Clinical Psychologists with expertise in the field of intellectual disabilities by circulating an advertisement about the study through the British Psychological Society (BPS) Division of Clinical Psychology, Faculty for PWID email discussion list (consisting of approximately 317 members). This provided a nationwide sample, from a diverse range of services and contexts. Inclusion criteria were:

- Individual is currently working or until recently has worked as a Clinical Psychologist in a service for PWID;
- has  $\geq 3$  years of experience in this role, and;
- experience of working to help care staff support sexual expression in PWID.

The advertisement also requested that recipients invite participation from other Clinical Psychologists who meet the inclusion criteria but may not be on the email list.

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<sup>15</sup> See extended paper 2.4.

Linstone and Turoff (2002) recommend a minimum of ten panel members, but acknowledge when increasing beyond this the Delphi quickly becomes labour intensive, with vast amounts of data being gathered. Furthermore, it is reported that improvements in reliability once the number of experts in the panel rises above 15 are negligible (Murphy et al., 1998)<sup>16</sup>. As a result of the level of time commitment required from the panel members, Hanafin and Brooks (2005) suggest attrition rates of 16-28% should be expected per round. Allowing for this level of attrition and aiming to have at least ten contributors in the third round, we therefore aimed to recruit a sample of 15-20.

### **2.3 Round One.**

Prior to the interviews, experts were sent a short summary of the relevant research. This described how policies and legislation have evolved to acknowledge PWID's sexual expression needs, but care staff are still struggling to support them in this, despite having relatively accepting attitudes towards those needs. This was to orientate the expert to the focus of the study and this has been found to build the research relationship from an early stage (Whitman, 1990). The primary author conducted individual interviews with the experts by telephone or in person – a mixed format approach, aimed to increase response rates (McKenna, 1989).

The focus of the interview was to discuss clinical experiences of working with care staff to support the sexual expression of PWID, in terms of what had and

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<sup>16</sup> See extended paper 2.5.

had not gone well. At the end of the interview, the expert was asked to suggest three potential guidelines for Clinical Psychologists when working with care staff regarding these matters. The guidelines from all participants were then collated into a long-list that was rated by the panel in terms of importance in Round Two. The guidelines were transcribed verbatim and only amended to ensure grammatical clarity.

#### **2.4 Round Two.**

A list of all suggested guidelines were compiled into a survey on Microsoft Word and sent to each expert by email. They were asked to rate each guideline in terms of importance on a 5-point Likert scale (-2 = not important at all, -1 = not very important, 0 = neutral, 1 = important, 2 = essential). A free-text space was provided for comments or feedback on the guideline, and on their decision. Where multiple guidelines appeared similar in content, they were grouped together in the survey, and a question was included as to whether those guidelines conveyed the same message. The experts were initially given two weeks to return their responses by email or by post (printed and filled in by hand), and then a further week following an email reminder.

#### **2.5 Round Three.**

The Round Three survey listed all suggested guidelines in Microsoft Word, along with anonymous information about panel responses in Round Two. The percentage of the panel that had rated the guideline each way was presented

below each point on the Likert scale. The surveys were personalised to also indicate how the individual expert had rated each item themselves compared to the rest of the panel (see figure 2). The comments the panel members made were gathered and presented below each individual guideline (anonymised). The survey was emailed to the experts. The instructions explained that they had the opportunity to rate the guidelines differently to how they had in Round Two, having seen the ratings and thoughts of others in the panel. In addition, a free-text space was again included for any further feedback, for example to explain their decision to change their response.

At Round Two, we received additional feedback from a member of the panel suggesting the guidelines may be more accessible if grouped under themes. Therefore, in Round Three the guidelines were presented in colour-coded groups based on the themes the expert had proposed. We included two additional questions at the end of the survey about whether grouping the guidelines was useful, and whether the group allocations suggested seemed appropriate. This approach provided the added benefit of re-ordering the guidelines – important since Delphi studies often report a tendency for more responses and feedback to occur on earlier items (e.g. Green & Dye, 2002).

## **2.6 Determining consensus.**

We conducted the current study across three rounds, which has been found generally sufficient to achieve consensus (Stone Fish & Busby, 2005). There is no universally agreed level of consensus to be sought through a Delphi, and

accepted levels tend to vary depending on the size of the panel and the aim of the research (Hasson, Keeney, & McKenna, 2000). In Delphi studies aiming to develop guidelines, emerging convention is to accept 80-90% agreement that a guideline is 'important' or 'essential' as 'approaching consensus', and  $\geq 90\%$  as 'clear consensus' (Ager, Stark, Akesson, & Boothby, 2010). With the panel for the current study being smaller and more homogenous than many examples of this sort of Delphi, we chose to accept only 'clear consensus' ( $\geq 90\%$  agree it is important or essential) for a guideline to be endorsed in the final set after the three rounds.

Presenting the panel's Round Two responses as percentages in the Round Three survey rather than as central tendencies (such as mean, median or interquartile range) was a way of summarising important distribution variations for the experts with maximum clarity. This meant that any bimodal distributions would not be hidden (Powell, 2003). We did not remove guidelines for which there was consensus amongst the panel that they were 'not important' or 'not essential' in Round Two ( $\geq 90\%$  of respondents not rating the guideline as 'important' or 'essential'). This allowed all participants to see ratings and feedback for all originally proposed guidelines at Round Three.<sup>17</sup>

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<sup>17</sup> See extended paper 2.6.

Figure 1. Example of item from Round Three survey

<p><b>38.</b></p> <p><b>Encourage staff to champion the sexual rights of those they care for, since, by not affording these rights sufficient attention, organisations and clinical commissioning groups may not be affording staff the time and reflective space to properly consider and meet the sexual needs of clients.</b></p>					
	This guideline is not important at all	This guideline is not very important	I feel neutral towards this guideline	This guideline is important	This guideline is essential
How <b><u>the panel</u></b> answered in Round Two			14%	50%	36%
How <b><u>you</u></b> answered in Round Two				✓	
<p>Comments others made:</p> <ul style="list-style-type: none"> <li>• Need to look at how systems listens to staff.</li> <li>• I think it should be the other way – Commissioners and managers with greater power need to ensure space is given for this, rather than putting pressure on relatively disempowered staff to push for this.</li> <li>• The wording is a little cumbersome so not totally clear.</li> </ul>					

Round Three answer ( <i>Type an 'x' in <b>one</b> box</i> )					
Comment:					

## 2.7 Final guidelines.

The guidelines for which there was consensus amongst the panel that they were important or essential were included in a final list. In the absence of UK quality criteria for Psychology practice guideline development, the guidelines were developed in accordance with the American Psychological Association's (APA; 2015) 'Professional practice guidelines: Guidance for developers and users'. We amended all endorsed guidelines in response to the written feedback provided in both Round Two and Round Three. The primary researcher initially amended the guidelines before sending them to the other authors individually, whose feedback on the amendments was incorporated to produce the final versions. Each of these guidelines was supplemented with two clinical vignettes demonstrating the implementation of the guideline in two different ways.

The vignettes were based on the clinical experiences discussed during Round One. To develop the vignettes the primary researcher revisited the recordings of the Round One interviews. The stories and experiences that had been used by



panel members to justify and explain their proposed guideline were extracted and written up as vignettes by the primary researcher. Any potential identifiers were altered to preserve anonymity, but the nature of the anecdote was kept true to how the panel member had described it. Once completed, the vignettes were sent to the other authors who checked them for clarity. Any amendments made at this part of the process were to enhance the way in which the vignette operationalised the guideline, but the content was kept faithful to the panel members' original description. We believed that including the vignettes alongside each guideline would help make the guidelines resonate with the reader in a way that conventional written clinical guidelines often do not (Gabbay & le May, 2004, 2011; Wieringa & Greenhalgh, 2015).

In some instances, the panel member that had proposed a guideline offered multiple examples of when the action they described had been used in practice. In these cases, both supplemental vignettes were based on the interview data from just that panel member. For all guidelines, at least one of the vignettes was rooted in the clinical experiences the original proposer had discussed in Round One. However, in some instances the second vignette was developed out of the experiences discussed by another participant, if this appeared to provide a richer or more contrasting example of context for this practice.

Feedback from Round Three highlighted that knowledge of relevant laws and legislation (e.g. Mental Capacity Act 2005, Deprivation of Liberties Safeguards, Sex Offenders Act 2003) was considered as essential for Clinical Psychologists when embarking on work with care staff around sexual expression in PWID.

Therefore, an overview of these documents was included in the final guideline document (see appendix K).

We validated the finalised guidelines and vignettes through a process of 'member checking', in which all 17 original panel members were sent the final guideline document.<sup>18</sup> No amendments were requested by the panel. The guidelines have also been piloted by a Trainee Clinical Psychologist and shared with other Clinical Psychologists in their community learning disability team. Positive feedback was received regarding their usefulness.<sup>19</sup>

### **3 Results**

Twenty-three individuals expressed an interest in taking part. Of these, three did not meet the inclusion criteria (Assistant rather than Clinical Psychologists), and three did not respond to correspondence arranging a time for the first round of data collection. This left a sample of 17, our 'expert panel'. The experts were aged between 29 and 61 years (mean = 40.5 years), 12 women and 5 men. Experience working in intellectual disability services ranged from 4 to 37 years, with a median of 10.5 years (see table 1 for further demographics). The number of participants contributing to each round is summarised in a flowchart in figure 2.

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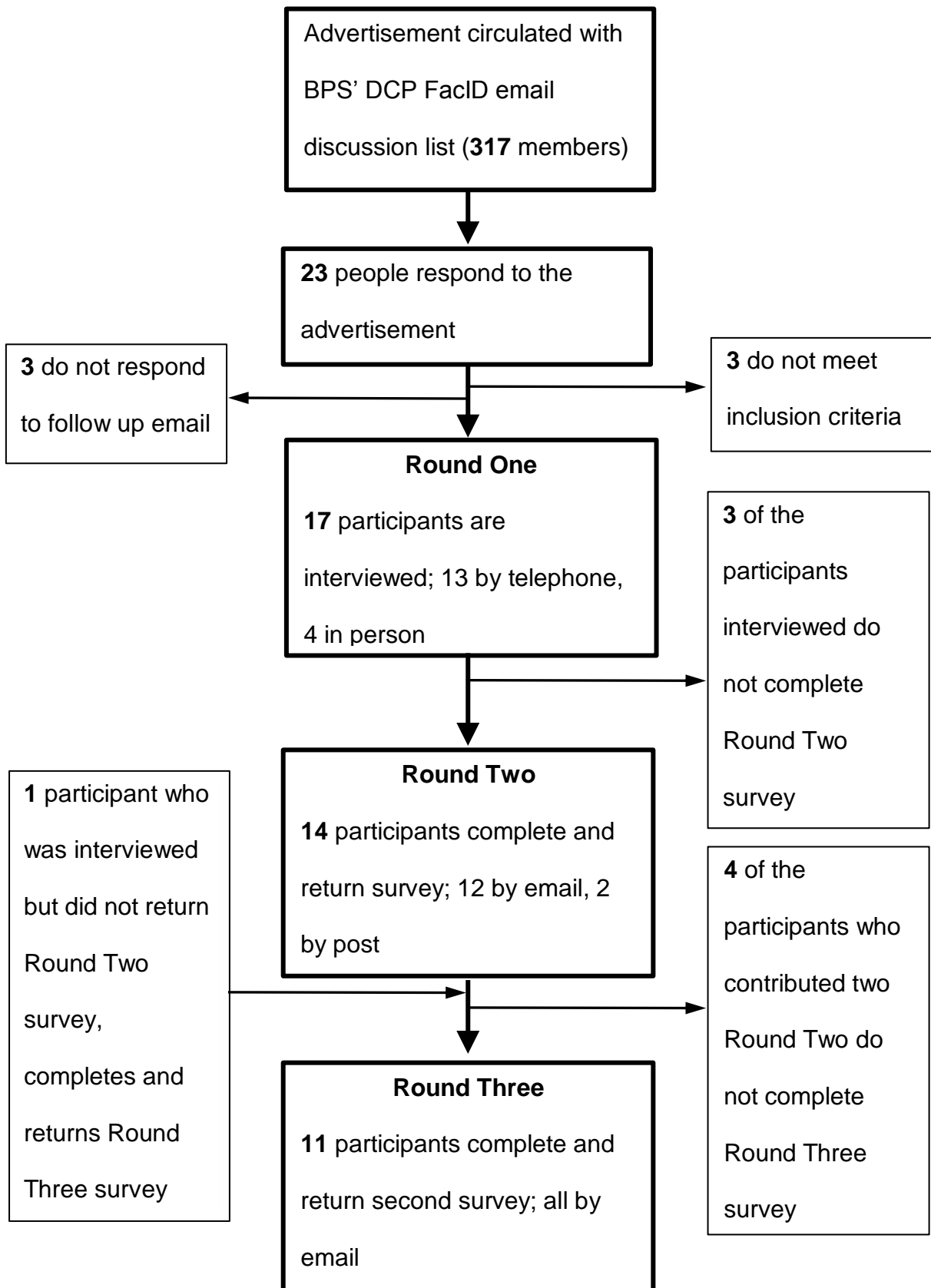
<sup>18</sup> See extended paper 2.8.

<sup>19</sup> For an overview see extended paper 3.4.

Table 1. Demographics of the expert panel (n = 17)

Age		Ethnicity		Sexual orientation	
20-29	1	White British	14	Heterosexual	14
30-39	9	White Scottish	1	Homosexual	2
40-49	4	White Irish	1	Prefer not to say	1
50-59	1	Indian British	1		
60-69	2				
Sex		Relationship status		Experience in ID services (years)	
Women	12	Married	7	1-9	6
Men	5	In a relationship	3	10-19	7
		Cohabiting	3	20-29	2
		Single	3	30-39	2
		Divorced	1		
Religion		Geographic location			
No religion	7	Berkshire	1	Staffordshire	1
Christian	4	Buckinghamshire	1	Surrey	1
Roman catholic	1	Cambridgeshire	1	Sussex	1
Quaker	1	Derbyshire	4	Yorkshire	1
Spiritual	1	Dublin, Ireland	1		
Agnostic	1	Fife, Scotland	1		
Atheist	1	Hampshire	1		
Agnostic atheist	1	Lancashire	1		
		Lincolnshire	2		

Figure 2. Flow chart of participant contributions



### **3.1 Round One.**

The 17 interviews lasted between 49 - 76 minutes. They generated 51 proposed guidelines. All participants were able to share multiple examples of clinical experiences of working with care staff members and teams, and to draw on these experiences to inform the three guidelines they proposed. To see all the proposed guidelines please contact the corresponding author.

### **3.2 Round Two.**

There was consensus agreement ( $\geq 90\%$ ) that 19 proposed guidelines were important or essential, with five achieving 100% consensus. For 12 of the proposed guidelines, responses were 'approaching consensus' (between 80% and 89% agreement) that they were important or essential. For the remaining 20 proposed guidelines, there was no consensus agreement.

All guidelines received at least one comment, with the most commented on receiving feedback from eight participants (mean = 3.49 per guideline). The number of guidelines commented on by each participant ranged from 0 to 35, with just one participant not offering any feedback. The mean of guidelines commented on by each participant was 13.14 (standard deviation = 10.35), though some offered their critique more readily than others (see table 2).<sup>20</sup>

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<sup>20</sup> Also see extended paper 3.2.

Table 2. Feedback comments provided in Round Two and Three surveys

No of guidelines commented on	Round Two respondents (n = 14)	Round Three respondents (n = 11)
0	1	4
1-10	6	2
11-20	4	1
21-30	2	2
31-40	1	1
41-51	0	1

### 3.3 Round Three.

Consensus agreement ( $\geq 90\%$ ) was reached that 12 proposed guidelines were either important or essential and were therefore endorsed as the final guidelines (see table 3). The endorsed set of guidelines were deemed to meet the quality criteria set out by the APA's (2015) guidance for practice guideline development by both the primary author<sup>21</sup> and an independent rater<sup>22</sup>. Of these, six obtained 100% consensus that they were important or essential. Responses were approaching consensus (between 80% and 89% agreement) for a further 15 proposed guidelines that were deemed important or essential. There was no consensus as to the importance of the remaining 23 proposed guidelines.

Though all of the guidelines again received at least a single comment, more of the comments were made by a small proportion of the participants in this round,

<sup>21</sup> See extended paper 3.3.

<sup>22</sup> A Trainee Clinical Psychologist who piloted the finalised guidelines. See extended paper 3.4.1 for an overview.

*Table 3. The guidelines endorsed for the final set and the level of consensus they reached (consensus percentages rounded to whole numbers for clarity)*

Theme	No.	Guideline	Level of consensus
Addressing staff attitudes.	1.	Normalise the sexual expression of people with intellectual disabilities; what to expect, that it can take a range of different forms (as can that of the general population), and what someone has a right to. This should be done not just in terms of feelings, but also things they have access to (e.g. online dating).	91%
Addressing uncertainty about rights and responsibilities of PWID.	2.	Ensure you have a working understanding of relevant law, such as the Mental Capacity Act (MCA) 2005 and Sexual Offences Act (SOA) 2003 (for those working in the UK). Be very clear with staff members about what capacity is and how it is assessed from the start. Staff need to be aware of relevant law in relation to capacity (e.g. MCA & SOA), but it is important to recognise that the complexities of its application can be very hard to grasp.	91%

	3.	The need to balance public protection with the rights of the individual must be understood by staff. An important element of this is not letting compassion for one's client obscure compassion for victims of inappropriate behaviour. Society deems some acts to be illegal (e.g. as stipulated by the Sexual Offences Act 2003 in the UK, which applies to everyone, including PWID). Staff should not be permitted to think that the presence of an ID pardons someone from breaking the law, or removes the damage their actions can cause others.	91%
	4.	Explicitly identify and agree where professional boundaries lie, giving staff members licence to have conversations about and support sexual expression with less of a feeling that they are making themselves vulnerable by doing so.	91%
Locating the problem, being part of the solution.	5.	Where there appears to be difficulties in supporting a PWID's sexual expression, gather the perspectives of multiple staff members to establish who this is an issue for and why. This should help to identify	100%



	<p>whether difficulties lie at the staff level, management level or organisation level, or any combination of these.</p> <p>Consent should be sought from the PWID to discuss their case with others, or where they lack capacity, a best interest decision made on whether this is necessary.</p>	
6.	<p>Where appropriate and useful for the case, take the time to get familiar with the organisation's/management's position statement on how clients' sexual expression is supported. If this is not operating in the best interests of the client, work with the organisation/management to explore ways this can be amended, and what it will take for their staff members to feel comfortable in abiding by this position statement (e.g., training for staff, reflective practice groups, team or individual clinical supervision).</p>	100%
7.	<p>PWID will sometimes want to do things that put them at a certain level of risk –</p>	100%

	<p>and will have the capacity to make the decision to do so.</p> <p>Adopting a shared risk-taking approach here – the staff, management, Clinical Psychologist and the PWID themselves agreeing that positive risk-taking in the current situation is in the individual’s best interests – can provide staff members with the permission and protection they often require to feel more comfortable in supporting the individual on such matters.</p> <p>Also, be clear with staff that supporting the individual in these more risky situations may require a certain level of agreed-upon intrusiveness, which again is permissible if it is in the best interests of the individual.</p>	
8.	Where appropriate for the case, organise workshops and training sessions for staff teams (including managers), in order to address gaps in understanding, their fears in working with these issues, and what can be expected of them. However, expected levels of change should be	100%

		appropriate to staff ability levels and the strength of their personal beliefs on the matter. If doing so, consider how you might gather practice-based evidence for the effectiveness of such interventions.	
	9.	Get to know what services and groups are available and accessible in your local area that can help individuals to meet people and socialise (such as nightclubs, dating agencies, voluntary services). Though this is not the sole responsibility of the Clinical Psychologist (a member of care staff should aim to do this also), it is important to model/encourage this where it is not occurring.	100%
Supporting care staff to understand and reflect upon their role.	10.	Normalise staff member's emotional reactions and prejudices. Work with staff to reflect on where these come from – what discourses they call upon (e.g. widely held beliefs about sexuality, about intellectual disabilities). Support staff to challenge any negative prejudices and reactions, or at least understand/incorporate different viewpoints.	100%

	11.	Support all staff members to consider the impact of high observation levels on sexual expression of PWID (e.g. does the PWID have privacy to masturbate, to spend time alone with another person?), and how this can affect the individual.	91%
	12.	Support staff members to not regard the person as the problem, but to also look at broader issues (i.e. their environment, the amount of privacy they get, the impact of how others respond to their actions). Encourage staff members to also consider risks when engaging in this process.	91%

*Note: One additional theme was identified that was not represented in the final guidelines: ('Reflections on one's own views and role').*

with four offering no comment on any guideline (see table 2). Only eight participants responded to the question at the end of the survey as to whether grouping the guidelines had seemed beneficial. Seven of those stated that it had been beneficial (88% consensus). With the low response rate, the researchers felt the 90% consensus threshold to be overly stringent for this item, and since there had been additional feedback provided in previous rounds that certain items should be placed together, we made the decision to group the finalised guidelines. On the question about whether the items had been grouped appropriately, the responses were more diverse. Of the four that

responded to this question, only one agreed with the themes suggested, and which guidelines had been allocated to them, with the others offering varying levels of suggested amendment. Therefore, we did not use the proposed grouping themes.

### **3.4 How consensus developed.**

Of the 11 respondents in Round Three, one did not contribute to Round Two, two made no alterations, one altered a single response, while another made amendments on four items. The other six panel members each made amendments on eight or more of the 51 guidelines. The alterations appeared to be evenly distributed across the guidelines, with no evidence for engagement with the process dropping in the later stages of the survey. Four of the endorsed guidelines had achieved 100% consensus for endorsement at Round Two, and maintained it at Round Three, despite some participants altering their responses. Two guidelines achieved 100% endorsement as a result of shifting responses.

When the overall responses from Round Two and Round Three were compared, it appears that less consensus was achieved in the final round, with fewer guidelines endorsed, more only approaching consensus, and more achieving no consensus at all. However, consideration of the results with outlying data removed (see table 3) offers a clearer picture of the process that was occurring in the group as a whole, particularly the distinct narrowing of the range of responses between the two rounds – the shift towards consensus

### **3.5 Consensus on overlapping guidelines.**

There were two instances when three guidelines had similar messages, and one instance when two guidelines did so. A number of participants did not respond to the question as to whether there was overlap amongst these guidelines (between one and three participants not responding to these questions in Round Two, and between three and four in Round Three). Despite a shift towards agreement occurring between Round Two and Round Three (see table 4), the responses did not reach the level of approaching or clear consensus criterion ( $\geq 90\%$ ) to indicate that the panel agreed that the guidelines said the same thing. Therefore, we left these guidelines as standalone items.

### **3.6 Finalised guidelines and clinical vignettes.**

Responses from the panel suggested that grouping the guidelines was helpful, but perhaps not in the manner offered in the Round Three survey. Through the process of organising the full list of original guidelines and comparing them in terms of overlap for the Round Two and Three surveys, the primary researcher identified them as falling under five themes (see table 2). The themes were discussed with the other authors and after minor amendments were made to the titles of some of the themes they were agreed by all. These were the themes used to group the finalised set of guidelines. The themes fell neatly into a linear order of when such principles might be considered within clinical practice. A fifth theme was also identified ('reflections on one's own views and role') but was not represented in the set that achieved consensus. Five guidelines fell under this

*Table 4: The level of consensus occurring across all guidelines, and range of responses by round (with and without outlier).*

	Round 2	Round 3	Round 3 with outlier removed
Consensus important (of which were 100%)	19 (15)	12 (6)	20 (9)
Approaching consensus important	12	16	15
Consensus neutral	0	0	0
No consensus	20	23	16
Consensus not important	0	0	0
Range of responses			
Spread of 2	5	6	9
Spread of 3	29	22	32
Spread of 4	13	9	9
Spread of 5	4	14	1

*Table 5: Responses as to whether certain guidelines appeared to represent the same content.*

Group of Guidelines	Round Two		Round Three	
	Yes	No	Yes	No
3, 4, 5	62%	38%	75%	25%
7, 8, 9	54%	46%	62%	38%
19, 20	73%	27%	67%	33%

theme, all of which carried a message relating to the importance of the Clinical Psychologist reflecting upon the way their own biases must be managed, and how the way in which they operate can influence the staff members with which they work. The feedback provided on these items (other than that which focused on wording, or whether the content had been covered elsewhere) alluded to a belief that the principles outlined should be evident in all work performed as a Clinical Psychologist, or that these things should be identified and addressed in supervision.

## **4 Discussion**

### **4.1 Summary of findings.**

This study drew on the clinical experiences of an expert panel of Clinical Psychologists in supporting care staff to support the sexual expression of the PWID in their care. Twelve guidelines were endorsed in the final Delphi round, making up the final set (see table 2). These guidelines fell into four overarching themes, under which the guidelines are discussed below.

### **4.2 Theme one: Addressing staff attitudes.**

Though this theme was represented in many different guises across eight guidelines in the full list, the panel's responses suggested that it was adequately captured within a single guideline. A common feature of these guidelines was that staff often needed to be given permission to see PWID as



having sexual needs and desires. The attitudes that care staff hold impact on the personal and professional care they give (Brown & Pirtle, 2008; Evans et al., 2009), and research suggests that care staff tend to report relatively liberal and accepting views about the sexuality of the PWID (Evans et al., 2009; Meaney-Tavares & Gavidia-Payne, 2012). However, Yool et al. (2003) and Saxe and Flanagan (2014) have suggested that these liberal views are held 'up to a point', but elements of discomfort remain. By endorsing guideline one, the panel appear to be suggesting that the 'point' that care staff's attitudes have been accepting 'up to' has not been sufficiently accepting to allow them to comfortably and confidently support the sexual expression of PWID in their care.

The panel reported most success in encouraging more accepting staff attitudes and practice when identifying the similarities between PWID and the general population in terms of sexual needs and desires. However, what appeared to distinguish guideline one from those that were not endorsed, was a focus on the difference between what PWID and the general population have access to, and opportunity for, as an outlet for sexual feelings and desires. Accepting that PWID have a right to opportunities for sexual expression and relationships puts the onus on frontline care staff to play a key role in facilitating these opportunities. The expectation to actively support sexual expression seems the greatest source of staff discomfort. This fits with suggestions from previous research that care staff often accept that PWID have sexual needs and desires, but struggle with what constitutes acceptable and appropriate sexual activity for this population (Cuskelly & Bryde, 2004; Fitcher, 2011; Swango-Wilson, 2010).

This appears to identify the 'point' up to which Saxe and Flanagan (2014) and Yool et al. (2003) suggest liberal and accepting views are held. Normalising the provision of opportunities for sexual expression identifies a way in which Clinical Psychologists could support this first step towards ensuring staff attitudes are more fully committed to upholding PWID's rights regarding sexual expression.

#### **4.3 Theme two: Addressing uncertainty about rights and responsibilities of PWID.**

Staff uncertainty about the application of laws and legislations governing matters of sexual expression was identified as an obstacle by all panel members. Furthermore, some panel members also disclosed personal confusion over their proper application. Feedback comments highlighted a common point of confusion as knowing in which cases the Mental Capacity Act (2005) or Sexual Offences Act (2003) are most relevant. This appeared to prompt the panel to ensure that the need for Clinical Psychologists to establish their own understanding of the relevant legal frameworks was highlighted (guideline two). They implied that without this consideration it would be difficult to guide and support care staff appropriately around this complicated issue. To simply expect that this understanding is already present and clear for everyone involved would be an oversight.

Understanding the legal framework within which they are expected to operate has been identified as a considerable source of anxiety for care staff (Rushbrooke et al., 2014b), and their lack of clarity may explain why their

reported accepting attitudes do not always lead to enabling practice (Abbott & Howarth, 2007; Saxe & Flanagan, 2016). Lyden (2007) has pointed to the need for care staff to receive support to feel comfortable and confident with the decisions they make within this legal framework, and this has been acknowledged by the endorsement of the guidelines within this theme.

Concerns around the risk of PWID perpetrating sexual offences have long been cited as a motivation for overly restrictive practice on the part of care staff (McCarthy, 1999; Rushbrooke et al., 2014b). However, guideline three highlights that there is also a danger of care staff being overly lenient in their responses to sexually inappropriate behaviour by those they care for. It is not uncommon for behaviours that constitute sexual assault to be 'euphemised' in the ID sector as challenging or sexualised behaviour (Murray & Powell, 2008), and here, a number of panel members quoted staff attitudes of "he doesn't know what he's doing", which seemed to minimise the seriousness of dangerous behaviour. This ultimately has the effect of removing a proportion of accountability from the perpetrator and foregoes the opportunity to educate the individual on the inappropriateness of the behaviour, and the alienation and negative consequences it elicits (Swango-Wilson, 2004). But, as has been stated by the inclusion of this guideline, such omissions are not acceptable. Not only because of the message the perpetrator receives (i.e., this action is permissible because I do not know what I am doing), but also the message the victim receives. If inappropriate behaviour towards them is not adequately addressed, this might perpetuate problems such as a lack of awareness among PWID that they are protected by law from being sexually abused (O'Callaghan

& Murphy, 2007). Guideline three suggests Clinical Psychologists need to be alert to, highlight, and discourage these processes.

A number of proposed guidelines under this theme suggested that care staff may need to be reminded that they have a responsibility to uphold PWID's rights to sexual expression. However, none of those guidelines were endorsed by the panel. The endorsed guidelines focused on the framework of what is permissible in terms of staff support. This suggests the panel overall felt able to assume care staff know of their responsibilities but found it necessary to be explicit with them regarding where professional boundaries lie when fulfilling those responsibilities. Clinical Psychologists should assume some responsibility by explaining to care staff what should be considered permissible (guideline four). If staff generally do hold accepting attitudes towards the sexual expression of those they care for, then supporting them to develop the confidence that they lack (Evans et al., 2009; Healy et al., 2009) may provide another positive step towards encouraging more enabling practice.

#### **4.4 Theme three: Locating the problem, being part of the solution.**

This theme was represented by more guidelines than the others, and all guidelines within this theme reached complete (100%) consensus. Guidelines within this theme sought to delineate the conceptualisation of the problem as lying mainly at the level of care staff, and to broaden the focus to consider the role that organisational factors play. Clinical Psychologists have a 'unique' skill set, which allows them to bring understanding of organisations at a systemic level, synthesising relevant literature and psychological theory (Health and Care

Professions Council (HCPC), 2015), which means they play a vital role in addressing multi-level problems. Guideline five highlights how this expertise should be used to take a broader perspective on what might not be working in an organisation in order to determine where to focus on nurturing change.

Many panel members reported encountering service-providers and managers that were reluctant or avoidant of establishing sex and relationship policies, guidance or care-planning for the organisation. This is reflective of recent research (Alexander & Taylor Gomez, 2017; Stoffelen et al., 2017) and is problematic since it provides a considerable systemic obstacle to care staff – they are either left to act ‘alone’ on personal beliefs, feeling uncertain or unprotected (Alexander & Taylor Gomez, 2017), or they fall in line with what they perceive the organisation’s (often restrictive) beliefs to be (Grace et al., 2017). Guideline six identifies the importance of gaining explicit understanding of the views and beliefs of the organisation as a whole, ensuring it is appropriate, and then getting them to commit to its implementation in a clear and transparent way.

Establishing a clear and healthy ethos about the sexual expression of PWID in their care prevents those at managerial and service-level from failing to acknowledge their culpability and allowing it to fall solely on the shoulders of the care staff. In order to maintain this approach, guideline seven highlights the need for all parts of the system supporting PWID to take on a role (and therefore some of the responsibility) in enabling their opportunity for sexual expression. Support needs regarding relationships and sexual expression vary

greatly depending on the individual's wishes and level of ability (English et al., 2017), and therefore person-centred, situation-specific approaches are generally required to address them (Herring & Wall, 2014). If care staff already hold accepting views, making clear to them what is expected and acceptable, and ensuring that they do not feel totally responsible when working in unfamiliar ways, could allow staff greater confidence to adapt their practice and meet the varying needs. Clinical Psychologists can also play a more direct role in this by modelling what 'enabling practice' might look like, as is set out in guideline nine. In this, the panel identified a way for Clinical Psychologists to be active in identifying and challenging the ineffective solution of not raising issues of the sex and relationship needs of PWID, with managers, care staff or PWID themselves.

More training for care staff was suggested to be important in guideline eight. This recommendation often comes up in research in this area, and since we have seen insufficient change in care staff practice, this may also be considered an ineffective solution. We are now in the fourth decade of studies recommending 'more training' for care staff (for early examples, see Brantlinger, 1983; Coleman & Murphy, 1983; Harvey, 1983), but the extent to which this has been acted upon is questionable. Though training improves staff attitudes around sexual expression in PWID (Brantlinger, 1983; McConkey & Ryan, 2001; Meaney-Tavares & Gavidia-Payne, 2012), care staff cite lack of training as the greatest difficulty to supporting sexual expression (McConkey & Ryan, 2001). Reported numbers of frontline care staff receiving such training run as low as 12% (Evans et al., 2009), with some authors reporting that training is

often not available at all (Rushbrooke et al., 2014b). Therefore, the inclusion of this as a guideline is unsurprising. However, in contrast to many of the studies previously making this recommendation, it appears here as one of twelve relatively diverse guidelines, highlighting how 'providing further training' can only be considered a small part of any potential solution for closing the policy-practice gap.

#### **4.5 Theme four: Supporting care staff to understand and reflect on their role.**

The guidelines within the final theme concentrated on supporting care staff to be conscious of their beliefs and values regarding the sexual expression of PWID, why they hold these, and the impact that working in line with them can have on those they support. These assertions reflect previous findings that the extent to which sexual expression in PWID is accepted is influenced by one's belief system (Brown & Pirtle, 2008; Löfgren-Mårtenson, 2004) and cultural orientation (Ditchman et al., 2017). Also, that care staff can benefit from being given a greater understanding of the extent to which these beliefs and values impact on the way they practice (Brown & Pirtle, 2008). Clinical Psychologists are trained to work in ways that enable other professions to think in psychologically-informed ways (BPS, 2010; HCPC, 2015), and supporting care staff to reflect in the way guideline ten suggests, highlights an effective way of modifying the anxieties that they hold. This allows care staff to acknowledge and address the personal barriers they have held around supporting certain complex individuals and issues (Wagnett, 2012).

Identifying and understanding personal biases also appear to have important links with the other guidelines within this theme. More conservative views about sexual expression in PWID are likely to be attached to scripts around protectiveness, which Swango-Wilson (2010) identified as increasing the likelihood that one would conceptually separate PWID from the wider social system. In doing so, the rights to opportunities and experiences held by those in the wider social system are less likely to be applied to PWID (Swango-Wilson, 2010), for example, the need for privacy (Löfgren-Mårtenson, 2004). Supporting staff to be aware of their own prejudices and biases therefore might be considered an important precursor to allowing them to appreciate the more systemic considerations the Clinical Psychologist should seek to address in guidelines eleven and twelve.

The endorsement of the guidelines in this theme further suggest that barriers to supporting sexual expression in PWID do still exist within the staff themselves (in the form of their views and beliefs). However, the panel acknowledges that this is not the entirety of the problem and identifies the role that Clinical Psychologists can play in facilitating change. Though interestingly, the panel did not endorse a guideline highlighting the need for Clinical Psychologists to reflect on their own values.<sup>23</sup>

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<sup>23</sup> See extended paper 4.1, 4.7.2, 4.7.3.



#### 4.6 Limitations.

Aside from those making contact from snowballing, the sample was recruited through the BPS's Division of Clinical Psychology, Faculty for PWID. However, not all Clinical Psychologists working in intellectual disability services choose to join the Faculty, and it is possible that those who choose not to do so share other characteristics or ideals from those who choose to join. Therefore, this level of homogeneity within the sample may be considered a limitation. The similarity of the sample was less clear in terms of the participants' flexibility. Participants appeared to vary in the number of responses they amended in Round Three based on the information provided about Round Two. Having not conducted any assessment of participant flexibility prior to the first round, it is not possible to determine the extent to which this diversity in level of movement was to be expected. The Delphi Method offers a way of facilitating collaboration that is suggested to quieten unhelpful group effects (Linstone & Turoff, 1975). However, it may be that those who are less open to seeing new positions or to noticing personal oversights, that have the greatest influence.

The small sample size also meant that outliers could have a greater influence, leaving us difficult decisions to be made as researchers. The responses of the participant that contributed to Round Three but not Round Two appeared to be masking the shift towards consensus that was occurring amongst the rest of the panel (see table 3).<sup>24</sup> It is testament to the democratic nature of the Delphi process that the views of participants are not discounted even if they cannot

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<sup>24</sup> See extended paper 4.2.

contribute to whole process, but this does leave the approach vulnerable to the limitation (as seen here) of a lack of consistency in approaches to responding across rounds.

It must also be acknowledged that there was no independent way of corroborating the effectiveness of the practice the Clinical Psychologists cited as evidence. During the interviews, the primary researcher questioned 'how' participants had known the clinical input they cited had been a success. This was generally met with discussions about changes in care staff approaches, services developing policies, or improved outcomes for the PWID. Therefore, the guidelines and vignettes are based on what the panel 'thought' had gone well, based on informal and subjective measures of outcome.<sup>25</sup>

#### **4.7 Clinical implications.**

Reflecting the recommendations increasingly emerging in much of the recent literature on the sexual expression of PWID, the findings here highlight the need for change to occur at all organisational levels, not just that of the frontline care staff, if the policy-practice gap is to be bridged. Clinical Psychologists occupy a level within the gap – understanding and contributing to overarching policy and legislation at national and service-level, whilst also working directly with PWID and those that care for them. Therefore, the profession has an obligation to ensure it is engaging in practice that supports the removal of barriers to the 'enabling practice' that the government's *Valuing People Now* (DH, 2009) states

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<sup>25</sup> See extended paper 4.7.1.

is required. The findings from this study provide a consensus-based framework for guiding Clinical Psychologists in doing so. The guidelines encourage those who consult them to consider the influence of all other organisational levels, and to appreciate the pressures that care staff experience as a result of not being adequately supported at these levels. They also encourage Clinical Psychologists to make strides towards nurturing change at these other parts of the wider system – particularly at management and service-level, since these parts should be considered as just as culpable for perpetuating the policy-practice gap if they fail to adequately support and protect their staff.

By adopting the principles of practice-based evidence, the study provides a model for how professionals can use their own practice and that of their colleagues as an indicator as to what is going well, and to prompt a search for new approaches. We hope that drawing attention to these processes can stimulate the initiation of new knowledge-creation cycles around supporting the sexual expression of PWID between colleagues, teams, and Clinical Psychologists more broadly.

#### **4.8 Future research.**

It would be useful for future research to explore the value of these guidelines. Firstly, we could explore their clinically utility; though they were developed out of clinical practice that had been experienced as effective, there is a vast range of service provision in Clinical Psychology across the UK, so they may be more useful for certain types of service than others. Secondly, the principles of

mindlines were used to inform the style and tone of the guidelines to make them more accessible, applicable, and easier to recall. Therefore, it would be valuable to assess how well they are retained at a six-month or year follow-up.

The overall aim of this study was to contribute to the narrowing or bridging of the policy-practice gap. However, it is more likely that sustainable change will be established if a multi-faceted approach is employed, removing obstacles at all organisational levels (Grol & Grimshaw, 2003). Therefore, future research should explore whether similar approaches to those used in this study could be used to establish some usable good practice guidance for other professions and organisational-levels. This would provide further prompting towards change at all levels.

In addition, research suggests that families often struggle to support the sexual expression of PWID and desire more support in doing so (La Grutta et al., 2009; Pownall & Jahoda, 2011). However, it was beyond the scope of this research to relate the guidelines to what families need also. Since issues that families experience will inevitably differ from that of formal caregivers, how families can best support the sexual expression of PWID in their care is an important area for future research.

#### **4.9 Conclusion.**

PWID continue to be denied knowledge and support around their sexual expression by care staff because they are perceived as too vulnerable or risky

(Rushbrooke et al., 2014b). But, equally they are vulnerable and risky because they are not given adequate knowledge and support. This circular pattern is maintained by care staff being charged with responsibility of upholding the rights of PWID to sexual expression, without adequate support to do so. The findings from this study have provided consensus-based guidelines to help Clinical Psychologists ensure they are contributing appropriate levels of support to care staff, and to thereby begin breaking this cycle. The guidelines also identify ways Clinical Psychologists can work to initiate change at other organisational levels. They set out approaches and considerations that are important for ensuring individuals at those levels (e.g. managers, service-providers and commissioners) begin to accept their responsibility for ensuring care staff feel supported and protected when supporting PWID's sexual expression. Therefore, Clinical Psychologists have a crucial role if the policy-practice gap is to be narrowed.

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## **Extended Paper**



## **1 Extended Background**

### **1.1 The shift in thinking about the sexual expression of PWID.**

The sexuality of people with intellectual disabilities (PWID) has historically been ignored or feared (Kempton & Kahn, 1991), with PWID generally viewed as either vulnerable, deviant, or simply asexual (for an overview see McCarthy, 1999; McRuer & Mollow, 2012). However, there has been a shift in this thinking, marked initially by the emergence of the 'normalisation' principle (Wolfensberger, 1972; Wolfensberger, 1983). This movement espoused PWID's right to an 'ordinary life', of which it is asserted that matters of sexuality should be considered a part (Robbins, 1990). The World Health Organization (WHO), identifies sexual expression as an inherent part of sexual health (WHO, 2006). Therefore, under article 25 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (2006), sexual expression should be considered a basic human right, and it states that governments are required to take action to ensure PWID are supported in doing so. The UK government first alluded to a need for the sexual expression of PWID to be supported in their 2001 'Valuing People' white paper (Department of Health, 2001). However, the paper's impotence in affecting change in the practice of clinicians and caregivers was hardly surprising considering mention of sexual needs amounted to just two sentences in a 149-page document. Identifying this shortcoming, in 2009 the government set out more explicitly, in 'Valuing People Now', that it is the responsibility of local systems and care services to 'enable practice' supporting PWID's choices around making and maintaining relationships (including sexual ones), as well as to marry, have civil partnerships, and to parent (Department of Health, 2009).

### **1.2 'Positive' attitudes to the sexual expression of PWID.**

There has been a considerable amount of research exploring attitudes towards the sexual expression of PWID, consulting a wide range of populations,

including parents (Cuskelly & Bryde, 2004; Evans, McGuire, Healy, & Carley, 2009), teachers (Brantlinger, 1992), students (Ditchman, Easton, Batchos, Rafajko, & Noopur, 2017), leisure industry workers (Gilmore & Chambers, 2010), the general population (Cuskelly & Gilmore, 2007; Karellou, 2003), as well as care staff (Evans et al., 2009; Grieve, McLaren, Lindsay, & Culling, 2009; Meaney-Tavares & Gavidia-Payne, 2012; Murray, MacDonald, Brown, & Levenson, 1999; Saxe & Flanagan, 2014; Yool, Langdon, & Garner, 2003). Often the findings of these studies are reported to indicate how 'positive' attitudes towards the sexual expression of PWID are. However, 'positive' is a value-laden term, and one that is not well defined within the literature. In their Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability) (ASQ-ID), Cuskelly and Bryde (2004) labelled agreement ratings of statements regarding the sexual needs and rights of PWID as 'more positive' or 'more negative', seeming to imply that liberal views are more favourable. Since then, a wealth of the research on attitudes to PWID's sexuality has utilised the ASQ-ID, and results are often consequently reported in terms of how 'positive' attitudes are. However, the term 'positive' infers that there is a good or correct attitude to hold, and that others are in some way inferior. The language appears to reveal the original researchers' bias. This fails to account for the fact that a wide range of views about what level of sexual expression is appropriate for PWID has been highlighted in previous literature, and that overly liberal views may not be positive if they result in responsibility and duty of care being neglected. Nonetheless, many researchers have adopted this language.

Allowing one's biases to influence one's research is not necessarily a bad thing, and can be an effective way of operating reflexively. However, transparency with the reader around what one's influences are and the role they played is essential in order for this approach to have value (Banister, 1999; Gergen & Gergen, 2007). Unfortunately, Cuskelly and Bryde (2004) provide no disclaimer regarding their own position in their paper introducing the ASQ-ID, nor is this addressed in later developments of the scale (Cuskelly & Gilmore, 2007). Many researchers since have utilised the ASQ-ID, and continue to report on how 'positive' attitudes are, without critiquing the implications of the term. In future research on attitudes towards the sexual expression of PWID, authors need to

be held accountable for the language they use. If value-laden terms such as 'positive' are to be used, they should be well defined and justified, or else terms that are less leading may be more appropriate, for example, reference to 'liberal' or 'accepting' views.

### **1.3 The discrepancy between staff attitudes and practices.**

Research suggests that care staff generally espouse relatively accepting and supportive views of the sexual expression of PWID. However, they appear to struggle to act in accordance with these views in practice, and consequently PWID continue to report being restricted. Psychological theory can be utilised to understand why care staff seem unable to practice what they reportedly preach. This discrepancy is explored using three different theories below.

#### ***1.3.1 Social desirability.***

The suggestion that care staff generally hold 'positive' attitudes towards the sexual expression of PWID is largely based on self-report data (Cuskelly & Bryde, 2004; Evans et al., 2009; Gilmore & Chambers, 2010; Meaney-Tavares & Gavidia-Payne, 2012; Saxe & Flanagan, 2014). The care staff providing this data were identified because of their role, and an important part of that role is to support those in their care to live 'a life like any other' (Joint Committee on Human Rights (House of Lords and House of Commons), 2008). This point will likely be at the forefront of many care staff members' minds following the string of abuse scandals regarding care staff for PWID that have come to light over the past three decades (e.g. the Longcare care homes, Budock Hospital in Cornwall, Winterbourne View). These things considered, it seems pertinent to question the extent to which the responses in the aforementioned research reflected what the care staff felt were the correct things to say, not necessarily their own beliefs and values.

The social desirability bias describes a tendency for research participants to provide an image of themselves that is favourable (Johnson & Fendrich, 2002).

The bias may not always represent an intention to deceive, as participants can sometimes believe what they report (a form of self-deception) (Huang, Liao, & Chang, 1998). None of the research on the attitudes of care staff regarding the sexual expression of PWID to date has included a measure of social desirability. Therefore, the extent to which the 'positive' attitudes often reported by care staff are representative of their personal beliefs and values arguably remains in question, particularly since research suggests care staff still engage in restrictive practice. There have only been two studies into the attitudes of professionals and care staff towards PWID more generally (i.e. not focused on sexual expression) that have included measures of social desirability (Strike, Skovholt, & Hummel, 2004; Yazbeck, McVilly, & Permenter, 2004), neither of which found significant links between more accepting attitudes and social desirability scores. However, it is to be expected that those working in the field would have accepting attitudes to PWID more generally, since it has often been found that level of contact with PWID is predictive of more positive attitudes to PWID (Seewooruttun & Scior, 2014; Werner & Scior, 2016). The sexual expression of PWID is a much more complex issue. Personal beliefs and morals can give rise to negative and restrictive attitudes about the matter, without making someone an ineffective or uncaring staff member overall. Therefore, this may be an issue upon which care staff often say what they believe they should, rather than what they believe. Until measures of social desirability are included in research on the attitudes of care staff towards the sexual expression of PWID this hypothesis remains untested.

### ***1.3.2 The principle of compatibility.***

An alternative explanation for the discrepancy between the attitudes that care staff report, and the restrictive practice that PWID report experiencing may be provided by the 'principle of compatibility' (Ajzen, 1988; Ajzen & Fishbein, 2005). The principle suggests that attitudes are better predictors of behaviour when both are measured at the same level of specificity. If the level of specificity of the attitude and behaviour are not well matched, then attitudes can be a poor predictor of behaviour.

Many of the studies that have reported the positive staff attitudes have done so through large-scale self-report questionnaires made up of generalised items. In fact, a majority have utilised the Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability) (ASQ-ID; Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007). The ASQ-ID poses statements about what is or is not appropriate or acceptable in terms of sexual behaviour for PWID generally (e.g. “Generally, adults with intellectual disabilities are able to make the distinction between sexual thoughts and sexual actions” (Cuskelly & Bryde, 2004, p. 263)), and asks participants to rate their agreement. In contrast, the evidence cited to highlight the continuation of restrictive practice consists of qualitative studies with very small samples of PWID (e.g. Bates, Terry, & Pople, 2016; Dinwoodie, Greenhill, & Cookson, 2016; Sullivan, Bowden, McKenzie, & Quayle, 2013), or autoethnographies (e.g. Löfgren-Mårtenson, 2004; Rogers, 2009; Wings-Yanez, 2014). When the findings from the two lines of enquiry are taken together (as they often are) they forge a confusing narrative of care staff having accepting and supportive attitudes to the sexual expression of PWID, but then contradicting these views in practice by denying those in their care this right. However, while the care staff are reporting views about PWID in general, the examples that are given by the PWID consulted have been much more specific in terms of time, place, service-context etc. Therefore, according to the principle of compatibility, the care staff attitudes would not be expected to be an effective predictor of care staff behaviour. It could therefore be argued that the attitudes that care staff hold towards the sexual expression of PWID in general is not where the problem lies. Consideration must be made of care staff attitudes towards the individuals they directly support. Exploring how these attitudes relate to the support they provide seems to be an important next step for research in the field. This has the potential to illuminate processes through which an individual can hold accepting beliefs about PWID’s sexual expression more generally, but feel that this may not be applied to a specific PWID in their care.

### **1.3.3 Theory of Social Representations.**

The social desirability bias and the principle of compatibility may offer explanation as to why the generally accepting attitudes that care staff claim do not match up with the support PWID report receiving. However, these explanations do not offer much insight into why care staff generally may be having difficulty fully embracing the shift in thinking on PWID's rights to sexual expression, and in putting shifts in policy into practice. Serge Moscovici's (1973, 1988) Theory of Social Representations provides a useful way of making sense of this issue. The theory provides a conceptual framework of how groups elaborate, transform, and communicate their social reality, which in turn influences how they operate in and on the world. Moscovici defines 'social representations' as:

"system(s) of values, ideas and practices with a twofold function: first, to establish an order which will enable individuals to orient themselves in their material and social world and to master it; and secondly to enable communication to take place among the members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their worlds and their individual and group history" (Moscovici, 1973, p. xiii)

Essentially, the theory of social representations proposes processes through which the unfamiliar is made familiar (Devenney, 2004). The theory is particularly pertinent for considering how sense is made of things which are not well understood (Moscovici, 1984), for example, the sexuality of PWID.

According to Moscovici (1981), social representations develop and evolve through communication between individuals or groups, in which they come to make sense of the phenomena in question. This occurs in the form of the interrelated processes of 'objectification' and 'anchoring'. Objectification describes a procedure through which a concept which is abstract, or novel is translated into more concrete or 'known' everyday realities. Anchoring is a process in which an abstract or novel concept is assimilated within the networks

of meaning that categorise familiar and understood concepts. In addition, three different types of social representation have been identified (Moscovici, 1988). Firstly, 'hegemonic' social representations are generally well-established at the large group or societal level. Hegemonic social representations manifest as common-sense knowledge that is taken for granted and tends to reside at the implicit level. 'Emancipated' social representations generally belong to sub-groups and are associated with specialized or scientific knowledge. They tend to provide amended or updated versions of existing hegemonic social representations, informed by new or deeper understanding. Finally, 'polemic' social representations are minority-held viewpoints, which generally conflict with the other social representations and are often the object of controversy.

In terms of PWID, the process of objectification would appear to have occurred with the rise of intelligence testing and the conceptualising of the 'mental age' which emerged across the 20<sup>th</sup> century. The idea of mental immaturity provided a concrete parallel through which PWID could be understood and conceptualised – as the perpetual child. Scientific measurement through psychometrics can be seen as an emancipated social representation of PWID. Provided by the early efforts of Binet and Simon (1905), through to the established psychometric products of Wechsler (2008), the acceptance of mental age as a cognitive measure became a central societal idea, and assimilated into the hegemonic social representation of PWID. It is in the process of anchoring of the newly established social representation that we can suppose the presumptions about the sexuality of PWID have traditionally been made. In assimilating the concept of PWID into networks of meaning associated with conceptualisations of children, matters of sexuality become inappropriate. The sexualisation of such individuals (the child and therefore the PWID) evokes fears of vulnerability or deviance – a conceptualisation of the sexuality of children being 'dangerous', which is rooted in the Victorian 'truth' discourses on sexual desire (Foucault, 1979).

For the past two decades care staff have been required by national and international policy (e.g. the Human Rights Act 1998, United Nations (UN) Convention on the Rights of Persons with Disabilities (2006)) to acknowledge

and support the rights of PWID to sexual expression. Though we have seen a shift to care staff holding more accepting views on this matter in that time, these views are only accepting 'up to a point' (Cuskelly & Bryde, 2004; Fitcher, 2011; Swango-Wilson, 2010). Furthermore, it appears that a similar shift has been occurring in the attitudes of the general public, with views becoming more accepting (Cuskelly & Gilmore, 2007), but with evidence that significant stigma remains (McConkey & Leavey, 2013). It therefore appears that despite a rise in more progressive thinkers campaigning for the sexual rights of PWID, these remain as emancipated or even polemic social representations, and have yet to elicit anything other than slight shifts in the prevailing hegemonic social representation. Nonetheless, the former have been enshrined in policy. This gives care staff clear indication of how they are supposed to think and feel, and this is reflected in the liberal and accepting views reported. The lack of support experienced in practice may be explained by staff holding more accepting 'explicit' attitudes, while their 'implicit' attitudes (evaluations that occur automatically and are less consciously accessible) are less accepting – a phenomenon that has been identified in recent ID research (Murch et al., 2017; Wilson & Scior, 2015). Such a process fits well with Moscovici's (1984) assertion that hegemonic social representations impose themselves upon us before we have time to think. Care staff may be attempting to follow new lines of thinking, but it does not yet reside at common-sense level for them.

#### **1.4 The competences of the Clinical Psychologist.**

The Clinical Psychologist's role goes beyond individual therapeutic intervention – they are expected to enhance the psychological well-being of service users through work at systemic levels (British Psychological Society (BPS), 2010). The BPS identify one of the core purposes of the Clinical Psychologist is to “undertake professional practice with individuals, groups, organisations and systems” (BPS, 2010, p. 2). With their skills in appraising and synthesising relevant literature, and their capacity to draw on a wide range of psychological theory, Clinical Psychologists are able formulate organisational problems at a systemic level (Health and Care Professions Council, 2015). This unique



combination of expertise equips Clinical Psychologists to provide insight in to why problems are occurring at a service, organisational, or societal level, and to develop solutions through research and intervention at various levels (BPS, 2010). Having formulated such problems, they are also equipped with the skills to implement applications and interventions to be carried out by others (e.g. care staff) (HCPC, 2015). With their unique skill set and reach across multiple levels of the health and social care structure, it is important that Clinical Psychologists strive to consider how they can support in the closing of the gap between policy and practice regarding the sexual expression of PWID.

### **1.5 Clinical Psychologists addressing sexual issues.**

The training that Clinical Psychologists receive on sexuality is markedly inconsistent in the UK, both in terms of breadth and coverage (Shaw, Butler, & Marriott, 2008). Many report difficulty in talking about the topic, and trainees often do not consider the sexuality of PWID without specific prompting (Butler, O'Donovan, & Shaw, 2010). These difficulties may be conflated by the existence of separate services for sexual health and sexual issues, implying specialist knowledge is needed (Kapp, 2011). Though some of the literature suggests that Clinical Psychologists struggling to address sexual matters is a long-standing issue (e.g. Byers, 2011), it by no means should be considered the case for all Clinical Psychologists. For example, Træen and Schaller (2013) have highlighted that Psychologists who have received supervision regarding sexual topics are generally more self-confident on the matter, and address those topics more often in their practice.

### **1.6 Practice-based evidence and evidence-based practice.**

Over the past 25 years, healthcare professions have exhibited an increasing commitment to evidence-based practice (EBP; Sackett, Richardson, Rosenberg, & Haynes, 1997) – a movement that seeks to ensure that clinical practice is informed by the latest research, either through direct consultation, or through evidence-based guidelines. The evidence base which healthcare

professionals are directed to call upon is predominantly made up of randomized trials, which prize standardization very much over ecological validity. This type of evidence may be appropriate for the field of medicine, where the mechanisms through which specific pathologies develop are relatively well-known (Green, 2008). However, such evidence is less applicable to Clinical Psychology in practice, where the development of the issues dealt with are unavoidably context- and culturally dependent. As a result of an over-emphasis on EBP, practice guidelines in psychotherapies are often perceived as irrelevant (Green, 2008), which has been perpetuating a gap between research and practice (Castonguay & Muran, 2014). The criticism that practitioners then receive for not implementing EBP informed guidelines, is unfair since the knowledge within them is decontextualized.

In contrast to the top-down process of EBP, Practice-based evidence (PBE) is an approach in which knowledge is established in the field at an individual and local level, complete with all of the contextual and cultural factors contributing to it. This evidence is then accumulated to develop a wider knowledge base. PBE has gathered increasing attention in the field of psychotherapy (Barkham, Hardy, & Mellor-Clark, 2010). Lucock et al. (2003) described how a commitment to systematically generating and utilizing PBE at a psychological therapy service-level allowed them to improve practice, through evidence tailored to their specific service context and needs, as well as fostering greater reflection in their therapists. The development of the transdiagnostic and 'pantheoretical' Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM; Barkham et al., 2001; Evans et al., 2002), has provided an accessible tool for services to shift towards PBE approaches. As well, developing a wider knowledge base, with many services across the UK committing to pooling data collected using the CORE-OM, as 'practice research networks' (PRNs; Barkham et al., 1998). PRNs provide a good illustration of how PBE should not be considered as an alternative to EBP, but an adjunct to it – PBE approaches merely seek to broaden the scope of the evidence accepted in EBP to maximise its relevance.

There has been less application of PBE to indirect work in Clinical Psychology, nor guidance for that practice. When applying PBE principles to practice more broadly, as opposed to direct individual psychotherapeutic intervention, a move away from overly linear processes of generating and disseminating 'rational' evidence remains important (Gabbay & le May, 2011). There is a need for evidence that can be incorporated into practice, rather than simply dictating it, and Fox (2003) has highlighted that it will take 'collaborative and transgressive research' to provide this. Our research was developed in line with these principles, and this is the lens through which the guidelines we have produced should be viewed and utilised. Not only should the guidelines be used by Clinical Psychologists to inform their practice, but they should equally be considered as a means of creating their own evidence on how a guideline can be best applied to the service-contexts and individual-contexts to which they apply them. Through this process, relevant evidence upon which to base one's practice can be developed, and the knowledge base grown by the social distribution of this evidence within services.

### **1.7 Clinical mindlines.**

Based on an immersive ethnography within GP practices, Gabbay and le May (2004, 2011) highlighted that healthcare professionals consistently demonstrate a tendency to react to a new or confusing problems not by consulting literature, policy, or standards of practice, but by turning to colleagues for informal consultation and/or by calling upon their own tacit understanding based on previous experiences. Through the amalgamation of lived experiences and shared anecdotal data healthcare professionals build clinical 'mindlines'; "internalized, collectively-reinforced, and often tacit guidelines" (Gabbay & le May, 2011, p. 44) about different issues. They will later call upon this tacit knowledge or share it with others, and mindlines will always be intuitively called upon when making rapid decisions in preference to clinical guidelines, which can be difficult to swiftly translate into practice.

The aim of this research is to help address the gap between policy and practice in supporting the healthy sexual expression of PWID, and by supporting care staff in developing their practice, Clinical Psychologists have a key role to play in this endeavour. In other areas where a policy-practice gap exists, for example children and health inequalities (Philip, Backett-Milburn, Cunningham-Burley, & Davis, 2003) and organisational responses to disabled parents (Crawshaw & Wates, 2005), findings have pointed to more interactive approaches to research on the issue, and the development of more innovative dissemination strategies as an effective way of addressing the discrepancy. Though the product of this research is a set of good practice guidelines, utilising the clinical mindlines paradigm as a conceptual framework for how the guidelines are developed and disseminated has allowed for a commitment to the interactive approach and innovative dissemination strategy needed. We have attempted to move away from the vague, dry clinical guidelines that Gabbay and le May (2011) found healthcare professionals so often passed over or forgot, and to harness the anecdotal and experiential knowledge that experts in the field hold, but can only share with colleagues in their immediate vicinity.

Our intention was foster the 'social distribution' of the experts' clinical mindlines (Gabbay & le May, 2011) beyond their usual reach (e.g. within their own service or department), and make them accessible to Clinical Psychologists across the UK. The Delphi Method provided a means of extracting this knowledge. But in order to increase the possibility that the guidelines will resonate in the way that mindlines do, the format of the guidelines needed to emulate that of the knowledge shared through mindlines. Levine and Bleakley (2012) suggest that this can be achieved in written guidelines if they take on the form of 'aphorisms' – "succinct sayings that offer advice" (p.153). Therefore, the guidelines have been kept faithful to the original wording of the participant who suggested them (only altered for grammatical clarity, or to assimilate feedback from the panel). Though not all of them are succinct, they are intended to be informal and conversational in tone. We also had to consider the various mechanisms through which knowledge becomes collectivised – the way in which mindlines develop. In a systematic review of knowledge exchange processes, Contandriopoulos, Lemire, Denis, and Tremblay (2010) identified that making

knowledge 'relevant' (timely, salient, and actionable), 'legitimate' (credible), and 'accessible' as key for maximising its chances of being collectivised. The vignettes attached to each of the guidelines provided a way of giving the guidelines more of these qualities; their relevance achieved by demonstrations of them in practice, their legitimacy provided by their basis in clinical experiences, and their accessibility demonstrated by the description of them being applied in multiple ways.

The knowledge we sought to obtain from the panel was not understood to be a set of concrete facts about what is good practice in working with care staff to support matters of sexual expression, but a set of ideas that could stimulate the initiation of a knowledge creation cycle. Nonaka (1994) describes how knowledge is not discovered and established, but should be considered as a 'multi-directional phenomenon' that is created and re-created by interchanges between people and groups in different contexts. In this respect, the guidelines are not intended to be an endpoint. They are not intended to be consumed as codified knowledge, implemented exactly as they appear on the page. But in consulting them, sharing them, and discussing them, we are intending for them to 'maximise the opportunity to create knowledge' (Wieringa & Greenhalgh, 2015), and for the Clinical Psychologists that use them to further develop the 'knowledge' with their colleagues by translating it to the context of their own service. It was this line of thinking that inspired the inclusion of more than one vignette to each guideline.

## **2 Extended Method**

### **2.1 Alternatives to the Delphi and why it was chosen**

There have been a number of consensus building methods developed over the latter half of the twentieth century, which range from the informal to the highly structured. Perhaps the most basic is the 'Interacting Group Method' (IGM). The IGM involves a moderator establishing a problem of focus and asking a selected group to discuss it (Van de Ven & Delbecq, 1974). The approach ultimately amounts to a mind-mapping session that reaches its conclusion when

the group are in agreement as to a solution, often through majority vote (Clayton, 1997). At the other end of the scale is the highly formal methods developed by American National Institute of Health (Fink, Kosecoff, Chassin, & Brook, 1984). One such example is the 'consensus conference group' approach, which consists of a selected group of experts in a given field (usually around 10) being presented to by various other experts or interest groups. The process takes place over the course of several days, with the selected group being given time to go away and deliberate what they have been presented. Both the presentation and the deliberations are chaired, and the process completes with a judicial style decision being made by the selected group.

More commonly used for the development of clinical guidelines, particularly in healthcare fields, are the 'Nominal Group Technique' (NGT) and the 'Delphi method', both of which aim to counteract group effects which might inhibit contributors from feeling they can speak freely. Developed by Delbecq and Van de Ven (1971), the NGT consists of a group selected for their interest or investment in a particular topic being brought together. Initially, group members record their ideas on the issue in private, before all ideas are anonymously fed back to the group by the facilitator for discussion one by one. Following the discussion, individual group members then record their judgements on the ideas (again in private) and anonymously vote on which they favour. The aim is to achieve consensus on the matter by the group being influenced by discussion as to solutions they do and do not agree with and why.

Though each of the above approaches was considered when developing this research, the Delphi method was selected as it appeared sophisticated enough that its findings would be respected, and that it could be conducted pragmatically without the needs for vast numbers of recruits or bringing a group together in one place. With the topic of helping care staff support the healthy sexual expression of PWID being relatively niche, we acknowledged those with a special interest in the topic would likely be dispersed geographically. The Delphi method provided the opportunity to pool the expertise of a nationwide sample, which could report experiences from different service set ups, while still providing a replicable approach.

## **2.2 The Delphi method.**

In a Delphi study a 'panel' of individuals considered 'experts' on the topic being explored are sent a sequence of carefully designed surveys (known as 'rounds'), which include the summarized responses and opinions of the entire panel from preceding rounds. The experts are given the opportunity to amend their responses in light of the information about how others answered. In the current study we utilised a 'classical Delphi' approach, which has the intention of establishing consensus and/or stability of panel responses, in this case on how Clinical Psychologists can best aid staff teams in supporting the healthy sexual expression in the PWID with which they work.

We conducted the study across three rounds. Delphi literature suggests that a level of consensus can often be achieved within this, and beyond three rounds attrition rates rise owing to participant fatigue with the process (Brooks, 1979; Custer, Scarcella, & Stewart, 1999; Cyphert & Gant, 1971; Sumsion, 1998; Walker, 1994; Walker & Selfe, 1996).

## **2.3 The Delphi method and group effects.**

It is thought that decisions made by groups of experts tend to be more reliable than that made by an individual (Murry Jr & Hammons, 1995), and that informed opinions of groups of experts are more objective than that of the individual (Franklin & Hart, 2007). Hill's (1982) 'N + 1' principle holds that a group will perform more effectively than their best member. Countering this principle, Steiner (1972) had previously highlighted evidence suggesting that the influence of the presence of others in the group leads to 'process loss'. However, one of the defining characteristics of the Delphi method – the anonymity of contributors – directly addresses the group effects, since the experts do not know who the other responses and comments belong to (Linstone & Turoff, 1975). Effects such as the impact of status and social desirability, and 'groupthink' (Janis, 1982) common in meetings or group tasks

are minimised through the anonymity (Charlton, Patrick, Matthews, & West, 1981; Dalkey, 1972; Goodman, 1987; Rudy, 1996; Sumsion, 1998). In line with this, Rowe, Wright, and Bolger (1991) suggest that the democratic anonymity of the Delphi approach has potential to circumvent 'process loss' effect, ultimately harnessing the power of the shared wisdom for 'process gain', should the Delphi process be carried out in a rigorous and valid manner.

#### **2.4 The design of the Delphi rounds.**

The first round of a Delphi study is traditionally open-ended, extracting information about the area of interest from the expert panel themselves (Custer et al., 1999). However, this approach is increasingly being discarded in more recent Delphi studies. Instead, it is becoming more common to identify key areas of interest or importance related to the topic in question by reviewing the current literature, and to develop Round One surveys based on this information (e.g. Balogh, Ouellette-Kuntz, Brownell, & Colantonio, 2011; Berk, Jorm, Kelly, Dodd, & Berk, 2011; Chen, Fetzer, Lin, Huang, & Feng, 2013; Creamer et al., 2012). We believe that this trend should be accepted with caution, since the information that the researcher provides to the experts can impact the way in which they respond. Therefore, the risk of introducing researcher bias through this process potentially compromises the validity of the approach. Furthermore, one of the main strengths of the Delphi method is that it provides a means of developing understanding on topics with little established literature (Martino, 1972), and topics that are rapidly changing (Patton, 2001). Feeding information into Round One from existing literature minimises the opportunity for new knowledge to be created, and can be considered as a failure to capitalise on what separates the Delphi method from the common survey approach – the prospect of exploring what 'should/could be' rather than 'what is' (Miller, 2006). One of the main aims of the current study was to draw together experiences and expertise that have been occurring in geographically dispersed and isolated contexts, in order to provide practice-based methods of addressing the longstanding gap between policy and practice when it comes to supporting the sexual expression of PWID. Since the relevant literature offers little as to how



this might be done, in the current study Round One was used to elicit information from the experts themselves in order to develop the items for the Round Two survey.

Okoli and Pawlowski (2004) and Schmidt (1997) both identify that the interpretations that the researcher makes when translating the Round One data into the Round Two survey as also potentially compromising the validity of the Delphi process. They state that any interpretations should therefore be member checked before proceeding to Round Two. Overcomplicating the procedure in the early rounds can make Delphi studies inefficient in terms of time (Procter & Hunt, 1994). It can also put considerable distance between the experts' contribution in its original form, and how it appears in subsequent surveys. For example, if a qualitative analysis is performed on the Round One contributions and 'themes' used as survey items at Round Two. For this reason, we felt it more valid to input data from Round One directly into Round Two untreated, meaning no interpretation was carried out at this stage, thereby minimising room for potential bias.

## **2.5 The expert panel.**

Delphi studies have been performed with as few as 4 and as many as 3000 participants (Thangaratinam & Redman, 2005). However, the quality of the representation is assessed in terms of the expertise of the panel rather than the number of 'experts' making up that panel (Powell, 2003). Murphy et al. (1998) suggest that improvements in reliability once the number of experts in the panel rises above 15 are negligible. Therefore, owing to the homogenous sample of the current study, and the narrow focus of the research, it was justifiable to make the pragmatic decision to recruit 15-20 participants.

The lack of consistency over how the 'expert' selected to participate in a Delphi study should be defined is an often debated element of the approach (Hasson, Keeney, & McKenna, 2000). Goodman (1987) suggested that the experts should be specialists in their field, whereas others have discussed how

selecting 'informed individuals', who have knowledge about the specific topic being investigated is sufficient to conduct a useful Delphi (Davidson, Merritt-Gray, Buchanan, & Noel, 1997; Green, Jones, Hughes, & Williams, 1999; Lemmer, 1998; McKenna, 1994). In addition, Keeney, McKenna, and Hasson (2010) state that the expert panel should be made up of individuals with not only good theoretical knowledge of the focal area, but with clinical experience of the problem. In keeping with the practice-based evidence framework of the current research, this assertion is particularly pertinent. It informed our decision to seek a panel of qualified professionals who are part of a special interest group in this area (therefore highly knowledgeable) that had clinical experience of working with staff teams around the issue of supporting healthy sexual expression in PWID.

## **2.6 Removing items during the Delphi procedure.**

We did not remove guidelines from the Round Three survey even if there had been consensus at Round Two that the guideline was not 'essential' or 'important'. This was a slight departure from emerging convention in Delphi studies. This was motivated by the fact that decisions about criteria for removing guidelines between rounds are unavoidably arbitrary – there are no established guidelines for doing so within the Delphi literature. Consequently, decisions made by those conducting a Delphi run the risk of biasing the range of opinions occurring across rounds (Hasson et al., 2000). The information provided to the panel in each round is thought to influence their subsequent responses (Cyphert & Gant, 1971; Dalkey & Helmer, 1963; Schiebe, Skutsch, & Schofer, 1975). Therefore, removing items without allowing the panel to change their views in response to seeing those of others could be argued to be forcing consensus rather than letting it occur. In support of this understanding it has been found that including all arguments provided by all participants produces more accurate results (Murphy et al., 1998).

## 2.7 Delphi quality criteria.

Diamond et al. (2014) conducted a systematic review of how consensus is operationally defined in Delphi studies. From this study, they produced a set of quality criteria for the reporting of studies using a Delphi approach. We utilised this quality criteria to guide the undertaking and reporting of this research. Table 5 documents the extent to which the study meets those criteria. All of the applicable quality criteria are evidenced within the report.

*Table 6. Evidence of how Diamond et al.'s (2014) quality criteria for reporting a Delphi were met.*

Criteria	Evident in this report?
Study objective	
Does the Delphi study aim to address consensus?	Yes.
Is the objective of the Delphi study to present results (e.g., a list or statement) reflecting the consensus of the group, or does the study aim to merely quantify the level of agreement?	Consensus of the group was established as to which guidelines were important and should be endorsed.
Participants	
How will participants be selected or excluded?	Inclusion criteria: Experience working in ID services. Exclusion criteria: Not a qualified Clinical Psychologist.
Consensus definition	
How will consensus be defined?	≥90% agreement that an item is essential or important.
If applicable, what threshold value will be required for the Delphi to be stopped based on the achievement of consensus?	N/A.

What criteria will be used to determine when to stop the Delphi in the absence of consensus?	Delphi to be stopped after three rounds as this should be sufficient to achieve consensus (Stone Fish & Busby, 2005).
Delphi Process	
Were items dropped?	Yes, following the final round.
What criteria will be used to determine which items to drop?	If there is not consensus that the item is essential or important.
What criteria will be used to determine when to stop the Delphi process or will the Delphi be run for a specific number of rounds only?	The Delphi will run for three rounds.

## 2.8 Member checking.

The 51 guidelines included in the Round Two and Three surveys (3 from each participant) were transcriptions of the guidelines that had been proposed during the Round One interviews. Following the completion of the three Delphi rounds, the 12 guidelines that had been endorsed by the panel were slightly amended to ensure grammatical clarity, and to incorporate the panel's feedback. Despite only being minor, the fact that these amendments were made following the final round meant it was necessary to validate the final guidelines with the panel. We achieved this through a process of 'member checking', aiming to ensure the credibility of the study (Birt, Scott, Cavers, Campbell, & Walter, 2016). In line with Cresswell's (2009) assertion that member checking is best undertaken with 'polished', interpreted data, the endorsed guidelines were emailed to panel members presented in their final form, in which they are intended to be disseminated in, along with the supplemental vignettes. All participants were sent the finalised document, regardless of how many rounds they had contributed to. Though we invited comments and objections, we stated that there was no need to respond if the final guidelines were deemed accurate and acceptable. Four responses were received, none of which featured any

objections to the guidelines or vignettes, and all of them extended gratitude for keeping the participant informed. Since the endorsed guidelines remained acceptable to the panel, this suggests that the minor amendments made did not affect the validity of the research - the level of consensus and endorsement was retained.

### **3 Extended Results**

#### **3.1 Demographics**

Though there was representation from across the UK and Ireland, the panel was relatively homogenous in terms of their demographics. A majority of the panel members were under 39 years of age, but over two thirds of them had more than ten years of experience working in ID services. For many panel members this included between one and three years pre-qualification. The panel predominantly identified as heterosexual, with two members identifying as homosexual and one preferred not say. However, all professed accepting views of the diversity of sexual orientation. Just four of the panel members were not in a relationship at the time of the study, with most being married. Though a high number of panel members did not identify with a religion, there was Roman Catholic, Christian, Quaker, and Spiritualist representation. Just one panel member was of non-white ethnicity.

#### **3.2 The nature of feedback provided.**

The content of the written feedback provided fell broadly under similar themes across the two rounds (see table 6). However, the proportion of comments falling under each theme shifted somewhat. Panel members had seen the Round Two comments of rest of the panel when completing Round Three, and consequently 49 Round Three comments (28%) made explicit reference to the comments of other panel members. It was common within these comments for panel members to endorse statements others had made, particularly regarding the wording of the guideline (e.g. "I agree with the comments about reducing jargon..."), or a need for greater context to aid the clarity of the guideline (e.g.

“Agree with keeping things focuses to an individual’s personal circumstances, need, desires and risk.”). Other comments voiced disagreement with the feedback provided by other panel members (e.g. “Whilst I appreciate the comments of the those above, I think it’s an important an issue to have someone take on this role.”).

Only 13 comments offered explicit feedback on why the panel member had chosen to amend their response or not, despite there being a total of 69 responses amended between Round Two and Three. However, within the context of the personalised survey it was often apparent in the feedback that was given why a shift may or may not have occurred.

*Table 7. Incidence and themes of written feedback comments from Round Two and Three surveys*

	Round Two	Round Three
Total members contributing to the round	14	11
Total written feedback comments made	158	176
Feedback theme		
Agreement with guideline	24%	15%
Wording	12%	21%
Suggested improvement	17%	10%
Disagreement with guideline	16%	10%
Overlapping with other items	16%	14%
More detail or context needed	12%	17%
Clinical Psychologists should be doing this in all practice	7%	10%
Not Clinical Psychologist’s role	2%	3%

The higher incidence of comments about wording at Round Three appeared to be a product of our decision not to amend guidelines between rounds, as we wanted the panel to be rating the same thing on both occasions. This gave a greater indication of how strongly the panel felt about that wording and allowed for more feedback to inform the tidying of the guideline into its finalised form, if

endorsed. The issue of guidelines being identified as needing more detail or context was also something that we were able to cater for, through the addition of the vignettes. These comments often focused on how the guideline might be applied, which the vignettes were intended to demonstrate. However, they weren't applied until the final set of guidelines had been agreed upon by the panel.

Overall, the written feedback comments suggested that the panel engaged well with the Delphi process. The panel interacted across the rounds and appeared to respond to the new information emerging in each round.

### 3.3 Assessment of guideline quality.

The BPS does not offer any specific quality criteria for the development of practice guidelines. NICE provide 'quality standards and indicators', but since they have been developed to scrutinise clinical evidence-based guidelines for specific conditions, they are a less appropriate measure of practice-based guidelines. Consequently, we used the American Psychological Association's (APA; 2015) 'Professional Practice Guidelines: Guidance for Developers and Users' as quality criteria to develop our guidelines in line with. Table 7 highlights the extent to which each of the required attributes are evident in the guidelines.

*Table 8. Evidence that the guidelines met the APA's (2015) professional practice guidelines quality criteria.*

Guideline attributes	Evidence
<p><b>Need</b></p> <p><i>“Professional Practice Guidelines” are encouraged (and approved) only for areas with a clearly demonstrated and documented need.</i></p>	<ul style="list-style-type: none"> <li>• Literature on the policy-practice gap.</li> <li>• Absence of guidance/policies for Clinical Psychologists working on sexual expression through care staff.</li> <li>• Anecdotal from pilot.</li> </ul>

<p><b>Respect for human rights and dignity</b> <i>“Professional Practice Guidelines” reflect sensitivity to cultural, individual, and role differences among psychological service-providers and their client populations, including but not limited to those due to age, gender, race, ethnicity, national origin, religion, sexual orientation, disability, language, and socioeconomic status.</i></p>	<ul style="list-style-type: none"> <li>• Aim to ensure PWID’s human rights are upheld.</li> <li>• Accepting of diverse values regarding sexuality.</li> <li>• Safeguarding considerations present within guidelines.</li> <li>• Indiscriminate of sexual orientation.</li> </ul>
<p><b>Delineation of scope</b> <i>“Professional Practice Guidelines” have a clearly defined scope in terms of content, users, and context. “Professional Practice Guidelines” are focused on professional practice rather than specific disorders or treatments.</i></p>	<ul style="list-style-type: none"> <li>• Developed for use by Clinical Psychologists in their work with care staff.</li> <li>• Focused on Clinical Psychologist practice regarding PWID sexual expression broadly.</li> </ul>
<p><b>Avoidance of bias</b> <i>“Professional Practice Guidelines” avoid bias or appearance of bias through consideration and/or integration of alternative views during the development and review process, when guideline developers are expected to provide the reasoning behind their decisions and judgments and ensure citations of relevant literature.</i></p>	<ul style="list-style-type: none"> <li>• Incorporated the views of Clinical Psychologists from a range of services.</li> <li>• Potential bias towards views that uphold PWID’s rights to sexual expression.</li> <li>• Identifies the rights of those that may be impacted by inappropriate behaviour.</li> </ul>
<p><b>Educational value</b> <i>“Professional Practice Guidelines” inform psychologists, the public, and</i></p>	<ul style="list-style-type: none"> <li>• Helpful for Clinical Psychologists and care staff.</li> </ul>



<p><i>other interested parties regarding desirable professional practices.</i></p>	<ul style="list-style-type: none"> <li>• Identifies important professional considerations (respect for PWID; respect for care staff; safeguarding; laws and legislations).</li> </ul>
<p><b>Internal consistency</b> <i>No part of the practice guideline conflicts with any other part in intent or application.</i></p>	<ul style="list-style-type: none"> <li>• Fit within themes that were present across the entire original list.</li> <li>• Found to be consistent by participants (including member checking), research team, and pilot.</li> </ul>
<p><b>Basis</b> <i>“Professional Practice Guidelines” take into account the best available sources on current theory, research, and professional literature and the APA Ethics Code so as to provide a defensible basis for recommended conduct.</i></p>	<ul style="list-style-type: none"> <li>• <i>“In some areas, expert professional consensus is the strongest form of evidence available” (APA, 2015, p.826)</i></li> <li>• In line with BPS code of ethics.</li> </ul>
<p><b>Flexibility</b> <i>“Professional Practice Guidelines” recognize the importance of professional judgment and discretion and do not unnecessarily or inappropriately limit the practitioner.</i></p>	<ul style="list-style-type: none"> <li>• Vignettes demonstrate and encourage the use of professional judgement when utilising the guidelines.</li> </ul>
<p><b>Feasibility</b> <i>Implementation of the particular “Professional Practice Guidelines” is feasible in the current practice environment. Following the guidelines should not place an excessive educational or financial</i></p>	<ul style="list-style-type: none"> <li>• Suggestions for workshops, training and input with staff teams do not exceed that outlined in Clinical Psychologist core competencies.</li> <li>• It is noted in the guideline document that not all of the</li> </ul>

<p><i>burden on psychologists beyond that of commonly agreed upon best practices.</i></p>	<p>guidelines will be relevant to a reader's context.</p>
<p><b>Compatibility</b>  <i>"Professional Practice Guidelines" take into account current APA policies and must be consistent with the APA Ethics Code.</i></p>	<ul style="list-style-type: none"> <li>• In line with BPS code of ethics.</li> <li>• A number of the guidelines allude to the importance of the Mental Capacity Act 2005, Sexual Offences Act 2003, and Deprivation of Liberty Safeguards.</li> </ul>

### 3.4 Evaluation of the guidelines.

#### 3.4.1 Piloting of the guidelines by a Trainee Clinical Psychologist.

The guidelines were piloted by a colleague of the author on the doctoral training programme. The colleague was given a copy of the guidelines, with no further instruction issued. The guidelines were used to inform a piece of work on her ID placement in a community learning disability team (CLDT) and were discussed with other Clinical and Assistant Psychologists in the team. I collected feedback on the use of the guidelines through an interview which lasted 36 minutes. The interview consisted of asking for an overview of the use of the guidelines, and a set of questions based around the American Psychological Association's (APA; 2015) 'Professional practice guidelines: Guidance for developers and users', which were consulted as quality criteria for the guidelines (see appendix L for summary of interview responses).

The team had received a referral from the manager of a private care company that support PWID in the community, stating that the staff team were becoming uncomfortable working with a particular service user and his 'sexual interests'. The trainee took on the case and worked with an Assistant Psychologist to

deliver a three-hour session for the staff team focusing on these difficulties, using the guidelines to develop and plan the session. The session was attended by support staff, team leaders and managers.

The main ways in which the trainee reported that the guidelines had been helpful were:

- Care staff appeared less tense once their discomfort, and their values and beliefs were normalised.
- Care staff and the Psychologists felt more confident to explore different ways of working and to make different decisions, since the guidelines gave something 'more concrete' to back them up with.
- The guidelines had encouraged her to explore with care staff 'why' they held the beliefs they did, and to see the impact of the acting in accordance with restrictive beliefs.

Formal outcomes for the input were not taken. But, as a result of the input it was reported that the care staff had committed to the adapting their practice to ensure considerations about sexual expression were being made, policies and personal care plans were amended to incorporate sexual and relationship needs, and the team set up a monthly speed dating event.

Interestingly, without being directly asked, the trainee reported that consulting the guidelines prompted her to reflect on her own beliefs and values regarding the sexual expression of PWID. Despite having years of experience of working with PWID (as an Assistant Psychologist and a healthcare assistant), the trainee reported that she had failed to pay much thought to their sexual needs and desires in the past. This suggests that though no guidelines were endorsed about the need for Clinical Psychologists to reflect on their own values (despite being suggested), the process of using the guidelines may in itself foster such reflection.

Responses on second part of the interview suggested that the quality criteria for the development of good practice guidelines has been met.

### ***3.4.2 Sharing the guidelines with a Consultant Clinical Psychologist.***

Once the guideline document was finalised, I also shared it with a local Consultant Clinical Psychologist who has many years of experience in working in services for PWID. Though he did not have an appropriate case to use the guidelines for at the time, he went through them and offered his critique. Below is the feedback he provided<sup>26</sup>:

*Hi Brad,*

*You have produced some really positive, helpful guidelines, which hark back to some brilliant days in the '90's when Ann Craft led the way for the rest of us to follow. The vignettes are very constructive and offer a wide range of options for psychologists to approach relationship issues that might arise in their work. I particularly like the Locating the problem, being part of the solution section, too, as that sets the context for all staff to work within.*

*If I have one negative note, it is that the vignettes largely describe partial stories and don't always complete the sequence of events after the psychologist has intervened, so the end result is not evident for the reader to recognise as a consequence of the intervention. I hope that isn't too picky!*

*Sorry I have not had a better chance to road test the guidelines, but I will hang on to them and see if I can do so in the coming weeks.*

*Good luck with the write up!*

*Cheers*

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<sup>26</sup> Consent was obtained from Dr John Robertson for his name and email correspondence to be included in the extended paper of this thesis.

*John*

*John Robertson*

*Consultant Clinical Psychologist*

John's feedback appears generally positive, and he suggests they appear to have value for using in practice since he wished to hold onto them to test them out in future.

In response to John's 'negative note', the reasons that the vignettes often do not go much further than the intervention delivered are twofold. Firstly, many of the clinical examples panel members described did not include extensive information about the sequence of events that occurred following their input. When they discussed the changes in care staff attitudes and outcomes for PWID during the Round One interviews, the panel members reported having generally learned of this through follow up meetings with care homes (care staff or managers) or service users (PWID). The panel members had not been present to witness the sequence of events after the intervention, but would hear enough about the improvements in the case to see that the intervention had been of some benefit. I did not wish to construct material outside of the clinical examples provided.

Secondly, the guidelines are intended to be used flexibly and applied to different service contexts. If the vignettes were too in-depth they run the risk of being interpreted as concrete approaches that must be followed regimentally, or irrelevant to certain service contexts. Furthermore, their flexible nature is intended to spark knowledge creation cycles amongst the professionals using them. Provoking the reader to muse a little about what might have happened following the intervention described, promotes further discussion about the issues they address, which arguably enhances the chances that the guidelines will be remembered.

## 4 Extended Discussion and Reflections

### 4.1 Clinical Psychologists suggest they do not need reminding to reflect.

The guidelines endorsed in the fourth theme (Supporting care staff to understand and reflect on their role) point to the importance of supporting care staff to reflect on their own values and beliefs. Staff biases and prejudices were identified as barriers to fully supporting the healthy sexual expression of PWID in their care. The panel suggest that helping care staff become conscious of these beliefs and where they come from is an effective way of supporting them to break down those barriers, and to alleviate some of their anxieties, as does previous research (Brown & Pirtle, 2008; Wagnett, 2012). In contrast, there was little mention of the importance of Clinical Psychologists reflecting on their own biases. Just two of the 51 guidelines originally proposed touched on this point, and only one came close to endorsement – achieving 86% consensus that it is important. For the other, 53% rated it as less than important. Some of the feedback comments on these guidelines was that reflecting on one's values is something a Clinical Psychologist should be doing anyway, but this was also minimal. So why might it be that the panel gave such little attention to personally being reflective?

There was a prevalence of systemic thinking across the guidelines and throughout the interviews, and this is captured in the third theme; 'locating the problem, being part of the solution'. The guidelines in this theme appeared to conceptualise the 'problem' as being PWID's sexual expression not being supported. These guidelines often asserted that there is a need to 'externalise' the problem (White, 2011) from the care staff, and highlight a need to consider 'ineffective solutions' (Watzlawick, Weakland, & Fisch, 1974) at all organizational and professional levels. From a systemic perspective, Clinical Psychologists must be considered (and consider themselves) as part of the system in which the problem is occurring. Therefore, they should consider any ineffective solutions they may be engaging in to maintain it, and reflecting on

their own biases and subsequent practice is surely a way they would be expected to do so.

The Clinical Psychologists all reported working individually. The absence of reflecting teams or partners means that there will likely have been an absence of questions and challenges that encourage one to explore how one's values and biases might be influencing one's practice. In such circumstances, it is essential for a Clinical Psychologist to explicitly consider the impact of their personal beliefs in order to commit to a self-reflexive approach (Burnham, 2005) and avoid 'blind spots'. The lack of attention the participating Clinical Psychologists gave this appears to provide some insight into how they make sense of their work and the narrative they hold of their role – a key interest in indirect systemic work with those supporting PWID (Haydon-Laurelut, Bissmire, & Hall, 2009). It appears that the Clinical Psychologists thought that being reflective is an inherent part of their role more broadly, and this was suggested by two of the feedback comments on the guidelines encouraging them to be reflective, which queried "should clinical psychologists really need to be told this?".

However, it is unclear how warranted the narrative that a thorough reflection of the impact of one's own biases will naturally occur in Clinical Psychologists is. The finalised guidelines have recently been piloted in the Clinical Psychology service of a CLDT. Anecdotal reports from the Psychologists there have been that using the guidelines elicited reflection on their own values and beliefs around the issues, and left them surprised at the little consideration they had given such thoughts in the past. This may suggest that contact with the guidelines alone may be sufficient to elicit reflection of one's own beliefs anyway. But, where this does not occur, there is no explicit prompt within the guidelines to do so.

The narrative Clinical Psychologists appear to hold about being reflective in all they do may well be warranted, since it is identified as a core competency of the profession (British Psychological Society, 2010; Health and Care Professions Council, 2015), and features heavily in all training programmes (British

Psychological Society, 2014). But, how Clinical Psychologists use reflection is a vastly under-researched area (Fisher, Chew, & Leow, 2015). Though some have provided evidence for the benefits of being reflective (Hurley, 1997; Ronnestad & Skovholt, 1983; Schon, 1983), research has provided no insight into how often and in what ways reflective practice is used (Wigg, Cushway, & Neal, 2011). In a qualitative study of experiences of reflective practice, Fisher et al. (2015) found that Clinical Psychologists would state that they were reflective and benefitted from this, but that they struggled to define 'how' they did so, and any processes this entailed.

Being a reflective practitioner is something that appears to be intimately wedded to the narrative that Clinical Psychologists hold about their profession, but it is important that they do not become complacent that thorough reflection will occur effortlessly in all of their thinking. A lack of openness and explanation of their approaches, both to themselves and to care staff, has at times led to Clinical Psychologists earning a label of remote and aloof 'hit and run professionals' (McBrien & Candy, 2012; Osborne-Davis, 1996). If the narrative Clinical Psychologists hold about their role leads them to believe they are inherently reflective, a consequent failure to actively reflect on the impact of their own beliefs and values may be an ineffective pattern in how they approach the problem, and one that precludes its resolution.

#### **4.2 Inconsistent contributions as a limitation.**

The participant absent for Round Two, but contributing to Round Three had rated 13 of the proposed guidelines as 'not at all important'. The extremity of these ratings put them in stark contrast to the other ratings, and since the rater had not contributed to the Round Two, the ratings had the effect of drastically broadening the range of responses compared to the previous round. The apparent shift away from consensus these ratings caused contradicted the narrowing of responses that had occurred in the rest of the panel, and when they were removed a shift towards consensus could clearly be seen. For this



reason, the 13 ratings of 'not at all important' were considered to be outlying data.

Ultimately, inclusion of the outlying data did not affect the overall results of the Delphi, since regardless of their extremity, the ratings were an indication that that panel member did not feel like those particular guidelines should be endorsed. Therefore, we did not treat the data any differently and included it with the rest. It did however feel important to include some indication to the reader of the shift towards consensus that had been occurring in the rest of the panel across the rounds. We achieved this by including a section in the statistical results table with the outlier removed. The decision to include this caveat was also informed by the fact that the justifications the panel member had offered for these extreme ratings in the written feedback section – statements such as “this is covered above” and “could be slotted in elsewhere”. Such statements suggest that the participant did not necessarily believe that the content of the guideline was in fact 'not at all important', but that the content had already been addressed.

### **4.3 Epistemological position.**

This research has been approached from a social constructionist epistemological position. The approach has been informed by Gabbay and le May's (2004) 'mindlines' paradigm (see section 2.1.3), a conceptual framework of how knowledge is developed through interaction between individual and groups of experts in a given field (in particular, healthcare professionals). Gabbay and le May (2004) highlighted how communication that occurs between healthcare professionals facilitates new understandings and solutions to novel or complex problems; the constructions of new truths, in the form of “internalized, collectively-reinforced, and often tacit guidelines” (p. 44). The intention of our research was to emulate the process of knowledge creation through communication between a group of experts.

The Delphi method is flexible in its application (Iqbal & Pipon-Young, 2009), and though this has led to ongoing debate as to the type of knowledge it professes to seek and produce (Keeney, McKenna & Hasson, 2010), the method has been found to lend itself well to a social constructionist epistemology (Engels & Kennedy, 2007; Rauch, 1979; Wallis, Burns, & Capdevila, 2009). From this perspective, the Delphi method is used to facilitate the negotiation of a new 'shared reality' between a panel of experts through multiple 'rounds' of communication (Linstone & Turoff, 1975, 2002).

A number of considerations are necessary when approaching research from a social constructionist perspective. Firstly, it is accepted that multiple realities exist, and that each of these realities will be inherently influenced by the community and culture within which they emerge (Berger & Luckman, 1991). Therefore, the limits of what can be inferred from the findings must be acknowledged; "descriptions and explanations can be valid so long as one does not mistake local conventions for universal truths" (Gergen & Gergen, 2007, p. 470). Applied to this research, it is important to acknowledge that attitudes towards ID and sexuality more generally differ greatly across cultures, as do the way ID services are set up. Therefore, the findings may be less relevant outside of the UK, and even more so outside of western culture. Equally, cultures and related attitudes are constantly evolving, and so what may be relevant today is dependent on the 'agreements' of today (Gergen, 1985), i.e. what a society currently agrees to be true. Consequently, in comparison to positivist approaches, research conducted from a social constructionist perspective may be argued to be lacking measures of validity, i.e., proximity to objective truths or reality. In response, McTaggart (1997) has argued that post-positivist approaches warrant a reconceptualization of what research should target in terms of efficacy. He suggests shifting attention to the changes elicited in relevant social practice, as a more appropriate and useful measure. In line with this assertion, the aim of this research has been to develop a means of eliciting change in the practice of Clinical Psychologists, and indirectly the care staff they support.

Secondly, though qualitative research methodologies often demand high levels of reflexivity, the extent to which one can achieve political and value neutrality in order to engage in the research process is questionable. From a social constructionist point of view, it is only through broader networks of meaning that a researcher can make sense of their findings, and therefore it is difficult to separate method from ideology (Gergen & Gergen, 2007). If attempting to bracket out one's own values is a futile endeavour, an alternative way of addressing such biases is to make them clear to the reader and allow oneself to be reasonably informed by them (Banister, 1999; Gergen & Gergen, 2007). Though, in doing so it is important to remain receptive to values and political impulses that are antagonistic to one's own (Banister, 1999), in order to facilitate transparency in the research process. Within this research, the primary researcher's biases have been made evident throughout – namely, the belief that PWID have a right to healthy sexual expression, and accordingly that accepting attitudes and supportive practice towards this end are interpreted as positive. It is acknowledged that this viewpoint may have influenced the choice of research question and methodology. However, when impartiality is not epistemologically an option, “the ideal scholar should know where he/she stands, and be responsible to his/her conception of the good.” (Gergen & Gergen, 2007, p. 474). The overview provided to participants ahead of Round One interviews contained an objective report of recent literature. Also, as the primary researcher, I strived to be led by the ideologies of participants during the interviews, even when at odds with my own. Supervision was also an invaluable tool for ensuring that any biases were noticed. It provided a space in which thinking and reasoning could be slowed down and picked a part, allowing for implicit assumptions to be identified and critiqued.

#### **4.4 Critical reflections.**

##### **4.4.1 'Positive' attitudes.**

When attitudes towards the sexual expression of PWID are explored in research, there is a tendency for them to be rated in terms of how 'positive' they

are. When initially writing my overview of past literature, I readily adopted this terminology. However, discussions with the other researchers led to us questioning how appropriate this term is, since it is value-laden and implies that the more liberal and accepting attitudes are, the better they are. This arguably overlooks the dangers involved in people holding overly liberal views of the sexual expression of PWID, for example, at what point do care staff begin to shun responsibility for safeguarding those in their care around sexual issues?

It appears that the prevalence of attitudes being considered in terms of how positive they are is rooted in Cuskelly and Bryde's (2004) Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability) (ASQ-ID). They report responses on the questionnaire as being 'more positive' or 'more negative' but fail to make any reference to their own attitudes and biases in determining what makes certain attitudes better than others. The measure has since been adopted by the majority of studies exploring attitudes to sexual expression in PWID, which have tended to have unquestioningly adopted the language of positivity.

Noticing this trend within the research prompted me to reflect on a number of levels. Firstly, it was important to become aware of my own biases, as these would likely affect the way in which the study was developed, and this could influence on the responses of those contributing. It was not considered necessary (or even possible) to utilise this insight in order to develop and conduct the research from a place of complete impartiality, but to be transparent in the write up about what biases had been present. This also made me conscious about the tone of the write up and the guidelines themselves. It felt important that both were balanced, and in spite of my own beliefs that PWID are currently overly restricted in their sexual expression, I felt it was important that factors around risk, responsibility, and accountability were not ignored. This felt especially significant considering how readily Cuskelly and Bryde's (2004) understanding of attitudes had been so readily adopted by those reading their work – myself included. These reflections allowed me to be mindful to give no less weight to input from participants about practice that might be considered to

be restrictive, and I believe this comes through in the inclusion considerations of the law and public protection in guidelines two and three, respectively.

#### **4.4.2 Decisions.**

The Delphi Method is an approach that can be applied very flexibly, allowing researchers to adapt it around the issues and/or the populations they wish to study. However, this means that there is no agreed upon approach to carrying out a Delphi, which left us many decisions to be made and justified as researchers. Firstly, we had to decide whether to adopt the recent trend of building a survey directly from the extant literature (e.g. Chen et al., 2013), rather than gathering data from the panel in the first round, out of which to develop a survey for Round Two.

Owing to a lack of detail in the literature about how care staff can best be aided to support sexual expression in PWID ('more training' being the favoured recommendation), we interviewed the panel. We then had to decide how to extract relevant data from interviews to develop the survey items. When the first round of a Delphi study takes the form of interviews, it is most common for the interview transcripts to be qualitatively analysed, and the extracted themes or categories used as the survey items (Thangaratinam & Redman, 2005). However, our goal was to develop a set of practice guidelines, which could be supplemented with vignettes of the practice that had informed them. By asking panel members to directly suggest guidelines that would make up the items that the panel as a whole would be rating, it was possible to remove the unnecessary additional hermeneutic level that qualitatively analysing the data would have brought. Furthermore, keeping the guidelines in their originally proposed form, allowed us to keep them connected to the examples of clinical practice that they had developed out of – which demonstrated our commitment to the principles of practice-based evidence.

The lack of clear guidelines or quality criteria for carrying out a Delphi study has led to the emergence of some approaches that appear somewhat contradictory

of the processes through which the Delphi is professed to work. For example, it has become common for items to be removed from the Round Three survey if they did not meet a certain threshold of consensus in the Round Two survey (e.g. Berk et al., 2011). However, this surely denies the panel the opportunity to change their mind on these items based on how others rated them. Therefore, we considered this approach to be forcing consensus, and did not remove items between Round Two and Three.

The flexibility of the Delphi Method meant that some decisions were a little more arbitrary. For example, the level of consensus that would be accepted, and whether this is adjusted on items that have particularly low response rates. We set the level of consensus as high ( $\geq 90\%$ ) based on the relatively homogenous sample. However, on an additional Round Three survey item that queried whether grouping the guidelines had been useful, not all respondents of that round answered that item. As a result, despite all but one respondent suggesting that grouping was useful, the responses were only 'approaching consensus' (88%). We made the decision to group the guidelines based on the strength of written feedback on the item that guidelines should be grouped.

There is little guidance on whether such decisions are justified within the Delphi literature, just that it is a 'flexible' method. This made the process at times feel a little uncontained. At these moments, frequent supervision and discussion within the research team felt incredibly useful. They helped to ensure all decisions were critically analysed so that the approach did not lose its rigour. Consultation with my field supervisor, who had experience of using the Delphi method, also offered invaluable foresight into the implications of different decisions. Furthermore, the grounding of the research in-line with the mindlines paradigm, and the principles of practice-based evidence provided a useful framework for steadying the project and a way to understand and then justify difficult methodological decisions were made.

#### **4.4.3 *Intended outcomes of the research.***

The research literature focused on the sexual expression of PWID has been consistently expanding over the past 30 years, and as a result, greater attention is being paid to the fact that PWID have sexual needs and desires. However, where research in the area falls short of stimulating positive change, is the tendency to merely describe the difficulties that care staff, families and PWID themselves have through qualitative research. This research only occasionally offers recommendations to help others support the healthy sexual expression of PWID. Where this does occur, it seldom ventures away from the tired suggestion of ‘more training for care staff’ and is significantly restricted in its generalizability as consequence of small sample sizes. In developing my research, I was adamant that I did not want to conduct a study that merely added to the pile described above. I felt that previous research had done a good job of helping us understand the problem but offered very little in the way of a solution. I wanted to produce something tangible that could be put into practice.

I think that it was the consulting of the clinical mindlines paradigm, and the practice-based evidence ideals it endorses that gave me a way of conceptualising how I could move beyond a description of the problem and offer a way of changing practice. The flexibility of the Delphi Method accommodated these ambitions well and has allowed me to make a contribution to the current body of scientific knowledge that will not stagnate. The product that embodies this contribution – the practice guidelines – are intended to foster new knowledge creation cycles in those that use them. As an alternative to decontextualized evidence-based guidelines, the guidelines produced in this study are to be seen not as a map to follow, but as a set of clues or prompts that encourages people to develop new knowledge for themselves. The inclusion of multiple vignettes for each guideline being an attempt to demonstrate this. It appeared that the guidelines achieved this end when they were piloted – the team they were used to help, committing to re-writing their sex and relationship policies, and starting a speed-dating event.

The knowledge created within teams stimulated by our guidelines, will be more tailored and relevant to those using them than any guidelines developed through overly clinical research evidence could be.

#### **4.5 Charitable donations**

Charitable donations have been made for every Clinical Psychologist that participated in the research. The donations were split evenly between Mencap and the British Institute of Learning Disabilities.

#### **4.6 Plans for dissemination**

Initially we will be submitting the journal paper to the Journal of Applied Research in Intellectual Disabilities (JARID). Once published, I will be applying to present this research and to share the guidelines at the BPS's Division of Clinical Psychology, Faculty for PWID annual conference in 2019. I will approach both the BPS and the British Institute of Learning Disabilities to enquire about the potential of the guidelines being endorsed by each organisation and being made available both as hard copies and online.

#### **4.7 Future research.**

##### ***4.7.1 Measures of outcomes***

A noted limitation of the study was that there was no independent way of corroborating the effectiveness of the practice that the panel members cited as evidence. Within this study 'good practice' in working to support care staff in supporting the healthy sexual expression of the PWID in their care, has been understood to encompass positive outcomes for both care staff and PWID. Within this practice, PWID should be left not feeling restricted in their sexual expression, whilst being sufficiently protected. For care staff, they should be left feeling more confident in how they can professionally support the sexual expression of PWID (where needed), whilst not feeling vulnerable in doing so. It would be beneficial if ways of measuring these outcomes could be developed



through future research. To date, measures mainly focus general attitudes towards sexual expression in PWID (e.g. Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007), and research focuses on self-reported shifts in these attitudes – which do not appear to necessarily be a good predictor of care staff behaviour.

#### ***4.7.2 The impact of Clinical Psychologists lacking confidence in matters of sex.***

With research suggesting that many Clinical Psychologists find it difficult to talk about sexual issues (Butler et al., 2010), it is quite possible that matters of sexual expression are not comfortably and confidently raised with care staff. This effect did not appear to be evident within the expert panel, but this was a group of Clinical Psychologists who had responded to a research advertisement regarding sexual expression in PWID. Therefore, they were all comfortable enough to volunteer to discuss it in a research setting. In contrast, the trainee Clinical Psychologist and other Clinical Psychologists in her team who piloted the guidelines had no special interest in sexual expression in PWID. They reported having not considered these issues to any great extent before, and that the team even lacked a specific policy around sex and relationships. It would be useful for future research to compare Clinical Psychologists who readily and confidently consider matters of sexual expression, with those who avoid it, with the aim of identifying how such confidence is established. Supporting Clinical Psychologists not to avoid matters of sexual expression in PWID would be a way of ensuring Clinical Psychologists are not perpetuating the policy-practice gap.

#### ***4.7.3 Implicit processes in Clinical Psychologists.***

When the panel did not endorse a guideline on the need for Clinical Psychologists to reflect upon their own beliefs and values, and the potential impact of these on their practice, it was implied that this something that they naturally do in all of their practice. However, the little literature existing and anecdotal evidence provided by the piloting of the guidelines, suggests that

Clinical Psychologist struggle to identify what it is they do when they reflect (Fisher et al., 2015), and when prompted to do so more explicitly this can uncover oversights. Therefore, it would be useful for future research to explore the implicit processes that Clinical Psychologists believe occur in their role, especially since it is the unique skillset of the Clinical Psychologist which should allow them to be instrumental in bringing greater understanding of, and ways to address gaps between policy and practice. But if these skills are not being explicitly called upon, it may limit the impact the profession could potentially have in encouraging and supporting change at multiple organisational levels, as is needed.

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## **Appendices**

## Appendix A

### Ethical approval from UoN Faculty of Medicine & Health Sciences Research Ethics Committee

**Saturday, February 10, 2018 at 5:10:09 PM Greenwich Mean Time**

**Subject:** RE: FMHS REC ref no N18082016 Expression in ID Study revised documents received

**Date:** Friday, 28 October 2016 at 13:31:06 British Summer Time

**From:** Sabir Louise

**To:** English Brad

Dear Brad

Thank you for submitting your revised application as requested. This is noted and you can start your project. Please let us know if you need to make any changes using the attached notice of amendment form.

With best wishes

Louise

Louise Sabir

Administrative Support

UoN Faculty of Medicine & Health Sciences Research Ethics Committee c/o

Faculty PVC Office,

School of Medicine

Education Administration

B Floor, Medical School

QMC Campus

Nottingham University Hospitals

NG7 2UH

e-mail: louise.sabir@nottingham.ac.uk

**From:** Sabir Louise

**Sent:** 20 October 2016 17:33

**To:** 'Brad English' <msxbke@noRngham.ac.uk>

**Cc:** Tickle Anna <lwaat@exmail.noRngham.ac.uk>; Nair Roshan  
<lwarn@exmail.noRngham.ac.uk>

**Subject:** FMHS REC ref no N18082016 Expression in ID Study approval letter

**Importance:** High

Dear Brad

Thank you for submitting this nicely written application which has been reviewed and approved. Please find a letter attached. There were two minor changes requested:

Information Sheet and debrief: Who to complain to: please remove: Research Innovation Services and replace with: The Administrator, The Faculty of Medicine and Health Sciences Research Ethics Committee, c/o Faculty PVC Office, B Floor, The Medical School, QMC Campus, Nottingham University Hospitals. NG7 2UH.

Consent form, protocol and information sheet and anywhere else this appears: please remove If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

Please submit revised versions of these documents for our records. There is no need for additional review or approval.

With best wishes

Louise

Louise Sabir  
Administrative Support  
UoN Faculty of Medicine & Health Sciences Research Ethics Committee c/o  
Faculty PVC Office,  
School of Medicine  
Education Administration  
B Floor, Medical School  
QMC Campus  
Nottingham University Hospitals  
NG7 2UH  
e-mail: louise.sabir@noRngham.ac.uk

**From:** Brad English [mailto:msxbke@noRngham.ac.uk]

**Sent:** 19 August 2016 13:56

**To:** Sabir Louise <mszls@exmail.noRngham.ac.uk>

**Subject:** Hard copy and application amendments

Hi Louise,

I handed in a hard copy of the eform and research proposal to the student services reception on the B floor – they said they would get the documents to you. I realised that the proposal I sent you electronically was not the most up to date version, and the eform needed a couple of slight amendments also, so I have attached the versions I wish to be considered to this email (and these match the hard copies). I hope that is OK.

Many Thanks,

Brad English  
Trainee Clinical Psychologist  
Trent DClinPsy, University of Nottingham



## Appendix B

### Accepted amendments to ethical approval

**Subject:** RE: Amendment 2 - FMHS REC ref no N18082016 Sexual Expression in ID Study - N18082016 TDCP Brad English – Friday 6th January 2017

**Date:** Tuesday, 17 January 2017 at 15:41:46 Greenwich Mean Time

**From:** Sabir Louise

**To:** English Brad

**Priority:** High

Dear Brad

Thank you for notifying the Committee of amendment no 2 06 Jan 2017. This is noted and approved. I am pleased to attach a letter for amend no 2 06 Jan 17 and amend no 1 06 Dec 2016.

Apologies for the delayed response.

With best wishes

Louise

Louise Sabir

Administrative Support

UoN Faculty of Medicine & Health Sciences Research Ethics Committee c/o

Faculty PVC Office,

School of Medicine

Education Administration

B Floor, Medical School

QMC Campus

Nottingham University Hospitals

NG7 2UH

e-mail: louise.sabir@nottingham.ac.uk

**From:** English Brad

**Sent:** 15 January 2017 15:40

**To:** Sabir Louise <mszls@exmail.noangham.ac.uk>

**Subject:** FW: Amendment 2 - FMHS REC ref no N18082016 Sexual Expression in ID Study - Friday 6th January 2017

Hi Louise,

Just thought I'd check to see if you had received my email regarding my second amendment. I've forwarded it (below) in case you hadn't.

Hope you are well,

Brad

**From:** English Brad <msxbke@exmail.noangham.ac.uk>

**Date:** Friday, 6 January 2017 at 15:29

**To:** Sabir Louise <mszls@exmail.noangham.ac.uk>

**Subject:** Amendment 2 - FMHS REC ref no N18082016 Sexual Expression in ID Study - Friday 6th January 2017

Hi Louise,

I wish to make a second amendment to my research protocol. I am now underway with recruitment and data collection, but have not yet met my desired number of participants. Many of the participants that I have interviewed have informed me that have spoken to other Clinical Psychologists they know about how they contributed to my study, and as a result the other Psychologists asked them to notify me of their interest in participating also. In my original protocol my recruitment strategy was solely through an advertisement and did not mention

snowballing or word of mouth, therefore I would like to now include snowballing and word of mouth so that I can include the further participants.

I hope that all makes sense, please contact me if it doesn't.

Best wishes,

Brad English

## Appendix C



Division of Psychiatry & Applied Psychology  
University of Nottingham  
YANG Fujia Building, B Floor  
Jubilee Campus  
Wollaton Road  
Nottingham NG8 1BB  
tel: 0115 8466646

### **Participant Information Sheet**

**(Version 2.0: 28/10/2016)**

**How do Clinical Psychologists address the difficulties of care staff in  
supporting the sexual expression of individuals with intellectual  
disabilities?  
A Delphi Study.**

**Name of Researchers:** Brad English  
Dr Anna Tickle  
Prof Roshan dasNair

I would like to invite you to take part in this research study. Before you decide we would like inform you 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. Ask us if there is anything that is not clear.

#### **What is the purpose of the study?**

The aim of the research is to identify the approaches to clinical practice that Clinical Psychologists have found to best help care staff in overcoming their

difficulties in supporting the sexual expression of individuals with the diagnosis of Intellectual Disability (ID) with which they work.

The purpose of the research is to produce a set of guidelines to inform the practice of Clinical Psychologists who are supporting care staff to positively support the sexual expression of individuals with ID in line with current government policy, e.g. 'Valuing People Now' (Department of Health, 2009a), 'Safeguarding Adults: Report on the consultation on the review of No Secrets' (Department of Health, 2009b).

### **Why have I been invited?**

You are being invited to take part because you are a Clinical Psychologist working within an Intellectual Disability/Learning Disability service. We are inviting 15 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.

### **What will happen to me if I take part?**

The research will last approximately one year and will be made up of three parts. Initially you will take part in a one-to-one interview with the primary researcher (BE) that will last one hour. This interview will take place at a venue that you communicate is convenient (e.g., your place of work) or by telephone or Skype and will be arranged for a time and date of your choosing in December 2016, January or February 2017. The second and third part of your contribution will take the form of a survey that you will receive via email. You will be required to fill out the survey in a Microsoft Word document and return the completed version to BE via email within two weeks of receiving it. You will receive the first of the two

surveys in March or April 2017, and the second in May or June 2017. Each survey will require approximately 20 minutes to complete. You will not be required to meet with the researcher following the initial interview.

### **Expenses and payments**

You will not be paid to participate in the study, but a donation will be made to an ID related charity (e.g. MENCAP) for every person that participates. Travel expenses will be offered for any visits incurred as a result of participation.

### **What are the possible disadvantages and risks of taking part?**

By being part of this research you will be required to give up approximately 100 minutes of your time. Since the subject matter is about sexual expression, some clinicians may feel mild embarrassment/discomfort in discussing this with the researcher at the interview stage.

### **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 you to reflect on your clinical practice around the issue in question. The guidelines produced may help to inform your clinical practice (and that of other Clinical Psychologists) around the issue in question based on successful experiences of people in a similar role to you.

### **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 Administrator, The Faculty of Medicine and Health Sciences Research Ethics Committee, c/o Faculty PVC Office, B Floor, The Medical School, QMC Campus, Nottingham University Hospitals. NG7 2UH.

### **Will my taking part in the study be kept confidential?**

The responses of all participants will be made known to all other participants and will be documented on the copies of the surveys received, but **all responses will be anonymised**. The names of those contributing will remain confidential both during and after the study.

We will follow ethical and legal practice and all information about you will be handled in confidence.

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. Any information about you which leaves the university site or the venue for the interview will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for one year after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for seven 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.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

### **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.

### **Who is organising and funding the research?**

This research is being organised by the University of Nottingham and funded as part of my DClinPsy training, by NHS Health Education East Midlands (HEEM).

### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the the University of Nottingham Faculty of Medicine & Health Sciences Research Ethics Committee.

### **Further information and contact details**

#### **Brad English**

#### **Trainee Clinical Psychologist**

Division of Psychiatry & Applied Psychology

University of Nottingham

YANG Fujia Building, B Floor

Jubilee Campus

Wollaton Road

Nottingham NG8 1BB

tel: 0115 8466646



**Dr Anna Tickle**

**Academic Tutor – DCLinPsy**

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tel: 0115 8466646

**Roshan das Nair**

**Professor of Clinical Psychology & Neuropsychology**

C22, Institute of Mental Health

Jubilee Campus

University of Nottingham

Nottingham

NG8 1BB

tel: 0115 8230589

References

DH (Department of Health) (2009a). *Valuing people now: A three-year strategy for people with learning disabilities*. London: The Stationary Office.

DH (Department of Health) (2009b) *Safeguarding adults: Report on the consultation on the review of No Secrets*. London: The Stationary Office.

## Appendix D



### CONSENT FORM

(Version 2.0: 28/10/2016)

**Title of Study: How do Clinical Psychologists address the difficulties of care staff in supporting the sexual expression of individuals with intellectual disabilities? A Delphi Study.**

**REC ref: N18082016**

**Name of Researchers:** Brad English  
Dr Anna Tickle  
Prof Roshan dasNair

**Please initial box**

**Name of Participant:**

1. I confirm that I have read and understand the information sheet version number 2.0 dated 28/10/2016 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.
  
3. I understand that the demographic 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 this data 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 from Round One of the study will be recorded and that anonymous direct quotes from the interview may be used in the study reports.

5. I understand that the information that I provide in Rounds Two and Three will be seen by other participants, but this information will not be attributed to me.

6. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person taking consent      Date                      Signature

## Appendix E

### Round One: Information Sheet

(Version 1.0: 14/03/2016)

**How do Clinical Psychologists best address the difficulties of care staff in supporting the sexual expression of individuals with intellectual disabilities? A Delphi Study.**

#### Definition of Terms

##### **Carer**

An individual who holds responsibility for caring for an individual with the diagnosis of Intellectual Disability (ID) on a regular basis (at least once a week), either through paid work or family ties.

##### **Support**

To provide assistance in order to help an individual access something which they could not alone.

##### **Sexual Expression**

For the purpose of this study please consider 'sexual expression' as:

*The action of making one's feelings or thoughts regarding sexuality known, either directly or indirectly, by means of verbal interaction, behaviour, and self presentation. This may relate to intimacy with other human beings (ranging from relationships that do not involve physical contact, to sexual intercourse), but does not necessarily involve another person (i.e. self-pleasuring). This can include the choice not to be sexually active.*

## **Background**

The sexuality of individuals with ID has historically been ignored and even feared (Kempton & Kahn, 1991), with those individuals tending to be viewed as asexual, vulnerable to abuse, or perverse/deviant (McCarthy, 1999; McRuer & Mollow, 2012).

More recently there has been a philosophical and ideological shift in terms of acknowledging people with ID as sexual beings. This population have sexual needs and desires, but often require extra support in understanding and fulfilling them (Azzopardi-Lane & Callus, 2014; David, Smith, & Friedman, 1976; Lesseliers & Van Hove, 2002). This has been reflected in the requirements set out by national and international policy (Department of Health, 2009; United Nations, 2006; World Health Organization, 2006).

In spite of this, literature suggests that those with ID still frequently report feeling restricted in their sexual expression (Healy, McGuire, Evans, & Carley, 2009; Kelly, Crowley, & Hamilton, 2009).

Carers difficulties have been well documented, namely; discomfort in discussing sex, fears of evoking sexual impulses, encroaching on privacy, and ambivalence between support and risk (Abbott & Howarth 2007; Konstantareas & Lunskey, 1997; Wilkinson, Theodore & Raczka, 2014).

However, this information has not led to change. The discrepancy between policy and practice remains.

## References

Abbott, D., & Howarth, J. (2007). Still off-Limits? Staff views on supporting gay, lesbian and bisexual people with intellectual disabilities to develop sexual and intimate relationships?. *Journal of Applied Research in Intellectual Disabilities*, 20(2), 116-126.

Azzopardi-Lane, C., & Callus, A. M. (2015). Constructing sexual identities: people with intellectual disability talking about sexuality. *British Journal of Learning Disabilities*, 43(1), 32-37.

David, H. P., Smith, J. D., & Friedman, E. (1976). Family planning services for persons handicapped by mental retardation. *American journal of public health*, 66(11), 1053-1057.

DH (Department of Health) (2009). *Valuing people now: A three-year strategy for people with learning disabilities*. London: The Stationary Office.

Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives. *Journal of Intellectual Disability Research*, 53(11), 905-912.

Kelly, G., Crowley, H., & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted'. *British Journal of Learning Disabilities*, 37(4), 308-315.

Lesseliers, J., & Van Hove, G. (2002). Barriers to the development of intimate relationships and the expression of sexuality among people with developmental disabilities: Their perceptions. *Research and Practice for Persons with Severe Disabilities*, 27(1), 69-81.

McCarthy M. (1999). *Sexuality and women with learning disabilities*. London: Jessica Kingsley Publishers.

McRuer, R. & Mollow, A. (2012) Introduction. In: McRuer, R. & Mollow, A. (Ed.) *Sex and Disability* (pp. 1–34). Duke University Press, Durham.

United Nations (2006). *Universal convention on the rights of persons with disabilities*. New York: United Nations.

World Health Organization. (2006). *Defining sexual health: report of a technical consultation on sexual health, 28-31 January 2002, Geneva*. World Health Organization.

Wilkinson, V. J., Theodore, K., & Raczka, R. (2014). 'As normal as possible': Sexual identity development in people with intellectual disabilities transitioning to adulthood. *Sexuality and Disability*, 33(1), 93-105.

## Appendix F



### Round One Interview Questions<sup>27</sup> (Draft Version 1.0: 14/03/2016)

1. Why do you think the discrepancy between policy and practice remains?
2. Tell me about a time when you have been required to have input with a service user when sexual expression was an issue.
3. What went well in terms of your input? What was the evidence for this?
4. What didn't go well in terms of your input? What was the evidence for this?
5. What were the most important factors at play in this clinical experience?

Based on this, can you suggest three potential 'guidelines' that could support Clinical Psychologists who find themselves in a similar position?

*If I pinned down to a sentence, how would you capture that?*

i.

ii.

---

<sup>27</sup> These questions will be asked flexibly and if other issues arise within one interview, the schedule will be modified slightly to include that aspect.



iii.

**Prompts:**

- Please tell me more
- please give me an example
- etc....

Is there anything else that you feel like we haven't covered?

Have you got any questions for me?

## Appendix G

### Screen shots of Round Two items;

#### *Example of similar and non-similar item presentation*

*\*These guidelines appear to have the same message\**

Do you agree?      YES / NO

**19.**  
**Be aware of how you feel about the matter in hand, but be mindful to shelve these personal beliefs and values, as these should not dictate the care you give, or the extent to which the client's needs are met.**

*Type an 'x' in **one** box*

This guideline is not important at all	This guideline is not very important	I feel neutral towards this guideline	This guideline is important	This guideline is essential

Comment:

**20.**  
**Reflect on our own understanding and values around how romantic relationships start and develop, and be mindful of how these influence what you work towards with a staff team; make use of formal assessment resources to structure this understanding in line with the law and human rights.**

*Type an 'x' in **one** box*

This guideline is not important at all	This guideline is not very important	I feel neutral towards this guideline	This guideline is important	This guideline is essential

Comment:

**17.**  
**Do a thorough assessment of the situation, but have the confidence to take the time you need over this. Be mindful not to get immediately drawn into the anxiety of the system.**

*Type an 'x' in **one** box*

This guideline is not important at all	This guideline is not very important	I feel neutral towards this guideline	This guideline is important	This guideline is essential

Comment:

*This guideline says the same thing as guideline number \_\_\_\_*

**18.**  
**Support care staff to not limit themselves to 'fixing the person', but to also look at broader issues (i.e. their environment, the amount of privacy they get, the impact of how others respond to their actions).**

*Type an 'x' in **one** box*

This guideline is not important at all	This guideline is not very important	I feel neutral towards this guideline	This guideline is important	This guideline is essential

Comment:

*This guideline says the same thing as guideline number \_\_\_\_*

## Appendix H

### Screen shots from Round Three survey;

- *Message issued regarding the proposed grouping of items*
- *A pair of items that appeared to overlap (as presented across two pages within survey)*

#### **\*\*Suggested Themes\*\***

One participant suggested in Round Two that the list would be more accessible if the guidelines are grouped according to the issue they set out to address. The participant suggested four 'types' of advice and grouped the guidelines in line with these. I have grouped the guidelines in this way and would like to request your opinion on:

- a) Whether you think that grouping the guidelines would be beneficial
- b) Whether you agree with the suggested groupings, or would group them differently

There is space to comment on the groupings at the end of the survey.

Suggested 'types of advice' groupings:

- Issues regarding the FORMULATION of the case  
*"Guidance on assessing a service to formulate the best way to promote sexual and personal relationships for people with intellectual disabilities."*
- Issues regarding the INDIVIDUAL REFERRAL  
*"Guidance on responding to individual referrals about relationships and sexuality issues."*
- Issues regarding the PROCESS of teaching the staff  
*"Guidance on setting up teaching and training for staff about sexuality and relationships."*
- Issues regarding the CONTENT of that to be taught to the staff  
*"Guidance on the key issues to include in the content of staff training about sexuality and relationships."*

Grouping into issues - key:

Orange = Formulation  
Blue = Process of teaching

Green = Individual referral  
Yellow = Content of teaching

**\*Guidelines 19, 20 appear to have the same message\***  
73% said yes, 27% said no

Do you agree now? YES / NO

**19.**  
Be aware of how you feel about the matter in hand, but be mindful to shelve these personal beliefs and values, as these should not dictate the care you give, or the extent to which the client's needs are met.


	This guideline is not important at all	This guideline is not very important	I feel neutral towards this guideline	This guideline is important	This guideline is essential
How <b>the panel</b> answered in Round Two		16%	38%	16%	30%
How <b>you</b> answered in Round Two					✓
Comments others made: <ul style="list-style-type: none"> <li>• Only if they are in conflict</li> <li>• Not sure of the wording...</li> <li>• Again, should clinical psychologists really need to be told this?</li> <li>• Important to be reflexive, but not necessarily to completely shelve our values – Depends on what these are, what's going on for client/system etc.</li> <li>• Are you not contradicting Guideline 15? If you believe this, should it also be applicable to care staff?</li> <li>• I don't like the wording of 'shelve'.</li> </ul>					
Round Three answer (Type an 'x' in one box)					
Comment:					

**20.**  
Reflect on our own understanding and values around how romantic relationships start and develop, and be mindful of how these influence what you work towards with a staff team; make use of formal assessment resources to structure this understanding in line with the law and human rights.

	This guideline is not important at all	This guideline is not very important	I feel neutral towards this guideline	This guideline is important	This guideline is essential
How <b>the panel</b> answered in Round Two		7%	7%	36%	50%
How <b>you</b> answered in Round Two					✓
Comments others made: <ul style="list-style-type: none"> <li>• Again, should clinical psychologists really need to be told this?</li> <li>• I much prefer this one, although I'm unsure what's means by the formal assessments for this.</li> </ul>					
Round Three answer (Type an 'x' in one box)					
Comment:					

**Appendix I**  
**All responses and feedback**

**Key**

- x = Round Two rating before shift    X = Round Three rating after shift**  
**XX = Rated the same for both rounds     = Rated Round Three**  
**X = Round Two rating (where Round Three not contributed to)**

**Notes**

- *Colour scheme of table indicates the groupings that the guidelines were presented in in the Round Three survey*
- *Percentages rounded to whole numbers for clarity*
- *P005 contributed to Round Three but not to Round Two*
- *Text below the tables:      Black text = comments offered at Round Two*  
*Red text = comments offered at Round Three*

**3. Get to know the barriers you are up against. Build an understanding of who the client’s sexual expression is a problem for and why.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003				X X	
P004			X X		
P005				X	
P006				X X	
P007					X X
P008					
P009			X X		
P010					X X
P011				x	
P012				X	x
P013					x
P014					x
P015				X X	
P016					
P017				x	X
Total R3			18%	55%	27%
Total R2			14%	50%	36%

- I don't think the use of the phrase: 'get to know the barriers you are up against' is helpful in this context.
- I wouldn't use the word 'barriers'. Consent to discuss with different people is important (best interests when no capacity).
- Same message – but I think that's ok, as it's an important one to reiterate.
- 3, 4, and 5 have similar but subtly different messages. 3 is clear and concise and specific. 4 & 5 could possibly be merged?
- I like the straight forward use of language here but feel it needs changing slightly. As with any referral, you're wanting to get to know the problem,

who's it a problem for and why and to understand what's sustaining the problem and what's helping/not helping. As well as opportunities for movement and change. It's not just about barriers. You're looking to understand the system and the individual because then you can look for where the system bends and the possibilities of change. Basically I've amalgamate 3, 4 and 5 but try to put it as succinctly as possible and in layman's terms.

- I think I agree with the comments about "barriers". That sentence isn't particularly helpful and could be omitted without any loss of meaning. I think it does fundamentally say the same thing as number 4.
- Agree with comments about 'barriers' in comments box above
- This is an important guideline but I feel the use of 'barriers' and 'problem' make it more of an issue. Sexual expression should be treated just the same as any other issue, so that staff see it that way. It is not barriers that staff are 'up against', it is barriers that the staff members have themselves, and they need a way of understanding why they have this, and what they can do about it.



**4. It is the Clinical Psychologist’s role to develop an understanding of the interpersonal system surrounding a client (including support staff, family and management), to identify where any anxiety, distress and risk lies, and to be a calming influence within this system.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002			X X		
P003				X X	
P004			X X		
P005				X	
P006				X X	
P007			x		X
P008					
P009				X X	
P010			X		x
P011				x	
P012				X	x
P013					x
P014					x
P015				X X	
P016					
P017			X X		
Total R3			36%	55%	9%
Total R2			29%	42%	29%

- ‘and to be a calming influence within this system.’ This is a high expectation!
- It doesn’t necessarily have to be a psychologist. A nurse or other trained professional could do just as well.
- I think psychologists play an important role here, but it is not necessarily always our role... In fact, in many services (mine included), sex and relationship work is not commissioned so it would be an unrealistic

expectation that this was the role of psychology. So, I agree with the statement but perhaps not so strongly about “psychology’s role” as this may not happen!

- Could you rephrase ‘calming influence’? or at least objectify what you mean? Ideally ‘calming’ would be the resultant outcome but sometimes despite best efforts, all the CP can do is ‘hold up a mirror’ to dysfunctional/unhelpful processes in the system.
- I think this guideline covers the previous one but adds in the role of containment. It could be made clearer though if it added in the wording of the previous guideline.
- You may not necessarily be calming – at least to begin with. You may be shaking up the system a little. I suppose it’s more about what the clinician above mentioned – containment, and what Barry Mason calls a position of safe uncertainty.
- I would agree with the comment about being a ‘calming influence’ and that it isn’t always the psychologists role
- Agree others could take this role. And psychologists could do this work WITH systems. There might be some occasions we need to increase concerns about risk
- This one is hard to rate as it is not the sole issue of the clinical psychologist. As we tend to work in teams, it is the responsibility of all staff members. It is likely that the clinical psychologist can assist/train other staff members regarding sexual issues, and supervise those who are having difficulties, but it is not ultimately the CPs responsibility. I too am not sure about ‘calming influence within the system’ and am not sure what you really meant by this.

**5. Talk with a range of staff to get multiple perspectives on issues at hand. This also provides the opportunity to gain understanding of attitudinal issues and organisational issues. The latter allowing you to gain better insight into where any problems/discomforts/disapproval/obstacles are located (i.e. at staff level, at managerial level, at organisational level).**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003				X X	
P004					X X
P005					X
P006				X X	
P007				x	X
P008					
P009				X X	
P010				X X	
P011					x
P012					X X
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3				45%	55%
Total R2				50%	50%

- It depends on the nature of the problem. The client's level of independence may mean very few staff if any need to be consulted.
- I agree with this.
- I think I like '4' best though (out of 3, 4, & 5) I don't think we're always a "calming influence" – sometimes we stir the pot!
- I like this one the best

- While being mindful of client's privacy, confidentiality and dignity.
- This is similar to number 3 and again using some of this wording would enhance number 4.
- I like this one. I think I'd probably just tweak the language to it sounds clearer. Attitudinal issues is an unusual phrase. Whilst there may be very few people/staff involved, you can acknowledge this in your guidelines. As I said before I'd amalgamate the first three. In fact 4 and 5 cover 3 so you could just drop that one.
- I think you could merge the 3 to encompass the message of getting to know the system well – all the people in the system, the barriers, and the organisational issues
- This is a good guideline and seems to encompass guidelines 3 and 4. This states things in the best way without making aspersion's that sexual issues are a problem, which they are clearly not – or at least shouldn't be.

**17. Do a thorough assessment of the situation, but have the confidence to take the time you need over this. Be mindful not to get immediately drawn into the anxiety of the system.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002					X X
P003				X X	
P004					X X
P005			X		
P006			X X		
P007				X X	
P008					
P009			X		x
P010					X X
P011				x	
P012 - 19				X X	
P013					x
P014				x	
P015		X	x		
P016					
P017				X X	
Total R3		9%	27%	37%	27%
Total R2			14%	43%	43%

- Agreed but likewise if the staff's anxieties are high this does need to be addressed otherwise you won't have them on board with your work, plus they may have a point given the expertise they have on the client and risks.
- Again, does it really need saying?
- This applies to lots of clinical work – not just that which relates to sex and sexuality
- This is applicable to a vast array of clinical issues!

- I'd risk assess first. I know some people whose behaviour is very risky and so taking one's time needs to be balanced with the need to address the risks. It's the same with any work we do.
- I still feel neutral toward this. As others said, although the idea is crucial to psychologist's work in this area, does it need saying, as it is crucial to all work psychologists do.
- Agree with the above comments that this relates to most clinical work – Good to separate out what would be different for the sexuality work
- I do not think this guideline is written in a good way and does tend to state the obvious. We should assess thoroughly everything we do and need to take what ever time we need. The way it is written says to me that we need to assess thoroughly (which is great), but that we may not be confident enough to take the time needed, and therefore a thorough assessment wouldn't be done. I feel though this is important it is something that should be second nature and shouldn't need to be a guideline. But if it is to be a guideline it needs to be written differently.

**34. Hypothesise and reflect on your relationship with the staff team, and positively connate connote staff's actions as much as possible. Consider how does it feel for them when you come in to talk to them about this. Think in terms of therapeutic relationships with staff.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001			x		
P002*				X X	X X
P003				X X	
P004					X X
P005				X	
P006	x	X			
P007					X X
P008					
P009			X	x	
P010				X X	
P011				x	
P012					X X
P013					x
P014				x	
P015				X X	
P016					
P017					X X
Total R3		8%	8%	42%	42%
Total R2	7%		7%	46%	40%

\*marked multiple boxes

- Also needs to be considered in supervision.
- Look up “connate”, and I’m not sure it says anything a good reflective psychologist wouldn’t naturally do.
- Also their understandings of sexuality, their desire to protect the individual (or desire to give the person as much choice as possible)
- Not clear who this should be done with – in supervision? With the staff team?

- I think this is important as it is with any work we do. I wonder if there's a more straight way of saying it rather than 'connote'.
- I agree that you could add more detail about how/where to do this? In supervision, direct with the staff team?
- I'm generally not sure how much the guidelines should set out issues that should be good practice to formulating any issue, and how much they should be specific just to sexuality and relationships. I guess it would be important to have reminders that sexuality and relationships are emotive subjects that impinge on staff members own feelings, experiences, moral and religious codes.
- I think a number of psychologists/professionals don't always frame staff intentions in a positive way → easily critical of them and dismissive of their needs. In terms of the 'doing' of this – I think this ought to be something a clinician aims to do through self-reflection and when formulating about the system. And I like the idea of bringing frustrations to supervision to help make sense of staff's intentions and needs/experiences.
- This is important, though I'm not sure we can hypothesise well until we have reflected first – but I may be wrong on this. I feel there are a lot of words used to say something simply, which makes it a complicated guideline. I think a different word should be used instead of 'connote' as many people wouldn't understand what it meant.



**38. Encourage staff to champion the sexual rights of those they care for, since, by not affording these rights sufficient attention, organisations and clinical commissioning groups may not be affording staff the time and reflective space to properly consider and meet the sexual needs of clients.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003				X X	
P004				x	X
P005				X	
P006			X	x	
P007					X X
P008					
P009					X X
P010			X X		
P011				x	
P012			X X		
P013				x	
P014					x
P015				X	x
P016					
P017					X X
Total R3			28%	36%	36%
Total R2			14%	50%	36%

- Need to look at how systems listens to staff.
- I think it should be the other way – Commissioners and managers with greater power need to ensure space is given for this, rather than putting pressure on relatively disempowered staff to push for this.
- The wording is a little cumbersome so not totally clear.
- I agree with the comments made above that it's managers who have the power to influence and create a culture that champion's rights. You might

want to encourage managers to get their staff onto training courses around supporting people with their sexuality.

- I agree that the wording of this could be altered to make more clear
- Looking at it again, the wording is a bit cumbersome. It seems to be saying something about both the staff role as advocates and on services' need to treat the issue as important. Maybe these aspects need to be separated, having a clear statement about encouraging staff to advocate for their clients' rights and needs and a separate one about encouraging commissioners and managers of services to demonstrate that they are adequately providing for people's needs.
- This again uses too many words. If guidelines are not put simply so that staff at all levels can understand, they will not be followed.

**39. Take the time to get familiar with the organisation's/management's position statement on how client's sexual expression is supported. If this is not operating on the best interests of the client, work with the organisation/management to look at ways this can be amended, and what it will take for their staff to feel comfortable in abiding by this position statement (e.g. training for staff, reflective practice groups, team or individual clinical supervision).**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002					X X
P003					X X
P004				X X	
P005				X	
P006				X X	
P007				x	X
P008					
P009				X X	
P010				X X	
P011				x	
P012				X X	
P013					x
P014					x
P015				X	x
P016					
P017				X X	
Total R3				72%	28%
Total R2				64%	36%

- This is important but it does feel really similar to what the guideline about understanding the barriers/hurdles to overcome
- This depends on the nature of the referral and the extent of the problem. It may not always be necessary to do this.

- Need to consider existing formal and informal guidance.
- This might be better done at an organisation to organisation level rather than be left to individual clinicians
- It depends on the level of support the client gets. I guess you could say “where appropriate”. It would be helpful if there were national standards you could refer people to.
- Like the comment about the importance of this being done at an organisational level. I would worry about the ability of current NHS services to free up time to provide training and reflective practice groups to private providers who ought to be developing and commissioning this training
- This is important but is putting a lot on the clinical psychologist. In times such as they are, is this realistic. Though I agree it is something which, ideally, should be done.

**41. Ensuring that you are in agreement with management over what is and is not permissible by staff is an important foundation to build. A manager should be advised to explicitly communicate permission to their staff team to operate in ways that uphold an individual's rights, but also not give permission to operate in ways in which they allow their own beliefs and values to justify restricting the rights of the individual.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003					X X
P004			X X		
P005				X	
P006			x	X	
P007					X X
P008					
P009			X	x	
P010				x	X
P011					x
P012				X	x
P013					x
P014					x
P015				X X	
P016					
P017					X X
Total R3			18%	45%	37%
Total R2			14%	36%	50%

- It's really not written very clearly just what the advice to psychologists is.
- It's vital to have a clear understanding of what the care provider is saying their staff can and cannot do. You need to tease a part what is based on insurance/the law etc and what is based just on the views of the manager and could therefore be change/challenged.

- This could still do with rewording for more clarity and more specificity
- I've slightly changed my view on this because I think there is something important to be said about management of services, though I don't think it's very clearly put here. The second sentence sets out a laudable aim. Maybe the first part should be more that the psychologist's role is to talk with the management about the importance of both supporting the individual's rights while being aware of staff sensibilities, and to point out to management issues in a service where this is not happening and to suggest possible solutions.
- I think some re-wording could help as I had to read this a couple of times.
- Again whilst this is important, the guideline is far too big. Many staff members would give up reading it. Guidelines must be simple so that any level of staff member can look at it and instantly understand what it means and what they have to do.

**43. Identify an individual within the MDT/service who is willing to take on the role of sexual expression and relationship lead. This individual should be afforded the time to stay up to date with research and policy, as well as taking responsibility of encouraging the consideration of sexual needs and desires of clients within the service. The individual can provide a valuable resource for advice and information for professionals within the team who are tasked with working with staff teams on these matters.**

Participants	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003				X X	
P004				X X	
P005			X		
P006		X X			
P007				X	x
P008					
P009			X	x	
P010			x	X	
P011			x		
P012				X X	
P013					x
P014					x
P015				X	x
P016					
P017				X X	
Total R3		9%	18%	73%	
Total R2		7%	14%	50%	29%

- This won't be appropriate for every setting so I don't think I should be "guidance". Could be listed as an option.
- Agree, unless this turns into a reason others in the team feel they can neglect this area (i.e. it becomes 'someone else's responsibility)

- Staff turnover complicates this
- Whilst I appreciate the comments of the those above, I think it's an important an issue to have someone take on this role.
- I still like this as an idea
- I still think this is just one option which may not be appropriate for general guidance
- I have put neutral to this, because although in an ideal world it would be very important, services are not in a position to do this.



**44. Where possible, proactively integrate yourself into services in order to begin building relationships with staff. Being more familiar with you will make it easier for staff to approach you with questions or concerns prior to them reaching a level where they require referral.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003				X X	
P004			X X		
P005				X	
P006			X X		
P007			X X		
P008					
P009			X	x	
P010		X X			
P011			x		
P012			X	x	
P013					x
P014					x
P015					X X
P016					
P017			X X		
Total R3		9%	55%	27%	9%
Total R2		7%	36%	36%	21%

- Very dependent on the situation. May not always be feasible.
- Not sure it is possible in our work context as configured, where we only tend to get involved once a referral is in
- Its essential but we really shouldn't need to tell psychologists to do this...
- If it were possible time wise this would be great.
- I agree with the first comment that this is not always practical. But you could say "where possible"

- In our service we have an allocated 'link worker' for each residential service in the area. Their role is to get to know the service really well and offer informal consultation where appropriate. This idea fits with this guideline, and may be useful as part of general guidelines for psychologists, but not sure it is specifically relevant to sexual expression issues.
- Maybe it should just say there are some pros and cons to being close with staff teams. Sometimes it may be easier to be an outsider raising questions about staff approaches. I'm reminded of, I think it's Fiedler's "Contingency Management Theory" which says whether you should a 'democratic' manager or 'authoritative' one depends on the work social environment (*it's a long time so I may have the name wrong!*)
- We should be doing this anyway. Shouldn't need to be a guideline.

**45. Get to know what services and groups are available and accessible in your local area that can help individuals to meet people and socialise (such as nightclubs, dating agencies, voluntary services), so that you are not identifying problems without offering solutions.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002					X X
P003				X X	
P004				X X	
P005				X	
P006				X X	
P007					X X
P008					
P009					X X
P010		x		X	
P011					x
P012				X X	
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3				55%	45%
Total R2		7%		29%	64%

- Very helpful to know.
- Not just a CP role – staff can do this too
- Other frontline staff to be a core collaborator in this.
- I agree with all of the above. This shouldn't be just for psychologists to do. In fact the whole topic shouldn't be just for psychologists to do. It seems more of a job for a nurse.
- Agree, not just a CP role.

- Or at least to know who might be able to provide more info on this. Staff in homes might not have the same connections members of LD teams have and thus might find it harder to access the info.
- This is very important but not a CPs role. This can be done by staff at a lower level or even by admin staff. It is also common sense and not sure that it should be a guideline.

**19. Be aware of how you feel about the matter in hand, but be mindful to shelve these personal beliefs and values, as these should not dictate the care you give, or the extent to which the client’s needs are met.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001		x			
P002			X X		
P003					X X
P004			X X		
P005				X	
P006		x	X		
P007					X X
P008					
P009			X X		
P010			x	X	
P011 – 7-9				x	
P012				X X	
P013					x
P014	Not rated, but commented on				
P015			X		x
P016					
P017			X X		
Total R3			55%	27%	18%
Total R2		16%	38%	16%	30%

- Only if they are in conflict
- Not sure of the wording...
- Again, should clinical psychologists really need to be told this?
- Important to be reflexive, but not necessarily to completely shelve our values – Depends on what these are, what’s going on for client/system etc.
- Are you not contradicting Guideline 15? If you believe this, should it also be applicable to care staff?

- I don't like the wording of 'shelve'.
- I think it's important to be aware of them, as your advice and work should be in accordance with the human rights and the values of the service you are working for. But your values may not be in conflict.
- Having read others' comments, I agree it is more about importance of being reflexive and reflective on your position & values, which is key to the role of CP in general, but can see the importance of highlighting this in this area.
- Also not a fan of 'shelve' – Whilst this would be important in all work it is important to recognise that sexuality has the potential to invoke strong reactions
- I understand what you are trying to say but this is worded quite badly.
- Not sure about the wording of this – being aware of our own beliefs and values is important, using supervision to reflect on this and ensure they are not impacting on/driving the direction of the work we do.

**20. Reflect on our own understanding and values around how romantic relationships start and develop, and be mindful of how these influence what you work towards with a staff team; make use of formal assessment resources to structure this understanding in line with the law and human rights.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003					X X
P004					X X
P005				X	
P006		X X			
P007					X X
P008					
P009				X	x
P010				x	X
P011 – 7-9				x	
P012				X X	
P013					x
P014					x
P015			X X		
P016					
P017					X X
Total R3		9%	9%	36%	46%
Total R2		7%	7%	36%	50%

- Again, should clinical psychologists really need to be told this?
- I much prefer this one, although I'm unsure what's means by the formal assessments for this.
- I prefer this one and the word 'influence' rather than 'dictate'. Also not all relationships are romantic and that's ok too. I'd put romantic/sexual.

- There is not always appropriate formal assessments available, although believe they should be used where they are.
- unsure about the latter bit and what is meant. And not all sexual relationships would be nec be romantic I guess
- why use the word 'romantic' when we are talking about sexual relationships per sae. They don't always have to be romantic. We may be talking about masturbation here as often occurs within our population.



**2. Make sure the client’s voice is heard, and think carefully about the level of confidentiality promised/kept. There will be some things it will be useful for staff to know, but others that they do not need to know, and may negatively affect the way they treat that individual.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001			x		
P002				X X	
P003				X X	
P004				X X	
P005			X		
P006				X X	
P007					X X
P008					
P009					X X
P010			X		x
P011					x
P012				X X	
P013					x
P014					x
P015					X X
P016					
P017				X X	
Total R3			18%	55%	27%
Total R2			7%	43%	50%

- Obviously, I think the clients voice should be heard. I would say, that sometimes the opposite happens and when staff do not know certain information they treat the client negatively – therefore, I am unsure about the wording of the second part. Maybe a more generic statements could work.
- I guess this depends on the context for information sharing. If there are safeguarding concerns then some of the information might need to be

shared to reduce risk, whilst in other circumstances the client's wishes should be respected more.

Where there aren't safeguarding issues, capacity about sharing information is also relevant to think about.

Further, important to think with the client about reasons why they do and don't want to share info (which you would do when assessing capacity to share info) and to think with them about their perceived hopes and fears to develop a shared plan of not just what to share, but how to share it (e.g. with them present or not).

I fully agree with the first half of the first sentence

- I think that you can't say 'useful' to know as we wouldn't break client confidentiality for 'usefulness' only in relation to risk.
- I agree with the comments above. It's standard practice to consider the limits of confidentiality with all the work we do so this should be common sense to psychologists. I'd also say it's important to consider why the client may not want information to be shared.
- Agree with the comments regarding breaking confidentiality being related to risk
- Reading others' comments I agree – making more specific reference to confidentiality and capacity to consent to sharing of information would be useful here. The first sentence is important – sharing information can only happen with client consent, and then only being shared on a 'need to know' basis.
- This is not a guideline just for this particular issue, this is what everyone should be doing anyway.

**15. It is important to accept that it will not be possible to bring all staff teams/members to a place where they understand and accept the sexual expression of the client. In cases where this is not possible, pushing them too hard can invoke a negative response and motivate them to stand by their opinions, which in turn can influence how they respond to future problems. Sometimes, in order to ensure a client's quality of life is preserved, they require support staff that can accept their sexual expression, and this might be a different staff team.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002			X X		
P003				X X	
P004					X X
P005			X		
P006	X X				
P007					X X
P008					
P009				X	x
P010				X X	
P011				x	
P012			X X		
P013				x	
P014	Not rated, but commented on				
P015				X X	
P016					
P017					X X
Total R3	9%		27%	37%	27%
Total R2	8%		16%	38%	38%

- I think it is very important to acknowledge that sometimes the person's environment is not right.
- Individual case issue; not really for a guideline.

- I agree with most of this, but I'm not sure about changing the staff team completely if they can't support – this really ought to be a last resort? Especially if the person is settled. Also important the person with ID has some say in this and consideration is given to what is 'good enough'.. Staff should have to follow care plans even if they don't agree with their content – These should be used to say what a person needs with regards sexuality. If not then the issue needs raising with social services. Hopefully at least some people within a given team could be a source of support for the person, even if others were only reluctantly following the plan.
- I think this is an important area, but not sure I fully agree with this statement.
- Training, education, support and supervision are key to facilitating staff to do their job to the best of their ability, and in the clients' best interests.
- Should read 'accept that it will not *a/ways* be possible....'?
- It may be the staff member needs to leave not the other way round as staff have a duty of care and shouldn't be discriminatory. The first two sentences maybe more pertinent when working with family members.
- I agree with the principle of this guideline, but think 'accept that it will not *a/ways* be possible', and add guidance on what remedial attempts should always, ethically be tried before consideration is given to moving the person to a new home (supervision, education, training and workshops, liaising with service management and looking into their organisational policies.....)
- I still think that this may be an issue in an individual case, but seems a bit drastic and specific to put in a general guideline
- I don't really feel this is a guideline. It is again, far too unwieldy.

**28. Sexuality, sexual expression, and intimate relationships need to be on your radar during initial assessment. Where direct discussion of this with the client makes them uncomfortable, information should be gathered from staff (e.g. do they have private time?)**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	
P003				X X	
P004				X X	
P005			X		
P006				X X	
P007				x	X
P008					
P009					X X
P010				X X	
P011				x	
P012			X X		
P013					x
P014				x	
P015				X X	
P016					
P017					X X
Total R3			18%	55%	27%
Total R2			7%	64%	29%

- I wonder whether this could be broader to encompass gender too?
- That depends on the referral. If it's to psychology then potentially yes.
- Unclear if the guidelines are for services or individuals so important to have clarity.
- I wonder if it is more common for the question to feel uncomfortable for us to ask, than the client being too uncomfortable about this. Even if the questions might make clients uncomfortable, what message do we

perpetuate if we also don't ask about sex. What are modelling to staff if we avoid these questions. If the client does feel uncomfortable when asked they we shouldn't pursue, but could discuss issues around why talk is uncomfortable (i.e. 'talk about talk'). Issues of consent also – we should get consent from client to discuss these matters when able to do so.

- CPs shouldn't need to be told this should they?
- In response to the last comment above CPs do need to be told this as it is often neglected.
- It should be an important part of holistic assessment but will not always be the most pressing issue
- Don't like the use of 'radar'. But again this is what we should always be doing.

**31. Identify a core group of people around the individual (staff members, professionals, family members) who take responsibility for talking about their sexual expression and needs. This group should be agreed with the individual and consist of people that they feel comfortable discussing the matters with. The group should be made up of people who are accepting of the individual's sexual expression, and who are comfortable discussing and supporting it. The group should periodically check in with one another to ensure that all feel supported and that approaches continue to be most helpful for the individual.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001			x		
P002				X X	
P003					X X
P004			X X		
P005				X	
P006			X X		
P007					X X
P008					
P009				X X	
P010		X X			
P011					x
P012			X	x	
P013			x		
P014			x		
P015			X	x	
P016					
P017			X X		
Total R3		9%	46%	27%	18%
Total R2		7%	43%	29%	21%

- Sometimes people may not want a group of people talking about their sex lives....?

- This is a good idea, I'm not sure how feasible it would always be.
- Interesting idea!
- Not sure how easy or ethical this would be to do?
- It could be offered but I agree with the first comment that not all individuals will want to discuss it with someone so I'd adjust this to reflect this. That it may not be a group but a website or a book if that's all the client wants.
- Ethically complicated – adding in a clause about 'with the client's agreement/consent' may help?
- Again because of the case specificity of this I wonder if its right to promote it as a "guideline"? Maybe it should just be flagged as a possible option? It may even be more appropriate to give "case examples" which illustrate these options (case examples always enliven boring guideline anyway!). So the guideline might read ***"Consider a range of supports for a person. This may be an outside person such as an advocate, a family member or friend, or a core group of staff and supporters" e.g. "Example: Brian was anxious about telling his mother he was gay. A small group of staff who knew his problem and had been through an education package with him, supported him to invite his mother over for tea and were there while he talked about his sexual identity."***
- If led by the person's wants (if they have capacity) - Important to think about how the group understand the person's sexuality/sexual-behaviour/risk also – What the remit and limits would be. Some comments above rightly mention the ethics and issues about a number of people talking about the person's sexuality – But wouldn't that be the case in work with a staff team anyway?
- This perhaps needs to be considered in an idiographic person centred way on a case by case basis – E.g. the person might identify a couple of staff members who they would like to be able to approach to talk about issues relating to sex and sexuality.



- This is an important guideline, as long as you make it clear that you are not advocating people should talk about sexual issues in a group situation.

**42. Ensure that you not only apply your psychological knowledge/expertise to the client, but also to the context of the situation. This should include consideration of why the staff teams might be responding in a certain way, but also being mindful of the processes you may be getting pulled into yourself.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002					X X
P003					X X
P004				X X	
P005		X			
P006			X X		
P007			X		x
P008					
P009				x	X
P010				X X	
P011				x	
P012				X	x
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3		9%	18%	27%	46%
Total R2			7%	36%	57%

- Again, do qualified clinical psychologists really need to be told this?
- This sounds the same as 3,4&5. I don't know whether it needs to be a separate guideline. I also agree that this should be common knowledge to CPs so may be do without this one as it seems to be covered in the first lot of questions.
- Agreed- this is part of a CP role, not specific to these guidelines?

- As per comment above, perhaps it is important to think about what would be different for working with staff teams around sexuality compared to in general. And also perhaps not just 'psychological' knowledge – Also need to consider the effects of stigma and prejudice on how the staff make sense of the client and their worries about how other agencies will perceive the work they do with the client.
- this has been covered elsewhere and again is what everyone should be doing anyway.

**6. Work with staff to identify any gaps between what they believe they should be saying or doing regarding the sexual expression of those they support, and what they actually think or believe. Support them to acknowledge this incongruence, and explore what might be done to minimise or manage this.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001		x			
P002				X X	
P003					X X
P004					X X
P005					
P006			X X		
P007 - 5					X X
P008				X	
P009					X X
P010			X X		
P011				x	
P012					X X
P013			x		
P014				x	
P015 - 3				X X	
P016					
P017				X X	
Total R3			18%	36%	45%
Total R2		7%	21%	36%	36%

- You would need a very well engaged team – this would come later in the sequence of guidelines I think
- I think that this guideline is very unclear, I don't see the difference between 'what they believe they should be saying' and 'what they actually believe'.
- Very similar to 3, but broader

- I think this is better worded in the guidelines below.
- I do think this guideline is clear. Acts of microaggression occur all the time so people may say they communicate one thing but at a micro level they are communicating something very different based on their beliefs. I think it's naive to think this discrepancy doesn't exist.
- Important but again needs simplifying.

**10. Be very clear with the staff team about what you are doing and why, both in terms of assessment and intervention. Share with them the resources etc. used so that they can understand the issues being addressed and how.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002			X X	X X	
P003					X X
P004				X X	
P005					X
P006			x	X	
P007					X X
P008					
P009					X X
P010			X X		
P011				x	
P012			X X		
P013					x
P014			x		
P015		X X			
P016					
P017				X X	
Total R3		9%	25%	33%	33%
Total R2		7%	33%	27%	33%

- Depends on issues of capacity and consent for sharing info. Also, if staff aren't on board with discussing sexuality then there could be risks of misunderstandings , or not supporting the work
- I think this varies depending on the circumstances
- Within the boundaries of clients' privacy, confidentiality, dignity. Perhaps on a need-to-know basis? Share whatever is in the clients' best interest, and is clinically indicated, with consent.

- I agree with the comments above. I'd add in on a need-to-know basis.
- If this guideline is included I agree with the final comment above – important to include this
- Again because of case specificity, maybe this is better worded as an option to be considered, with pros and cons? E.g. ***“In order to gain staff support and commitment to work with the individual, it may be helpful to share...etc. However there may be times when this is not appropriate because of the sensitive and confidential nature of the issues.”***
- Agree with comments above
- This is essential but as stated above there are many issues within this that need to be addressed and explicitly stated.

**13. Care staff are the experts on the client, acknowledge the value of their input. Staff will often *know* the client very well; the clinical psychologist's role is to help them *understand* that client.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002			X X		
P003					X X
P004			X X		
P005			X		
P006		x	X		
P007				X X	
P008					
P009				X X	
P010		X X			
P011					x
P012			X	x	
P013					x
P014				x	
P015			X X		
P016					
P017			X X		
Total R3		9%	64%	18%	9%
Total R2		14%	29%	36%	21%

- ' Care staff are the experts on the client' ....they *can* be, but not always!
- Care staff are knowledgeable but I wouldn't say they were experts on the client. More that they are likely to know them better than anyone else and have expertise.
- Sometimes care staff aren't the experts... Safeguarding issues/lack of training/lack of a stable staff team. I agree with the second half of this statement.



- The reason I think it's less important is because I don't think psychologists should need to be told this.
- I think there are conflicts between the first and last part of the statement. I think it is very important for psychs to think about their positioning in relation to the staff team, and to recognise that the team will have much more day to day experience ('expertise') about the person they support. Psychologists bring skills and ideas that they can use to hypothesise alongside the staff team to support all involved to become more curious and insightful about what might be going on for a client/staff system. In case it is of any interest/use, I like Barry Mason's writing on 'authoritative doubt' and try and adopt a similar position when working with staff
- A key message for all our work
- Sometimes this expertise is coloured by one's own values, principles, beliefs etc. and we are unaware of this.
- A very important point but this is not unique to these guidelines, but an inherent part of all CP working in ID services
- Staff have expertise. They're not the experts. So I'd reword this.
- I am unsure what this guideline would add to a CP's practice
- I agree with some of the statements about the ambivalence about staff knowledge and understanding. Perhaps better to put that psychologists should always respect the staff's day to day knowledge of the person, while being sensitive to the staff's own personal and team issues, and integrate the information into a holistic formulation of the person's issues.
- I liked the comments above. Perhaps if it is reworded to something that recognises the knowledge and experience staff bring, rather than framing them as 'experts' on the client.  
Is there any value in separating out guidelines relating to general approaches to working with staff teams from those more specifically relating to sexuality? Or how might this recommendation be different in relation to sexuality?
- We would like to think that care staff know the clients better than we do, but this is not always the case. It depends on many things. We have to be careful with this.

**14. Don't overcomplicate the intervention, focus on the simple things first to help staff understand.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001	Not rated, but commented on				
P002				X X	
P003				X X	
P004				X X	
P005			X		
P006			X X		
P007		X		x	
P008					
P009			X X		
P010			X X		
P011					x
P012		X X			
P013					x
P014			x		
P015		X	x		
P016					
P017		X	x		
Total R3		36%	36%	28%	
Total R2		8%	46%	31%	16%

- Everyone is an individual, this guidelines seems a bit generic.
- This is part of the teaching involved – again, this should be self-evident for good teaching.
- I think it wouldn't necessarily be clear cut what the simple things are. We may need to prioritise what we do with staff. This recommendation seems to fit more with educating/taking an expert position, different to hypothesising with staff.
- A mistake seen very frequently...

- The intervention may be complicated if that's what the client requires!  
Support staff to understand the complexities and nuances as necessary.
- Unclear what is meant.
- Agreed, I think this is too generic and I'm not sure how much it's needed, unless you add in an example to illustrate the point.
- Is there something somewhere about importance of risk assessment and ensuring safeguarding/client safety considered? Important to address this as a priority in cases where risk is actually v. high
- Not sure about this. It seems to be saying only do what you have to do and don't do too much. Very often sexual issues are part of a previous trauma and therefore are complicated.
- Too generic?

**22. Be proactively enabling. Map out clearly for the staff ahead of time what can be expected of them. This can be framed within the resources you provide and the services you signpost to; these provide practical indicators of what is reasonable to expect of them, and therefore acceptable and legal for them to do.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001			x		
P002				X X	
P003					X X
P004			X X		
P005				X	
P006				X X	
P007				x	X
P008					
P009			X X		
P010					X X
P011				x	
P012				X X	
P013					x
P014					x
P015				X X	
P016					
P017				X X	
Total R3			18%	55%	27%
Total R2			21%	50%	29%

- Sometimes this may not be possible.
- And to be clear where their responsibilities end – Staff can feel overly responsible sometimes
- Also quite vague.
- I agree with the middle comment.

- Agree about helping them to not feel overly responsible – reducing the degree to which they feel responsible might support them in allowing someone to express their sexuality more (might mean they seek to protect less strictly).
- This needs to be made clearer. Not completely sure what you are saying.

**25. Organise workshops and training sessions for staff teams, in order to address gaps in understanding, as well as their fears in working with these issues. However, expected levels of change should be appropriate to staff ability levels and the strength of their personal beliefs on the matter.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001			x		
P002				X X	
P003					X X
P004				X X	
P005				X	
P006				X X	
P007				X X	
P008					
P009				X X	
P010					X X
P011 – 8-9				x	
P012				X X	
P013				x	
P014					x
P015					X X
P016					
P017				X X	
Total R3				73%	27%
Total R2			7%	64%	29%

- As above there should be guidelines on what should be expected from a staff member.
- We also need to be mindful of the financial constraints on teams and the business models they operate under. Hard to get organisations to free up staff for all the various sessions we want with them so need to prioritise what is going to be most helpful

- Workshops will be needed for a good deal of the material covered here
- Not sure of the evidence base for staff training in effecting change in the way they respond to behaviour?
- It's more important to get the management / team leader on board. If they're not present then training will make little difference.
- Again maybe this is an option for intervention rather than a guideline for general psychologists work. In some situations it may be more appropriate to bring in outside trainers.
- It would be good to gather evidence on these sessions as they are done (often the evidence comes through practice).

In addition to the financial constraints of teams, there are also issues when there is an expectation that NHS services should provide such training to private providers claiming to be experts on providing person centred care. Placing this training as 'additional' (and not core to a person's needs and part of the provider's mandatory training) is problematic. However the training might not be otherwise available to teams.

- This is important but could be stated much more simply.

**30. Initiate the practice of talking about issues of sexual expression as an MDT – bring it up enough to normalise it and make it a more comfortable conversation for colleagues (we need to challenge ourselves and each other).**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003					X X
P004			X X		
P005				X	
P006			X X		
P007				x	X
P008					
P009			x	X	
P010				X X	
P011				x	
P012				X X	
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3			18%	46%	36%
Total R2			21%	43%	36%

- I totally agree. It isn't just the psychologists job to be curious about sexuality, gender, but we are often the only ones with the conviction to do it
- I'm ambivalent because it's very situation dependent.
- Perhaps links with other items recognising that it can be a difficult topic for staff
- CPs shouldn't need to be told this should they?



- Yes this would be good but only when appropriate or when a referral regarding sexual issues is presented.

**35. Normalise staff's emotional reactions and prejudices, while supporting them to be critical of prejudices and views, and where they come from. What discourses are they drawing on? In terms of the intersections of the client's identity and the polarities of semantics – challenge them to think in terms 'both/and' rather than 'either/or', for example, when balancing the supporting of sexual expression and potential risk.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001			x		
P002				X X	
P003					X X
P004				X X	
P005				X	
P006			X X		
P007					X X
P008					
P009				X X	
P010				X X	
P011				x	
P012				X X	
P013					x
P014				x	
P015				X X	
P016					
P017					X X
Total R3			9%	64%	27%
Total R2			14%	57%	29%

- I like this idea but I think it is too full of jargon
- It's very jargon for a guideline. Needs saying more simply.
- did you mean 'sematic polarities'? – This related to formulating; normalising; positively connoting intentions of all within a system
- needs to sit alongside all the staff discussion items

- Unclear
- This seems similar to 3,4 and 5
- I still think this point needs simplifying – clearer and to the point
- Could be clearer
- I agree with the comments about reducing jargon. I think in some ways this links to the positive connotation too – a means of making sense of staff reactions/prejudices in the context of dominant discourses
- Too many words to explain something simple.

**37. Given many staff members' level of expertise and professional background, it is important to operationalise what 'reflection' is. Provide staff with a toolkit to engage in structured reflection.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002					X X
P003				X X	
P004			X X		
P005		X			
P006		x	X		
P007				X X	
P008					
P009			X		x
P010					X X
P011				x	
P012			X X		
P013					x
P014					x
P015				x	X
P016					
P017				X X	
Total R3		9%	37%	27%	27%
Total R2		7%	14%	36%	43%

- Do you mean the MDT or the care staff? But potentially yes this would be helpful.
- Importance depends on staff team.
- unsure about if structured reflection would be carried forward by a team, operationalised in a useful way
- Is this for when the staff are talking with the client? I'd be more specific here.

- No need for 'structured'? Introducing the concept of reflection to staff teams, either formally, or informally through modelling, will be helpful
- Like much in the guideline, this is both something we should consider across a variety of interventions not just sexuality, and also case specific – may not be a “one size fits all”
- If people don't know what reflection is, then this is a different topic entirely. It is not something that should be included within a set of sexual guidelines.  
If staff do not understand reflection, this must be addressed separately, not included here.

**50. Involve service users in the process wherever possible. Generally clinical psychologists themselves do not have an intellectual disability – hearing the message from a people with intellectual disabilities (and potentially someone other than the service user) carries more weight with staff teams.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	
P003				X X	
P004			X X		
P005	X				
P006			X X		
P007				X	x
P008					
P009			X	x	
P010			X X		
P011				x	
P012			X	x	
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3	9%		46%	27%	18%
Total R2			21%	36%	43%

- This might be more appropriate at the systemic level as part of a proactive approach but might more tricky at the level of individual intervention.
- By definition a clinical psychologist couldn't have an LD. If you've got GCSEs you don't have an LD.
- I'm pretty sure there are no clinical psychologists who have an ID??

- May or may not be feasible.
- I don't think someone with an ID could become a psychologist
- I don't know any
- I'm not sure you can say 'generally CPs don't have an ID'. I'm aware this is trying to be politically correct but is probably not accurate so this bit may need re worded or omitted.
- I agree. CP's can't by definition have an LD. What would be really useful is a video resource which had people with an LD talking about sex along with clinicians also talking about how they support someone. See *Supporting Derek* video about dementia for an example.
- I like the 'wherever possible' part, as this is an ideal that I have found hard to do in practice. I agree no need for 'generally CP's.....ID', but about hearing user's personal experiences can be more powerful than theoretical input
- I've been in situations where a parson with an ID has been asked to comment on someone with very different needs to themselves, and I think have shown much less insight because their situations were very different. While I want to give maximum voice to service users I think we have to be wary about just who we approach and what we expect from them. So, may or may not be feasible I think!
- I agree with the comments about CPs and ID.

I think this is a great idea but would need to be thought about carefully and would depend on the referred person's needs (they would need to consent) and also the needs of the person with the ID themselves (a risk that if this is in guidelines that professionals might coerce a person with ID to talk about personal issues they'd prefer not to) – Could video materials be presented instead? E.g. use of actors?

- Service users should be involved in as many decisions as possible. Nothing about us without us. This just needs to be stated as such.

**51. Make use of positive portrayals of sexual expression and relationships in the media, such as advertising campaigns and news features.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002			X X		
P003				X X	
P004			X X		
P005	X				
P006			X X		
P007					X X
P008					
P009			X X		
P010			X X		
P011				x	
P012				X X	
P013			x		
P014				x	
P015			X		x
P016					
P017					X X
Total R3	9%		55%	18%	18%
Total R2			43%	36%	21%

- Difficult to do for anything considered not 'normal'
- I'd give an example here to illustrate the point. E.g images of people cross-dressing are often depicted as looking a certain way that may not be empowering or respectful.
- I am not sure I did rate this so highly first time – it does not feel so important now
- I do not believe this is feasible, and I do not think it is the role of a CP anyway.



**8. Give staff the permission to not be scared to talk about matters of sexuality, and model how they can be discussed in an open and relaxed way. In doing so it is often important to normalise the diversity of sexual needs and experiences in the general population, and encouraging an awareness beyond the staff's own sexual experience**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003				X X	
P004					X X
P005			X		
P006				X X	
P007					X X
P008					
P009				X X	
P010			x	X	
P011				x	
P012				X X	
P013					x
P014					x
P015			X X		
P016					
P017				X X	
Total R3			18%	64%	18%
Total R2			14%	57%	29%

- This guideline is not very clear – the concept would probably be covered by merging 7 & 9?
- I think these are similar messages but one is about normalisation and the other is about dealing with societal/ cultural narratives about sex in general .. giving permission being key. (for me this one is similar to guideline 6).

- It is important for staff to feel they can talk about issues, but this is surely covered in one of the above guidelines.

**9. Prior to beginning any work with staff, it is helpful to have an open discussion with them about how the sexual expression of people with intellectual disabilities can be a difficult topic to discuss. The aim of acknowledging and showing that you accept this is to create a safe space in which the staff can reflect honestly about how their own values fit with the issue.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003				X X	
P004					X X
P005			X		
P006			X X		
P007					X X
P008					
P009					X X
P010				X X	
P011					x
P012				X X	
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3			18%	36%	46%
Total R2			7%	36%	57%

- Also important to be aware that individual staff member's own experiences might make certain topics more difficult, and to try and be respectful of this. E.g. difficulties involved in talking with staff about a client who has sexual interest in children with a staff member who has been abused.

- I like this one the best
- 8 and 9 can be merged.

**7. Normalise the sexual expression of people with intellectual disabilities; what to expect, what is healthy, what is normal and what someone has a right to. Not just in terms of feelings, but also things they have access to (e.g. online dating).**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003				X X	
P004					X X
P005			X		
P006					X X
P007					X X
P008					
P009					X X
P010					X X
P011					x
P012				X X	
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3			9%	27%	64%
Total R2				29%	71%

- I'd be worried that the what is 'healthy' 'normal' could be misinterpreted by some as suggesting that there are more healthy/normal sexualities than others. I would prefer it to be more along the lines of formulating – making distinctions between sexuality and what the person does, the effects on others, linking to a risk assessment and what people without ID have access to
- 'Normal' is a difficult concept – especially if only 'normal' equates to 'OK'

- Not clear whether this is work for patients or carers.
- This feels similar to the one above (but not the first one in this pink box)
- See if you can amalgamate this with 8 and 9 as they cover the same thing.
- What is 'healthy' and what is 'normal'. Be very careful here.

**1. Be very clear with staff about what capacity is and how it is assessed from the start. Staff should be aware of the mental capacity act, but will not necessarily be aware of or understand the complexities of it.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002			X X		
P003				X X	
P004				X X	
P005					X
P006					X X
P007					X X
P008					
P009					X X
P010				X X	
P011					x
P012				X X	
P013					x
P014					x
P015				X X	
P016					
P017					X X
Total R3			8%	46%	46%
Total R2			7%	43%	50%

- I feel there is often a lack of understanding about capacity, as well as how this applies to sex and relationships.
- Minor point, the MCA excludes sexuality from it's areas of application. We're talking about the Sexual Offences Act.
- With regards the last sentence, we also shouldn't EXPECT staff to have a good grasp of this, especially as many professionals get confused by it.

We should be supportive and empathic to staff trying to understand this and not criticise.

- Staff do need to know what decisions they can/cannot make on someone's behalf
- I can comment on this from an Irish perspective (different to British situation) if you think it relevant?
- I was unsure about the comment about the MCA excluding sexuality – Not something I had heard (please could you let me know if there is anything I need to be aware of here – Thanks)
- This is important but it should be at the beginning of the guidelines.



11.

**Educate the staff on the impact and/or consequences of not having sexual and emotional relationships.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	
P003				X X	
P004		X X			
P005	X				
P006				X X	
P007					X X
P008					
P009				X X	
P010			X X		
P011				x	
P012			x	X	
P013			x		
P014					x
P015				X	x
P016					
P017				x	X
Total R3	9%	9%	18%	56%	18%
Total R2		7%	21%	43%	29%

- It's also about the impact of not being able to express or satisfy your sexuality/libido etc not just relationships.
- My preference would be to try and think with staff and other key people involved about the advantages and disadvantages of doing any work, drawing in evidence base to say how work has been helpful for others in the past. As opposed to educating. There might be some instances in which the process could result in us changing out opinion about what to do with the work.

- Helpful for 'buy-in'
- Should this read 'potential impact and/or consequences'?
- Whilst I feel this is important I am not sure we ourselves 'know' what the impact is.. does this fit into a wider understanding of social connectedness/ quality of life.
- Do we have any evidence of what the impact is? This guideline could be more about collaborative thinking with staff about what the possible impact could be/are for the individual client?
- Like the suggestion about thinking about this as one element of QoL/social connectedness
- And the impact is ??????????????????????????????????????
- Is educate the wrong word – need to more allow for discussions to be had to get staff thinking about it.

**12. Risk management should not be mistaken for risk elimination. Staff should be given permission to accept a certain level of risk in order to allow the client the opportunities that those without disability have. This may in turn require a certain level of intrusiveness into a client's life, which again should be accepted but minimised, as long as it serves to increase the client's access to desired opportunities.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	
P003				X X	
P004					X X
P005					
P006				X X	
P007					X X
P008					
P009					X X
P010				X X	
P011					x
P012			x	X	
P013					x
P014					x
P015				X X	
P016					
P017				X X	
Total R3				63%	27%
Total R2			7%	43%	50%

- I found this one complicated. It seems to include a couple of ideas in my opinion. The content seems very much in keeping with the MCA/best interests, and person centred approaches to risk assessment/'positive risk taking'

- Easier said than done. We are naturally risk averse often. Top-down explicit, unequivocal support is essential.
- I think there is also something about shared risk taking being important...
- I agree with the last comment made above.
- Agree re shared risk taking
- I also wondered if there are a couple of ideas here – One sentence seems to be about recognising that it is sometimes important to allow there to be risk; the other seems to be about recognising there are times we need to intervene? I liked the idea about linking this explicitly to the MCA and best interests/positive risk taking.
- Risk should be addressed earlier. But the way this is written, to my mind, is very dangerous.

**16. Promote a ‘skills, knowledge and opportunity’ framework for assessing individuals, encouraging staff teams to develop a more holistic understanding of the person and their behaviour. Social and/or sexual skills, and opportunities for meeting and interacting with people should be considered as well as the commonly covered sexual knowledge.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	X X
P003				X X	
P004			X X		
P005					X
P006					X X
P007					X X
P008					
P009			X X		
P010					X X
P011				x	
P012				X X	
P013					x
P014					x
P015				X X	
P016					
P017					X X
Total R3			16%	34%	50%
Total R2			13%	40%	47%

- Although opportunities may be few and far between
- Yes, I agree that this should all be considered as standard practice.
- I would say this is important wouldn't it!? a simple, useful framework.
- This is rather vague – it would need examples
- Very true!
- **This is important but should be placed earlier.**

**18. Support care staff to not limit themselves to ‘fixing the person’, but to also look at broader issues (i.e. their environment, the amount of privacy they get, the impact of how others respond to their actions).**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	
P003				X X	
P004				X X	
P005					X
P006 - 16					X X
P007					X X
P008					
P009					X X
P010				x	X
P011				x	
P012 - 16				x	X
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3				27%	73%
Total R2				43%	57%

- Yes and risks.
- I think this is essential and that working systemically with the LD population is key. “The person is not the problem, the problem is the problem”
- Goes with skills/knowledge/opportunity framework of No.16.
- **Yes although they’ll need to have a risk management plan.**
- **I think this could be included earlier in the guidelines.**

**21. Discuss with the staff the problems that staff teams commonly encounter when issues arise around the sexual expression of an individual with intellectual disability. Problem solve potential scenarios ahead of time so that the staff are not caught off guard.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001			x		
P002				X X	
P003					X X
P004				X X	
P005	X				
P006				X X	
P007					X X
P008					
P009				X X	
P010		X X			
P011				x	
P012				X X	
P013				x	
P014				x	
P015				X X	
P016					
P017				X X	
Total R3	9%	9%		64%	18%
Total R2		7%	7%	72%	14%

- A lot of the problems encountered are covered in the other guidelines
- Quite vague.
- Links with no 11?
- There is a little vagueness but I think there is an important message about pre-emptive planning for future scenarios
- This is addressed earlier.

**23. Establishing staff members' appreciation of the developmental stages of a romantic relationship, and development as a sexual being more broadly. Highlight the parallels between the developmental processes of all of us; many individuals with intellectual disabilities can and do go through the same developmental stages, just delayed, and requiring support to do so (e.g. in terms of dating before sleeping together (relationship development), or engaging in teenage-like experimentation in adulthood (sexual identity development)).**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002			X X	X X	
P003				X X	
P004				X X	
P005					X
P006					X X
P007					X X
P008					
P009					X X
P010				X X	
P011 - 7				x	
P012			X X		
P013					x
P014					x
P015					X X
P016					
P017				X X	
Total R3			16%	42%	42%
Total R2			13%	40%	47%

- This is part of the teaching involved – teaching needs to highlight similarities and differences for people with intellectual disabilities.



- All relates to person's circumstances and need. Perhaps this links to other recommendations about normalising a person's sexuality. A person with ID's sexual development isn't necessarily delayed.
- Covered to an extent by guideline 7
- Development isn't necessarily delayed, and also some people might not progress through some cognitive and emotional developmental stages. Agree with keeping things focuses to an individual's personal circumstances, need, desires and risk.
- covered above. 'Romantic' used again. What are the developmental stages? This would be a teaching issue in itself.

**24. Normalize people with intellectual disabilities’ sexual identity. The pacing of this needs to be carefully considered. The role of the clinical psychologist is often to marry up the needs of the client, and the staff’s ability and willingness to support these needs. Since the inability felt by staff is often associated with not having the ‘skills’ or with deep-rooted beliefs, it is important not to expect too much from them too quickly – the approach should be akin to graded exposure rather than flooding.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002			X X		
P003			X X		
P004				X X	
P005	X				
P006	x		X		
P007			X X		
P008					
P009					X X
P010				X X	
P011 - 7			x		
P012 - normalising			X X		
P013				x	
P014	Not rated, but commented on				
P015				X	x
P016					
P017				X X	
Total R3	9%		45%	36%	9%
Total R2	7%		39%	39%	15%

- I agree although they also have a duty of care so in the same way as other care requirements there are some discussions I’d expect them to be able to do.

- I don't think it's really clear what it's saying
- I'm unsure what flooding would look like with regards normalisation
- Overlaps with others (e.g. guideline 7)
- This needs to be considered within, and balanced with, an advocacy, rights-based, capacity framework. E.g. Management, or indeed an individual staff's 'willingness' to facilitate another adult's right re intimacy etc, has its boundaries. This is particularly tricky as I work within a disability service which has a religious ethos (i.e. strong beliefs regarding sex), coupled with capacity legislation that's in its infancy.
- Re-reading this I feel less clear about it – I think this guideline could be shorter, simpler and more clear? E'g' Normalise....identity. intervention should be paced at a rate taking into account the service user and support worker's needs and ability to make changes'
- I've changed a little her because although its unclear there are two messages, about people with ID's sexual identity and about the need to be aware of staff's own issues. I guess both are covered elsewhere.
- This is covered above. Be careful with 'normalising' sexual issues. It is a very great area and very diverse.

**26. Help staff to appreciate that sexual expression is as important as any other area of an individual's care.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003					X X
P004					X X
P005	X				
P006 - 49					X X
P007				x	X
P008					
P009					X X
P010				X X	
P011				x	
P012			X		x
P013					x
P014				x	
P015			x	X	
P016					
P017					X X
Total R3	9%		9%	27%	55%
Total R2			7%	43%	50%

- Food, shelter and safety/being free from pain is more important, but yes I agree.
- Covered in several other guidelines
- This is similar to another guideline above but I like the simplicity of the wording here. I also agree with the first comment.
- Yes I agree this is important
- Agree with the comment about their being more primary needs – The need for safety is also more important than the need for sexual contact

so important to consider this when thinking about if protections/ some form of restrictions might be important.

But yes – An **important** aspect of someone's care, and of being human

- Could be slotted in elsewhere.

**27. Identify with staff the different levels of influence operating on them regarding issues of sexual expression in people with intellectual disabilities (e.g. personal values, religious beliefs, organisational approaches, societal norms and values).**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	
P003				X X	
P004			X X		
P005	X				
P006				X X	
P007					X X
P008					
P009			X X		
P010					X X
P011				x	
P012			X X		
P013					x
P014					x
P015					X X
P016					
P017					X X
Total R3	9%		27%	27%	37%
Total R2			21%	29%	50%

- Depends on context and permission from staff – Perhaps risks asking more of them than they were willing to discuss.
- Covered in 8, 9, 5, 15, 24 etc...
- This is covered in other guidelines although I like the wording of this one as it's clear and straightforward.
- This has been covered above.

**29. Support the staff to consider the impact of high observation levels on sexual expression (e.g. do they have privacy to masturbate, to spend time alone with another person?), and how this can affect the individual.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003					X X
P004				X X	
P005	X				
P006				X X	
P007					X X
P008					
P009				X X	
P010					X X
P011				x	
P012 - SKO				X X	
P013					x
P014				x	
P015					X X
P016					
P017					X X
Total R3	10%			45%	45%
Total R2				57%	43%

- Part of all other items about content
- This has already been covered.

**32. Highlight to staff how immediately shutting down an individual's attempts to communicate matters of sexual expression because it is uncomfortable, or because one feels ill-equipped to have those conversations can be damaging for the individual, and the relationship.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002			X X	X X	
P003					X X
P004					X X
P005	X				
P006 - 11				X X	
P007					X X
P008					
P009					X X
P010				X X	
P011				x	
P012				X X	
P013				x	
P014				x	
P015					X X
P016					
P017				X X	
Total R3	8%		8%	42%	42%
Total R2			6%	53%	41%

- Equally, we don't all talk to everyone about sex. Perhaps it is ok that some care staff won't feel comfortable doing this. Finding a way to validate the conversation and signpost to someone they can talk to?
- I agree with the comment above.
- This is not a separate guideline. Should be included with others above.



**33. Explicitly identify and agree where professional boundaries lie, giving staff licence to have conversations about and support sexual expression with less of a feeling that they are making themselves vulnerable by doing so.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003					X X
P004				X X	
P005					X
P006					X X
P007					X X
P008					
P009					X X
P010				X X	
P011				x	
P012				X X	
P013					x
P014					x
P015			X X		
P016					
P017					X X
Total R3			9%	36%	55%
Total R2			7%	43%	50%

- Links to other items about supporting staff to talk about sexuality; recognising their responsibilities and the limits of their responsibilities.
- This is nice and clear, although similar to other guidelines.
- Unclear what is meant by this 'professional boundaries' – who is this referring to?
- This is essential and should be earlier in the set of guidelines.

**36. Help staff to think about the lived experience of the person, discussing how clients choose the staff to confide in and why.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001			x		
P002				X X	
P003					X X
P004			X X		
P005					X
P006				X X	
P007					X X
P008					
P009			x	X	
P010			X	x	
P011				x	
P012	Formatting error in R2			X	
P013					x
P014					x
P015			X X		
P016					
P017					X X
Total R3			28%	36%	36%
Total R2			31%	31%	38%

- Again a bit unclear.
- This also should be included earlier.

40. It is generally beneficial to help staff to appreciate the similarities between themselves and those they care for. This line of thinking should not only be applied to the individual's rights around sexual expression, but equally the related responsibilities. Both belong to the individual, and the individual alone, and they should not be taken away without very good reason (e.g. people from multiple professions have agreed the risk is too high).

Participant	Not at all	Not very	Neutral	Important	Essential
P001				x	
P002				X X	
P003					X X
P004				X X	
P005			X		
P006 -48					X X
P007					X X
P008					
P009				X X	
P010			X X		
P011				x	
P012			X	x	
P013					x
P014					x
P015				X X	
P016					
P017			x	X	
Total R3			27%	46%	27%
Total R2			14%	50%	36%

- I'm not sure I understand this guideline.
- Fits nicely with number No.48.

- Fits with person centred thinking in ID. As well as emphasising similarities, we need to attend to differences, linking with items on opportunity/skill/oppression etc.
- As well as the similarities it is also important to acknowledge differences – e.g. differences in terms of power/access/abilities/experiences of marginalisation
- ‘similarities’ between us and those we care for. Not sure what you mean about this within a set of sexual guidelines.

46.

People with intellectual disabilities often don't have the opportunity to explore their sexual needs and desires, and when they do they are often told what they are doing is wrong. Normalize the diversity of sexual expression and practice (e.g. LBGTQ, BDSM, fetishes) by reflecting with the staff on the practices engaged with by the general population.

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002					X X
P003				X X	
P004			X X		
P005	X				
P006 - 8				X X	
P007					X X
P008					
P009					X X
P010			x	X	
P011					x
P012 - normalise				x	X
P013					x
P014				x	
P015			X X		
P016					
P017					X X
Total R3	9%		18%	27%	46%
Total R2			21%	29%	50%

- For the avoidance of doubt/confusion the abbreviations need to be made explicit
- Similar to point 8.
- Links with previous items concerning normalization.

- This links with other guidelines. Need to be careful on reflecting with staff on different sexual practices.

**47. Encourage staff to reflect on why referrals regarding sexual expression have been made – consider whether the sexual expression would still be deemed a concern if the person did not have an intellectual disability.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	
P003					X X
P004					X X
P005	X				
P006			X X		
P007					X X
P008					
P009				X X	
P010				X X	
P011				x	
P012				X X	
P013					x
P014				x	
P015			X X		
P016					
P017					X X
Total R3	9%		19%	36%	36%
Total R2			14%	43%	43%

- But if this were the case, it shouldn't necessarily stop us getting involved as there might be issues relating to the ID or staff's anxieties about their responsibilities. Perhaps links to other items concerning hypothesising, reflecting, formulating
- Referrals re issues of sexual expression do not come to our service unless there is a significant risk issue attached to this, then the focus is

very much on the risk. So the concern would be present whether or not they had an ID. May not be the case for all ID services

- I agree with the first comment. It might be beneficial to offer a consultation with whoever made the referral so they're not pathologising normal behaviour.
- This is covered above.



**48. The need to balance public protection with the rights of the individual must be fully understood by staff. An important element of this is not letting compassion for one's client obscure compassion for victims of inappropriate behaviour. Society deems some acts to be illegal, staff should not be permitted to think that the presence of an ID pardons someone from abiding by the law, or removes the damage these actions can cause others.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	X X
P003					X X
P004					X X
P005	X				
P006 - 40					X X
P007					X X
P008					
P009			x	X	
P010					X X
P011					x
P012				x	X
P013					x
P014					x
P015 - 12					X X
P016					
P017					X X
Total R3	9%			16%	75%
Total R2			7%	13%	80%

- Should be about law, MCA. Also needs to be in somewhere that the person with an ID can be a victim of abuse and not okay to assume that seemingly consensual sex might not be
- High priority.

- I agree. However, the police force here unofficially believe a person with ID automatically is not responsible or accountable for his/her behaviour (even when there is capacity). A damaging message for all concerned.
- Perhaps should be a mention of the Sexual Offences Act which is more relevant here than MCA.
- This should be within issues of MCA and not listed separately.

**49. Take time to discuss with staff teams that sexual expression is a human need, relating it to their own lives and experiences.**

Participant	Not at all	Not very	Neutral	Important	Essential
P001					x
P002				X X	
P003					X X
P004				X X	
P005	X				
P006 - 26					X X
P007					X X
P008					
P009				X X	
P010				X X	
P011				x	
P012				X X	
P013					x
P014				x	
P015			X X		
P016					
P017					X X
Total R3	9%		9%	46%	36%
Total R2			7%	50%	43%

- *I can't remember which one but I think this is similar to one above*
- links with normalization items
- several places above
- This is captured in lots of the other guidelines
- This is the same as guideline 26
- This is included elsewhere.

## Appendix J

### Example of guideline finalisation process.

#### Triangulation with research team

#### Researcher AT:

Original Guideline	
<p>1. Be very clear with staff about what capacity is and how it is assessed from the start. Staff should be aware of the mental capacity act, but will not necessarily be aware of or understand the complexities of it.</p>	
<p>Feedback (Round 1; Round 2)</p> <ul style="list-style-type: none"><li>I feel there is often a lack of understanding about capacity, as well as how this applies to sex and relationships.</li><li>Minor point, the MCA excludes sexuality from <u>it's</u> areas of application. We're talking about the Sexual Offences Act.</li><li>With regards the last sentence, we also shouldn't EXPECT staff to have a good grasp of this, especially as many professionals get confused by it. We should be supportive and empathic to staff trying to understand this and not criticise.</li><li>Staff do need to know what decisions they can/cannot make on someone's behalf</li><li>I can comment on this from an Irish perspective (different to British situation) if you think it relevant?</li><li><b>was unsure about the comment about the MCA excluding sexuality – Not something I had heard (please could you let me know if there is anything I need to be aware of here – Thanks)]</b></li><li><b>This is important but it should be at the beginning of the guidelines.</b></li></ul>	<p><b>Tickle Anna</b> Yes – this is right: <a href="http://www.cps.gov.uk/legal/p_to_r/rape_and_sexual_offences/consent/#a02">the Sexual Offences Act 2003 s30</a> covers issues re: capacity and specific sexual acts with / by people with 'a mental disorder': <a href="http://www.cps.gov.uk/legal/p_to_r/rape_and_sexual_offences/consent/#a02">http://www.cps.gov.uk/legal/p_to_r/rape_and_sexual_offences/consent/#a02</a></p>
<p>Amended Guideline</p> <p>Be <b>very</b> clear with staff about what capacity is and how it is assessed from the start. Staff need to be aware of the <b>Mental Capacity Act</b>, and how this applies to matters of sexual expression, but be empathetic about how the complexities of it can be very hard to grasp.</p> <p>Clinical Vignette 1</p> <p>Bill (Clinical Psychologist) worked with a staff team in a group home, who supported Ross (PWID) with 24-hour care. Ross had verbally expressed a desire to meet someone whom he could "kiss and cuddle, and maybe more...". However, the staff felt that Ross would not be capable of selecting an appropriate partner, and feared he would end up sexually assaulting or being sexually assaulted. Therefore, the staff discouraged or distracted Ross from these wishes.</p> <p>Bill arranged a meeting with a number of the staff members, in which he explained the <b>Mental Capacity Act</b>, and in particular how it is intended for each decision as it comes. Together, they separated out the different decisions that Ross had alluded to (from meeting someone from daycentre for a public date and holding hands, to having them stay over), and discussed how Ross did not necessarily lack capacity for all decisions related to sexual expression. Bill and the team then collaboratively developed social stories for each of the decisions, which were utilised as a reminder for the team to take each decision as it comes, but also as a resource for them to share with Ross and informally assess his capacity on each decision.</p>	<p><b>Tickle Anna</b> October 13, 2017 I wonder if this needs to start with: 'Ensure you have a working understanding of relevant law, such as the Mental Capacity Act 2005 and Sexual Offences Act 2003.' Then the guidance. I don't think it should be taken for granted that all psychologist will have this, especially those new in post etc. There is a comment right at the end in the groupings section about this and I agree with it.</p> <p><b>Tickle Anna</b> Deleted: mental</p> <p><b>Tickle Anna</b> Deleted: capacity</p> <p><b>Tickle Anna</b> Deleted: act</p> <p><b>Tickle Anna</b> Deleted: mental</p> <p><b>Tickle Anna</b> Deleted: capacity</p> <p><b>Tickle Anna</b> Deleted: act</p>

Orange = Formulation  
Blue = Process of teaching  
Green = Individual referral  
Yellow = Content of teaching

Grouping into issues - key:

\* It's all complex (to do with issues to do with the MCA allowing for consent to be given on someone's behalf, and contradictions between the SOA 2003 and MCA in terms of application and issues around the Court of Protection giving consent to things on people's behalf in many cases but this not being appropriate for sex) and grounded in various precedents – worth looking at this for a summary: [http://www.familylaw.co.uk/news\\_and\\_comment/miranda-](http://www.familylaw.co.uk/news_and_comment/miranda-)

[mourby-capacity-to-consent-to-sexual-relations-where-are-we-now#.Wd-ByVtSyCg](#)

However, because we're talking about sexuality broadly, not just sexual activity, the MCA might well be the key law when it comes to choices to express sexuality in ways other than direct sexual contact. So, the MCA is not irrelevant but the SOA is more relevant for specific sexual acts... It does look as though the person who generated guideline one might not be aware of this. My inclination would be, especially in light of the comment about the Irish perspective (I assume they will be covered by different laws?), to phrase this as:

'Be very clear with staff about what capacity is and how it is assessed from the start. Staff should be aware of relevant law in relation to capacity (e.g. the Sexual Offences Act 2003 and Mental Capacity Act 2005), but may not be aware of, or understand, the complexities of its application'.

I also agree with the comment somebody has made about not expecting staff to have a grasp of this, especially re: the Sexual Offences Act and this might change things a bit... I wonder if it should be 'Staff should be advised of relevant law in relation to capacity (e.g. X and Y) as they may not be aware of it, or understand, the complexities of its application'.

This does also cast a bit of a shadow over the vignette, where there is no mention of the Sexual Offences Act, which would be relevant to the first steps towards sexual activity, but it might be worth putting in a footnote to say something like "The Sexual Offences Act 2003 would be consulted regarding direct sexual contact" or something like that?

This is quite handy too: <https://www.nursingtimes.net/roles/learning-disability-nurses/decisions-about-sex-for-people-with-learning-disabilities/5033828.article>

Clinical Vignette 2

A staff team which Joan (Clinical Psychologist) worked with were becoming increasingly anxious about what they should and should not be supporting Linda (PWID) with in terms of her sexual expression. Joan met with the team's manager Wayne, and provided him with ways that he could explain the Mental Capacity Act to the team in simple accessible terms/rules of thumb. One example was to ensure that he as the manager conveyed the message that capacity to make decisions should be assumed in all of those they work with unless there is evidence against this. For evidence to be valid, it would have to fall under at least one of four guidance notes (the four criteria for being able to make a decision in section 3(1) of the Mental Capacity Act). These were subsequently put into bullet points by Wayne and stuck on the wall of the staff office.

**Tickle Anna**  
Can you say something more about this in terms of in what way she might be expressing it / what the specific issues were? This would clarify that the MCA was the appropriate law, rather than SOA.

**Tickle Anna**  
Deleted: mental

**Tickle Anna**  
Deleted: capacity

**Tickle Anna**  
Deleted: act

**Tickle Anna**  
Deleted: mental

**Tickle Anna**  
Deleted: capacity

**Tickle Anna**  
Deleted: act

Researcher RdN:

Original Guideline

1.

Be very clear with staff about what capacity is and how it is assessed from the start. Staff should be aware of the mental capacity act, but will not necessarily be aware of or understand the complexities of it.

Feedback (Round 1; Round 2)

- I feel there is often a lack of understanding about capacity, as well as how this applies to sex and relationships.
- Minor point, the MCA excludes sexuality from its areas of application. We're talking about the Sexual Offences Act.
- With regards the last sentence, we also shouldn't EXPECT staff to have a good grasp of this, especially as many professionals get confused by it. We should be supportive and empathic to staff trying to understand this and not criticise.
- Staff do need to know what decisions they can/cannot make on someone's behalf
- I can comment on this from an Irish perspective (different to British situation) if you think it relevant?
- I was unsure about the comment about the MCA excluding sexuality – Not something I had heard (please could you let me know if there is anything I need to be aware of here – Thanks)
- This is important but it should be at the beginning of the guidelines.

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Amended Guideline

From the start, be clear with staff about what mental capacity is and how it is assessed. Staff need to be aware of the Mental Capacity Act (MCA), and how this applies to matters of sexual expression, but recognise that the complexities of the MCA can be hard to grasp.

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Clinical Vignette 1

Bill (Clinical Psychologist) worked with a staff team in a group home, who supported Ross (PWID) with 24-hour care. Ross had verbally expressed a desire to meet someone he could "kiss and cuddle, and maybe more...". However, the staff felt that Ross would not be capable of selecting an appropriate partner, and feared he would end up sexually assaulting or being sexually assaulted. Therefore, the staff discouraged or distracted Ross from these wishes.

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Bill arranged a meeting with a number of the staff members, in which he explained the mental capacity act and in particular how it is intended for each decision as it comes. Together, they separated out the different decisions that Ross had alluded to (from meeting someone from daycentre for a public date and holding hands, to having them stay over), and discussed how Ross did not necessarily lack capacity for all decisions related to sexual expression. Bill and the team then collaboratively developed social stories for each of the decisions, which were used as a reminder for the team to take each decision as it arises, but also as a resource for them to share with Ross and informally assess his capacity on each decision.

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Orange = Formulation  
Blue = Process of teaching

Grouping into issues - key:

Green = Individual referral  
Yellow = Content of teaching

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#### Clinical Vignette 2

A staff team which Joan (Clinical Psychologist) worked with ~~was~~ becoming increasingly anxious about what they should and should not be supporting Linda (PWID) with in terms of her sexual expression. Joan met with the team's manager Wayne, and provided him with ways that he could explain the mental capacity act to the team in simple accessible terms/rules of thumb. One example was to ensure that as the manager ~~he~~ conveyed the message that capacity to make decisions should be assumed in all of those they work with unless there is evidence against this. For evidence to be valid, it would have to fall under at least one of four guidance notes (the four criteria for being able to make a decision in section 3(1) of the mental capacity act). These were subsequently put into bullet points by Wayne and stuck on the wall of the staff office.

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### Finalised guideline and vignettes:

**Normalise the sexual expression of people with intellectual disabilities; what to expect, that it can take a range of different forms (as can that of the general population), and what someone has a right to. Not just in terms of feelings, but also things they have access to (e.g. online dating).**

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#### Clinical Vignette 1

Steve (PWID) and June (PWID) live in the same care home. When a romantic relationship developed between them their staff became very anxious over this, and a referral over how they were to deal with this was made to the Community Learning Disability Team (CLDT). Steve and June had become increasingly physical in their affection towards one another in communal areas (holding hands, petting and kissing in the lounge), had been taking themselves off to one of their rooms in order to try and spend time alone together, and expressed a wish to sleep in the same room. Both had been deemed to have capacity to consent to the relationship, and to engage in sexual relations with one another.

After picking up the case, alongside her work directly with June and Steve, Joan (Clinical Psychologist) conducted two sessions with the staff team. In the first session Joan spent time initially listening to the staff concerns, which were mainly focused around whether they should be stopping the relationship. After listening to the staff, Joan began to pose relatively simple questions to them; how would June and Steve's relationship be treated if they

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did not have an ID? Is their ID sufficient reason to deny them this opportunity to love and feel loved, considering they both meet the criteria for having capacity? Is it unusual for two people to want to do this with one another? Can significant risk in supporting them in this relationship be identified and articulated (e.g. how does it fit in with formal risk assessment)?

In order to allow these questions to resonate, and provide time for the staff to reflect on their thoughts about the matter, Joan left four weeks between the first and second session. When Joan returned, the staff reported having initially agreed among the team to allow June and Steve time alone in their rooms together. They described how they had not been as uncomfortable about seeing/doing this as they had anticipated; “he had not been immediately trying to rip her clothes off or anything” they explained. Though they were still not yet comfortable in allowing June and Steve to stay the night in one another’s rooms, it appeared that staff’s beliefs/fears had begun to shift.

#### Clinical Vignette 2

When the staff at Justin’s (PWID; 19-years-old) group home had been helping him clean his room they noticed ejaculate on the sheets and towels – it was apparent that Justin had been masturbating. The staff were aware that it was documented on Justin’s file that there had been an incident at the age of seven when Justin had acted sexually inappropriately towards another child. Knowing this information many of the staff were apprehensive about discussing the newly emerging sexual expression with Justin, fearing that he would again become sexually inappropriate or even predatory. Therefore, they chose to avoid anything that may “encourage him to become more sexual” (staff member’s words).

Bill (Clinical Psychologist) met with manager of the group home and Justin’s key worker (the only two people who could be spared time for a meeting). Bill discussed how exploratory behaviour is common in young children, and sometimes this is of a sexual nature. He prompted them to think about

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examples of this happening in their only lives, in people they knew, or in TV and film – they thought about children playing ‘doctors and nurses’, showing each other their private parts, or asking their parents awkward questions about the human body. Together, they reflected on the likelihood that all of these individuals would grow up to be sexual predators. They then moved on to discuss (and agree) that masturbation is a healthy form of sexual expression for an individual of his age, but that owing to his ID Justin may require some support in knowing how to do this safely – in particular, the importance of cleaning up afterwards (both his room and himself). Acknowledging that these were matters that the staff team feel uncomfortable with, Bill pointed them to ‘Hand Made Love’ book and DVD set by Dave Hingsburger about how to support PWID around matters of masturbation (<http://diverse-city.com/online-store-2/dvds/>). This further normalised the idea that PWID masturbate, but also provided staff with language and approaches that they would have been too uncomfortable to come up with alone.

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**Appendix K**  
**Final guideline document with vignettes**

**Supporting care staff to enable healthy sexual expression in people with  
intellectual disabilities**

**Good practice guidelines for Clinical Psychologists**



*Image courtesy of Mencap*

## Introduction

Care staff are often faced with the task of supporting the healthy sexual expression of the people with intellectual disabilities (PWID) they support. Depending on the confidence and beliefs of care staff members, this is a task that can be experienced as confusing, distressing and uncomfortable.

Clinical Psychologists can often be involved or consulted when care staff are struggling to understand and/or accept what support they should be providing, and why. The following guidelines are intended as a resource to support Clinical Psychologists in this work.

It is not expected that all of the guidelines should be adhered to in every case they are used for. In many cases only a selection of the guidelines may be appropriate or helpful.

The guidelines are intended to be used flexibly – the use of the same guideline may look very different dependent on the case and the issue it is used to address. Two clinical vignettes have been developed for each of the guidelines in order to demonstrate the flexibility of their application, and to illustrate what they might look like in practice.

Some of the guidelines cover practice that we expect of Clinical Psychologists in their everyday practice anyway. Those guidelines will hopefully act as reminder to make sure we get the simple things right when faced with new and complex challenges. However, though it is noted in the guidelines that care staff need to be reflective when working with this issue, no guideline points out the need for Clinical Psychologists to do so. Being reflective in one's work (e.g. being aware of the origins of one's beliefs and values, and how they can influence one's practice) is an essential part of a Clinical Psychologist's job role, and will be particular pertinent in work around the sexual expression of PWID.

The next section offers a brief overview of some of the key legislation that governs matters of sexual expression in PWID. It is included here as a quick

reference since these documents are alluded to in a number of the guidelines. Following that, the guidelines are set out under four themed headings. Finally, the clinical vignettes are presented under their corresponding guideline.

## **Key legislation we must help care staff to be aware of**

### **Mental Capacity Act (MCA) 2005**

The MCA is a legal framework regarding the making of decisions.

PWID should be presumed to have capacity to make a decision for themselves until there is valid evidence to suggest otherwise.

When a person's capacity to make a decision for themselves is in doubt, those supporting them must do everything possible to support them in achieving that capacity. This can mean the providing of information (e.g. sex education) or explaining potential consequences for the decision either way (in an unbiased manner).

If a person is deemed to lack the capacity to make a decision on one occasion, this does not mean that they will necessarily lack the capacity on a future occasion.

The five key principles of the MCA are:

- The person is assumed to have capacity until it is established otherwise.
- The person must not be treated as lacking capacity until all practicable steps have been made to help them to have capacity for the decision without success.

- The person must not be treated as lacking capacity because the decision they are making appears unwise.
- Any decision made on a person's behalf under the MCA must be made in the person's best interests.
- A decision made in a person's best interests, must equate to the decision that is least restrictive of the person's rights and freedom to act

Though the capacity to consent to sexual intercourse is a decision commonly considered in relation to the MCA, the decision to have sexual intercourse with another person is not one that can be made in a person's best interests (this one of a number of 'excluded decisions'). However, this does not mean that when a person whose capacity is unclear is known to be having sex, that those caring for them necessarily have the right to stop and/or prevent the behaviour, just that they should not initiate or encourage it.

For a person to have capacity to make a decision, they must:

- understand the information relevant to the decision.
- be able to retain that information.
- be able to use or weigh up that information as part of the process of making the decision.

In relation to capacity to consent to sex, generally the essential information for the person to know is:

- the mechanics of the act, and that it should feel good.
- that there are health risks involved, such STIs and STDs like HIV.

- that sex between a male and a female can result in pregnancy.
- that both parties must consent and that each has the right to say no.
- that there can be an emotional element to it, and there is sometimes the potential for your (or others') feelings to get hurt.

Most importantly, capacity must be considered on a decision-by-decision basis. A person may not have the capacity to consent to sexual intercourse, but it is extremely rare that a person does not have the capacity to decide to engage in any sexual behaviour at all, with a partner, or alone. It is also essential to avoid making arbitrary links between intimate relationships and sexual behaviour. Though the two *can* co-occur, this is not inevitable. Therefore, be careful not to restrict a person's chances at love and intimate relationships just because you fear it will definitely lead to risky sexual behaviour – this is a myth!

### **Deprivation of Liberties Safeguards (DoLS)**

Under the MCA the DoLS set out how sometimes it is in a PWID's best interests to restrict their freedom to act. An example would be the agreement that a staff member should gently redirect a service user's hand when they begin masturbating in public.

Such decisions should not be made by an individual, but should be agreed between a care team, with an independent person confirming that the PWID lacks the capacity to consent to the action. All such decisions must be well documented ahead of them being enacted.

All other less restrictive and practicable alternatives must be attempted before it is agreed that a person's freedom to act must be encroached upon in this way.

### **Sexual Offences Act (2003)**

This is a legal framework regarding offences that can be perpetrated against another person that are of a sexual nature. The 'general offences' under this act include rape, sexual assault, exposure and voyeurism, and these apply to everyone, including PWID. Behaviour that meets the definition of a sexual offence should not be condoned just because a person has a disability, the offence still has a victim. Where the behaviour is serious, it is the role of the Court of Protection to decide whether the perpetrator 'knows what they are doing or not'.

This act also sets out a number of offences intended provide increased protection to PWID, included under the 'offences against people with mental disorder'. These offences consist of:

- Having sex with PWID when their choice is impeded or manipulated (e.g. through deceptions or threats).
- Making a PWID have sex with someone else.
- Exposing a PWID to sexual activity unnecessarily (i.e. outside the realms of sex education).
- Staff having sex with PWID (this includes health and social care staff, volunteers, therapists, cleaners, taxi drivers etc.).

Guilt for these type of offences is dependent on the perpetrator knowing or being reasonably expected to know that the person has an intellectual disability.

## **Good practice guidelines**

### **Addressing staff attitudes**

Normalise the sexual expression of people with intellectual disabilities; what to expect, that it can take a range of different forms (as can that of the general population), and what someone has a right to. Not just in terms of feelings, but also things they have access to (e.g. online dating).

### **Addressing uncertainty about rights and responsibilities of PWID**

Be very clear with staff about what capacity is and how it is assessed from the start. Staff need to be aware of the mental capacity act, and how this applies to matters of sexual expression, but be empathetic about how the complexities of it can be very hard to grasp.

The need to balance public protection with the rights of the individual must be fully understood by staff. An important element of this is not letting compassion for one's client obscure compassion for victims of inappropriate behaviour. Society deems some acts to be illegal as stipulated by the Sexual Offences Act 2003 – this act applies to everyone, including PWID. Staff should not be permitted to think that the presence of an ID pardons someone from abiding by the law or removes the damage their actions can cause others.

Explicitly identify and agree where professional boundaries lie, giving staff licence to have conversations about and support sexual expression with less of a feeling that they are making themselves vulnerable by doing so.

### **Locating the problem, being part of the solution**

Where there appears to be difficulties in supporting a PWID's sexual expression, gather the perspectives of multiple staff members to establish who this is an issue for and why. This should help to identify whether difficulties lie at



the staff level, management level or organisation level, or any combination of these.

Consent should be sought from the PWID for us to discuss their case with others, or where they lack capacity, a best interest decision made on whether this is necessary.

Where appropriate and useful for the case, take the time to get familiar with the organisation's/management's position statement on how client's sexual expression is supported. If this is not operating in the best interests of the client, work with the organisation/management to look at ways this can be amended, and what it will take for their staff to feel comfortable in abiding by this position statement (e.g. training for staff, reflective practice groups, team or individual clinical supervision).

PWID will sometimes want to do things that put them at a certain level of risk – and will have the capacity to make the decision to do so.

Adopting a shared risk-taking approach here – the staff, management, Clinical Psychologist and the PWID themselves agreeing that positive risk-taking in the current situation is in the individual's best interests – can provide staff with the permission and protection they often require to feel more comfortable in supporting the individual on such matters.

Also, be clear with staff that supporting the individual in these more risky situations may require a certain level of agreed-upon intrusiveness, which again is permissible if it is in the best interests of the individual.

Organise workshops and training sessions for staff teams (including managers), in order to address gaps in understanding, their fears in working with these issues, and what can be expected of them. However, expected levels of change should be appropriate to staff ability levels and the strength of their personal beliefs on the matter.

Get to know what services and groups are available and accessible in your local area that can help individuals to meet people and socialise (such as nightclubs, dating agencies, voluntary services). Though this is not the sole responsibility of

the Clinical Psychologist (a member of care staff should aim to do this also), it is important to model/encourage this where it is not occurring.

### **Supporting care staff to understand and reflect upon their role**

Normalise staff's emotional reactions and prejudices. Work with staff to reflect on where these come from – what discourses they call upon (e.g. discourses about sexuality, about intellectual disabilities). Support staff to challenge any negative prejudices and reactions, or at least understand/incorporate different viewpoints.

Support the staff to consider the impact of high observation levels on sexual expression (e.g. do they have privacy to masturbate, to spend time alone with another person?), and how this can affect the individual.

Support staff members to not regard the person as the problem, but to also look at broader issues (i.e. their environment, the amount of privacy they get, the impact of how others respond to their actions). Encourage staff members to also consider risks when engaging in this process.

## Good practice guidelines with supplemental clinical vignettes

### Addressing staff attitudes

**Normalise the sexual expression of people with intellectual disabilities; what to expect, that it can take a range of different forms (as can that of the general population), and what someone has a right to. Not just in terms of feelings, but also things they have access to (e.g. online dating).**

#### Clinical Vignette 1

Steve (PWID) and June (PWID) live in the same care home. When a romantic relationship developed between them their staff became very anxious over this, and a referral over how they were to deal with this was made to the Community Learning Disability Team (CLDT). Steve and June had become increasingly physical in their affection towards one another in communal areas (holding hands, petting and kissing in the lounge), had been taking themselves off to one of their rooms in order to try and spend time alone together, and expressed a wish to sleep in the same room. Both had been deemed to have capacity to consent to the relationship, and to engage in sexual relations with one another.

After picking up the case, alongside her work directly with June and Steve, Joan (Clinical Psychologist) conducted two sessions with the staff team. In the first session, Joan spent time initially listening to the staff concerns, which were mainly focused around whether they should be stopping the relationship. After listening to the staff, Joan began to pose relatively simple questions to them; how would June and Steve's relationship be treated if they did not have an ID? Is their ID sufficient reason to deny them this opportunity to love and feel loved, considering they both meet the criteria for having capacity? Is it unusual for two people to want to do this with one another? Can significant risk in supporting them in this relationship be identified and articulated (e.g. how does it fit in with formal risk assessment)?

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In order to allow these questions to resonate and provide time for the staff to reflect on their thoughts about the matter, Joan left four weeks between the first and second session. When Joan returned, the staff reported having initially agreed among the team to allow June and Steve time alone in their rooms together. They described how they had not been as uncomfortable about seeing/doing this as they had anticipated; “he had not been immediately trying to rip her clothes off or anything” they explained. Though they were still not yet comfortable in allowing June and Steve to stay the night in one another’s rooms, it appeared that staff’s beliefs/fears had begun to shift.

#### Clinical Vignette 2

When the staff at Justin’s (PWID; 19-years-old) group home had been helping him clean his room they noticed ejaculate on the sheets and towels – it was apparent that Justin had been masturbating. The staff were aware that it was documented on Justin’s file that there had been an incident at the age of seven when Justin had acted sexually inappropriately towards another child. Knowing this information many of the staff were apprehensive about discussing the newly emerging sexual expression with Justin, fearing that he would again become sexually inappropriate or even predatory. Therefore, they chose to avoid anything that may “encourage him to become more sexual” (staff member’s words).

Bill (Clinical Psychologist) met with manager of the group home and Justin’s key worker (the only two people who could be spared time for a meeting). Bill discussed how exploratory behaviour is common in young children, and sometimes this is of a sexual nature. He prompted them to think about examples of this happening in their own lives, in people they knew, or in TV and film – they thought about children playing ‘doctors and nurses’, showing each other their private parts, or asking their parents awkward questions about the human body. Together, they reflected on the likelihood that all of these individuals would grow up to be sexual predators. They then moved on to discuss (and agree) that masturbation is a healthy form of sexual

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expression for an individual of his age, but that owing to his ID Justin may require some support in knowing how to do this safely – in particular, the importance of cleaning up afterwards (both his room and himself).

Acknowledging that these were matters that the staff team feel uncomfortable with, Bill pointed them to ‘Hand Made Love’ a book and DVD set by Dave Hingsburger about how to support PWID around matters of masturbation (<http://diverse-city.com/online-store-2/dvds/>). This further normalised the idea that PWID masturbate, but also provided staff with language and approaches that they would have been too uncomfortable to come up with alone.

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### **Addressing uncertainty about rights and responsibilities of PWID**

**Be very clear with staff about what capacity is and how it is assessed from the start. Staff need to be aware of the mental capacity act, and how this applies to matters of sexual expression, but be empathetic about how the complexities of it can be very hard to grasp.**

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#### Clinical Vignette 1

Abdul (Clinical Psychologist) worked with a staff team in a group home, who supported Ross (PWID) with 24-hour care. Ross had verbally expressed a desire to meet someone whom he could “kiss and cuddle, and maybe more...”. However, the staff felt that Ross would not be capable of selecting an appropriate partner and feared he would end up sexually assaulting or being sexually assaulted. Therefore, the staff discouraged or distracted Ross from these wishes.

Abdul arranged a meeting with a number of the staff members, in which he explained the mental capacity act, and in particular how it is intended for each decision as it comes. Together, they separated out the different decisions that Ross had alluded to (from meeting someone from daycentre for a public date and holding hands, to having them stay over), and discussed how Ross did

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not necessarily lack capacity for all decisions related to sexual expression. Abdul and the team then collaboratively developed social stories for each of the decisions, which were utilised as a reminder for the team to take each decision as it comes, but also as a resource for them to share with Ross and informally assess his capacity on each decision.

#### Clinical Vignette 2

A staff team which Fatimah (Clinical Psychologist) worked with were becoming increasingly anxious about what they should and should not be supporting Linda (PWID) with in terms of her sexual expression. Joan met with the team's manager Wayne and provided him with ways that he could explain the mental capacity act to the team in simple accessible terms/rules of thumb. One example was to ensure that he as the manager conveyed the message that capacity to make decisions should be assumed in all of those they work with unless there is evidence against this. For evidence to be valid, it would have to fall under at least one of four guidance notes (the four criteria for being able to make a decision in section 3(1) of the mental capacity act). These were subsequently put into bullet points by Wayne and stuck on the wall of the staff office.

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**The need to balance public protection with the rights of the individual must be fully understood by staff. An important element of this is not letting compassion for one's client obscure compassion for victims of inappropriate behaviour. Society deems some acts to be illegal as stipulated by the Sexual Offences Act 2003 – this act applies to everyone, including PWID. Staff should not be permitted to think that the presence of an ID pardons someone from abiding by the law, or removes the damage their actions can cause others.**

#### Clinical Vignette 1

Ivan (Clinical Psychologist) received a referral for Shauna (PWID) whom had been consistently inappropriately groping and kissing staff and other

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attendees at her day service, against their wishes. The staff from her group home were seeking advice on how to manage and reduce the behaviour. Along with functional analyses of what Shauna was doing, Ivan emphasised to the staff team the necessity of getting the police involved when the behaviour constituted breaking of the law, especially as the behaviour continued despite being deterred. It appeared to Ivan that in their protectiveness over Shauna, the staff were somewhat blinded to the impact the behaviour has on its recipients. Ivan highlighted to the staff team what they were overlooking by asking them to consider whether their feelings and/or actions would be any different if it was a friend or relative on the receiving end Shauna's actions? or if Shauna herself was being treated in a similar way by a stranger?

#### Clinical Vignette 2

John (PWID) was originally referred to Anastasia's (Clinical Psychologist) service in relation to his low mood, which was being related to his social isolation by the referrer. It emerged through the assessment process that John is often sexually inappropriate to people he engages with. He is indiscriminate in who he aims this behaviour at – staff, peers, members of the public. Though it made them incredibly uncomfortable, his supported living care staff somewhat accepted the behaviour, reasoning that “he doesn't know what he is doing”. Upon further engagement with staff, Anastasia saw that by dismissing John's inappropriate behaviour they were not required to challenge it, and many staff achieved this by avoiding John as much as possible.

Anastasia held a session with the staff team. She began by sharing her formulation of John's behaviour, explaining how their avoidance was perpetuating his inappropriateness since he has no boundaries. She went on to outline how it is common for staff teams to assume that a PWID does not have the capacity to know what they are doing, but that this is an unhelpful blanket rule. In this case it was preventing John from learning what behaviour is and isn't permissible – since there are no explicit consequences – and making others want to avoid him, leaving him isolated and lonely. Together

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they explored for what actions John could and could not be considered to have the capacity to understand what he is doing. Through her explanation of the situation, Anastasia was able to highlight to the staff that they have a duty of care to confront him about the behaviour and involve the police where appropriate, since not doing so (and not allowing him to learn what was inappropriate) was preventing him from establishing functional relationships.

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**Explicitly identify and agree where professional boundaries lie, giving staff licence to have conversations about and support sexual expression with less of a feeling that they are making themselves vulnerable by doing so.**

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#### Clinical Vignette 1

Hordur (Clinical Psychologist) has found it imperative to ensure that care organisations have in place clear policies and guidelines on supporting the sexual needs of people in their care. He has found that staff work most comfortably when senior figures within an organisation have translated national policy and legislation into what that means for their staff and those within their care. When this is consolidated into the organisation's own policy and into individual care plans the staff can be clear on what is expected of them and they can feel protected in the decisions they make, freeing them from feeling like they are acting on their own volition. Therefore, when Hordur accepts a referral regarding sexual expression and this is not explicitly in place, he requests that the organisation rectify this.

#### Clinical Vignette 2

Beth (PWID) was very uninhibited in her interactions with men. She would often engage in sexual behaviour with men upon their first or second meeting, and though she appeared to be aware of the risks of unprotected sex, she would rarely object when a man wanted intercourse without contraception. The supported living staff that supported her at home were very concerned by this behaviour, but were so uncomfortable in talking to her about sex, they

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would either simply try and dissuade her from going out and meeting people, or would avoid talking with her about her actions. Jane (Clinical Psychologist) had been working with Beth for six months around her self-esteem and emotional regulation. Noting that staff felt it was not their place to support, advise or educate Beth about sex, Jane (with Beth's consent) invited the staff members that had most contact with Beth into one of their sessions in which they would be discussing her sexual relationships. Jane used this as an opportunity to model to staff how to have conversations about sex in a professional and bounded way, and how this would not necessarily elicit further risky sexual behaviour. Following the session, Jane spent a while with the staff members reflecting on where the professional boundaries lie, and to what point they can be expected to support Beth in these matters – honouring their duty of care whilst not being inappropriate.

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### **Locating the problem, being part of the solution**

**Where there appears to be difficulties in supporting a PWID's sexual expression, gather the perspectives of multiple staff members to establish who this is an issue for and why. This should help to identify whether difficulties lie at the staff level, management level or organisation level, or any combination of these.**

**Consent should be sought from the PWID for us to discuss their case with others, or where they lack capacity, a best interest decision made on whether this is necessary.**

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#### Clinical Vignette 1

When Bobby (Clinical Psychologist) receives referrals in which a PWID's sexual expression has been identified as a problem, early on in his input he asks staff members and the manager(s) of the team to complete the 'Sex Knowledge and Attitudes Test' (SKAT). He generally finds it important to ensure that at least some night staff also complete the SKAT, since sexual behaviour and/or thoughts often occur at night, but the night staff are less

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likely to have attended additional training (e.g. around sex and relationships) and have less contact with managers.

### Clinical Vignette 2

At team meetings for her Community Learning Disability Team (CLDT), Anya (Clinical Psychologist) frequently highlighted that they needed to pay greater attention to the sexual and relationship needs of their clients. Eventually it was agreed she would head a working group, which spent a few hours each month working on an assessment and training framework to be distributed to all of the care homes with which the team worked. Once completed, members of the working group went out to the care homes that they worked with and presented this framework to both staff and management. Part of the initial meetings was to discuss with staff about how their team would support different aspects of sexuality within the home. Asking questions such as; 'what does privacy mean for the people we support?'

'what level of physical affection will we accept in general areas?'

'do we condone the same level of physical affection between two people of the same sex?'

This worked to clearly identify any differences in opinion, to open a space for considering why this might need to be discussed (e.g. differing values/beliefs between care staff, belief that the organisation does not condone something), and the chance to establish how the team would deal with different aspects of sexual expression in the future.

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**Where appropriate and useful for the case, take the time to get familiar with the organisation's/management's position statement on how client's sexual expression is supported. If this is not operating in the best interests of the client, work with the organisation/management to look at ways this can be amended, and what it will take for their staff to feel comfortable in abiding by this position statement (e.g. training for staff, reflective practice groups, team or individual clinical supervision).**

#### Clinical Vignette 1

Priya (Clinical Psychologist) noted that a number of those on her caseload had been referred as their staff were struggling to work with matters of sexual expression. In response to this Priya invited managers and team leaders from the services supporting each of the individuals to a workshop on supporting sexual expression. Priya led a discussion on what the services were willing to support in terms of sexual expression, how this fitted with local, national and international policy, and how they were currently providing this support. This allowed the group to identify areas where their services might currently be engaging in overly restrictive or relaxed practice, and to collaboratively come up with approaches they might utilise to address these shortcomings. This process gave the team leaders and managers ownership over the revised positions and solutions, which in turn fostered greater acceptance of them and motivation to cascade them to their staff.

#### Clinical Vignette 2

Tyrone (Clinical Psychologist) developed a pro-forma regarding how sexual expression is supported within a service, which he ensured was completed at the beginning of any case regarding sexual matters. Though he preferred to complete this in person with staff teams and/or management, it could equally be completed in his absence. The document began by stating the rights of PWID to healthy sexual expression as set out by the *UN Convention of the rights of people with disabilities*, *Valuing People Now*, and local guidelines. The team then answered questions on what this means for the residents and staff in that particular team, and how they might best go about ensuring they

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are working in a way that abides by relevant legislation. This approach helped Tyrone to establish if a clear position statement existed within the service, whether it was appropriate, and whether staff were clear on it.

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**PWID will sometimes want to do things that put them at a certain level of risk – and will have the capacity to make the decision to do so.**

**Adopting a shared risk-taking approach here – the staff, management, Clinical Psychologist and the PWID themselves agreeing that positive risk-taking in the current situation is in the individual’s best interests – can provide staff with the permission and protection they often require to feel more comfortable in supporting the individual on such matters.**

**Also, be clear with staff that supporting the individual in these more risky situations may require a certain level of agreed-upon intrusiveness, which again is permissible if it is in the best interests of the individual.**

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#### Clinical Vignette 1

Jack (PWID) and Roy (PWID) lived in the same group home and were in a romantic relationship. Both had been deemed to have the capacity to consent to a sexual relationship with one another. Jack had a much more submissive personality than Roy, who could be very domineering. In light of this, staff felt uncomfortable in allowing the couple to stay the night in one another’s bedroom – as Jack and Roy often requested to do after their weekly date night. Staff feared that Roy would pressure Jack to do things that he didn’t want to and would refuse to leave (they believed that this had already happened once).

Ira (Clinical Psychologist), who had done the capacity assessments, noted that not allowing the two to spend the night together was an unjustified deprivation of their liberties. Ira agreed with the team manager that Jack and Roy’s rooms would be fitted with a buzzer that would sound in staff areas. If Jack felt pressured by Roy, and unable to end the interaction, he was to sound the buzzer, at which point staff would come and sensitively intervene

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by redirecting Roy away from the room or asking Jack to 'help them with something'.

#### Clinical Vignette 2

Jason (PWID) was keen to search for a girlfriend and expressed to his support staff a wish to make an online dating profile. Though staff felt that he should not do this, Lyn (Clinical Psychologist) suggested that the feared risks in him doing so (mainly that he would be dishonest in his profile and would end up being rejected by people he met with it when his disability became apparent) could be managed by staff closely supporting him in creating and using the profile (e.g. supervising any dates from a distance). Staff were also worried that Jason would receive little interest if he was open about his disability on the profile, but Lyn felt that dealing with this outcome would be an important experience for Jason.

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**Organise workshops and training sessions for staff teams (including managers), in order to address gaps in understanding, their fears in working with these issues, and what can be expected of them. However, expected levels of change should be appropriate to staff ability levels and the strength of their personal beliefs on the matter.**

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#### Clinical Vignette 1

When Daniel's (PWID) staff team notice that he becomes sexually aroused in communal areas, they hastily re-direct him to his bedroom or the bathroom. However, he often tends to re-emerge in the same state of arousal and becomes frustrated when he again asked to vacate the communal areas.

Famara (Clinical Psychologist) held a two-hour workshop with key members of the staff team. He began by sharing with them his formulation of Daniel's current situation, before taking time to support them in reflecting on the things that they currently do that may perpetuate Daniel's difficulties, and things that they could do to helpfully address them and support him. Most notably, staff described a fear that talking to Daniel about sexual matters was crossing a

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boundary and may entice sexual feelings towards them. Famara offered an alternative view, suggesting that by demonstrating that conversations about sexual matters were possible, any inappropriate sexual feelings (e.g. towards staff) can be dealt with early, rather than occurring as a sexual advance 'out of the blue'. Furthermore, Famara suggested the team purchase the 'Jason's private world' DVD\* that could be used to help Daniel gain a better understanding of sex and his body in a boundaried way. Some staff were less comfortable in sharing this material with Daniel, so were not given the responsibility of using such resources but were still expected to engage with Daniel on sexual matters when needed.

Famara checked in with the staff a few weeks after his input, and they reported that Daniel less often becomes aroused in communal areas and does not become frustrated about being re-directed to his room since he appears to successfully masturbate to climax when in there.

\* *A sex and relationships education DVD for young men with learning disabilities* (<http://www.fpa.org.uk/product/jasons-private-world#product-content>)

#### Clinical Vignette 2

Due to a colleague being on long term sick leave, Gene (Clinical Psychologist) had an extremely high case load. She could see that the staff team at Jerry's (PWID) day services would benefit from some training around how to manage Jerry's sexually disinhibited behaviour, but Gene did not have the capacity to deliver this. Gene signposted the manager of the day service to the local MENCAP branch who offered training to services outside of their organisation and requested that they pay for a staff course on sexuality and relationships. The manager explained that she could not financially spare all of her staff for an afternoon to complete the training, and that they did not have the funding to pay for it twice. Gene advised that select members of the team (that would likely be receptive) underwent the training and were then tasked with feeding back what they learned to the rest of the team.

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**Get to know what services and groups are available and accessible in your local area that can help individuals to meet people and socialise (such as nightclubs, dating agencies, voluntary services). Though this is not the sole responsibility of the Clinical Psychologist (a member of care staff should aim to do this also), it is important to model/encourage this where it is not occurring.**

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#### Clinical Vignette 1

Upon starting a new job, Gloria (Clinical Psychologist) takes time to visit local community services and activities in order to ensure she knows what is available to her clients. She commits to spending an afternoon every two months to repeat this process.

#### Clinical Vignette 2

Joey (Clinical Psychologist) has signed up to email alerts and newsletters from organisations that promote social and dating activities for people with intellectual disabilities, such as [stayuplate.org](http://stayuplate.org), [www.nottshelpyourself.org](http://www.nottshelpyourself.org) (Nottinghamshire), and [spaceinclusive.co.uk](http://spaceinclusive.co.uk) (East Midlands).

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### **Supporting care staff to understand and reflect upon their role**

**Normalise staff's emotional reactions and prejudices. Work with staff to reflect on where these come from – what discourses they call upon (e.g. discourses about sexuality, about intellectual disabilities). Support staff to challenge any negative prejudices and reactions, or at least understand/incorporate different viewpoints.**

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#### Clinical Vignette 1

After having implied to staff that come to support him in his flat that he sometimes has sexual fantasies about children, Rory (PWID) was referred to the Clinical Psychology Service to explore/address this. Eros (Clinical Psychologist) found that Rory did have such fantasies, but was extremely distressed about them, and anxious that one day he would act on them –

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despite desperately not wanting to. Acknowledging that it may be hard for the care staff to work with people who had such fantasies, in addition to his work with Rory, Eros conducted a session with the team about how they felt about Rory having such thoughts. Together they explored how staff felt uncomfortable about Rory's fantasies, especially since many of them had children themselves. Eros also strived to help the staff see that it was acceptable to dislike the fantasies, while still showing Rory compassion. With Rory's consent, Eros explained to the team that Rory also felt incredibly uncomfortable about these thoughts and highlighted that they did not have to ultimately make the choice between denouncing Rory's fantasies or accepting them. Eros explained to the staff how they were justified in feeling uncomfortable about Rory's fantasies, but by accepting that they occur, and that Rory has little control over this, it did not ultimately prevent them from supporting him in exerting his control to not act upon them. Eros emphasised to the staff that in terms of the denouncement and acceptance, it did not have to be a case of 'either/or' but could be a case of 'both/and'.

#### Clinical Vignette 2

Harry (PWID) has always told the staff team at his group home that he wants a girlfriend. However, recently he was found in the toilets at his adult learning college engaging in mutual masturbation with a male peer. Harry's staff made the referral to Clinical Psychology expressing a view that Harry was being coerced into this behaviour and did not know what he was doing. Part of Stella's (Clinical Psychologist) input on the case was to spend some time with Harry's three main support workers at home. She encouraged discussion about how they had come to the conclusion that this physical intimacy with another male was not wanted or enjoyed by Harry. It became apparent that Harry's verbal communication that he wanted a girlfriend had fit neatly with the staff's hetero-normative bias, which in turn conflicted with ideas about sexual contact with another male being in his interests – "we know he's not gay" they asserted. However, Stella discussed with the team how people do not all necessarily have to identify as straight or gay, and how Harry's apparent need to engage in same-sex behaviour in secret (and only speaking of wanting a 'girlfriend') may give some indication that he feels these desires

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would not be accepted. The staff stated that this gave them a completely new potential explanation, and insight into the impact of the expectations they place on Harry.

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**Support the staff to consider the impact of high observation levels on sexual expression (e.g. do they have privacy to masturbate, to spend time alone with another person?), and how this can affect the individual.**

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#### Clinical Vignette 1

Over the preceding weeks Dean (PWID), had started displaying sexually disinhibited behaviour, and had been visibly aroused in public places, which concerned his staff. He had recently experienced a number of epileptic seizures, and in order to monitor future seizures had been put on 24-hour staff surveillance (which he had happily agreed to because it made him feel safe). Frank (Clinical Psychologist) took some time to sit with Dean's keyworker to consider Dean's routine before and after the seizures. They identified that he no longer had the privacy in which to masturbate, which appeared to be leading to sexual tension which was surfacing in public.

#### Clinical Vignette 2

Dylan (PWID) would occasionally bring people that he had met at a local club night for people with intellectual disabilities back to his supported living flat. However, generally upon arrival the staff on duty would allow the person in communal areas but refuse to allow Dylan to have the person into his flat. Consequently, Dylan had taken to engaging in sexual intercourse with such partners at opportune places such as behind shops and in parks. Because this behaviour appeared risky, the staff had made a referral to Clinical Psychology querying Dylan's capacity to consent to these sexual relationships. Upon picking the case up, Claire (Clinical Psychologist) formulated that the reason such risky sexual behaviour was occurring was because Dylan had little alternative in meeting his sexual needs. She met with Dylan's staff to explain this, and to highlight how in trying to reduce the perceived risk by not allowing Dylan to engage in sexual behaviour at home,

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they may actually increase the risk he is exposed to by forcing him to meet his sexual needs in inappropriate and rushed moments. This information encouraged staff to be more accepting of Dylan having partners to stay over if they appeared to have capacity also, giving him the time to do this in a more composed manner.

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**Support staff members to not regard the person as the problem, but to also look at broader issues (i.e. their environment, the amount of privacy they get, the impact of how others respond to their actions). Encourage staff members to also consider risks when engaging in this process.**

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#### Clinical Vignette 1

Having become aware that Trudy, a member of Scott's (PWID) care staff, had been dealing with his attraction to her by pretending they were married, Coral (Clinical Psychologist) took time to explain to Trudy that this sends a confusing message over who it is appropriate to have relationships with. It was agreed that this increased the risk of Scott acting inappropriately towards Trudy, and that it should be included in Scott's risk management plan that staff should sensitively maintain and explain professional boundaries to him.

#### Clinical Vignette 2

Aaron (PWID) would often insert things into his anus for sexual pleasure. However, the things he would insert would sometimes cause him physical damage and would cause hygiene concerns (e.g. a TV remote). Concerned for his safety, the staff at Aaron's group home tried to prevent the behaviour by removing things from his environment that might be inserted. In addition, a referral was made to the Clinical Psychology service in the hope they could get some help in stopping him from engaging in the behaviour. Alex (Clinical Psychologist) asked the staff team to see the situation differently; Alex saw the problem as being that there was nothing in Aaron's environment that was safe to insert into his anus, rather than the behaviour itself being problematic. Upon Alex's recommendation, the staff supported Aaron to the local branch of Ann Summers. With Aaron's consent, they explained to the staff in the shop that Aaron requires accessible and simple information, to which they

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responded by helpfully showing Aaron different toys which could be used to stimulate himself as well as giving him some simple guidelines on keeping them clean.

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## Appendix L

### **Pilot of good practice guidelines for Clinical Psychologists supporting care staff to support the healthy sexual expression of people with intellectual disabilities**

The guidelines were piloted by a colleague on the doctoral training programme. The colleague was given a copy of the guidelines, with no further instruction issued. The guidelines were used to inform a piece of work and were discussed with other Clinical Psychologists. I collected feedback on the use of the guidelines through an interview which lasted 36 minutes. The interview consisted of asking for an overview of the use of the guidelines, and a set of questions based around the American Psychological Association's (APA; 2015) 'Professional practice guidelines: Guidance for developers and users', which were consulted as quality criteria for the guidelines.

#### **Overview**

Chelsea is trainee Clinical Psychologist and is on a third-year placement in a community learning disability team (CLDT). In addition to Chelsea, the team consisted of four qualified Clinical Psychologists and three Assistant Psychologists. The team had received a referral from the manager of a private care company that support PWID in the community, stating that the staff team were becoming uncomfortable working with a particular service user and his sexual interests. Chelsea took on the case and worked with an Assistant Psychologist to deliver a three-hour session for the staff team focusing on these difficulties, using the guidelines to develop and plan the session. The session was attended by support staff, team leaders and managers.

Chelsea reported that some of the staff team felt really quite uncomfortable, but this was eased by the normalising of these feelings of discomfort (guideline ten). She felt one of the major benefits of the guidelines was that they provided something concrete to back up decisions and thinking around this uncomfortable topic, for both Clinical Psychologists and care staff alike.

Chelsea found that the guidelines were particularly helpful in encouraging her to help the care staff to reflect on their beliefs and values and how these were informing their practice. This in turn had the value of prompting care staff to question their current approaches and to consider how they might be more supportive of healthy sexual expression (for example, why most of the females they support were on contraceptive medication, and whether this should be the case).

Chelsea admitted that despite having years of experience in working with PWID, matters of their sexual needs and desires had not been something to which she had paid much thought. She described how the process of consulting the guidelines prompted her to reflect on her own values and beliefs about the sexual expression of PWID, and to consider why this had not occurred to her before. This suggests that though no guidelines were endorsed about the need for Clinical Psychologists to reflect on their own values (despite being suggested), the process of using the guidelines may in itself foster such reflection.

After completing their input, Chelsea and the Assistant Psychologist unprompted used the guidelines as a checklist in order to review whether they had considered everything that the guidelines covered.

### **Interview schedule**

*Responses summarised in italics*

**It is essential that there is an established ‘need’ for practice guidelines to be developed for practicing psychologists. Without this caveat, there is a risk of “unnecessary proliferation of guidelines” (APA, 2002, 2015).**

**In discussing these guidelines with your Clinical Psychology department, was the need for guidelines on this matter reflective of that highlighted by the literature?**

The Clinical Psychology service in the CLDT had no formal guidance or policy around sex and relationships in place, and the team admitted that it was an

issue that they often overlooked. The team tend to turn to resources developed by British Institute of Learning Disabilities (BILD), but these offer little explicit guidance. The team reported finding the guidelines really useful, and particularly like how accessible the vignettes made them. They suggested that it is common for the team to encounter care staff who have had no concrete training or guidance on how to support sexual expression in PWID, and that it was felt that the vignettes provided a good way of thinking with staff about the issues.

**Did the scope of the guidelines feel sufficiently broad?**

***Were they limited to specific disorders, presentations or treatment approaches?***

*No, but maybe more consideration of how mental health conditions of service users.*

*They definitely felt like they could be applied in a range of ID settings – community, inpatient*

***Did they feel respectful of the dignity and human rights of both PWID and care staff?***

*Yes, the vignettes showed how we have to think of individual need. Also, they help staff to feel acknowledged and respected – especially with the normalising of their views and attitudes.*

***Was any form of bias apparent in the guidelines?***

*It is very pro-ID, but perhaps this reflects the area of need. Using the example that sexual offences act is applicable across the board helped to balance, so they were not overly biased.*

***Did they have educational value for psychologists, the public, and other interested parties?***

*Definitely, the vignettes were shared with the staff and they found them very useful. A shortened version of these specifically for the care staff would be great. It prompted their thinking in an area where they have no formal guidance and they said they will now be incorporating matters of sexual expression into their personal care plans.*

**How usable did you find the guidelines to be?**

***Did they demonstrate internal consistency, or were some contradictory?***

*They were not contradictory, some of the legislation does not fit well together, but the guidelines and the overview, and the way they were written made this easier to get your head around. None of the guidelines were contradictory.*

***Were they flexible and allow for professional judgement?***

*Yes. The clinical vignettes helped that as well. They allow you to think about it more from a formulation perspective – it allows you the room to have those thoughts, rather than telling you ‘this is the guideline, this is the way it should be’. And also in the way we have used them, we haven’t just put guidelines or training on the care staff’s desk, we have used ideas from them, we have prepared our input using them, and then gone back through the guidelines after, using it like a checklist to make sure we’d considered everything.*

***Were they feasible?***

*Yes. Covered in the last answer.*

***Did you feel they were compatible with the BPS Code of Ethics and Conduct (2009, 2017)?***

*I think so, but I don’t when I last looked at the BPS code!*

Was the language used appropriate, positive, and accessible?

***How would you rate the language used in terms of clarity?***

*Very clear. As mentioned before, especially with the vignettes, and colleagues though that too. It makes them conducive to being implemented in both a bottom-up and top-down manner – which is needed.*

*I think it would be interesting to do a similar thing with care staff – I think they would have said similar things to the Clinical Psychologists, despite the power difference.*

***To what extent was the language used aspirational?  
(avoidance of words like ‘should’ and ‘must’ in favour of  
‘encourage’ and ‘recommend’)***

*I do not feel that they were too ‘you should do this... and you must do that’.  
I think it was unavoidable with the inclusion of the legislation and acts, and this comes through in some of the guidelines and vignettes. But they were not overly prescriptive at all and can be used flexibly.  
Also, as Clinical Psychologists which should be able to translate and used these in line with our own practice.*

***Did the language used feel inclusive? (e.g. inclusive of diverse dimensions of identity)***

*It did not feel like anyone was excluded, it felt like everyone was considered.  
Care staff brought diverse experiences (e.g. trans issues), and we were able to apply the guidelines easily.*

***Did the language appear flexible enough to accommodate future changes to practice and policy?***



*I'm not sure. The guidelines were flexible, the language was accessible. The outcomes for the staff team we worked with was that they thought of lots of ways they were going to adapt their practice, they were going to update all of their policies to reflect sexual expression needs, and they had also been inspired to set up monthly or bi-monthly speed-dating events!*

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## A Delphi study.

Brad English, Dr Anna Tickle, Dr Kate Moore, Prof Roshan dasNair

### Background

Previously the sexuality of people with intellectual disabilities (PWID) has been feared and ignored (McCarthy, 1999). Recently, there has been a philosophical shift in thinking and it is now more accepted that PWID have sexual needs and desires (Chapman, Ledger, Townson, & Docherty, 2015). This has been ratified in policy at national and international level (e.g. Department of Health, 2009). In spite of this shift PWID feel they are restricted in their sexual expression (English, Tickle, & dasNair, 2017). Care staff that support PWID report having relatively accepting views, but only 'up to a point', and feel that some level of restrictive practice is often necessary (Saxe & Flanagan, 2014).

Clinical Psychologists hold a unique skill set within health and social care (Health and Care Professions Council, 2015). This leaves them well placed to be a part of supporting the the implementation of policy at service level as well supporting frontline care staff to help to ensure PWID's basic human rights are upheld. However, matters of sexual expression are a topic that some Clinical Psychologists find confusing and uncomfortable (Shaw, Butler, & Marriott, 2008). Pockets of good practice have been emerging across the UK, but they have done so in isolation.

### This study

The aim of this study was to gather examples and experiences of working to help care staff support healthy sexual expression, from a sample of Clinical Psychologists with expertise in this area.

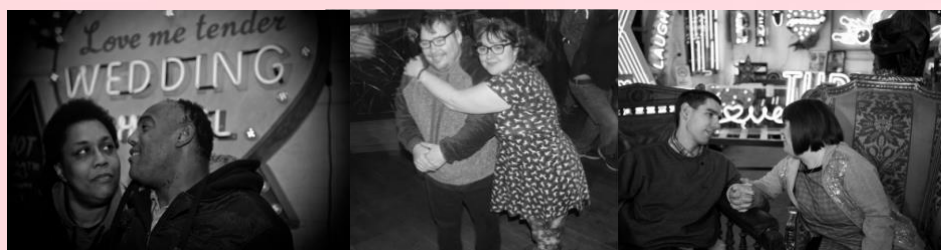
We achieved this using the 'Delphi Method' (Linstone & Turoff, 1975) – an approach to establishing consensus amongst a group of experts as to what the most important things about a certain topic are.

### Clinical mindlines paradigm

This study was informed by Gabbay and le May's (2011) 'clinical mindlines' paradigm. This proposes that rather than refer to policies or the latest research, when healthcare professionals are faced with a gap in their knowledge, they tend to turn to colleagues or their own previous experiences to inform them. Therefore, new knowledge is created and shared in anecdotal and tacit form within the field of healthcare. We wished to emulate this process by developing the guidelines through the sharing of experiences, and making them as accessible and flexible as possible.

### Objectives

- To produce a set of consensus-based good practice guidelines that had the quality of informally shared wisdom.
- To supplement each of the guidelines with two vignettes of the guidelines being put into practice in different ways.



### Final consensus-based good practice guidelines

Normalise the sexual expression of people with intellectual disabilities; what to expect, that it can take a range of different forms (as can that of the general population), and what someone has a right to. This should be done not just in terms of feelings, but also things they have access to (e.g. online dating).

Ensure you have a working understanding of relevant law, such as the Mental Capacity Act (MCA) 2005 and Sexual Offences Act (SOA) 2003 (for those working in the UK). Be very clear with staff members about what capacity is and how it is assessed from the start. Staff need to be aware of relevant law in relation to capacity (e.g. MCA & SOA), but it is important to recognise that the complexities of its application can be very hard to grasp.

The need to balance public protection with the rights of the individual must be understood by staff. An important element of this is not letting compassion for one's client obscure compassion for victims of inappropriate behaviour. Society deems some acts to be illegal (e.g. as stipulated by the Sexual Offences Act 2003 in the UK, which applies to everyone, including PWID). Staff should not be permitted to think that the presence of an ID pardons someone from breaking the law, or removes the damage their actions can cause others.

Explicitly identify and agree where professional boundaries lie, giving staff members licence to have conversations about and support sexual expression with less of a feeling that they are making themselves vulnerable by doing so.

Where there appears to be difficulties in supporting a PWID's sexual expression, gather the perspectives of multiple staff members to establish who this is an issue for and why. This should help to identify whether difficulties lie at the staff level, management level or organisation level, or any combination of these.  
Consent should be sought from the PWID to discuss their case with others, or where they lack capacity, a best interest decision made on whether this is necessary.

Where appropriate and useful for the case, take the time to get familiar with the organisation's/management's position statement on how clients' sexual expression is supported. If this is not operating in the best interests of the client, work with the organisation/management to explore ways this can be amended, and what it will take for their staff members to feel comfortable in abiding by this position statement (e.g., training for staff, reflective practice groups, team or individual clinical supervision).

PWID will sometimes want to do things that put them at a certain level of risk – and will have the capacity to make the decision to do so.

Adopting a shared risk-taking approach here – the staff, management, Clinical Psychologist and the PWID themselves agreeing that positive risk-taking in the current situation is in the individual's best interests – can provide staff members with the permission and protection they often require to feel more comfortable in supporting the individual on such matters.

Also, be clear with staff that supporting the individual in these more risky situations may require a certain level of agreed-upon intrusiveness, which again is permissible if it is in the best interests of the individual.

Where appropriate for the case, organise workshops and training sessions for staff teams (including managers), in order to address gaps in understanding, their fears in working with these issues, and what can be expected of them. However, expected levels of change should be appropriate to staff ability levels and the strength of their personal beliefs on the matter. If doing so, consider how you might gather practice-based evidence for the effectiveness of such interventions.

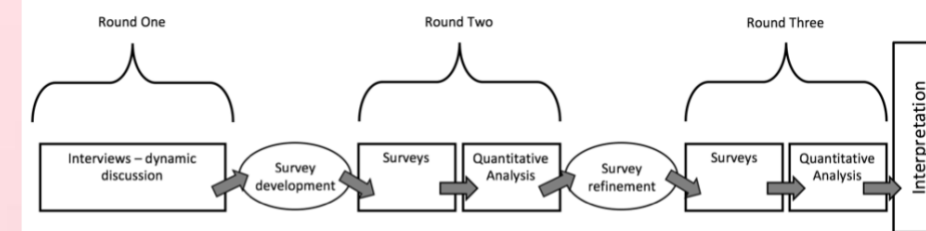
Get to know what services and groups are available and accessible in your local area that can help individuals to meet people and socialise (such as nightclubs, dating agencies, voluntary services). Though this is not the sole responsibility of the Clinical Psychologist (a member of care staff should aim to do this also), it is important to model/encourage this where it is not occurring.

Normalise staff member's emotional reactions and prejudices. Work with staff to reflect on where these come from – what discourses they call upon (e.g. widely held beliefs about sexuality, about intellectual disabilities). Support staff to challenge any negative prejudices and reactions, or at least understand/incorporate different viewpoints.

Support all staff members to consider the impact of high observation levels on sexual expression of PWID (e.g. does the PWID have privacy to masturbate, to spend time alone with another person?), and how this can affect the individual.

Support staff members to not regard the person as the problem, but to also look at broader issues (i.e. their environment, the amount of privacy they get, the impact of how others respond to their actions). Encourage staff members to also consider risks when engaging in this process.

### Study procedure: The Delphi Method



### Method

The Delphi Method seeks to establish consensus amongst a group of experts, known as a 'panel'. We recruited a panel of 17 Clinical Psychologists through the mailing list for the British Psychological Society's Faculty of PWID. The experts were aged between 29 and 61 years (mean = 40.5 years), 12 women and 5 men. Experience working in intellectual disability services ranged from 4 to 37 years, with a median of 10.5 years. We conducted our Delphi across three rounds.

- In **Round One**, the panel were interviewed individually, and each proposed three guidelines for good practice when helping care staff support sexual expression.
- Round Two** was a survey in which all 51 guidelines proposed (3 per panel member) were presented and the panel were asked to rate the guidelines in terms of importance, and to give any written feedback on the guideline. Fourteen panel members contributed to Round Two.
- The survey was then amended and personalised for **Round Three**. For each guideline, information was presented regarding how the individual had rated it and how the panel as a whole had. The panel members were given the opportunity to change their rating in light of the information, and to provide further feedback. Eleven panel members contributed to Round Three.

We accepted ≥90% panel members agreeing that a guideline was important as indication that consensus had been reached, based on established convention in Delphi studies (e.g. Ager, Stark, Akesson, & Boothby, 2010). All guidelines meeting this threshold were endorsed as the final set. In addition, we supplemented each guideline with two vignettes based on the clinical experiences reported in Round One interviews. Using anecdotal examples was intended to aid dissemination and retention in line with how 'clinical mindlines' are socially distributed and shared.

### Results

The panel reached consensus that 12 guidelines were important or essential (see table to the left). These guidelines fell under four themes: 'Addressing staff attitudes', 'Addressing uncertainty about rights and responsibilities of PWID', 'Locating the problem, being part of the solution', and 'Supporting care staff to understand and reflect upon their role'.

### Discussion

This research provided insight into the important role Clinical Psychologists play in helping care staff support PWID's sexual expression. Central to the role are:

- Direct work with care staff to clarify their understanding of PWID's rights.
- Normalising and encouraging reflection on the values care staff hold.
- Clinical Psychologists must put to use their unique professional skill-set to share understanding about how organisational approaches are maintaining the gap between policy and practice, and what needs to be done about it., at managerial and service levels.