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**A Qualitative Study of Mothers' Experiences of
Supporting the Sexual Development of their Sons with
Autism and an Accompanying Learning Disability**

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*Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical
Psychology*

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CHAPTER 1: SYSTEMATIC REVIEW

What are the key themes relating to the beliefs and experiences of people with learning disabilities in relation to their sexuality and intimate relationships?

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Abstract

In order to best support people with learning disabilities to have safe and healthy relationships and express their sexuality effectively, we need to understand their perspectives and experiences, which are currently under-represented in the literature. The aim of this study was to synthesise qualitative research exploring the experiences and beliefs of people with learning disabilities in relation to their sexuality and intimate relationships. A systematic search carried out in CINAHL, Medline, PsycARTICLES, PsycINFO, Psychology and Behavioural Sciences and EMBASE identified eight relevant papers. The quality of these papers was evaluated using an existing quality framework. Meta-ethnography was used to synthesise the findings of these studies and to develop a new interpretation. This process resulted in the new third-order themes: 1) *“Everybody loves to be loved”*: Desire for intimacy; 2) *“People think they can rule you because you’ve got a disability”*: Lack of control; 3) Sex is *“not for us”*; 4) *“I seen sex on TV once”*: Misconceptions and confusion about sex and relationships and 5) *“They want our safety”*: Keeping safe. This review highlights the importance of intimate relationships to people with learning disabilities and the barriers they face in developing these relationships. It illustrates the importance of people with learning disabilities having the information, opportunities and support to be able to make informed decisions about their sexual identity and relationships. This review outlines the implications of its findings for service providers.

Introduction

The sexuality of people with learning disabilities is an area that is often overlooked (Brown et al., 2000). Historically, two contradictory beliefs about the sexuality of people with learning disabilities have perpetuated; that people with learning disabilities are child-like or asexual and consequently need protection from abuse (McCarthy, 1999), or conversely that people with learning disabilities are hypersexual and society needs to be protected from them (Taylor Gomez, 2012). As a consequence of these inaccurate beliefs, the sexual needs of people with learning disabilities have not been prioritised in both the literature (Rojas et al, 2014) and by caregivers (Szollos and McCabe, 1995). The ‘normalisation’ principle in the 1970’s contributed to deinstitutionalisation and integration of people with learning disabilities into the community; however, this had little impact on improving their sexual rights (Brown, 1994). More recently, sexuality and relationships has been addressed in national and local policies, such as *The Same as You?* (The Scottish Executive, 2000); *Valuing People* (Department of Health, 2001) and *The Keys to Life* (The Scottish Government, 2013). There is some evidence to suggest that, in addition to change in policies and guidance, there has been a positive shift in societal and caregiver attitudes towards people with learning disabilities developing intimate relationships (Bazzo et al., 2007).

Despite some apparent changes in attitudes and policies, people with learning disabilities face practical barriers to developing intimate relationships. They often have poorer social networks than their non-learning disabled peers (Wiener and Schneider, 2002) and spend more time under the supervision of family caregivers or professionals, thereby limiting opportunities to develop relationships (Shakespeare, 2000). Furthermore, people with learning disabilities often have poorer sexual knowledge and understanding in comparison

to their typically developing peers (Jahoda and Pownall, 2014). This may be partly due to limited access to informal sources of information about sex and sexuality, for example through a peer group (Ailey et al., 2003). People with learning disabilities are likely to depend on family and professionals to provide them with information about sex and support to develop intimate relationships (Pownall et al., 2011). Research conducted on professionals' views in this area however, found that supporting sexuality was not something they view as important (Abbott and Burns, 2007). Furthermore, services can create barriers to intimate relationships by limiting private spaces (Knox and Hickson, 2001) and by acting as 'new institutional walls' by observing and controlling relationships (Lofgren-Martenson, 2004). It has also been proposed that difficulties may arise in developing relationships as a consequence of impaired communication and social skills (Wiener and Schneider, 2002).

Despite these barriers, encouragingly people with learning disabilities are increasingly being given the opportunities to make decisions about their own lives (McCarthy, 1999). This has led to an increase in qualitative research exploring the views of people with learning disabilities in relation to their sexuality and intimate relationships. This allows the opinions of people with learning disabilities to challenge widely held societal assumptions and prejudices. Qualitative research aims to explore individuals' experiences and attitudes in depth (Ring et al., 2011) to understand the subjective realm of the human experience (Braun and Clarke, 2013). Understanding the experiences of people with learning disabilities is crucial in order to inform appropriate and sensitive support and education, staff training and organisational policy which best meets their needs.

This systematic review will identify and synthesise themes from qualitative studies exploring the experiences and beliefs of people with learning disabilities with regard to their sexuality and intimate relationships. The area of sexuality is large and heterogenous

and encompasses a range of topics, including gender specific issues and issues affecting those who identify as lesbian, gay, bisexual or transgender. Focusing on these more specific areas was considered to be outwith the scope of the current review. The purpose of this review is to explore the themes regarding the sexuality and intimate relationships of people with learning disabilities in general.

The research question this review will seek to determine is:

- What are the key themes relating to the experiences and beliefs of adults with learning disabilities about their sexuality and intimate relationships?

Method

Search Strategy

A search strategy was designed in consultation with a librarian. Searches of electronic databases were conducted to identify peer-reviewed articles published in the English language. The EBSCO host was used to search CINAHL, Medline, PsycARTICLES, PsycINFO and Psychology and Behavioural Sciences databases and the OVID host was used to search EMBASE databases. Search terms were mapped to subject headings in databases, where possible (in Medline, CINAHL, EMBASE and PsycINFO).

The following search terms were used:

1. intellectual disab* OR learning disab*OR mental* retard* OR developmental disab* OR developmental delay

AND

2. sex*OR intima* OR relationship* OR love

AND

3. qualitative OR interpretative phenomenolog* OR IPA OR thematic content analysis OR narrative* OR experienc*

Boolean operators (OR and AND) were used to combine search strings and the proximity codes were adapted as appropriate for the individual databases. All articles identified by searches were assessed for their relevance in accordance to the inclusion and exclusion criteria. The last database search was conducted on 3rd March 2017.

Hand searching of three key journals (Sexuality and Disability, Journal of Applied Research in Intellectual Disabilities and the British Journal of Learning Disabilities) was conducted for articles published in the last ten years. Hand searches of the reference lists of articles included in the review were also conducted.

Inclusion and Exclusion Criteria

The following inclusion criteria were set:

- Studies exploring the experiences or beliefs of adults with learning disabilities about their intimate relationships.
- Studies exploring the experiences or beliefs of adults with learning disabilities about their sexuality.
- Studies utilising qualitative methodology.
- Participants aged 16 or over.
- Studies published in a peer-reviewed journal.
- Studies published in English.
- Studies published since 2000.
- Studies published in Western countries to ensure homogeneity of the articles and to take into consideration cultural differences in experiences of sexuality.

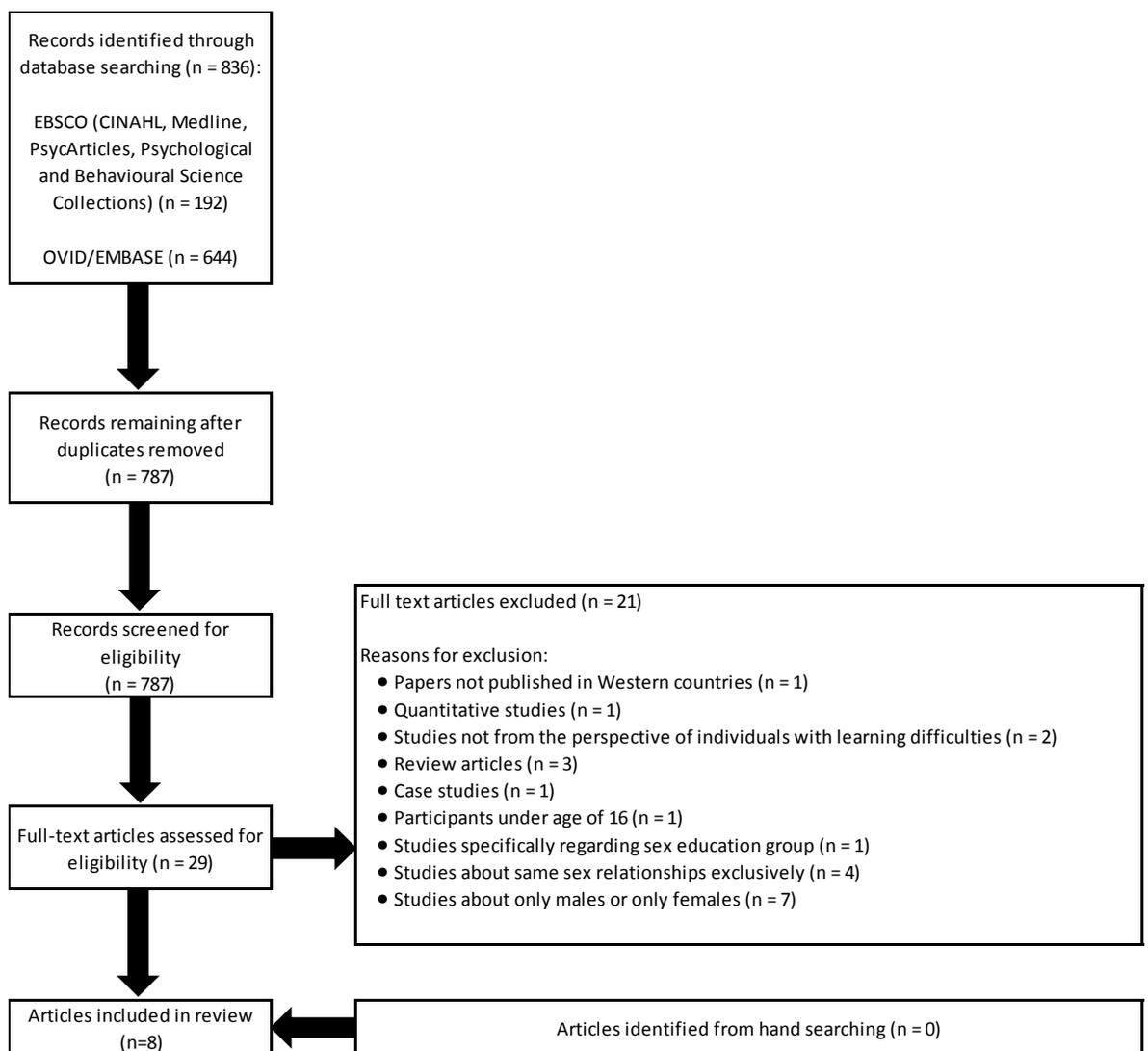
The following exclusion criteria were set:

- Studies utilising quantitative methodology.
- Case studies.
- Mixed method studies.
- Studies not published in English.
- Studies examining same sex relationships exclusively.
- Studies examining the perspective of only males or only females.
- Studies from the perspective of staff, family or professional caregivers.

Procedure

The review process was based on PRISMA guidance (Liberati et al., 2009). Initially the titles of the papers were examined and compared to the review objectives. If these were deemed to be potentially relevant, the abstracts were consulted. If abstracts were not available, or did not provide sufficient information to assess the relevance of the article, the full text of the article was obtained and its relevance was decided upon from there. Eight papers were identified for inclusion in the final review. Their reference lists were then examined. No further studies were identified. An overview of the screening process is provided in Figure 1.

Figure 1: Overview of systematic search process and study selection



Data Extraction

A data extraction table was compiled for the eight included studies (see Table 1). This table provided a description of each study characteristics including authorship, year and country of publication, study aims, participant characteristics, data collection method, method of analysis and themes.

Table 1. Characteristics and Themes of Included Studies

Authors, Year and Country	Study Aims	Data Collection Method	Method of Analysis	Sample	Themes
White and Barnitt (2000) England	To explore whether individuals with LD feel empowered or discouraged when they engage in an intimate relationship.	Semi-structured interviews.	“Qualitative methodology emerged from hermeneutic phenomenology-four readings approach”.	3 males and 5 females aged 18 to 35.	1) Experience of relationships 2) Future of current relationships 3) Others’ involvement in relationships 4) Positive and negative views of relationships
Lesseliers and Van Hove (2002) Belgium	To explore how the sample perceived their relationships and sexuality.	Semi-structured interviews.	“Qualitative enquiry”.	23 females and 11 males aged 20 to 65.	1) Experiencing relationships under structural and personal pressure 2) Love? Yes but not too much 3) The experience of sexual intimacy 4) Love? Oh yes but it’s not allowed 5) Confusing relational conflicts and insufficient or parental support 6) The burden of guilt and disapproval 7) Painful confrontations: sexual abuse at home and in service facilities 8) Getting married and having children: not always a choice 9) Sex education: very much needed
Kelly et al. (2009) Ireland	To provide an understanding of the views, experiences and aspirations of people with LD in Ireland in relation to their sexuality and romantic relationships.	A series of focus group and individual interviews.	Thematic analysis.	7 females and 8 males aged 23 to 41.	1) The extent of participants’ knowledge about sexuality issues and practices 2) Participants’ expressed desire for sexual and intimate relationships 3) Prohibition

Authors, Year and Country	Study Aims	Data Collection Method	Method of Analysis	Sample	Themes
Sullivan et al. (2013) Scotland	To explore the experiences and perceptions of close relationships of people with LD.	Semi-structured interviews.	Interpretative phenomenological analysis.	6 males and 4 females aged 41 to 60.	Superordinate theme: Touching people in relationships Subthemes: 1) Is wrong 2) Unsafe to talk about 3) Suggesting is safe 4) No freedom or fun 5) Being touched
Rushbrooke et al. (2014) England	To explore the experience of intimate relationships of adults with LD.	Semi-structured interviews.	Interpretative phenomenological analysis.	4 males and 5 females aged 21 to 58.	1) Desiring relationships 2) Expressing sexuality 3) Having relationships 4) Who has control?
Rojas et al. (2014) Spain	To explore the ideas of individuals with LD in relation to their sexuality and sexual lives.	Semi-structured interviews.	Thematic coding.	10 males and 6 females, aged 18 to 39.	1) Couple relationships 2) Sexual relations 3) The role of families and professionals
Wilkinson et al. (2015) England	To explore the experiences of 4 young people and their carers in relation to their sexual identity alongside their LD identity.	Semi-structured interviews with people with LD and their carers.	Interpretative phenomenological analysis.	2 males and 2 females aged 19 to 22 and their carers.	1) Struggle for “as normal as possible” adult identity 2) The struggle for sexual identity as a ‘normal’ adult identity.
Turner and Crane (2016) USA	To explore how adults with mild LD live out their socio-sexual lives.	Semi-structured interviews and observations	Thematic analysis.	3 males and 2 females aged 21 to 54 with mild LD.	1) Sensuality 2) Intimacy 3) Sexual experience 4) Sexual attitude 5) Sexual self-identity

Quality Appraisal

It is recognised that the use of quality appraisal tools to rate qualitative research is an area of some controversy. It is suggested that quality checklists are too rigid, thereby jeopardising the unique characteristics of qualitative research (Barbour, 2001) and that there is a lack of transparency when using quality appraisal tools (Dixon-Woods et al., 2004). In an attempt to overcome these difficulties, Walsh and Downe (2006) designed a quality appraisal framework for qualitative research, based upon the review and synthesis of existing tools (Appendix 2). They identified 12 essential criteria that can be used to assess the quality of qualitative studies, irrespective of their theoretical stance. This tool was used to assess the identified papers for this review. If a study was considered to meet over 50% of the prompts, it was considered to have met the essential criteria for that standard. The issue of subjectivity when using this tool was recognised and therefore a second researcher, who was independent to the study, rated a sample of the studies (n=5). Overall, the ratings were generally consistent with any discrepancies being resolved through discussion, resulting in full agreement. The framework was used to provide an overall indication of the quality of the studies, rather than to exclude studies that had not met a predetermined threshold (See Table 2).

Table 2: Quality Appraisal of Articles

Essential Criteria	Clear rationale	Contextualised by the literature	Method appropriate	Data collection appropriate	Sample/sampling appropriate	Analytic approach appropriate	Context described	Clear audit trail	Data in support of interpretation	Researcher reflexivity	Sensitive to ethics	Relevance and transferability
White and Barnitt, (2000)	✓	✓	✓	x	✓	X	✓	X	X	✓	✓	✓
Lesseliers and Van Hove (2002)	✓	✓	X	X	✓	X	✓	X	X	✓	✓	✓
Kelly et al. (2009)	✓	✓	X	✓	✓	X	✓	✓	✓	X	✓	✓
Sullivan et al. (2013)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Rushbrooke et al. (2014)	✓	✓	✓	✓	✓	✓	✓	✓	✓	X	✓	✓
Rojas et al (2014)	✓	✓	✓	✓	✓	✓	✓	✓	✓	X	✓	✓
Wilkinson et al. (2014)	✓	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Turner and Crane (2016)	✓	✓	✓	✓	✓	✓	✓	✓	✓	X	✓	✓

Method of Synthesis

Meta-ethnography (Noblitt and Hare, 1988) was adopted in order to synthesise the research studies. Meta-ethnography is an interpretive approach intended to combine the findings of qualitative research to establish a new underlying interpretation or third-order construct, whilst still preserving the concepts and integrity of the original data (Britten et al., 2002).

It allows transparency with regard to the process of analysis and how the findings are obtained. This review followed the seven-stage process outlined by Noblitt and Hare's (1998) and the process was also informed by the descriptions and worked example provided in Britten et al. (2002).

The initial stages of meta-ethnography involved determining the research question, defining the focus of the review and identifying the studies to be included. The studies were then read several times to facilitate familiarity with the detail and content of each. Each study was then compared to the next in chronological order, examining the similarities and differences in concepts between each. Common concepts that emerged were compiled as headings into a table. Quotations and descriptions that were concordant with each concept were organised under these headings. New third-order themes were created that explained the emergent concepts and these are outlined in the results section.

Results

The themes presented by the authors in the eight studies are displayed in Table 1. Five new third-order themes were developed through the process of meta-ethnography: 1) *“Everybody loves to be loved”*: Desire for intimacy; 2) *“People think they can rule you because you’ve got a disability”*: Lack of control; 3) Sex is *“not for us”*; 4) *“I seen sex in films once”*: Misconceptions and confusion about sex and relationships and 5) *“They want our safety”*: Keeping safe. Each of these themes will be discussed in turn. Quotations directly from participants in the studies are presented in italics, quotations from the papers are not.

“Everybody loves to be loved.”- Desire for Intimacy

This theme encompassed the wide range of experiences described by people in relation to intimate relationships with others. A number of participants were in relationships or married. They described the value they placed in these relationships and their affection towards their partners:

‘[The relationship] means a lot to me...Er, I couldn’t part with him. Right, I love him that much, its part in me heart.’ (Rushbrooke et al., 2014, pg. 534).

Although many participants were not in relationships, they expressed their desire to meet a partner:

‘I love [girlfriends] myself! It’s too good! (...) I wish (to) God I’d one myself!
(Kelly et al., 2009, pg. 312).

“I’d like to have a proper boyfriend, I really would, ‘cos I’m a kind loving person and I don’t hurt people.” (White and Barnitt, 2000, pg. 273).

Some participants described their loneliness as a result of not being in relationship. They talked about their distress at not having achieved traditional life goals, for example getting married or having children:

“I see that in my family they are married and have children and all that... well it makes me cry, but my great hope is to have a house, a partner, and to have a daughter.” (Rojas et al., 2014, pg. 60).

The process of starting a relationship was often fraught with difficulty and one individual compared it to *“looking for a needle in a haystack”* (Rushbrooke et al, 2014, pg. 536).

Many described a lack of confidence in initiating relationships or were restricted by their limited social opportunities and by the influence of family and professional caregivers.

There was a range of sexual experiences described by participants in the studies. Although the majority of participants found sex embarrassing to discuss with the interviewer, the studies highlighted some positive experiences of sex for both men and women. One woman said, *“Yeah, very. I do like sex. A lot.”* (Rushbrooke et al., 2014, pg. 535). This was in contrast to other studies that highlighted the differences in the experiences of men and women (Rojas et al, 2014; Lesseliers and Van Hove, 2002). In these studies, for some female participants, sex was considered something secondary, necessary to maintain a relationship, whereas to male participants, sex was a core aspect of the relationship. This was demonstrated by this woman’s statements about sex, *“I just did it to play... he liked it, I didn’t.”* (Lesseliers and Van Hove, 2002, pg. 74). This is consistent with the passive attitude that McCarthy (1999) found when interviewing women with learning disabilities about their sexuality.

In addition to sex, relationships were desired in order to fulfil emotional needs including ‘company, support, love and affection’ (Rushbrooke et al., 2014, pg. 534). People described finding pleasure in spending time in one another’s company:

“Um, she makes me a coffee, I make her a coffee, we have a coffee, we’ll listen to a CD in the bedroom or we’ll go for a lovely walk.” (Sullivan et al, 2013; pg. 3460).

Many people placed emphasis on non-sexual intimate behaviour and this physical intimacy was considered to be an important part of a relationship and was related to a feeling of connectedness with a partner:

“He used to put his two arms around me instead of just one it was two [...] it made me feel more secure.” (Sullivan et al., 2013; pg. 3462).

***“People think they can rule you because you’ve got a disability”*: A Lack of Control**

All the studies identified the lack of autonomy that people with learning disabilities believed they had with regard to developing intimate relationships. There were a number of factors that contributed to this sense of lack of control. Many participants described their lack of confidence in initiating contact with potential partners. Some described being explicitly prohibited from developing relationships by professionals or family caregivers. It was apparent that many participants believed professional or family caregivers had the ultimate control over their relationships:

“You can’t choose the colour that you like. As well as your boyfriend you can’t pick.” (Rushbrooke et al., 2014, pg. 537).

Many participants described their experiences of relationships being explicitly forbidden by their family or professionals:

“[...]I said to my mother, um, I’m going to invite her to stay with me 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.” (Sullivan et al., 2013, pg. 3460).

There appeared to be a tension between the participant's chronological age and ongoing dependence on others, with caregivers finding it difficult to acknowledge participants' adult identity:

“He doesn't think I am capable of living with my partner [...] He is my legal guardian and I love him a lot but I don't know why he doesn't allow me to take that step. I have told him many times that I am 37 years old.” (Rojas et al., 2014; pg. 60).

Many described being reprimanded for engaging in intimate behaviours or expressed their fears of the potential consequences of doing so, for example that they may risk losing their residence (Lesseliers and Van Hove, 2002; Kelly et al., 2009; Rojas et al; 2014). As a consequence of this, some participants engaged in secrecy to hide relationships from others.

It was not always clear whether the prevention of relationships developing was always intentional, for example through people moving to other residential settings. One woman expressed that she did not want to fall in love again because she had to move and so lost the person with whom she had a relationship (Lesseliers and Van Hove, 2002). In addition to prohibiting relationships, some participants reported the impact of the environment on their autonomy, and described a lack of opportunity or privacy to pursue intimate relationships:

“Having support there all the time we couldn't feel like we could do things what normal people do in a relationship. Like, kiss, cuddle, hold hands...And we felt like that we didn't have space and it felt quite intimidating for me, having staff there all the time. And it was like a bit of a pain in the arse as well, because we couldn't,

like, have a proper conversation, cause staff'd be like ear wiggling, d'you know what I mean, so we felt uncomfortable as well." (Rushbrooke et al., 2014, pg. 538).

For some participants, they were dependent on support from staff to be able to find opportunities to meet partners:

"[the gay bar is] open too late... I need someone who can work that long."

(Wilkinson et al, 2015, pg. 101)

Participants' lack of control over developing relationships also appeared to relate to their perceived lack of skills or confidence in developing relationships. Sometimes attempts to initiate intimate and non-intimate relationships were not reciprocated:

"I-I like to be friends with them and sometimes, uh, they don't want to be friends with me. Or I don't want-or uh, socialising-socialising with me." (Turner and Crane, 2016, pg. 682)

Sex is "not for us"

Participants across several of the studies discussed their own beliefs or the beliefs of others about the inappropriateness of sex because they had a learning disability (Lesseliers and Van Hove, 2002; Kelly et al., 2009; Sullivan et al., 2013; Rushbrooke et al., 2014). They discussed being punished for engaging in sexual behaviours, or even if people suspected this had been the case:

"Somebody said we were having sex, but we weren't having sex at all, we were just chatting [...] and they took us down and put us in detention together." (Sullivan et al., 2013, pg. 3460).

“I did kiss one of them on the lips at the time. Ya know, it was just nice (...) and she was happy and I was happy so [...] I was caught and then I got told off...”

(Kelly et al., 2009, pg. 312).

Some participants used negative language to talk about sex, for example describing sex as “*yucky or dirty*” and “*not for them*” (Lesseliers and Van Hove, 2002, pg. 73); highlighting possible underlying beliefs that people with learning disabilities should not engage in sex.

These views also appeared to be reflected by caregivers:

“Cause I had brain damage, [Mum] thinks that I shouldn’t be with men. I should be on my own. But I don’t want that, I’d sooner have a relationship.” (Rushbrooke et al., 2014, pg. 535).

et al., 2014, pg. 535).

It was clear that some participants did not feel comfortable discussing sex and often used indirect terms when referring to sex, despite being the age where sexual relationships would typically be developing or developed (Sullivan et al., 2013). This may be a normal response when discussing sex with a stranger; or one might surmise that people believed it was inappropriate to either engage in or discuss sexual behaviours. Wilkinson et al (2014) highlighted the tension that existed for participants between their learning disability identity and their ‘normal’ identity. It was proposed that the people in the study felt that having a sexual identity was an unachievable goal for them because of their learning disability. This view also appeared to be shared by their carers and their dependence on their carers to provide support about sex, meant that their sexual needs were not addressed.

Having a learning disability also made it difficult to form relationships and one person suggested that starting relationships were easier for “*people who are more attractive, slimmer, that’s the way I see it.*” (Rojas et al, 2014).

“I seen sex in films once.”- Misconceptions and confusion about sex and relationships

Many of the studies detailed participants’ misconceptions and inaccurate information that people held about sex and relationships (Kelly et al., 2009; Lesseliers and Van Hove, 2002; Sullivan et al., 2013; Rojas et al., 2014, Turner and Crane, 2016):

“I think they just make love, ken, man and wife and he just makes love to her [...] it’s all about like, how to make babies, and how like that. And how the, how the man puts his penis in the lady’s vagina and then makes the egg and then there’s the baby.” (Sullivan et al., 2013, pg. 3461).

“Grace: And what kind of things did [your mum] tell you about [sex education]?”
Elizabeth: About the development. About people touching me (...) Harassment.”
(Kelly et al., 2009, pg. 310).

This first description illustrates the participant’s understanding of sex in purely mechanistic terms, with the ultimate goal to reproduce, rather than for pleasure. These quotations suggest that the sex education these participants had received had focused primarily on the biological and harm-reduction aspects of sex education. Some participants lacked confidence in understanding the relational aspect of sex and felt they were given little support or guidance in understanding how to develop and maintain a relationship:

“Well, when you know you truly like someone, I don’t know, for example, how to carry out a relationship, I mean as I have never tried, I don’t know how to go about it.” (Rojas et al., 2014, pg. 61).

Information about sex was often gathered through the media, for example by television and films, and in Turner and Crane’s (2016) study, one participant described learning about sex by watching pornography. Receiving information about sex in this way appeared to have

an impact on the sexual acts they engaged in and the language that they used to describe these acts, for example, thinking of sexual behaviours in terms of “affairs”, as it is commonly labelled on television programmes (Kelly et al., 2009). These participants described how their understanding of sex had been influenced by the media:

“When you’re in bed. Beside them (...) They put their hands around ya (...) Or give ya a kiss or something (...) And someone walks in and found ya in bed. Someone else (...) And then war break out.” (Kelly et al., 2009, pg. 311).

“I seen [sex in films] once. They were lying- sitting down beside the fire with two glasses of wine [...] and romantic music playin’ on the CD player in the background and the nice fire lit and all.” (Kelly et al., 2009, pg. 310).

These quotations highlight the impact that accessing information about relationships through the media has on an individuals’ understanding, by providing an unrealistic, confusing and idealistic depiction of relationships and sex. Clearly, learning about sex from pornography has the potential to be even more maladaptive, particularly if it portrays negative gender stereotypes or abusive sexual acts.

“They want our safety”- Keeping safe

Participants across four studies discussed their understanding of their vulnerability (Lesseliers and Van Hove, 2002; Sullivan et al., 2013; Rushbrooke et al., 2014; Wilkinson et al, 2015). Males and females in two studies described incidents of abuse they had experienced (Lesseliers et al., 2002; Sullivan et al., 2013):

“I had to go to the hospital to get an abortion as well. I had to get rid of it as well and it wasnie, it wasnie my doing, but I just had to get it done [...] because, um, I

was surely, I should say raped. Really bad. Really bad. It was horrible.”

(Sullivan et al., 2013, pg. 3462).

“Really awful. In fact one of my boyfriend’s actually attacked me.” (Rushbrooke et al, 2014, pg. 536).

Many participants appeared to recognise that caregivers saw them as vulnerable:

“They want our safety. If I’m delayed a bit longer I have to call them to make sure I’m, why I’m a bit late or something.” (Wilkinson et al., 2015; pg. 100).

They also described the ways caregivers tried to protect them as a consequence of their vulnerability, for example in Rushbrooke et al.’s (2014) study, staff accompanied one woman on dates with her partner:

“The guy mightn’t like it. Cause he says, ‘why do you always have to have staff around you all the time?’ Which is understandable, I wouldn’t like it myself.”
(Rushbrooke et al, 2014; pg. 536).

In Wilkinson et al’s (2015) study, it was suggested that carers are often “caught in the tension between empowering young people with learning disabilities and the concern that young people and adults with disabilities are at greater risk of abuse.” (pg.102) and some participants recognised that this behaviour was as a consequence of protection. Some participants recognised their own vulnerability and sought out support from caregivers, for example to help them to identify appropriate partners:

“I think I do need a bit of support. But a bit of help... and that’s to like meet people... And so yeah, gives me a bit of confidence to speak, and see if I can meet the right one, and could say to them, “well what do you think about this fella?” and they could come and meet him and see like if he’s seems to be like a bit dodgy.”
(Rushbrooke et al., 2014, pg. 536).

Discussion

These findings demonstrate that the area of sexuality for individuals with learning disabilities is fraught with tension. Many of these individuals clearly desire intimate relationships with others but they lack the control and autonomy over their own lives to be able to pursue and maintain these relationships. It highlights the polarised views that appear to exist in individuals with learning disabilities in relation to their sexuality. Many individuals described fulfilling, healthy sexual relationships; with others describing negative, out-dated views that reflect prejudicial societal views of the past. Furthermore, the positive experiences of many of these individuals lies in stark contrast to the devastating experiences of those who have been victims of abuse. A further significant finding of this review was the inaccurate information and beliefs that many individuals held about sex; which appeared to be a consequence of relying upon informal sources of sex education, for example through the media.

This review clearly demonstrates that, unsurprisingly, individuals with learning disabilities do desire and find pleasure in affection and intimacy, but face barriers in establishing such relationships. These findings highlight the importance of individuals having the opportunities and support to be able to develop significant intimate relationships, which could include sexual intercourse or other non-sexual forms of physical intimacy and affection. Caregivers appear to play a significant role in the relationships of individuals with learning disabilities, often leaving them feeling powerless to pursue and maintain relationships. It was apparent that caregivers directly or indirectly prohibited intimate relationships and even non-sexual physical acts of affection. These findings are consistent with other research in this area (Knox and Hickson, 2001; Lofgren-Martenson, 2004). It is important to consider the attitudes and beliefs of family members and professional

caregivers to help us understand why this prohibition of sexuality may be occurring. Research suggests this may be due to beliefs that people with learning disabilities are either asexual and childlike (Szollos and McCabe, 1995) or hypersexual (Taylor Gomez, 2012). It is likely that these attitudes contribute to caregivers' ambivalence or resistance in supporting people with learning disabilities from developing intimate relationships with others (Hingsburger and Tough, 2002).

Given that statistics suggest that individuals with learning disabilities are more likely to be abused than their non-learning disabled peers (Horner-Johnson and Drum, 2006), it is understandable that staff would want to protect individuals from abuse. The vulnerability of people with learning disabilities was identified in several of the studies in this review, and some participants disclosed experiences of sexual and physical abuse. Some participants recognised that others viewed them as vulnerable, and others perceived themselves as vulnerable as a result of their learning disability. Individuals with learning disabilities have poorer knowledge of sexual matters than their non-learning disabled peers which may impact their understanding regarding consent (O'Callaghan and Murphy, 2007) and how to identify abuse in a relationship (Murphy and O'Callaghan, 2004). These factors can result in an increased vulnerability to abuse, however, Turner and Crane (2016) suggest that overprotection may become a self-fulfilling prophecy, where individuals become more socially and sexually incompetent and consequently more vulnerable. It is therefore imperative that services strike the appropriate balance between protecting individuals from harm, whilst allowing individuals to explore and express their sexuality to avoid placing them within a 'Prison of Protection' (Hingsburger 1995).

Understandably, many participants felt uncomfortable discussing sex openly with interviewers and used indirect terms when referring to sex (Sullivan et al., 2013). This may have been a natural consequence of discussing a very personal and sensitive issue; or this could reflect their negative beliefs about sex. Despite some embarrassment, encouragingly, some participants described positive beliefs about sexual behaviours; however, other studies revealed that people thought sex was wrong or inappropriate. Some described being warned against or punished for engaging in intimate behaviours. Furthermore, it is suggested that caregivers are reluctant to discuss sex with individuals with learning disabilities for fear this might encourage sexual behaviour or may be an intrusion on their privacy (Abbott and Howarth, 2007; Murphy and Elias, 2006). The negative attitudes expressed by participants in Kelly et al's (2009) study may in part be a consequence of legislation in relation to individuals with learning disabilities in Ireland, where the law states that unless married, people with learning disabilities cannot engage in sexual intercourse. Although this act has never been used to bring a prosecution, Kelly et al (2009) suggest that the presence of this law undermines the rights of those with learning disabilities in Ireland.

The findings of this review demonstrate that education, training and resources need to be available to promote healthy and adaptive beliefs amongst both individuals with learning disabilities and their caregivers, so that the policies that promote safe sexual expression are facilitated into the day-to-day reality in services. Turner and Crane (2016) suggest that staff should have open conversations about an individual's sexuality, sexual interests, history and challenges as part of care planning meetings. This would help to normalise the idea that sexuality is an important part of an individual's overall identity and help services consider how best their needs can be met. It is also important that services consider that sexuality encompasses more than just sex; and that people may wish to express their

sexuality through a range of intimate behaviours such as handholding, touching, talking, embracing or kissing.

This review also contributes to our understanding of the gender differences that exist in the area of sexuality. There are differences in how males and females experience sex. The findings of this review indicate that although some women described positive experiences of sex, for many others, they described a passive role in sexual encounters, often characterised by a lack of pleasure and this was consistent with the findings of other studies (McCarthy, 1999; Bernert and Ogletree, 2013). It is suggested that limited communication skills can affect an individual's ability to be able to direct their partners to act in pleasurable ways (Bernert and Ogletree, 2013). Research also suggests that women often engage in abstinence due to their concerns about possible negative outcomes of sex, for instance unwanted pregnancies and sexually transmitted infections (Bernert and Ogletree, 2013). It is pertinent that both males and females are empowered to be able to make informed decisions about sex based on accurate and balanced information.

A striking finding of this review was the level of inaccurate information about sex expressed by the participants in these studies. Furthermore, many individuals were clearly seeking out information and resources, particularly in relation to developing and maintaining relationships. Research has found that individuals with learning disabilities have less access to informal sources of sex education and rely more heavily on caregivers to provide them with information about sex (Pownall et al., 2011); but in the present study, individuals indicated that they felt embarrassed and fearful of discussing sex with family members or carers. Furthermore, it is important to be cognisant of the type of sex education offered to individuals with learning disabilities. The findings are consistent with

evidence that suggests that sex education is usually biologically oriented and taught as rules and restrictions (McCarthy, 1999). The findings of this review indicate, that if individuals with learning disabilities are not given formal methods of sex education, then information may be gathered from informal, opportunistic methods, such the media, which can result in inaccurate, idealistic and unhelpful ideas. Support and training must be provided to family members, carers and staff, who are likely to be the primary source of sex education for individuals with learning disabilities. Clearly, people need to be aware of potential negative outcomes and risks associated with sex; but education should not be exclusively risk-focused. This education also needs to focus on positive and pleasurable aspects of sexuality and relationships. Research by Frawley and Wilson (2016) found that young people with learning disabilities said that they wanted informal opportunities to discuss sexuality and relationships with professionals present to provide guidance and structure. Services should therefore consider how these opportunities could be enacted. It is pertinent that we consider the perspectives, beliefs and wishes of individuals with learning disabilities themselves, so we can provide support that is meaningful and sensitive to their needs.

Individuals with learning disabilities should be able to make informed decisions about whether or not they wish to engage in intimate relationships or abstain from sexual behaviours, however, it is critical that decisions about abstaining from sex should not be made as a result of fear, misinformation or as a consequence of overprotection. Health and social care providers must achieve the delicate balance between protecting individuals with learning disabilities from harm, whilst allowing them the opportunities and providing them with the support to make informed decisions about their own sexuality and relationships.

Limitations

This review discusses themes synthesised from studies regarding the sexuality of adults with learning disabilities. Clearly, there are gender-specific issues as previously discussed. There are also issues affecting those who identify as lesbian, gay, bisexual or transgender. For example, sex education is usually biased toward heterosexual relationships (Chivers and Mathieson, 2000). People with learning disabilities who identify as LGBT face barriers to making choices in relation to their sexuality as professionals working with them make heterosexist assumptions and same-sex sexual behaviours are often interpreted as threatening or challenging (Abbott & Burns, 2007). The author considers that papers exploring attitudes and experiences of learning disabled females or males exclusively, or addressing those who identify as LGBT should be subject to synthesis to facilitate our understanding of these pertinent issues; however, this was considered to be outwith the scope of the current review. The author suggests that these topics should be addressed in separate reviews to ensure that they are given sufficient consideration.

The cultural context of each study should also be considered when reading this review. For example, it is important to note that Kelly and colleagues' (2009) study was conducted in Ireland, where religion influences education curriculum and social policy and this is likely to influence the attitudes of participants in this study. This study highlighted the prohibition of sexuality, although this theme was also identified in other studies.

Although efforts were made to audit the review process, by having the papers rated by an independent marker and by discussing the third-order themes with another researcher, the process of meta-synthesis involves a degree of subjectivity and interpretation. The process of synthesis will have inevitably been influenced by the authors own experiences and

values and it should be noted that this review will be one of several possible ways of interpreting the studies included in this review. Furthermore, the author was conducting research exploring the sexuality and sexual development of young adults with autism and a learning disability from the perspective of their mothers. It is important to note that this research may have had an impact on the interpretation of the studies included in this review. The author was engaging in a reflective journal whilst conducting these pieces of work in order to minimise any bias.

Conclusions

This synthesis provides insight into the beliefs and experiences of individuals with learning disabilities in relation to their sexuality and intimate relationships. The review clearly indicates that intimate relationships are an important aspect of their lives but that at present; various factors inhibit their ability to engage in these relationships. This review illustrates that consideration should be taken when providing health and social care to ensure that individuals with learning disabilities have the opportunities to be able to develop safe and positive relationships. For example services should consider how to provide private spaces and social opportunities to meet others. Sexuality should be considered as one of the overall factors that contribute to an individual's wellbeing as part of the care planning process. Furthermore, education and accessible resources are essential to provide accurate information on the positive and emotional aspects of sex and relationships, in addition to providing information about the biological aspects of sex and the associated risks. Families and caregivers play a key role in the provision of sex education and in supporting sexuality and the development of relationships and they need to feel confident and supported in doing so. Individuals with learning disabilities need to receive proactive support in order for them to develop positive sexual identities and relationships. It is pertinent that that we continue to listen to the experiences, beliefs and

wishes of individuals with learning disabilities so we understand how best to meet their needs.

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CHAPTER 2: MAJOR RESEARCH PROJECT

A Qualitative Study of Mothers' Experiences of Supporting the Sexual Development of their Sons with Autism and an Accompanying Learning Disability

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Plain English Summary

Background: Sexual development is an important part of growing up. People who have autism and a learning disability have sexual feelings and demonstrate many of the same sexual behaviours as typically developing people. However, sexual development can be a difficult time for young people with autism and a learning disability as it can often be hard for them to understand social rules. Their parents play an important role in supporting them with their sexual development and providing with them with information about sex. Understanding the experiences of their parents can help us to support families with the sexual development of young people with autism and a learning disability.

Aims: This study aimed to better understand mothers' experiences and beliefs in relation to the sexual development of their sons with autism and a moderate or severe learning disability.

Methods: Five mothers of males aged between 16 and 24 were interviewed about their experiences of supporting their sons with their sexual development. The semi-structured interviews were audio recorded and then transcribed and analysed using interpretative phenomenological analysis.

Results: The findings of the study showed that mothers play an important role in supporting their sons' sexuality. Mothers also worried about the potential impact of some of their sons' challenging sexual behaviour. They viewed their sons' sexuality as an important part of their identity, but they also saw it as a potential burden to their sons. They described their worries about giving their sons information about sex in case this increased their sons' sexual behaviours. They talked about the importance of communicating clearly when discussing sexuality with their sons. Mothers also discussed their fears of their sons being abused. A further important finding was that mothers worried about who would love their sons when they were no longer able to.

Conclusions: The study provides us with new understanding of mothers' experiences of supporting their sons with autism and a moderate or severe learning disability with their sexual development. This was found to be an important issue for these mothers. Families need to be given more support and information to help them feel confident to support their sons with their sexual development. Services also need to be aware of how to provide physical affection to people with autism and a learning disability when their families are no longer around.

Abstract

The sexuality and sexual development of individuals with autism-spectrum disorder (ASD) and an accompanying learning disability is a neglected area, despite the fact that this group have the same sexual desires as their typically developing peers. Due to the socially marginalised position these individuals are often placed in, parents play a key role in supporting them with their developing sexuality. It is therefore important to understand parents' experiences and perspectives about their offspring's socio-sexual needs. Five mothers of sons with ASD and a moderate to severe learning disability aged 16 to 24 were recruited from voluntary organisations and interviewed. Interviews were audio recorded then transcribed and analysed using interpretative phenomenological analysis (IPA) to draw out key themes from their narratives. These narratives were fraught with tensions; mothers' acknowledged their sons' sexuality as an important part of their developing identity, but their sons' sexuality brought many challenges. They wanted to provide their sons with appropriate education, but were concerned that by doing so, they could increase problematic sexual behaviours, which could result in serious negative consequences. The mothers also expressed their concerns about who would love their sons when they grew up. There was an overarching sense that these mothers were desperate for support and information to help improve their confidence in supporting their sons' socio-sexual needs. This study highlights the need for sensitive and person-centred support to both young people with ASD and an accompanying learning disability and their families in relation to their sexuality and sexual development. It also highlights that services need to consider how to meet this group's need for physical intimacy and affection when their family members are no longer able to do so.

Introduction

Sexual development is a critical milestone of adolescence, occurring irrespective of intellectual ability (Koller, 2000). Sexual development is a time of growth and exploration, characterised by a myriad of physical, psychological and behavioural changes which often brings challenges for young people and their families (Kar et al., 2015). Often sexual development is a sign of a young person's growing autonomy, however, for young people with autism-spectrum disorder (ASD) and an accompanying learning disability, their continuing support needs means they often do not gain the same independence as their typically developing peers and may continue to rely upon their families for support in many areas of their lives, including with their sexual development.

The sexuality and sexual development of individuals with ASD is often considered to be a neglected area (Gougeon, 2010), which may be a result of the inaccurate perception that these individuals have no interest in sexual behaviour and developing intimate relationships. However, research has dispelled these myths by clearly demonstrating that both those with high functioning autism and those with ASD and a learning disability desire intimate relationships with others (Hellemans et al., 2007) and demonstrate a range of sexual and intimate behaviours including masturbation, handholding, hugging, kissing, touching and attempted sexual intercourse (Byers et al., 2013; Hellemans et al., 2007; Van Bourgondien et al., 1997). Encouragingly, there appears to be increasing acknowledgement that these individuals have a basic right to a sexual life. Despite this, the reality is that the sexuality of individuals with ASD can be difficult to navigate due to the sensitive and deeply personal nature of this area and the particular challenges facing this group in relation to their sexual development.

These distinct challenges facing individuals with ASD in relation to their sexual development relate to their specific impairments in social communication; social interactions and repetitive, restricted and stereotyped repertoire of behaviour (American Psychiatric Association, 2013). Those with ASD and a learning disability also experience impairment in intellectual functioning and adaptive functioning in conceptual, social and practical skills (American Psychiatric Association, 2013). These impairments can have a significant impact on how these individuals are able to express their sexuality. Individuals with ASD and an accompanying learning disability, particularly those with moderate and severe learning disabilities, are likely to lack the capacity to make decisions necessary to form healthy relationships and maintain appropriate sexual boundaries (Swango-Wilson, 2009). Since relationships may not be possible for this group, it is critical that we consider how these individuals can express their sexuality in a safe and appropriate way.

A specific challenge in the expression of sexuality lies in the fact that these individuals' sexual desires are accompanied by a lack of social understanding, and can therefore impact their ability to make judgements about the appropriateness of engaging in particular behaviours in public. Research demonstrates that some young males who have ASD and a learning disability have been found to expose themselves to others, masturbate in public places and attempt to touch other peoples' genitals (Gillberg & Coleman, 1992). Such behaviours pose a potential risk to others and increase the individuals own vulnerability to sexual abuse. Many of the behaviours exhibited by these young men are normal sexual behaviours, for example, masturbation (Fegan et al., 1993) but are enacted in inappropriate ways. It is suggested that individuals with ASD may exhibit inappropriate sexual behaviour as a way of imitating what they believe to be normal sexual acts (Day, 1994). This is likely to be a consequence of their lack of understanding about the social norms governing acceptable sexual behaviours.

Furthermore, the repetitive, restricted and stereotyped behaviour often exhibited by individuals with ASD can lead to inappropriate fixations and obsessions. Some case reports highlight difficulties in relation to stalking, paraphilia's and compulsive masturbation, although these incidences are considered to be rare (Ray et al., 2004; Realmuto and Ruble, 1999). These individuals have a propensity for self-stimulating behaviours; which can manifest in masturbation; and research highlights that this is often carried out in unsafe or inappropriate ways (Kempton, 1998). Due to the lack of capacity and opportunity these individuals have to develop consenting, healthy relationships, masturbation is likely to be one of the only appropriate sexual outlets available to this group.

Given these difficulties, it is important to understand how best to support individuals with ASD and an accompanying learning disability to explore their sexuality in a safe manner. Parents play a critical role in providing these young people with support with their sexual development. The socially marginalised position these individuals are often in limits their opportunities to engage in sexual experimentation and they do not have access to the informal learning opportunities available to their typically developing peers and therefore often rely on their parents to provide this information. Previous research has been conducted to explore the family perspective of young people with learning disabilities' sexual development. Pownall and colleagues (2011) carried out qualitative research to compare their experiences supporting similarly aged siblings with and without learning disabilities with their sexual development. The findings suggest that mothers found it more difficult to discuss sexual matters with their child with a learning disability than with their typically developing child. This study highlighted the tension that exists between their learning disabled offspring's emerging adulthood and their ongoing dependence for support with their needs. It also illustrated that mothers adopted a reactive approach to

dealing with sexual matters; but their typically developing offspring's growing autonomy forced them to have these discussions; whilst their learning disabled offspring's ongoing dependence needs provided reasons for avoiding discussions about sex. Mothers felt there was a lack of resources and information about how to support their offspring's sexual development; this is consistent with other findings that highlight the lack of confidence and support parents of people with learning disabilities report in dealing with sexual matters (Clegg et al., 2001).

As parents play such a crucial role in providing sex education and support to their offspring with ASD and a learning disability, understanding their perspectives gives a valuable insight into the support needs of these young people, particularly as many of these individuals will not be able to articulate their own experiences and beliefs. A study by Ruble and Dalrymple (1993) adopted a questionnaire approach to explore parents' experiences of supporting their offspring with ASD in relation to sex education, socio-sexual awareness and sexual behaviours. The results suggested that parents believed sex education was less relevant and they were less likely to provide this education to individuals with more significantly impaired verbal skills. However, there was no significant relationship between the verbal skills of individuals with ASD and their display of inappropriate behaviour. There was considerable variation in their concerns and beliefs regarding sexuality, although the most significant concern was identified to be their child's behaviour being misconstrued as sexual, or sexual behaviours being misunderstood. Quantitative studies such as Ruble and Dalrymple's provide valuable information about parents' beliefs and experiences but do not allow us to understand the personal circumstances in which these are embedded. Pownall et al.'s (2011) aforementioned qualitative study provides valuable insights into the perspectives of mothers of individuals with learning disabilities but we continue to have a limited understanding of the

experiences of the needs of those with ASD and an accompanying learning disability. It is vital that we develop insight into the support needs of this group. Understanding how best to support individuals with ASD and an accompanying learning disability and their families will enable them to explore their sexuality in a safe and positive way.

This study aimed to address the gap in the literature by undertaking an exploration into the lived experiences and beliefs of mothers of sons with ASD and a learning disability, specifically those with moderate and severe learning disabilities, in relation to their sexual development. The study utilised interpretative phenomenological analysis in order to understand how these individuals made sense of these major life experiences (Smith et al., 2009). It is recognised that the experiences of fathers are equally pertinent and also need to be explored, but only mothers were included in the present study to ensure homogeneity of the sample. The study was open to mothers of sons and daughters but only the former responded to recruitment advertisement for the study. Therefore, the primary aim of this study was to explore mothers' perspectives, beliefs and experiences regarding their sons' sexuality and sexual development.

Method

Design

A qualitative design was employed to understand the experiences and beliefs of mothers of sons with ASD and an accompanying learning disability with regard to their sexuality and sexual development.

Interpretative phenomenological analysis (IPA) investigates how individuals make sense of major life experiences (Smith et al., 2009) and allows descriptive and rich accounts of these experiences (Smith & Osborn, 2008). Given that this study is following a line of previous work (Pownall et al., 2011) and was intended to increase our understanding of mothers' individual experiences and perspectives, IPA was selected due to its inductive approach, in addition to its capacity to conduct an in-depth exploration of individual cases. At the epistemological level, IPA is underpinned by its emphasis on phenomenology and understanding the perspective of the individual. It is also characterised by its emphasis of the role of dual hermeneutics, in the form of a two stage interpretation process; the researcher attempts to make sense of the meaning that the individual gives to their subjective experiences (Smith and Osborn, 2008). IPA has often been used to explore major emotional life experiences and has been used effectively to explore sexuality and life transitions (Smith and Osborne, 2008).

Ethical considerations

Ethical approval was obtained from the College of Medical, Veterinary and Life Sciences, University of Glasgow Ethics Committee (Appendix 3) and practice guided by The British Psychological Society (BPS) Code of Human Research Ethics (2014). Applications for amendments were requested to widen the inclusion criteria from 16 to 25 to 14 to 30 and to

those fluent in English as opposed to English as their native language. An amendment was also requested to advertise the study on the website and social networking platforms of voluntary organisations and to advertise at training events. These amendments were granted.

Participants

A purposive, well-defined, homogenous sample was employed to allow detailed examination of similarity and variability within the sample (Smith et al., 2009).

The following inclusion criteria were set:

- Only mothers were invited to participate. This was to ensure homogeneity of the sample, in line with the IPA approach (Smith et al., 2009).
- The participant's daughter or son was required to have a diagnosis of ASD and a moderate to severe learning disability. This was confirmed by mothers during initial discussions to determine suitability.
- The participant's daughter or son had to be aged between 14 and 30.
- The participant had to be one of the primary caregivers to the young person. The mother was not required to be biologically related to the young person, but had to have lived with the young person throughout childhood and adolescence.
- Participants were required to be fluent in English.

Whilst mothers of both sons and daughters with ASD and a learning disability were invited to participate in the study, only the former responded to recruitment advertisement. There are higher levels of males with ASD than females, a ratio of approximately 4:1 (Ehlers and Gillberg, 1993) and this ratio is considered to account for this.

This study followed recommendations by Smith et al. (2009) who suggest between four and ten participants for a professional doctoral research project using IPA.

Various steps were taken to ensure the rigour and validity of the analytic process was maintained. A sample of the audio recordings was listened to by the author's research supervisor to ensure the quality of the interview. A sample of the transcripts and the emerging themes were also read by the author's research supervisor to provide an audit of the process of analysis. The primary researcher maintained a reflective journal throughout the analytic process to chart key decisions that were made when drawing out themes. A summary of each interview was created in order to ensure that the final themes were a true reflection of the experiences of each of the participants. The primary researcher ensured that the final themes were grounded in quotations from the participants' narratives (Elliott et al., 1999).

Recruitment

The principal researcher provided information about the study to ten voluntary organisations providing care, support or advice to individuals with ASD and/or learning disabilities and/or their carers and one educational establishment. Details of the study were also disseminated by another researcher conducting a project in a similar area. The primary researcher attended training events aimed at professionals working with this group to circulate details of the study. Following initial contact with the organisations, the primary researcher followed up with telephone calls to answer any questions that staff had about the study. Face to face meetings were offered to all organisations to answer any additional questions. Employees in the organisations disseminated information regarding

the study (Appendices 4 and 5) to service users directly or online. Interested participants then contacted the primary researcher directly. The researcher discussed the study over the telephone with each participant, to answer questions about the research and to ascertain their suitability to take part in accordance with the inclusion criteria. If they wished to proceed and met the inclusion criteria, an interview was subsequently arranged.

Recruitment ran from August 2015 until April 2017. It was extended due to the primary researcher's maternity leave. There were difficulties recruiting to the study despite details of the study being widely disseminated to a variety of organisations. These difficulties in recruitment prompted the decision to widen the inclusion criteria and allow for the advertisement of the study online as previously discussed.

Sample

Participants consisted of five mothers of sons with a diagnosis of ASD and a moderate to severe learning disability. Their sons were aged between 16 and 24. Their sons received full time support from their families or professional caregivers.

Five mothers made initial contact with the researcher but did not respond to follow-up contact. Two mothers were excluded from taking part because upon discussion with the primary researcher, it was established that their child did not have a learning disability.

Background information about each participant is detailed in Table 1 to provide context (Pseudonyms have been used to preserve anonymity):

Table 1. Participant Characteristics.

Anne lives with her husband and her son, James, who is 24 and has ASD and a learning disability. She also has an older son who no longer lives at home. James will be moving out soon into his own accommodation where he will receive full time care.
Frida lives with her husband and two sons. Her older son, Kian, is 16 and has ASD and a learning disability. He attends a specialist day school.
Jane lives with her son, Daniel, who is 16, who has ASD and a learning disability. She has an older son who no longer lives at home. She has a partner but they do not live together. Daniel spends time with his father and step-mother and their children. Daniel attends a specialist day school.
Elaine lives with her son, Sam, who is 16 and has ASD and a learning disability. She is separated from Sam's father. Sam attends a specialist residential school.
Wendy lives with her husband. Her youngest son, Chris is 24 and has ASD and a learning disability. He has lived in his own home for four years, where he has a full care team in place.

Interview Procedures

Individual interviews were conducted by the principal researcher in offices of voluntary organisations or on University of Glasgow premises. Interviews lasted between 49 minutes and 84 minutes in duration. Efforts were made to ensure all settings were comfortable and free from interruptions. One interview was conducted over the telephone. It has been suggested that telephone interviews may result in loss of important non-verbal information and consequently impact on data analysis (Novick, 2008). Previous studies have found telephone interviews to be a sensitive approach, with no apparent differences in

the quality of data obtained by face to face and telephone interviews (Sturges and Hanrahan, 2004). It was recognised that the topic of the interview was sensitive and potentially distressing and therefore every effort was made to ensure that the participant was happy with the method of the interview. The researcher monitored the emotional impact of the discussions throughout. A telephone interview was selected in this instance as it was the most convenient method for this participant.

The principal researcher adopted an exploratory stance during the interviews, using a semi-structured approach, with open-ended questions to allow discussion and to reveal rich, detailed narratives. The topic guide (Appendix 7) was established through discussion with the author's research supervisor and in consultation with the existing literature. It was piloted with one of the participants, providing the researcher with an opportunity to practice interview technique and to assess the appropriateness of the topic guide. Feedback was gathered from the author's research supervisor and no significant issues emerged and no changes made to the topic guide. This interview was therefore considered appropriate to be included within the analysis.

At the outset of each interview, the researcher described the rationale for the study; the nature of the interview and gave the participants another chance to read the information sheet and ask any questions. The researcher made every effort to ensure that each participant had a comprehensive understanding of what the study would involve and the purpose of the research. Each participant provided written consent (Appendix 6) and they were reminded that they were free to withdraw from the process at any time. Given the sensitive and potentially distressing nature of the topic, they were also offered the

opportunity to take a break at any time, although this offer was not taken up by any of the participants.

The interviews were audio recorded and transcribed verbatim by the principal researcher to enable familiarisation with the content. Pseudonyms were assigned to preserve anonymity and any information that could potentially identify the participants was removed from the transcripts. Audio recordings were destroyed following the transcription process.

Researcher reflexivity

A key part of the process of IPA involves the researcher reflecting upon how their own experience and beliefs may influence the data collection and analysis process. Alongside data collection and analysis, the researcher was carrying out a systematic review on the experiences and beliefs of individuals with learning disabilities in relation to their sexuality and sexual experiences. The researcher also had experience as an autism practitioner and as a trainee clinical psychologist working with adults with ASD and an accompanying learning disability who had experienced difficulties with their sexual development. To ensure that these prior experiences did not prejudice the emerging themes, the researcher engaged in an active reflection process. This involved recording her reflections following the completion of each interview and throughout the data analysis process to consider sources of bias and identify any potential impact they might have on interpretation of the data and emerging themes. Through this reflective process, the researcher recognised that the initial themes identified from the analysis were impacted by her desire not to contribute to the overly negative discourse around the sexuality of individuals with ASD and learning disabilities. As a consequence, the emerging themes were not considered to be

a true reflection of the challenges being described by the mothers in the study. Upon consultation with the author's research supervisor, changes were made to the initial themes. The emergent themes from a sample of data were audited by another member of the research team to ensure the reliability of the findings.

Data analysis

In line with Smith et al.'s (2009) recommendations, the first stage of analysis involved reading the transcripts several times to ensure familiarisation with the data. The transcripts were then re-read and comments were added to provide a description or summary of the data and to make any initial interpretations. Instances of interesting or unusual uses of language; moments where high-levels of emotion were expressed; tensions or contradictions in the mothers accounts were identified. Emergent themes were then identified from the initial notes, by creating a summary phrase to encompass the crux of the theme; these were often direct quotations from participants. Superordinate themes and subthemes were then identified by exploring and making connections between the emergent themes. Once each transcript had been analysed, patterns and connections across interviews were explored. These themes were discussed during research meetings.

Results

All of the participants engaged well in the interview process and appeared to give open and considered responses to the questions put to them. It was clear that the topic of sexuality appeared to be of real and immediate concern to the mothers in this study although the impact on each was quite different.

Four superordinate themes with a further four subthemes emerged from the analysis and are summarised in Table 2. The rationale for the order of the themes reflects the order of the discussions during the interviews. Each of the superordinate themes and subthemes is discussed below. Themes are presented in quotations and italics to illustrate each theme. In the presented extracts [...] indicates that some text has been removed.

Table 2: Superordinate themes and Subthemes

Superordinate Themes	Subthemes
Emerging sexuality	An unfair burden? A challenge to address?
Challenges of providing sex education	<i>“I don’t know the right thing to do”.</i> <i>“There is no point beating about the bush.”</i>
Abuse: an unbearable prospect	
Love in the future	

Emerging sexuality

An unfair burden?

For many of these mothers, there was a real sense of conflict in relation to their sons' emerging sexuality; they recognised the potential impact of challenging sexual behaviours but they also recognised that their sons' sexuality was an important part of their identity. Some of the mothers appeared to believe that sexuality was a burden to their sons and described feelings of injustice and sadness surrounding the incongruity between their son's cognitive abilities and their sexual development:

“When he was about 12 his voice started to break and [my other son] was older when that happened and I thought this is particularly sad that a lad that is developmentally delayed and very immature should be going through puberty quicker.” (Anne)

Anne's narrative demonstrates the emotional impact of watching her son develop into an adult, whilst failing to mature emotionally. Many participants also expressed sadness that their sons had sexual feelings and desires, but did not have the capacity to be able to form appropriate, healthy relationships to be able to enact these feelings:

“It's one of those things where I sometimes think with the level of intellectual disability Sam has, and the way his autism affects him with regard to his understanding of social and everything else, I think it's really unfair, if there is a God in this world, I think it's really unfair, really you couldn't take all the mechanisms and make them not work?” (Wendy)

Anne's son had experienced significant challenges with his sexual identity, which had caused him considerable distress and had resulted in him engaging in serious sexually related self-harm. The following quotation illustrates the significant emotional impact that this incident had on her and her husband:

“We were just shocked and profoundly, profoundly sad about it all, that he should do something so horrible [...]. We just wept, it was just so sad [...] and it just brought home to us, how very, very vulnerable James is.” (Anne).

There was a tension in these narratives, between their acknowledgement of the importance of their sons’ sexual identities and the overarching sense that their sons’ lives would be easier if they did not have these sexual desires.

A challenge to address?

The mothers in this study described their sons’ physical, emotional and behavioural changes as they transitioned through adolescence. In relation to their sons’ sexual development, the mothers described somewhat polarised views dependent on whether their sons had displayed problematic sexual behaviour or not. For Wendy and Elaine, despite their concerns about the challenges that might arise during this time, adolescence had in fact been quite unremarkable. Their sons had exhibited sexual behaviours, for example masturbation, but had required little intervention from their mothers to ensure these were enacted appropriately. Elaine discusses how her experiences of Sam’s sexual development contrasted with her expectations:

“Well when the masturbation started, I was really worried because I had heard horror stories, well stories about kids who would do it anywhere, that would just take their clothes off, but right from the start, he seemed to know it was a private thing. Even if I was to go upstairs and he was masturbating in his room, he made a certain noise, that means don’t come in.” (Elaine)

For these mothers, their main concern was about the potential negative consequences if their sons’ typical behaviours were interpreted by others as deviant, as demonstrated by this quotation:

“I think a few times he has been in the gents [...] and he can stare at things and he is not necessarily staring at the guy next to him having a pee [...] but a few men have made comments because I suppose they are feeling vulnerable [...] I suppose from my point of view its people’s perceptions of what he is doing that is likely to cause more problems than necessarily what he does do.” (Wendy)

The experiences of Wendy and Elaine appeared to be contrasting to those of the other mothers. For other mothers, their sons’ adolescence had been an incredibly difficult time within the family due to their sons’ display of challenging sexual behaviours that had the potential to have a devastating impact on their future. These behaviours included exposing themselves in public; inappropriate touching of others; masturbating in inappropriate places, for example family areas in the home; demonstrating a pre-occupation with genitals and one incident of serious sexually related self-harm. In Jane’s situation, these sexual behaviours had been directed towards her, which had been challenging for her to deal with:

“I was kind of half lying on the sofa and he walked passed me and just quick as a flash, he just looked at me [...] and jumped on top of me [...] what he wanted to do was jump on top of me and rub himself on me.” (Jane).

These mothers appeared to adopt a reactive approach to manage these behaviours, responding to each behaviour as it emerged. There was also a sense that they found these behaviours shocking and felt unprepared to deal with them. For Frida, there was the additional complication that her son’s sexual behaviours were incongruent with the family’s cultural beliefs. Overall, it appeared that these mothers were struggling to cope with the responsibility of constantly trying to monitor and prevent challenging behaviours escalating. The interviews identified a significant fear of how these challenging sexual behaviours could detrimentally impact their sons’ lives. Jane explained her fears about her

son being detained as a consequence of his challenging sexual and violent behaviour directed towards her:

“I am scared he will be removed from me and I won’t be able to look after him anymore. I am scared that neither of us will have a choice in it and he would be sent to forensic medicine [...] I am scared he will be removed, medicated [...] that is my absolute biggest fear, that is what I am really scared of, like his life being drastically altered [...] and being taken away from each other.” (Jane)

This quotation illustrates Jane’s worries, fears and her feeling of powerlessness in this situation. Jane’s account was characterised by tensions and conflicting feelings; she desperately wanted to continue to care for her son, but was also at times frightened of his behaviour and the potential ramifications it could cause. Frida and Anne’s sons had both been questioned by the police about their behaviour. No further action was taken once the police had established their sons’ level of capacity. Nevertheless, this was understandably a frightening ordeal for the young men and their mothers.

There appeared to be an overarching fear that sexual behaviours, or even typical behaviours that were interpreted by others to be sexual, could limit the life opportunities and experiences available to their sons, as illustrated by this quotation:

“I suppose that’s the overriding factor of everything to do with him. I want him to have as wide a range of activities, places he can go to, that he can access. I don’t want him to have a small world he is limited to. And if we don’t look at these kind of behaviours and do something with them, we are going to limit that access. We are going to make his world smaller, rather than bigger.” (Wendy)

For one of the mothers, Anne, these fears had been realised. Her sons’ behaviour had become so challenging and stressful that she made the very difficult decision that he needed to move into his own accommodation:

“Social work said we needed to be with James at all times. If he came back to the house, we had to be there and if we weren’t there [his support service] needed to inform the police, so because of all the restrictions this put on our lives, [my husband] and I decided enough is enough and we decided it was best for him to move out and for us to solely be his parents.” (Anne)

Another participant, worried about the potential impact of her son’s masturbation on his younger brother, who he shared a bedroom with. Frida explained:

“At least I try to learn him not to do that in front of other people, especially his brother [...] he is still a child, so it is not good for him to see this. So for me, how can I feel? I have no choice I have to live with this situation, but at least reduce the risk for my son, my other son.” (Frida)

Challenges of providing sex education

“I don’t know the right thing to do”

The mothers in this study all talked about trying to support their sons to make sense of their behaviour. They appeared to adopt a reactive approach, responding to different sexual behaviours as they emerged. However, the mothers seemed to face a significant dilemma in relation to providing sex education to their sons. They recognised the importance of helping their sons to understand social rules and norms however, they were fearful of the potential consequences of providing information about sex. It appeared that they were frightened that this could heighten their sons’ sexual desires; exacerbate challenging sexual behaviours or that they could attempt to implement what they learnt in an inappropriate way, which could potentially result in them harming another person and lead to devastating

consequences for their sons. In general, the mothers focused on helping their sons understand the differences between public and private settings and understanding appropriate touch. However, the mothers expressed their uncertainty about what resources to use and what topics to cover with their sons because of their worries about the potential detrimental consequences. One participant explained her concerns about giving her son materials about female genitalia after he showed curiosity about the differences between males and females:

“I am very aware of his susceptibility if he sees something. I am quite worried he will try to enact it. I am worried about him seeing sex on TV or anything like that. Because I feel right now he is really open to anything sexual and I am worried if he sees something, he won’t be boundaried to know that it is between two consenting people.” (Jane)

This quotation highlights the concerns that mothers have in relation to their sons’ accessing information about sex through the media. It highlights the importance of providing structured, formal sex education to help them make sense of the sexual material that is often portrayed through different contexts, for example the media.

For some of the mothers, the support they provided their sons had focused on helping them to understand the appropriate places to masturbate and this had been somewhat successful. This was in sharp contrast to Anne’s experience, where it was suggested that the education that her son had received had resulted in him perseverating on certain aspects of it, resulting in him attempting to inappropriately touch a young boy; which had subsequently been reported to the police,

“It has been suggested retrospectively you know, how effective was that education when it led to that, and certainly [the voluntary organisation’s] impression was,

with all the visual imagery, it had made him more fixated on certain aspects and it had made him worse behaviourally.” (Anne)

The mothers recognised the importance of meeting their sons’ socio-sexual needs but lacked the confidence in deciding what information to share and how and when to provide it,

“I don’t want him to think it’s wrong because it’s absolutely not wrong, but we are going to have to work on the how’s and the when’s and when it is appropriate and how are we going to manage that? Because [...] his understanding of language at that point was very limited [...] so I suppose I was trying to work out how to tackle that but, how, I had absolutely no idea.” (Wendy)

Their perceived lack of available resources that were appropriate to their sons’ needs appeared to contribute to their lack of confidence:

“I am surprised to learn that the resources aren’t just there. It’s something I am quite surprised about- it seems to be the one area of development that is brushed over a lot.” (Jane)

The mothers expressed their surprise and frustration, that despite the issue of sexuality being one of such significance, there was a lack of suitable resources to meet their sons’ needs.

“There is no point beating about the bush”

The participants talked about the challenges associated with talking to their sons about their sexuality due to their limited verbal communication skills and their difficulty understanding the subtleties of social rules and norms. They talked about the importance of discussions being clear, considered and explicit. The mothers in this study appeared to

be conscious of the critical role they played in supporting their sons' sexual development. They all described an in-depth knowledge of their son's sexual behaviours. There was a general perception that this level of knowledge was necessary in order to protect their sons. Wendy described how this differed in comparison to her experience with her other son:

“I need to be more open and honest and there is no point beating about the bush with Chris. If you want to explain to somebody about Chris, you have to be explicit. That’s the way it is. There is no embarrassment, I have to know exactly what he is doing, you have to be able to explain it to me, and we have to be comfortable with this. Because ultimately, we are trying to keep him safe. Whereas with [my other son] the conversations are completely different, there is probably more embarrassment and innuendo than anything else, because it is such a private and intimate thing.” (Wendy)

Some mothers described feelings of discomfort about their role in relation to providing support to their sons with their sexual development. One participant explained her conflicting feelings about having detailed insight into her son's sexual behaviours:

“As far as I am his mother and [my husband] is his father and we didn’t know anything about [my other son’s] sex life and we don’t feel like we want to be privy to too much sort of personal detail, about the specifics because we feel in many ways that would be obstructive. But the other side of it is that we recognise that James is a vulnerable adult and we love him more than any of the professionals [...] it’s very difficult because we don’t want to know about the personal stuff because we are his parents, but we would want to be protective of him and we wouldn’t want anyone making decisions that aren’t the best decisions for him.”
(Anne)

Whilst most expressed their preference that they did not have such a significant role in and knowledge of their sons' sexual behaviours, they all expressed acceptance that this was just part of being a mother of a son with learning disabilities. Jane explains her feelings with regard to assisting her son maintain cleanliness after he had engaged in masturbation:

“I am used to a certain level of intimacy in terms of personal care, and so I am used to that and it’s just an extension of that. I think it might be different if I wasn’t providing personal care in other areas, I might have struggled more. I mean, I would rather not. If I could choose some of the things I didn’t have to do they would be the things I would choose. But I just have to.” (Jane)

There was a sense that most of the mothers had an open-minded approach towards sexuality, however, for Frida, who is from a predominantly Muslim country, her cultural background meant that sexuality was not a topic that would typically be addressed openly within the family. It appeared that Kian's sexual behaviours, namely his difficulty understanding where to engage in masturbation and where to undress, meant she had been forced to address sexual issues more openly as illustrated in this quotation:

“In our culture, we are not allowed to [masturbate] [...] I can’t, I can’t get him not to do this, because it’s a natural thing, so [...] at least I try to teach him not to do it in front of people, especially his brother.” (Frida)

Abuse: an unbearable prospect

There was a real sense of fear in these mothers accounts that despite all their support and input in their sons' lives, that their sons were still inherently vulnerable and there was the potential for them to be abused. There appeared to be a sense among the mothers that the prospect of abuse was such a horrific one, that it was almost unbearable to think about and therefore the mothers often avoided these thoughts because of the associated distress. Jane

talked about her fears that her son could be abused or could engage in an abusive act towards another person:

“Well I think he is really vulnerable because he doesn’t really understand the implications of his actions, he doesn’t understand consent, whether that is his own consent or someone else’s consent. I am worried about him being, em, sexually abused. That is my biggest worry. I am worried about him, I don’t think he would sexually molest someone but that incident with me has opened up in my head, what if he tries to do that to someone else, without that, you know sexual assault.” (Jane)

The prospect of their sons being vulnerable to abuse from others was understandably a highly emotive and difficult topic for mothers to discuss and even contemplate, this was evident by this subject only arising towards the end of the interviews and by many participants faltering before using the word ‘abuse’. The participants described their worries about how they would recognise if their sons were abused, because of their limited communication and the importance of being able to interpret their sons’ behaviour:

“It’s always on the back of my mind. I think, how will I know? Because his communication is such, I will not know if anything is going on that shouldn’t be going on. Because he can’t tell me. The only way I would eventually work it out is because his behaviours would show something wasn’t right, but by the time I worked it out by seeing the behaviours and working out what could potentially be the problem, I know that he could be exposed to whatever he has been exposed to for quite some time. Now, up until now, everything has been great and I am not suggesting for one second this is something that is foremost in my mind, because it’s absolutely not. But it is there and I would be lying if I said it wasn’t.” (Wendy)

Love in the future

The mothers described their overarching desires for their sons to have full, enriching lives where they are safe, respected and cared for, however, there was a sense of both sadness and acceptance that these full lives would not include an intimate relationship with another person. The mothers appeared to have made adjustments to the hopes and dreams they had for their sons as demonstrated in this quotation:

“For me as a mum, I would be happy if he had a girlfriend or got married, in future, have children. But these are all wishes [...] if he lives a happy and safe life, that’s what I want. It doesn’t matter if he doesn’t marry or have children, no it doesn’t matter to me. I just want him to be more independent on himself and happy and safe and that’s it.” (Frida)

The mothers described their fear about how their sons would be supported when they are no longer around. There also appeared to be a sense of sadness that whilst they knew it was likely that their sons would be cared for and supported by their carers in the future, they would be unlikely to be loved by another person. Many of the mothers described the physical intimacy they shared with their sons and the pleasure that they both found in this. They expressed their worries about the potential long-term impact of this lack of physical affection:

“I think of him as a young adult and I suppose he is not going to have that sexual experience, and that is a sad thing really, because he loves touch and he loves cuddles and I wonder how that is going to affect him in adulthood.” (Elaine)

Two of the mothers discussed literature that they had read about support staff of people with learning disabilities supporting individuals meet their sexual needs through prostitution or by introducing sexual aids to assist masturbation:

“[In the study I read] they provided opportunities for the young people to extend their masturbation but using mirrors or sex aid and they even had workers in the appropriate cases and I thought this was a really great thing [...] the idea of discussing that and bringing that up would seem really inappropriate and if I was to, I mean, I haven’t, but if I was to input into Daniel’s masturbation, whether it be a mirror or a sex aid, I feel like I would be put into the place of being a sexual abuser” (Jane).

The two mothers who did raise these topics did so with tentativeness. Their uneasiness appeared to be related to their concerns about how raising these topics may be interpreted by others. This was evident in the above quotation from Jane’s narrative. Both mothers also made it clear that this was something they had no intention of acting on.

Whilst the lack of intimacy and relationships was a significant source of sadness for these mothers; it seemed that this was a symptom of an overall lack of control their sons had in their lives as illustrated here:

Interviewer: “You mentioned that you don’t think Daniel will develop a relationship in the future, how does that make you feel?”

Jane: “I do feel quite sad about that, but I feel sad in general. I am not going to be able to look after Daniel forever. Daniel is going to need care for the rest of his life, so it ties in with that to me, that he will never lead an independent life. And that includes relationships, intimacy, and just being able to do what he wants in life, whether that is to stay in bed until 12pm on a Sunday, or go out whenever he wants to, or have an intimate relationship, or speak to someone when he wants to. He’s not going to be able to do that, it’s up to other people to do that”.

These poignant narratives highlight the mothers’ sense of anxiety surrounding the uncertainty about who will provide the care, love and experiences for their sons when they

are no longer able to. They also highlight their sadness at the lack of control they have over ensuring their sons live full and varied lives.

Discussion

Findings and Implications

The aim of this study was to explore the attitudes and beliefs of mothers in relation to the sexuality and sexual development of their sons with ASD and an accompanying learning disability. It is important to note that these findings should be interpreted carefully as they may represent the perspectives of a very particular group of mothers; it is possible those who were drawn to participate in this study had particularly extreme or distressing experiences. Furthermore, it is likely only those who felt comfortable talking about these sensitive and very personal issues agreed to take part.

It was clear that irrespective of the impact of the sexual behaviours their sons' exhibited, the issue of sexuality was one of significance to all the mothers in the study. The narratives were fraught with tensions. The mothers described trying to support their sons' emerging socio-sexual needs; whilst trying to prevent challenging sexual behaviours which they feared could have devastating consequences. They believed they played a critical role in their sons' developing sexuality, but sometimes expressed discomfort about the level of intimate knowledge they had about their sons' sexual behaviours. They sought full, rich lives for their sons, and recognised the important role that sexuality served as part of their identity, but also viewed their sons' sexuality as a burden that could potentially limit the fullness of their sons' lives.

A significant finding of this study was the varied experiences of young people with ASD and a learning disability and their families in relation to their sexual development. The findings highlight that challenging sexual behaviour is not an inevitable part of

adolescence of this group. For two of the mothers in this study, their sons' adolescence was quite unremarkable, in contrast to their expectations. One young person appeared to have an innate sense about where it is appropriate to masturbate; highlighting that difficulties discriminating between public and private settings is also not inevitable. Much of the behaviour described by the mothers in this study is typical. However, a lack of social understanding meant that such behaviours were expressed inappropriately, for example masturbating in public settings. Mothers appeared to be concerned that these behaviours would be misinterpreted by others as deviant. This is a finding that is supported by the results of a survey of parents of children with ASD by Ruble and Dalrymple (1993).

The mothers in this study felt that their sons' adolescence and emerging sexuality had been an incredibly difficult time for both their sons and their families. It was clear that these mothers often felt shocked, unprepared and unable to cope with what they faced. The difficulty seemed to be in part due to the commencement of challenging sexual behaviours such as masturbating in public; inappropriate touching of others and exposing oneself in public. These experiences appeared present significant distress to the mothers despite the fact that the behaviours are known to be common challenges for these young people (Gillberg and Coleman, 1992). The mothers had serious concerns about how their sons might enact their sexual desires and the potentially devastating ramifications. This study also highlights that mothers can sometimes be the object of sexual behaviour. It is normal for any young person to experiment with their sexuality; however these young people often have a wide social group to do so. Consistent with other evidence (Cole and Cole, 1993), the mothers pointed out that their sons had a very small social group. Therefore, it was likely that their sons' sexual expression and experimentation would take place within the confines of this small social network (Koller, 2000). This was linked to the mothers' views

that their sensitive awareness about their offspring's particular needs and circumstances are needed when supporting young people and their families with their sexual development.

The evidence base points to the lack of confidence, information and professional support reported by parents of young people with learning disabilities (Clegg et al., 2001; Pownall et al., 2011) and the reactive approach adopted by mothers when approaching issues relating to sexuality of their offspring with a learning disability (Pownall et al., 2011). This is consistent with the findings in this study. Mothers in this study expressed their worries that by providing their sons with information about sex, they could inadvertently exacerbate sexual problems, which could in turn could limit their sons' opportunities; or even result in their detainment. One mother felt these fears had been realised, as there was a suggestion that the sex education her son had received had led to challenging sexual behaviours. Interestingly, a study by Van Bourgondien et al. (1997) found that individuals were more likely to engage in person-oriented sexual behaviour if they had received sex education while those who had not received sex education, were more likely to engage in masturbation practices. This highlights the necessity that sex education for this group is person-centred, with careful thought given to how and what topics to cover.

This study contributes to the existing evidence base that highlights the pertinence of supporting mothers and other caregivers to provide effective education and support about sexuality and sexual development to their children with ASD and learning disabilities (Koller, 2000; Sullivan and Caterino, 2008). It supports the view that sexuality education resources need to be person-centred, developmentally appropriate and be relevant to the strengths, limitations and specific needs of the individual (Koller, 2000). They also need to be easily accessible to parents and carers. Since families are the primary source for

providing information about sex to individuals with ASD and learning disabilities, it is imperative that they feel confident to tackle these issues. They need to feel well supported to facilitate appropriate sexual expression so that sexuality is not viewed as burdensome and life limiting and instead be one aspect of a varied and full life. Gougeon (2010) suggests tackling such difficulties by recognising them as a social skill deficit, rather than a deviant or problematic behaviour in order to address the social barrier and stigma associated with such problems. Having an open dialogue about sexuality and sexual problems is key to addressing the stigma that is attached to them and encourages discussions about how to address difficulties that parents and young people encounter. This will help caregivers feel more comfortable in the level of intimacy that is often required to effectively support their offspring to express their sexuality; for example teaching their sons about effective and safe masturbation practices. Whilst the mothers in this study clearly felt comfortable to discuss this personal and sensitive issue, this is unlikely to be representative of many mothers in similar situations. This study also highlights that we must also be mindful of the impact of culture on how families cope with sexuality. It is crucial that health and social care services adopt a proactive, sensitive approach to provide support to young people and their families from different cultural backgrounds.

The topic of abuse was something that mothers discussed, albeit with hesitation. Previous research has highlighted concerns regarding the vulnerability of girls to abuse and clearly there are gender-specific concerns affecting females regarding the risk of pregnancy (Dilorio et al., 2009). This study however, clearly highlights that abuse is a real and significant concern to mothers of sons also. Sadly there is an increased risk of abuse for young people with ASD and learning disabilities (Mansell et al., 1998) and therefore it is entirely to be expected that this would be a significant concern for mothers in this study.

Hingsburger (1995) posits that individuals with disabilities can be inadvertently placed in a “Prison of Protection” by caregivers and emphasises that individuals should be provided with the education to protect themselves. However, for those with more severe learning impairments, providing this education and assessing the effectiveness of this education can be difficult due to the very nature of their impairments.

A powerful finding of the present study was mothers’ perceptions about the importance of touch and intimacy to their sons. It highlighted mothers’ worries about who would provide this physical affection to their sons when they were no longer able to. The importance of physical touch for these individuals has been demonstrated in other studies also (Hellemans et al., 2007). The present study therefore poses an important question about how to meet the needs for physical affection expressed by these young people. It is unclear how social care services are currently meeting these needs, although there is some evidence to suggest that services can create barriers to individuals engaging in physically intimate behaviours by limiting private spaces (Knox and Hickson, 2001) and by preventing opportunities for intimacy with others (Lofgren-Martenson, 2004). It is recognised that this is a complicated and difficult area to navigate, particularly for those with more severe impairments, where the issue of capacity and consent is one of particular significance. However, it does seem vital that services be cognisant of these needs for physical intimacy and affection and consider how best to meet them when parents and other family members are no longer able to do so.

Clinical Implications

The mothers who participated in the present study clearly felt comfortable to discuss this sensitive topic, but it is likely this would not be the case for many parents experiencing

similar difficulties. The current findings highlight the need for sexuality of individuals with ASD and an accompanying learning disability to be discussed routinely in clinical practice, alongside their other health and social needs, in order for any difficulties to be identified. This will allow for person-centred support and interventions to be offered to both the young person with ASD and a learning disability, and their parents and carers who may be struggling with the challenges associated with their child's sexual development. By discussing these issues routinely, it is hoped that this will help reduce the stigma of sexuality and help to reframe sexual problems in this group as a social skills deficit, rather than deviant behaviour. It is also important that parents and carers are made aware of where they can access resources about sexuality so that they feel well supported to address this topic with their offspring.

Limitations

This study has a number of strengths and valuable contributions to the evidence base, however it is important to note the limitations of the study. As previously discussed, these include the possibility that the mothers who chose to participate had experienced more extreme difficulties or were more open to discussing this intimate area. There were also great difficulties recruiting to this study. Challenges with recruitment may suggest the area of developing sexuality is not as problematic as currently thought for families or alternatively, sexuality may still be taboo for many families, who may be reluctant to discuss this topic.

Furthermore, the study was intended to capture the experiences of mothers of both sons and daughters. Perhaps future research could focus on mothers' perspectives of their

daughters' developing sexuality, to allow a comparison and exploration into the similarities and differences between genders.

It is also important to note the different developmental stages of the sons of the participants who participated in this study. Some of the participants were at the stage of transition from adolescence into adulthood; whilst others had passed this transitional stage and were either living or about to be living independently, which may have had an impact on the mothers' experiences and perspectives.

Conclusions

This study provides new insights into mothers' experiences and beliefs in relation to the sexual development of their sons' with ASD and learning disabilities. Irrespective of the particular nature and circumstances of the participants, the mothers' narratives highlight the enormity of sexuality for these young people and their families and the significant role these mothers play in supporting their sons' emerging sexuality. Overall, there was an overwhelming sense that mothers lacked confidence, information and professional support to enable them to support their sons' socio-sexual needs. The study also illustrates the important issue of how to provide these young adults with the physical affection they desire when their families are no longer able to do so. Given the significant issues that have been highlighted, further research needs to be conducted into the sexual needs and education of this neglected group so that we can understand how best to meet the needs of these families and their offspring.

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Appendix 1: Manuscript Submission Guidelines

Autism provides a major international forum for research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders.

1. Editorial policies

1.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

As part of the submission process you will be asked to provide the names of 1 peer who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

1.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

1.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

1.3.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the [Research Information Network](#) (RIN), *Autism* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. All research articles should have a funding acknowledgement in the form of a sentence as follows, with the funding agency written out in full, followed by the grant number in square brackets:

This work was supported by the Medical Research Council [grant number xxx].

Multiple grant numbers should be separated by comma and space. Where the research was supported by more than one agency, the different agencies should be separated by semi-colon, with “and” before the final funder. Thus:

This work was supported by the Wellcome Trust [grant numbers xxxx, yyyy]; the Natural Environment Research Council [grant number zzzz]; and the Economic and Social Research Council [grant number aaaa].

In some cases, research is not funded by a specific project grant, but rather from the block grant and other resources available to a university, college or other research institution. Where no specific funding has been provided for the research we ask that corresponding authors use the following sentence:

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity dependent on the peer review policy of this journal outlined above, you can withhold this information until final accepted manuscript.

For more information on the guidance for Research Funders, Authors and Publishers, please visit: <http://www.rin.ac.uk/funders-acknowledgement>

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2. Publishing policies

2.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' [International Standards for Authors](#) and view the Publication Ethics page on the [SAGE Author Gateway](#).

2.1.1 Plagiarism

Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to

have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

2.2 Contributor's publishing agreement

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3. Article types

The Journal considers the following kinds of article for publication:

1. **Research Reports.** *Full papers* describing new empirical findings;

2. **Review Articles.**

(a) *general reviews that provide a synthesis of an area of autism research;*

(b) *critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.*

Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

3. **Short Reports.** Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.

4. **Letters to the Editors.** Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

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4. Terms for Autism

UCL and NAS conducted a survey within the UK of stakeholders connected to autism, to enquire about preferences regarding the use of language. Based on the survey results, we have created guidelines on terms which are most acceptable to stakeholders in writing about autism [here](#).

5. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Autism is hosted on SAGEtrack a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/autism> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit [ScholarOne Online Help](#).

All papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

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6. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. *Autism* does not require a declaration of conflicting interests but recommends you review the good practice guidelines on the [SAGE Journal Author Gateway](#).

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7. Other conventions

7.1 Research ethics

All papers reporting animal and human studies must include whether written consent was obtained from the local Ethics Committee or Institutional Review Board. **Please ensure that you have provided the full name and institution of the review committee and an Ethics Committee reference number.**

We accept manuscripts that report human and/or animal studies for publication only if it is made clear that investigations were carried out to a high ethical standard. Studies in humans which might be interpreted as experimental (e.g. controlled trials) should conform to the Declaration of Helsinki

<http://www.wma.net/en/30publications/10policies/b3/index.html> and typescripts must include a statement that the research protocol was approved by the appropriate ethical committee. In line with the Declaration of Helsinki 1975, revised Hong Kong 1989, we encourage authors to register their clinical trials (at <http://clinicaltrials.gov> or other suitable databases identified by the ICMJE, http://www.icmje.org/publishing_10register.html). If your trial has been registered, please state this on the Title Page. When reporting experiments on animals, indicate on the Title Page which guideline/law on the care and use of laboratory animals was followed.

7.2 Patient consent

Authors are required to ensure the following guidelines are followed, as recommended by the International Committee of Medical Journal Editors, Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published.

Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent should be obtained if there is any doubt. For example, masking the eye region in photographs of patients is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic pedigrees, authors should provide assurance that alterations do not distort scientific meaning and editors should so note. When informed consent has been obtained it should be indicated in the submitted article.

7.3 Statistical analyses

Where statistical analyses have been carried out please ensure that the methodology has been accurately described. In comparative studies power calculations are usually required. In research papers requiring complex statistics the advice of an expert statistician should be sought at the design/implementation stage of the study.

7.4 Randomized controlled trials

Autism requires a completed CONSORT 2010 checklist and flow diagram as a condition of submission when reporting the results of a randomized trial. Templates for these can be found on the CONSORT website [www.consort-statement.com] which also describes several CONSORT checklist extensions for different designs and types of data beyond two group parallel trials. You should ensure that your article, at minimum, reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your trial report and may enhance its chances for eventual publication.

7.5 Prisma

Autism requires a completed PRISMA checklist and flow diagram as a condition of submission when reporting the results of a systematic review. Templates for these can be found on the PRISMA website www.prisma-statement.org. You should ensure that, at minimum, your article reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your systematic review and may enhance its chances for eventual publication.

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9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

9.2 Journal Style

Autism conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

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9.4. Manuscript Preparation

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. SI units should be used throughout the text.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring that readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#).

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

Artwork, figures and other graphics such as tables should be uploaded through SAGE's Online Submission System alongside the main body of the text, as a separate file to ensure best quality in production. For further guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

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This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

9.4.5 English Language Editing

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit [English Language Editing Services](#) for further information.

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10. After acceptance

10.1 Lay Abstracts

Upon acceptance of your article you will be required to submit a lay abstract of your article to the Social Media Editor, Laura Crane (journalautism@gmail.com). Lay abstracts are brief (max 250 words) descriptions of the paper that are easily understandable. These abstracts will be made available to researchers and clinicians, as well as the general public (including individuals with autism spectrum disorders and their families).

These abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

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We will email a PDF of the proofs to the corresponding author.

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11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

Katie Maras

Department of Psychology

University of Bath, UK

Email: katiemaras.autism@gmail.com

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Appendix 2: Quality Rating Framework (adapted from Walsh and Downe, 2006)

Stages	Essential Criteria	Specific Prompts
Scope & Purpose	1. Clear statement of and rationale for research question/aims/purposes	<i>Clarity of focus demonstrated</i>
		<i>Explicit purpose give such as descriptive/explanatory, intent, theory building, hypothesis testing</i>
		<i>Link between research and existing knowledge demonstrated</i>
	2. Study thoroughly contextualized by existing literature	<i>Evidence of systematic approach to literature review, location of literature contextualize the findings, or both</i>
Design	3. Method/design apparent, and consistent with research intent	<i>Rationale given for use of qualitative design</i> <input type="checkbox"/>
		<i>Discussion of epistemological/ontological grounding</i> <input type="checkbox"/>
		<i>Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology)</i> <input type="checkbox"/>
		<i>Discussion of why particular method chosen is most appropriate/ sensitive/ relevant for research question/aims</i>
		<i>Setting appropriate</i>
	4. Data collection strategy apparent and appropriate	<i>Were data collection methods appropriate for type of data required and for specific qualitative method?</i>
		<i>Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?</i>
<i>Was triangulation of data sources used if appropriate?</i>		
Sampling Strategy	5. Sample and sampling method appropriate	<i>Selection criteria detailed, and description of how sampling was undertaken</i>
		<i>Justification for sampling strategy given</i>
		<i>Thickness of description likely to be achieved from sampling</i>
		<i>Any disparity between planned and actual sample explained</i>
Analysis	6. Analytic approach appropriate	<i>Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory)</i>
		<i>Was it appropriate for the qualitative method chosen?</i> <input type="checkbox"/>
		<i>Was data managed by software package or by hand and why?</i>
		<i>Discussion of how coding systems/conceptual frameworks evolved</i> <input type="checkbox"/>
		<i>How was context of data retained during analysis</i> <input type="checkbox"/>
		<i>Evidence that the subjective meanings of participants were portrayed</i> <input type="checkbox"/>
		<i>Evidence of more than one researcher involved in</i>

		<i>stages if appropriate to epistemological/theoretical stance</i> <input type="checkbox"/>
		<i>Did research participants have any involvement in analysis (e.g. member checking)</i> <input type="checkbox"/>
		<i>Evidence provided that data reached saturation or discussion/rationale if it did not</i> <input type="checkbox"/>
		<i>Evidence that deviant data was sought, or discussion/rationale if it was not</i>
Interpretation	7. Context described and taken account of in interpretation	<i>Description of social/physical and interpersonal contexts of data collection</i>
		<i>Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena</i>
	8. Clear audit trail given	<i>Sufficient discussion of research processes such that others can follow 'decision trail'</i>
	9. Data used to support interpretation	<i>Extensive use of field notes entries/verbatim interview quotes in discussion of findings</i>
<i>Clear exposition of how interpretation led to conclusions</i>		
Reflexivity	10. Researcher reflexivity demonstrated	<i>Discussion of relationship between researcher and participants during fieldwork</i> <input type="checkbox"/>
		<i>Demonstration of researcher's influence on stages of research process</i> <input type="checkbox"/>
		<i>Evidence of self-awareness/insight</i> <input type="checkbox"/>
		<i>Documentation of effects of the research on researcher</i>
		<i>Evidence of how problems/complications met were dealt with</i>
Ethical Dimensions	11. Demonstration of sensitivity to ethical concerns	<i>Ethical committee approval granted</i>
		<i>Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants</i>
		<i>Evidence of fair dealing with all research participants</i> <input type="checkbox"/>
		<i>Recording of dilemmas met and how resolved in relation to ethical issues</i> <input type="checkbox"/>
		<i>Documentation of how autonomy, consent, confidentiality, anonymity were managed</i>
Relevance and transferability	12. Relevance and transferability evident	<i>Sufficient evidence for typicality specificity to be assessed</i>
		<i>Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies</i>
		<i>Discussion of how explanatory propositions/emergent</i>

	<i>theory may fit other contexts</i>
	<i>Limitations/weaknesses of study clearly outlined</i>
	<i>Clearly resonates with other knowledge and experience</i>
	<i>Results/conclusions obviously supported by evidence</i>
	<i>Interpretation plausible and 'makes sense'</i>
	<i>Provides new insights and increases understanding</i>
	<i>Significance for current policy and practice outlined</i>
	<i>Assessment of value/empowerment for participants</i>
	<i>Outlines further directions for investigation</i>
	<i>Comment on whether aims/purposes of research were achieved</i>

Appendix 3: University of Glasgow Ethics Approval Letter

10 August 2015

Professor Andrew Jahoda
Mental Health and Wellbeing

Academic Department

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow G12 0XH

Dear Professor Jahoda

MVLS College Ethics Committee

Project Title: Mothers' Perspectives about the Sexual Understanding and Development of their Children with Low Functioning Autism

Project No: 200140171

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Project end date: 31 December 2016.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:
(http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely



Professor William Martin
College Ethics Officer

Approval200140171.docx

Appendix 4: Participant Invitation Letter

Dear Participant,

You are being invited to take part in a research study. The title of this study is “Mothers’ Perspectives about the Sexual Understanding and Development of their Children with Autism and a Learning Disability”. We are looking to recruit 6 to 12 mothers of young people, aged 14 to 30, with autism and a moderate to severe learning disability. Sexuality and sexual development is a vital part of growing up for all young people, but for young people with autism and a learning disability, this area is often not given much attention. We are interested in interviewing mothers about this issue, as they play such an important role in supporting their child. The aim of this study is to improve our knowledge of the experiences and views of mothers about their child’s sexuality and sexual development. This will help to improve the support and resources that are available to support young people and their families.

It is really important that you understand the purpose of this research and what the research will involve for you, before you agree to take part. Please read the participant information sheet that is alongside this letter carefully before you decide if you wish to take part. If you have any questions about this research or if you would like to find out more information, please do not hesitate to get in touch, my contact details are at the end of the Participant Information sheet.

Yours sincerely,

Rebecca Pryde

Doctoral Student of Clinical Psychology, University of Glasgow

Appendix 5: Participant Information Sheet



The Sexuality of Young People with Autism & Learning Disabilities

Mothers' Experiences

Information for participants in the research project

1. Study title

Mothers' Perspectives about the Sexual Understanding and Development of their Children with Autism and a Learning Disability.

2. Invitation

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with friends or relatives if that would be helpful for you. We are also very happy to answer any questions that you might have or give you more information that you might want. Our contact details are at the end of this document. Please take time to decide whether you or not you wish to take part.

3. What is the purpose of the study?

The sexual understanding and development of young people with Autism and a Learning Disability is something that is not usually given much attention. Yet this is a vital part of growing up for all young people. This is an area of concern to mothers as well, particularly as they play a very significant role in supporting the development of their child's sexual understanding. However, there has been little research about mothers' views.

In this study we want to find out about mothers' experiences and views. We hope that this will lead to better support for families and the young people themselves.

It is hoped that the insight into mothers' views will help with the provision of sensitive support to families, and help schools, colleges and health professionals to work more effectively in partnership with them.

4. Why have I been chosen?

You have been asked to take part in the study because an organisation in contact with you thinks that you are a mother of a young person with Autism and a moderate or severe Learning Disability in the right age range for the study (14-30 years). We are hoping to recruit around 6 to 12 participants for this study.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. You will be given the information sheet and a copy of your consent form to keep. If you do decide to take part you are still free to withdraw at any time without giving a reason. Deciding not to take part will not impact any other aspect of your relationship with University of Glasgow or the voluntary organisation that you receive a service from.

6. What will happen to me if I take part?

The researcher, Rebecca Pryde, will arrange to meet with you in the premises of the voluntary organisation you receive a service from, or on University of Glasgow premises, whatever is more convenient for you. We will ask everyone to complete an interview, this could take from 60 – 90 minutes. The questions will include a description of your family, your views on your child's sexual development, how you and your child have coped with their sexual development and some of the challenges you have faced and sources of support you have received in regard to sexuality. You can stop the interview at any time, to take a break or if you decide you no longer want to take part.

7. What do I have to do?

If you decide you want to take part in the study or you want to ask for further information, please contact the primary researcher using the contact details at the end of this information sheet.

If you are happy to be contacted in relation to this study, please tell the person that told you about the study. A member of administration team will then contact you within two weeks to check that you have all the information that you need. They will only contact you if you give permission to do so.

If you decide you do wish to take part, the researcher, Rebecca Pryde, will meet with you to ask you questions with regard to your child and their sexual development, which should last around 60 – 90 minutes. Although there will be a general structure to the interview, the information you give will guide the interview. You will be able to raise any other issues you want to discuss at the end of the interview. You will be able to take a break or stop the interview at any time.

8. What are the possible disadvantages and risks of taking part?

We do not anticipate that there will be any risk to you completing the interviews. However, we do recognise that this may be an emotive topic for you and if you do become distressed during the interview, you will be offered a break or to stop the interview at any time.

9. What are the possible benefits of taking part?

Whilst there will be no direct benefits to you, the study will improve our understanding of mothers' experiences and views. We will use the results from this study, along with findings from other research, to develop workshops for mothers and for professionals who work with young people with low functioning autism.

10. Will my taking part in this study be kept confidential?

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. We might use direct quotations from your interview in the final report, however, you will not be able to be identified by this information and you will need to provide consent in order for us to do this.

Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

11. What will happen to the results of the research study?

We hope to publish this article in a scientific journal. If this is the case, you will not be identified in this publication.

We hope that the results will provide a greater understanding of mothers' points of view. In turn, we hope that this understanding will help schools, colleges and health professionals to provide more sensitive support to families with regard to their sons and daughters' sexuality. We also hope that it will help professionals to work alongside families more effectively.

12. Who is organising and funding the research?

There is no specific funding for this research which is being organised by the University of Glasgow.

13. Who has reviewed the study?

This project has been reviewed by the College of Medical, Veterinary and Life Sciences, University of Glasgow Ethics Committee.

14. Contact for Further Information

If you have any further questions please contact Rebecca Pryde

By telephone: 0141 211 3878

Or email: r.pryde.1@research.gla.ac.uk

Thank you for taking the time to read through this information sheet.

Appendix 6: Participant Consent Form



University of Glasgow | College of Medical,
Veterinary & Life Sciences

Centre Number:
Project Number:
Subject Identification Number for this trial:

CONSENT FORM

Title of Project: Mothers' perspectives about the sexual understanding and development of their child with autism and a learning disability

Name of Researcher(s):

Rebecca Pryde

Professor Andrew Jahoda

Please initial box

I confirm that I have read and understand the information sheet dated 06.07.2016 (version 3) for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I agree for the interview to be tape-recorded.

I agree for anything I say to be used in the final report about this research

I understand that I will not be able to be identified from the information that is published.

I agree to take part in the above study.

Name of subject

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

(1 copy for subject; 1 copy for researcher)

Appendix 7: Interview Topic Guide

Introduction

I am grateful for you agreeing to talk to me today. I know that this might not be an easy topic to discuss but it will be helpful for us to understand your experiences of supporting X to learn more about this area. I am interested in finding out about your experiences and what has been important to you.

Context

It would be helpful to find out about you and X. So if you could start by telling me about X, what he/she is like, other people at home and a bit about your life at home?

Child Development

It has been really useful to hear about X and your family, thank you for sharing that with me. I would like to hear about your experiences of X growing up into a teenager/adult.

- What was X like as a child?
- What was X's personality like?
- What changes did you notice as X became a teenager?
- How did you feel about those changes?
- What were the main challenges during this time?
- How did this experience differ to sibling's development?
- What support did you have from family, friends, and other agencies?
- What is X like now?
- Do you have worries or concerns for him at the moment?
- What about in the future?

Family Beliefs and Attitudes about Sexuality

It would be really helpful to find out a bit about how your family deal with sexuality in general.

- How have you dealt with any siblings' puberty/growing autonomy?
- How openly do you discuss these issues as a family?

Child's Sexuality

Now I would like to go on to speak about X's sexual development.

- Has X shown any sexual behaviours. If so, what?
- Establish if anything inappropriate about this behaviour and consequences of this behaviour.
- How did you feel about this?
- Did you experience any reactions from others, what were these?
- How confident did you feel in supporting X with issues regarding sexuality?
- How did you deal with sex education for X?

Sources of support?

- What are your main sources of support- practical, emotional?

- Where do you get information and advice about sexual development and relationships?

Other areas

I want to make sure that I have got a good understanding of your experiences of X's sexual development. Is there anything important that you want to talk about that we have not already covered?

Appendix 8: Sample of Analysed Transcript

Descriptive/exploratory comments	Transcript	Emergent themes
	<p>R: You talked about challenging behaviour and suggested there might be link there with him going through puberty, could you tell me a little bit more about that?</p>	
<p><i>Making sense of sexual behaviour</i></p> <p><i>Making adjustments to cope with developing sexual behaviour</i></p> <p><i>Acceptance of unusual sexual behaviours- the new normal</i></p> <p><i>The development of systems at home to facilitate and encourage sexual expression</i></p> <p><i>Perception of the link between puberty and challenging behaviour?</i></p> <p><i>Supporting son to understand sexuality and cope with sexual urges</i></p> <p><i>Education drive by inappropriate sexual behaviours- a reactive approach</i></p> <p><i>Mother as recipient of sexual behaviour</i></p> <p><i>Surprise at his curiosity about sexuality- challenges stereotypical ideas of ASD</i></p> <p><i>Mother as information gatherer- seeking information and resources about sexuality</i></p> <p><i>Finding a common</i></p>	<p>P: Em, from what I understand, from his age and his development and from what I witness about what he is going through, he wants a lot more alone time. We have a bit of a system at home. He obviously has an attachment to a jacket, which he uses and takes off to his room and he will now say to me, "want to catch a coat", which comes from very early on, when he first started asking for specific jacket, I would get it for him and I would say "come on, catch a coat". And so now it's called catch a coat, and that's what he always says, or catch a jacket. Em, and then he goes to his bedroom, no then he asked to take it to his bedroom and I was like, "Ok", and now it's just a thing that he does now.</p> <p>So yes, an increase in this and alongside his challenging behaviours increasing and his awareness of other people, he has started to try to put his hand in between peoples' legs and says, he uses the world willy. "Touch your willy, hope to see your willy". He did it to a few learning assistants in his class, em, and they, they have been using social stories about what is private on your body and private, where you can touch yourself in private. So we have been working a lot on that, so he's kind of stopped, he did it to a couple of pupils as well, but now he's kind of stopped that at school, but he will still do it to me. Suddenly, lunge and say "want to catch a willy with me." Before in the past, before it got as intense as it did, I tried to explain to him that I didn't have a willy, I had a vagina. And he said, "want to see your vagina". I was quite surprised when he said that, it sort of showed me his ability to go, "oh that's something different", and I want to see that. Em... and I felt like I could totally relate at that point. His awareness is just opening up and he just wants to know. So I said, I would show him, I would get a picture for him. And he said, "what day, when can I see this picture?" and I said, "oh I don't know, I will get it for you." And then I thought, where will I get a picture, what's an appropriate picture? I haven't actually done it yet. I've got these books, [...], I don't know if you know of them, they are about sexuality and</p>	<p><i>Adjusting to the emerging sexuality</i></p> <p><i>Adjusting to the new normal</i></p> <p><i>Supporting my son's emerging sexuality</i></p> <p><i>Acceptance</i></p> <p><i>Coping with emerging sexuality</i></p> <p><i>"I just have to get on with it"- coping with sexual behaviours</i></p> <p><i>Mother as information gatherer</i></p> <p><i>Sex education- a help or a hindrance?</i></p> <p><i>"I don't know the right thing to do". Uncertainty.</i></p> <p><i>Supporting the emerging sexuality</i></p>

<p><i>ground</i></p> <p><i>Feeling uncertain about providing sex education</i></p> <p><i>Fears about the possible negative outcomes of providing sex education</i></p> <p><i>Vulnerability of son and of others</i></p> <p><i>Making sense of problematic behaviour</i></p> <p><i>Mother as recipient of sexual behaviour</i></p> <p><i>Fear- awareness he could cause me harm</i></p> <p><i>The need to more vigilant</i></p>	<p>development. So I was going to look for the female equivalent, and maybe show him that, but I would need to read it first and see what it said, because I am very aware of his susceptibility if he sees something, I am quite worried he will try to enact it. I am worried about him seeing sex on TV or anything like that. Because I feel right now he is really open to anything sexual and I am worried if he sees something, he won't be boundaried to know that is between 2 consenting people.</p> <p>We have had one incident at home, because he has suggested that I come through to his bedroom with him to help him catch a coat, for a hug, and its like, "no mum doesn't come through for a hug, you take your coat, that's just you and your coat." And one day, I was kind of half lying on a sofa and he walked passed me and just quick as a flash, he just looked at me, threw the coat on me, and jumped on top of me. And he wasn't doing anything, what he was wanting to do was just jump on top of me and rub himself on me, he wasn't touching me or anything, it only lasted a few seconds but he is really strong, he is like over 6ft and really quite big and with him doing that, I need to be more on it with him and I know what I like, I like this jacket and I like hugs from my mum, and I like this thing, so I am going to put it all together, that will be great. Em, so it's just trying to be aware of that with him.</p>	<p><i>Vulnerability</i></p> <p><i>Vulnerability of self, son and others</i></p> <p><i>Challenges with the emerging sexuality</i></p>
	<p>R: And when Daniel was much younger, were these things you thought about, some of the difficulties that might arise when he was older? Was puberty a worry for you?</p>	
<p><i>Relationship between sensory sensitivities and sexual behaviour?</i></p> <p><i>Viewed as an inevitability?</i></p> <p><i>Providing a safe space and privacy to explore sexuality as a priority</i></p> <p><i>Recognising the importance of sexual needs</i></p>	<p>P: It wasn't a worry for me, I was always aware that this might happen, because he used to rub himself up against things when he was younger. And I was always aware that given the limited communication we had, I was always sure that he was allowed the space to do stuff like that in private, because I do know of other families where they have stopped their child from a young age from doing anything like that completely it made me realise that I disagreed with that lot. And I feel like its every person's right to a sexual relationship, even if that is with themselves. And so I made sure that he always had the room and the space to do that, if that's what he wanted to do and I think that's really important for him to be able to do that.</p>	<p><i>The right to a sexual identity</i></p>

	R: So would you say that your beliefs about how sexuality should be broached, how are they different from [your other son], who is older and doesn't have autism and a learning disability?	
<p><i>Similarities in approaches between LD and non-LD son.</i></p> <p><i>Discussions about sex stop as non-LD son reaches adulthood vs. ongoing dependence needs.</i></p> <p><i>Not the same necessity to discuss sex with non-LD son.</i></p>	<p>P: It's the same in terms of, in that I feel quite open about it. With my other son, I made myself quite open to talk about it, but he didn't want to, He was like 'No!' We have always had an open relationship to be able to joke about things, like sex, or like anything around that, it isn't a taboo subject. Me and [my other son] haven't spoken about it in a serious manner, well we did in sex education, but we have never spoke about it in a serious way. Like he doesn't tell me about his sex life and I don't tell him about mine (<i>laughs</i>). But yeah we share jokes about things like that.</p>	<p><i>Mother's critical role in sex education.</i></p>
	R: So when [your other son] was younger, did you sit down and have talk to him about sex, what prompted you to do that?	
<p><i>Proactive approach to non-LD son- driven by chronological age.</i></p> <p><i>Impact of religion on sex education provided at school for non-LD son.</i></p>	<p>P: I think it was a decision I made, and it's hard to think because it was quite a while ago. I think it was a decision I made and an understanding I had that he was becoming a teenager and it was overdue and I don't think that the school provides enough or the correct sex education for some people. And he was going to a catholic school, we are not catholic, but he was going to school and I was aware that they weren't teaching him about safe sex or contraception, so I wanted to make sure that we spoke about that and that he knew about that.</p>	
	R: And what about with Daniel, when you tried to talk to him about privacy, was that again a decision you made, or did something in particular prompt that?	
<p><i>Sex education guided by his behaviour- reactive approach.</i></p> <p><i>Incongruence between cognitive development and physical/sexual development.</i></p>	<p>P: It was prompted by his behaviour, it was something that was on my mind. I wasn't really sure, because of his learning disability, when was appropriate. And then I think I started to realise that it's not so much about development, because developmentally, mentally, he is probably about 4 years old or something, but physically, he is 16 and that is actually kicking in and overriding and that is kicking in and overriding his mental abilities. Does that make sense?</p>	<p><i>Uncertainty about sex education- "I don't know the right thing to do."</i></p> <p><i>Feeling conflicted.</i></p>
	R: Yes, it does.	

<p><i>Sense of urgency</i></p> <p><i>Whose role is it to provide sex education?</i></p> <p><i>Feeling unsupported- lack of resources</i></p> <p><i>Feeling stuck and frustrated- dependent on others</i></p> <p><i>Dilemma- uncertainty about sex education- desire to meet his needs whilst protecting him and others from harm.</i></p> <p><i>What is appropriate to teach him? Need for an individual approach</i></p> <p><i>Acceptance that son will not have sex.</i></p> <p><i>Placing trust in others- awareness of the potential for abuse. .</i></p>	<p>P: And then I realised, right I need to do something about this now, because he has all these, what's the right word, urges, and desires but he has the mentality of a 4/5 year old. Em, it just seemed really important and at school, and as much as they have really helped with the issue of privacy and social stories and what is private and what is not private, and what is OK and what is not OK, I have spoken to his teacher about it and she said she is doing a course, and I think she is doing it later this year and he needs something now, and I don't know about his classmates, and what their sexual development and needs are, but it just seems like it shouldn't go along with just what the teacher has learnt. I am surprised to learn that the resources aren't just there. I am surprised by that, that we are going to have to wait until she goes to a course. And she is a great teacher, and I understand that it is probably her first time in this role with children of their age, with their needs but yeah it's really frustrating, because I feel it should be more tailored to what is going on for each individual at that time. Daniel is ready for more and I don't really know what is appropriate for me to be sharing with him or telling him, cause he I just so <i>[hesitates]</i> I don't want to spur any more interest. I am not going to teach him about sex- because I know that, that's not appropriate, but it's also about keeping himself safe and his vulnerability, if he is expressing a desire to touch or see someone else's genitals and you know, I have to be really sure about the people who are round about him, and trust that every single person that is in his life, has the correct response, and yeah, I feel like he is really vulnerable, so yeah, he is really vulnerable, and I am worried about that. Em, I guess probably a lot of people in my situation are.</p>	<p><i>Who do I turn to for support?</i></p> <p><i>The sex education dilemma: "I don't know the right thing to do".</i></p> <p><i>Vulnerability</i></p>
	<p>R: You mentioned that you feel he is very vulnerable, would you mind telling me a bit more about that?</p>	
<p><i>Hesitation before saying abuse- too horrific to think about/verbalise?</i></p> <p><i>Fears of son perpetrating abuse- forcing self to consider it as a reality.</i></p> <p><i>Fraught with fear and anxiety</i></p>	<p>P: Well I think he is vulnerable because he doesn't really understand the implications his actions, he doesn't understand consent, whether that is his own consent or someone else's consent. I am worried about him being, em <i>[hesitates]</i> being sexually abused. That is my biggest worry. I am worried about him, I don't think he would sexually molest someone but that incident with me, has opened that up in my head, what if he tries to do that to someone else, without that, you know... sexual assault. What if he tries to touch someone, just now it has just been me and at school, with</p>	<p><i>Abuse: an unbearable prospect.</i></p>

<p><i>Possible consequences of challenging sexual behaviour</i></p> <p><i>Feelings of confliction</i></p> <p><i>Feeling uncertain- importance of making the right decision for my son. No right answer, no easy solution.</i></p>	<p>everyone who knows him, but if he tried to do that to someone in the street, that opens up a whole other area. So I am kind of scared about that, so I don't know what would happen if that was to happen. And I am worried that if he doesn't have the right level of opportunity to masturbate, there will be a bigger chance of that happening and then on the other hand I am worried that if he gets to go off and masturbate whenever he wants and meets his sexual needs through that, I just don't know what the right thing to do is.</p>	<p><i>Feeling uncertain- "I don't know the right thing to do".</i></p>
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Appendix 9: Major Research Project Proposal

**Mothers' Perspectives about the Sexual Understanding and Development
of their Children with Low Functioning Autism**

Major Research Project Proposal

Date of submission:

Version 2

Word count: 3348

Abstract

Background: Sexuality and sexual development is a key part of human development. Typically the general population will receive information about sex experientially or from informal sources, usually their peer group. For individuals with low functioning autism, their socially marginalised position places the emphasis on families to support them with their sexual development. It is therefore important to understand sexual development and sexuality of young adults with low functioning autism from a family perspective.

Aims: The primary aim of this study is to understand mothers' experiences of the sexual development and understanding of their child with low functioning autism.

Methods: 6 – 12 mothers of young people aged 16 – 25 with low functioning autism will be recruited from voluntary organisations. Each participant will complete an in-depth interview exploring their experiences of her child's sexual development and sexuality, their attitudes towards her child's sexuality, the social, emotional and practical challenges and sources of support available.

Applications: The findings of this study should be used to develop resources and support regarding sexuality in young people with low functioning autism.

Introduction

Sexuality is a central part of human development. It encompasses a range of phenomena including self-image, emotions, values, attitudes, beliefs, behaviours and relationships (Koller, 2000). A young person's sexual development can present as a challenge to any family. Often it is a signal to parents that their offspring is transitioning from a child to an adult and a sign of their growing autonomy and independence. Usually young people will seek support and information about sex from their peers or experientially. For individuals with autism and learning disabilities, sexual development can present a different range of challenges. These individuals often do not have the same social networks that typically developing young people do and therefore are less likely to receive sex education through informal means, such as their peer group (Jahoda & Pownall, 2014). As they are likely to spend most time under supervision of adults, they are unlikely to have the opportunity to develop intimate relationships (Ailey, Marks, Crisp & Hahn, 2003). Consequently, parents of young people with autism and learning disabilities usually need to take responsibility for providing sex education, however, research suggests that parents of young people with learning disabilities lack confidence and support in dealing with sexual matters (Clegg, Sheard, Cahill & Osbeck, 2001). Given the significant role that parents play in supporting young people with autism and learning disabilities during this time, it is important to understand their experience of the sexual development of their offspring in order to provide appropriate support.

Previous research has been conducted to explore the family perspective of young people with learning disabilities' sexual development. Pownall, Jahoda, Hastings and Kerr (2011) conducted a study utilising an interpretive phenomenological analysis approach to compare and contrast 8 mothers' experiences of supporting the sexual development of their child with a learning disability with a typically developing sibling aged up to five years older or younger. The findings suggest that mothers found it more difficult to discuss sexual matters with their child with a learning disability than with their typically developing child. It was proposed that the socially marginalised position of the young people meant that their mothers did not think it was necessary to address their sexual development as they were less likely to form more intimate relationships. Mothers in the

study expressed the view that their offspring with a learning disability were likely to have a delayed or absence of sexual desires and feelings. Furthermore, mothers felt there was a lack of resources and information about how to support their offspring's sexual development. A study by Jahoda and Pownall (2014) found that typically developing adolescents had greater sexual understanding than adolescents with learning disabilities. Typically developing adolescents reported more formal and informal sources of information about sex. These studies demonstrate the inequity in knowledge and resources about sex for individuals with learning disabilities compared to the general population.

Individuals with autism have persistent deficits in social communication and social interaction across multiple contexts and restricted repetitive patterns of behaviour, interests or activities. These impairments must be present in the early developmental period (American Psychiatric Association, 2013). Due to the impairment in social interaction and communication, individuals with autism often lack interpersonal skills that develop naturally in others. For instance, individuals with autism may require support to understand facial expressions, emotions and appropriate social interactions and may struggle to understand other people's points of view (Baron-Cohen, 2001). Autism is a spectrum disorder and therefore individuals with autism are a very heterogeneous group, ranging from individuals with mild symptoms, e.g. Asperger's Syndrome or high functioning autism, to individuals with low functioning autism, who present with severe autistic traits and a learning disability. A learning disability is defined as significant deficit in intellectual functioning and adaptive functioning in conceptual, social and practical skills, occurring before the age of 18 (American Psychiatric Association, 2013). The socio-sexual education needs of individuals with Asperger's Syndrome and the needs of those with low functioning autism are likely to be quite distinct from one another. Individuals with high functioning autism or Asperger's Syndrome may develop intimate relationships during adolescence or adulthood, and therefore socio-sexual education is important to prepare them for these relationships. However, it is unlikely that individuals with low functioning autism, particularly those who have more severe learning disabilities, will develop intimate relationships. A mother's

role for these individuals is likely to have an emphasis on helping them understand the changes in their bodies, for example menstruation or to practice safe and appropriate sexual behaviours, including masturbation. Masturbation is likely to be one of the only means of appropriate sexual outlet for individuals with low functioning autism, but research indicates that this is often completed in an inappropriate or unsafe manner (Kempton, 1998). Individuals may find it difficult to discriminate between public and private settings and consequently may engage in inappropriate sexual behaviours, for instance undressing or masturbating in public, making inappropriate comments or engaging in improper physical contact (Hellemans, Colson, Verbraken, Vermeiren & Deboutte, 2007). Stokes, Newton and Kaur (2007) found that individuals with autism exhibited socially inappropriate behaviour, including inappropriate touching, monitoring others' activities and following behaviours compared to typically developing individuals. Given these findings, it is important to understand how families cope with these challenges and support the young person.

There appears to be a scarcity in research regarding sexual development for young people with autism, and in particular, low functioning autism. This may be due to beliefs held by carers, parents and professionals that young people with autism do not have an interest in sexual relationships (Gougeon, 2010). Due to the nature of their impairments, it is often mistakenly believed that individuals with autism are unable to form attachment towards others and therefore cannot develop loving relationships (Aylott, 2000). However, research indicates that the majority of adolescent, both with high and low functioning autism, demonstrate sexual interest and sexual behaviours. Research has highlighted that individuals with mild to severe autism demonstrate sexual behaviours, including masturbation and sexual interest towards others (Van Bourgondien, Reichle & Palmer, 1997). Individuals with learning disabilities and autism do express sexual interest and exhibit sexual behaviours, but due to the unique impairments they present with, do require support to express these appropriately. Furthermore, research suggests that parents lack confidence in delivering sex education and individuals with autism lack knowledge and skills in dealing with sexuality in comparison to typically developing individuals.

Aims of present study

This study will seek to establish how sexual understanding and development is explored in young people with autism and a moderate to severe learning disability, within a family context, using an interpretative phenomenological approach to interview mothers. Aims of the study include:

- What are mothers' experiences of their child's sexual development?
- What are mothers' attitudes towards their child's sexual development?
- What are the social, emotional and practical challenges associated with their child's sexual development?
- What resources and support can mother's draw upon to support their child's sexual development?

Plan of Investigation

Research Design

This study will utilise an Interpretative Phenomenological Analysis (IPA) approach. IPA has been selected as this approach investigates how individuals make sense of their experiences (Pietkiewitc & Smith, 2014) and allows descriptive and rich accounts of these experiences (Smith & Osborne, 2008). IPA is often used to explore major emotional life experiences and has been effectively used to explore sexuality and life transitions (Smith & Osborne, 2008).

Participants

This study will follow recommendations by Smith, Jarman and Osborne (1999) who propose 10 participants and Smith (2003), who suggest that typical sample sizes should be between 6 and 12. These numbers account for data saturation, when no new themes are emerging from the analyses. This study will therefore aim to recruit between 6 and 12 mothers of young people with low functioning autism, who are aged between 16 and 25.

Inclusion and Exclusion Criteria

The young person must have a diagnosis of autism and a moderate to severe learning disability. This will be confirmed with the mother. To ascertain that the individual has a moderate to severe learning disability, sample questions will be asked from the ABAS-II (Harrison & Oakland, 2003).

The young person must be aged between 16 and 25. The mother should be one of the primary caregivers to the young person. The mother does not need to be biologically related to the young person, but should have lived with the young person throughout childhood and adolescence.

The study aims to recruit males and females, but recognises that there are higher levels of males with autism than females, around 4:1 (Ehlers & Gillberg, 1993). A study by Brugha and colleagues (2009) found 1.8% of males in England had an ASD, compared to 0.2% of females. Given this ratio, the study may include a disproportionate number of males and females.

Fathers or any other family members will be excluded from the study. This is to ensure homogeneity of the sample, in line with the IPA approach (Smith, Flowers & Larkin, 2009). Parents of young people with a mild learning disability will also be excluded. This is due to the issues presented to individuals with mild learning disabilities are likely to be quite different as to those with moderate to severe learning disabilities. Mothers who do not speak English as their first language will be excluded from the study.

Recruitment Procedures

The research team has pre-existing links with voluntary organisations, including Scottish Autism, Autism Initiatives and PASDA. The project will be discussed with staff in these organisations and information will be provided about the study and the inclusion criteria. Staff will be asked to identify potential suitable participants and provide them with an information pack. This will include the contact details of the researchers. Interested individuals will be asked to contact researchers to organise an appointment to discuss the study; ask any questions and to sign a consent form if they wish to proceed. Staff at organisations will be asked to keep a record of potential participants whom they have passed the information packs to. Potential participants will be asked if they are happy for an individual independent of the research to contact them after two weeks of receiving the information, to ensure they have all the relevant information. A member of secretarial staff will conduct this. Participants will not be paid for their participation in the study.

Data Collection

Participants will be asked to complete an information sheet prior to the interview. This will gather information including their age, ages and gender of all of their children, marital status, occupation and postcode.

Semi-structured Interview

Consistent with the IPA approach, this study will utilise a non-directive, semi-structured interview approach. The topic of this study is of a sensitive nature, and therefore two pilot interviews will take place to test the topic guide to ensure that participants feel comfortable to talk openly about their experiences. It is hoped that data from these interviews will also be included in the final analysis. The interview will commence with general topics regarding the young person and family situation. This will help the mother feel comfortable, but also provide a valuable context to the information gathered from the interview. Although there will be a general structure, the interviewee will lead the conversation, and this information will guide the interview. The interviewer will use open-ended questions to gather information; avoiding the use of leading questions. Mothers will be able to raise any other issues at the end of the interview.

Data Analysis

The transcript will be read closely a number of times, and then key significant points will be highlighted. The transcript will then be re-read and key themes will be determined, with relevant quotations being identified. Similar themes will be grouped together into one category. This process will be repeated for each transcript. The themes for each transcript will be compared and then brought together to create a master table of comparative themes which will be used for the discussion. To ensure transparency and rigour, an audit will be conducted on the first transcript and a reflective journal will be kept throughout the process to chart decisions. These themes will be discussed in research meetings (Elliott et al., 1999). When no new themes have emerged from analysis of the interviews, it will be assumed that data saturation has been reached.

Settings and equipment

The location of the interviews will be at University of Glasgow premises when the building is staffed between 9am – 5pm. If participants are unable to attend this location, alternative accommodation will be sought within the voluntary organisations, also during daytime hours. If

neither of these locations is viable, interviews may be conducted over the telephone. Interviews will be audio recorded using a digital recorder. A laptop encrypted to NHS standards will be required for the transcription.

Health and Safety Issues

Informed written consent will be sought from all mothers who are taking part in the study. This will include consent to record the interviews and how data will be stored and anonymised.

Participants will be given a copy of their form. Participants will be made aware that they can withdraw their consent at any point during the study. The interview topic is of a sensitive nature and participants may feel uncomfortable discussing these issues. The researcher will monitor the participants' emotional responses throughout the interview. The participants will be assured that they can withdraw from the process at any time. Participants will be able to continue the discussion following completion of the interview. If participants do feel distressed, they will be given details of appropriate people to contact for support. Participants will be provided with a summary of the findings of the study and will be able to contact the researcher to discuss this further. Previous research of a similar nature has been conducted in the past, and researchers have found that mothers have been very motivated to engage in this process and discuss similar themes, despite the sensitive nature of the topic.

Ethical Considerations

Ethical permission will be sought from the University of Glasgow ethics committee. The parents will be informed that they can withdraw from the interview at any time in the process. All information will be treated in a confidential manner. Participants will be assigned a number which will be attached to their recordings. Direct quotations will be used in the final report, but there will be no patient identifiable information used. Participants will be informed that direct quotations will be used and will need to provide consent for this. Data will be stored on a University of Glasgow laptop, encrypted to NHS standards. Paper copies of anonymous data will be stored in a

locked filing cabinet at the Psychology Department, Administration Office, Gartnavel Hospital. Transcriptions will be kept for 5 years before being destroyed, in line with University of Glasgow policy. Recordings will be deleted as soon as they have been transcribed.

Financial Issues

A voice recorder and foot pedal will be required to record and transcribe interviews and an encrypted laptop will be borrowed from University of Glasgow. There will be costs to send information sheets to participants.

Timetable

Submission for ethical approval	August 2015
Pilot study to trial interview guide	November-December 2015
Data collection completed	By March 2016
Submission of thesis	End of July 2016
VIVA	September 2016

Practical Applications

This study will enhance our understanding of some of the social, emotional and practical challenges a child with low functioning autism's sexual development presents to mothers. This should inform resources and support available for these families.

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