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Introduction

Article Eight of the Human Rights Act (1998) is explicit in respecting the rights of every person with regards to family and private life, which includes forming and maintain relationships with other people. However, autonomy in this area can be problematic for adults with IDD. Although they have the same curiosity toward romantic relationships (Dupras and Dionne, 2014), as their non-disabled peers, young people with IDD typically have less freedom when growing up to experiment with their sexuality and with relationships (Pownall at al. 2011). While, adults with IDD highly value loving relationships (Bates et al, 2017), they face barriers to developing intimate relationships. Such barriers, it has been argued, can lead to the creation of a 'suspended adolescence' (Azzopardi-Lane and Callus, 2015, p.2)

Some of these barriers may be found in the formal health and social care sector, e .g. restrictive and risk-averse organisational policies (Bernert, 2011), highly supervised relationships and a lack of privacy (Winges-Yanez, 2014). Other barriers may come from informal, i.e. family carers. Carers UK (2019) estimates that 8.8 million people in the UK are informal carers and it is estimated that approximately half of all adults with IDD are living in the family home, usually supported by their parents (Foundation for People with Learning Disabilities, 2020).

The purpose of this paper is to contribute to the academic literature on family carers' experiences and views on intimate relationships for people with IDD. In doing so, we do not seek to give primacy to the parental perspective over and above that of adults with IDD themselves. We recognise and share the weaknesses of any such approach (Friedman et al, 2014). As outlined in the method section below, the study reported here was one of a series and the views and experiences of adults with IDD themselves were always prominent throughout the whole research project.

Literature Review

Parents, especially older parents, are typically described as holding conservative views regarding their offspring's sexuality (Rose and Jones, 1994; Hubert, 2010). Parents can be fearful of approaching the topic due to concerns about encouraging sexual behaviour (Abbott and Howarth, 2007). They may fear to raise a topic that is irrelevant if they perceive that their offspring has no interest in sex or intimate relationships (Pownall et al, 2012). However, there is research evidence which demonstrates that some parents recognise that their offspring are often isolated and so *do* want their offspring to form intimate relationships (La Grutta et al, 2009, Rogers 2010, Rogers and Tuckwell, 2016), and friendships. Typically, younger parents of people with IDD are more accepting of their sexuality (Swango-Wilson, 2008) but can still lack confidence discussing this topic with them

(Garbutt, 2008). Mothers were more likely to discuss sexuality compared to fathers, although discussions are typically reactive and often feel embarrassing and uncomfortable for the parents (Pownall et al, 2011). Parents of children with IDD can be uncertain about how to support their sexual needs or provide appropriate sex education (Dupras and Dionne, 2014), indicating that they may welcome assistance with from external sources (La Grutta et al, 2009).

More liberal parental attitudes are expressed towards the sexuality of sons, as opposed to daughters, with IDD (Tamas et al, 2019). More conservative attitudes persist towards daughters with IDD, as parents fear they are more sexually vulnerable than males (DiIorio et al, 2003). This fear is grounded in reality, as evidence suggests that women with IDD can experience high levels of abuse in intimate relationships from partners (McCarthy et al, 2017). Evidence suggests that mothers were particularly concerned about their daughter's vulnerability and felt young women with IDD would not be able to make informed decisions around sexual relationships and contraception. However, despite this, they had not discussed sex in more detail with them (Pownall et al, 2012). Perhaps in response to their concerns, parents took control over aspects of their offspring's sexual lives such as where and with whom they socialised, and the contact people had with partners, such as staying overnight / having a closed bedroom door (Rogers, 2009). Striking the delicate balance between independence and control is a reoccurring theme in the literature on parental attitudes (Pownall et al, 2011; Pownall et al, 2012).

Most research which explores the views of parents on sexuality issues focuses on children and young people. However, it is essential to explore parental views on sexuality and relationships throughout the life span, as more adults with IDD live with their family as opposed to other environments, such as in registered care homes or other social care environments (Public Health England, 2020). In this research, we focussed on intimate relationships for people with IDD over the age of 18.

Parents have been shown to hold less liberal attitudes in this area compared to professionals and compared to members of the public (Morentin et al, 2008; Tamas et al, 2019). However, knowledge is limited, and in particular, there is limited research exploring what impact parents have on the development of intimate relationships for adults with IDD whether the adult lives in the family home or not. Abbott and Howarth (2007) reference how organisational policies have been used as a tool by support staff to uphold the rights of people with IDD to engage in a consenting relationship where the parents opposed it. This suggests that parents can influence their adult offspring's intimate lives even if they do not live at home.

The majority of research regarding parents and the sexuality of people with IDD, specifically children and young people, focuses predominantly on the sexual element such as providing sex education or

attitudes to sexuality. There has been limited exploration of the support family members provide or their views on supporting adults with IDD to develop and maintain intimate relationships with a partner. One aim of the current study is to explore how adults with IDD can be supported to form loving relationships, whether sexual or not, from the perspective of family carers. Another is to provide useful evidence for guiding further research and the development of support for family carers.

Method

The data from family carers was collected for Study 3 of a programme of studies investigating support for adults with intellectual disabilities to form and maintain loving relationships. Other studies in the programme gathered data from adults with IDD themselves, paid support staff and specialist dating agencies. Findings from the other studies are reported elsewhere

(Authors' own 2020, Authors' own 2020, Authors' own in preparation). The whole research programme ran from October 2017- April 2019.

Participants

Participants were all relatives of people diagnosed with an IDD. There were nineteen relatives in total, 17 were relatives of adults, and 2 were relatives of teenagers[i]. Ages of the people with IDD they were discussing ranged from 15-56 years old, with a mean of 29 years.

[Insert Table 1 here]

Participants were thirteen mothers, five fathers and one sister[ii]. Evidence suggests that fathers are difficult to recruit in research (Macfadyen et al, 2011). However, in this study, fathers made up 26% of the sample, which is encouraging. 45% of the participants took part in a telephone focus group, therefore their age and ethnicity was unknown, however almost all appeared British and one European. Participants were recruited via social care providers, advocacy groups and via national networks. Participants discussed the range of experiences their relatives had regarding relationships; from being married to having no experience in this area. However, it was the case that the majority of the people with IDD the participants were discussing were not in a long-term relationship and their living situations were a mix of social care housing with support and still living in the family home.

Procedure

Semi-structured open-ended questions were developed by the researchers into a focus group discussion guide to elicit responses from participants of their experiences of supporting their

relatives to develop and maintain relationships. The project had a steering group of professionals and an advisory group of people with IDD who provided feedback on the questions to ensure they were appropriate and to ensure that the perspectives of people with IDD were always centred. The guide included questions about their relatives' social circle, whether/how they were looking for a relationship, and the relationship support their relatives have had.

Recruitment challenges and the potentially challenging nature of some of the topics meant that it was a lengthy process to recruit to the required sample size. Sensitive topics, such as sex, can be a significant factor in influencing families' engagement in research and can potentially result in only those comfortable discussing such issues participating (Lewis, 2009). However, we did recruit parents who were somewhat uncomfortable with the topic, as well as those more at ease. For the face to face groups; one took place in a local advocacy centre, another in a social care organisation's office and one at a participant's home. The face to face focus groups were facilitated by one of the researchers and notes were taken by a research assistant. Only one researcher took part in the telephone-based focus groups. Focus group discussions lasted 60-90minutes, were audio-recorded and transcribed.

Due to the recruitment challenges, three of the six focus groups took place by telephone conference call. The use of telephones as a method for conducting focus groups is advantageous when discussing sensitive topics such as sexuality as it offers a level of anonymity for participants (Greenbaum, 1998), perhaps resulting in a more candid discussion with less embarrassment. However, this method can result in less interaction between participants than the traditional face to face method (Greenbaum, 1998). In this project, we believe the focus groups were successful in enabling a back and forth interaction between participants and facilitators in both the face-to-face and telephone meetings.

Relatives signed consent forms and were informed both verbally and in writing before commencement of the session that they were free to leave at any time and could request their data be removed up until the point where it has been analysed and anonymised.

Ethical approval was given by the Social Care REC Ref No 17/IEC08/0053, and The Association of Directors of Adult Social Services (ADASS) recommended it to local authorities. Although this was a sensitive topic, no group discussion had to be ended prematurely due to embarrassment or distress, and no participants withdrew. The primary researcher conducting the focus group was comfortable discussing this topic and was prepared to offer support and signposting to organisations if there were issues raised within the groups, but this was not necessary.

Analysis

The data was analysed using latent thematic analysis (Braun and Clarke, 2006). The responses to each topic raised by the focus group facilitator were grouped based on similarities. Two researchers independently reviewed the data to compare the main themes to ensure consistency. The concepts expressed were summarised, resulting in many initial themes which were then collapsed into wider themes, enabling commonalities and diversity concerning reported views and experiences to be identified. Care was taken to ensure that the content of any emerging themes was grounded in the original data.

Findings

As a relatively small-scale piece of focus group research, using purposive sampling, the findings are of limited generalisability. Nevertheless, they throw some light on the main concerns and experiences of key people who influence the romantic lives of people with IDD. Following the thematic analysis, four broad themes, containing nine sub-themes, were identified.

Insert figure 1 here

Desire for a "normal" adult life

While there are, of course, many different ways of living and increasing social acceptance of being single for some or all of adulthood, many people still aspire to have a partner (Kislev, 2019). Previous research demonstrates that, like most people, people with IDD aspire to have a relationship (Bates et al, 2017). The majority of participants in this study reported that their relatives with IDD also wanted a 'normal family life', including a partner and sometimes children. Rogers and Tuckwell (2016) MICHELLE – I think this was your addition describe relationships and intimacy as "a foundation to life, loss, expectations and dreams" and that seemed to resonate with most of our participants.

Sadness when it doesn't happen

Some participants reported that, for their relatives, a lack of a partner was a cause of despair, having a negative effect on their emotional wellbeing:

I think it is affecting M's mental health, becoming more low about not being in a relationship – not having the same as his peer group. (Sister/telephone Group)

One mother explained how her son used dating sites, including gay sites (despite claiming to be heterosexual). She was unsure if he wanted a sexual relationship or a friendship because he was lonely:

He says "I have gone to dating sites and no one wants to go out with me, so I must be gay" - so he doesn't understand and I don't know if he has the capacity to understand. (Mother/ Focus Group)

Participants felt that when their relatives saw siblings and staff members "settling down", they wanted the same. One mother shared her sadness that this was unlikely to happen for her son, despite it being a significant part of his identity. Another mother reported that her son wanted to adopt a child, but she doubted this would ever be possible:

That's the main thing he wants, he's already recognised and said to me very clearly that 'this is not the life I wanted, I wanted to get married, have children'… like his brother. (Mother/ Telephone)

There are limits

Not all participants were positive about all potential aspects of adult relationships for their sons and daughters. In particular, many expressed concern at the prospect of parenthood for adults with IDD. They did not welcome this, as they felt their relatives would struggle to look after children due to their own support needs:

They can't look after themselves, so how on earth…? You've got to think about the child as well … it opens a whole can of worms. (Mother/ Focus Group)

Impact of Disability – Relationship Skills and Vulnerability

Participants were aware that while the majority of their relatives wanted a partner, there were issues relating to their disability which made relationships challenging. This included a lack of understanding (either due to their disability or a lack of skills), and their vulnerability as a result.

Lack of understanding due to disability or skills

Having an IDD created barriers to relationships with a partner, both practically and emotionally. There was a consensus that a lack of social skills and knowledge of how to maintain a relationship can prove detrimental. Examples given were not calling/ texting, people not having sufficient verbal skills to maintain a conversation or the awareness that they need to do this to maintain a relationship. One parent described how they had helped set up a date and the couple with IDD sat in silence watching TV, another how his son went on numerous dates but was unable to build a relationship:

He finds it hard to maintain contact after, he wouldn't think about sending a text- although he is getting better (Father/ Focus Group)

A lack of relationship skills can pose a barrier in understanding the complex, and confusing, rules of relationships. Some participants felt that their relatives had missed out on typical teenage behaviour during which people often learn these rules:

I don't think he understands the real meaning of relationships, in a loving, giving and taking kind of way. (Mother/ Focus Group)

Because relationships are complex and have rules and boundaries linked to societal norms, participants felt their sons and daughters were disadvantaged in not knowing these and described how this could even lead to allegations of abuse against them:

His forthright behaviour of hugging and trying to kiss has meant that, many years ago, he was twice accused of sexual assault by women who were far more disabled. (Mother/ Telephone)

His friendship attempts are like a child's - "do you want to be my friend?" or "would you like to have sex?" It doesn't go down very well. (Mother/ Telephone)

Parents felt that any potential partners of their sons and daughters would have to understand their particular needs, and they were worried that it could be difficult if the partner had their own support needs. Finding a partner who has a similar level of disability was considered essential but challenging. Participants with relatives with a mild IDD felt they were disadvantaged as they were "too able" for social events aimed at people with IDD and "too disabled" to fit in with the mainstream. Even where specialist IDD dating agencies were used, this mildly disabled group of people were frequently sent on (unsuccessful) dates with people with higher needs:

Finding a match at the same level (of disability) is difficult … hard to find someone who is just the same. (Mother/ Telephone)

Vulnerability to abuse

All participants had concerns focused on safety around finding a partner, particularly online, which is unsurprising considering the abuse people with IDD often face (Smeaton *et al,* 2015). One sister restricted her brother's internet access, due to concerns regarding pornography, fearing this would damage his idea of what is a loving relationship is. Social media was highlighted as a concern due to a lack of knowledge of how to use it safely, resulting in the people with IDD being abused or allegations of abuse being made against them:

At the point "suck my cock" appeared on her timeline, I deleted quite a lot of her friends and we kept it that way and have fixed her privacy settings, so she cannot have too many people, but has now learnt what she can and can't say (Mother/ Telephone)

Mainstream online dating aroused concern from participants, fearing that their relatives would be exploited due to their disability and 'set up to fail' by being rejected by other members.

If you look like you have a learning disability you get some pretty nasty comments. There are some nasty people out there. And if you don't, they work it out. I just think it [online mainstream dating] is probably setting people up for a hard knock (Mother/ Telephone)

Such concerns were reflected in Authors' own (2020) which depicted similar experiences by people with IDD on such sites.

Some participants had supported family members to use online dating sites for people with physical disabilities or autism. The reaction was mainly negative due to cost, website content, locations of available partners and fears about exploitation:

Got lots of supposed young women wanting to marry him, seeing the vulnerability and wanting an English passport. (Mother/Telephone)

We tried the Asperger's dating site and it had a lot of images… adult content… that I do not think is helpful. (Sister/Telephone)

Participants reported that none of their relatives using such sites had developed a relationship.

A minority of participants had supported family members to use specialist learning disability dating agencies which were generally viewed positively. However, the distance between matches was an issue, reflecting the findings of (Authors' own 2020). Parents were reassured as all members were screened, and references were required. Everyone agreed there should be more IDD dating agencies, due to their limited capacity/ geographical spread:

I think specialist sites are better, but this often means great distances between people and there are some real practicalities that make it really tricky. (Mother/Telephone)

Parents had concerns regarding their child being the least able person in a relationship, due to fears of abuse/exploitation. Nevertheless, they were also concerned when their child was the more able person, as they saw this as an unequal match and not right for their child. However, finding an equal match in terms of the disability level is very hard, and probably unrealistic, in a small dating pool, with few potential partners to choose from.

Barriers to Developing Relationships

External barriers to developing relationships related to a lack of opportunities to meet people (due to lack of funding, few or no social activities and a lack of staff hours for appropriate support) and the restrictive attitudes and/ or behaviour of support staff and relatives.

Lack of opportunities

A lack of places to meet new people was a reoccurring theme among participants. This appeared to be linked to the age of their relatives: they reported that there were more social events aimed at people aged 18-25, rather than for older adults. Reports from participants with relatives under 30 suggested that they were more likely to have a partner or have someone in their social circle they were attracted to, whom they had met at college or a social group. Some participants felt the small social circles of their relatives were due to attending residential school (which are often some

distance from home) or attending a mainstream school, (where they one of the very few disabled pupils). Both these situations meant their relatives had got to know few people with IDD locally and as peer groups were implicitly and explicitly defined as other people with IDD of similar ages, this was problematic:

The value of a peer group becomes more visible when looking for a relationship… I guess it starts by encouraging friendships and relationships, and making that possible. Sometimes it's ok to hang out with people like you. (Mother/ Telephone)

However, it was acknowledged that peer groups were often effectively 'closed' groups, i.e. consisting of the same people year after year, with few if any, new people coming along:

He goes to disabled events, because they are the ones you are invited to and they are soft and safe, but it is the same people he has been engaging with for 20 years or so. (Sister/ Telephone)

Participants reported that social clubs for people with IDD had been hit by public spending cuts and that this had had an adverse impact on their relatives' social lives. A lack of funding in social care services was also highlighted in terms of inadequate support hours leading to limited opportunities for socialising. One father described how his son's girlfriend lived far away, and there were not enough support hours to allow many visits between them. Supporting his relationships was complicated further by a lack of drivers on the staff teams, as neither person with IDD could travel independently, resulting in limited opportunities for them to spend time together to develop a loving relationship. Parents also complained that organisational barriers existed with regards to people with IDD having 'normal' adult social lives, including staying out late into the night if they wanted to. This was often prevented by staff needing to change shifts in the evening. However, some parents reported a gradual change in this regard, especially where people with IDD had direct payments.

Barriers from staff

Approximately half of the participants reported that their relative with IDD lived in supported accommodation. Almost all parents felt that such social care services could, and should, do more to facilitate relationships. Some expressed mild criticism, while others were more forthright, strongly apportioning blame. Some participants reported they had had to be proactive in this area, in an attempt to motivate the staff. For example, one parent passed on details of an acquaintance she had met with her son, so that the staff could follow this up, in the hope they would facilitate further meetings, but she did not think the staff had done that:

It may have been a bit too much like hard work. (Mother/Focus Group)

There was an expectation amongst parents that it was the role of staff to support the development of relationships, and they were aware of how important this support was to any success:

We expect the staff to step in and to help people to maintain a relationship or get it off the ground (Father/ Focus Group)

Where this did not happen, parents felt that it was because staff employed in support services reflected the views of wider society:

The system is formed by the society that we live in … basically there are still a lot of people that feel that people with learning disabilities shouldn't have a sexual relationship, for whatever reason, mostly because of the safeguarding reason (Mother/ Focus Group)

It was felt that relationships were on the "too hard" list for many providers. There was a feeling that staff were not proactive and did not prioritise actively supporting people to develop relationships:

I wouldn't say [finding love] was particularly high priority. Some staff think 'how can I make X's life better' and some of them don't, it's just practical caring to make sure he is washed dressed and fed. (Father)

In our sample, parents of younger people were generally more positive about the relationship support provided to their sons and daughters, than the parents of the older people with IDD. However, this was not always the case, and an example was reported to us of young people with IDD facing strict barriers to relationships in a residential college:

Relationships were very much discouraged, there was no sex education or even relationship education …If a couple did show an interest in each other, they would be separated and if they continued, they would actually be thrown out of the college. That was all about covering the arse of the college, because the college were petrified that the parents …would sue the college. (Father/ Focus Group)

Participants reported concerns that support providers were too risk-averse. One participant explained how she had spent years trying to persuade her brother's support staff to help him make a friend, but she felt frustrated that the staff seemed overly concerned with safety issues. Staff had expressed concerns about what type of support they would need to give a relationship and were worried about the man with IDD doing something the woman did not like:

Everything feels so threatening for them [staff] …. They are going to have meetings about how to support him and I wait to hear, but it's very slow and he is getting more and more distressed. (Sister/ Telephone)

There was a feeling amongst parents that some service providers take the 'safe' option for fear of something 'going wrong', and that staff usually assumed (sometimes wrongly) that parents do not want their relative to have a relationship:

They assume we do not want our children to have a relationship which could turn out to be abusive …so they take that overprotective view to cover their own backs (Father/ Focus Group).

Barriers from Families

It was by no means the case that parents saw only support staff and professionals as barriers to relationships. They fully recognised that families were also barriers to the development of relationships for people with IDD and that in many cases, parents' reputation as being too over-protective was justified:

Some people don't think their son or daughter is worth it [having a relationship] because that's the message they've been told … especially for older parents. (Mother)

Several participants knew of other parents who had stopped their relative with IDD from having a relationship, including a couple who wanted to marry, but whose parents had forbidden it:

They were made for each other, but one of the families didn't support it, so it [marriage] didn't happen. (Mother)

Our sample contained three parents of a long-established couple with IDD. They reported that they had posed barriers to their relatives' relationship and set obstacles to try to stop their relatives from marrying:

I said 'well, first of all you have to finish college and then you need to get a job'. All of these obstacles were put in front of them. (Mother/ Focus Group)

Their relatives with IDD planned their wedding in secret, which led to their parents realising how serious they were:

They came downstairs with an arm full of paperwork … they had been to the church, the hotel, they had got menus, L got the wedding dress sorted out, she has been in the most expensive dress shop in X several times. They had totally researched it and there was no way… we just said 'well, why not'? (Mother/ Focus Group)

These parents were the oldest in the sample, and their initial views and objections were perhaps typical of parents in the past (Hubert, 2010). They were now supportive of their relatives.

Other parents also spoke honestly about the barriers they put in the way of their sons and daughters having full adult experiences. One father of a man with complex needs was very cautious of

approaching the topic of sex or relationships with his son. He stated that his son was non-verbal and did not have the Makaton signs relating to relationships to articulate his needs, but that he, as his father, was unwilling to address this:

It would be very difficult, dangerous to introduce that [signs for partner, etc] because you are not quite sure where it would go. If you start introducing something, you are really letting the "genie out of the bottle"… It's best for someone like X that innocence is maintained. (Father/ Telephone)

In this kind of situation, the person with IDD is not being seen as an adult, and his sexuality is being viewed as something to be afraid of. Perceiving people with IDD as innocent and childlike is reflective of historically held views of people with IDD (McCarthy, 1999).

Family members were aware that they were sometimes guilty of providing 'too much' support, which could be an additional barrier to relationships. Parents acknowledged that they are more involved in all elements of their sons' and daughters' lives and thus it is harder for their relatives to keep information private, a normal part of growing into adulthood:

Hard to get the right amount of support in at the right time … sometimes we have almost put in too much support, too soon, so that it has got out of her control – it's the parents' hands, not theirs. (Mother/ Telephone)

Support needed to develop relationships

Families Supporting Relationships

As stated above, parents recognise that they are often seen by staff as being opposed to relationships. However, several participants played a pivotal role in supporting their relatives' relationships, both emotionally and/or practically. They provided support whether the person with IDD lived with them or not. Examples of active family involvement included a father asking the mother of a woman with IDD if his son could date her daughter, a sister spending hours researching dating agencies for her brother with IDD and a mother helping her son to support his girlfriend in the hospital, after she had a seizure on a chaperoned date.

Whilst families were generally happy to actively support their relative, some participants did express resentment:

*I spent a lot of time researching the dating site and asked them [staff] 'Why am **I** doing this? Why aren't part of his support hours being used to do this, so I do not have to come home at the end of a long day and work until midnight'? (Sister/Telephone)*

The mothers in our sample described how they often provided emotional support, filling in the subtle clues that people with IDD may not have learnt. Examples included: explaining the unwritten rules of dating (*She misses the subtilties and I have to help – help to make the invisible, visible (Mother)),* analysing why relationships did not work out, supporting their relative to understand expressions and body language and purchasing a book on dating for people with autism.

Parents also reported that they were sometimes involved in the actual "dating" process, which could include helping their relative communicate with a potential partner:

We have to analyse every text- we do that too – when "we" are dating. (Mother/Telephone)

When she decided she was going to break up with him, we had to go through the whole process, what she was going to do and I helped her to write a letter. (Mother/ Telephone)

Parents also said they took an active role in supporting their relatives with regards to sex education, which might involve reinforcing what the school or college had covered in lessons, sometimes buying books to help their relative. Some parents were concerned that their son or daughter did not understand basic facts about sex:

Lack of understanding-no sperm, no baby – you are fine… for goodness sake, how many times have we done sex education? And obviously bits were not sinking in and I find it quite scary (Mother/ Telephone)

Parents of older people with IDD reported that often their relative had had no sex education. Some family members provided this themselves and often felt uncomfortable in this role, but felt it was necessary:

Having to explain some of those quite intimate things, is not the kind of conversation I have had with anyone really (Sister/ Telephone)

Few family members were aware of specialist sex education resources to help them or knew where they could be signposted for support. Those least connected with social care and support services were least knowledgeable about what is available.

Professional Support

There was a strong consensus amongst our participants that there should be a suitable level of expertise within social care organisations and that staff should be trained in this area to best support their family members:

It would be nice to have someone at X [support provider] to have knowledge and expertise, that you could go to, to help people (Father/ Focus Group)

There was also a strong consensus that education, advice and training should be provided to people with IDD themselves. Parents felt that it should be focused not just on sex, but all on all elements of relationships, including friendships:

I am not sure H would understand what having a really good friend is (Father/ Telephone)

Something about making sense of the rules, and an understanding what makes a real relationship - that is fundamental and needs to come before anything to do with sex (Mother/ Telephone)

The parents generally felt that many people with IDD did not understand what a long-term committed relationship entailed and that any professional support offered needed to reflect that. One mother spoke of how Disney influenced her daughter as a model for relationships, and how these simple messages were difficult to untangle, as in reality, relationships are very complex. Other parents agreed and felt that men with IDD also had similar, limited understanding of the real and complicated nature of adult relationships:

My son thinks you meet someone and you marry them and you have children, but as far as the relationship goes, he doesn't seem to have much of an idea about what goes on in between (Mother/ Telephone)

Our participants also felt that professionals should offer families some support in this area. They did not necessarily feel this needed to be formal training, but perhaps more space for discussion. It was felt there were few informal places for families to come together for support and discussion once their children reached adulthood, as, due to funding cuts, family forums have ceased:

Main challenge as a family carer- We are not prepared, are we? We are not trained, we are not proactive, we are reactive (Mother/ Telephone)

Discussion

There was a clear message from virtually all participants that their relatives with IDD wanted a relationship, and this was respected by almost all our participants. The parents and siblings in this study, a self- selected group, generally displayed liberal attitudes towards dating and sexuality for people with IDD, reflecting the findings of La Grutta et al. (2009). The oldest participants reflected the most conservative views, which is consistent with the research literature (Rose and Jones, 1994; Hubert, 2010). They had initially resisted their children's' decision to marry but now viewed the marriage positively. Parents of younger people with IDD were often progressive in their attitudes which again reflects the research literature (Swango-Wilson, 2008). They had high aspirations for their children, which sometimes also included parenthood. It appeared that, unlike Garbutt (2008),

our participants were generally confident, if not always comfortable, discussing the topic of sex and relationships with their relative.

There is very little previous research on parental or sibling support for the development and maintenance of relationships for adults with IDD, with most literature exploring staff attitudes and practices regarding this. However, because the highest proportion of adults with IDD in the UK live with their family, it is vital to understand how their relatives think and behave. This study suggests that families often provide the same kinds of emotional and practical support as paid staff (Bates et al, 2017). Pownall et al. (2011) highlighted how parents were keen for their offspring to develop friendships due to their social isolation. Some of our participants in this study reflected those concerns, and they appeared to fill the void and take on the role of friends, especially if the person still lived at home. For example, conversations around terminating relationships, preparing for dates and flirting were had with family members, where for most people this would usually occur between peers. Parents also supported the practicalities of dating, such as taking someone to their partner's home. Prental support appeared to happen even when a person lived with 24-hour staffed support. A lack of funding for 1-1 support hours to take people to their partners or social events was an issue for some parents, and they recognised that unless they provided the support themselves, it would not happen. This suggests that inadequately funded services have a significant impact on individuals with IDD's ability to develop and maintain loving relationships, especially those unlikely to have additional unpaid support from families.

Palmer et al. (2012) highlighted how family members and support workers provide general support for people with IDD to use the internet for a variety of purposes (though dating was not listed amongst them). A unique finding of this study was the support that participants provided to their relatives to develop and maintain relationships online. In this study, relatives were engaging on social media with their family member with the express purpose of helping them to maintain relationships, participate in online dating (setting up profiles, reading messages and organising dates made online) and to engage in conversations with partners (or potential partners) via text. As in Lofgren-Martenson et al*'s* study (2015), participants felt their family members did not understand the "rules" of what is considered appropriate on the internet, and they felt this needed be supported. Previous research indicates that women with IDD are considered more vulnerable than men by family members (DiIorio et al, 2003; Pownall et al, 2011 and 2012). However, in this study, men with IDD appeared equally vulnerable, as they were often contacted online by people who appeared not to have an IDD and who were potentially looking to exploit them financially. This was complicated by the fact some men with IDD were reported in this study to be seeking a partner who

did not have a disability and so fake accounts with photos of pretty women could be an appealing offer.

One clear theme running throughout the findings is how the lack of support for people with IDD and their family members is itself a factor in constructing risks, fears and consequent behaviours which disempower adults with IDD. For example, in this study, one participant described how she blocked internet access to stop her brother accessing online pornography. She did this with good intentions, fearing that pornography would warp his understanding of sexual relationships, which a common enough fear, especially regarding young people (Rogers 2016). However, it is evident that if social care services were available to help the man understand that the point of pornography is to arouse, not depict real life or real sexual relationships, he might have been empowered to make his own decisions about watching it or not. Likewise, the woman with IDD who received abusive comments on social media could have benefitted from services which supported her to make her own decision about who to accept and reject as online friends, rather than have her mother take the decision out of her hands. The paucity of strong enabling support for both people with IDD and their families itself acts a disabling barrier.

Limitations

The main limitation of the study was that the sample was self-selected and thus is potentially biased towards family members who were positive regarding relationships. This was a sensitive topic, and recruitment was a challenge.

While we do not know the ethnic background of all participants, it is reasonable to assume that those taking part by telephone were broadly similar to those who attended focus groups in person. If that is the case, then this was a predominantly White British sample. Therefore the views of parents from other ethnic backgrounds may well be different and are not represented here.

Conclusion

Evidence suggests that people with an IDD clearly want to form loving relationships, enjoy the same adult lives as others and their right to do so is enshrined in legislation. What is clear from this research is that families can and do help those with IDD, even when the person has paid support staff. It would be wrong to continue to see parents predominantly as barriers to the development of relationships for adults with intellectual and developmental disabilities, as historically has been the case. Rather parents are aware of the lack of support available to their sons and daughters and themselves as key supporters. They recognise this as a disabling barrier to their relatives achieving the kinds of relationships they would like. Thus they often step up themselves, even when they do

not want especially want to and they naturally make some mistakes along the way. Parents have a unique interest in the lives of those they love and this study suggests that parents can be acutely aware of their offspring's social, emotional and practical challenges in this area and are doing their best to assist.

References

Abbott, D. and Howarth, J. (2007) 'Still Off-Limits? Staff Views on Supporting Gay, Lesbian and Bisexual People with Intellectual Disabilities to Develop Sexual and Intimate Relationships?', *Journal of Applied Research in Intellectual Disabilities*, 20(2): 116-126.

Azzopardi- Lane, C. and Callus, A. (2015) 'Constructing sexual identities: People with intellectual disability alking about sexuality', *British Journal of Learning Disabilities*, 43(1): 32–37.

Bates, C., Terry, L. and Popple, K. (2017) 'Partner selection for people with intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities*, 30(4): 602–611.

Bernert, D.J. (2011) 'Sexuality and Disability in the Lives of Women with Intellectual Disabilities', *Sexuality and Disability*, 29(2): 129-141.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2): 77–101.

Carers UK (2019) *Juggling work and unpaid care: a growing issue.* Available from http://www.carersuk.org/images/News_and_campaigns/Juggling_work_and_unpaid_care_report_final_0119_WEB.pdf (Accessed 8.5.20)

DiIorio, C., Pluhar, E., and Belcher, L. (2003) 'Parent-Child communication about sexuality: A review of the literature from 1980–2002', *Journal of HIV/AIDS Prevention and Education for Adolescents and Children*, 5 (3-4): 7–32.

Dupras, A. and Dionne, H. (2014) 'The concern of parents regarding the sexuality of their child with a mild intellectual disability, *Sexologies', European Journal of Sexology and Sexual Health / Revue européenne de sexologie et de santé sexuelle*, 23(4): 79–83.

Foundation for People with Learning Disabilities (2020) *Learning disability statistics: support.* Available from https://www.mentalhealth.org.uk/learning-disabilities/help-information/statistics/learning-disability-statistics-/187696 (Accessed 8.5.20)

Friedman, C., Arnold, C. K., Owen, A. L., & Sandman, L. (2014). "Remember our voices are our tools:" Sexual self-advocacy as defined by people with intellectual and developmental disabilities. *Sexuality and Disability*, *32*(4), 515-532.

Garbutt, R. (2008) 'Sex and relationships for people with learning disabilities: A challenge for parents and professionals', *Mental Health and Learning Disabilities Research and Practice*, 5(2): 267–276.

Greenbaum, T. L. (1998) *The handbook for focus group research* (2nd ed), Thousand Oaks, CA: Sage Publications Inc.

Hubert, J. (2010) 'My heart is always where he is. Perspectives of mothers of young people with severe intellectual disabilities and challenging behaviour living at home', *British Journal of Learning Disabilities*, 39(3): 216-224.

Kislev, E. (2019) *Happy singlehood: The rising acceptance and celebration of solo living,* Oakland Claifornia: University of California Press.

La Grutta, S., Lo Baido, R., Calì, A., Sarno, I., Trombini, E. and Roccella, M. (2009) 'People with Down's syndrome: adolescence and the journey towards adulthood', *Minerva Pediatr*, 61(3): 305-21.

Public Health England (2016) *People with Learning Disabilities in England 2015*., https://healthwatchgateshead.co.uk/wp-content/uploads/2016/08/PWLDIE-2015-final.pdf

Lewis, R. (2009) 'Recruiting parents and children into a research project: a qualitative exploration of families' decision-making processes', *International Journal of Social Research* Methodology, 12(5): 405-419.

Lo¨fgren-Ma˚rtenson, L., Sorbring, E. and Molin, M. (2015) 'T@ngled Up in Blue": Views of Parents and Professionals on Internet Use for Sexual Purposes Among Young People with Intellectual Disabilities', Sexuality and Disability, 33(4): 533–544.

Macfadyen, A, Swallow, V, Santacroce, S and Lambert, H (2011) 'Involving fathers in research, *Journal for Specialists in Paediatric Nursing'*, 16(3): 216–219.

Malli, MA, Sams, L, Forrester-Jones, R, Murphy, G and Henwood, M (2018) 'Austerity and the lives of people with learning disabilities A thematic synthesis of current literature', *Disability and Society*, 33(9): 1412-1435.

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

McCarthy, M., Hunt, S. and Milne, S. K. (2017) 'I know it was every week, but I can't be sure if it was every day: Domestic violence and women with learning disabilities', *Journal of Applied Research in Intellectual Disabilities*, 30(2): 269–282.

Morentin, R., Arias, B., Jenaro, C., Rodríguez-Mayoral, J. and McCarthy, M. (2008) 'Love and Loving Relationships in People with Learning Disabilities: A Scientific Approach', *Tizard Learning Disability Review*, 13(2): 33-41.

Palmer, S.B., Wehmeyer, M.L., Davies, D.K. and Stock, S.E. (2012) 'Family members' reports of the technology use of family members with intellectual and developmental disabilities', *Journal of Intellectual Disability Research*, 56(4): 402–414.

Pownall, J.D., Jahoda, A., Hastings, R. and Kerr, L (2011) 'Sexual understanding and development of young people with intellectual disabilities: mothers' perspectives of within-family context', *American Journal of Intellect Developmental Disabilities*, 116(3): 205-19.

Pownall, J. D., Jahoda, A. and Hastings, R. P. (2012) 'Sexuality and sex education of adolescents with intellectual disability: Mothers' attitudes, experiences, and support needs', *Intellectual and Developmental Disabilities*, 50(2): 140–154.

Public Health England (2020) Research and analysis Chapter 5: adult social care. Available from https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england/chapter-5-adult-social-care (Accessed 8.5.20)

Rogers, C. (2009) '(S)excerpts from a life told: Sex, gender and learning disability', *Sexualities*, 12(3): 270–288.

Rogers, C. (2010) 'But it's not all about the sex: Mothering, normalisation and young learning disabled people', *Disability and Society*, *25*(1): 63-74.

Rogers, C., and Tuckwell, S. (2016) 'Co-constructed caring research and intellectual disability: An exploration of friendship and intimacy in being human', *Sexualities*, *19*(5-6): 623-640.

Rogers, V. (2016) *'We need to talk about pornography: a resource to educate young people about the potential impact of pornography and sexualised images on relationships, body image and self-esteem'.* London: Jessica Kingsley Publishers.

Rose, J. and Jones, C. (1994) 'Working with Parents', in A. Craft (ed.) *Sexuality and Learning Disabilities*, London: Routledge. pp. 23–49.

Smeaton E., Franklin A. and Raws P. (2015) 'Meeting the Needs of Children and Young People with Learning Disabilities who Experience, or are at Risk of, Child Sexual Exploitation', *Education Journal*, 242: 12-16

Swango-Wilson, A. (2008) 'Caregiver Perception of Sexual Behaviors of Individuals with Intellectual Disabilities', *Sexuality and Disability*, 26(2): 75-81.

Tamas, D, Brkic Jovanovic, N, Rajic, M, Bugarski Ignjatovic, V and Peric Prkosovacki, B. (2019) 'Professionals, parents and the general public: Attitudes towards the sexuality of persons with intellectual disability', *Sexuality and Disability*, 37(2): 245–258.

Winges-Yanez N. (2014) 'Discourse Analysis of Curriculum on Sexuality Education: FLASH for Special Education', *Sexuality and Disability*, 32(4): 485-498.

[i] These parents were included as they were interested in discussing sexuality in the context of preparing their children for adulthood.

[ii] For ease of reading, we refer to the participants as parents in this paper, except where the sibling perspective is significant.