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Introduction

The right to sex and a relationship is a prominent issue for people with a disability internationally, as evidenced by its inclusion in the United Nations Convention on the Rights of Persons with Disabilities. This stipulates that there must be “effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships, on an equal basis with others” (United Nations, 2007: 13–14). However, autonomy in this area can be problematic for adults with intellectual and developmental disabilities (IDD), evidenced across countries including the UK (Bates et al, 2017), South Africa (Kahonde et al, 2020), Israel (Neuman, 2020) and Taiwan (Chou et al, 2019). Despite having equal curiosity toward intimate relationships with their non-disabled peers (Dupras and Dionne, 2014), young people with IDD typically have less freedom when growing up to experiment with their sexuality and with relationships (Pownall at al, 2011). Adults with IDD highly value loving relationships (Bates et al, 2017) but face barriers developing them.

Some of these barriers may be found in the formal 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 settings, for example from responses of family carers. Approximately half of all adults with IDD in the UK are living with family, usually supported by their parents (Foundation for People with Learning Disabilities, 2020). In countries with less developed health and social care systems there are likely to be fewer opportunities for people to live outside the family home; for example in South Africa, 98% of people with IDD live with their families (Kahonde et al, 2020). However, in the countries like the UK, even when people with IDD no longer live with their families, parents (especially) may still influence the development and maintenance of intimate relationships (Abbott and Howarth, 2007).

Literature Review

Parents can be fearful of approaching the topic of intimate relationships due to concerns about encouraging sexual behaviour (Abbott and Howarth, 2007). They may feel raising the topic is irrelevant, for example if they perceive that their offspring has no interest in intimate relationships (Pownall et al, 2012). This response by parents has been noted internationally, sometimes even after parents have witnessed displays of sexual behaviour by their offspring (Manor-Binyamini and Schreiber-Divon, 2019). Some parents, however, recognise that their offspring are isolated and so *do* want them to form intimate relationships (La Grutta et al, 2009). Such parents may express sadness that attaining a partner is unlikely for their child (Pryde and Jahoda, 2018). Typically, younger parents of people with IDD are more accepting of their sexuality (Swango-Wilson, 2008) but they may still lack confidence discussing this topic with them (Garbutt, 2008). Some studies have found mothers are more likely to discuss sexuality than fathers, although such discussions are typically reactive and parents often feel embarrassed and uncomfortable (Pownall et al, 2011). The international literature suggests that the cultural context influences parental comfort in discussing this topic. Parents in North America and Europe appear more comfortable discussing sexuality with people with IDD than those in some other cultures, for example in Asia (Chou et al, 2019) and in Africa (Aderemi, 2016). Parents of children with IDD can be uncertain about how to support their sexual needs or provide appropriate sex education, and few countries (apart from in North America) have any formalised sexuality support for family members (Dupras and Dionne, 2014). Evidence nevertheless suggests that parents across continents would welcome external assistance (La Grutta et al, 2009; Pownall et al, 2011; Neuman, 2020)

More liberal parental attitudes are expressed towards the sexuality of sons with IDD than daughters (Tamas et al, 2019). Women with IDD are often restricted, due to fears about pregnancy (Foley, 2013), particularly in countries with minimal social care support. Some parents highlight concerns regarding raising potential grandchildren (Kahonde et al, 2020). Even in countries with highly developed social care support, conservative attitudes persist towards daughters with IDD, as parents fear they are more sexually vulnerable than sons. This fear is grounded in reality, as evidence suggests that women with IDD can experience high levels of intimate partner abuse (McCarthy et al, 2017). Mothers were particularly concerned about their daughters' vulnerability, and felt women with IDD would be unable to make informed decisions about sexual relationships and contraception. Despite this, most had not discussed sex in more detail with them (Pownall et al, 2012). Striking the delicate balance between independence and control is a recurring theme in the literature on parental attitudes (Pownall et al, 2012). Sometimes this balance was attempted, by taking control of certain aspects of their offspring's intimate relationships. Examples include allowing them to socialise, but being selective over where and with whom they socialise; and permitting intimate partners, but limiting the potential for sexual contact between them (Foley, 2013) by not allowing them to stay overnight or not permitting a closed bedroom door (Rogers, 2009).

When it comes to adults with IDD and intimate relationships, parents have been shown to hold less liberal attitudes in this area compared to both professionals and members of the public (Tamas et al, 2019). Knowledge of this is limited, however; in particular, there is limited research exploring what impact parents have on the development of intimate relationships for adults with IDD, irrespective of whether the adult with IDD lives in the family home, or not. In England , social care regulator the Care Quality Commission (CQC) states that social care's regulatory obligation is to support people to develop and maintain relationships, including intimate relationships~~ if required~~. Social care staff

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have a duty to “understand the importance of enabling people to manage their sexuality needs. This includes making sure people have access to education and information to help them develop and maintain relationships and express their sexuality” (CQC, 2019: 2). There is potential here for conflict between staff and parents. Abbott and Howarth (2007) found that support staff sometimes relied on organisational policies to uphold the rights of people with IDD to engage in a consenting relationship, despite parents asking them to prevent this. A rights-based sexuality and relationships policy gave staff the confidence to say that they had to support people in line with organisational policy, which was not to restrict consenting relationships between adults.

There has been limited prior exploration of the support family members provide, or of their views on supporting adults with IDD to develop and maintain intimate relationships with a partner. The study reported here aims to explore how adults with IDD can be supported to form loving relationships, whether sexual or not, from the perspective of family carers, and has the potential to inform further research, and the development of support for family carers.

Method

Data from family carers was collected for a study (Study 4) in 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, paid support staff, and specialist dating agencies (Figure 1). Findings from these other studies are reported elsewhere (Authors' own 2020; Authors' own, 2020).

Insert Figure 1 here

Participants

Participants in the study were all relatives of people diagnosed with an IDD. There were 19 relatives in total; 17 were relatives of adults and 2 were relatives of teenagers[i]. The ages of the people with IDD they were discussing ranged from 15-56 years, with a mean of 29 years (Table 1). Although the study was originally focussed on adults, due to difficulty in recruiting participants, two relatives of teenagers were included.

[Insert Table 1 here]

Participants were variously mothers (n=13), fathers (n=5) and a sister. Other studies have reported difficulty in recruiting fathers in research (Macfadyen et al, 2011); in this study, fathers made up 26% of the sample. Participants were recruited through social care providers, advocacy groups and national networks; they discussed the range of experiences their relatives had regarding relationships, from being married to having no experience in this area. Most of the relatives with IDD participants discussed were not in a long-term relationship, however; their living situations were a mix of living in social care housing with support and living in their family home.

Procedure

Semi-structured open-ended questions were developed 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 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 had had.

Recruitment difficulties and the potentially challenging subject matter meant that recruiting the required sample was a lengthy process . Sensitive topics, such as sex, can be a significant factor in influencing families' engagement in research and can result in only those comfortable with discussing such issues participating (Lewis, 2009). However, we were able to 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 an advocacy centre, another in the offices of a social care organisation and one in a participant's home. Focus group discussions lasted 60-90 minutes, and were audio-recorded and transcribed.

Due to the challenges in recruiting the sample, three of the six focus groups took place by telephone conference call. Telephone groups were only used when it was not possible to hold a physical group due to geographical distances between available participants. The use of telephones as a method for conducting focus groups is advantageous when discussing sensitive topics as it offers a level of anonymity for participants, perhaps resulting in a more candid discussion with less embarrassment (Greenbaum, 1998). However, this method can result in less interaction between participants than the traditional face-to-face method (Greenbaum, 1998). Our experience in this study was that all focus groups were successful in enabling an in-depth discussion, with ‘back and forth’ interaction between participants and facilitators, regardless of the format.

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

Ethical approval was given by the Social Care Research Ethics Committee (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 ready to offer support and signposting to organisations if there were issues raised, but this was not necessary.

Analysis

The data was analysed using latent thematic analysis (Braun and Clarke, 2006). To ensure consistency, two researchers independently reviewed the data to compare the main themes. The concepts expressed were summarised, resulting in many initial themes; these 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

Following the thematic analysis, four broad themes, containing nine sub-themes, were identified. The themes are shown in Figure 1.

Insert figure 2 here

Desire for a "normal" adult life

The majority of participants in this study reported that their relatives with IDD wanted a 'normal family life', including a partner and sometimes children.

Sadness when it doesn't happen

Some participants reported that, for their relatives, a lack of a partner was a cause of despair, harming 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 of male aged 56)*

One mother explained that her son used dating sites and had attended speed dating events, but that no women wanted to date him. He became saddened by this lack of response so began accessing gay dating sites (despite stating he is heterosexual) as he was able attract interest from men. However, he said he did not want to have sex with them. His mother and felt the desire to be in a relationship, even if this was not sexual, was driving this behaviour. The experience also raised concerns about his understanding of intimate relationships and what they typically entail.

He says "I have gone to dating sites and no one wants to go out with me, so I must be gay" (Mother of male aged 30)

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 his dream:

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 of male aged 37)

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 this is required to maintain a relationship. One parent described setting up a date; the couple with IDD sat watching TV.

He finds it hard to maintain contact after, he wouldn't think about sending a text- although he is getting better (Father of male aged 25)

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 of male aged 25)

Because relationships are complex and have rules and boundaries linked to societal norms, participants felt their relatives were disadvantaged in not knowing these, and described how this could, at times, 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 of male aged 37)

Participants felt that any potential partners of their relatives 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 with a similar level of disability was considered essential, but challenging, in a small dating pool with few potential partners to choose from.

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 support needs:

> *Finding a match at the same level (of disability) is difficult … hard to find someone who is just the same. (Mother of male aged 26)*

Several participants had concerns regarding their relative being the least able person in a relationship, due to fears of abuse/exploitation. Nevertheless, they were also concerned when their relative was the more able person, as they saw this as an unequal match and not right for them.

Many participants felt that their relatives' learning disabilities impacted their ability to develop relationships further to include starting a family. Many expressed concerns 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 of male aged 35)*

Vulnerability to abuse

All participants had concerns focused on safety in finding a partner, particularly online. One sister restricted her brother's internet access, due to concerns regarding pornography, fearing this would damage his idea of what 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 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 she has now learnt what she can and can't say (Mother of female aged 22)*

Mainstream online dating aroused concern from participants, fearing that their relatives would be exploited or 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 of female aged 20)*

Some participants had supported relatives 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 of male aged 26)*

> *We tried the Asperger's dating site and it had a lot of images… adult content… that I do not think is helpful. (Sister of male aged 56)*

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

A minority of participants had supported their relatives to use specialist learning disability dating agencies, which were generally viewed positively. Parents were reassured, as all members were screened and references were required. However, the distance between matches was an issue. 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 of female aged 20)*

Barriers to Developing Relationships

External barriers to developing relationships related to a lack of opportunities to meet people (due to lack of funding, few 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 recurring theme, which seemed to be linked to the age of their relatives: they reported that there were more social events aimed at people aged 18-25 than for older adults. Reports from participants with relatives under 30 suggested that they were more likely to have a partner or to 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 (often some distance from home) or attending a mainstream school, (where they were one of 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 of female aged 22)*

It was acknowledged, however, that peer groups were often effectively 'closed' groups, i.e. they consisted of the same people, year after year, with few, if any, new people attending:

> *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 of male aged 56)*

Participants reported that social clubs for people with IDD had been affected by public spending cuts, and that this had diminished their relatives' social lives. A lack of funding in social care services was also highlighted; inadequate support hours led to limited opportunities for socialising. One father explained that his son's girlfriend lived far away; there were inadequate support hours to allow them many visits. Supporting his relationships was complicated further by a lack of drivers on staff teams. As neither person with IDD could travel independently, this resulted in limited opportunities for spending time together to develop a loving relationship. Participants also complained about organisational barriers to people with IDD having 'normal' adult social lives, including staying out late if they wanted to. This was often prevented by staff needing to change shifts in the evening. However, some participants reported a gradual change in this, especially where people with IDD had direct payments, where family members managed their relatives support package and employ support staff directly.

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Barriers from staff

Approximately half of the participants' relatives with IDD lived in supported accommodation. Almost all participants felt that social care service providers could, and should, do more to facilitate relationships. Some expressed mild criticism, while others strongly apportioned blame. Some participants reported they had had to be proactive in this area, in an attempt to motivate staff. One participant, for example, passed on details of an acquaintance she had met with her son, so that the staff could follow this up and facilitate further meetings, but she did not think the staff had done this:

> *It may have been a bit too much like hard work. (Mother of male aged 43)*

There was an expectation amongst participants 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 of male aged 25)*

Where this did not happen, participants felt that it was because staff 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 of female aged 15)*

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 a 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 of male aged 25)*

Participants reported concerns that support providers were too risk-averse. One participant explained that she had spent years trying to persuade her brother's support staff to help him make a friend, and felt frustrated that the staff seemed overly concerned with safety issues. Staff had expressed concerns about the type of support they would need to give to 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 of male aged 56)*

There was a feeling amongst participants 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 of male aged 24).*

Barriers from families

It was by no means the case that participants saw only support staff and professionals as barriers to relationships. They recognised that families could also be also barriers to the development of relationships for people with IDD, and reported that, in many cases, parents' reputation as 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 of male aged 30)*

Several participants knew of other parents who had stopped their relative with IDD from having a relationship:

> *They were made for each other, but one of the families didn't support it, so it [marriage] didn't happen. (Mother of female aged 31)*

Our sample contained three parents of a long-established couple with IDD. They reported that they had themselves posed barriers to their relatives' relationship, setting obstacles to try to stop them 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 of female aged 31)*

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 of male aged 31)*

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 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 of male aged 26)*

In this kind of situation, the person with IDD is not being seen by his father as an adult, and his sexuality is being viewed as something to be afraid of.

Family members were aware that they were sometimes guilty of providing 'too much' support, which could be an additional barrier to relationships. Participants acknowledged that they were involved in *all* elements of their relatives' lives and that this made it 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 of female aged 22)*

Support needed to develop relationships

Families Supporting Relationships

As already stated, participants recognised that they were often seen by staff as 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 expressed 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 of male aged 56)*

The mothers in our sample described how they often provided emotional support, filling in the subtle clues that people with IDD may not have learned. Examples included: explaining the unwritten rules of dating (*She misses the subtleties 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.

Participants 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 of male aged 26)*

> *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 of female aged 20)*

Participants 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 were concerned that their relatives 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 of female aged 20)*

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 of male aged 56)*

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 was 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 of male aged 25)*

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 on all elements of relationships, including friendships:

> *I am not sure H would understand what having a really good friend is (Father of male aged 26)*

> *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 of female aged 22)*

The participants 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. Others 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 of male aged 16)*

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 of male aged 32)*

Discussion

Like most people, people with IDD aspire to have a relationship (Bates et al, 2017). There was a clear message from virtually all participants that their relatives with IDD wanted a relationship; this was respected by almost all participants.

The participants 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). This reflects attitudes from countries including Europe, North America and Israel (Pryde and Jahoda, 2018; Neuman, 2020) The oldest participants reflected the most conservative views, which is consistent with the research literature in countries such as Greece (Karellou, 2007). 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, reflecting the research literature (Swango-Wilson, 2008). They had high aspirations for their children, which sometimes also included parenthood, an area for concern internationally, including in countries with sufficient social care support (Foley, 2013; Chou et al, 2019; Neuman, 2020). It appeared that, in contrast to Garbutt's research (2008), our participants were generally confident, if not always comfortable, discussing the topic of sex and relationships with their relative.

There is little previous research on parental or sibling support for the development and maintenance of relationships for adults with IDD. Most literature explores staff attitudes and practices regarding this. However, because approximately half of all adults with IDD in the UK live with their families, 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) has shown that parents were keen for their offspring to develop friendships due to their social isolation. Some participants in this study reflected those concerns; they appeared to fill the void, taking on the role of friends, especially if the person still lived at home. For example, conversations about terminating relationships, preparing for dates, and flirting were had with relatives, whereas typically this would occur between peers. Parents also supported the practicalities of dating, such as taking someone to their partner's home. Parental support appeared to happen even when a person lived with 24-hour staffed support. As already reported, a lack of funding for individualised support hours to take people to meet their partners or to social events was an issue for some parents, who recognised that, unless they provided the support themselves, it would not happen. This suggests that inadequately funded services have a significant impact on the ability of individuals with IDD 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, some relatives were using 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 engage in conversations with partners (or potential partners) via text. This is reflective of experience in other European countries; for example, in Sweden, participants in Lofgren-Martenson et al*'s* study (2015) felt their relatives did not understand the "rules" of what is considered appropriate on the internet, and felt this needed to be supported. Previous research has indicated that women with IDD are considered more vulnerable than men by family members (Pownall et al, 2011; 2012). In this study, however, men with IDD appeared equally vulnerable; they were often contacted online by people who appeared not to have an IDD and who were potentially looking to exploit them financially. Such issues are predominantly raised in advanced economies (Europe, North America etc) but are likely to increase in emerging economies (such as Africa and Asia) where internet access and usage is increasing (Poushter, 2016).

A theme running throughout the findings is how 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, one participant described how she blocked internet access to stop her brother accessing pornography. She did this with good intentions, fearing that pornography would warp his understanding of sex, a common fear (Rogers, 2016). Within the UK, people with IDD typically only access relationship and sex education (RSE) within schools or colleges (Enow et al, 2015), leaving adults vulnerable through a lack of necessary skills and information. The provision of RSE could help people with IDD to develop the necessary skills to support their sexuality and relationships (Enow et al, 2015). This could enable the man to understand that the point of pornography is to arouse, not to depict real sexual relationships. This could potentially empower him 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 education that supported her to make her own decisions about whom to accept and reject as online friends, rather than have her mother take the decision for her. RSE can be beneficial to people with IDD, however for it to be effective it must be delivered by practitioners with the necessary skills and knowledge (Hanass-Hancock et al., 2018). The care regulator in England (CQC, 2019) states that social care staff should support people to access RSE if required. However, the paucity of available RSE for people with IDD itself acts a disabling barrier, often leaving relatives to provide education with no training or support. This issue is observed internationally; research in Canada and Taiwan indicates that providing RSE to families of people with IDD has a positive impact (Dupras and Dionne, 2014; Chou et al, 2019).

The United Nations Convention on the Rights of Persons with Disabilities (2007) maintains that people with disabilities have the right to sex and relationships, however the UK is not fully achieving this, along with other countries, as evidenced in the literature review (Dupras and Dionne, 2014; Neuman, 2020). Participants in this study blamed support staff, citing their failure to support relationships due to risk-averse attitudes, their uncertainty, and the low importance attached to this area. Charitou et al (2020) underline the need for the sexuality and relationships of people with IDD to be prioritised by policymakers and welcome the publication of CQC guidance that h states support in this area must be provided if required. Charitou et al (2020) stress that staff need training to reduce uncertainty and ensure consistency, in combination with a clear organisational policy.

Future research could explore how families and social care staff can be supported to work collaboratively to best assist people with IDD to manage sexuality and intimate relationships, covering areas such as sexual safety and empowerment.

Limitations

A limitation of this study was that the sample was self-selected and thus potentially biased towards family members who were positive about relationships. This was a sensitive topic, and recruitment was a challenge. As a relatively small study using focus groups and purposive sampling, its findings cannot be generalised. Nevertheless, these throw some light on the main concerns and experiences of the key people who influence the romantic lives of people with IDD.

Demographic information was not routinely collected about participants. All participants in the face-to-face focus groups appeared to be white British people; for the telephone focus groups the ethnicity of participants is unknown. The research literature has highlighted the different attitudes displayed in diverse cultures, many of which are present within UK society and the lack of a diverse cultural context for the discussion is thus a limitation of this research.

Conclusion

Evidence suggests that people with an IDD want to form loving relationships and enjoy the same adult lives as others. 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 no longer lives in the family home and has access to paid support staff. It would be wrong to continue to see parents predominantly as barriers to the development of relationships for adults with IDD, as historically has been the case. Rather parents are often aware of the lack of support available to their sons and daughters and see themselves as their key supporters. They recognise this as a disabling barrier to their relatives achieving the kinds of relationships they would like. They often 'step up' themselves, even when they do not especially want to, and inevitably make some mistakes. 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 often doing their best to assist.

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

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