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'Love makes me feel good inside and my heart is fixed': What adults with intellectual disabilities have to say about love and relationships

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Abstract

Background: Adults with intellectual disabilities have historically been hindered, rather than supported, in their desire to form loving relationships. This paper sought to explore with them what kinds of support they wanted in the 21st Century.

Method: Semi-structured in-depth interviews were conducted with 40 adults with intellectual disabilities in the United Kingdom.

Results: Participants placed a high value on having a partner and being supported to maintain and develop a loving relationship. The factors which constrained them in achieving this included a lack of social opportunities, barriers created by social care services and limits on them exercising autonomy. Facilitating factors included access to specialist dating agencies, strong family and staff support and opportunities to learn about relationships.

Conclusions: The importance of a loving relationship as a source of pleasure and meaning in the lives of adults with intellectual disabilities who are often disadvantaged in many other spheres of life is emphasised.

KEYWORDS
adults, love, relationships

1 | INTRODUCTION

It is well established that historically it was very difficult for people with intellectual disabilities to have the adult relationships they wanted. The eugenic practices of compulsory sterilisation and institutionalisation with strict sex segregation, were imposed on people with intellectual disabilities in many parts of the world through much of the 20th century (Kempton & Kahn, 1991). Despite these most abusive of circumstances and the best efforts of those around them to prevent relationships, many people with intellectual disabilities still managed to have both sex and

relationships, good and bad, heterosexual and same sex (McCarthy, 1999, Thompson, 2001).

In the past, adults with intellectual disabilities were simply not considered to have the same emotional, psychological or social needs for self-fulfilment as other people (Swango-Wilson, 2008). As Box and Shawe (2016) state, this view, combined with structural and organisational issues, restrict people with intellectual disabilities from forming relationships and thus leads to a denial of the human right to express their sexuality.

Despite the historic abuses they endured, finding a life partner was, and is, an important life goal for many people with intellectual

disabilities, as it is for other people (Bates et al., 2017; Rojas et al., 2016). Their rights to relationships and relationship support is enshrined in policy (e.g Care Quality Commission, 2019; Dept of Health, 2001), the law (e.g the Human Rights Act 1998) and international human rights treaties (e.g UNCRPD, 2006). Furthermore, fulfilling close relationships are widely recognised to be a key indicator of quality of life (Sullivan et al., 2016). Consequently, the need to support adults with intellectual disabilities in achieving their relationship goals is increasingly understood. Alongside this is the recognition that understanding the views of people with intellectual disabilities is critical to creating policies and practices that treat individuals as they wish to be treated. Nowhere can this be more important than the issue of personal and intimate relationships.

2 | BACKGROUND AND LITERATURE REVIEW

Previous research has highlighted that the negative views of significant others present barriers to adults with intellectual disabilities achieving their relationship goals (Lofgren-Martenson, 2004; Rojas et al., 2016). The phenomenon of 'diagnostic overshadowing' which affects so many areas of life for people with intellectual disabilities, particularly health care (Harris & Sheehan, 2017) is also known to affect their sexuality and relationships. This means that their identity as a person with intellectual disabilities can get in the way of them establishing an identity as an autonomous adult with ordinary desires and relationship goals (Wilkinson et al., 2015).

Previous research has found that, when asked, adults with intellectual disabilities express positive views about relationships and say that they provide them with satisfaction, self-esteem and security (Sullivan et al., 2016). Their aspirations to be in a relationship have been reported to be strong, though many were aware that the 'prohibitive climate in which they lived' (Kelly et al., 2009:313) had a negative impact on their chances of success. Fulford and Cobingo (2018) noted in a thematic synthesis conducted in 2018 that people with intellectual disabilities both appreciated the support they received from paid and unpaid carers, whilst also resenting the limits sometimes placed on them when it came to friendships and relationships.

Lafferty et al., (2013) found that mutual support and companionship were important to their participants, and that the absence of relationships led to loneliness. Intimate relationships were also noted to be a pathway to social status and acceptance. Similar findings were found by English and Tickle (2018) in their qualitative meta-synthesis of 14 research studies on relationships of people with intellectual disabilities. In addition, they found that the physical or sexual expression of love was not considered important by all participants, with some explicitly saying that they were aware that support staff or their families disapproved of this and reprimanded them for it. They found that people with intellectual disabilities often spoke of the restrictions placed on them by services, such as rules about no overnight guests and in general the relationship support they received was minimal.

In a different meta-ethnographic synthesis of qualitative studies published at the same time, Whittle and Butler (2018) reviewed 16 studies on sexuality and relationships of people with intellectual disabilities and found similar results. One of their key findings was that people with intellectual disabilities are often 'under others' power' (p.75) when it came to conducting their relationships, by which they meant living with service restrictions, being monitored, experiencing pressure to end relationships, etc.

This research study aimed to build on previous research by attempting to exploring relationship issues in some breadth and depth with 40 adults with intellectual disabilities in England.

3 | METHOD

The data for this study were 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 10 specialist dating agencies and 40 family carers and support staff. Findings from the other studies are reported elsewhere (Bates, 2020; McCarthy et al., 2020). The whole research programme ran from October 2017- April 2019.

3.1 | Participants

Forty adults with intellectual disabilities were interviewed: 20 men, 19 women and 1 said 'other'. Their ages ranged from 22–71.

75% (30) were white British, and 25% were from BAME communities (4 Black British, 4 Asian and 2 were of mixed heritage). This means that BAME people with intellectual disabilities were well represented in this study, as only 13% of the UK population is from a BAME community (Race Disparity Unit, 2020).

Just over half of the sample (23) were in a relationship at the time of the study. Five of the interviews conducted were dyadic, with both halves of a couple present. The rest were carried out with individuals.

Despite considerable efforts to recruit people with intellectual disabilities who had relationships with people of the same sex (whether they openly identified as gay or not), our sample was overwhelmingly heterosexual: 38 said they were attracted to the opposite sex, 2 to the same sex.

This research project incorporated a number of different elements of inclusive research practice: we had a paid consultation/advisory group of adults with intellectual disabilities who met regularly to help shape the interview schedule. They also advised on how we might best recruit participants and helped extensively with dissemination through accessible events and producing video material.

All of the study participants had capacity to consent, which was sought using information sheets and consent forms, in easy read versions (including the use of pictures). Confidentiality, anonymity

and voluntariness were stressed to all participants before and during the study. We were aware that some participants might find it upsetting to talk about the difficulties they experienced in finding romantic relationships, so we arranged for support to be in place for them if they felt they needed it, though in the event, none did.

3.2 | Data collection

Semi-structured in-depth interviews were used in this research, because they have a focus and structure, but allow for the sometimes necessary deviation from the format, for example follow-up questions, re-phrasing for clarification. Thus, they offer an excellent opportunity for adults with intellectual disabilities to express their views (Ottmann & Crosbie, 2013).

Questions were devised to be relevant to the participants' experiences, as far as we could anticipate them and they were direct, specific and mostly open-ended. In long interviews, there are inevitably differences in depth of questions and answers. As intellectual disability is an umbrella term which encompasses a wide range of abilities and communication styles, certainly not all our participants answered all questions with the same degree of fluency or, indeed, interest. Some questions were relatively straightforward, for example *Do you know what a 'dating agency' is?*, whilst others were more abstract and complex *Can you say what love means to you*?

Hollomotz (2018) argues that researchers can get the most from people with intellectual disabilities by respecting what they have to offer and having faith in their ability to give accurate and meaningful accounts. This was the underpinning principle of this research project. We found that our participants were generally very willing, and able, to articulate what love and loving relationships meant to them. They also had insight into what the main barriers were for them in meeting partners and sustaining relationships and ideas for how they could be overcome.

Interviews were generally long, with an average length of 68.2 mins (range 23–100 mins). There was no particular difference in the length of the interviews of women compared to men (average 67.2 mins vs 65.2 mins), but, as might be expected, the interviews of couples were considerably longer than those of individuals (average 82.4 mins). It is recognised in the literature that people with intellectual disabilities may not be able to concentrate in research interviews for long periods and researchers should be alert to this (Hollomotz, 2018). In this research study, all interviewees were offered short breaks and/or the option of continuing the interview on another occasion, but few wanted to do so. Most of our participants were very engaged with the topic of the interviews, they wanted to share their views and thus gave their time generously. Previous research suggests that people with intellectual disabilities often want to engage in research to help improve the quality of lives of other people with intellectual disabilities (McCarthy et al., 2017, McDonald et al., 2013.

3.3 | Data analysis

The stages of data analysis were as follows: interviews were audio recorded and transcribed. Two researchers independently reviewed and used open coding on each transcript using the thematic analysis procedure outlined by Braun and Clarke (2006). Codes were discussed between researchers and a high level of agreement was found in the initial codes. As stated by Braun and Clarke in their later work on thematic analysis (2019:592) coding involving more than one researcher should be 'collaborative and reflexive, designed to develop a richer more nuanced reading of the data, rather than seeking a consensus on meaning'. In this instance, however, through discussion and reflection, we found it relatively easy to reach consensus. Axial coding was used to identify the connections amongst the open codes. The resultant codes were clustered into sub-themes, and sub-themes were then grouped in terms of similar meanings across all participants, so that main and over-arching themes could be created which reflected the whole group.

The thematic analysis sought to offer a detailed understanding of both the themes which emerged across interviews and from the individuals' own accounts, in an attempt to build up a particular pattern of shared meaning across the whole data set.

As with all successful qualitative analyses, the authors sought to make defensible inferences from the rich, first person accounts of the lived experiences of participants. Whilst we did not engage in formal respondent validation or member checking, as a strategy for achieving trustworthiness and credibility the authors widely shared their findings with people with intellectual disabilities through accessible workshops and videos[1] and it has been clear that many recognised their own experiences in our research findings. For example, we held two half-day workshops in different parts of the United Kingdom. Interest in these was very high, with demand for (free) tickets exceeding supply. At each event, we had approx. 50 people with intellectual disabilities, some with staff or family support. We presented the research findings in an accessible way, using easy read information and video and facilitated small group discussions to get people's feedback. Many of the participants with intellectual disabilities contributed from the floor, speaking of their own experiences, which resonated with those of the research participants.

3.4 | Ethical issues

A favourable ethical opinion was obtained from the SCREC (Social Care Research Ethics Committee) REF No 17/IEC08/0053. There were no particular ethical concerns identified by the REC.

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[1]One video features existing dating agency service providers and people with intellectual disabilities who have used their services. It can be viewed here https://vimeo.com/336573029. The other, more general video made for, and with, people with intellectual disabilities discussing how important relationships are for them is available here https://vimeo.com/332887161
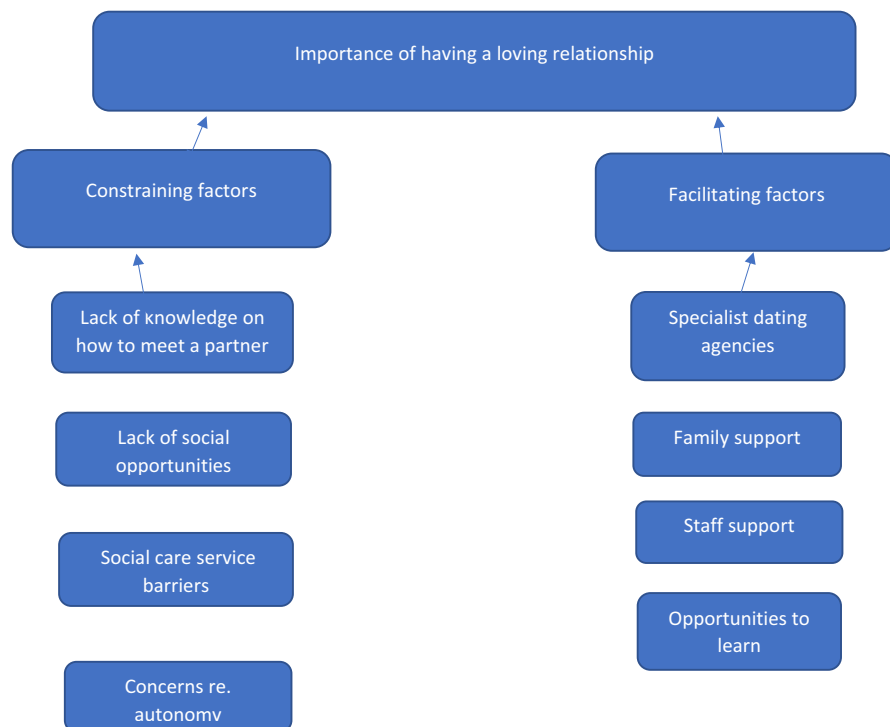
FIGURE 1 Themes arising from qualitative data

Participants were recruited via adult social care agencies and were thus introduced to the study by known and trusted workers (McDonald et al., 2013). To counteract any possible resulting acquiescence, the research team ensured that they went through participant information and consent procedures slowly and carefully with each individual.

The main ethical issue which arose during the course of the study was the debate amongst the research team about the ethics of interviewing established couples separately or together. We could see ethical arguments for and against both methods (e.g one half of a couple feeling inhibited to speak openly about their partner whilst they were in the room vs the discomfort of a researcher interviewing someone alone, already knowing personal things about them, because their partner had mentioned them in a previous interview). This had not been picked up as an issue by the ethics committee, so it was up to the research team to determine. In the end, the research team decided it was best to interview couples separately, except where they expressed a strong wish to be interviewed together (which 5 did). Time constraints and our wish to include as many participants as we could prevented us from adopting the method employed by Lafferty et al., (2013) in their similar study, namely interviewing people both as couples *and* separately.

3.4.1 | Findings

As Figure 1 demonstrates, the main over-arching theme of the findings was the very high value our participants placed on having a loving relationship. Within this, there were two main strands of findings: factors which constrain and factors which facilitate relationships.

The importance of having love in your life

Most of the participants, men and women, those in relationships and those who were single, strongly stated that love, and having a loving relationship, was very important to them. They were also able to articulate why. One or two participants gave humorous or playful answers, for example:

> Love is… saying cute names… when I say I love my girlfriend, I love her like she's my universe, she's everything…But like, I always say to her, "I love you until infinity and beyond, no return." She can't beat that. You can't beat infinity.

But most people spoke seriously about the importance of love in the abstract and the actual consequences of being in a loving relationship. For example, people described mutual support as being very important:

> I'm loving the relationship, because we both help each other when we're out together. I like that situation, that's what encourages me more to keep it going.

> Someone who cares about me, has my back, enjoy moments with, be with someone I really like and who feels the same about me.

Others emphasised the confidence and self-esteem they got from being in a relationship:

> It makes you feel confident, it makes you feel happy.

It feels good that there's someone you can come back home to and someone you can grow old with.

Some participants placed a high value on what they personally gained from their relationship:

Someone to care for you, help with your ups and downs. Someone to comfort you and hug you, tell you everything's going to be okay and that. Yeah, it's just really nice to have that.

Whereas others concentrated more on what they felt they were able to offer the other person:

Love to me is caring for people. No, caring for a person.

I like buying things and stuff like that, or...like taking them out for a meal...surprising them or buying them flowers and stuff.

If she's not well, I make sure she's alright.

Many participants were able to describe, not so much the practical, mutually supportive aspects of relationship, but rather they expressed the sheer joy of loving and being loved:

I would say if others have the opportunity to achieve what we have, then I would say grab it with both hands and don't waste time.

I say, love is a wonderful thing.

Love brings you happiness, brings you contentment.

Love makes me feel good inside and my heart is fixed.

As might be expected, many of our participants had lived for long periods of their adult lives without a partner, and thus they were well able to articulate the feelings that came with living without love. They described how their lives were diminished through loneliness:

I lived on my own for ten years and that was very lonely.

Sometimes I get lonely and I think if I had got somebody who I could trust it would make me more happier.

I can't imagine spending the rest of my life on my own, growing old on my own, I don't think it would be the nicest place.

Others described how their lives were diminished through the feelings of exclusion they experienced by not having a normative adult relationship for long periods or permanently:

I felt so excluded because I wasn't having the babies, I wasn't living with anyone, in a relationship with them. I was off on my own. I felt so excluded.

I had to find myself jealous of everyone else.

The fact that people generally placed a high value on being a relationship did not mean that they were unaware of the downsides. Some families and staff members who took part in the linked projects in this research programme felt that people with intellectual disabilities often were unrealistic about relationships, having an overly romanticised, 'Disney' view of relationships (Bates et al 2020), but we found that was generally not the case when we spoke to people with intellectual disabilities themselves. On the contrary, they had a balanced view and were not blind to the realities of relationships. Indeed, some had had past relationships which were abusive, difficult and very challenging:

My ex-husband – we had a child together, but he was such a horrible man, he was abusive and a cheater. He cheated on me loads of times when I was pregnant.

The police came and everything, he got arrested and I got a junction[2] out of him as well

Others, who had not necessarily had such negative experiences, nevertheless had insight into the different phases and stages that long-term relationships go through. People understood that the efforts made at the outset, may not be sustained, for example:

You dress up all nice for the first date and by three months, you're in your leggings with no makeup on.

Some participants used metaphor and simile, for example '*Love is like a roller-coaster*' to describe the process and others understood that sometimes effort and determination was required to sustain a relationship:

We do have our ups and downs, we have our differences, but the key thing is just work through it, no matter how tough or bad the situation is.

As can be seen above, despite their intellectual and communication challenges, many participants had, and were able to articulate,

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[2]A legal injunction, which will state that someone must keep their distance and refrain from contact.

a sophisticated understanding of love and loving relationships. They were also able to say what either prevented or supported them, and their peers, from achieving their goals.

3.4.2 | Constraining factors

Lack of knowledge on how to meet a partner

The first thing which made it hard for participants to realise their relationship goals was that many simply did not know how to meet a partner in the first place and they had not been supported to find out. Some had tried to be proactive and opted for the only avenues they were aware of, that is mainstream dating sites or introduction services like speed dating. For all our participants, such mainstream, especially online, dating experiences proved to be very negative. Actual dating agencies were prohibitively expensive and mainstream speed dating proved to be a frustrating experience:

> You have to be really, really quick, it was like a job interview…it didn't work, because it takes me about half an hour to get my words out.

None of those who had tried online dating had positive experiences:

> It was extremely bad, I think it's full of weirdos out there.

> I have been on Tinder, but I didn't have a very good experience. This guy said he liked me and all that, then he started to send me pictures of his you-know-what.

Either through personal experience or through hearing about the experiences of others, participants felt that the risks of online dating outweighed the benefits for them:

> You never know if they're going to be a paedophile or a murderer.

> It could be somebody pretending to be somebody else.

Lack of social opportunities

A particular issue for our participants was a lack of naturally occurring opportunities to meet potential partners. They spoke of a lack of social opportunities; a perennial problem, but one that has become worse since austerity cuts to social care services (Malli et al., 2018). Those who lived outside big cities found that a lack of public transport curtailed any social opportunities they might otherwise have been able to attend. Similarly, a lack of finances was also a barrier, with many simply not being able to afford relatively modest activities ('*It costs £12 for cinema ticket in town, I can't afford that*'). Very

few of our participants were employed and thus were not able to meet a potential partner at work, as many people do (Nolsoe, 2020). Though some attended educational or day opportunity services, they invariably had known the other people there for many years, sometimes from their school days and so tended not to see them as potential dating partners.

Social care service barriers

Many of our participants felt that staff numbers were a constraint on their freedoms:

> If I want to see my boyfriend, it depends on the staffing really. It depends on how many staff is on, cause there is six of us living here now and, you know, we need all the help we can get from staff- there's a diabetic, there's autism, there's other people with learning disabilities, it's hard.

Staff shift patterns were also cited as reasons why people with intellectual disabilities could not socialise in the way they wanted to, with social events finishing too late in the evening for day staff to continue to support people.

Social care staff have to abide by the rules and regulations of their employing bodies when it comes to people with intellectual disabilities having their partners stay overnight (Bates, 2019). In this study concerns were reported about the rights and privacy of any co-residents, when one person in a household wanted their partner to stay over (not something that other adults tend to worry about when they live in shared houses). Partners staying over also raises potential safeguarding concerns and thus many people with intellectual disabilities find their freedoms in this area restricted:

> If I want to stay with my boyfriend, I have to clear it with staff and I think they have to do a check thing or something. And do a safeguarding if I'm staying out.

Some of our participants expressed concerns that the staff who supported them were not proactive in offering relationship support. By this, they meant that staff did not offer support (though may give it if requested), nor was it a subject that was regularly talked about. Consequently, people did not know what was and was not reasonable for them to expect:

> 'I don't know how much support staff can give me around relationships.

Similar concerns about a lack of proactive support were made by the parents and family carers in our linked study (Bates et al in preparation).

Other participants seemed to have a clearer idea about what they wanted and expected from staff and were frustrated when such support was not forthcoming:

Staff should have done more…and they're supposed to… Like maybe assist you more to find someone, to go out there and help you. And if they couldn't do it, then try and find someone else who could do it.

Some participants expressed concerns about staff not being the right sort of person for them to talk to. This was sometimes because of age differences, for example '*if they were older…if they had been through things, it makes much difference. But if they're young, they don't understand*' or where women with intellectual disabilities wanted support from women staff, for example '*I wouldn't want to talk to a male, because it's like woman-to-woman is better*'.

Concerns regarding autonomy

The final constraining factor which emerged as a strong sub-theme related to the adults with intellectual disabilities expressing concerns over infringements on their rights to exert their autonomy. They complained about surveillance, lack of privacy and interference:

Being too watching, too overpowering and interfering as well'.

I just don't get no privacy with my boyfriend…staff make sure that I'm ok and make sure we're fine and stuff like that.

I need to tell them [staff] beforehand what I'm going to do and everything.

Some participants expressed in strong terms (deduced from their tone of voice, the emphasis in their speech) their resentment at both support staff and parents making decisions about relationships for them, for example:

I've experienced that often… having people overpowering me, deciding things for me.

A minority of the more articulate participants were able to explain how being prevented from making their own decisions was, in effect, preventing their personal growth into autonomous adults:

I know my family care, but they shouldn't stop me, because I'm an adult, like I'm human, let me make my own mistakes and then I know, okay, that was a mistake… But I don't know if it's going to be a mistake if I don't try…

3.4.3 | Facilitating factors

Participants were also asked what kinds of positive relationship support they had received and/or would like to receive. This was felt to be important because those who support people with intellectual disabilities need to know what kinds of help they actually appreciate.

Specialist dating agencies

The first issue raised was strong support for dating and friendship agencies especially for people with intellectual disabilities (see McCarthy et al., 2020 for more details.) Unlike their experiences with mainstream dating services, which were very aversive (see above), the specialist agencies were found to be very supportive:

The support we had was fantastic.

They'd sit… a few tables away, so we had the support, but we didn't have someone sat in between us over a candlelit dinner.

However, it is important to note these services did not work for all our participants. There were particular difficulties for people with mild intellectual disabilities who complained about being matched for a date with people less able than themselves; the agencies generally had far more male members than female, meaning that heterosexual men could wait a long time for a date; likewise those who were looking for same-sex partners were similarly disadvantaged.

Family support

Some participants found strong support from their own families, and for the most part they were talking about their parents, though occasionally an adult sibling was mentioned. They described receiving both practical and emotional support to seek out a partner and to maintain a long-term relationship, up to and including marriage (though this was rare):

We're very blessed in the sense that we have enough support, we have… We've got a good family network.

My mum was just absolutely wonderful when we wanted to get married…really, really supportive.

Occasionally participants would explicitly say that they only sought relationship support within the family, for privacy reasons:

I'll talk it out with my mum…I don't want to get the staff involved, because it's a family affair.

Social care staff

Some people with intellectual disabilities gave the impression of strong and warm relationships with social care staff in which they felt supported with respect to their relationship: '*Staff are really happy for me, as long as I am happy, they're happy as well*'.

Others described staff as approachable and sources of sound guidance, for example '*I can talk to the staff…they do give good advice*'.

As with some parents, some support staff were willing and able to offer the practical support that some participants needed to be able to maintain their relationships:

> Staff make sure that I make arrangements to meet him and, you know, give me the support, the time and everything, yeah, they're very good.

Opportunities to talk, share and learn

Some participants spoke very positively about the opportunities they had been given to learn about relationships, including educational workshops, support groups, attending events designed to facilitate discussion about all aspects of adult relationships, for example '*It's good to talk with other people and you can see you are not the only one with this problem*'. Some of these opportunities were provided by the same organisations who ran the specialist dating and friendship agencies, others were provided independently, for example by the *Supported Loving*[3] network.

4 | DISCUSSION

The importance of this research lies in the dual nature of the exploration - on the one hand we explored with people with intellectual disabilities the practical support they wanted and needed to find and maintain relationships. But more significantly, we attempted to do something which is all too rarely done with people with intellectual disabilities, that is, to explore their inner world. We asked abstract questions about what it means to love and be loved and many of the participants were able to reflect on and address these questions. As can be seen above, (and occasionally elsewhere, e.g Turner & Crane, 2016) their responses suggest that their romantic and emotional lives are as rich as anyone else's.

Whilst people with intellectual disabilities, like everyone else, have the right to be protected from actual abuse as far as is reasonably possible, there is no logical, moral or ethical reason why they should be protected from the 'everyday' highs and lows of relationships. Adults with intellectual disabilities will, like everyone else, sometimes make bad choices, sometimes choose a partner who turns out to be a grave disappointment, may love someone dearly, but still get their heart broken. These things are part of the human experience and whilst painful, there is no reason to prevent adults with intellectual disabilities from exposure to them. (In 2016, Spanish researchers recognised this fundamental point by calling their study on relationships and people with intellectual disabilities '*Being alive*' (Rojas et al., 2016)). Whilst professionals and parents often emphasise the risks inherent in dating and relationships (see for example Rushbrooke et al., 2014), adults with intellectual disabilities themselves tend to emphasise the benefits and in this research project, they had a generally positive view of relationships

as life enhancing. They did not, on the whole, see relationships as being a source of potential disappointment, unwanted pregnancies or sexual abuse, as support staff and family carers often do (Bates et al 2020). It is important for those who support adults with intellectual disabilities to recognise and work with this tension, as otherwise questions need to be asked about whose agenda and best interests are being served. Hollomotz (2011) has convincingly argued that having sexual vulnerability as the dominant discourse does not ultimately serve the best interests of people with intellectual disabilities.

It was apparent in this study and has also been found elsewhere (Björnsdóttir et al., 2017; Lofgren-Martenson, 2004) that support staff and family carers often act as 'gatekeepers' in the lives of adults with intellectual disabilities. In this study, they were sometimes gatekeepers of experiences, in that they sought to protect adults from risks commonly faced by other adults, as well as prevent them from having normative life experiences, for example partner spending the night, going out late in the evening. They sometimes acted as gatekeepers of knowledge, in that in that people with intellectual disabilities were not given the full information they needed about social and dating opportunities. They also sometimes acted as gatekeepers regarding basic rights of individuals, for example by not informing people with intellectual disabilities of their rights to autonomy and privacy and their right to protest against unfair treatment.

This study has implications for improvement in policy, practice and attitudes. Our findings suggest that the most effective thing for those who support people with intellectual disabilities would be to seek to reduce or eliminate the constraining factors outlined above. This would involve having (proactive and reactive) conversations with people with intellectual disabilities about how they might be able to meet a partner. If this were part of individuals' formal support plans it would give it more priority and be acknowledged by all those around them that it was a valid and important concern. This should go hand in hand with seeking to facilitate more social opportunities with a range of people. In the United Kingdom, legislation (e.g., the Care Act 2014) now recognises the reduction of isolation as an eligible support need; therefore, such help should be provided if individuals need this.

Family carers and support staff may understandably feel powerless to address the issues outlined above regarding understaffing, staff shift patterns and the rules and regulations which inhibit relationship formation and maintenance. However, what they can do is to make sure that senior managers and commissioners of such services are made aware of the impact of their decisions and actions and seek to hold them accountable. The Care Quality Commission has published guidance on what is expected in this area; inspectors can ask questions and providers can be held accountable if not supporting sexuality and relationships (CQC 2019).

Family carer and support staff can also play an important role in empowering people with intellectual disabilities to find their own voice and to speak up and speak out about the conditions they face

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[3]For details of the *Supported Loving campaign*, see https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving

and the resulting impact on their lives and relationships. Finlay et al., (2008) point to the importance of (amongst other things) paying attention to the small, frequent everyday areas where choices can be respected and decision-making enhanced. In the other studies linked to this project, staff and family carers gave examples of how they empowered people with intellectual disabilities by genuinely listening to their concerns and desires and trying to be careful not to abuse the influence and power they inevitably had over their lives (Bates et al., 2020a, b). This is clearly linked to the concerns raised by people with intellectual disabilities in this study about autonomy and how they are prevented from exerting choice and control over their lives.

The corollary of eliminating the constraining factors is to simultaneously seek to build on the facilitating factors outlined above. Some of our participants spoke very warmly about the relationship support they had received from individual staff or family members and it is clear that many others would appreciate the same kind of assistance and encouragement, in both practical and emotional ways.

There was low representation of people with intellectual disabilities who wanted or had same-sex relationships in this study, which was disappointing to the research team who made concerted efforts to recruit a diverse sample. The relationship needs of people with intellectual disabilities who are not heterosexual remain relatively unexplored, though sexual activity of men with intellectual disabilities who have sex with other men has received considerable attention, but more so in the past rather than now (e.g. Thompson 1994, Cambridge, 1999). The lives of women with intellectual disabilities who are romantically and sexually interested in other women continue to be under-researched (Wilson et al., 2018). Bisexuality amongst people with intellectual disabilities has also received very little attention, with Bates, 2020 a notable exception.

It has been noted in the literature that ' there is not a prominent body of research about people with ID who either identify as lesbian, gay, bisexual, transgender, intersex or are questioning (LGBTIQ) their sexual orientation' (Wilson et al 2016:172) and the study reported here does very little to change that. In one of the linked studies, we reported on innovative practices within specialist dating agencies that embraced equality and diversity in both gender identity and sexual expression (McCarthy et al., 2020). However, in this study, gender identity was not discussed by participants at all (even by the person who identified as 'other') and sexual expression was almost entirely spoken about in in terms of couple relationships, not in a broader context. Even within the data on couple relationships, there was relatively little said on gender roles and gendered behaviour, other than abusive relationships being reported more (but not exclusively) by women.

Finally, our participants spoke very highly of specialist dating and friendship agencies (which often also provide educational and social events) and this points a clear way forward. Where these exist locally, then their use is strongly recommended for as many people with intellectual disabilities as want to join them. Where they do not exist locally, then both staff and family carers are encouraged to consider working with people with intellectual disabilities to form their own services. Evidence suggests that the existing services are very willing to share expertise and assist others in setting up their own services (McCarthy et al., 2020) and the authors have a produced a video to encourage the development of this service model (see the footnote on p.x for details).

5 | LIMITATIONS

Our participants were a self- selected group and so it is unsurprising that people who chose to participate in research about relationships were interested in, and valued, them. Also just over half of our sample were in a relationship at the time of their participation, a much higher proportion than is usual for adults with intellectual disabilities (Emerson et al., 2005). Therefore, their views and experiences should not be seen as being representative of all adults with intellectual disabilities.

The minimum age for participants in this study was 18 (a condition of the funding) and it is regrettable that we were not able to recruit anyone in the 18–22 age range. Future research into the experience of those with intellectual disabilities in this early stage of adulthood is important. In the general population, first and formative romantic and sexual relationships are known to have a lasting impact on people's lives (Reissing et al., 2012; Collins, 2003) and thus, it is important to have a better insight into these for people with intellectual disabilities.

By choosing interviews as our research method, we have effectively excluded those with more severe and profound intellectual disabilities. Their experiences when it comes to intimate relationships thus remain under-researched and under-valued.

6 | CONCLUSION

Historically, the emotional and psychological needs of people with intellectual disabilities have been neglected (Sant Angelo, 2000), with only their basic physical needs being seen as important. It has never been, and still is not, a priority to ensure that people with intellectual disabilities live rich and full adult lives in all senses. Intellectual impairment may close off some avenues of enrichment (academic attainment, professional achievement or participation in some artistic or cultural activities, for example). All the more important, then, that those who support people with intellectual disabilities should seek to enable them to find pleasure and meaning wherever they can in life, and a loving relationship is surely one fundamental aspect of this.

DISCLAIMER

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