

Exploring support for adults with learning disabilities to find loving relationships

RESEARCH FINDINGS

It has always been difficult for people with learning disabilities to assert their adult status and engage in loving and sexual relationships with others

People with learning disabilities in this study reported that love, and having a loving relationship, was very important to them, but that they still faced many barriers

Both social care staff and parents of were supportive of adults with learning disabilities having relationships, but were concerned about abuse and exploitation

The under-funding of services is itself a barrier to full participation in adult life

Specialist dating and friendship agencies play a key role. However, LGBT+ people with learning disabilities face more obstacles than most and some agencies struggle to meet their needs

Video resources now exist for people with learning disabilities and social care staff practitioners to assist with developing and maintaining relationships

BACKGROUND

FINDINGS

In the past, institutionalisation (with strict gender segregation) and compulsory sterilization were used to prevent adults with learning disabilities from enjoying opportunities for a full life including social and sexual relationships. Even though, in more recent decades, such practices and ideas have fallen into disrepute, adults with learning disabilities still often find themselves in a position where they are not given the support they need to find, and keep, a partner, despite this being a life goal for many.

Evidence suggests that LGBT+ people with learning disabilities experience particular challenges when it comes to relationships.

This study aimed to increase awareness and understanding of the importance of formal and informal support for adults with learning disabilities to form loving relationships.

Methods

The study involved:

- in-depth semi-structured interviews with 40 people with learning disabilities (using both individual and couple interviews – according to participant preference) to identify what was individually and collectively important to them when it came to relationships and support for relationships;
- interviews and focus groups with 90 people to generate knowledge about how key stakeholders, including people with learning disabilities, their families, and social care practitioners, understand the key barriers to support;
- analysis of data from 10 dating agencies.

Resources were developed, in partnership with people with learning disabilities, to raise awareness of the importance of relationships and how they might be supported.

Participants reported that love, and having a loving relationship, was very important to them

Despite it not always being easy to talk about, and despite the fact that some participants were not very articulate, the research team were nevertheless able to obtain very rich data from the interviews with people with learning disabilities.

Consequently, through a detailed qualitative analysis, they were able to isolate the reasons why relationships were so valued including:

- for mutual support (with several couples reporting that they were able to do things together, which they could not have managed alone);
- to enhance confidence and self-esteem (the feeling of being chosen by, and special to, another person);
- the satisfaction that comes from being able to give care and attention to someone, as opposed to always being on the receiving end; and
- from the sheer delight of loving and being loved (“Love brings you happiness, brings you contentment... love is a wonderful thing.”)

Participants were well able to say how they felt without loving relationships; they felt their lives were diminished. People described long-term loneliness, a dread of the future if they had no one to share it with and a determination to find a new partner if they lost the one they had: “I just don’t want to be on my own anymore.”

Participants also expressed how being denied the opportunities they wanted for relationships

made them feel socially excluded. For example, one participant described how she felt seeing other young women her age paring off, living with partners, having children, when “I was off on my own. I felt so excluded.”

Despite the importance of relationships, many participants described the many barriers they faced

Barriers included not knowing how to meet a partner (some participants simply did not know how to go about it and had not been advised by social care staff or parents) and having bad experiences if they tried to follow mainstream routes. Many had tried online dating sites, but had universally found it problematic (ie they were ignored) or abusive (they were mocked or humiliated).

The majority of participants felt that they lacked social opportunities. Sometimes this was caused by transport barriers (people were not able to travel independently to venues and/or public transport was very restricted, especially in rural areas); sometimes people felt that they lacked the money to pay for transport and social activities. LGBT+ participants wanted to socialise with other LGBT+ people, but there were few opportunities for this within learning disability services and they worried they would not be accepted in mainstream gay venues.

Having opportunities for a social life was extremely important, not only to ward off the loneliness which some said they felt, but as an opportunity to meet potential partners and to develop the necessary social skills for relationship development.



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It was also apparent from analysis of the data that barriers to relationships were caused by social care services. Examples of this were services which ran very tight rotas, with the minimum number of staff possible. This meant that there were too few staff to support people to leave their residential accommodation and there was a lack of one-to-one support. As individuals are unlikely to be able to develop and maintain an intimate relationship whilst constantly in the company of their fellow residents, this has obvious consequences.

Staff shift patterns were also cited by all participant groups (people with learning disabilities, staff, parents and dating agency personnel) as being detrimental to the social and personal lives of adults with learning disabilities. This was particularly the case for people wanting to socialise in the evenings. Having to leave events early to fit in with staff rotas effectively meant that many people with learning disabilities were prevented from normative adult experiences.

Some staff and families were very supportive; others were not and could be difficult about relationships

Participants reported mixed experiences, with some having received good advice, emotional and practical support. Some participants found their family members or support staff to be approachable and non-judgemental. Others reported the opposite and complained that when they sought support, at best it was not forthcoming and at worst, it was “downright obstructive”.

Concerns seemed to focus on not being respected as an adult and allowed autonomy (“I’ve experienced that often... having people overpowering me, deciding things for me.”). This includes the autonomy to make mistakes regarding relationships. Some participants were acutely aware that parents and support staff meant

well and were trying to protect them, but felt they wanted to make their own decision, even if they had negative consequences (“I’m an adult, like I’m human, let me make my own mistakes”).

Other concerns expressed in relation to social care staff were that staff were passive, rather than active or pro-active, when it came to relationship support and thus the people with learning disabilities did not know what they could or should expect from staff in this area.

KEY FINDINGS FROM SOCIAL CARE STAFF

Staff were aware of their important role in supporting people with learning disabilities to have relationships, but felt they needed more training and support from managers (and other professionals)

That such training and support is still not being routinely provided to frontline staff suggests it is not a priority for service managers and commissioners.

This leads to staff adopting risk-averse approaches; when they do not know how they should be supporting service users, they err on the side of caution, for fear of getting it wrong and being held personally responsible: “I definitely need to know more about “what” the system allows”. A common example given by both staff and people with learning disabilities was whether or not it was allowed for an adult with learning disabilities to have a partner stay overnight.

Staff were concerned about people with learning disabilities being vulnerable to abuse and exploitation in relationships (especially women)

Combined with the lack of training and managerial guidance noted above, staff expressed strong concerns about the vulnerability of people with learning

disabilities in relationships, especially if they were seeking or had relationships with non-disabled people. This was particularly the case with women with learning disabilities and was cited by a number of participants as being the reason why women did not receive as much encouragement as men with learning disabilities.

Many staff felt parents of adults with learning disabilities were often barriers to them having relationships

Many of the staff felt that parents found it difficult to accept the fact that their son or daughter with learning disabilities may have the same sexual and relationship desires as other adults: “Parents are so used to being so protective that they often cannot see that their child has become an adult.”

However, many staff also reported that there had been a generational shift, with parents of younger adults with learning disabilities more accepting and supportive of relationship, compared to parents of older adults. This has been reported in the literature for many years and still appears to be a common perception.

KEY FINDINGS FROM PARENTS OF ADULTS WITH LEARNING DISABILITIES

Contrary to the views of the social care staff, parents in the study were on the whole very supportive of their sons and daughters having relationships

The parent participants reported being supportive both in theory (“I would love a relationship to happen”) and in practice. It is important to note that the parents were a self-selected sample, who opted into the study and thus are not representative of parents as a whole. The kinds of support that parents reported giving to their sons and daughters involved practical support, such as helping them to

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arrange dates, driving them to social events, as well as emotional support (“When she decided she was going to break up with him, we had to help her through the whole process”).

Like staff, parents were highly attuned to the possibility of abuse and exploitation

These concerns related to relationships generally, but, again, similarly to staff, concerns were heightened for those with daughters rather than sons. They were most acute when it came to the idea of relationships with non-disabled people: “I would be deeply concerned if she ever had anything other than a friendship with someone without a learning disability, due to the imbalance of power.”

Parents thought staff were often not prepared to take any risks regarding socialising and relationships

It is interesting to note that while social care staff thought parents were often over-protective, the parents thought the same about support staff.

KEY FINDINGS FROM SPECIALIST DATING AGENCIES

There is no known register of specialist dating agencies for people with learning disabilities. The research team had no prior involvement with the agencies, although some were known through their extensive contacts throughout the UK. They used the Supported Loving network to reach out to agencies and searched online. They approached all 11 known dating agencies in the UK at that time (10 in England, 1 in Scotland); 10 agreed to take part.

The agencies all gave far more support to people than a mainstream dating agency would

The agencies reported that they went far beyond simply matching people for dates. They provided preparation and support prior to any date, practical and emotional support during a date (through chaperones) and support after a date. They also provided ongoing relationship support, sometimes for many months and years. They frequently arranged social events and educational workshops for

their members. They occasionally offered support to social care staff and parents too.

Most agencies were part of a wider service or bigger organisation

This seemed to be important to their long-term development and survival. Small stand-alone dating agencies did not seem to be a financially viable model in the long term, as unlike mainstream dating agencies, they were unable to charge high membership fees.

All the dating agencies had a gender imbalance in their members and prospective members

One of the biggest challenges to all agencies was the fact that they all had far more men joining than women. As the vast majority of members were seeking heterosexual relationships, this posed an obvious problem. Agencies tried various strategies to recruit more women (i.e. discounts or even free membership for women, approaching women’s groups, putting on activities they thought might especially interest women), but the problem proved fairly intractable.

RESOURCES

Two videos were produced from this study:

LOVE IS A WONDERFUL FEELING

People with learning disabilities talking about the importance of being supported to have relationships, plus the views of social care staff and parents.

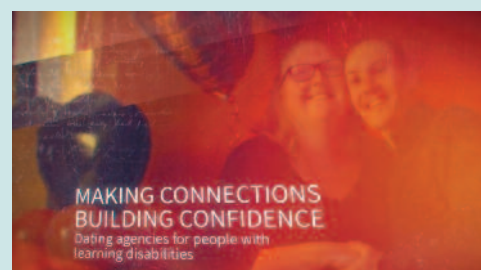
<https://vimeo.com/32887161>



MAKING CONNECTIONS BUILDING CONFIDENCE. DATING AGENCIES FOR PEOPLE WITH LEARNING DISABILITIES

People talking about the work of specialist dating and friendship agencies for people with learning disabilities and the important role they have in helping people live full adult lives.

<https://vimeo.com/336573029>



CONCLUSIONS & IMPLICATIONS

- Evidence suggests that adult social care rarely prioritises or facilitates loving adult relationships for people with learning disabilities. This is despite the fact that this research, like previous studies, clearly demonstrates that many adults with learning disabilities do want to find a loving, long-term partner.
- This study explored a key formal model of relationship support – the specialist dating agency model – but also looked at the more typical informal support provided by family carers and adult social care practitioners. A key feature of the study was including the views of adults with learning disabilities, exploring what they wanted and needed in terms of relationship support.
- Satisfaction with the specialist dating agencies was very evident among people with learning disabilities. They spoke very highly of the staff and volunteers who worked in them and of the social events which were put on for them. Adults with learning disabilities reported increased confidence and self-esteem as a result of their membership of these organisations.
- Their satisfaction with the more informal support they received from family carers and social care practitioners was more mixed, with both positive and negative experiences reported. Although concerns about abuse and exploitation were uppermost in the minds of parents and staff, adults with learning disabilities themselves viewed relationships, and the opportunities for potential relationships, within a more positive framework.

COMMENT

Members of the project advisory group with learning disabilities were asked for their views on the relevance of the findings from this research:

- “I think it could change the way people get support” (JA)
- “This research might help staff actually sit down and listen to what people with learning disabilities want, not tell them what they can have and can’t have” (RW)
- “At the end of the day people with learning disabilities have rights and choices and this research shows that” (CA)
- “I think this research will help organisations to take this issue on board” (JW)
- “I hope this research will help services to set up dating agencies – there isn’t one in Kent, is there?” (JA)

JOURNAL PAPERS

Bates C, McCarthy M, Milne Skillman K, Elson N, Forrester-Jones R, Hunt S (2020) “Always trying to walk a bit of a tightrope”: the role of social care staff in supporting adults with intellectual and developmental disabilities to develop and maintain loving relationships, *British Journal of Learning Disabilities*, Published online <https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12320>

McCarthy M, Milne Skillman K, Elson N, Bates C, Forrester-Jones R, Hunt S (2020) Making connections and building confidence: a study of specialist dating agencies for people with intellectual disabilities, *Sexuality and Disability*, Published online <https://link.springer.com/article/10.1007/s11195-020-09619-2>

For more information about the study, summaries of the findings and access to the free video resources visit www.kent.ac.uk/tizard/research/research_projects/new_research-pages/love_project.html

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

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The study represents independent research funded by the National Institute for Health Research (NIHR) School for Social Care Research (NIHR SSCR). The views expressed are those of the authors and not necessarily those of the NIHR SSCR, NIHR or Department of Health and Social Care,