

The Right to a Relationship

Addressing the barriers that people with learning disabilities face in developing and sustaining intimate and sexual relationships

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National Development Team for Inclusion

First Floor
30-32 Westgate Buildings
Bath BA1 1EF
T: 01225 789135
F: 01225 338017

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www.ndti.org.uk



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1. Executive Summary

People with learning disabilities want to develop and sustain intimate relationships just like everyone else, but they often face barriers to exercising this fundamental human right. Everyone has a right to develop and experience intimate relationships, which are an important part of personal relationships and include both romantic and sexual relationships.

These rights are enshrined in law, and research shows that positive, intimate relationships are good for us – and also that social isolation and loneliness, often experienced when people lack such relationships, is bad for us.

Focusing on the experiences of people living in Oxfordshire, our project set out to answer the following questions:

- 1) What barriers, resulting from the way support services are commissioned and delivered, do people with learning disabilities experience in developing and sustaining intimate relationships? Which of these barriers are unintended or intentional?
- 2) How common are these barriers among people with learning disabilities?
- 3) What commissioning and support practices help people with learning disabilities to develop and sustain intimate relationships?
- 4) What policy and/or practice changes are needed to address these barriers and promote the supportive practices identified?

Our aim was to provide evidence to make a convincing case for change within services and people's lives, and to use knowledge gained through the research to campaign for change.

This was a co-produced research project with self-advocates (Pam Bebbington, Jackie Scarrott, Dawn Wiltshire) and supporters (Lisa Davidson, Jess Tilling) from My Life My Choice; and researchers from NDTi (Vicky Mason-Angelow, Agnes Turnpenny, Anna Marriott) working together in all stages of the project. Doing research together taught us lots of new things. We believe this kind of approach is important so that local authority managers and providers are interviewed and challenged by people with learning disabilities who can share their lived experience of the issues being explored, not just professional researchers.

We collected data using a mixed-methods approach between May 2018 and January 2019:

- focus groups with 53 people with learning disabilities,

- semi-structured, interviews¹ with seven people with learning disabilities,
- an online survey to which 87 people responded (40 people with learning disabilities; 17 family carers; 22 support staff; 8 commissioners), and
- semi-structured, interviews with three local authority managers and two service providers.

People with learning disabilities want to have relationships. They are the same as people without learning disabilities: having different relationships – friendships, romantic and sexual relationships – is an important part of their lives. However, unlike people without learning disabilities, institutional and attitudinal barriers prevent many people with learning disabilities to exercise and enjoy this fundamental human right.

Our research found that people with learning disabilities experience many barriers in developing and sustaining intimate relationships. These include:

- Limited opportunities to meet potential partners. There are some clubs and social events organised by and for people with learning disabilities (such as Stingray Nightclub and Mates ‘n’ Dates in Oxford) but people often do not have the support to get to these.
- Some staff and family members prevent people from being in a relationship, or make it very difficult to stay in a relationship. Sometimes this happens on purpose but sometimes it is not intended. The problems that were identified included:
 - Rules of what is allowed and not allowed. Not all services have clear policies about how to support people’s relationships, and even if they do these are usually not written with people with learning disabilities.
 - Lack of support to go out, go on dates, visit friends and girlfriends/boyfriends.
 - People with learning disabilities are sometimes not treated as adults who have the right to relationships by people around them: sexuality is still a taboo and many people are overprotective.
 - Lack of knowledge and skills. Some services do not give staff training on how to support people in intimate relationships.
- People with learning disabilities themselves have limited knowledge about sexuality and keeping safe. Although there are accessible resources and services, people providing services, families, and people with learning disabilities are often not aware of these.
- Unsupportive friends and housemates can make it difficult for people to be in a relationship.
- Lack of money and transport to go out, visit partners, and go on dates.
- Intimate relationships are not seen as a priority when commissioning services; unless there are concerns about risks and safeguarding.

¹ Interviews were undertaken by a self-advocate and a supporter

We also found things that helped people to be in an intimate relationship:

- Being recognised and respected as adults with rights, the same as everyone else.
- Having supportive social and community networks: family, staff, advocate, friends
- Having knowledge about relationships and sexuality, and confidence to meet new people.
- Having a life with lots of opportunities to meet people and form relationships.

Sometimes providers struggle with supporting people to have intimate and sexual relationships because:

- Austerity and cuts to services mean that people do not get the amount of support they need.
- The difference between a bad decision/mistake and risky behaviour is not always clear. Providers have a duty to protect people from harm and worry about getting this right.
- They do not fully understand the legislation around capacity and consent, and they want to avoid taking any risks.

Based on the research, we have put together the following recommendations:

- 1) Relationships should be clearly addressed in person-centred support plans and be part of individual outcomes. This would also help make sure that enough funding and support are available to the person. They should be reviewed regularly.
- 2) There should be a more coordinated approach in supporting couples to ensure that the support provided meets their needs as individuals and as a couple.
- 3) Relationships should be part of Education, Health, and Care (EHC) plans, especially around transition. EHC plans should set out how and when young people are going to get sex and relationship education and start working towards future aspirations early. This is to help young people prepare for what they aspire to in the future.
- 4) Staff should have training in supporting people with intimate relationships. This training should not be just a one-off; it needs to be updated and refreshed regularly. There should be a network to help to co-produce, organise, and deliver this training and allow the sharing of good practices.
- 5) Adults with learning disabilities of any age should have access to sex education and relationship training. Also, schools and colleges should do more on sex and relationship education. Knowledge can help people be safe.
- 6) People with learning disabilities need to know and understand their rights. They also need to learn what to do when providers or carers are saying that they are not allowed to do something that, in fact, they are.
- 7) Local offers should extend to personal and intimate relationships and signpost people with learning disabilities, families, and services to available social events, activities, and services, such as clubs, dating agencies etc. This would also highlight where gaps are and help the local authority and organisations to target funding and activities.
- 8) Sexual health and family planning services should be accessible for people with learning disabilities and offer accessible information.
- 9) Providers and staff need to take the time to get to know people and open up conversations about relationships. They should find out about what people like, what they are interested in, and what they want from their lives. This can build trust and help with embarrassing and personal conversations.
- 10) Getting the right staff with the right attitude is important. Supporting relationships should be seen as part of a support worker's role and come up already in the job interview.

Based on our recommendations, NDTi and My Life My Choice would also like to suggest the following activities and where future research is needed:

- 1) Work with organisations to review their policies, find out how they actually support people with intimate relationships, and come up with ways of improving this.
- 2) Work with families and find out what help they need to support this area of people's lives.
- 3) Identify, quality-check, collate available resources about intimate relationships and sexual health, and make them accessible for people.
- 4) Clear guidance for people with learning disabilities about what their rights are in the area of intimate relationships. We have discussed this with the British Institute of Human Rights and would like to work with them to produce related resources.
- 5) Development of a charter about people with learning disabilities' rights to have sexual relationships - we have had conversations with the Tizard Centre at the University of Kent, Supported Loving, and Mencap's Sexuality and Relationships Manager about working together to develop this.



2. Literature Review

People with learning disabilities want to develop and sustain intimate relationships just like everyone else, but they often face barriers. Intimate relationships are an important part of personal relationships and include romantic and sexual relationships.

People with learning disabilities have a right to develop and experience intimate relationships. These rights are entrenched in law, including:

- The [Human Rights Act 1998](#): Sets out the right to marry and have children; and the right to respect for a family life.
- [Convention on the Rights of Persons with Disabilities](#) 2006, which the UK signed in 2009: This sets out and protects the rights of disabled people in all areas of life including those relating to marriage, family, parenthood and relationships.
Specifically:
 - Article 5: Equality and non-discrimination
 - Article 6: Women with disabilities
 - Article 8: Awareness – raising
 - Article 12: Equal recognition before the law
 - Article 19: Living independently and being included in the community
 - Article 22: Respect for privacy
 - Article 23: Respect for home and the family
- [Valuing People Now 2009](#) highlights importance of enabling people to form all kinds of relationships.
- [Care Act 2014](#) recognises personal relationships as an element of wellbeing.
- [Building the Right Support 2015](#) states that people should be able to develop and maintain relationships.

Positive relationships are good for us (Handley et al, 2015) and social isolation and loneliness can have a negative effect on mental and physical health (Luanaigh & Lawlor, 2008). Being denied the opportunity to form meaningful relationships can have a negative impact on health and wellbeing. Relationships take various forms from familial relationships to friendships, as well as intimate relationships.

The sexuality of people with learning disabilities has historically been a topic surrounded by taboos and stereotypes that either viewed people as ‘asexual’ – not interested in sexual relationships and in need of protection – or overly sexual and ‘locked away’ from society in long-stay hospitals and institutions (Johnson & Traustadóttir, 2005; Whittle & Butler, 2018).

We know from our own experiences and from reviews of the research in this area, that people with learning disabilities are no different from people without learning disabilities. Many want romantic and sexual relationships, including companionship, partnerships, sex,

marriage and children, but they often face many barriers when trying to develop these relationships, such as the disapproval of relatives or the lack of support from services (Healy et al, 2009; Brown and McCann, 2018; Whittle and Butler, 2018). These are such that only 3% of people with learning disabilities live as a couple, compared to 70% of the general adult population ([Mencap](#)).

In 2016 NDTi conducted a review of the evidence on the barriers that people with learning disabilities face in developing sexual and romantic relationships (Harflett and Turner, 2016). The research identified many barriers, including societal, staff and family attitudes, limited sex education, a lack of accessible information and few opportunities to meet people. One set of barriers that the review highlighted are those that arise as a direct result of the way services and support for people with learning disabilities is commissioned and delivered. Rules and practices in residential care and supported living such as those around curfews, visitors, overnight guests and single beds combined with limited privacy and a culture of risk aversion among staff can all get in the way of developing and sustaining sexual relationships (see e.g. Cambridge et al, 2003; Hollomotz et al, 2009; Bates et al, 2017a). Limitations in how support is delivered can make it difficult to meet people, develop and maintain relationships (e.g. not having enough support to go out, attend social events etc.).

More recently, Bates et al. (2017b; 2017c) noted that people with learning disabilities have the same aspirations for a companion to share experiences with as those without a learning disability, and highly value the companionship and support that a loving partner provided. Romantic love also has a reparative effect for those who have experienced some form of abuse. The authors also highlight that it is still common for people with learning disabilities to meet their partners in segregated environments, for example special clubs and residential services.

In 2016-17, Research in Practice for Adults (RiPfa) commissioned NDTi and My Life My Choice (MLMC) to co-deliver training to practitioners around supporting people to develop positive sexual relationships. The experiences of this small group of four trainers with a learning disability included:

- One person not allowed to cook his girlfriend dinner on Valentine's day because he had not been risk assessed by her supported living home
- One person only able to see his girlfriend who lives in supported living twice a month because there are not enough staff to support her to visit him.
- One person who is married and lives independently being told that her husband had to leave the room when her carer was there because of the terms of their contract.

The research evidence and the personal experiences of members of MLMC suggest that such experiences are common place. MLMC and NDTi believe that the rights of people with learning disabilities to have a sexual relationship are being breached frequently and systematically through rules, regulations, practices and policies being implemented by commissioned services and support.



3. Research questions

We believe that there are rules, regulations, policies, and practices in commissioned learning disability support that stop people from exercising their right to intimate – romantic and sexual – relationships. Our research therefore set out to answer the following questions:

- 1) What barriers, resulting from the way support services are commissioned and delivered, do people with learning disabilities experience in developing and sustaining intimate relationships? Which of these barriers are unintended or intentional?
- 2) How common are these barriers among people with learning disabilities?
- 3) What commissioning and support practices help people with learning disabilities to develop and sustain intimate relationships?
- 4) What policy and/or practice changes are needed to address these barriers and promote the supportive practices identified?

The research focuses on people living in Oxfordshire, and was conducted in to provide evidence to make a convincing case for change within services and people's lives. Knowledge gained through the research will be used to campaign for change by commissioners and providers; and to empower individuals to self-advocate for change in their own lives, through raising awareness and developing 'Charters for Change'.



4. Methodology

4.1 The research team and how we worked together

This was a collaborative research project with self-advocates (Pam Bebbington, Jackie Scarrott, Dawn Wiltshire) and supporters (Lisa Davidson, Jess Tilling) from My Life My Choice; and researchers from NDTi (Vicky Mason-Angelow, Agnes Turnpenny, Anna Marriott) working together in all stages of the project. The team created the data collection instruments together, self-advocates collected data with support, and the team analysed the data together. Regular face-to-face meetings were held to plan and discuss progress and emerging findings. All documents and communication were prepared using plain language and PhotoSymbols to make them as accessible as possible. NDTi and My Life My Choice developed the recommendations jointly and NDTi led on the writing the main report while My Life My choice led on developing the videos and the easy-read report.

4.2 Ethics

Ethical approval was sought and gained from DRILL's research ethics committee.

4.3 Data collection

Data was collected via a mixed methods approach over a four-stage process:

- focus groups with people with learning disabilities,
- semi-structured interviews with people with learning disabilities,
- online survey with questionnaires for people with learning disabilities, family carers, support staff and commissioners, and
- interviews with local authority managers and service providers.

4.4 Participants and procedures

Approximately 115 people participated in the project throughout the various stages:

- 53 people took part in focus groups;
- 87 people responded to the online survey (40 people had learning disabilities);
- 12 people were interviewed (seven had learning disabilities).

Although there were some overlaps between participants in the different stages (e.g. all interviewees also took part in focus groups etc.), we estimate that the research reached at least 65 people with learning disabilities. This section provides more detailed information about each stage and how we collected data.

Focus Groups

Focus groups were organised around eight self-advocacy groups run by MLMC in Oxfordshire between May and July 2018. Table 1 summarises the number of participants by location. A ninth focus group was planned but had to be cancelled because local support staff were not willing to cooperate with the research team (more on this in Chapter 6, Discussion).

Table 1: Focus group locations and participants

Location	Number of participants
Wantage	4
Oxford	5
Abingdon	8
Oxford Young People	9
Chipping Norton	5
Henley	7
Banbury	9
Didcot	6
Total	53

Participants were made aware of the research focus group being part of their monthly advocacy meeting one month prior to the session being run. The session leader told potential participants about the research and provided them with an information sheet.²

Before each session, researchers explained what participation would involve, checked participants' understanding, and answered any questions. Those individuals who decided to take part in the focus group then completed the consent form. Those who did not want to take part, or preferred to talk to researchers alone, could leave the room at this point; no participants left at this stage.

Focus groups lasted between 30 and 90 minutes. Discussions were either audio- or video-recorded as per participants' wishes. The topics were introduced via three short role plays written by MLMC self-advocates, and these were followed by facilitated discussions. Local staff were present at all but two focus group sessions.

² Examples of information sheets, consent forms and topic guides are available on request.

Interviews with people with learning disabilities

Seven people with learning disabilities were interviewed as part of the study by MLMC researchers. Participants were either those who could attend the focus group but wanted to share their stories in more detail or those who could not come to the focus groups and wanted to take part in the research.

At the beginning of each interview participants were given an information sheet and had the opportunity to ask the researcher questions about this. If they wished to continue, participants then completed the consent form.

Interviews were either audio or video recorded depending on the participant's preference and lasted for 30 to 60 minutes. Each interview was guided by a semi-structured interview schedule and was attended by one MLMC self-advocate and one supporter. The self-advocates took responsibility for asking the questions and supporters only asked further questions if clarifications or more details were necessary.

Online Survey

The online survey was run via Survey Monkey for six weeks from August 17th 2018 to September 28th 2018. Four separate questionnaires were set up to capture information from:

- People with learning disabilities themselves;
- Family carers of people with learning disabilities;
- Support staff working with people with learning disabilities;
- Commissioners and/or service providers for people with learning disabilities.

Links to each of the questionnaires³ were sent to contacts and networks by MLMC and NDTi in Oxfordshire, and also published on their websites and social media (Twitter) feeds.

If participants followed the link to the questionnaire, they were provided with information about the research on the Survey Monkey landing page. If participants were happy with this information, they were then asked to consent to having understood this information and to take part in the research by clicking 'OK'. If participants did not click 'OK' at this stage, then they could not complete the questionnaire.

Participants could choose to remain completely anonymous and submit the survey without any personal information. However, surveys submitted anonymously could not be withdrawn from the research, which was made clear to participants. There was also an option for participants to provide personal details at the end of the survey, which would allow them to withdraw themselves from the study within three weeks from the submission of their responses.

³ Copies of the questionnaires are available on request.

A total of 87 people (40 people with learning disabilities; 17 family carers; 22 support staff; 8 commissioners) completed their respective online questionnaires. It is not possible to say how many respondents with learning disabilities had help, and what type of help, to complete the questionnaire because we did not collect information about this. MLMC did not offer any support to answer online or paper questionnaires.

Interviews with local authority managers and service providers

We approached potential participants in November 2018 asking if they were interested in assisting MLMC and NDTi in their research. Eighteen providers and seven commissioners were contacted this way. The email included a summary of the research so far and practical information (when and where the interview could take place). Three commissioners and two providers agreed to participate and were interviewed in January and February 2019. One interview was done on Skype and four interviews were face-to-face, two in MLMC's and two in the respondents' offices. One MLMC researcher with support attended all interviews. MLMC and NDTi prepared the interview guides together.⁴ Interviews were either audio or video recorded.

In an attempt to recruit further participants, MLMC contacted 15 providers by phone. No providers picked up the calls and nobody responded to voice messages.

4.5 Analysis

Our approach to the analysis of interview and focus group data was informed by thematic analysis (Braun & Clarke, 2006). Responses to the online questionnaires were summarised descriptively.

Data was analysed collaboratively with MLMC researchers, supporters, and NDTi researchers working together. We held three analysis sessions where MLMC researchers revisited the information collected in focus groups, interviews with people with learning disabilities, and interviews with providers and commissioners. These sessions were facilitated by a supporter (LD) or an NDTi researcher (AT) and were structured as follows:

- The facilitator presented the purpose of the analysis and the questions to be answered. These were based on the interview topic guides and research questions.
- The team watched some of the recorded focus groups and interviews together.
- The facilitator paused the videos to ask questions and allow researchers to share their thoughts and interpretation of the data.

Each session lasted around two hours and was audio-recorded. Based on these discussions and detailed notes of the recorded interviews and focus groups, AT wrote up the analysis. The full report and findings were then presented to the whole team who had the opportunity to provide feedback and suggest changes and worked together on the discussion and recommendations.

⁴ Copies of the interview guides are available on request.



5. Findings

This section presents the characteristics of the people who took part in the research and the main findings from the data. To protect the anonymity of participants, quotes are presented without indicating which focus group or interview they come from.

5.1 Focus groups and interviews

Fifty-three people took part in the focus groups and seven people with learning disabilities were interviewed; all interviewees also participated in a focus group. Out of the 53 people, 31 were men and 22 were women. All participants were aged 18 years or over. No information was collected about the services they used or their relationship status and history.

Focus groups and interviews raised many of the same issues, therefore findings are presented together here.

Participants talked about **different types of relationships that were important to them:**

- Close friendships
- Family
- Intimate relationships: boyfriends and girlfriends, engagements, marriage.

Although a few people were in a long-term relationships and there were many examples of intimate relationships and people wanting an intimate relationship, some participants also talked about not wanting these and being happy with their close friendships.

Many participants also mentioned **the challenges of meeting people**. A few people said that clubs and dating agencies (such as Mates and Dates) are a good way of meeting possible partners. Online dating sites and apps were seen as potentially dangerous by some but with little knowledge or information on how to avoid or minimise these risks.

“Online dating sites are a bit risky. You have to put in your address, email and phone number. So I just don't do it. I don't know where else to look though.”

Several participants talked about how hard it is to find a relationship when one has a learning and/or a physical disability. They felt this was harder than for those without these disabilities. A number of people talked about being shy and feeling nervous about meeting new people and being rejected. Everyone agreed that people with learning disabilities were

the same as everyone else in the need for personal relationships and being able to have intimate relationships.

“I don't like being on my own, it's boring.”

“My sisters all have relationships, I want one too.”

“We have lived together for many years, we have been together for 20 years. But we don't want to get married, we want to stay single.”

Participants also talked about **what is important in a relationship** and mentioned different things: companionship (girlfriend/boyfriend also their best friend), feeling loved, having someone to talk to, good feelings, shared interests and religious beliefs.

“I liked having a relationship. I liked to talk to him. Tell him everything.”

“Being able to talk openly with each other is good.”

“I do not want a girlfriend until I meet someone who has the same beliefs as me. It would be really good to meet someone who has the same religion as me. I would then think about them being my girlfriend.”

Participants in focus groups and interviews mentioned lots of **things that helped them to develop and maintain intimate relationships**. **Support from other people** was one of the most important things. This can be paid support (from staff), support from family, and friends. It was also acknowledged that these can also act as barriers.

Participants agreed that support should help people to do what they want and “should not interfere”. This was very clearly expressed by one of the participants:

“I don't agree with people getting involved in your relationship. If you are over 18, no one can tell what you what to do. It is up to you what you do. It is none of their business, it's your business. It is your right and you should be able to be on your own.”

People who use services thought that the role of staff should be to support them to achieve their aims and live the life they wanted. This also meant that staff should take their side in case of conflicts with family.

“My staff have arranged dates for me, even though my mum doesn't want me to.

“Mum and dad have different opinions to me. I wanted them to listen to me like my friends did. I would like a carer to help me with things like this. I really would. I think my parents are slowly realising there is part of me that is different.”

Supportive families were seen as very helpful and much appreciated by participants.

“Having my mum and her mum agreeing and able to talk to each other. They help us. We can see each other at our parents' houses.”

“My family met him and they are very happy. My brother's happy, he wants us to live in the new places that are being built. They want us to live together before we get married. He has met my dad and my brother and they liked him. And that's how we are now, we are very happy and we love each other.”

Some people mentioned that staff and family can also provide safety and reassurance, and help to deal with difficult situations, such as being bullied when out on a date, or difficult break-ups.

Support from friends is also highly valued and can help people to overcome shyness and nervousness. They can also be a good source of advice.

“It is good to have someone there. It helps if you are nervous.”

“If you need support and advice it is good to have friends to talk openly with. It is not so embarrassing.”

Living arrangements and having enough paid support and access to other services were also very important. The service where people live and the support they have greatly affect their ability and opportunities to develop and maintain relationships. No one type of accommodation was seen as more helpful, participants agreed that this depended on the rules of the service and the attitudes of staff. Some services allowed and even supported people to have intimate relationships but there were many that did not.

“We share a bedroom. We have a double bed.”

“We are allowed to spend time together in our bedrooms, and we can close the doors. We like this time alone together to do the things we like with each other. The old manager said he didn't care what we got up to in our rooms because that is our business.”

“When I visit I am allowed in his room, as long as it is tidy, we can shut the door which is good because we want some privacy.”

Living close to boyfriends/girlfriends or being able to access activities where one can meet others, including potential partners, was also seen as helpful. Some people can do this independently but others might need more support.

“I knew some other people at the house and she moved in. So we met there. We got to know each other because I was visiting my friends.”

“I got talking to this girl I met on the bus on way home from work. I got her number and we started texting. It was easier to say what I wanted to say on text than in person. We met up as friends first and a few months later we actually got together.”

When thinking about what **made it more difficult for people to have intimate relationships**, many of the same categories were mentioned:

- Unsupportive staff, family, and friends;
- Restrictive living arrangements, inadequate support and access to activities.

People also talked about past experiences of break-ups, abuse, and difficult relationships that made it more difficult for them to form new intimate relationships, especially without access to support and helpful environments.

“He moved back to [the country he came from]. It made me sad. I would like another relationship but it makes me sad.”

“I was sexually abused by my uncle when I was younger. He touched me in my private parts. He is dead now. But I think it has stopped me having a boyfriend now. I don't know how I'd be with someone touching me there now. I also worry that they wouldn't understand when I was having a bad day. They might not understand what I am physically going through.”

“It was really hard to have relationships after what happened to me, especially because it was in my family. But I am married now, five months tomorrow, but it was hard.”

Some participants also discussed how families and staff do not treat them as adults with rights who want and are able to have intimate relationships. They complained of being treated as in need of protection or unable to make their own decisions, especially when families or staff disagree with their choice of partners. This also meant that people could not get support and information to solve any problems that might have come up in their relationship.

“My parents didn't agree with me being able to have a relationship. Because she had mental health problems and I have disability problems. So it didn't work.”

“None of them wanted us to be together. They tried to split us up, because they didn't think I was the right person.”

“I try to talk to my parents, but my dad is too busy. I can't have an honest conversation with him. They are in their own little world half the time. I would like more time to talk to them about it.”

“Half my family have met him and don't like him, and the other half don't want to meet him. They don't think he is right, but I do. He is better than all the rest.”

Disagreement between families and staff over whether people with learning disabilities should be supported to be in an intimate relationship can have a negative impact on people.

“We want to get married and our families do as well. They want us to live together before we get married, but our staff won't let us.”

Although no one type of service was highlighted as less supportive than others, it emerged quite clearly that the more people live together, the more difficult it is to have enough privacy and conflicts with other housemates are more likely to develop. Conflicts with housemates could lead to difficulties, for example staff restricting people's privacy in order not to 'upset' others or cause jealousy.

Some services impose rules that make it very difficult for people to maintain relationships; sometimes these are attributed to legislation and safeguarding but in reality they are often arbitrary or disproportionate. For example, services do not allow people to have visitors or private time in their rooms behind closed doors. There were many examples of this happening.

“Any visitors to the house have to be checked by my manager and the police. They have to be checked for drugs.”

“I have to ask permission to visit from the boss man. It’s bad.”

“We’re not allowed on our own. The manager got involved and we had to have an advocacy meeting and the staff decided we couldn’t be on our own.”

“Our staff have told us we are not allowed in each other’s rooms. I don’t understand why. I just want to have a chat with him in private. Some things are confidential.”

“I can go into his room, but I have to tell the staff where I am going. I don’t know why.”

Some people reported examples of where their rights are clearly being violated:

“I’ve got a boyfriend but the staff won’t let me give him a cuddle or a kiss.”

Not having access to support was also a major problem for some people, for example:

- Not being allowed to go out without staff support but not having enough support to go on dates;
- Not having access to transport, difficulty to travel to meet boyfriend/girlfriend, especially if they live further away
- Not having the opportunity to go out to events or having to leave early because of staff hours and rotas.

“One of the guidelines is that we have to have staff with us when we go out. We are not allowed to go out on our own and I don't think that is fair. We have a club on a Friday and because I don't have staff to take me, I can't go. “

“It's hard to see each other because she lives a long way away. She has support to come and see me. If we had more support, then we would maybe see each other more. At the moment it is too far for me to see her more.”

“I go over on a Saturday and have to come back. It is a long way to go. It would be nice to stay over and come back on a Sunday, but I would have to ask one of the carers or something.”

However, a few others saw this as an opportunity to do what they wanted without ‘interference’ from staff.

Money and the way services were commissioned was also mentioned by a number of participants, as a major barrier:

- Not having enough money to visit one’s partner;
- Rules about benefits and living together;
- Systems are not flexible enough to allow people who use services to move in together.

“It is too far for me to see her more. It costs a lot.”

“I have been told I am not allowed to move in with her because I might fall down the stairs, but I might fall down the stairs where I live at the moment!”

A few participants also talked about **how they overcame these barriers**. For some this was about **determination and sticking together**.

“You have to tell them that you are going out and that it is none of their business.”

“We weren't going to let anyone get in our way. We had to break down the barriers, but we wouldn't have them get in our way. A lot of people tried to split us up and we fight to the end to get married. We have had our ups and downs, but everyone does.”

Others mentioned the importance of **having an advocate** – whether a paid supporter, social worker, family member, or a friend – who could help them to speak up.

“We had to get an advocate to help us with a meeting. We didn't get what we wanted but it helped us say what we wanted to.”

“Talking to your social worker and family can help.”

Having the right amount and type of support was also seen as helping people overcome these difficulties, get out and build confidence.

5.2 Online survey

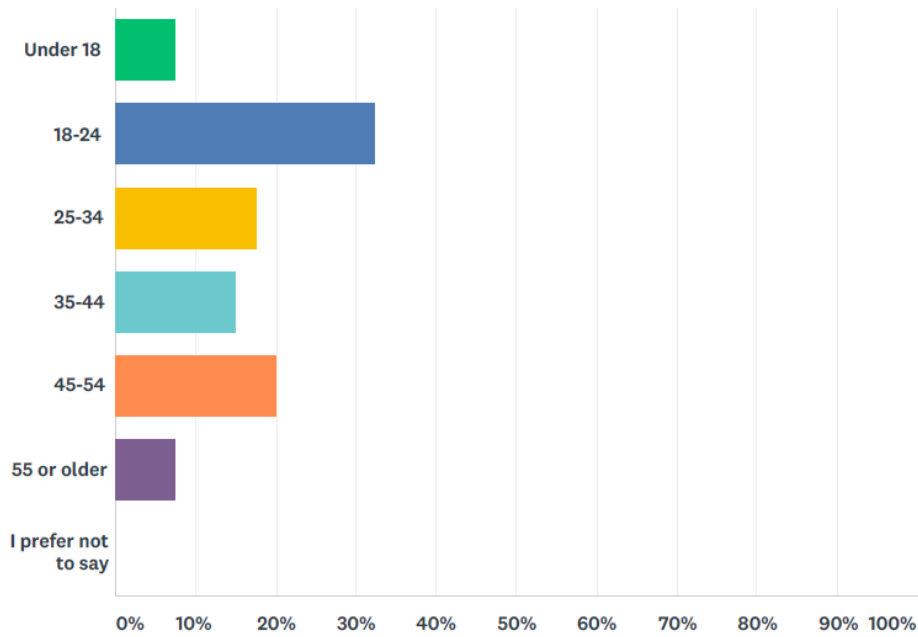
This chapter gives a summary of the characteristics of respondents and the responses for the online survey by type of questionnaire.

People with learning disabilities

Forty people with learning disabilities completed the online questionnaire. Of these, 23 individuals completed the questionnaire on their own, 15 did so with support and two people did not provide an answer to this question.

Seventeen men, 21 women and 2 individuals who did not want to provide this information completed the questionnaire. The ages of participants ranged from under 18 to 55+, but the vast majority were aged 18 to 55 years (Figure 1).

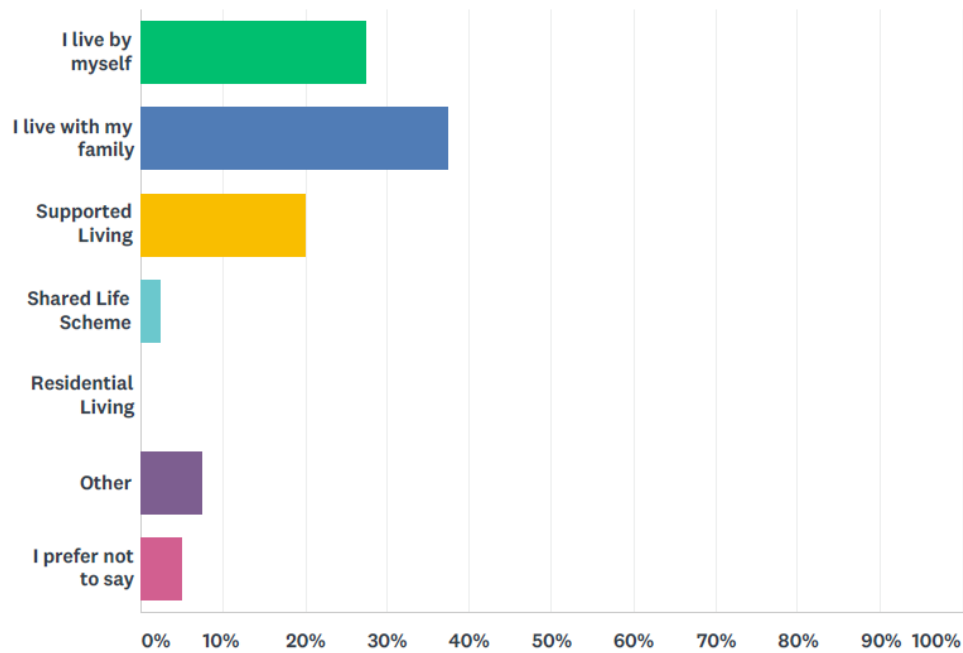
Figure 1 Age distribution of respondents with learning disabilities (n=40)



Ten participants lived in Oxfordshire, 28 lived elsewhere in the country and two did not want to provide an answer to this question.

Participants lived in a variety of settings, but the majority lived independently or with family (Figure 2).

Figure 2 Where respondents with learning disabilities live (n=40)



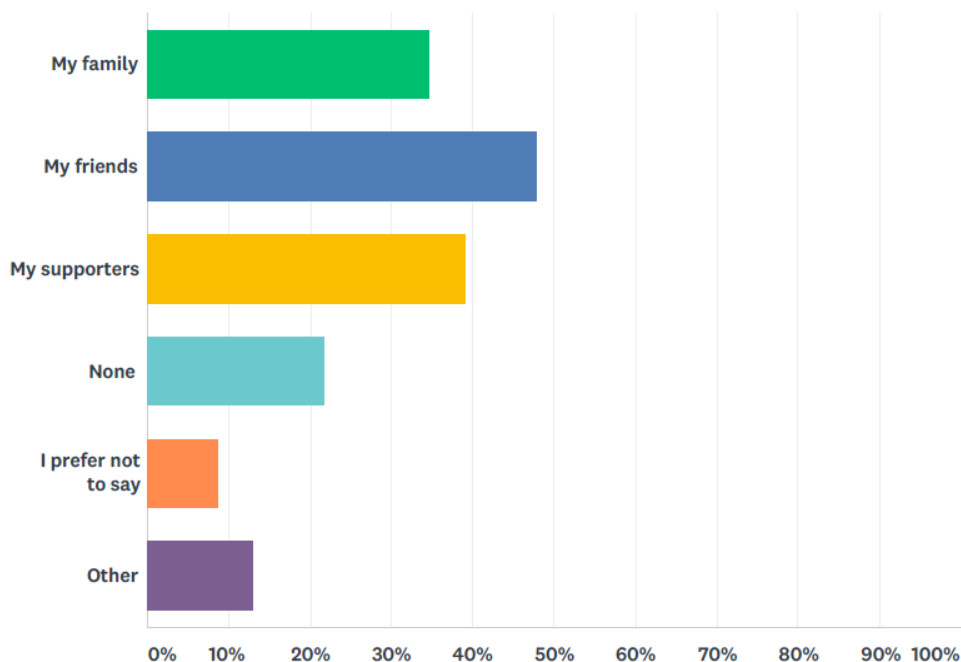
The participants who selected 'other' stated that they lived with their partner, with friends or alone with some support four days a week and family living next door.

The majority of respondents had experience of being in a relationship. Eleven participants were currently in a relationship, 23 were not, three were not sure, two preferred not to say and one did not answer this question. For those individuals currently in a relationship, these relationships were predominantly good with one person saying they were hoping to get married in the future. When asked if they had been in relationships in the past, 14 individuals said they had been, six had not, six were not sure, one preferred not to say and 13 participants skipped this question.

When asked about their relationship preferences, all 21 women said they liked men, whilst 13 of the men said they liked women, one liked both men and women, and three preferred not to say. The two participants who preferred not to provide us with details of their sex also did not provide us with details of whether they liked men or women.

When asked about the support they have received around their intimate relationships the greatest source of support for participants was their friends, followed by their families and supporters (Figure 3).

Figure 3 **Greatest source of support for intimate relationships**



When asked how these people had helped support them with their romantic relationships, participants said that they talked to them about their relationships or desire to have one, they let them spend time with the partners, and paid for their wedding.

When participants were asked what had hindered them having romantic relationships either now or in the past, 16 participants stated that nothing had hindered them, six said their

families, four said their support staff, three said their friends, five preferred not to say and six did not provide an answer to this question.

For the 13 participants who said either their families, supporters or friends hindered them having a romantic relationship, the reasons for this included: these individuals not talking to them about their relationships, not listening to them when they talked about relationships, not letting them spend time with their partners, interfering in their relationships, saying negative things about their partners, and worrying about them. Some participants also felt that their families wanted to have them all to themselves or did not approve of their partners to the extent that they found them someone else:

“Because my mum wanted me all to herself. I was never allowed my own freedom, my space nor settle down.”

When asked what other things hindered participants having relationships, responses included: participants not feeling experienced enough, having bad experiences in past relationships such as people cheating on them or leaving them, sometimes in difficult life situations; not being able to find someone they want to date; their impairment (specifically around speech, language, and autism); a lack of confidence in their social skills; a fear of what other people will say; and a fear of being bullied.

Family Carers

Whilst 17 participants completed the family carers’ online questionnaire, only 16 were family carers. As a result, only 16 responses have been analysed.

Only three participants were family carers to someone with a learning disability who lived in Oxfordshire; the remaining 13 were family carers to those living elsewhere in the country.

Seven participants had supported their family member with elements of their romantic relationship, nine had not. Of the seven who had provided support, this has included: having conversations about relationships; providing advice; providing practical support such as lifts to and from dates; co-ordinating with the partner’s parents; helping arrange weekends together; and planning holidays. For two family carers, providing this support made them feel good as they were:

“Pleased to be able to help them enjoy life together as a couple.”

One family carer expressed frustration at providing this support, as:

“The girlfriend's parents do not want them to do anything but hold hands.”

When providing this support only one family carer had sought advice and/or information from ‘professionals’. They felt that as the parents of their son’s girlfriend were of a very different opinion to them and their son, none of the professionals knew what to do for the best. This tied in to their frustration quoted above.

Of the remaining family carers who had not sought advice or information from anywhere, four were not sure whether they would have liked to have sought this information.

These family carers did not feel that they had faced any specific challenges to providing relationship support to their relative, but they did suggest that having differing opinions within different families was difficult. One participant also stated that it was hard when their family member liked someone, but that person did not like them back.

Of the family carers that had not provided any support to their relative (around their romantic relationships), there were a variety of reasons for this, including:

“Because she has never shown much interest in having one, and the whole issue is fraught with all sorts of anxieties.”

“I have tried to get care home help, independent living staff help, and social worker (SW) as I think my son is gay. They have been hopeless. SW just said “that would be opening a can of worms”. What can you say?”

“Have tried but not been able - his girlfriend broke up with him at 16. At 24 he still thinks he's not good at relationships.”

“Complex needs so not interested.”

“I would love to support her with this, but I am not sure how to go about it. I think she is romantically interested in a boy that she knows, but I have tried contacting his mother and she has not responded. I have since heard from other people that he is sleeping with lots of different people, which would be a concern for me as I wouldn't want my sister to get hurt (emotionally).”

“Due to not knowing how to even start, have instead tried to increase their social circle.”

When asked what had stopped them supporting their family members with their romantic relationships, responses suggested that the current climate within social care is at play, as well as the attitude of support staff:

“Support worker and funds. Funds not being available. Support workers don't want to support clients to go out in the evening, support worker discussing and not organising, like a fun day for people of learning disability to be able to meet with prospective dates. Boundaries at work as well, not allowing worker to discuss match making with customers.”

“Care system.”

“Access to resources/places for her to meet people and where she could meet people she connects with on a romantic level.”

They also shared their own fears and anxieties:

“It is just an issue that has not really arisen. I do worry about what my role should be.”

“Fear of them acting inappropriately (obsessive behaviour or over-sexualised). And I suppose fear of them being hurt in the process.”

Participants were asked if there was anything else they would like to tell us about intimate relationships for people with learning disabilities. A range of responses were received that further revealed uncertainties and dilemmas for family carers, suggesting a significant level of unmet need for support:

“I do not feel supported by our son's support staff, they find the relationship difficult and I think embarrassing.”

“My daughter's relationships have been short and not involved her wanting intimate contact. When she's ready for sex I'm sure I will need some additional support.”

“I would like her to have a "normal" life, and would not oppose or interfere, but cannot be unaware of her vulnerability.”

“Attitudes and opinions of others can sometimes be conflicting and can cause anxiety, i.e. is my help considered by others to be a negative thing. I feel it is best to keep social care/health staff at a distance from their relationship as there always seems to be someone or other who has an ‘opinion’ on the matter and can make you feel as if you are doing something wrong!”

“Care system have been hopeless. He has autism and needs help with sexuality. Just called police when he touched another service user inappropriately and then answer to problem was to put locks on room doors. He has now decided relationships aren't for him.”

“Little opportunities for romance. Not encouraged by supported living.”

“I would love it if there was more support and resources in my local area.”

“I find that the issues of capacity and consent are misunderstood.”

These responses suggest that family carers want their relatives to have the romantic relationships they desire, but the systems in which they live their lives and expectations of society generally mean that this can be extremely difficult to achieve. Family carers involved in this research seem to feel let down by the support that is available to them and want the system to change.

Support Staff

Only 18 of the 22 respondents to the staff survey were actually support workers or PAs to someone with a learning disability, so only 18 responses have been analysed for this report.

Of these, only three supported individuals who lived in Oxfordshire. Thirteen supported people who lived outside of Oxfordshire and two did not provide an answer to this question. Seven participants had supported people with elements of their romantic and sexual lives.

This support had included:

“I supported the person to explore dating agencies and websites also encouraging them to socialise more within their community to meet new people.”

“Support about dating, appropriate relationships and use of sex workers.”

“Sexuality and relationship workshop.”

“Purchased sex aids. Supported them to go to clubs or meeting places of their choice and provided information on safe sex.”

Seven participants had not provided any relationship support, one participant was not sure if they had and three did not answer this question.

For the participants who had provided support in this area, doing so was a positive experience:

“Happy that I was able to broaden options for the person I supported whilst building their confidence in dating and meeting new people.”

“I had given them info that could keep them safe and that they could meet people and develop relationships.”

Two of these participants had sought information from others before providing support to those they work with, including from nurses, the local sexual health clinic, and the organisations they worked for. These participants found this information useful, but it wasn't always in a format that they could give straight to the person they were supporting:

“I had to explain it in an easier way as the format was not very "easy read".”

One respondent who had not asked for any information, felt that having such information would have been useful.

Of the seven respondents who had not supported people with learning disabilities with intimate relationships, three provided details of why this was the case:

“We have taken our service user to clubs where other people male and female come, but he has never shown interest on any one.”

“The family and friends are against the person having any sort of relationship with male friends. The person is also forbidden to have any friendship with males she lives with.”

“Because my role is to run a friendship group for people with learning disabilities, not to offer individual support unless it is required. If a person needed support to develop or maintain a romantic relationship, I would either do what I could to support or refer to an appropriate professional to support that person.”

Four participants have faced challenges to providing relationship support to those they work with. With two participants stating:

“Every day is a challenge supporting this person as the family are never happy. There is a lot of don'ts, not necessarily what is in the person's best interest.”

“Very little professional support to help people manage their relationships.”

Only three participants had received some training in this area, which included:

“I have done the Family Planning Association course on delivering sex and relationship workshops to people who have a learning disability.”

“Discussion, open conversation – allowing free discussion of sex/sexuality issues means that you are less restricted talking about it with people you support.”

“One-day group training, one-day group workshop.”

A further three participants would have liked to have had some training in this area, stating that this should include:

“How best to support people with mental health problems and disability to have healthy intimate relationships.”

“The extent to where the relationship can go e.g., marriage or having babies?”

“How to educate the person we are supporting to practice safe sexual relations.”

Only one participant said the organisation they worked for did have a policy in place relating to the support they should provide people with learning disabilities about their intimate relationships; six said their organisation did not and two were not sure.

Of the six respondents who said their organisation did not have such a policy, four felt that the organisation should and one participant was not sure. The unsure participant stated:

“I think we have the MCA & a focus on capacity. As long as those aspects are adhered to then more layers of bureaucracy aren't helpful. If two people are over the age of consent, can consent and understand the risks that come with safe/unsafe sex or dating in today's crazy world then it should be supported.”

At the end of the questionnaire participants were asked if there was anything else they would like to tell us. The responses received were as follows:

“We do keep an eye to see if our service user is interested to have any kind of relationship. If required we would surely support him/her.”

“I think there needs to be a lot of work done on supporting people to develop and maintain friendships, as well as romantic relationships. We have supported over 1,500 people with learning disabilities over the last 10 years to attend a friendship group, and this is still a key area for many people – to make and maintain healthy friendships. We have avoided the dating site type of project because of the huge amount of work needed for members to develop their relationships safely and with proper support - or to deal with things when they go wrong, as sometimes it will inevitably do.”

“In my experience you have a group of supporters that are utterly horrified that people with LD are having sex and you have a group of people that support people with LD to live their lives in a manner of their own choosing. More emphasis needs to be put on capacity and the fact that the people you support are adults, not your children and have hopes, dreams & fears as wild as anyone else's.”

Commissioners and service providers

Whilst eight participants completed the commissioner and service provider online questionnaire, only six individuals were commissioners or service providers. As a result, only six responses have been analysed.

Of these six individuals, only two knew that the services they commission or provide have policies about the rights of the people with learning disabilities to have relationships within their services. One participant said their services did not have such policies, two did not know, and one did not answer this question.

The participant who said that the service they commission or provide does not have such a policy stated that the reason they do not have one is because the law around this issue is clear:

“Upholding the law doesn't require a special policy. The person is assumed to have capacity until proven otherwise.”

This participant did not feel that any policies should be created, because of the clear legal guidelines around this issue. Instead they felt that providing staff with training on mental capacity legislation and relevant practice may go some way to ensuring they are confident and comfortable providing such support within the organisations they work for.

5.3 Interviews with local authority managers and service providers

Three local authority managers/commissioners and two service providers agreed to be interviewed for the research. The three local authority participants were responsible for the overall direction of adult social care, the management of social workers/care managers, and purchasing services from providers. Both service providers offered a range of services for people with learning disabilities including supported living, residential care, and day opportunities and had a combined reach of over 320 people in Oxfordshire. One of the providers was a local charity, while the other was part of a larger company with coverage out of the county. The commissioner and provider interviews were analysed separately.

Local authority managers

Local authority managers agreed that people with learning disabilities have the same right to intimate relationships as everybody. Sexual and romantic relationships are part of ‘ordinary life’: people should be able to lead the life they choose and services should support them in this. There are people whose ‘whole life’ is controlled by services – it is crucial that they are more enabling and support people to live the life they choose.

However, one of the respondents emphasised that this is a ‘right’ and not a ‘duty’, and social services cannot be expected to be matchmakers. Ultimately, services and the council should support people with learning disabilities to have a life where intimate relationships can ‘develop naturally’.

“Services should support people to make these choices. Sometimes they do it well, sometimes they don’t do it well.”

They also felt that the council has a range of practices and mechanisms in place to ensure that people have good services. For example, they worked with service users to define what good looks like. But they also recognise that practice can be quite variable and they do not always have information about what providers do to support people to have intimate relationships. There are more than 20 providers and 700 service users with learning disabilities in Oxfordshire.

Respondents were aware that some services still want to provide ‘care’ (rather than person-centred support) and sex is often taboo. There are many misunderstandings around capacity, consent, and safeguarding. The majority of providers and staff are risk averse – they would rather not allow people to get involved in intimate relationships or “make mistakes”.

Participants also thought that high staff turnover and low pay affected how well services could support people to have intimate relationships. Some staff who are not well-paid “struggle to focus on enabling people and tend to be overprotective”. One of the respondents also acknowledged that intimate relationships can be more difficult in ‘group living situations’.

They all agreed that **policies are important but it is more important that people with learning disabilities are ‘seen as individuals’**, that staff fully understand this, and know how to support each person. This should be agreed and followed by everyone.

“Seeing people as individuals, not as a diagnosis or label because everybody is unique in their own individual ways.”

All three participants mentioned that most services are already offering training to staff, but that this is often not specifically about supporting intimate relationships. They felt that only services where intimate relationships are identified as an “issue” or “need” by the social worker, tend to offer specific training, although this is usually about safety and risk.

Respondents thought **training about intimate relationships** would be useful to “ensure that staff get those basic skills and understandings”. When talking about what this could look like, they suggested that it should:

- “go back to basics”;
- “be co-produced” and represent the “voice of people with learning disabilities”;

- use a strength-based approach;
- represent good practices from providers – also give a platform to providers to share their experiences;
- “give space for staff to think and stretch themselves”;
- be interactive and hands-on.

They also suggest that **training** should help staff to understand:

- why relationships are important;
- how to know if someone wants and can agree to a relationship;
- emotional and physical boundaries to keep safe;
- how to find a partner safely;
- risks of using social media and dating apps.

Respondents also emphasised that it is not always easy to get this right: **there are many barriers** and there is a “long way to go”. They mentioned many reasons why this is the case:

“Intimate relationships are very personal and there are different opinions on what is appropriate/right and wrong.”

They feel it is not always easy to make a distinction between ‘sexual needs’ and ‘intimate relationships’. Some might not want the commitment of a relationship but still have sexual needs. There are legal limits on what the local authority can fund and direct payments cannot be used to pay, for example, for sexual services. How can these people be supported safely?

Participants also talked about the difficulty of balancing legal duty to protect people and people’s right to makes mistakes and unwise decisions.

High staff turnover was also mentioned as a reason why some providers might be reluctant to invest in staff training. Low pay and difficult conditions might not attract the right people to work in the sector.

There are also **gaps in the provision of support**, especially:

- Transition from children’s to adult services. This is an age when people – teenagers and young adults– need more support around intimate and sexual relationships but this is often not happening.
- Working with family carers to offer support around intimate relationships.
- Education and information about sexual health for individuals with learning disabilities.

Local authority managers did not mention resources and the effect of cuts on individuals (poverty, reduced hours etc.) and services, although we did not ask about them about these issues in the interviews with managers.

Service providers

Providers we spoke to, agreed about the **importance of having clear values** in making sure that people are supported to have intimate relationships. They said it is important to be ambitious for people, to give them the right support to live the life they choose and to respect them as individuals with rights.

They also said that policies are important and that they need to be implemented. One of the providers thought that policies “can be a bit dry”. The other provider said that it is good to keep policies simple so that staff can easily refer to it if they are unsure about something.

“A policy is only as good as it is in practice, no point in having written policies if they are not implemented.”

Training was seen as very important and not just specifically about intimate relationships. Staff need to understand how to put values into practice and they also need sound knowledge about related topics such as safeguarding, capacity, consent, positive behaviour support etc. Both providers mentioned the importance of on-the-job coaching, so that staff are actively supported in situations that are unfamiliar or “tricky”.

The providers we spoke to also felt that staff need to know and trust that if something goes wrong, they will not get into trouble – as long as they did their best and acted in good faith.

“People need to be supported to make mistakes.”

“Everybody needs to feel able to complain.”

It was also acknowledged that sometimes getting the balance right – between supporting and protecting people – is difficult and everybody should understand and appreciate this.

“We don’t want to be prescriptive about what people should do.”

One of the providers mentioned three things that often hinder staff in providing good support with intimate relationships:

- embarrassment,
- relationship with family, for example issues around confidentiality (what should they share with families),
- worries about capacity and consent.

The prevailing culture of risk aversion within social care, and managers shifting the blame to their staff if something goes wrong were highlighted by the interviewees as not helpful. They also agreed that sometimes commissioners do not “get it”, and how difficult it is to provide the right support to people especially for those who have limited support packages.

However, they acknowledged that ultimately it is the provider's responsibility to ensure that rotas and hours do not get in the way of people living an ordinary life.

It was also raised that services/providers also need support in order to support people well. Participants suggested that this should come from:

- the management of the organisation;
- Local authority commissioners and social workers;
- professionals and other organisations (e.g. NHS).

It is important to get help quickly and easily, without having to go through and wait for lengthy referrals.

One of the providers noted that with austerity and cuts, resources seem to be more concentrated on "essentials" and it is getting harder to support people to develop and maintain intimate relationships. Sometimes providers use Deprivation of Liberty Safeguards, and restrictive definitions of mental capacity. The Mental Capacity Act is a "fantastic piece of legislation and you can live by it" but many providers and staff do not understand it or chose not to understand it. It is sometimes easier to limit people's freedom and rights to intimate relationships than giving them the right support.

As an example of **something that worked well**, one of the providers mentioned training about relationships for people with learning disabilities who use their services. This training was organised with help from external professionals separately for boys, girls, and couples to make sure they are less embarrassed and more comfortable to talk about intimate relationships. The topics the training covered include sexual health, contraception, and keeping safe.

Both interviewees identified major gaps in supporting people with learning disabilities to develop and sustain intimate relationships:

- LGBT+ people with learning disabilities get very little support.
- Working with families, and supporting people who live with their families and don't come into contact with services.

Finally, shared living arrangements were also mentioned as sometimes being tricky to navigate, including: ensuring privacy, dealing with conflicts and jealousy. Housemates can be a barrier to intimate relationships and people are often stuck in living arrangements that no longer work for them. They need more help and flexibility to move out and move in together if that is what they wish.



6. Discussion

The discussion aims to reflect on how well the project achieved its objectives (aims and research questions) and responded to the outcomes set out by DRILL, summarised below:

- Increase our knowledge about key issues and new evidence of what works and enables us to achieve independent living and fulfil our potential.
- Disabled people are empowered and have direct influence on decisions about the policies, legislation and services which affect them.
- Disabled people experience improved wellbeing, independent living, choice and control through participating in or engaging with DRILL.
- Exert influence on policy making and service provision to support disabled people to achieve independent living, through the coproduction of a robust set of research findings.

6.1 What did we find out about what helps or hinders people with learning disabilities to have intimate relationships in Oxfordshire?

We interviewed seven people with learning disabilities, three local authority managers, two service providers, and held eight focus groups involving 53 people across Oxfordshire. We also conducted an online survey to which 87 people responded.

People with learning disabilities want to have relationships. Unsurprisingly, they are the same as people without learning disabilities: having different relationships – friendships, romantic and sexual relationships – is an important part of their lives. However, unlike people without learning disabilities, institutional and attitudinal barriers prevent many people with learning disabilities to exercise and enjoy this fundamental human right.

Our findings show that people with learning disabilities experience many barriers in developing and sustaining intimate relationships. These include:

- Limited opportunities to meet potential partners. There are some clubs and social events (such as the Stingray night club or Mates 'n' Dates in Oxfordshire) but people often do not have the support to get to these.
- Some staff and family prevent people from being in a relationship or make it very difficult to stay in a relationship. Sometimes this happens on purpose but sometimes it is not intended. The problems that were identified included:
 - Rules of what is allowed and not allowed. Not all services have policies on relationships and even if they do, these are usually not written with people with learning disabilities.
 - Lack of support to go out, go on dates, visit friends and girlfriends/boyfriends.

- Not seeing people with learning disabilities as adults who have the right to relationships: sexuality is still a taboo and many people are overprotective.
- Not knowing how to support people. Some services do not give staff training on relationships.
- People with learning disabilities themselves have limited knowledge about sexuality and keeping safe. Although there are accessible resources and services, people providing services, families, and people with learning disabilities are often not aware of these.
- Unsupportive friends and housemates can make it difficult for people to be in a relationship.
- Lack of money and transport to go out, visit partners, and go on dates.
- Intimate relationships are not seen as a priority when commissioning services, unless there are concerns about risks and safeguarding.

We also found things that helped people to be in an intimate relationship:

- Being recognised and respected as adults with rights the same as everyone else.
- Having supportive social and community networks: family, staff, advocate, friends
- Having knowledge about relationships and sexuality, and confidence to meet new people.
- Having a life with lots of opportunities to meet people and form relationships.

Sometimes providers struggle with supporting people to have intimate and sexual relationships because:

- Austerity and cuts to services mean that people do not get the amount of support they need.
- The difference between a bad decision/mistake and risky behaviour is not always clear. Providers have a duty to protect people from harm and worry about getting this right.
- They do not fully understand the legislation around capacity and consent, and they want to avoid taking any risks.

We were surprised by some of the things we found:

- Local authority managers and service managers sometimes do not know about what services do, to help people with learning disabilities to have intimate and sexual relationships.
- There are many people who do not get enough support to go out and do things, and their lives are restricted by services' rules.
- For some people this was the first time anyone had spoken with them about sex and relationships.

6.2 What did we learn from doing research together?

Doing research together also taught us that:

- It is important to listen to other people's stories. We need to talk to a lot of people as people have had different experiences: some positive, and some negative.
- It is good to work in a team because we all have different skills and strengths, and we can support each other. It is useful to take the time to get to know each other and build relationships. This helps with communication.
- We need to ask questions in a way people can understand. Role play was really helpful, and everybody enjoyed writing and doing it.
- Being a researcher is a responsibility.
- It is good for local authority managers and providers to be interviewed and challenged by people with learning disabilities.

Doing research together also helped us to:

- Learn new skills and push ourselves to do things we have not done much in the past.
- Understand how to respond to people when they became emotional or upset.
- Cope with some sad and upsetting stories. We could talk about these together, offer each other emotional support, and decide together if we needed to do anything.
- Feel more confident.

6.3 What challenges did we face?

We faced some challenges in trying to find out about intimate relationships. A number of participants in the focus groups were visibly embarrassed, uncomfortable, or found it funny to be talking about relationships in this way. They were comfortable being in the focus group, but reacted by sniggering and as if they thought they were talking about something they shouldn't be.

One focus group had to be cancelled because staff made it impossible for us to run the session. They thought people with learning disabilities in the group should not be talking about intimate relationships because they did not have capacity and permission from their parents. This showed their lack of understanding and knowledge about mental capacity and negative attitudes towards people with learning disabilities. They also treated us badly, disrespecting self-advocates and leaving everyone upset. We raised this with their managers who dealt with the case quickly.

Some participants reported abuse from their past. This was very upsetting and the team talked about this and checked they were all ok. We also had to decide if something had to be done and if these were current safeguarding issues. We spoke to the group co-ordinator and we were reassured these were known cases but they would check with key workers if more support was needed.

6.4 What are the limitations of our research?

Like any other research, our project had some limitations that we needed to take into account when thinking about our findings. First, many people with learning disabilities we spoke to attend self-advocacy groups and are in contact with MLMC, so they probably know more about their rights than others. This means the picture may be worse than we found. If even the people who have been coming to MLMC groups for years simply accepted staff telling them they cannot kiss or cuddle their partner, other people who know less about their rights might be even less likely to challenge this sort of situation.

Although we were impressed with how many people responded to our survey, many of them were not from Oxfordshire and we do not know how typical their experiences were.

Very few commissioners responded to the online survey and even fewer service providers were willing to speak to us. This probably reflects their attitude to the importance of sexual and romantic relationships. We also felt that those who spoke to us, sometimes said what they thought we wanted to hear, rather than what they believed or what was actually happening.

6.5 What impact our research has had so far?

When we started the research we wanted to make a difference in the lives of people in Oxfordshire and beyond. We were very happy to see some of this happening already. One of the couples in the research had been together for many years but were still not allowed to go out or live together. We complained to the manager and now they are allowed out together by themselves.

Two members of the research team (Pam and Jess) presented our research at a [Making Research Count event organised by the University of York in January 2019](#). This was attended by 27 participants including self-advocates, family carers, service providers, and local authority commissioners. Our presentation received very positive feedback and we also shared it with participants.

MLMC produced a vlog about having a relationship and the experiences of the research for Valentine's day. As Valentine's day is meant to be all about love and relationships, it was a good opportunity to explain what we have been doing. We wanted to make it as accessible as possible so we decided to create a video and shared it on social media. The film is available [here](#):⁵

Anna Marriott from NDTi produced a webinar for RiPFA entitled "Supporting people with learning disabilities to have positive sexual relationships" using some of the research findings. This webinar is aimed at frontline staff and will be available in June 2019.

Jess, Pam and Anna presented at a Supported Loving event in April 2019. There was very positive feedback from the self-advocates there about the importance of this research.

⁵ <https://youtu.be/wQpU41N76mw>



7. Recommendations and further activities

Based on the research, we have put together the following recommendations:

- 1) Relationships should be clearly addressed in person-centred support plans and be part of individual outcomes. This would also help make sure that enough funding and support are available to the person. They should be reviewed regularly.
- 2) There should be a more coordinated approach in supporting couples to ensure that the support provided meets their needs as individuals and as a couple.
- 3) Relationships should be part of Education, Health, and Care (EHC) plans, especially around transition. EHC plans should set out how and when young people are going to get sex and relationship education and start working towards future aspirations early. This is to help young people prepare for what they aspire to in the future.
- 4) Staff should have training in supporting people with intimate relationships. This training should not be just a one-off; it needs to be updated and refreshed regularly. There should be a network to help to co-produce, organise, and deliver this training and allow the sharing of good practices.
- 5) Adults with learning disabilities of any age should have access to sex education and relationship training. Also, schools and colleges should do more on sex and relationship education. Knowledge can help people be safe.
- 6) People with learning disabilities need to know and understand their rights. They also need to learn what to do when providers or carers are saying that they are not allowed to do something that, in fact, they are.
- 7) Local offers should extend to personal and intimate relationships and signpost people with learning disabilities, families, and services to available social events, activities, and services, such as clubs, dating agencies etc. This would also highlight where gaps are and help the local authority and organisations to target funding and activities.
- 8) Sexual health and family planning services should be accessible for people with learning disabilities and offer accessible information.
- 9) Providers and staff need to take the time to get to know people and open up conversations about relationships. They should find out about what people like, what they are interested in, and what they want from their lives. This can build trust and help with embarrassing and personal conversations.
- 10) Getting the right staff with the right attitude is important. Supporting relationships should be seen as part of a support worker's role and come up already in the job interview.

Based on our recommendations, NDTi and My Life My Choice would also like to suggest the following activities and where future research is needed:

- 1) Work with organisations to review their policies, find out how they actually support people with intimate relationships, and come up with ways of improving this.
- 2) Work with families and find out what help they need to support this area of people's lives.
- 3) Identify, quality-check, collate available resources about intimate relationships and sexual health, and make them accessible for people.
- 4) Clear guidance for people with learning disabilities about what their rights are in the area of intimate relationships. We have discussed this with the British Institute of Human Rights and would like to work with them to produce related resources.
- 5) Development of a charter about people with learning disabilities' rights to have sexual relationships - we have had conversations with the Tizard Centre at the University of Kent, Supported Loving, and Mencap's Sexuality and Relationships Manager about working together to develop this.



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