Supporting people with learning disabilities to make and maintain intimate relationships

Claire Bates, Louise Terry and Keith Popple

Abstract

Purpose – The purpose of this paper is to understand some of the barriers people with learning disabilities experience with regards to relationships and consider the possible changes professionals could make to address these.

Design/methodology/approach – The current paper will draw on case studies extracted from Bates et al. (2016), using them to illustrate a number of themes/issues that relate to the support that people with learning disabilities received and needed from staff to develop and maintain relationships.

Findings – People with learning disabilities continue to experience barriers with regards to relationships. Their rights and choices are not always respected and a climate of risk aversion persists in areas such as sexual relationships. The research highlighted the balancing act staff must engage in to ensure that they remain supportive without being controlling or overprotective of individuals in relationships.

Research limitations/implications – Professional/support provider views were not included but these could have lent an additional perspective to the issues discussed.

Practical implications – An increased understanding of human rights entitlements should be encouraged among people with learning disabilities so they know when their freedom is being unlawfully restricted. Sexuality and relationship training would be beneficial for support staff. This could cover a wider range of areas such as contraception and supporting individuals who have experienced sexual/domestic abuse in starting new relationships.

Originality/value – This paper explores the barriers to relationships from the perspective of people with learning disabilities and offers practical solutions to address them.

Keywords Safeguarding, Relationships, Mental Capacity Act, Learning disability, Sex, Consent

Paper type Viewpoint

Introduction

A loving, committed relationship with an exclusive partner is valued highly (Shackelford et al., 2005; O’Reilly et al., 2009). Passionate and intimate relationships are important to people with learning disabilities (Siebelink et al., 2006). The value of personal relationships has been enshrined in law by the HM (1998) which states that everyone has the right to a “private and family life” including marriage. People with learning disabilities are often unaware of this right (Healy et al., 2009). The importance of relationships is now incorporated into British law as part of the Care Act (Department of Health) (2014); under the principle of wellbeing, the development and maintenance of personal relationships is considered an eligible need.

In the UK, Valuing People (Department of Health (DoH), 2001) sought to develop opportunities for people with learning disabilities “to form relationships, including ones of a physical and
sexual nature” (p. 81). Valuing People Now (Department of Health (DoH), 2009) highlighted a lack of progress. There are no statistics on how many people with learning disabilities in Britain have a partner but Emerson et al. (2005) found that only 4 per cent of participants interviewed had a partner. In the 2011 census, 49 per cent of UK adults were married (Office for National Statistics, 2011), and, of course, many more were in relationships but unmarried. This suggests that far fewer people with learning disabilities are in relationships compared to the wider population. While actual rates are unclear, research in the 1970s appeared to suggest that marriage was a relatively more common arrangement for people with learning disabilities (Craft and Craft, 1979; Mattinson, 1970). Craft and Craft (1979) identified that 24 per cent of participant couples included one partner without a learning disability but often with additional needs (such as poor mental health or criminal behaviour). No current research was found identifying the number of relationships between individuals with a learning disability and those without. However, such relationships are often a cause for concern amongst professionals. It seems possible that the increased priority afforded to safeguarding in recent years may have led to greater caution regarding this type of relationship and a reduction in the number of such relationships that are supported and maintained.

Tindall (2015) highlighted how safeguarding processes have created a climate of liability avoidance, with providers striving to reduce how their exposure to criticism if something goes wrong. People with learning disabilities are more likely to experience abuse (McCarthy, 1999), and women with learning disabilities are more likely to experience domestic violence (McCarthy et al., 2016). Arguably, these are greater risks for people with learning disabilities engaging in relationships and staff may, understandably, seek to protect them from such risks. Support staff have been found to hold moderately positive attitudes towards the sexuality of people with learning disabilities and to be less restrictive than family members (Morentin et al., 2008). However, people with learning disabilities report being restricted by staff with regards to intimate relationships (Hollomotz, 2008; Kelly et al., 2009). Policies and programmes put in place to protect women’s safety often restrict their sexuality (Bernert, 2011) and when sexual relationships occur they are highly supervised (Winges-Yanez, 2014). People with learning disabilities cite issues such as a lack of privacy and a reliance on others for support. This creates a “suspended adolescence” (Azzopardi-Lane and Callus, 2015, p. 2) where sexual maturity is denied.

The literature review highlights the barriers and risks that people with learning disabilities experience regarding relationships. They face an increased risk of abuse and domestic violence (McCarthy et al., 2016) from unsuitable partners. Their relationships may be restricted by staff (Hollomotz, 2008; Kelly et al., 2009), sometimes because staff are complying with strict safeguarding practices (Tindall, 2015). They may also be unaware of their rights regarding relationships (Healy et al., 2009), meaning that they are more likely to accept externally imposed restrictions without challenge.

Method

The data presented here were originally collected as part of research exploring partner selection for people with learning disabilities (Bates et al., 2016). The current paper draws on that research to illustrate some of the barriers to relationships experienced by people with learning disabilities, particularly in terms of their support and accommodation. It also offers suggestions as to how issues could potentially be addressed. Detailed descriptions of the methodology, ethical considerations and analysis are provided by Bates et al. (2016).

In total, 11 participants with learning disabilities were recruited via a gatekeeper from two UK social care providers. Participants had to be adults in receipt of a specialist service for people with learning disabilities with the ability to communicate in sentences and discuss abstract topics such as love. Participants had to have had at least one relationship over six months that included physical contact (e.g. kissing). All participants were in a long-term committed relationship, four were married, four were engaged (with plans to marry in the near future) and two lived together and had discussed marriage. Only one participant had no plans to live with or marry their partner.
Gatekeepers (senior staff members within the social care organisations who knew participants well) arranged pre-meetings for potential participants. At these meetings the researcher explained the research, checked that they understood it, and ensured that they both met the inclusion criteria and could provide informed consent.

Ethical approval was obtained from London South Bank University Research Ethics Committee. Due to the sensitive nature of the research, contingency plans were formulated to address any potential disclosures of abuse and what action to take if a participant became distressed. Participants were interviewed two or three times, with each interview lasting between one and one-and-a-half hours. The research focussed on the views of the participants, therefore no other information was sought such as support documentation, staff views or organisational policies. Interviews were transcribed and analysed using Van Manen’s (1990) hermeneutic phenomenology. The current paper draws on case studies from Bates et al. (2016), using them to illustrate three themes that relate to the support that people with learning disabilities received and needed from staff to develop and maintain relationships. The three themes are: accommodation, sexual relationships and risk avoidance.

Findings

The Family Planning Association’s (2008) “It is My Right” campaign highlighted that 94 per cent of professionals think barriers exist that prevent people with learning disabilities from having relationships. The key barriers that relate directly to professionals will be discussed in relation to four individuals. The issues illustrated by these case studies were common throughout the wider sample. The majority of participants had experiences of their accommodation impacting upon their relationship with a partner, specifically surrounding their lack of autonomy. Issues relating to participants’ capacity and autonomy to engage in physical relationships and the discussion of risk were a common feature within interviews. Pseudonyms are used throughout. These four individuals were selected to highlight the issues from a diverse range of support needs and living situations:

- Mary – higher support needs (lives in 24-hour supported accommodation, does not go out independently and requires substantial support with daily living needs);
- Liam and Emma – low support needs (live in 24-hour supported accommodation but go out independently and require minimal support with daily living needs); and
- Kerry – receiving minimal support within her own home (not every day).

Mary: a woman in her 40s. She lives in a small flat in a shared house with 24-hour support. She has a partner, Gary, who lives in another shared house. The couple need support to organise and go on dates, their only alone time is when he visits her flat. Gary does not stay overnight. Mary’s flat is only large enough for a small single bed. When asked if Gary had ever stayed the night she appeared confused by this concept. The couple do not have sex and Mary showed poor knowledge in this area (she was unable to identify a condom). It is possible that Mary lacks the ability to consent to a sexual relationship; however, she reported enjoying a physical relationship which includes kissing and cuddling. It is possible that staff restrict her sexual activity as during the interviews she stated three times that she must “keep her nightdress on” but did not have a reply when asked where this instruction came from.

Liam and Emma: Liam and Emma are a young couple who live in a shared house and began their relationship there. The couple wish to marry and live alone but felt this was not happening as fast as they wanted. Their relationship has caused conflict among house-mates who complained to staff about the couple showing affection in communal areas. Staff mediated the tension by asking them to only kiss/cuddle in private and only allowing them to share a bed on weekends. Despite the fact that Emma has experienced sexual abuse in the past, the couple enjoy a sexual relationship but use double measures of
contraception to avoid pregnancy. Staff provided both with advice on contraception and to Emma specifically on saying no to anything she felt uncomfortable with (due to her previous experiences).

Kerry: is in her 30s. She previously lived in a care home but now lives in her own flat receiving minimal support. Kerry is engaged to Dean who lives in his own flat. She has had numerous sexual relationships and has experienced domestic abuse from ex-partners. Staff can only provide advice. Kerry reported how staff have advised her on how to keep safe in her sexual relationship including STI advice and contraception.

Accommodation: impact on choice and autonomy

Participants lacked choice in some areas of their lives, e.g. where or with whom they lived. This was not controlled by the support provider but by commissioners, housing providers or social workers. This recalls Fyson et al.’s (2007) research, where participants were excluded from making life-altering choices such as with whom they lived. Liam and Emma expressed unhappiness in their current accommodation due to the restrictions placed on them by staff and conflict with housemates. Controlling their sleeping arrangements could be considered unlawful under the Department of Health (DoH) (2005). There was no evidence in interviews to suggest that the couple had challenged staff. Instead, they appeared to accept the restrictions passively but with resentment. Liam and Emma’s account resonated with Azzopardi-Lane and Callus’s (2015) notion of “suspended adolescence”. Staff seemed to experience conflict between the rights of the couple and the desires of the other tenants and possibly perceived the restriction as a compromise. However, some of the restrictions implied possible control by staff as opposed to support. It appears that some participants still felt they required the staff’s permission to engage in normal adult activities such as sharing a bed. Sharing a bed was not an option for Mary, whose situation echoed Hollomotz (2008), where housing providers did not always provide a double bed. It is possible that staff did not consider Mary to be an adult who might wish a partner to stay overnight, or simply that the housing provider had not been challenged to consider providing her with a double bed.

Sexual relationships: capacity and consent

Since the 1980s there has been increased focus on supporting the right of people with learning disabilities to have sexual relationships (McCarthy, 1999) and this was reflected in government initiatives such as Valuing People (DoH, 2001). The interviews in the current study demonstrated the knowledge that staff are required to have in order to provide adequate advice surrounding safe sex and contraception as part of meeting individuals’ support needs. A positive aspect revealed by the research was that all individuals involved were supported in their relationships. However, not all participants needed support to develop them. While increased engagement with people who do not have a learning disability may be seen as a benefit, it also means that people with lower support needs, such as Kerry, engage in relationships with partners who could be considered “undesirable”. Such relationships may have been accepted more in the past (e.g. Craft and Craft, 1979). Under current safeguarding legislation staff have a duty of care to protect vulnerable adults leading to such relationships being challenged. However, if a person has the capacity (like Kerry) to consent to a relationship, staff can only offer advice and support. This highlights the importance of staff remaining vigilant regarding the signs of potential abuse and knowing what advice and support to offer people in these situations.

The DoH (2005) enshrines an individual’s right to make a decision in law, and states that capacity should always be assumed unless there is an evidence to suggest otherwise. From the discussions in interviews, however, it appears that not all participants knew their rights. For example, Mary may have been instructed by staff to leave her nightdress on with Gary, and Liam and Emma effectively required permission to have sex. Mary’s interview responses suggested that she may not have the capacity to engage in a consensual sexual relationship at
this time. Staff supported Mary with almost all aspects of her relationship with Gary, including organising/attending dates and contacting him by phone. The only time Mary spends alone with Gary is in her flat. It is unclear what support Mary has had to help her understand sexual relationships, and it is possible that with support she would be able to make an informed choice to engage in a sexual relationship. This example demonstrates the complex task that staff face in the development and maintenance of relationships. It also highlights the balance staff are required to achieve between enabling individuals to engage in relationships while still protecting them from harm, including considering their capacity to make decisions. Staff appear committed to supporting people to engage in relationships. However, it is possible that in organisations where relationships are afforded a lower priority, such support may not be forthcoming.

Risk avoidance

Tindall (2015) discussed the culture of risk avoidance in organisations in relation to the fear of criticism from professionals or regulators. Possible indications of such an attitude were identified within both organisations, including the double use of contraception for Liam and Emma, and Mary’s insistence that she was unable to remove her clothing with Gary. Regarding contraception, staff insisted Emma used an oral contraceptive and Liam used condoms. Staff may have wanted to prevent sexually transmitted infections; however, the couple had no previous sexual relationships. Screening at a family planning centre could have taken place to eliminate any fears of infection. This suggests that staff may have been fearful of a pregnancy, despite the couple being adamant that they did not want children. The couple’s sexual relationship could be considered “highly supervised” (Winges-Yanez, 2014). McCarthy (2009) also highlighted conservative attitudes towards people with learning disabilities in relation to parenthood, as evidenced by the contraceptive injection Depo-Provera being disproportionately used for women with learning disabilities compared to the wider population. McCarthy (2009, p. 203) argued that this practice gave “providers control over clients’ choice”. However, the organisation supporting Emma was not risk averse in all areas and should be praised for actively supporting Emma’s sexual relationship (in terms of providing emotional support and sexual health advice) despite her previous experiences. Perhaps the organisation supporting Mary would experience higher levels of criticism if Mary engaged in a sexual relationship, because of her possible lack of capacity. Considering this, it could be argued that they were demonstrating positive risk-taking by enabling Mary to spend time alone with Gary engaged in physically affectionate behaviour, if not penetrative sex.

Discussion

The research on which this paper was based only involved people with a learning disability and not the staff providing their support or family members. The inclusion of staff or family members would have provided an additional perspective on the issues discussed. Participant numbers were small and only included individuals supported by two organisations, limiting the study’s representativeness – the quality of support surrounding relationships might be expected to vary widely among social care providers. The original research focussed on the views of people with learning disabilities regarding partner selection, therefore organisational policies relating to relationships and sexuality were not examined or discussed with participants. This could have provided an insightful perspective but was not within the remit of the study. Similarly, participants were not asked explicitly about their understanding of rights, capacity to make decisions and challenging staff advice. However, participants’ narratives implied that they were unaware of their rights surrounding relationships or possibly unwilling to challenge decisions they were unhappy about.

The research suggests possible improvements in the social care system that might enable individuals to have broader options when selecting where and with whom they live. Ideally, couples such as Liam and Emma would be able to live as partners in a home of their own. Affording couples more choice regarding living arrangements could help avoid issues, such as
those highlighted by Liam and Emma, where staff have to mediate tension between the different needs and rights of those living in communal homes. Valuing People Now (DoH, 2009) said that people with learning disabilities should have the right to choose where and with whom they live. Support providers are sometimes in the difficult situation of advocating with commissioners and social workers if accommodation no longer suits the needs or wishes of the individual or couple. Where such arrangements cannot be changed, staff may benefit from input on how to address conflict in a shared living environment without restricting individuals’ rights.

A climate of “protectionism” and “risk aversion” appears to persist towards people with learning disabilities. Restrictions may be more subtle than in the past but still remain. This suggests that more input could be provided directly to people with learning disabilities to ensure they know their rights and, if they have the capacity to make a decision, that they are aware it is their decision, not staff’s. Of course, due to the nature of some peoples’ learning disabilities, the involvement of staff within relationships remains essential. Any restrictions that are put in place, such as when an individual lacks the capacity to consent to a sexual relationship, should be in the individual’s best interests. However, in some instances it appears there could be a more balanced approach to safeguarding. While staff must consider individuals’ safety, it is important that these needs are not prioritised at the expense of their other needs. These examples highlight a possible need for some organisations to have a better understanding of the DoH (2005) and to provide support in accordance with this, such as not placing restrictions on individuals who have the capacity to make their own choices.

The role of staff often requires the provision of both practical and emotional advice surrounding sex and relationships. It is not clear what support staff have received to equip them to do this, especially when working with individuals who have been sexually abused. It is suggested that support providers consider this as a training need in order for staff to better support individuals regarding sex and relationships. Staff could be made aware of additional support which is available such as: sexual therapists (from organisations such as Relate) who work with adults with learning disabilities, and organisations like Respond who provide counselling to people with learning disabilities who have been sexually abused. There was no discussion in interviews of sexual activities other than penetrative sex, suggesting that people with learning disabilities may not be fully aware of other ways they could enjoy a more physical relationship and increase intimacy with a partner. This highlights a possible need for sessions for adults with learning disabilities that focus on sexual issues beyond biology and contraception and address the emotional aspects of sex and enjoyment beyond penetration for both men and women. This could be provided either for couples or for single sex groups.

It might be argued that the climate of risk aversion discussed above reflects the environment within which service providers operate. Professionals and regulators may benefit, in some instances, from being less critical of providers who have taken all reasonable steps to minimise harm to individuals while upholding their human rights and ability to make decisions. Relationships are a part of human nature, which is unpredictable, and only when this climate of risk aversion reduces relationships can truly flourish.

References


McCarthy, M. (2009), “‘I have the jab so I can’t be blamed for getting pregnant’: contraception and women with learning disabilities”, *Women’s Studies International Forum*, Vol. 32 No. 3, pp. 198-208.

McCarthy, M., Hunt, S. and Milne-Skillman, K. (2016), “‘I know it was every week, but I can’t be sure if it was every day’: domestic violence and women with learning disabilities”, *Journal of Applied Research in Intellectual Disabilities*.


**Corresponding author**

Claire Bates can be contacted at: c.bates@kent.ac.uk