**Title: Supporting people with learning disabilities to make and maintain intimate relationships**

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# Abstract

**Purpose**: To understand some of the barriers people with learning disabilities experience with regards to relationships and the changes professionals need to make to address them.

**Methodology**: The current paper will draw on case studies extracted from Bates *et al*. (in press), utilising 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 provided an additional perspective to the issues discussed.

**Practical implications-** An increased understanding of human rights entitlements is needed among people with learning disabilities as they need to know when their freedom is being unlawfully restricted. Sexuality and relationship training should be compulsory for support staff and 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 provides practical solutions to address them.

**Keywords**: Learning disability, relationships, sex, safeguarding, consent, capacity

# Introduction

A loving, committed relationship with an exclusive partner is valued highly (Shackelford *et al*., 2005 and O’Reilly *et al*., 2009). Being in a long term relationship has been found to increase economic status (Chun and Lee, 2001), and promote emotional wellbeing (Blanchflower and Oswald, 2004) and better physical health (Waite, 1995). 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 Human Rights Act (1998) which states that everyone has the right to a ‘private and family life’ which includes marriage. This right is often unknown by people with learning disabilities (Healy *et al*., 2009). The importance of relationships is now incorporated into British law as part of the Care Act (2014), under the principal of wellbeing, the development and maintenance of personal relationships is considered an eligible need.

In the UK, *Valuing People* (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* (2009) highlighted a lack of progress. No statistics exist which indicate exactly how many people with learning disabilities in Britain have a partner but Emerson *et al’s.* (2005) *National Survey of People with Learning Disabilities* found that only 4% of participants interviewed had a partner. In the 2011 census, 49% of UK adults were married (Office for National Statistics, 2011). This data did not include how many people were in relationships but unmarried. This suggests that fewer people with learning disabilities were in relationships compared to the wider population. Research in the 1970’s appeared to show higher rates of marriage for people with learning disabilities (Craft and Craft, 1979 and Mattinson, 1970). Craft and Craft (1979) identified that 24% of participants 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. This implies that the caution surrounding this type of relationship has only existed in recent years, possibly due to the increased priority afforded to safeguarding. Better safeguarding may have resulted in a decrease in the number of relationships for people with learning disabilities that were deemed undesirable by professionals.

Tindall (2015) highlighted how safeguarding processes have created a climate of liability avoidance, with providers striving to receive the least amount of criticism if something goes wrong. Research has shown that 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, there is a greater risk to people with learning disabilities engaging in relationships and staff may want to protect them. Support staff have been found to hold moderately positive attitudes towards the sexuality of people with learning disabilities and were 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 and Kelly *et al*., 2009). Policies and programs 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.

# Method

The data presented here was originally collected as part of a PhD that explored partner selection for people with learning disabilities (Bates *et al*., in press). Eleven participants with learning disabilities were recruited via a gatekeeper from two UK social care providers and interviewed. Inclusion criteria were: adults in receipt of a specialist service for people with learning disabilities, and the ability to communicate in sentences and discuss abstract topics such as love. Participants had to have had at least one relationship over 6 months which included physical contact (e.g. kissing). All participants were able to give informed consent. Ethical approval was obtained from London Southbank University Research Ethics Committee. In Bates *et al.* (in press), interviews were transcribed and analysed using Van Manen’s (1990) hermeneutic phenomenology. The current paper will draw on case studies from Bates *et al*. (in press) and utilises 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 - Support required for better relationships

The Family Planning Association’s ‘It is My Right’ (2008) campaign highlighted that 94% of professionals think barriers exist which prevent people with learning disabilities from having relationships. The key barriers that relate directly to professionals will be discussed in relation to four individuals. Pseudonyms are used throughout.

* **Kerry**- Receiving minimal support within her own home (not every day)
* **Liam and Emma**- Low support needs (live in 24 hour supported accommodation but go out independently and require minimal support with daily living needs)
* **Mary** -Higher support needs (lives in 24 hour supported accommodation, does not go out independently and requires substantial support with daily living needs)

**Mary:** A woman in her forties. 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 housemates 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 inher thirties. 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 is not controlled by the support provider but by commissioners, housing providers or social workers. This is reflective of Fyson *et al.’s* (2007) research where participants were excluded from making life-altering choices such as who they lived with. 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 Mental Capacity Act (2005). There was no evidence 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 people with learning disabilities’ right to have sexual relationships (McCarthy, 1999) and this was reflected in Government initiatives such as Valuing People (2001). The interviews demonstrated the knowledge that staff are required to have in order to provide adequate advice surrounding safe sex and contraception as part of 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. The benefit of this is increased engagement with people who do not have a learning disability, but this has led to people with lower support needs, such as Kerry, engaging in relationships with partners who could be considered ‘undesirable’. In the 1970’s participants engaged in relationships with ‘undesirable partners’ (Craft and Craft, 1979) and this appeared to have been accepted. Under current safeguarding legislation staff have a duty of care to protect vulnerable adults and as such these relationships would be 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 Mental Capacity Act (2005) enshrines an individual’s right to make a decision in law, and states that capacity should always be assumed unless there is evidence to suggest otherwise. It appears that not all participants knew their rights. Possible evidence to support this view comes from Mary being instructed to leave her nightdress on with Gary, and Liam and Emma asking permission to have sex. Capacity should always be presumed, however, based on her responses in the interview, it is unlikely that she has the capacity to engage in a consensual sexual relationship at this time. Staff support 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 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 people may be excluded.

## **Risk Avoidance**

Tindall (2015) discussed the culture of risk avoidance in organisations in relation to the fear of criticism from professionals or regulators. There are indications that this attitude was occurring to some extent 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 implies 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’ which resonates with Winges-Yanez (2014). McCarthy (2009) supports this view, highlighting 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) argued that this practice has been perpetuated to give ‘providers control over clients’ choice’ (McCarthy, 2009, p. 203). However, the organisation supporting Emma was not risk adverse 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 experience. It could be hypothesised that the organisation supporting Mary would experience higher levels of criticism if Mary engaged in a sexual relationship due to her possible lack of capacity. Considering this, it could be argued that they are demonstrating positive risk taking by enabling Mary to spend time alone with Gary engaged in physical affection, if not penetrative sex.

# Discussion

The research 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 which limited the study’s representativeness as it only included individuals supported from two organisations. The quality of support surrounding relationships could vary widely among social care providers.

It is recommended that improvements to the system should be considered to ensure that individuals have broader options when selecting where and who to live with. In principle, couples such as Liam and Emma should be able to live alone if they wish to and, equally, individuals should have the option not to share their home with someone. Affording couples more choice regarding living arrangements would go some way towards avoiding the issues highlighted by Liam and Emma where staff are required to mediate tension between the different needs and rights of those living in communal homes. *Valuing People Now* (2009) identified that people with learning disabilities should have the right to choose where and with whom they live. Support providers have an obligation to advocate on behalf of those they support by championing their individuals’ rights and where possible challenge commissioners and social workers if accommodation no longer suits the needs of the individual. 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’ persists towards people with learning disabilities. People still experience restrictions which may appear subtle but possibly reflect this. It needs to be made clear to people with learning disabilities what their rights are and that, if they have the capacity to make a decision, staff are unable to oppose this. However, 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 restricting a person who lacks the capacity to consent to a sexual relationship, should be done ‘in that person’s best interests’. However, in some instances there needs to 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 freedom and wishes unless it has been established that they lack the capacity to decide for themselves. More needs to be done to ensure that organisations act within the law and that restrictions are not placed on individuals who have the capacity to make their own choices. This will require better staff training and more professional attitudes. People with learning disabilities will not have true autonomy until they are treated and respected as adults and decisions are based on facts rather than the opinions and personal views of those involved in their care.

The role of staff often requires the provision of both practical and emotional advice surrounding sex and relationships, what is unclear is what support the 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 best support individuals regarding sex and relationships. Staff should also 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 difficulties 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.

Strategies to support intimate relationships for people with learning disabilities in this research, and recommendations within the research literature, appear reactive. Strategies typically include training for staff to better support those already in relationships. There is little focus on the proactive instigation of relationships. Staff may be risk adverse in promoting relationships due to potential safeguarding issues or grief if the relationship fails. This fear may be limiting individual’s ability to develop relationships. More work needs to be done surrounding the promotion of dating agencies style initiatives such as Luv2meetU, and Stars in the Sky. People with learning disabilities may not be aware of how to instigate relationships and such organisations could provide a vital service.

Professionals and regulators need to be less risk adverse and not criticise 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 lifts can relationships truly flourish.

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