

Accessible Summary

- Support staff play an important role in helping people with learning disabilities to meet a partner and have a relationship. Not getting good support can make it difficult for people to have a relationship
- Many support staff want to help people to have a relationship, but are worried about people being abused. This is especially true for those who do not have a lot of staff support.
- Support staff do not always get good support themselves to help people with learning disabilities to have relationships, such as training and a policy to follow. This makes it hard for them to know what they are allowed to help with.

Abstract

Background -People with intellectual and developmental disabilities (IDD) face challenges in developing and maintaining intimate relationships, frequently requiring support from staff .

Method-Focus groups were conducted with 26 social care staff members to explore the support they provided to people with IDD to find a potential partner and/or develop an existing relationship.

Results- Staff reported that many people with IDD wanted to be in a relationship and that they did what they could to facilitate this, sometimes providing substantial support. Some staff had to address complex issues relating to sexuality, often with no training and with a lack of clear organisational policies.

Conclusion-The need for external inspection and regulatory bodies to prioritise relationship support is emphasised.

Introduction

The Human Rights Act (1998) respects the rights of every person with regards to family and private life, including forming and maintaining relationships. The desire for love and intimate relationships among people with IDD is no different from the wider population (Siebelink et al, 2006). Yet people with IDD face challenges in exercising this right due to negative societal attitudes and prejudices that, historically, resulted in forced segregation of the sexes and sterilisation of women (Craft and Craft, 1981, Kempton and Kahn 1991). In the 1980's/90's there was a recognition that people with IDD had the right to have sex and relationships. Materials were developed so staff could deliver appropriate sex education. Prime examples are *Sex and the 3Rs* and *Sex and Staff Training* (McCarthy and Thompson 1992, 1994) which were based on their practical work and academic research and were reflective of UK context and legislation. The first pack has been regularly updated and remains in print (2016). Nevertheless, today many people with IDD continue to have limited opportunities to develop intimate relationships (Chou et al, 2015). Evidence suggests that people

with IDD report a number of obstacles; restrictive organisational policies (Bernert, 2011), a lack of privacy and highly managed sexual relationships (Winges-Yanez, 2014). People with IDD often have a poor knowledge of their sexual rights and therefore are not well placed to challenge the restrictions imposed upon them (Healy et al, 2009). A meta-analysis of research in this area (Whittle and Butler, 2018) found that staff were the biggest barrier to relationships and that people with IDD felt powerless to challenge restrictions. Staff-controlled access to social opportunities, meaning that people with IDD rarely socialised outside of organised groups, fostering loneliness and a lack of intimacy. Some people with IDD reported being fearful of engaging in 'prohibited' behaviours (ranging from kissing to sexual intercourse) in case this resulted in 'punishments' from staff (Whittle and Butler, 2018).

The fact that staff often hold contradictory views about the sexuality of people with IDD, seeing them as both asexual and hypersexual, has been reported in the literature for decades (Craft 1987, McCarthy 1999). With such views, staff can become uncertain of how to support people and resort to overprotective approaches (Hollomotz, 2011). Staff motivations to want to protect people with IDD are valid, as there is an increased prevalence of sexual abuse towards people with IDD and domestic violence towards women with IDD (McCarthy et al., 2017). Staff have been shown to hold gendered attitudes, typically viewing women with IDD as sexually innocent, vulnerable to abuse and requiring protection, while seeing men with IDD as more sexually driven and liable to engage in problematic and predatory sexual behaviour (Young et al. 2012). The juggling act staff feel they perform between helping people regarding sex and relationships (such as finding a partner) *and* protecting them from harm is commonly reported in the literature (Maguire et al, 2019). Feely (2016) acknowledges the conflict faced by staff who limit privacy through observation, record keeping and reporting potential safeguarding concerns, but also uphold a commitment to supporting sexual rights. Staff have to walk a fine line balancing the need to protect, without being overly controlling, and limiting sexual freedom through lack of privacy (Feely, 2016).

Staff anxiety regarding sexual relations has possibly been heightened due to the complexity and possible misunderstanding of the Mental Capacity Act (MCA). The MCA was introduced in the UK in 2005 and is intended to protect individuals' rights to make decisions. Its first principle is a presumption of capacity and only if this is in doubt should capacity be assessed. Capacity assessments may be undertaken in areas such as consent to sexual activity, marriage and contraception. If an individual lacks capacity regarding sexual activity, a best interest decision can be made to protect them, often by restricting sexual contact. The MCA recognises an individual's right to make an 'unwise decision' and does not necessarily see this as evidence for a lack of capacity. However, assessors struggle to distinguish the difference (Williams et al., 2012). There is an

argument that people with IDD are disadvantaged, often having to “prove” their capacity regarding sexual decisions, which is not asked of the general population (Arstein-Kerslake, 2015). People with IDD often lack capacity for sex due to a lack of appropriate education rather than as a result of their mental impairment (Series, 2015). The issues of capacity for sex regarding people with IDD are complex and staff are often left to decide what activities are lawful and what must be legally prevented (Series, 2015). Willner et al (2012) identified that social care staff, even after receiving training, have limited knowledge of the MCA, its principles and applications.

Maguire et al (2019) argue that decisions made regarding support for a person’s sexuality and relationships are rooted in staff’s personal beliefs, their work experience and their own morals and religion. This often results in staff responding reactively, rather than proactively, and the importance of sexuality for people with IDD being minimalised. Bates et al. (2017) identified restrictive practices from staff, but overall championed the role of support staff as they were the main facilitators of relationships and without their support relationships for people with IDD would not have developed or endured. Staff provided support to couples in terms of relationship advice, support to get married and move in together, as well as advice around contraception.

The current study aimed to explore the views and practices of UK support staff to help people with IDD to develop loving and lasting relationships.

Method

Participants

Participants were all staff members supporting adults with an IDD. Twenty-six staff took part. Twenty-three came from three social care charities across the south of England. The remaining three staff came from different organisations supporting adults with an IDD. All participants were either support workers or front-line managers, except one person who delivered sex education to adults with IDD. There was a broad range of ages and experience within social care and a quarter of staff came from BAME communities. The sample included 23 women and 3 men.

Participants were recruited via social care providers and national networks. The people with IDD the participants supported had a range of experiences surrounding intimate relationships, though the majority were single, predominantly living in 24-hour social care housing, with a minority living independently with minimal support.

Procedure

Participants were asked to take part in focus groups exploring how people with IDD were, or could be, supported to form and maintain relationships. The researchers created an interview guide with semi-structured questions. An advisory group of people with IDD were consulted regarding the questions to ensure they fitted the research aims and reflected their lived experience. All focus groups lasted approximately two hours and were audio recorded. Participants were informed that they could withdraw from the research at any time and could request that their data be removed (up until the point where it has been analysed and written up).

Due to the sensitive nature of the study, research data will not be made available to be shared in a public repository.

Ethical approval was given by the Social Care REC Ref No 17/IEC08/0053.

Analysis

The data was analysed using latent thematic analysis (Braun and Clarke, 2006). The responses to each topic raised by the focus group facilitator were grouped together on the basis of similarities. Two researchers independently reviewed the data to compare the main themes to ensure consistency. The concepts expressed were summarised, resulting in a number of initial themes which were then collapsed into wider themes, enabling commonalities and diversity with regard to reported views and experiences to be identified. Care was taken to ensure that the content of any emerging themes were grounded in the original data.

Findings

Following the thematic analysis, three main themes, containing six sub-themes were identified and can be seen in Figure 1.

[insert figure 1 here]

Sensitive insights into the emotional/psychological needs of people with I DD

The participants demonstrated that they had listened to people with IDD and had good insights into their needs. They were aware that many of the people they supported desired an intimate relationship; like many people in society, they wanted to love, and be loved by, a partner. Some staff were aware that being in a relationship related to individuals' personhood, or being accepted for who they were – and this was important for them:

“But I do think some of them would love to be in a relationship, you can tell... Imagine if someone would love him for all his “isms”, behaviours and things? Because he is desperate to be loved”

Staff reported that those people with IDD who were in a relationship found it to be a positive experience providing love and companionship, especially if they had limited family contact. Staff felt that this held true, even if there were difficulties in the relationship, such as one partner developing dementia:

“When R came along and showed a little interest, it was a bit more love given to H, from what she lost from her mum and dad....R has come along and lifted her spirits and given her something to look forward to”

Understanding 'imaginary' relationships

Staff showed respectful insights into behaviours by some people with IDD which could be easily misinterpreted or ridiculed. This was most apparent when it came to ‘imaginary’ relationships. The participants did not dismiss these, but rather understood them to be an expression of the sadness some people felt at being single most or all of their adult lives:

“We know people who are desperate for a relationship...That [making up relationships] is almost expressing a need, an emotion in itself, a desire to have some sort of relationship”

These sensitive insights reflect the work of Hollomotz (2011) who understood that these imaginary relationships created a sense of belonging and filled a void in peoples’ lives.

Longing for relationships can lead to risky behaviours

Participants recognised that sometimes the desire for a relationship was so strong that it placed individuals at risk, because they would engage in unhealthy or abusive relationships rather than be alone:

“She is willing to have any man... she just wanted to be married again. Any man will do basically, she just wants to be in a relationship, so even though the ones she is in are not good for her, all we can do is advise, as she has capacity. It’s not good”

Some participants reported that when it came to some people with more complex needs demonstrating their desire for sexual contact, this was not always conveyed appropriately and was considered a behavioural issue. For example, one woman was sending “sexual notes” to female staff and there were two cases where men were being sexually inappropriate towards female staff.

“One young man with LD wants a relationship with someone “normal” and focuses all his attention on young female staff. It is very difficult as he is overly flirty with staff and you have to say ‘back off, mate, that is not appropriate’”

In this study, staff felt some people with IDD were sexually frustrated, but that this had not been addressed due to a lack of knowledge and training on how to respond. There are also similar examples in the literature going back decades, highlighting how female staff are frequently exposed to intrusive sexual behaviour by men with IDD and pointing to a lack of clear management guidance in dealing with it (Thompson et al. 1997). This finding suggests that in the past twenty years adult social care does not seem to have progressed very far in the support provided to people with IDD in this area.

Challenges faced by staff in supporting people with IDD with relationships

Vulnerability of People with Small Support Packages

All participants felt the most vulnerable people with IDD were those who receive minimal support, often living alone and making independent decisions regarding sex and relationships. They felt this group were often socially isolated and desperate to meet a partner, but perhaps lacked the skills and knowledge of how to keep themselves safe. Staff are limited in how far they can protect such people, as they can only provide advice. Staff gave examples of where they had intervened where abuse was occurring (for example helping people to safeguard their money over fears of financial abuse). Staff said they did this even when this was not part of the commissioned support, because this group of relatively able people did not have anyone to play a safeguarding role. However, they also understood the limits of their role:

“The bad support was, for me, that the social worker didn’t intervene – it wasn’t really down to us to be safeguarding him”.

Staff explained how vulnerable these people with IDD potentially were by referring to incidents whereby individuals had been exploited for money or sex. Staff felt people were so desperate for relationships that they would place themselves in dangerous situations that they did not understand. Participants were particularly worried about the vulnerability of those who met strangers from the internet:

“She is desperate to find a boyfriend, but she was putting herself in bad situations with people who were never going to be her boyfriend, just meeting them in the street and promising them all sorts, sending people pictures on the internet...it’s been really difficult.”

Walking a tightrope – balancing control and autonomy

Staff spoke of the difficult balance involved in supporting people to have relationships, but also to keep them safe. Most staff wanted people to have the opportunities to make mistakes, but they were also fearful of risk, and considered that other professionals felt the same, in particular social workers. Participants feared that even if a person with IDD had capacity to engage in a sexual relationship, that they, the staff, would be blamed if something went wrong:

“The biggest fear is this, sort of like, always trying to walk a bit of a tightrope between, you know, duty of care to somebody and allowing them to, you know, to have self-determination of their own life and, you know, do they really understand what the, what the expectations are of them and what they might be getting in to?”

They gave an example of a woman with IDD who wanted a relationship but lacked capacity to engage in a sex (and is having sex education to try to change this). They felt that if the woman found a partner before the next capacity assessment, they would have to limit sexual contact, due to her vulnerability:

“Because we are protecting her from the bad, we are also stopping her from the good.”

People with IDD’s ability to keep themselves safe online was a source of concern. Participants cited a lack of awareness of what is appropriate to share, not having privacy settings on social media and a limited awareness of online norms/ rules as important factors. They reported that most people with IDD had had no education around these issues. Participants knew of several men with IDD who had got into trouble with the law by contacting young girls online. Some participants wished they could control people’s internet access to keep them safe. But they understood that, generally, this was not possible, and they just had to offer advice as best they could:

“Facebook could be a great tool, and is a great tool, to connect to friends and people you know. But people add her all the time... there is this constant stream of guys adding her on Facebook”

Organisational barriers

Participants were able to articulate what they thought the main organisational barriers were for their service users.

Restrictive staff attitudes

Most participants raised concerns regarding the negative impact that “old fashioned” staff attitudes and culture have on the development and maintenance of relationships for people with IDD. A minority of staff stated that they did not feel that people with IDD were truly treated as people, with the same human rights as everyone else:

“We are not treating people as people still.... The smallest things make the biggest difference, don’t they, to everybody’s lives.... It is still the old culture rippling on. It is all about risk.”

The participants in this study were a self-selected group and predominantly positive with regards to relationships for people with IDD. However, there were examples of negative and judgmental attitudes in one focus group. For example, staff from one service expressed disapproval that a man with IDD, with capacity to consent to sex, had casual sex with people he met online. They believed their organisation was overly tolerant and that other organisations would not “allow” this:

“He had a relationship and destroyed it and is now exploiting himself...He lets himself down because of his behaviours and need for attention.”

The same participants also displayed similar judgemental attitudes towards a couple with IDD who were seen showing physical affection in public:

“...full blown kissing and touching [over clothes] and they were sitting on a bench where people are walking up and down”.

They implied that they did not want the individuals, and perhaps their organisation, to be judged negatively for this.

There was also a minority of staff who felt the people they were supporting had no interest in developing a relationship. This may be true, however their comments possibly reflected low aspirations for the people they support:

“They [people with IDD] are happy with what they know – ‘I am safe, I get my dinner, I get my tablets, I go out to activities.’”

Staff were asked what benefits they felt people with IDD experienced as a result of being in a relationship and some could only see this from their own perspectives e.g. the benefit to staff due to a reduction in challenging behaviour:

“He is more willing to listen to staff... Willing to do whatever you ask him to do [as a benefit of him being in a relationship]”

Lack of guidance and support for staff

Only a minority of participants had received training in sexuality and/ or relationships, despite having to deal with complex issues. They stated that it was typical in their services to react after an incident related to sexuality or relationships, rather than to proactively support people. They felt their services relied on external professionals and not on developing internal capacity, which they felt could be more beneficial in the longer term. Staff expressed a need for training on how to have conversations with people with IDD regarding sexuality and relationships:

‘Staff training would be great because, you know, people are really reliant on us and are looking to us all the time, especially the two people I am thinking of that are in a relationship in our service...they are looking to us constantly for guidance on how to navigate all of life, you know, it’s all confusing, difficult, frightening and we are not always right. Some good training around how to react, how to support people, I think would be really, really good actually.’

The majority of staff were unsure if their organisation had a policy on sexuality and/or relationships, and if they did have one, they could not explain what it covered. This lack of organisational clarity, as evidenced through a lack of training and policies left staff uncertain of how they should support people regarding relationships, and as suggested above, reluctant to take any risks:

“Organisations can be, I think, concerned or scared to always support somebody, to take that step because... where does the responsibility then sit if something goes wrong?”

“I definitely need to know more about “what” the system allows, how can we support them to love and have relationships”

Discussion

This study demonstrated that staff are aware of a clear desire for romantic relationships among many people with IDD and they know that that many people require support from staff in this area. Staff provided support to facilitate their relationships, but also played a key role in helping people to keep safe, albeit in a climate of uncertainty.

Almost all staff felt that they needed training in this area to ensure they provided the right support and to empower them with the knowledge to challenge others if needed. Staff were not receiving the training they needed, despite dealing with complex issues. This is a disappointing finding, especially when seen in a historical context: at the turn of the century, the UK Government's strategy for people with learning disabilities (*Valuing People* 2001) outlined the importance of their choice to have relationships and a family, and to be supported to do so. But the UK government failed to produce a new strategy. This, in combination with austerity measures which saw substantial cuts to social care (Malli et al. 2018) had a negative impact. The findings of this research suggest that IDD services rarely consider relationships and sexuality training to be essential.

This lack of imperative regarding training comes from the top: the UK social care regulator, the Care Quality Commission (CQC) only state that "induction and ongoing training on sexuality and relationships will help staff to respond to situations in a considered way" (CQC, 2019, p.7). It does not state what the training should include, how often and who should provide it.

It is not only staff training, but also policy development which appears to have gone backwards. The 1990's saw statutory and voluntary organisations being obligated to devise policies which addressed sexuality (McCarthy, 1999). In Murray et al. (1999) 84% of staff questioned were aware of their organisation's sexuality policy. In this study the majority of staff said their organisation either did not have a sexuality policy or they did not know what it contained. Participants agreed that they would look for, or at, their service's relationships policy only if they 'needed to', which suggest relationship support was not seen as part of everyday support.

The CQC make no reference to sexuality policies except in the supplementary questions that an inspector can choose to ask i.e. "does the organisation have a relationship and sexuality policy, including an easy read version?" (CQC, 2019, p.8). This signifies that the regulators also feel that although relationships may warrant specific guidance, they are not important enough to form part of the formal inspection process. CQC's ambiguity, combined with a lack of organisational focus and training provision around sexuality, leaves staff vulnerable as they are unsure of what is "allowed".

Previous literature indicates that staff are typically more concerned about the sexual vulnerability of women than men (Barger et al 2009). In this study, staff were concerned about people with IDD of both sexes who had minimal support and who made all their own decisions regarding sex and relationships. Staff felt that social isolation, combined with limited support hours, made both men and women vulnerable to abuse. Our participants shared the views of Maguire et al (2019) that support was often a complex juggling act of balancing help for people to meet their aspirations and

protection from abuse. As in the Maguire et al (2019) study, our participants found this ‘walking the tightrope’ particularly challenging when they had little or no training and no knowledge of organisational policy. Uncertainty surrounding whether staff can intervene was a concern among staff. Staff made blanket statements regarding capacity such as “he has full capacity”, while not understanding that capacity is decision specific. This highlights that staff may not fully understand the MCA (as in Willner et al, 2012). This is problematic as staff are often responsible for raising potential safeguarding concerns where the law may be being breached.

In this study, participants reported that some people with IDD engaged in abusive or concerning behaviours to meet their needs for a relationship or sexual contact. Staff were aware that loneliness has a detrimental effect on both mental and physical health (Leigh-Hunt et al 2017), yet they struggled to help their service users to meet significant others. Although the Care Act (2014) made the reduction of loneliness an eligible need, it does not appear that local authorities are meeting this need, as, due to austerity, many social clubs have closed and social support has been reduced (Malli et al, 2018). This means that leaving romantic relationships aside, even making and keeping friendships is problematic for many people with IDD (Gilmore and Cuskelly 2014).

Negotiating and supporting sexual relationships can be complicated and challenging. An organisation called Supported Loving (www.supportedloving.org.uk), which champions the rights of people with IDD to have relationships, have compiled resources/ guidance for people with IDD, staff and families.

Limitations

This research had limitations, as all studies do. Firstly, it was a self-selected sample, which may have introduced unknown biases. Female participants outnumbered males which may have altered the responses (although the sample was broadly representative of the adult social care workforce). It is reasonable to assume that staff who were negative about relationships for people with IDD would be less likely to volunteer to participate. Therefore, those who did volunteer to take part in the study are likely to have been more progressive in regard to their attitudes in supporting relationships for adults with I DD.

Conclusion

In many contexts, support staff in group homes and supported living accommodation struggle to balance control and guidance with service users’ autonomy (Hellzen et al 2018) and this is evident when it comes to relationships and sex. Staff need to be careful not to abuse the influence and power they inevitably have over service users, as people with IDD are often not well placed to exert their rights and stand their ground. This study suggests that many support staff do show insight into, and respect for, the relationship needs of adults with IDD. With the right training and organisational

support, they could be enabled to talk seriously with people with IDD about the support they want and need and to provide it accordingly.

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