Background

Having a partner valued by people with learning disabilities (LD) (Kelly et al. 2009; Rushbrook et al. 2014)

The Human Rights Act (1998) states that all individuals have the right to a ‘private and family life’ which includes the right to marry. This right is often unknown by people with LD (Healy et al., 2009).

Valuing People (Department of Health 2001) aspired for people with LD ‘to form relationships, including ones of a physical and sexual nature’. Valuing People Now (DoH 2009) indicated a lack of progress.

UK Government policy supports the relationships evidenced by the Care Act (2015) citing the reduction of isolation as an eligible need but limited focus in CQC regulations / inspections
Barriers Faced by People with LD

People with learning disabilities are denied support to pursue sexual relationships (Family Planning Association 2008).

Policies can be implemented which limit sexual expression (Bernert 2011). Sexual relationships can be highly supervised (Winges-Yanez 2014). Rushbrook et al. (2014) highlighted staff fear regarding the risks of abuse associated with relationships.

Adults and young people with learning disabilities experience higher levels of abuse (Horner-Johnson and Drum 2006, Smeaton et al. 2016). Domestic abuse occurs more frequently within relationships for women with learning disabilities (McCarthy et al. 2016).

May have a limited ability to evaluate risk and require support from staff in this area (White and Barnitt 2000).

Balance of wanting people to have relationships but fearing for their safety (Lafferty et al. 2012)
My PhD Research

Participants

Eleven participants recruited from two UK social care charities
All over 18 years old and diagnosed with a learning disability
All able to verbally communicate in sentences and be able to discuss abstract concepts such as love.
All had experience of a relationship which lasted over six months. The relationship did not have to include sexual intercourse but had to include a degree of physical closeness such as cuddling.
People within same-sex relationships were not recruited. It was felt that the potentially unique barriers and challenges faced by this group of individuals deserved more attention than was possible within the limits of this research.
Results

The importance of having a loving relationship

All participants desired a partner to love and who loved them. Participants frequently shared how much they loved and valued their partner.

Caroline: *We just held hands and that’s how it started. We were really, really in love.*

Joe: *She’s [wife] a great person in my life, friendly, kind, funny. Fun to be with, I love you so much. So happy about the person I am married to, and also, she is my soul mate.*
Companionship - All the participants shared a need to be with someone and to feel special to someone. Some participants expressed loneliness which did not appear to be influenced by the number of people they came into contact with.

Emma: Well, the thing that makes me happy being with someone is I would rather live with someone, a partner, than being on my own because I don’t like being on my own.

Support- Sometimes a partner replaced the possible need for staff support and possibly enriched and strengthened couples’ relationships through encouraging trust in their partner’s ability to care for them.

Liam: Yeah she [Emma] cares about me and about me getting ill. Don’t want to get ill get headache. Yeah keep me well look after me.
Physical Relationships

Only 4 of the 11 participants stated that they had sexual intercourse. All reported enjoying physical contact with a partner and saw this as central to a loving romantic relationship. Relationships consisted of a significant amount of affection such as cuddling and kissing which participants valued. Some participants’ expressed how physical contact was an instrument for developing intimacy.

*Emma*: I wanted to get closer to Liam [through sexual intercourse].
*Liam*: Share everything with each other, sleep with each other

*Researcher*: So how do you know when someone loves you?
*Carrie*: Cuddles
*Joe*: Or kiss
Barriers to Relationships

Some participants said that living in a group environment created barriers to their relationships. Such as jealously and lack of privacy from housemates:

Researchers: You tried [to have sex]?
Carrie: Pamela tried to come in
Researchers: That’s a bit difficult then. Do you not have a lock?
Joe: Yeah we did, we tried that. She keeps knocking. We gave up on that didn’t we?

Or from staff

Emma: We only do at weekends [share a room]
Liam: Or half term...We can do what we want in our own house without being told what we can and can’t do

Carrie: I asked the support staff if Joe can move into my room and they said that’s fine.
Staff Support

Staff often found themselves in conflicting roles—expected to both encourage autonomy and independence and to protect people. In roles such as organising dates, managing conflict and providing sexual health advice.

*Kerry: Staff said that because he has them [warts] we must not undress or go naked when he has them. Because they said that I may catch them. So staff said that if we do it then he has to wear a condom.*

*Caroline: If we say for instance we have an argument or something the staff would support us and would know what to do or say or whatever.*

*Researcher: Oh right. What the staff wanted you to try it out. What did they say?* 
*Alan: They said how did you get on in X [local town for date]? And they said do you want to do it again?*
LOVE WITH A DISABILITY
What is Supported Loving?
Do people with learning disabilities understand their right to have a partner stay in their room?

- Yes: 21%
- No: 71%
- Don't Know: 8%

Staff felt most people with learning disabilities who can consent did not understand they had the right to have someone sleep in their room.
Reasons Why Couples in 24-hour Support Did Not Share a Bed

- The couple did not want to (4%)
- They only have a single bed (19%)
- They never asked (23%)
- They lacked capacity for sex (10%)
- Their parents did not want this (14%)
- Their tenancy forbids it (2%)
- The organization/manager said it was not allowed (10%)
- The social worker/care manager said it was not allowed (8%)
- The staff felt uncomfortable (10%)
The responses were mixed but painted a grim picture. People were being restricted from a variety of barriers:

• **Support restrictions**— either policy or management prohibiting this or staff feeling uncomfortable

• **Parental Control** – this survey did not include people who lived at home, just people living with 24-hour support HOWEVER parents were still control of an important aspect of their adult children’s lives

• **Environmental restrictions**- People only had a single bed. Single beds = single lives

• **Unaware**- Most staff reported the reason couples did not share a bed was that people had not asked, we suspect that some staff would not want to suggest something that the person didn’t raise themselves.

However, if the person doesn’t know they are allowed an overnight guest, why would they ask?
What are staff’s concerns about sex and relationships?

- Some staff that come from an elderly care background have different views on what people with a learning disability needs are.
- A common perception of people with a learning disability is that sexual relations are wrong even if they are in a loving relationship.
- There is little access to resources for staff and individuals to gain knowledge on this area.
- We need to recognise the challenge of talking about the risk and how we can support people to take risks in a positive way.
- Staff are often afraid to raise this topic for fear of being reported under safeguarding.
- It seems to be a totally taboo subject from an early age.
- I believe that staff need educating around people we support and sexual relationships.
What Would Help More People to Enjoy a Loving Relationship?

- Nobody talks about the emotional and social side of relationships.
- Educate staff and explore with individuals what they would like from a relationship and don’t be afraid to support them to achieve it. Sometimes things go wrong, but this something is an experience we all go through in our lives.
- Ensure they know it’s normal, it’s aloud, it’s natural, that we had humans are programmed to enjoy sex, educate and allow choice.
- More info and training/discussion groups for people with a learning disability to understand and explore their right to intimate personal relationships. Support to challenge limiting beliefs they may hold. More training for staff.
- More education - more open discussions with people with learning disabilities, families and staff.
- Deal with the risk element and address it full on.
- People get stuck on sex and pregnancy. these are not insurmountable issues to talk about. Everyone needs a chance. some are scared of how much support people will need.
- Provide information to people about their rights. Train staff.
- More training for workers is essential, but also training/awareness raising for families and people with learning disabilities too.
- Awareness sessions for parents and social workers.
Current Research Projects

University of Kent - Tizard Centre

• Exploring Support for People with Learning Disabilities to Find Loving Relationships

• Exploring the Experiences of Bisexual People with a Learning Disability
How Can YOU Get Involved?

• Join the Supported Loving Network
• Come to a Supported Loving Network Event
• Listen to Our Podcast
• Tell us how about something good you or your organisation has done around love, sex or relationships
• Write a blog post to share and inspire others
• Make a video to share and inspire others
• Tell EVERYONE about Supported Loving 😊

WE WANT EVERYONE TO HAVE LOVE IN THEIR LIVES - HELP US MAKE THIS A REALITY FOR ALL