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A Life More Ordinary

Recommendations from the Our Social Networks Project

“What is love?”

“Finding the right person and feeling comfortable in their silences and being happy you’re there and being there when they’re sad. Every part of a person, being good or bad.”

Thank you

We want to acknowledge and thank the many people who have already supported us in forming this thinking.

This document is not a complete and fixed set of recommendations. Instead we hope that it can be used as a starting point for discussion and debate. We want it to inform practice across organisations, but also prompt conversations with staff and of course people with a learning disability and their families.



Introduction

Between 2017-2020, the Our Social Networks collected stories from people with a learning disability about their friendships and relationships. We recorded 41 interviews with over 60 people. We listened back to the stories and analysed in more depth, 25 transcripts of the recordings.

The stories told us that:

- friendships and relationships are vital to us having a good life;
- friendships and relationships give us a sense of validation and pride;
- friends help us to make sense of ourselves and our life events;
- it is important to have a shared history with another person beyond our family;
- we all need companionship.

The stories also exposed:

- How difficult friendships and intimate relationships continue to be for many people with a learning disability.
- For many people with a learning disability, their social networks revolve exclusively around family and staff.
- The lack of power that many people with a learning disability have over their friendships and relationships.
- That many people feel they need to seek approval or even permission to make decisions about their friendships and relationships.
- That within social care, safeguarding and protection often overshadows people's rights, particularly in respect to intimate relationships.
- There are often barriers within service provision around processes and resources.
- That friendships and relationships are viewed as an added extra - something that would be lovely but not the core business of support and certainly not the core role of support staff.
- That current Relationships and Sexuality Education is not adequate.
- Organisational approaches to relationships and sexuality are often reactive and ad hoc.
- That many people have experienced bullying, particularly in school, and often do not feel accepted or safe in mainstream environments. Many described only finding this acceptance by accessing specific learning disability groups.
- How people need proactive support to find and develop friendships and relationships.

For us to connect with others we need to have an understanding and trust in ourselves. Friendships and relationships cannot be understood without consideration of identity, self-worth, agency, and power.

Supporting something in principle alone is not enough. The facilitation of friendships and relationships requires the same level of attention and work that we invest in other areas – employment for example.

We have sought to identify some practical recommendations below; We recognise that what is required is a shift in mindset and approach that positions friendships and relationship as a

fundamental right and core to social care. We understand that the practical suggestions below relate to processes and that changes to them alone will not secure this cultural shift.

We understand the capacity of support staff to build trusting relationships with the people they support will depend on how much control they have and how valued they feel at work. In practice, this means staff need to feel they are paid fairly and trust that their voice and ideas are heard. If staff feel they are supported to flourish they are in a better position to create relationships based on trust with people with a learning disability. (<https://collaboratecic.com/exploring-the-new-world-practical-insights-for-funding-commissioning-and-managing-in-complexity-20a0c53b89aa>)

Recommendations

1. Friendships and relationships to be an important part of support plans

Proactive support, a prerequisite for relationships to thrive, requires structural support. Support plans should automatically contain information on friendships and relationships. This would provide a space/permission for people with a learning disability to regularly review and share their hopes and any questions. It would also support the cultural shift required amongst staff and organisations in prioritising relationships within social care.

2. All people with a learning disability should have the chance to tell their story.

Storytelling helps build empathy amongst those listening and helps build identity in those telling their story. We all tell stories; at work, at school, time spent with friends outside school or after work. But some people with a learning disability don't have these opportunities.

We do not mean storytelling to create case studies, or for evaluation's sake. People should be supported to tell the story of their life, where they grew up, who they are and the challenges they have faced, even if this is emotional for them. We believe there is also scope for organisations to embrace storytelling techniques in more formal ways for recording the events of someone's life.

It was also felt that care plans focus too much on compliance and ticking boxes. We should work to ensure that care plans are shaped by the people we support, and not on compliance.

Could a one-page profile be replaced with a one-hour recording of someone's life? Can staff learn what the people they support like, not by reading documents but by listening to the stories they tell? In our experience how someone tells their story, their tone of voice, the way they say certain words can tell us much more than the printed word ever can.

Storytelling can help us understand who the people we support are, who they were and who they want to be.

3.. Offer people with a learning disability ongoing spaces for conversations around friendships and relationships.

Many people with a learning disability had few positive comments about their experience of Relationships and Sexuality Education (RSE). Traditionally the focus has been on safeguarding against harm; pregnancy/STIs with little room for a more holistic interpretation. Much confusion and fear persist for people with a learning disability and there is a need for an ongoing safe space to explore questions.

This responsibility sits with us all, particularly schools, families, advocacy movements, providers, and day centres. Training sessions on relationships and sexuality in isolation do not appear to be sufficient; instead, training should be one part of the approach to developing practical skills, understanding of emotions and understanding of self.

4. Early years support for families around relationships and sexuality

A consistent theme to emerge from the stories was the central role families played in supporting intimate relationships. Without pro-active facilitation from families, it is unclear if relationships would flourish. Families need support to understand their role in supporting identity and agency.

One way to do this is to work with the families of young children with a learning disability. We need to provide support to families before their children reach puberty, to prepare them and give them the confidence they need to support their children to enter into relationships. We should support families to allow their children to see that they have power, agency and can make decisions, that mistakes can and will be made but that's okay.

5. Support for families and people with a learning disability around positive risk-taking.

It can be scary for parents, families to let go and allow their children to take risks. Equally, it can be daunting for individuals to make this leap. For most people, the most significant positive risk-taking takes place during teenage years. But people with a learning disability, their families and carers need extra support to facilitate this.

We need to proactively engage with and support families, to explore and understand their real concerns and work with them to put in place mitigations to allow everyone to let go and begin exploring independence.

The sensible time for this is between primary and secondary aged- education. But we know that for many people today this hasn't happened and needs to take place regardless of the individual's age.

It is best for an individual's well-being that these conversations take place before parents are unable to support a move to a more independent life.

6. Re-think the role of support staff

Job descriptions and recruitment processes should explicitly reference supporting people with a learning disability, friendships, and intimate relationships.

If social care is to realise its aspiration to secure a good life for people with a learning disability, the role of support staff needs to be re-framed with an emphasis on supporting people with a learning disability to build connections – including pro-active support of intimate relationships.

7. Support social care staff to understand people's right to have relationships and explore their sexuality.

Support staff often feel they lack the knowledge, skills, permission and safety to support intimate relationships for people with a learning disability. Induction and ongoing training need to address this.

Concerns and fears about safeguarding are often prioritised at the expense of rights. Relationships are often peripheral within a support context. In part, this is due to the fear of getting it wrong and unconscious bias. Staff need to have the confidence and competence to proactively support relationships, and this will require an investment in training, starting with induction.

8. More formal peer-support networks to help people work together.

In consultations around our findings, service providers identified the need to share practice across organisations.

People with a learning disability highlighted the need for opportunities to come together to talk about friendships and relationships.

People are not always aware of the opportunities that already exist. Regional networks could support interaction across providers.

9. All organisations supporting people with a learning disability should develop a relationship and sexuality policy

This will ensure that support staff have clarity around their role and allow them to engage in pro-active support of intimate relationships.

Policy must support a holistic understanding of relationships and sexuality providing space for staff to support people with a learning disability to explore sexuality in the broadest sense.

It is also important that staff understand their role in involving and exploring with family members the importance of relationships including intimate relationships.

10. Friendships & relationships become a compliance issue.

The social care sector in Wales is focused on compliance. Currently, friendships and relationships are not a mandatory reporting criterion for CIW which makes it more difficult for social care providers to make this a priority.

If someone says they would like a friend or partner but do not have one, we should all be asking 'why?'