



A Life More Ordinary

Findings from the Our Social Networks oral history project about the friendships and relationships experienced by people with a learning disability.

Paul

What is love?

Kim

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.

Accessible version of report: <https://www.youtube.com/watch?v=6Y8rhYv74sY>

Please note to protect anonymity we have changed the names of participants.

Thank you

We want to acknowledge and thank our participants for their generosity in sharing their stories with us. And thanks to our funders, the Heritage Lottery Fund and the organisations below who contributed to our match funding.

We hope this document 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/carers.

And finally thanks to all of those individuals and organisations who supported the project and helped to shape this thinking.



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1 Executive Summary

Our Social Networks, funded by the National Lottery Heritage Fund, was developed as a result of the learning from Mencap Cymru's previous Heritage project, Hidden now Heard (HnH) <https://www.peoplescollection.wales/users/15475>.

HnH captured the stories of former patients and staff at long-stay institutions across Wales. Patients at these institutions had the freedom to form long-term friendships and in some cases intimate relationships. The stories challenged the linear narrative of progress often presented a round resettlement into the community and captured the resilience and humanity of the people who lived in long-stay institutions.

The aim of Our Social Networks was to capture the experience of friendships and intimate relationships for people with a learning disability. The intention was to provide a space for reflection and voice around an often-marginalized aspect of life for people with a learning disability. The project was designed to influence inclusion within the heritage sector, challenge perceptions amongst the public and raise awareness within the learning disability community, including support staff, providers and families.

Our Social Networks was not a research project; the oral histories were often a recorded conversation between two friends or partners. Although the project team developed a topic guide and suggested questions to encourage conversation, there was not a specific research question that the project was seeking to answer. Instead, the project hoped to capture a piece of people's experience and aspirations.

It became increasingly clear to the project that the stories constituted a body of evidence and that these could support insight into the reality of friendships and relationships for people with a learning disability.

1.1 What we did

The project conducted 40 oral histories across Wales between 2018-20 (pre-covid) of which 25 were considered as part of this thematic review. The transcripts reviewed included:

- 10 conversations between partners
- 9 conversations with individuals
- 6 conversations between friends

1.2 What we learnt from the stories

The stories shared with the project were analysed and several themes were identified:

- The importance of friendships and relationships in forming identity and self-worth.
- Friendships and relationships were not always easy for people with a learning disability.
- Membership and belonging were often only found in specific groups for people with a learning disability.

- Staff and families need to provide pro-active support to facilitate friendships and especially intimate relationships.
- Structural barriers and limited resources prevent social care providers from meeting people's needs for connection and relationships.
- Social Care providers often prioritise activities and practical support at the expense of friendships and relationships.
- People with a learning disability often seek approval /permission from others.
- Bullying was experienced by many participants and continued to have an impact on people's sense of self-worth and ability to trust others.
- Many participants equated sex with having children. Of the narrators who spoke about sex, few had had a sexual relationship and many were under the misconception that sex was only for conception and not pleasure or intimacy.
- Stories exposed the lack of access to good Relationship and Sexuality Education.
- A cross-cutting theme was the tension between safeguarding people without jeopardising people's rights to friendships and relationships.

1.3 Next steps

The report includes a series of practical recommendations based on the stories. We know recommendations in a report may have little impact. It is our hope this document is not viewed as a final and static set of recommendations but instead forms a starting point for discussion and debate to inform practice within organisations, staff and of course people with a learning disability and their families.



2. Methodology

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2.1 Our Social Networks Team

The oral histories were recorded by 4 members of the Our Social Networks Team, including the two Project Officers for North Wales (Fiona Owens, Rachel Organ) Project Manager (Anna Suschitzky) and Senior Project Manager (Paul Hunt).

The topic guide was developed by the Senior Project Manager in consultation with the National Museum of Wales during the development stage of the project.

The analysis of the transcripts was completed by the Head of Strategic Programmes and Project Manager. The thematic analysis was not a central function of the original application, but the project team felt that there was a lot to learn from the stories people shared.

Due to capacity and limited resource, the analysis was completed exclusively by staff without a learning disability. Whilst all the oral histories reviewed were stories from and about people with a learning disability, it is important to acknowledge the interpretation has not benefitted from the direct perspective of people with a learning disability.

2.2 Consent & Copyright process

The function of the project's approach was to increase the control participants had during the process. The project team understood the intimacy created through oral history and the potential for discomfort or regret retrospectively.

The consent and copyright processes were first designed during the Hidden Now Heard Project. Using prior experiences, the documents were refined and aimed to capture an even wider array of choices individuals could make when deciding how their interview was to be used. OSN made capacity a central part of the process. This was in part due to concerns from the team around the influence individual's support networks might have on people's decision to take part.

If someone consented, the OSN staff arranged another visit to record a conversation. OSN returned to share the recording, check any embargoed sections and to seek consent for the interview and transcript to be used by the project (for example in exhibitions) and/or stored in St Fagan's, and to agree copyright.

2.3 Data Collection

All data were collected through Oral Histories. Oral History is a field of study and a method of gathering, preserving and interpreting the voices and memories of people, communities, and participants in past events; these were recorded as conversations between friends/partners or as individual interviews. The audio informed the curation of 6 pop up exhibitions held in one venue for one week and 2 scattered multi-venue multi-installation exhibitions spanning two months.

16 of the 25 transcripts reviewed for this analysis involved a conversation style oral history between 2 friends or partners.

All audio (pending consent and copyright) will be available at the archives at St Fagans National Museum of History. Audio clips from the project are also available at the people collection Wales. <https://www.peoplescollection.wales/users/31136>

2.4 Participants

The project has reviewed 25 transcripts involving 40 people; 37 of these were individuals with a learning disability or autism and 3 were non-disabled individuals (interviewed with a friend or partner with a learning disability).

The project sought to record conversations between friends and partners across Wales. Of the transcripts reviewed:

9 interviews were with individuals.

6 interviews were conversations with 2 friends.

10 interviews were conversations between romantic partners.

2.5 Recruiting participants

The project recruited participants from service providers, organisations or groups for people with a learning disability, including colleges, day centres and self-advocacy groups.

The project delivered an introductory session where potential participants were able to find out more about oral histories.

For those that were interested, the staff team arranged to meet to discuss the project in more detail including consent and copyright. This second meeting also allowed prospective participants to build some rapport with the OSN staff team.

Following this meeting, the staff team would encourage people to speak with family/support structures before finally deciding to proceed with the oral history.

Recordings took place at individual's homes to ensure they were as comfortable as possible when sharing their story. Equally other participants felt more comfortable sharing their story in a safe place; away from family or their support networks.

2.6 Analysis

Our approach to the analysis of the oral histories has been informed by thematic analysis (Braun & Clarke, 2006). The transcripts were coded, and codes organized into sub-themes and larger themes. The team took an inductive approach, allowing the content of the stories to dictate the themes.



3. Findings

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This section presents the characteristics of the people who took part in the research and the main findings from the data.

Again, this was not approached as a research project, participants were not required to answer specific questions around demographics. However, the transcripts provide insight into certain characteristics.

In terms of gender, 42.5% of participants were male and 57.5% were female

Over 50% of the transcripts analysed involved people in a relationship. We know from previous research that this is not representative. In a recent survey undertaken by Mencap across the UK, only 6% of respondents with a learning disability were in a [relationship](#). It is possible that people in a relationship felt more confident that they had something to contribute to the project.

In terms of the living circumstances of those stories that were analysed:

- 32% were living with family
- 35% were living independently
- 33 % were living in supported living/residential support/or had some access to formal support

3.1 The themes

3.1.1 Pride and self-worth

Several participants **expressed pride in their friendship**; a sense of validation that they had friendships that had endured over many years.

It is also important to acknowledge that many friends appeared to have less access to each other at the time of recording, but the lack of regular contact did not seem to undermine the significance of these friendships:

Carrie

I'm still very much in touch with one of my friends from college even now, we do a hell of a lot together, uh, that's really nice....still do sleepovers

Ffion

So we have been friends since toddlers. And it has been that way ever since.

Participants enjoyed reminiscing around **shared experiences and history**, these were often shared as evidence of the authenticity of their friendship.

People were also keen to share the depth of their friendships and mutual regard. Friendship seems to be a huge source of pride to many participants, supporting a sense of **self-worth** and **validation**, perhaps a reflection of our need to know that we are valued by people beyond our immediate family.

Ffion

So we are really, really good friends. Even better friends because we finish each other's sentences, we know what each other is thinking, and it is just great.



Fred

So, between Jeff from the rugby and 'X', if you like, from the bowls, if I don't ring either of them for one day, they think there's something wrong, or I'm in hospital, or I'm away for some reason. So, I talk to them every day.



There were also stories of friendship based on **mutual trust and regard** with friends supporting each other to deal with bereavement and to make sense of the world.

Bethan

I looked after you, didn't I? I sat with you. Lots of people at his Mum's thanksgiving service. I went to support Ben and his Dad. I've known your Dad a long time, haven't I?



Ben

What's it like now, all these years without your Mum? How do you feel that life's getting on with you at the moment?



For those couples whose transcripts were reviewed, intimate relationships were also a source of **validation and a sense of acceptance**, clearly contributing to people's sense of worth.

Again, there was real pride in being married or even being in a relationship which is likely to reflect the social value placed on these structures:

Liz

When I was a kid I didn't have a card, I didn't have a Christmas present I didn't have anything from the age of five years of age so since I've grown up and since I got to know Mike and I've had Birthday cards and Christmas presents and all that but before I meet Mark and all that I didn't have anything and that is really emotio and upsetting.

3.1.2 Membership and belonging

There was a similar sense of pride in having access or being part of a wider group of friends:

Fred

Me and the boys

For many participants, particularly those that had attended mainstream schools, joining a **specific community-based group** for people with a learning disability provided a safe space for friendships to develop. For several people this was their first and only experience of **belonging** and safety and belief they could develop and retain friendships:

Alison

and do you have friends outside that group?
Do you have like a best friend at the moment
or...

Dorothy

No Alison

Alison

So they're your main friends within that...

Dorothy

People First is my ideal community

Another aspect that was common for couples in a long-term relationship was the importance of the **extended family of their partner**; they were often a key source of additional support and in many ways were **as significant as the partner**. There was a sense that partners were gaining a new family or membership of a larger community through their relationship/marriage.

Alison

Is there anything that you feel you've learnt by being with Vivian?

Marion

Well, Margaret do help me, you know, help the both of us and she comes up and, comes up to us don't you Margaret? And we do have a telephone call off her...

3.1.3 Pro-active support

Participants often required proactive support from staff, families, or advocacy groups to **access friends**. The stories conveyed a **dependence** on others both for practical support but also to instigate and implement ideas and plans.

Participants expressed a level of frustration around their dependence on others and the inevitable lack of control:

Kim

And I had support then so we used to go outside support, cause, unfortunately, I can't take my electric chair outside of here so I can't go to the cinema or, or out for a meal without support.

The stories shared also suggest the significance of groups for people with a learning disability, with friends only accessing each other at these groups. It was unclear why people rarely instigated contact with members beyond the safety of these environments.

Erica

We don't see each other much outside (the group) but it is mainly through (the group), and things they've organised, usually, where we see each other like they've got a Halloween Big night out coming up, so we'll be all dressed up for that in Halloween gear, as you do.

Whilst the need for facilitation seems to be a common theme for all kinds of contact and connection, the stories shared demonstrated that **romantic relationships** were often only a possibility when people with a learning disability were **actively supported by** family or staff members.

The support required from parents/staff was both moral, emotional and practical, but crucially it required families and staff to be pro-active and not merely reactive.

Nesta

And we'd drop Vivian off in Marion's so that they had their own space then and leave them and that went on for about a year... So then I took him and let him choose a ring and, and that's what we did then we left him alone then and it was up to them two to...



Kim

What happened originally was one of the people that work in one of the units went to one of the managers and said 'they're both adults, they have a right to have a bit more time', so it was, thankful to a good person, who stood up for us. And then it got extended half-past past 11.



There were a few rare examples within the stories of people with a learning disability taking the first step to initiate a relationship.

Similarly, there were very few stories that shared an experience of ending a relationship, which is significant given that it is likely that ending relationships require as much **personal agency** as it does to initiate a relationship.

Lauren

I don't like confrontations, so with anyone I've broken up with, I've always text them, because I don't like phone calling them...If I was thicker skinned, and if I didn't take confrontation and negative comments so bad, or dwell on stuff as I do, I probably would phone them.



3.1.4 Choice and Control (agency)

The majority of the transcripts reviewed involved people living independently or with families. However, for those participants living within formal support services, there were **structural barriers** to intimate relationships within these environments.

Participants felt there was often more emphasis on regulation and safety at the expense of relationships:

Frank

Well basically, normally most of the time all the bedrooms have single beds in so all they've done is push two single beds together but because of the framework on the outside, it leaves quite a gap between the two beds so it's not the ideal situation. You know basically, we basically have to roll up another quilt.

Kim

Soul destroying. You can't lie next to your husband that night and even do some simple things like fall asleep with your head on his chest.

In addition to risk and regulation, there was also an issue with **staff resource**. Staff availability dictated what participants could do and when:

Kirsten

Saturday I want to be with my babe, so I want to be with my babe Saturday night not Friday night....

Anna

And why don't you meet up on a Saturday night?

Kirsten

Well I can't see him its always too busy.

Anna

You're not allowed to see him?

Kirsten

Staff said no..

Anna

And why do the staff say no?

Kirsten

Because there's no staff on.

Kim

There is so many cutbacks that sometimes, these people that make the decision, they lose sight of even what two hours a week can do. Erm, what



Participants also give insight into the complications around the **lack of privacy** for people dependent on support who are in intimate relationships:

Paul

So I'm just thinking if you're in a restaurant would that support worker sit on the same table as you?

Kim

Yes

Paul

How does it feel having... you know you're going out with your other half but there, but there's someone else there? Do you describe him as erm, like erm...

Frank

It depends, like yeah, it depends very much on the person you're with. 'Cause they could make or break a situation.

Kim

I found that definitely. They could either make your day or destroy your day.



The stories capture the practical barriers to intimate relationships for people with a learning disability within social care settings. However, there is also an indication that the sector or at least the current interpretation of support work fails to prioritise relationships as a core function. **Relationships are peripheral to support:**

Anna

How have your friends reacted to your relationship? (...) And what about support staff or you mentioned your Social Worker before?

Liz

Yeah, um they're alright about it but they did say as long as...as long as the relationship don't interfere with the support of one-to-one it don't matter.

A theme that was present across many of the stories analyzed was the idea that people with a learning disability did not have **control** over their lives. Often families and support staff felt they were best placed to make these decisions:

Ben

Yeah, and that went on for about 12 years. Twelve or thirteen years. A long time. I wanted to move to Aberystwyth. There was a bungalow up there. I was going to move. We had a roundtable talk with the parents. Mam was there. And they said it's too much responsibility, you can't move to Aberystwyth.

People with a learning disability often sought **approval or permission** from others before making a decision. There was almost a sense that people were not practiced at making a decision or taking responsibility and were opting to delegate control.

Fiona

How long do you think it will be before you get married, do you think?

Dave

Not sure. If Corin's mum is happy if we can get married or not. Because it's up to our parents to decide-

Similarly, the safety and security that people felt within their family environment seemed to make it **harder for people to contemplate a life independently of their family**. In one example a participant contemplating the future of their relationship suggested that their partner could move into the family home. In this instance, the participant couldn't imagine a future beyond their family home.

One participant shared the need to conceal their relationship from their parent because they anticipated that their parent would not support it.

Anna

OK, so what did your Dad think about it?

Ben

I didn't tell him. Keep it quiet.

Anna

Why did you decide not to tell your Dad you had a girlfriend?

Ben

He'd be annoyed.

There were some examples within the stories of people taking control. Describing the night of their wedding one participant shared the joy of the private celebrations after the official ceremony. This feels significant because of the presence of mischief and fun, **without seeking permission** from family or support structures.

Liz

Basically, we stayed in a hot tub and the hot tub was absolutely out of this world we were in the hot tub, fully naked (*laughing*) and both absolutely pissed out of our heads (*laughing*) I meant we were drunk.

Connected to this idea of control and choice, people shared their dissatisfaction at the level of access or contact they currently had with their partners but often were unclear how to change things themselves. For individuals living with family or in supported living, ad hoc or

spontaneous catch-ups with friends or partners seemed very rare. Often partners were reliant on structured activities and groups and rarely had access to each other alone.

Anna

So how often do you see each other then?

Ben

Uhhhh (exhales) Now this where we, this is what's Hard yes. Uh Mondays in Odyssey, Tuesdays and hopefully Sundays in the one-four-seven

Several people who shared their stories were in an intimate relationship; many of these were either married or engaged. However, for the couples that were engaged, it was not clear from their stories if the engagement would lead to marriage. There was a sense of pride in being engaged.

For most of us, engagement is a step on the journey to marriage, but for many people with a learning disability engagement appeared to be the destination.

Becky

We actually got engaged four weeks—

Thurston

Just under a month ago, wasn't it?

Becky

Under a month ago. Hopefully we'll come out as being married in the end. When I see him up a bit. And that's about it. Living together, hopefully, one day.

3.1.5 Physical intimacy and sex

All couples spoke of their need for **physical intimacy**, but the majority did not consider sex to be part of their relationship or an essential expression of intimacy. Instead, physical intimacy was expressed through holding hands, hugging and kissing. Couples also explained the importance and value of being able to share the same bed as their partner.

Becky

And then the year after we decided to sleep together, didn't we?

Thurston

Yeah.

Becky

but I'm really not interested in anything about sex really.

Anna

What about other kinds of like cuddles and kisses and—

Thurston

Oh yeah, we do lots of that, yes.



Tanya

It was really good I really liked it cuz like just kind of going to bed together waking up together and you've got that person next to you. I really like that. And I think like erm... I think it sounds a bit cruel to say but initially, I was a bit nervous. I don't know what you think Lou but like afterwards it didn't really resonate that I was nervous because it's Lou.



Anna

Is a physical relationship or sex important to your relationship?

Thurston

Never had it. We don't want—we decided when we started we didn't want kids, didn't we?



Many participants **equated sex with having children**. Of the narrators who spoke about sex, few had had a sexual relationship. Many were under the misconception that sex always resulted in conception, alongside an unspoken understanding that pregnancy was to be avoided at all costs.

Dave

We don't have sex, but— Because we're not having babies



Whilst we interviewed many couples and individuals who were in a relationship, only one participant was explicit around the importance of sex for pleasure:

Anna

Do you remember where your first kiss was?

Liz

Yes, I do remember it was in bed.

Anna

Is it important to your relationship, having a physical relationship together?

Liz

But I...we have had um in that bed and in my bed.



Many people shared their **discomfort with sex**, often the stories exposed the shame that people feel around sex or desire. This is not surprising given that the existing literature suggests that people with a learning disability are often denied access to sexual identity or expression. https://esource.dbs.ie/bitstream/handle/10788/3060/hdip_sheridan_c_2016.pdf?sequence=1 <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/sexuality-research-and-statistics>

Chris

What I find difficult is the fact that people can be in love and have sex and intimacy I don't understand that. I can feel lust towards somebody of the opposite sex but I can't love someone I feel lustful about and I find it difficult to feel sexual about the person that I feel in love with.



For some participants sex was too exposing, people did not feel comfortable with that level of vulnerability.

There were also a significant number of individuals who had never experienced an intimate relationship or any kind of physical intimacy. For one individual they shared their joy at having their first kiss when they were in their 50s.

Anna

No - so you've never had a partner?



Dorothy

No.

Chris

As in sexual or boyfriend/ girlfriend relationship? Never!



Anna

But you never had like a romantic boyfriend or someone you've been romantic with or physically intimate with?



Stina

No.

Ffion

I'm sadly single. I..meaning that I'm not in a relationship. I would like to be in one



3.1.6 Loneliness and bullying

It was evident from the stories, that many people had **small social networks often limited to family**, although this was rarely communicated directly by participants. An example of this included the absence of friends at weddings. Families are a prominent part of most weddings, but the stories shared seemed to indicate that for people with a learning disability weddings were often exclusively attended by family members.

Understandably, given the stigma associated with loneliness, participants were often keen to present access to a wide social network. It was unclear if this was what people desired or whether there was a genuine misunderstanding around what it meant to be or have a friend:

Liz

I've got millions of thousands of friends in Wrexham all over.



Although very few stories explore current feelings of loneliness, several participants shared their past experiences of loneliness at school.

Erica

I think for me when I have felt most alone in life, it's got to be through for school years, and not alone in the sense that my family were always around me, but alone in the sense that I wasn't living in the same world everyone else was, I was watching through a window and only wishing I could live the



Nearly 50% of participants whose transcripts were reviewed shared their experience of **bullying** at school, for some the experience was so extreme that it impacted their attendance at school. In other cases, people shared their need to act in a certain way to protect

themselves, but the stories suggest that this experience continues to impact people's identity and worth.

Erica

Oh, horrendous for me, horrendous to make friends. I didn't have any friends at school, I was the one that no-one wanted to be friends with ...why I don't know but nobody ever, ever...I was bullied horrendously to the point that I actually missed a lot of school.



Ben

I didn't like school at all. I got bullied....they used to lock me in the toilet.



John

I used to cry in school when I didn't understand stuff so I got bullied for that so I kind of went through a long period where I pretended like I didn't care and I was seen as a class clown



Several participants, predominantly with autism, shared their experience of **feeling like an outsider**. People shared the **loneliness** of not being able to relate or connect with others and the desire to fit in:

Laura

It made me learn, um, that like even though I have learning disabilities I wasn't just a weirdo. I wanted to be normal as well,



It is perhaps not surprising that those individuals who had experienced feelings of exclusion at school continued to feel in some way **inadequate or not enough**. They also shared that they somehow felt responsible for not fitting in:

Chris

I think people find me fun to be around and a pleasure to be around people have said erm... but I still feel inferior, I feel different, I feel second class citizen, I don't necessarily always feel I wanna be there.



3.1.7 Skills to nurture friendships and relationships

The stories suggest that people had different interpretations of friendships. It seemed that only a few participants were able to distinguish between friendships and acquaintances, and these participants often had autism as opposed to a learning disability. For many people with a learning disability, friendships often included transactional relationships, for example, a person who worked in a café or shop.

For those participants in supported living, there was also a belief that staff were friends. Often people interpreted kindness as a friendship. People had gratitude for anyone who gave their time.

Anna

So what is it about the staff that, that um .. makes you feel like you are good friends?

Miles

They be treated the staff, they be kind, they be kind... they all be kind and er shopping...always kind to us.



Many participants were able to articulate the **complexity of their friendships**, friendships were not always straightforward. For these individuals, there was an understanding that friendships evolve and **conflict is also part of friendships**. Participants demonstrated their ability to **resolve conflict and repair** friendships

Edgar

I know there's, there's been ups and downs, but that's part of friendships.



Bethan

Well, I think there's good and bad between both of us.



Ben

We have our disagreements and sometimes I don't want to talk to her- about two weeks sometimes.



Some participants, often those with autism or those with fewer support needs, were able to share real insight into people and themselves in the process evidencing their **capacity for reflection** and perspective.

A few participants were able to articulate their difficulty in processing emotions.

Chris

Definitely, I think the one thing I can't do since my brain was frozen is cry and I would love to cry because if I could cry I could get rid of all of this stuff. I can't do that and I don't know why.



There was certainly a sentiment from some participants that they didn't have the belief in themselves to engage in friendships and relationships

Dorothy

Difficult to make friends cause I-I kept trying to ehm, to be somebody that I'm not, trying to be overly friendly or trying to be funny or trying to just...Cause I think, I look back now, I'm thinking why was I so pathetic for a bunch of random people who didn't want to be my friends in the first place maybe I just don't feel equal enough or good enough that I could be loved back or somebody could think of me in a way that I could think of them



Many participants with Autism shared their **difficulty trusting** others. Often participants spoke of a fear of showing vulnerability and a need to keep people at a distance because there was no evidence that people would be fair or kind:

Erica

I never felt that I knew somebody well enough, or trusted somebody well enough to be in my own parent's house.



Chris

When I get to know people properly and they are not quite who I thought they were that's very shattering for me



There was a real sense for some participants that friendships were predominantly a source of stress. The energy required attempting to understanding the motivations and intentions of others was both draining and painful.

Chris

I cope with life better the more I can spend time on my own.



Many of the participants felt that they had learnt about **sexuality and relationships** as an adult through groups for people with a learning disability as opposed to school. As adults, this was often explored once people entered into a relationship. Crucially this kind of one-to-one education and support was often reactive and not considered the right of all adults with a learning disability.

Anna

What kind of sex education did you have in school, then?


Fred

None.

Anna

Nothing at all?

Fred



None. We had PSE, but it was about—believe it or not, the PSE I had was all on the public sector. So, it was on what jobs were out there, how you can get a career, Careers Wales got involved, but there was no sex education whatsoever.

However, a couple of participants explained they had proactively sought information:

Anna

And are there other places that you learnt about sex and relationships? From friends or people?

Carrie



And Sara taught it from reading books. Um, she ordered it from Amazon.

Many of the stories exposed the limitations of Relationships and Sex Education in its current form. Participants sometimes had a limited understanding of the **concepts around relationships**, there were examples where participants indicate they were on a date, but they were talking about a staff member.

It was unclear from the stories that were shared how effective Relationships and Sex Education training was in translating theory into practice, and perhaps the bigger problem was the very few opportunities that people had to gain practical experience. While people had attended numerous relationship and sexuality training sessions they continued to feel fearful of the consequences of sex and nowhere to go to dispel myths or ask awkward questions.

The stories of friendships and intimacy have provided a glimpse into the everyday experiences of adults with a learning disability across Wales. Beyond the individual stories, the project has exposed the benefit of this approach. Our stories help us to make sense of who we are and how we connect with those around us.



4. What did we learn from the stories?

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There is no doubt that for most people who shared their stories; having friends or being part of a relationship was an important part of their lives and who they were as individuals. The stories told us:

- 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.
- Friends allow us to have a shared history that supports a sense of belonging.
- We all need companionship, this may look different to each of us, we may find it in different places and forms, but we all seek in some way opportunities to share experiences and our lives.

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 – supporting. friendships and relationships are not perceived to be the core part of the support.
- That current Relationships and Sexuality Education is inadequate.
- 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 groups for people with a learning disability.
- People with a learning disability need proactive support to find and develop friendships and relationships.

What did we learn from the process?

- It was difficult to obtain stories from people in supported living, which is perhaps an indication of 'gatekeeping'.
- People were often uncomfortable talking about sex and certainly eager that any references to sex were not included within reports/audio.
- People with a learning disability felt like they had to refer to someone else for

- permission to take part.
- On several occasions, a potential participant who had initially indicated an interest would decline to take part having had a conversation with their family.
- On a couple of occasions, staff or parents prevented the project from even having an introductory meeting with an individual to talk about the project. "It's not for them - they wouldn't understand or have anything to contribute".
- There were examples where staff within supported living environments would defer decisions to family members as opposed to the individual with a learning disability. There were two clear cases where a person who had the capacity wanted to tell their story having consulted with their support staff, but this was blocked by parents.
- Many participants did not know either their age or date of birth. This raises an important question about the challenges of supporting people with a learning disability around developing an identity and telling their story,

What did we miss?

- The sample of participants sharing their story is not representative; inevitably some stories have not been captured or considered.
- The project failed to benefit from a more diverse group interpreting the oral histories, it is likely that we would have captured different interpretations from the stories had we involved people with a learning disability.
- The thematic analysis has not considered the stories of parents/carers or staff, again this would have provided greater depth with the analysis and recommendations.
- Oral history is not an inclusive approach to storytelling, as a consequence, the project failed to capture the stories of people with more complex needs and may not have done justice to those with specific communication needs.

In many ways, the stories reinforce existing research and thinking. Ultimately the social care sector, in its broadest sense, fails to prioritize connection for people with a learning disability.

It is clear from the stories that friendships and relationships help restore us and help us grow trust in ourselves and those around us. Equally developing and sustaining friendships and relationships is never easy. In many ways, we need to understand ourselves, our emotions and aspirations to help navigate the complexity of relationships.

The stories suggest that friendships and relationships for people with a learning disability cannot be understood without consideration of identity, self-worth, agency, and power.

Supporting something in principle is not enough. The facilitation of friendships and relationships requires the same level of attention and work that we as professionals and families invest in paid employment or travel training. These things don't just happen.

We have sought to identify some practical recommendations below; we recognize that what is needed is a shift in mindset and approach that positions connection as a fundamental right and core to social care. We understand that the practical suggestions below relate to process and that changes in process 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 and their families. (<https://collaboratecic.com/exploring-the-new-world-practical-insights-for-funding-commissioning-and-managing-in-complexity-20a0c53b89aa>)



5. Recommendations

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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? This could be an important chance for people with more complex needs. 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.



