

People First – Women’s Group

Katherine

People First is the national independent self-advocacy organisation of people with learning disabilities in Scotland. People First is about giving people with a learning disability the right to make their own choices and to have a voice. We should be listened to and be able to take control of our own lives in our homes and in the community. We want to be treated with respect and not be put down by other people. We have over 1000 members all over Scotland. Members meet together in local groups. We support each other and campaign for better lives for people with learning disabilities. We also choose people to sit on local and national planning groups. We work with managers in social work and health, workers in the Scottish Government and other professionals to make our voices heard.

In some areas of Scotland, we have women’s groups. Women talk about all sorts of things in the groups:

- Our bodies
- Relationships
- Keeping safe
- Sex and birth control
- No means No

Bianca and I are also members of a Parent’s Group. We meet in Edinburgh once a month. We have made friendships and we support each other as parents. We also speak to social workers, other professionals and academics who develop training for nurses and emergency staff.

Bianca

Today we want to draw your attention to some of the barriers we have faced in our education and the ways that this may affect some of the decisions we make. We're going to look at women's experiences today and hopefully get you thinking about how you could help to improve services.

Many people with learning disabilities were taken into long stay hospitals until these began to close after the Community Care Act 1990.

Part of the reason for putting people in institutions was an attempt to keep people with learning disabilities from having relationships and sex. This forced prevention of relationships has never worked. People in these institutions still had sex, they just needed to be sneaky.

That was all a long time ago but attitudes and services still have not caught up with the changes in society since then. What we need is understanding that people with learning disabilities want to be in loving relationships just like everybody else. There is no point trying to prevent this. The sensible thing is to support people to achieve the happiest relationships they can.

People with learning disabilities are more at risk of being victims of harmful sexual behaviour. They are also more likely to display harmful sexual behaviour. We believe that by being educated on sex and healthy relationships that the risk of both of these can be reduced.

People with learning disabilities are not given the same education around sex and relationships as people without a learning disability. We have the right to have relationships but professionals either say no or don't speak about relationships at all and this puts people at more risk.

We are going to talk our experiences of sex education and relationships. When we are doing this we want you to think about your own experience of sex education.

Things we want you to think about are:

- Did it prepare you for life?
- Did it prepare you for the encounters that you have had?
- If not, how did you learn about sex?

Katherine

There is a number of barriers that make it difficult for people with learning disabilities to develop healthy relationships. For example, information about sex and relationships is not often given because it is assumed that people with learning disabilities do not want to have relationships, they do not need to know anything about sex as they won't be having sexual relationships.

But we all know that is not the case.

This is my experience...

I attended both mainstream and special schools. I did not get any education about sex and relationships. That did not prepare me at all for forming relationships or keeping myself safe. It also didn't prepare me to teach my own children.

Luckily I now feel confident about this from support and discussions in parent's groups.

Bianca

Nothing was ever discussed with me at school. It was a completely alien subject. My mum used to put leaflets under my pillow about having your period and changes to your body. She just could not talk to me about it.

Nobody spoke about being gay, you would hear things about Elton John and I had a teacher who said she shared a flat with a woman but it was only much later that I realised what she meant.

When it came to my own kids, I had some help from a worker from Children 1st. They helped me think about talking to them early. My kids said the school were still not good at talking about it, so it was important I got it right.

I actually felt comfortable talking about it. It was very important because lots of my daughter's friends were getting pregnant at 15 and I really wanted her to wait.

Katherine

These are some of the members of the women's groups experiences of sex education.

"I didn't have any sex education at all. I wasn't told about having a period and I thought I was dying and had to figure it out for myself. I think in the long stay hospitals they should have taught people sex education. They could have taught me so I would have understood"

Bianca

"I didn't know about periods, I started secondary school the nurse went it's just your periods your becoming a woman. When I met my husband and done it, it was sore and the next minute your pregnant and you can't take it in, can't get rid of it because of my religion so what am I going to do about it. When I told my Mum and she said it's one of these things. In special school I didn't get anything at all. When you don't know anything at all its frustrating and upsetting its

difficult when you have a learning disability it's so hard to understand"

Catherine

These are some quotes from women's group members about how they learned about sex and relationships in life. Unfortunately, these are very upsetting.

"Mines was very bad because the person told me to go into a wee room and told me to take my trousers down and he sexually assaulted and that's how I learned. It was so terrifying, and I couldn't scream because he had his hand over my mouth. It was horrendous I felt dirty"

Bianca

"I have guys that have used me for one thing. One time when I was in the house there was a guy who was threatening I will kill you and your son if you don't and I had to talk to someone I was working with and the police as well and it just totally frightened me and I couldn't go out and I didn't want to work in the shop because he stayed up the road from me"

"I was never taught about what harmful sexual behaviour was. As a disabled person I did not know what this was. And even when I became a victim I did not understand what this was. Until I became an adult, I became to hear things and heard from TV being spoken about but as a child I was never told"

Now, we want to tell you about the different barriers to people with learning disabilities learning about sex and relationships throughout their lives.

Katherine

Parental barriers

It is normal to worry about these things when our children are growing up. What helps is having other parents to speak to, professionals who are confident and access to the resources that are out there.

The more comfortable parents are in discussing these issues, the better placed they are to be able to help their children.

Bianca

Professional barriers, such as teachers, talking about risk in terms of stranger danger which puts a fear into people instead of explaining it in terms of relationships and healthy sexual relationships.

It is important that sex and relationship education is supportive and gives young people a real chance to discuss their concerns and ask question.

A group of members have looked at the available resources used in schools which teach about sex, healthy relationships and consent. These are available at rshp.scot

We found both good and bad points about this information. We felt that there was a very good range and amount of resources available to use. These covered very important issues and included videos, power point slides, and activities over a wide range of topics. There were different levels of information, for early years children right through to senior level school students. They also had good amount of detail.

However, from the point of view of people with learning disabilities, the resources were not in a suitable format for us to read and understand. Although we were supported to understand the information, others with learning disabilities may not find it as easy if they do not have the support there.

We felt that the videos did not explain things very well and the information is not in easy read format. We think that this website is a very useful tool to have but we wondered how adults with learning disabilities would have access to this and have the right support to go through it and understand it.

We feel that being taught this information in school once is not enough for anyone. Lots of people with learning disabilities said that it was at the wrong time for them and then when they did need the information, they had forgotten it.

There needs to be a different approach. For example, we are taught how to cook in school, but this then continues throughout our lives and this is how we improve and remember these skills. Being taught about healthy relationships, consent and sex once in school as a teenager is not enough and this has to be backed up through continuous support, the same way people with learning disabilities might receive support for other things in their lives.

Other support is needed to make sure that people with learning disabilities get the right education which will support and promote healthy relationships and reduce the risk of showing harmful sexual behaviour and also the risk of becoming a victim.

This is a difficult subject for young people to talk about. It is very important that the adults around them are comfortable and confident to talk about it. Young people need to feel comfortable to ask questions and feel supported to explore the subject in detail. We now have social media and the internet to contend with. This can be good because there is useful information there. But it can be a bad thing to get lots of information all at once or to see things that show sex in a very unhealthy way.

Katherine

I would like to finish by saying what support for relationships should be like for people with learning disabilities.

This is what support should look like -

- How to find and manage relationships should be taught and supported in the same way we are taught other life skills, such as budgeting. If we can get support with money, why not support us with developing healthy relationships?
- We should be allowed to make mistakes as this is also how we learn and the support should not be judgemental. It should help us think through mistakes so we can make positive changes in the future.
- Support should be delivered in an adapted way for people with learning disabilities and information provided in easy read format.

- Support should be personalised and it should be provided at a better pace that suits each person. This will mean education and support being available at different times in schools and continuing after people leave schools.
- We feel that life-long support should be available in managing relationships. These are vital skills that we all need in life.
- For example, understanding a situation such as a relationship breaking up, considering whether to start a family and then supporting parenting as our own children develop.
- Support should also be given from people who we can trust. It should be delivered in a positive and caring manner by people who believe that it is a right for us to have relationships.

That is a really important thing, being able to find a loving relationship is a basic human need, we all need this so it should also be seen as a basic human right which people with learning disabilities should be supported to achieve.

Thank you for listening today.