



Women with learning disabilities' experiences of decision-making

Think about the last 'big' decision you made. Not the types of decisions you make every day like what to eat for lunch, but the sorts of decisions you need to consider more carefully, such as buying a house.

Like most people, it is likely that you gathered information about your options and spoke to other people before making your decision. As a society we can take it for granted that everyone is able to make decisions in this way.

However for women with learning disabilities, making decisions about their lives may not be so clear-cut, for a number of reasons.

Without tailored support, people with learning disabilities can find decision-making difficult and abstract, causing fear about not knowing 'how' to make decisions or making the wrong one, and confusion when a quick decision is called for.

"They need to understand that being able to communicate with one person with a learning disability doesn't mean you can communicate with us all – there needs to be an awareness that the service needs to be flexible to suit different communication styles and needs."

– A member of People First (Scotland)'s Equally Safe Group, 2024

Women with learning disabilities frequently have their opinions undervalued or ignored. Because this is such a common experience it can be difficult for them to trust professionals and share their experiences in the first place.

"They need to know we've lived a life not being listened to and that we see that! Every new person is starting again, to build the trust, to see if they're decent with us, to see if it's worth sharing our stories with them or whether they'll just take no notice of what we say. You just shut down when you get the sense they're not listening."

– A member of People First (Scotland)'s Equally Safe Group, 2024



“It’s really bad when people don’t believe what you’re saying to them and often they’ll tell the social worker what you’ve said and you didn’t want the social worker to know. It’s really worrying to think that the police or NHS staff are talking to social workers behind your back. It means you can’t trust them and it’s especially worrying when you’ve got children that the social workers will just come in and say ‘oh you obviously can’t look after yourself or them’ and just take them away.”

– A member of People First (Scotland)’s Equally Safe Group, 2024

“It’s also really bad when the people there to help you don’t even talk to you – they speak to whoever you’re with, ask them all the questions. So services need to communicate directly with the person and be honest with them, take the time necessary to listen to them.”

– A member of People First (Scotland)’s Equally Safe Group, 2024

Such assumptions can lead to professionals making decisions for women with learning disabilities, instead of with them. Examples include sharing sensitive information and making referrals to other agencies without their involvement or consent, and even making decisions about how they live their lives, where they live, who they have relationships with and the support they receive.

“I went to the police and social work to get help and I was pregnant at the time. Social work lied to me and told me they were worried about me and the baby and they were going to take me to a doctor’s appointment.

I didn’t go to the doctor, there was no appointment. When I was in the car, they told me they’d got a court warrant behind my back the night before and I was flung into a locked care home miles from home for eight years. I got put on a guardianship too. I spent four years fighting tooth and nail with the help of a lawyer to get out. So that’s what you get for asking for help!”

– A member of People First (Scotland)’s Equally Safe Group, 2024

When people are unable to seek out, understand, weigh-up, and/or retain information fully, their decision-making ability is also affected. This is often referred to as a person’s ‘capacity/incapacity’ to make a decision.



Under these circumstances, the law can grant other person(s) or organisations legal power to make decisions on someone's behalf. This is called substitute decision-making. In Scotland, there are various forms of formal substitute decision-making. These include Power of Attorney, where an attorney or attorneys are appointed by the person before they lose capacity, and Guardianship, where a guardian or guardians are appointed by the court when the person has been assessed as lacking capacity. These forms of decision making require court authority and cannot be decided by individuals or organisations alone.

Women with learning disabilities are frequently subjected to formal substitute decision-making processes when they report gender-based violence. These types of decision-making remove people's human rights to make autonomous and voluntary decisions about their lives. This can lead to a form of safeguarding that is as bad as, if not more damaging, than the abuse it tries to prevent and perpetuates women with learning disabilities' risk of harm by not supporting them to make their own fully informed decisions.

"We need support from people with decision making, not them just flying in and pushing us into corners with no choice. Why couldn't they just involve me in the decision making about how to protect me? This is why women with learning disabilities don't report. It stole so many years of my life."

– A member of People First (Scotland)'s Equally Safe Group, 2024