

THINK: Decision-making

Watch our video about Decision-making (https://vimeo.com/1049579151)

Purpose of this section: This section focuses on how women with learning disabilities are supported to make informed choices, express their views, and have those views respected.

Who should complete it:

- Frontline staff: Reflect on how you support understanding, offer choices, and avoid assumptions about capacity.
- Managers: Consider how systems, forms, and staff training enable or hinder supported decisionmaking.

Tip: Use this section to review how decisions are explained, recorded, and followed through, particularly where there may be legal guardianship or support needs.

Autonomy

Autonomy means being able to make your own decisions instead of being coerced by others. It is a fundamental human need that is essential to our well-being.

As human beings we are all used to making choices. When women are subjected to gender-based violence it is important that they are supported to regain control of what they do and what happens to them. This does not always happen for women with learning disabilities, who are particularly at risk of having decisions made for them.

"Traditional service and support models often perpetuate dependency and lack of agency by focusing on impairments and considering persons with disabilities as passive recipients of care. This approach is at odds with the Convention on the Rights of Persons with Disabilities, which is grounded in personhood, autonomy and community inclusion."

- United Nations Special Rapporteur on the rights of persons with disabilities, 2023



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

What does good support to make decisions look like?

Everyone involved in supporting women with learning disabilities when they are at risk of harm has a duty to ensure that an appropriate balance is struck between 'protection from harm', and promoting their autonomy, wellbeing and human rights.

The United Nations Convention on the Rights of Persons with Disabilities says that persons with disabilities have the same rights to make their own decisions as everyone else, and that appropriate measures must be taken to support them to exercise their legal capacity.

Part of an informed and effective support service is to help people to re-gain control of their lives by offering tailored support to make informed decisions. This is sometimes called *supported decision-making*. By offering practical advice and support you can empower women with learning disabilities to do this. Here are some examples of how:



- Make time to listen, hear and get to know about people's lives and how they want to live, as well as their strengths and goals
- ▶ Take time to build effective relationships based on trust
- Be open and honest
- ▶ Communicate and share information in ways that people like and understand
- ▶ Provide people with information about their rights to make their own decisions about their lives
- Provide people with support to weigh up pros, cons and risks and to access emotional support
- ▶ Give people information about independent advocacy and help them to access it if they want
- Avoid influencing decisions by asking yes and no questions
- ▶ Allow people time to understand and make informed decisions

By supporting women with learning disabilities in this way you can shift safeguarding activity from a focus on people's disabilities, risk and behaviours to building genuine, equal, trusting relationships with women with learning disabilities. This in turn allows for a better understanding of their lives, thereby enhancing their safety and resilience.

There are accessible supported decision-making resources available to help increase participation and engagement at what can be a very scary and distressing time. See the Inclusive Resources and Signposting (https://equallysafe.scld.org.uk/toolkit/inclusive-resources-and-signposting-9/) section.

By routinely providing opportunities and support to make informed decisions about their lives, service providers can empower women with learning disabilities to gain the confidence and skills to live safe, loving and equal lives.

"Making our own decisions is good for our wellbeing, confidence, and learning. It allows us to practice making our own decisions, take responsibility and learn from our mistakes."

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