Supported decision-making

Aims

This module aims to improve understanding of:

- What we mean by supported decision-making
- The effects of removing the right of women with learning disabilities to make their own decisions
- How to support women with learning disabilities who have been affected by gender-based violence, to make their own informed decisions.

Learning outcomes

By completing this module, you will have a better understanding of:

- How to support women with learning disabilities to make informed decisions, express their views, and have those views and decisions respected.
- How to avoid making assumptions about a person's capacity to make their own decisions.
- Issues around decision-making and risk and how they apply to women with learning disabilities.

What is decision-making?

All of us make dozens of decisions every day, from what to wear, to what to have for lunch, to how to use our spare time in the evening.

Less frequently, we make bigger decisions with bigger consequences, like buying a new car, or whether to start, or finish, a relationship.

Making our own decisions is fundamental to being an adult. Our right to make our own decisions is enshrined in UK laws.

Even though the decisions we make about our own lives are ours alone to take, we often ask for help as part of the process. This could be a shop assistant, a friend, or a work colleague. We might look for technical knowledge from a specialist. Sometimes we don't need advice, we need someone to encourage us to make the decision our gut is telling us to make.

Activity 1

Purpose: This activity aims to get you to start thinking about your current understanding of decision-making.

Activity

Reflect and take notes on:

- How do you make your own decisions in everyday life and what does this mean to you?

Need some help?

Think about:

- The types of decisions you make in everyday life and how you go about making those decisions, for example what to have for lunch, or planning your next holiday.
- What you need to help you make these decisions, for example the types of information and advice you need.
- How important it is for you to be able to make your own decisions and what the benefits are of being able to do this.

Activity 2

Purpose: The purpose of this activity is to explore:

- The decision-making experiences of victim/survivors with learning disabilities
- How these compare to other women's experiences
- The effects of making decisions *for* women, instead of *with* them.
- What decision-making practice looks like in your organisation right now.

Activity

First, read what women with learning disabilities say about their experiences of decision-making *(https://equallysafe.scld.org.uk/toolkit/think-decision-making-6/women-with-learning-disabilities-experiences-of-decision-making-21/)* .

Now reflect and take notes on:

- Any experiences in the lives of someone you know or have worked with, that are like the ones you have just read about?
- How you currently work with women to make decisions.
- How you currently work with women with learning disabilities to make decisions.

Need some help?

Think about:

- A time when someone you know or have worked with (for example a victim/survivor of coercive control), had a decision(s) made *for* them instead of *with* them.
- What the effects of this could be on their thoughts, feelings, behaviour and level of engagement and trust.
- How you have felt, or would feel, if other people made decisions for you.
- How you support women with and without learning disabilities to make decisions about their lives. Is this any different and why?

Supported decision-making

Making informed decisions for ourselves instead of someone else making them for us is a human right, not a privilege. All of us get support from different sources to help us make decisions.

Supported decision-making is an approach that enables people to make their own informed decisions by providing the support they need to understand information, consider options, and communicate their choices.

It focuses on offering practical support which respects what the person wants, what matters to them and the choices they make.

This approach increases the voice, agency, choice and control of people with learning disabilities. It levels the playing field by giving them what they need to make informed decisions. By doing this, we challenge assumptions about ability and ensure that decisions reflect the person's own views.

With the right support people with learning disabilities can be at the centre of their decision-making and experience increased voice, agency, choice, and control.

What do we mean by 'informed decisions'?

Informed decisions are choices that are made with a clear understanding of facts, risks, benefits and potential outcomes associated with the options available.

Supported decision-making is about giving people the information they need to make good decisions. Crucially though, we must recognise that with all the information in the world, other people will still make what we think are 'bad decisions'.

We all have the right to take control of our own lives by making our own decisions. Even if those decisions appear to be risky, our choices should be respected and supported, for example when a woman chooses to return to an abusive partner.

Protecting women's right to make their own choices is important because it:

- Gives women the autonomy to make choices about *their* lives, and improves their self-esteem and general wellbeing.
- Enhances quality of life. For example, choosing to engage in life-enhancing social activities even when this carries a risk.
- Aligns with the principles of person-centred support because the preferences of women are prioritised.
- Recognises the danger of removing someone's autonomy in order to live a risk-free life.

> "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."
>
> *– Member of People First (Scotland)'s Equally Safe Group, 2024*

You can find out more about risk enablement here *(www.bsab.org/info/2/information-professionals/16/managing-risk-risk-enablement)* .

Trauma, coercive control and learning disability

Women with learning disabilities commonly experience multiple traumas, including gender-based violence, throughout their lives.

Women with learning disabilities also frequently have their right to make their own decisions taken away from them, particularly when they have experienced gender-based violence. This loss of control over their lives can lead to additional trauma.

It is therefore essential to understand the effects of trauma and coercive control when supporting women with learning disabilities, who are also victim/survivors of gender-based violence, to avoid repeating these patterns and causing additional trauma.

Effects of trauma from gender-based violence

Trauma from gender-based violence can have immediate and long-term effects on our ability to make decisions.

Short term effects include:

- **Emotional changes:** trauma often causes feelings of fear, guilt, shame and anxiety, that cloud our judgement and affect our ability to make decisions, resulting in choices that do not reflect our real needs or preferences.
- **Cognitive changes:** trauma can overwhelm us, making it difficult for us to focus on decisions.

Long term effects include:

- **Ability to assess risk:** significant trauma, particularly in childhood, can affect our ability to weigh up risks and consequences.
- **Changes in the brain:** trauma can lead to changes in the areas of the brain that are responsible for memory and decision-making that can result in impulsive behaviour and difficulty in processing information. Trauma can also cause us to focus on potential risks and dangers that can make it difficult for us to make balanced choices.

Effects of coercive control

Coercive control is a pattern of behaviour that is intended to increase perpetrators' power and control over victims by isolating them and removing their independence and choices. Perpetrators do this by isolating them from support, manipulating and exploiting them, depriving them of their independence and controlling their everyday behaviour.

The effects of coercive control extend beyond victim/survivors' relationship with their abuser, impacting them long after they have left their abuser.

The long-term effects of this often leaves victim/survivors struggling with the smallest of decisions. Dependency on their abuser, anxiety and confusion, loss of autonomy, self-esteem and psychological manipulation can have a significant effect on their ability to make future decisions.

Activity 3

Purpose: The purpose of this activity is to improve understanding of supported decision-making, and the effects of this on victim/survivors with learning disabilities.

Read the following statements and choose whether you think they are true or false.

Supporting women with learning disabilities to make informed decisions can aid their recovery from gender-based violence.

> **True:** By promoting a culture of supported decision-making, you can support victim/survivors with learning disabilities to navigate uncertainty, as well as empowering them to achieve better outcomes for themselves, such as:
>
> - Increased confidence
> - Greater control
> - More options
> - More realistic expectations
> - Achieving their desired goals
> - Minimising risk

Specialist support is needed to assist women with learning disabilities to make decisions.

False: When support is offered in the context of trusting relationships, there are a number of things we can all do to support women to make their own decisions. These steps are:

- Clearly identify the issue.
- Collect relevant information.
- Compare the options by considering the potential risks, benefits and short and long-term outcomes of each option.
- Make a decision.
- Implement the decision.
- Review the decision.

This is not a checklist or box-ticking exercise. The process of supporting someone to make their own decisions should take place within the context of a trusting relationship, and perhaps over a number of conversations.

Advocacy services can support women to make informed choices.

True: Advocacy services can play a crucial role in promoting autonomy by supporting women with learning disabilities to make their own decisions.

Advocacy services may include communication aids, support from professional advocates, and tailored communication strategies to help victim/survivors make their own choices and communicate their decisions.

Supported decision-making in practice

Activity 4

Purpose: The purpose of this activity is to think about what poor support to make decisions looks like in practice and how to prevent it.

Activity

First watch this short animation of an example of poor practice in supporting victim/survivors with learning disabilities to make decisions.

Supported decision-making: Poor practice *(https://vimeo.com/1165438746)*

Now reflect and take notes on:

- How the woman with a learning disability in the animation was prevented from making her own decisions.
- What the support worker could have done differently, to support the woman with a learning disability to make her own decisions.

Need some help?

Think about:

- What the support worker did wrong.
- Why it was wrong.
- How it made the victim/survivor with a learning disability feel and respond.
- What could the potential short and long-term consequences be for the victim/survivor with a learning disability?
- Could a supported decision-making approach have helped?
- How could a supported decision-making approach have helped?

Now, listen to what members of People First (Scotland)'s Equally Safe Group advise about supporting victim/survivors with learning disabilities to make decisions in this video.

Watch our video *(https://vimeo.com/1165404627)*

Activity 5

Purpose: The purpose of this activity is to think about what good support to make decisions looks like in practice and how to promote good practice in your organisation.

Activity

Watch this short video of the same professional offering support to another woman with learning disabilities.

Supported decision-making: Good practice *(https://vimeo.com/1165438773)*

Now reflect and take notes on:

- What practitioners can do to embed supported decision-making in their everyday work.
- What service providers can do to embed supported decision-making in their organisations' policies and procedures.

Need some help?

Think about:

- The types of decision-making processes you have previously used to support victim/survivors with or without learning disabilities, whether they were effective and why they were/were not effective.
- Practical steps you can take to support victim/survivors with learning disabilities to make their own informed decisions.
- What resources and support you would need to do this.
- Whether you and/or your colleagues feel confident in supporting women with learning disabilities to make informed decisions, and if not, what would help, for example further information, guidance, or training.
- Which policies and procedures could help your organisation to embed supported decision-making practices, for example Equality Diversity and Inclusion strategies, staff recruitment, induction, and development procedures.

Supported decision-making resources

For further guidance and advice about putting supported decision-making into practice, click here *(https://peoplefirstscotland.org/wp-content/uploads/2019/02/Framework-Final.compressed.pdf)*

For further guidance and advice about communicating with people with learning disabilities, click here *(www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability)*

Substitute decision-making

When one person decides to make a decision on behalf of somebody else, this can be called substitute decision-making. You might have had the experience of someone taking a decision out of your hands and making it for you.

Women with learning disabilities report that decisions are frequently taken out of their hands when they report gender-based violence. The individuals and authorities that do this believe that they are acting in the women's best interests, and that the women concerned lack the capacity to make good decisions for themselves.

However, in removing control and limiting individual autonomy they risk making decisions that do not reflect what people with learning disabilities want and what matters to them.

Taking someone's autonomy away by making decisions on their behalf may mirror traumatic experiences they have had within a relationship. So, workers must be particularly mindful of this. Giving people the time and support they need to make their own decisions is crucial.

Substitute decision-making can be done formally in law. Guardianship and Power of Attorney are two examples of when people are given legal authority to act as substitute decision-makers.

You can find out more about this here. *(www.publicguardian-scotland.gov.uk/)*

Activity 6

Purpose: The purpose of this activity is to improve understanding of substitute decision-making, and the effects of this on victim/survivors with learning disabilities.

Read the following statements and choose whether you think they are true or false.

To safeguard victim/survivors with learning disabilities, you should always decide what is in their best interests, as they lack the capacity to make their own decisions.

False: The law in Scotland says that you should always presume that an adult i.e., those over the age of 16, is capable of making their own decisions. This can only be overturned where there is medical evidence stating otherwise.

The Adults with Incapacity (Scotland) Act 2000 also requires professionals to encourage adults who 'lack capacity' to make their own decisions as much as possible as well as supporting them to use existing skills, and develop new skills needed to do this.

Therefore, you should always presume that, like most women, women with learning disabilities are able to make their own decisions with the right support, and adapt your practice to their support needs and preferences.

When an individual has been assessed by an approved mental health professional as 'lacking capacity', professionals are legally required to make all decisions on their behalf.

False: This is not an 'all or nothing' definition. The Adults with Incapacity (Scotland) Act 2000 recognises that:

- A person's capacity can vary over time and/or in different situations.
- Individuals may lack capacity to make some decisions while having capacity to make other decisions. It depends on the decision at hand, but their right to be included in decisions about their life never changes.

The Act aims to protect people who lack capacity to make some decisions, but also to support their involvement in making decisions about their own lives as far as they are able to do so.

Therefore, even if you know someone has a guardian you should always adapt your practice in supporting women to make their own decisions. With the right support all of us can make our own choices and decisions.

Making decisions for women with learning disabilities can lead to additional trauma and harm.

> **True:** Women with learning disabilities report that substitute decision-making can lead to a form of safeguarding that is at least as damaging as the abuse it tries to prevent and perpetuates their risk of harm by taking away their right to make their own decisions.

Quiz

You can now test your understanding of supported decision-making by completing this short true or false quiz.

1. If a woman finds making a decision difficult, it is usually kinder and safer for professionals or family members to make decisions on her behalf.

> **False:** Most women can make decisions with the right support. Taking decisions away can reduce confidence and risks repeating patterns of control that many gender-based violence survivors have already experienced.

2. Supported decision-making means helping someone to understand their options, not steering them toward what professionals think is best.

> **True:** Good support involves explaining choices clearly, giving time, and respecting the woman's right to decide – even when her decision feels uncomfortable or risky to others.

3. The level and type of support a woman needs to make decisions may change depending on stress, trauma or what is happening in her life at that moment.

> **True:** Decision-making is not 'fixed' for any of us. Services need to be flexible and responsive, willing to offer more support at some times and less at others.

Recommendations for practitioners

1. Take time to ask about the person's goals, wants and needs.
2. Identify what practical support a person needs to make a decision.
3. Adapt communication to individual needs and preferences.
4. Promote choice, control, and independence while balancing duty of care.
5. Identify personal and organisational barriers to supported decision-making.
6. Reflect on your own practice and attitudes and commit to changes that promote rights-based practice.

Recommendations for organisations

1. Make a plan for your team to undertake further training in supported decision-making, such as this module.
2. Embed supported decision-making in your organisation's policies and procedures.
3. Include discussions around supported decision-making practices in all staff support and supervision sessions, annual appraisals, and personal development reviews.

Further information and resources

For further information about decision-making see the THINK: Decision-making section of the Equally Safe and Supported self-assessment toolkit: THINK: Decision-making | Toolkit | Equally Safe and Supported *(https://equallysafe.scld.org.uk/toolkit/think-decision-making-6/)*

To access additional resources that can help you support victim/survivors with learning disabilities to make informed decisions, click here: Inclusive resources and signposting | Toolkit | Equally Safe and Supported *(https://equallysafe.scld.org.uk/toolkit/inclusive-resources-and-signposting-9/#rlslider_2)*