



## Just Include Me Practical Guides Series

# Consent and Decision-Making

Supporting equitable care and improved health outcomes for people with intellectual disability.



This guide will help you identify and apply decision-support strategies within clinical care to preserve the rights of people with intellectual disability to make health decisions.

## Consent and supported decision-making

People with intellectual disability have the right to make decisions about their healthcare and receive the support they need to do so.

Supported decision-making means supporting people to understand information, consider options, communicate their preferences and participate in decisions about their healthcare. This may involve communication supports, accessible information, additional time, trusted supporters or other reasonable adjustments.

A person may need support to make decisions, but this does not automatically mean they cannot provide consent.

### Getting consent



In NSW, any person is presumed to have decision-making capacity unless there is evidence to suggest otherwise. Consent should be sought directly from the person wherever possible, with appropriate support provided to enable them to make their own decisions.

Consent is an ongoing process of communication, support and checking understanding before and during healthcare interactions.

**A person may be unable to consent if they are unable to:**

- understand the general nature and effect of the treatment or procedure
- comprehend and retain information that is material to the decision, in particular as to the consequences of the decision
- retain, use and weigh the information in making the decision
- communicate their decision by any means.

If a person is unable to provide consent, substitute decision-making processes may be required in line with NSW legislation and policy.

Even where substitute decision-making is required, the person should still be involved in discussions and decisions as much as possible.



## Supporting decision-making in practice

### Where to start

People with intellectual disability have the right to participate in decisions about their healthcare and receive the support they need to do so. Supporting people to participate in healthcare decisions is a core part of person-centred and inclusive care.

### Support the person to participate in decisions

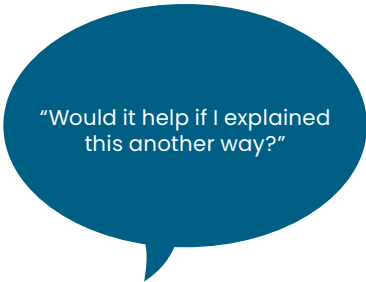
Always start with the person.

Do not assume a person lacks capacity because they have an intellectual disability.

Provide information in ways the person can understand.

Ask what supports and adjustments may help the person make decisions.

Respect the person's will, preferences and right to make choices.



"Would it help if I explained this another way?"

### Build trust and support understanding

People are more likely to participate in decisions when they feel safe, respected and supported.

Use plain English and explain jargon.

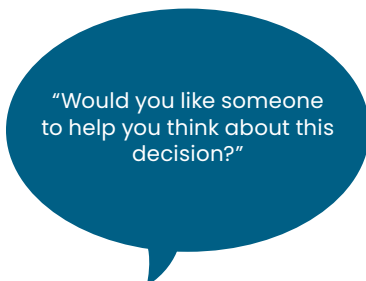
Allow extra time for questions and discussion.

Use Easy Read, visuals or written information where helpful.

Explain one idea at a time.

Check understanding throughout the interaction.

Ask if the person would like support from someone they know and trust.



"Would you like someone to help you think about this decision?"

### Support decision-making with reasonable adjustments

Find out about the person's communication, sensory and support needs.

Ask the person what support works best for them.

Use supporters and adjustments that help the person participate.

Ask if the person would like support from someone they know and trust.

## Support the person to make the decision

Allow time for questions and discussion.

Break complex decisions into smaller steps.


Focus on one idea at a time.

Discuss benefits, risks and alternatives clearly.

Check understanding throughout the interaction.

Repeat or rephrase information if needed.

Ask if the person would like support from someone they know and trust.



"I'll explain this step by step."

## Confirm understanding and consent

Consent should be checked before and during procedures or treatment.

Ask the person to explain the decision in their own words.

Check that the person understands what will happen next.

Make sure the person knows they can ask questions or change their mind.

Revisit consent if circumstances change.

Record how the person was supported to participate in the decision-making process.

Document how participation and understanding were supported:

- communication supports or reasonable adjustments used.
- how understanding and consent were checked.
- who was involved in supporting the decision.
- any follow-up actions or agreed next steps.



"Is this still okay with you?"

## Respect the person's decision


Respect the person's right to make decisions about their healthcare.

Support the person to express their will and preferences.

A person's decision may differ from what family members, supporters or health professionals would choose.

People have the right to make decisions that involve different priorities, preferences or levels of risk.

Continue providing support and information without pressure while being aware that personal values, assumptions or bias may influence how decisions are presented or supported.



"This is your decision, and we are here to support you."

## 🔍 Check – Am I supporting decision-making effectively?

Have I provided information in an accessible way?

Have I allowed enough time for discussion and questions?

Have I checked understanding throughout the interaction?

Have I considered reasonable adjustments and support needs?

Is the person being supported to express their will and preferences?

### 📋 Inclusive practice tips

#### ❌ **Don't assume a person lacks capacity because they have an intellectual disability**

Do support the person to participate in decisions using communication supports, reasonable adjustments and accessible information.

A person may need support to make decisions, but this does not automatically mean they cannot provide consent.

#### ✅ **Do allow time for the person to make a decision.**

Big decisions can take more time. Make sure information is provided in an accessible format and clearly explained to the person. Allow time for questions, discussion and reflection.

#### ❌ **Don't talk only to supporters or family members**

Do speak directly to the person and involve them in discussions about their healthcare wherever possible.

#### ✅ **Do ask the person if they need support to make the decision.**

Consider the supports and adjustments a person needs to express their preference and make decisions. The person may not recognise that they need support, but they may show it through their actions or words that the decision is difficult for them.

Ask the person if they would like support from someone they know and trust.

#### ❌ **Don't ask the person to make multiple decisions at the same time.**

Do focus on one decision at a time and break complex decisions into smaller steps where possible. Explain what you are planning to do and check the person's understanding.

Give the person time to process information and ask questions.

 **Do explore benefits, risks and possible outcomes together.**

Support the person to understand the different options available and what each option may involve. Explain possible benefits, risks and outcomes in a way the person can understand.

Take time to discuss what matters most to the person and how different options may affect their daily life, comfort, goals or preferences. Check understanding throughout the conversation and allow time for questions and reflection.

 **Don't assume agreement means understanding or consent.**

Check understanding by asking the person to explain information in their own words. Make sure the person knows that they can ask questions and change their mind at any time.

 **Do document the decision-making process and supports provided.**

Clear documentation supports continuity of care and helps demonstrate how the person was supported to participate in decisions about their healthcare.

Record:

- how the person was involved in the decision
- what communication supports or reasonable adjustments were used
- how understanding and consent were checked
- who was involved in supporting the decision
- any follow-up actions or agreed next steps.

 **Don't let personal values or bias influence the decision-making process.**

Support the person to express their own will, preferences and priorities and respect their right to make decisions about their healthcare.

A person's decision may differ from what family members, supporters or health professionals would choose.

 **Do revisit consent throughout care**

Consent is an ongoing process and should be checked before and during procedures or treatment.

**★ Reflect and improve practice**

**What did you learn that you didn't already know?**

- What helped support the person's participation in decision-making?

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- What strategies supported understanding and communication?

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- What challenges came up, and how did I respond?

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- What could I try differently next time?

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- Is there anything important that should be recorded or shared to support future care?

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## ★ Learn more

Scan the QR code below to learn more.



Video from the Victorian Office of the Public Advocate, considering how to better include people in their health decisions.



CID Supported Decision-Making Framework.



Easy Read Supported Decision-Making resources.

 [www.cid.org.au/resource/consent-and-decision-making](http://www.cid.org.au/resource/consent-and-decision-making)

Council for Intellectual Disability made this guide. CID for short. You need to ask CID if you want to use pictures from this document. You can contact CID at [health@cid.org.au](mailto:health@cid.org.au)

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