Down Syndrome Australia

Supported decision making and Down syndrome

This resource explains what supported decision making is, why it is important, and how to make it happen. We hope this resource may be useful for family members, care workers, health professionals and others who are supporting a person with Down syndrome to make their own decisions.

People with Down syndrome can find it harder to understand and communicate information for different reasons. This means people with Down syndrome sometimes need help to make decisions and understand the consequences (what could happen as a result of the decision).

People with Down syndrome have the right to be involved as much as possible in the decisions about their lives. The United Nations Convention on the Rights of Persons with Disabilities says that people with disability should receive the support they need to make the decisions that affect them. Sometimes family members or support workers make decisions for the person with Down syndrome. This may be because they think that the person with Down syndrome does not understand the decision, or they do not know how to support the person to be involved in making the decision.

The purpose of this resource to provide suggestions and advice on how to support people with Down syndrome to be involved in decision making.

Disclaimer

The information in this resource is general in nature. It is not legal advice and should not be relied on as such. Down Syndrome Australia is not responsible for any decisions made as a result of using this information. Down Syndrome Australia encourages people to seek their own legal advice.

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What is supported decision making?

Supported decision making is about helping a person with disability understand the information they need, such as considering the possible consequences, when making a decision, so that they can make the choice that is best for them.

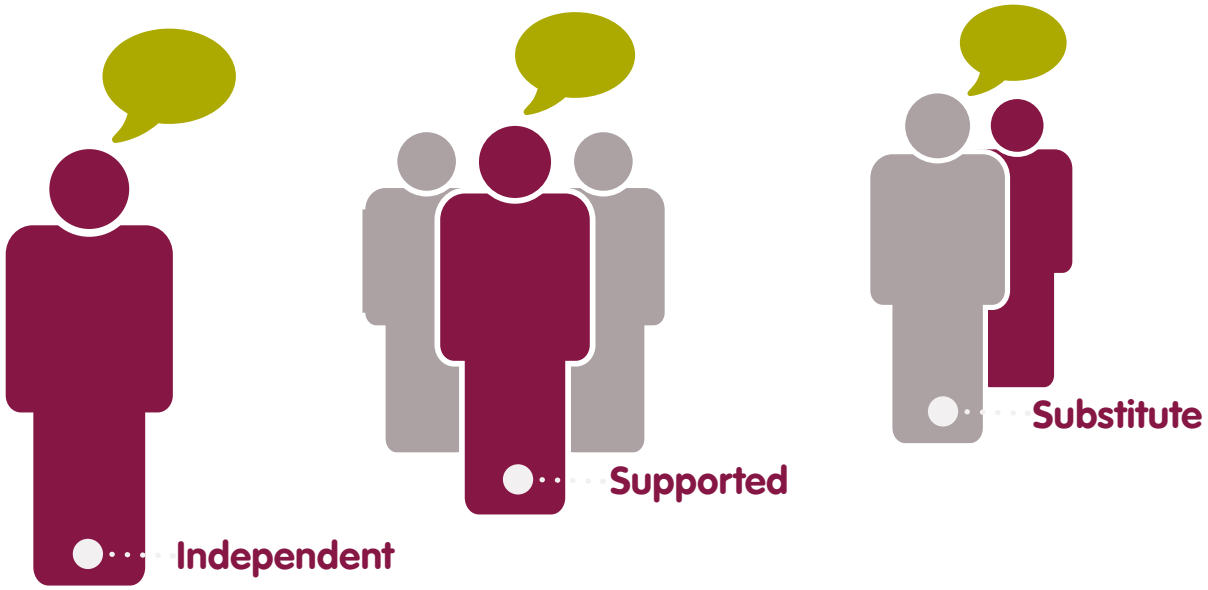
Everyone uses supported decision making. We check with family and friends, colleagues and classmates, mentors and mates before we make decisions. We talk through the possible good and bad outcomes of a decision with trusted people when we're thinking about all sorts of things – like whether to go on a blind date, buy a used car, change jobs, renew a lease, and so on.

The right to make decisions

Making decisions that affect your own life is an important human right. Having the freedom to make your own decisions is part of becoming an adult. It makes you feel confident, capable and trustworthy.

People with disability are often not allowed to make a lot of their own decisions. This usually happens because someone else takes on the role to protect the person with disability from the consequences of poor choices. This can start from a very young age.

Young people with intellectual disability in particular are often not supported to learn from the consequences of their decisions because families work hard to keep them safe. Then as they get older, they may not have the same chances as their peers and siblings to start making their own decisions.



When people with intellectual disability become adults, they often have less practice at making their own decisions. Instead, the people around them such as parents and service providers, make choices for them about major life issues. These decisions might be major things like choosing their doctor, managing their money, deciding to move out of home and who they spend time with. But these decisions can also be other small day-to-day decisions such as what to eat, where to shop and what to watch on TV.

Dignity of risk

Having the chance to learn about the positive and negative consequences of decisions is known as 'dignity of risk'. People learn how to make well-thought-out decisions by being given the chance to also make bad ones. This is how everybody learns to make good choices – not just people with disability.

Who can help with supported decision making?

The focus of supported decision making is *how* to help someone make a decision, instead of whether the decision itself is wise or not. The usual way to do this is for a person with disability to choose people they know and trust to be part of an informal support network to help make decisions. Members of the network should respect the person's wishes, preferences and right to make their own decisions, and honour the choices and decisions the person makes. Potential supporters may be friends, family, volunteers, community members or another trusted person. These unpaid supporters help the person with disability:

- gather, understand and think about the information needed to make the decision
- weigh up the pros and cons
- predict likely outcomes and consequences
- think about options.

With this support, the person makes the decision themselves.

It can be difficult to know who should help with the process of supported decision making.

A person suitable to help with supported decision making is:

- trustworthy
- knowledgeable about the specific issue
- independent (has no conflicts of interest)
- patient.

It is very important to make sure the person with disability isn't influenced by people who could benefit from the person making the decision. It is best not to have paid support workers in the support network, as they could have a conflict of interest. For example, if the person was making a decision about changing service providers, the support worker themselves would be affected.

Finding somebody suitable can take some time, however it is worth putting in the effort. This is because it will give more independence to the person with Down syndrome and they will be more involved and engaged in the decisions they make.

What role can families play in supporting decision making?

Family is extremely important when helping people with Down syndrome make day-to-day decisions, for example, helping the person with Down syndrome to think about employment opportunities after they finish school. However, sometimes the closeness of family can cause problems with the process of making major life decisions. Because, while a family member may have the best intentions, they also have their own opinions, fears, and biases that can make it hard for them to be truly independent. It can also be a problem when the decision affects them personally.

For example, a parent may not want to worry their child about the risks of surgery, so might play down or hold back information about what is going to happen. However, this takes away the person's ability to make an informed decision. Instead, an impartial doctor in the team of supporters could help the person with Down syndrome decide whether or not the surgery is a good choice for them.

Developing decision making skills

Decision making is a skill that is learnt gradually over time. It is not fair to expect somebody to suddenly be able to make great decisions if they haven't had much practice, but it does not mean they shouldn't be given the opportunity. It is possible for a person with Down syndrome to learn these skills, but it might take longer. This is why supported decision making needs to be practised as early as possible, not just in adulthood. This means involving the person with Down syndrome in both minor and important decisions from early childhood all the way through to adulthood.

People with Down syndrome sometimes find it hard to process complicated verbal information. They may forget key words in long sentences and only remember the end of the sentence instead.

However, young children can practise making decisions if the child's preferred option is given first and their least favourite last. This reframing, using the communication style that is best for that person, can help to improve listening and thinking skills.

Families can also improve decision-making skills by allowing people with Down syndrome to live with the consequences of poor decisions. Parents and siblings can also help the person with Down syndrome develop problem solving skills instead of always stepping in to stop things going wrong.

It's good for people with Down syndrome to know what supported decision making is, as well as the benefits of making their own decisions. There are helpful links at the end of this resource including age-appropriate resources.

Tips to support decision making skills

> **Start early and practise!** Give young children safe decisions to make with limited options, instead of open-ended options. For example, 'Do you want to wear the black or blue pants?' rather than, 'Which pants do you want to wear today?' Showing the actual items to choose from will help make decisions easier.

> **Don't fall into the trap of thinking that making decisions for somebody is the better choice.** Making decisions for people with Down syndrome might be easier than involving them in the process, but it comes with a cost to their independence and life skills.

> **Make sure the kind of communication the person understands best or prefers is used.** This could be verbal communication, key word sign, using visual aids or the actual item related to the decision.

> **Remember that just because you disagree with a decision, it does not mean the person who made it isn't capable of making decisions.**

> **Don't overreact if a decision results in negative consequences.** We all make decisions that don't work out the way we thought they would. It's not necessarily a negative if things don't go to plan, because the person with Down syndrome has a chance to learn from their mistakes.

> **Ask other families.** Peer support can be useful for families of people with Down syndrome who are new to the process of using supported decision making. Through peer support, families can ask for advice and share stories of people in similar situations and learn from each other.

Supported decision making in practice

It is important for people with Down syndrome to find others who can help them with decisions who are independent. It is important to avoid getting support from people who have a conflict of interest. A supporter might take advantage of a person with an intellectual disability (e.g. an employee of an NDIS service provider helping decide where to buy supports) and people with Down syndrome may need help to see when this is happening.

It is often helpful to have a group or network of supporters, or to have safeguards in place to make sure no one takes advantage or abuses their trust. An example of this could be checking with a couple of supporters within the network when making a big decision, rather than relying on one person to help make all the big decisions.

A critical part of decision making is communication. Supporters need to communicate clearly to make sure the person with Down syndrome understands the different parts of the process. Supporters can ask helpful questions such as:

- What does a good day look like to you?
- Can you think about other things you like?
- What are the bad things that might happen?
- What are the good things that might happen?
- Do you think people in your family/network would worry about this decision?

It's important to understand that if a person uses little or no spoken communication they can still be involved in making their own decisions. We need to take the time to get to know the person, understand their communication, and provide practical support to help them communicate their choices.

Decision support checklist

Decision supporters can:

- ◯ Let the person with Down syndrome know they have the right to make their own decision.
- ◯ Use and support the person's preferred communication methods. This could include using communication devices or getting information in Easy Read.
- ◯ Use a decision-making resource e.g. Support My Decision by ADACAS (see link at the end).
- ◯ Identify/write down the decision to be made.
- ◯ Work out what information is needed and help the person to find it.
- ◯ Explain the information. You can use the communication tips in the **Down syndrome communication and language fact sheet**
- ◯ Talk about the choices available.
- ◯ Talk about previous decisions and what happened.
- ◯ Talk about the positive and negative consequences of the decision.
- ◯ Draw up a visual chart of the options if possible.
- ◯ Support the person to identify and manage the risks in the decision.

What is a nominee?

A nominee is a person, appointed by the person with Down syndrome, who can act on the person's behalf in regards to the NDIS and other Commonwealth departments, like the Department of Social Services. It is important to note that you do not have to have legal guardianship to be a nominee. There are different types of nominees for the different agencies. For example, within the NDIS, there are plan nominees and correspondence nominees. Appointed nominees are able to relate to government departments regardless of guardianship decisions. Nominees can use the tips outlined above to ensure the person with Down syndrome is involved in any important decisions in relation to NDIS or other supports.

For more information about nominees within the NDIS, please visit: **https://www.ndis.gov.au/understanding/families-and-carers/guardians-and-nominees-explained**

What is substitute decision making?

A substitute decision maker is a person who makes decisions on behalf of another person. This is mainly a legal term, but it also applies in everyday situations for people with intellectual disability who may not have many opportunities to make small day-to-day decisions.

Supported decision making can be both a part of, and an alternative to, substitute decision making. Supported decision making allows a person with Down syndrome to make their *own* decisions and have significant input into other decisions that affect them – instead of having someone else make every decision for them.

Powers of attorney, and guardians are the two primary types of substitute decision makers in Australia. Both need a formal legal process to set up. The main difference between them is that guardianship orders are decided and put in place by a tribunal or court, while powers of attorney are voluntary. People with Down syndrome should be supported to be as independent as possible in decision making and a voluntary approach is often the best way to support this. It is important to note that guardianship is not mandatory when the person with Down syndrome turns 18.

Each Australian state and territory has its own legislation covering how a substitute decision maker for adults are appointed (people aged 18 and over).

What is decision-making capacity?

Decision-making capacity is a legal term. The legal definition of decision-making capacity is different in each state or territory. In general terms, it means a person is able to make a well-informed choice by:

- understanding the information they need to make a particular decision
- seeing possible consequences and risks that might happen.
- weighing up and assessing the options.

Legal capacity means a person is able to make legal decisions for themselves. People who are judged not to have 'legal capacity' are not allowed to make their own (big) decisions. All adults are assumed to have legal capacity, including people with Down syndrome, unless a guardian has been appointed or power of attorney granted through the proper formal legal processes. A guardian can be appointed just to make some decisions about specific areas, such as treatment or accommodation, which means the person still has the capacity for other decisions.

Decision-making capacity is not an all-or-nothing concept. For example, a person with Down syndrome may have the capacity to make decisions about relationships but not have capacity to make a financial decision.

A person's decision-making capacity is not always the same. People can have the capacity to make decisions on one day but not on another day – if they are unwell, for example.

> *Decision-making capacity does not mean that a person (regardless of whether they have a disability or not) will necessarily make the best or most sensible decisions.*

A person's capacity might be assessed differently by different people, but a person with Down syndrome should not be deprived of control just because they don't always make great choices. People without disability make risky decisions all the time without their capacity being questioned.

Handy links to help support decision making

Support My Decision is an online toolkit to help with making decisions and supporting decision making. This toolkit has been developed by the ACT Disability, Aged and Carer Advocacy Service (ADACAS) and is available at: **http://support-my-decision.org.au/**

ADACAS have developed principles for Decision Supporters. These are available here: **http://plone-dev.ace-hosting.com.au:8080/adacas/decision-support/AdacasprinciplesforSDM.pdf**

Capacity Australia is a not-for-profit charity that promotes autonomy of decision making. They have more information about Decision Making Capacity available on their website at: **http://capacityaustralia.org.au/about-decision-making-capacity/**

The NSW Council of Social Services has developed a practical guide to help workers who help people make decisions. This guide is called *Skilled to Thrive: supporting decision making and problem solving using the Tree of Life*. The guide is available at: **https://www.ncoss.org.au/capacity-building/sector-support/templates-and-resources/skilled-to-thrive-supporting-decision**

The WA Individualised Services website contains a set of resources on supported decision making. It includes videos and a set of four booklets with sections you can use as workbooks with some practical tools you can use. The website is: **http://waindividualisedservices.org.au/wais-publications-and-resources/**

The My Choice Matters website has great online courses to help people with intellectual disability develop their skills in making their own decisions. For more information visit: **http://www.mychoicematters.org.au/index.php?option=com_content&view=article&id=61&Itemid=101**

Speak out Tasmania has a video on making decisions. It's a four-minute animation for people with intellectual disability. The video is available at: **https://www.youtube.com/watch?v=WmWO3E1kJT4**

An inquiry into Equality, Capacity and Disability in Commonwealth Laws was conducted by The Australian Law Reform Commission in 2014. The inquiry made recommendations for the development of National Decision Making principles. The report and recommendations can be found at: **https://www.alrc.gov.au/publications/equality-capacity-disability-124-summary**