

ndis

National Disability Insurance Scheme

Consultation Paper: Supporting you to make your own decisions

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Contents

1. Public Consultation	3
1.1. Request for feedback and comments	3
2. Our Vision	4
3. Why is support for decision making important?	4
3.1. Decision making for people with a disability	5
3.2. Human Rights and Legislative considerations	6
3.3. Issues we have heard	6
4. Proposed Support for Decision Making policy	8
4.1. Key principles	9
4.2. Our goals	9
4.3. Decision Making Capability Framework	9
4.3.1. Circumstances that influence decision making	11
4.3.2. Decision Supporters	14
4.3.3. Decision Factors	15
5. Opportunities for change	17
5.1. What will be different for participants and decision supporters?	18
6. Our timelines and next steps	18
Appendix A - Consultation questions	19
Appendix B - Framework in Action – An Example	20
Appendix C - Proposed next steps	23
Appendix D - Glossary	28
Appendix E –Text Alternatives	31

1. Public Consultation

1.1. Request for feedback and comments

The National Disability Insurance Agency (NDIA or 'we') want to strengthen the National Disability Insurance Scheme (NDIS) based on advice from the Independent Advisory Council (Council). We are working towards a NDIS that is simpler, more consistent, flexible and easier to use for all Australians. This will support and enable you to have more choice and control over your life. It will also help make the Scheme more sustainable and available for future generations.

Support for decision making will become even more important as we focus more on flexibility and choice and control. We need to make sure we give you the right information, resources and support to help you make decisions about using your NDIS funding and throughout your NDIS journey.

We would like to know what you, your families, advocates and carers think about the suggested Support for Decision Making policy. This paper is particularly important for participants with complex needs including those with significant cognitive impairment.

Along with the Support for Decision Making policy framework, we are also asking for feedback on a new approach to Home and Living. We have heard that many of you have not had a chance to think about options for where and how you live. You can have your say on our new approach to Home and Living and respond to the consultation paper ["An Ordinary Life at Home"](#).

The feedback you give us will help us decide what our new policies will say and how we can put them into action. It will also help us to work with parents, families, carers, advocates, providers and the disability community to help them support you to make decisions. The consultation questions can be found at [Appendix A](#).

Closing date for submissions: Friday 10 September 2021, 5pm AEST

Email: agencypolicy@ndis.gov.au

Any questions about the consultation process can be sent to this email address.

2. Our Vision

Imagine an Australia where people with disability live ordinary lives. An Australia where people with disability have the freedom to make their own choices. An Australia where disability doesn't limit the everyday choices you have available. An Australia where your right to make decisions about things that matter to you are not limited because of your disability.

Part of the reason for creating the NDIS was to achieve this vision. The [National Disability Insurance Scheme Act 2013](#) (or NDIS Act) recognises that decision making is a human right for people with disability. The NDIS Act requires a shift away from where other people make decisions for people with disability. We want people with disability to make their own decisions. This respects every person's human right to be involved in decisions about things that impact their life. We know this is not always the case now. Many people with disability will need support to make decisions and we want to make this support a reality.

The options you have today may be limited and fail to give you opportunities to explore different choices. Many people with disability are not recognised as having capacity to make decisions. If this happens to you, it may cause you to have low expectations of your life chances and opportunities. It may also cause you to have low expectations about what decisions you can make. Often this leads to decisions being made for you. We want to help you have more opportunities to decide on what you want and how to access it.

Living an ordinary life means making decisions all the time. Many are small decisions like what to have for breakfast. Other decisions can be life-changing, like where to live and who to live with. By making decisions we all get better at it and find ways to become more involved in our communities. We want you to be able to make the same life decisions as everyone else. Supporting you to make your own decisions is an important part of supporting you to live an ordinary life.

This paper looks at how the NDIA can:

- help to improve your experience of making decisions
- improve your experience along your NDIS journey
- improve your everyday decision making
- help the people around you to support you to make your own decisions.

3. Why is support for decision making important?

Making decisions is important to personal well-being.¹ It is how all of us make sure our personal preferences, values and desires are put first. Learning to make decisions starts at a young age. It is a process that happens for all of us. We learn from our experiences.

As we get older we typically make bigger and more important decisions. All of us need to have an opportunity to make decisions and experience the consequence of these decisions

¹ Davidson, G., Kelly, B., Macdonald, G., Rizzo, M., Lombard, L., Abogunrin, O. & Martin, A. (2015). Supported decision making: a review of the international literature. *International Journal of Law and Psychiatry*, 38, 61-67.

to be able to learn. All of us use what we have learned throughout our life to help us make future decisions.

The support available and our expected responsibility for decision making changes as a person transitions through life. Children are guided by their parents or carers to make choices and decisions. This experience increases as all of us grow. Most young adults continue to be supported in some way by their parents or carers in the form of guidance and advice. Adults rely on information and advice from families, friends and paid professionals to make decisions.

This paper refers to 'Supported decision making' and 'support for decision making'.

Supported decision making describes the process of supporting people to make decisions

Support for decision making is the term used to describe the range of informal, formal, paid or unpaid, supports and resources that are made available to help a person, and those around the central person, to reach a decision. Support for decision making promotes self-determination, control, and autonomy.² It builds and encourages independence. This compares to **Substitute decision making**, where someone has authority to make decisions of behalf of a person.

3.1. Decision making for people with a disability

People with disability have the same right as everyone else to make decisions.

Unfortunately, you can also be prevented from making decisions, or communicating your needs. This can be because of the limitations of services, supports and systems.

You have the right to get support and practice to make every day decisions. This can be asking advice from a friend, or getting formal legal or professional advice for larger decisions. Not having the opportunity to make your own choices and decisions may affect your wellbeing, quality of life and sense of self.³

Decision making is a skill that you can learn and improve with practice. Practice means having the chance to make decisions and having options to choose from. These can be big decisions or small decisions.⁴ This includes everyday decisions, like what clothes to wear, or big decisions, like where to live. We know that many of you have not had the chance to make these decisions.

All people with disability have the right to take a risk, to learn from your experience and use this experience in future decisions. This means making decisions where the outcome is not clear. This is called 'dignity of risk' and is an important part of building your decision-making ability.⁵ It is also part of what makes us human.

Support for decision making is an important part of the NDIS. About 60 percent of adult NDIS participants have a disability that may affect the way they think. Sometimes these participants will need extra help to make decisions. This includes participants with:

²Devi, N. (2013). Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN convention on the rights of persons with disabilities. *The Journal of Law, Medicine & Ethics*, 41(4), 792-806.

³ Bernadette Curryer, Roger J. Stancliffe & Angela Dew (2015) Self-determination: Adults with intellectual disability and their family, *Journal of Intellectual & Developmental Disability*, 40:4, 394-399, DOI: 10.3109/13668250.2015.1029883.

⁴ Choice making is the act of selecting an option from what is available. Decision making is a process of evaluation, consideration and conclusion.

⁵ Marsh, P., & Kelly, L. (2018). Dignity of risk in the community: a review of and reflections on the literature. *Health, Risk & Society*, 20(5-6), 297-311.

- acquired brain injury
- intellectual disability or cognitive impairment
- psychosocial disability
- other episodic or degenerative disabilities.

Participants with other sensory, physical or communication disabilities may also need support for decision making from time to time.

It is also important to acknowledge the cultural perceptions of disability and family. Different communities (e.g. Aboriginal and Torres Strait Islander or Culturally and Linguistically Diverse (CALD)) may understand and approach disability and decision making differently. This can affect whether people see the need for supports outside the family or community. It is important that we provide the chance for participants from all communities to explore decision making in a culturally sensitive way.

3.2. Human Rights and Legislative considerations

Australia is a signatory to the [United Nations Convention on the Rights of Persons with Disability](#) (CRPD).⁶ Article 3 of the CRPD refers to the basic right to dignity and individual autonomy, including the freedom to make our own choices. Article 12 recognises that people with disability have the same legal capacity as others in all aspects of life. Article 4 of the CRPD requires nations to replace substitute decision making with supported decision making in a way that respects a person's will and preference. This will help people with disability to have greater independence.

Along with other laws, the NDIS Act helps put Australia's obligations under the CRPD into practice. The NDIS Act includes principles that highlight the importance of support for decision making. These include:

- a) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports. (Section 4(4))
- b) People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity. (Section 4(8))
- c) People with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves (Section 5(a))

These principles are also supported by The Australian Law Reform Commission in its report [Equity, Capacity and Disability in Commonwealth Laws](#) (ALRC Report 124).⁷

3.3. Issues we have heard

The Independent Advisory Council (Council) has supported frameworks that promote support for decision making for a long time. In August 2016, the Council recommended

⁶ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

⁷ ALRC report *Equality, Capacity and Disability in Commonwealth Laws* (ALRC report 124). [alrc_124_whole_pdf_file.pdf](#)

changes to NDIA policy and practice to improve support for decision making for participants with intellectual disability. In July 2019, the Council expanded on this and provided [formal advice](#) to the NDIA Board which recommended the development of a Support for Decision Making Policy Framework.⁸

In 2019, Mr David Tune completed a [Review of the National Disability Insurance Scheme Act 2013](#). This review made several recommendations that also related to support for decision making.⁹ These included:

- improved service delivery from NDIA staff and their Partners in the Community
- helping people engage with and understand the NDIS
- creating resources to help participants decide which supports to use

Recommendation 1(b) also related to the role of nominees, guardians and the intersections between the NDIS and state and territory guardianship legislation.

The NDIA has also heard a range of issues about the current support for decision making in the NDIS from participants, families and key stakeholders. Some of the issues we have heard include:

- People with disability experience chronic disempowerment
 - Chronic disempowerment means that people with disability might find it very difficult to know, or speak up about, what they want or feel.
- Formal Decision Making Supports are not consistent
 - The way Guardians and Trustees work with the NDIA is inconsistent because each state and territory has different laws and rules.
- There is a lack of emphasis on building decision making capacity
 - There is not much readily available information and support for parents, carers and professionals to work with people to support and build their decision making capacity. Because of this, people with cognitive impairment are often left out of decisions about their lives.
- Life transitions are not well supported
 - Resources and supports are not always available to help with transitions such leaving school, moving into employment or further education or moving out of home.
- Some participants have no informal supports to help them to make decisions
 - We know that some people with a disability do not have people in their lives to help them work with the NDIS or to help them to develop and use their NDIS plan.
- Advice from NDIA Staff and Partners is not consistent

⁸ Independent Advisory Council to the NDIS (2019). Support for Decision Making in the NDIS. [Support+for+decision+making+in+the+NDIS+-+July+2019.pdf \(squarespace.com\)](#)

⁹ Tune, D (2019). Review of the National Disability Insurance Scheme Act 2013, Removing Red Tape and Implementing the NDIS Participant Service Guarantee [NDIS Act Review - final - with accessibility and prepared for publishing1 \(dss.gov.au\)](#)

- We know that NDIA staff and partners have different levels of understanding about support for decision making practices and how best to support participants with decision making. We know that we have relied too heavily on nominee appointments.
- Potential for real or perceived provider Conflict of Interest
 - There can be a conflict of interest between a service provider's interests and the participant's preferences. This can lead to participants being left out of decisions about their lives or from having their wants and needs considered.
- Potential for undue influence
 - This is the potential for an informal supporter to influence a decision that is convenient or beneficial for them without fully considering or exploring the decision. This may be done unintentionally.

More information about the current state of decision making support and issues we have heard can be found in the [Companion Paper: Supporting you to make your own decisions](#).

4. Proposed Support for Decision Making policy

We have developed this proposed Support for Decision Making policy to make sure you can take part in decision making. This proposed policy has been developed with ideas from the [Independent Advisory Council \(Council\)](#), as well as other Support for Decision Making frameworks,¹⁰ peak bodies and advocacy organisations.

The policy puts you at the centre of decision making. It will guide the NDIA's strategies to support you with decision making. It will also provide guidance for you and your decision supporters, as well as our staff, partners and providers. These strategies will take account of your individual needs by considering your decision making capability. Capability includes several factors including:

- life stage
- experience
- decision factors
- other personal and environmental factors
- the support you already have helping you with decision making.

Many people have important roles in support for decision making. This includes NDIA and partner staff, providers, participants, families, carers, and existing community and mainstream services. We can provide more discussion on the role of these people if you want.

¹⁰ Brophy, L, McSherry, B., Kokanovic, R., Moeller-Saxone, K., Herrman, H., Guidelines for supported decision making in mental health services, <https://healthtalkaustralia.org/wp-content/uploads/corporate/Guidelines-for-Supported-Decision-Making-in-Mental-Health-Services.pdf>; Bigby, C., & Douglas, J. (2015). Support for decision making - A practice framework. Living with Disability Research Centre, La Trobe University; Australian Supported Decision Making Network, (2016) Discussion Paper calling for the development of a National Supported Decision Making Framework

We are sharing this policy to get feedback so we can be sure we get it right and are likely to be effective. We will consider all the feedback before we finalise the actions we will take to implement it.

4.1. Key principles

The key principles of our Support for Decision Making policy are:

1. Every person, without exception, has the right to make decisions (or contribute to decisions) about things that affect them.
2. Decision making capability varies between people. It also varies across different areas of life. Having experience making decisions increases your capability.
3. Your decision making capability can be increased by:
 - a. having support tailored to you, what supports you already have and type of decision you need to make
 - b. increasing the opportunities for you to make decisions yourself
 - c. increasing the capacity of your support network.
4. Making sure you have the information, supports and resources you need to understand and communicate your choices and your capability to make decisions, in whatever format you need.

4.2. Our goals

The goals of the policy are to:

1. Increase opportunities for you and future participants to:
 - a. be actively involved in making decisions about your life, and
 - b. exercise real choice and control
2. Support the development of your capability in making decisions (and helping you to explore and make those decisions)
3. Build the capacity of decision supporters, agency staff and partners to recognise and enable the will and preference of participants
4. Strengthening a support for decision making approach in the appointment of nominees

4.3. Decision Making Capability Framework

In order to implement our policy we have to have a good understanding of the decision you need to make, your ability to make those decisions and what support you need to make them. We call this your decision making capability. We have developed a framework to understand your decision making capability and are seeking feedback to make sure we have it right. An example of how this framework could be applied in the context of moving out of home can be found at [Appendix B](#).

When trying to make a decision, we think you should be able to weigh up the positives and negatives for each option and consider alternatives. We know this isn't always the case now. You should be able to get the support you need to do this. For real decision making, you must also be able to consider the consequences of each option and then decide which one is best for you.

A decision usually results in an action. Not taking any action can also be considered a decision. Making a decision suggests there has been a selection from more than one option. Decision making is how you think about making a choice from the options available.

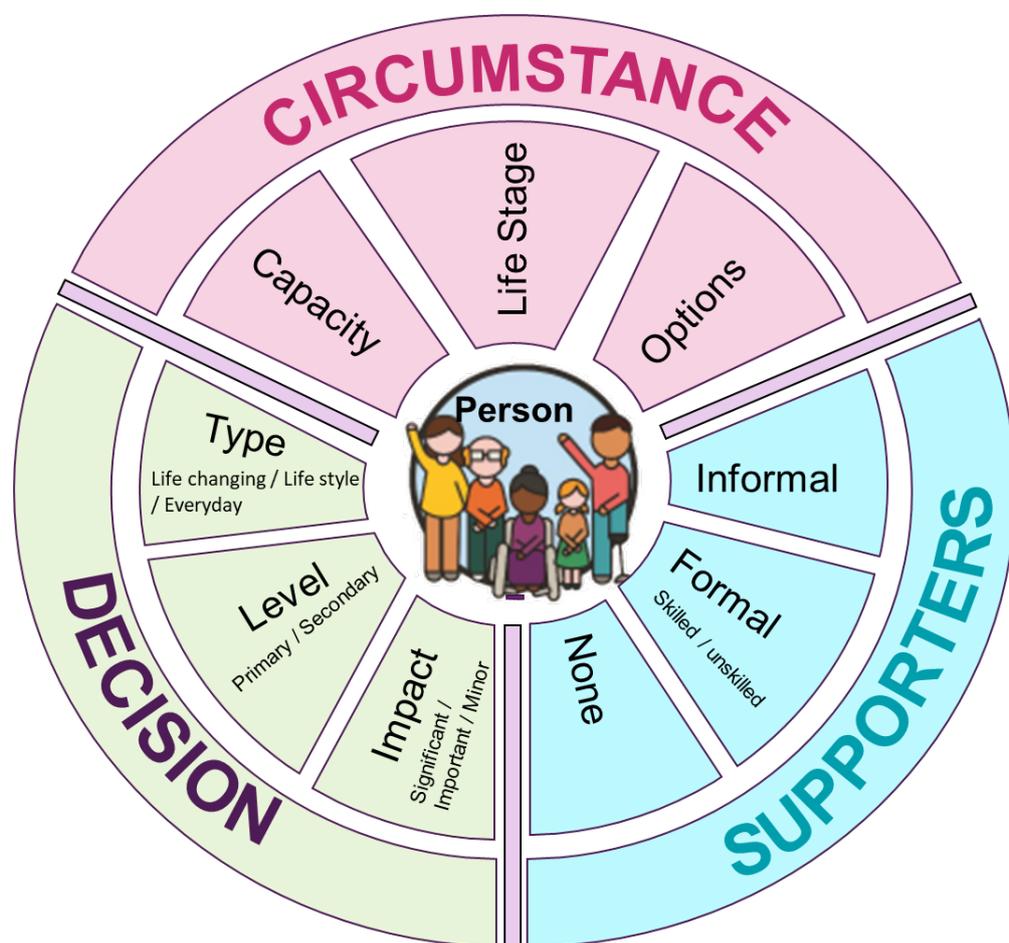
We have intentionally made this framework broad. We know that support should consider your decision making capability.

Capability in decision making is made up from a range of things like:

- your previous experience with decision making
- the decision you need to make and how important it is to you
- your health or life stage
- why you need to make a decision (e.g.: because you have to or you want to)
- the availability and skill of the people who can support you

We know that capability can change over time. **Figure 1** shows the factors that influence a person's decision making capability.

[Text alternative for Figure 1 Decision Making Capability Framework](#)



4.3.1. Circumstances that influence decision making

Your individual circumstances combine to influence decision making. Circumstances include:

- your capacity to make decisions,
- your life stage and previous experience in decision making,
- your exposure to alternate options.

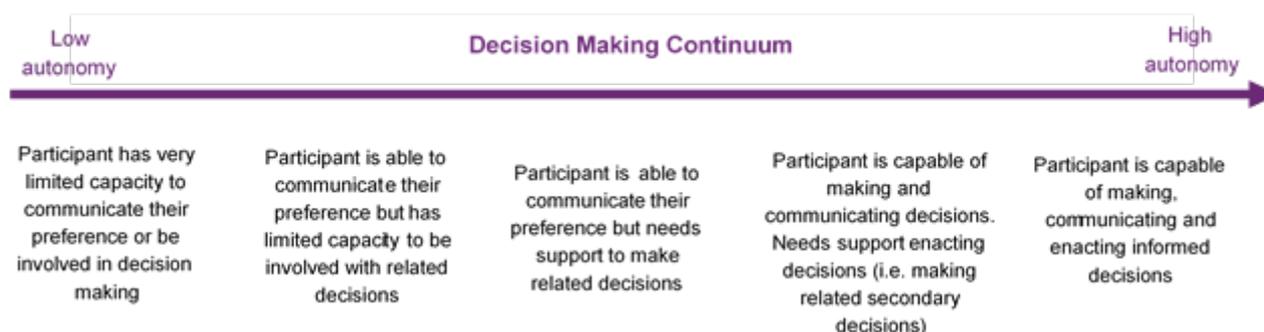
The next three sections discuss these circumstances.

Decision Making Capacity - A continuum

Decision making capacity is like a continuum. Independent decision making is at one end. This is when someone is able to make all their own decisions based on the options and information they have. This is called high autonomy. Substitute decision making is at the other end of the scale. This is when someone has another person that makes decisions for them e.g.: a guardian).¹¹ This is called low autonomy. Autonomy means how much you can do without help. A person's decision making autonomy is fluid. This means it can fluctuate from time to time and is influenced by many things.

Figure 2 shows the scale from low autonomy to high autonomy

Text alternative for Figure 2: Decision Making Continuum



Life stages

Decision making skills start to develop at a young age. All through our education and development, our capacity for decision making is practiced. For example, children start to think about what activities they want to do outside school, they start choosing friends, and they start deciding how to dress. These are all opportunities for us to get experience in decision making.

When we are children or young people most of our decisions are made by the adults in our lives but as we get older, we start being more independent in making decisions. We start to develop preferences and make decisions in our own interests. As young adults we start to make decisions that get more and more important. We start to think about things like what to study, where to live, who we want in our lives. We start to have opportunities to make decisions, with both good and bad consequences. These experiences help us learn and grow.

¹¹Independent Advisory Council to the NDIS (2019). Support for Decision Making in the NDIS.

This means that your stage of life is important to consider. Our proposed support for decision making policy framework will help us to understand how much support you might need to make decisions, when moving through various life stages.

We recognise that life stages often determine the sorts of decisions being made. This is included in the policy framework. Identifying what decisions you generally make at each life stage helps us to consider what strategies are needed to build your capacity to make these decisions in future. Some typical decisions include leaving school and starting work or getting their own place to live.

Figure 3 shows the typical decision and the potential strategies to build decision making capacity for each life stage.

Text alternative for Figure 3: Life Stage, decision examples and strategies to build capacity

Typical decision making across the lifespan

Life Stage

Children (<12)

Parents & caregivers make decisions

- make choices from available options
- Learn and experience consequences of choice

Young People (13-17)

Increased opportunity and responsibility for decision making

- Increased experiences and opportunity
- Greater awareness of consequences
- Family main support, supplemented by peers and other role models, e.g.: teachers, sporting coaches

Young Adults (18-25)

Increased decision making opportunities and experiences

- Instigate independent decision making
- Build and utilise a group of trusted and diverse voices in seeking guidance and exploring options

Adults (25+)

Assume primary responsibility for decision making for self

- Increasing experiences further inform and shape subsequent decisions
- Greater awareness of trusted sources in decision making including professional advisors and colleagues

Ageing (>55)

Potential for decreasing capacity
Utilisation of decision making partners

- Sharing of 'will and preference' in the event of inability to make own decisions
- Greater utilisation of substitute decision makers

Decision Examples

Children (<12)

Likes/dislikes
What toy to play with?
What snack to eat, what clothes to wear,
Choosing friends, hobbies, games.
How to spend pocket money
Exploring behaviour and consequences

Young People (13-17)

Considering life goals
Friends, clothing, recreational activities, school subjects, sports, after school and weekend jobs, exploring relationships and sexuality, pushing boundaries, challenging authority figures, risk taking

Young Adults (18-25)

Setting life goals
Social activities, friends, post school options, transport and travel, exploring sexuality and relationships, world views

Adults (25+)

Career choices, lifestyle and living arrangements, friendships, family, recreational activities, political and religious beliefs

Ageing (>55)

Health, lifestyle and living arrangements, care planning, recreational pursuits, family and friends

Strategies to build capacity

Children (<12)

Develop communication (verbal or alternative)
Exposure and opportunity for choices through play and daily activities
Experience safe consequences
Attend and observe meetings about me
Building family and carer awareness of choice and decision making support

Young People (13-17)

Enhance and broaden language (verbal or alternative)
Increase opportunity for day to day decisions
Guidance to experience safe consequences
Prepare for transition from school
Develop strategies for exploring increasingly sophisticated decisions (e.g.: breaking down and staging decisions; commencing early)
Intentionally develop networks of family and friends

Young Adults (18-25)

Participate in meetings
Early and active consideration of lifestyle and decisions that flow
Explore and increase understanding of personal will & preference
Increasing awareness of decision making consequences
Foster deeper and broader networks
Develop range of peer networks friendships and relationships

Adults (25+)

Daily exercising of choice and decision making agency
Further develop nuance, language and communication of and about personal choice and preference
Build informal supports into trusted advisors
Strengthen networks of family and friends into circles of support or Microboards
Engage in self-advocacy and peer support

Ageing (>55)

Continued enjoyment of decision making and consequences
Explore and consider 'will and preference'
Generational change in family supporters
Increased utilisation of circles of support in anticipating and exploring major life transitions

Options – Exposure to choice

When trying to make decisions, you should be able to:

- weigh the positives and negatives of each option
- consider the alternatives
- consider your particular situation
- have the support you need to make the decision

Involving a child in decisions about what to wear is an example. This might involve:

- supporting the child to consider the range of clothing options
- supporting the child to consider the weather.

If the child wants to wear their favourite blue t-shirt on a cold day, they may need to be prompted to think about being cold. The child may still decide to wear only the blue t-shirt, but they will learn from experiencing the consequence of being cold.

It is important that decision supporters help you to think about what life could be. Options should not be limited to what has been traditionally offered. People with disability have the same rights as others to explore new possibilities. This includes supporting them to broaden their options. To do this, you should be supported to:

- understand options
- explore possibilities
- understand the consequences
- make decisions based on these explorations.

For example, asking a young adult “what would you like for lunch”? If they have only ever had to decide between one or two options, they are likely to choose something they are already familiar with. This is not real choice or decision making. There are many more options that the person could be supported to explore before making their final decision. Decision supporters will need to take the time to encourage the person to explore things that may not have been considered. These options may be outside of their current life experience.

4.3.2. Decision Supporters

There are many different decision supporter roles. Some are formal which means they do it as a job or they do it officially. Some formal supporters are paid to provide support but some formal supporters do not get paid, like nominees. Others are informal which means they don't have an official agreement to help you.

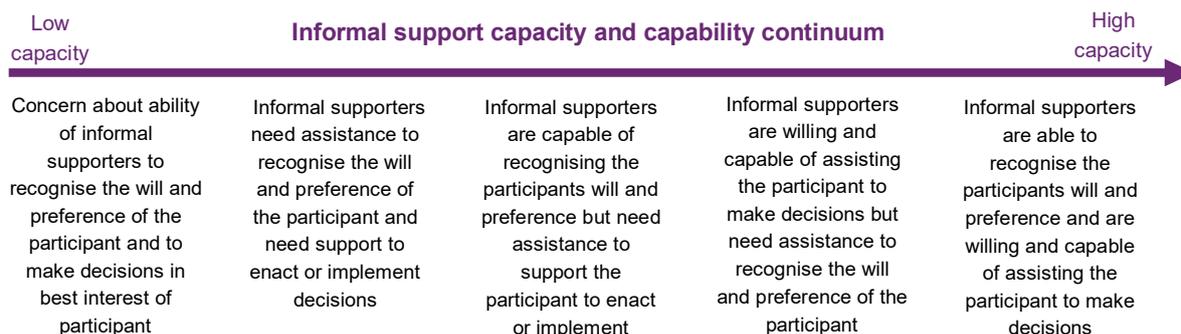
Informal Decision Supporters

As well as understanding your natural capacity for decision making and any formal decision supporters that are helping you, it is just as important to consider what informal decision supporters you might have. Being able to understand what informal decision supporters might be available to you and how well they can support you to make decisions, will help us to know, what strategies will be best suited to you and your current circumstances.

Just like it is important to understand how well you make decisions, it is just as important to understand how well your informal decision supporters can help you make decisions. Some informal decision supporters are willing and able to help and they sit at one end of the scale. Sometimes you may not have anyone to help you make decisions or the people around you don't know how to help you make decisions that are in your best interest. They sit at the other end of the scale. This is a continuum just like the continuum of how well people can make decisions themselves.

A continuum for understanding the capacity of informal decision making supports is set out below in **Figure 4**:

Text alternative for Figure 4: Informal support capacity and capability continuum



We will develop resources to help your informal decision supporters to understand your will and preference and be able to help you explore other possibilities and options.

Formal Decision Supports

Formal supporters can be support coordinators, service providers or independent advocates who support you to make a decisions. Formal decision supporters can help you explore and consider options. Formal supporters can also be substitute decision makers, meaning they make decisions for you. These include legally appointed guardians or nominees. An NDIS nominee only makes decisions that are related to the NDIS.

When you have a substitute decision maker like a guardian or a nominee, they will make decisions on your behalf. They should still try to give you opportunities to be part of making decisions about you and your life. They should also try to understand your will and preference. That means, they should try to find out what you think, what you want and what you feel about things.

We will keep encouraging substitute decision makers to involve you in decisions about you and help you to practice your decision making. We will also try to influence substitute decision authorities to help their staff to do this too.

4.3.3. Decision Factors

The actual decision you need to make is important to consider when identifying what supports you need to make that decision. It's necessary to understand the **type** and **level** of decision that is being made as well as the **impact** of the decision or how import it is to you.

Type of decision¹²

The **type** of decision refers to the ongoing consequence the decision will have on your life. This could be a direct impact or an indirect impact. We describe the types of decision as: Life changing, lifestyle related, and everyday decisions.

1. **Life changing decisions** (also called pervasive decision) are often decisions made at important life stages. They also tend to have an impact on life milestones. For example, deciding to do further education or getting a job are life changing decisions. Other life change decisions might be change jobs, deciding where to live or deciding to start an intimate relationship.
2. **Lifestyle related decisions** are decisions that are related to how you want to live and what you like to do. An example could be deciding how to keep fit and healthy, what to do in spare time. Examples might also include deciding which therapy or support to access, or which service provider to use.
3. **Everyday decisions** are decisions we make throughout each day. For example, deciding what to eat, what movie to watch, what to wear. Most of you face many everyday decisions. Some of you don't have many opportunities to make these sort of decisions. An example is a young person living in residential aged care who may not have a choice about what to eat.

Level of decision

The **level** of decision refers to whether the decision is the primary decision or whether it is a smaller or secondary decision that is required to enable a primary decision.

1. **Primary decisions** refers to the end goal or outcome. An example of a primary decision is the decision to move out of your family home.
2. **Secondary decisions** refer to the smaller decisions that you need to make that relate to the primary goal. An example of a secondary decision is deciding where you want to live, who you want to live with, how much do you want to spend.

Impact or Importance of decision

The **impact** refers to how important that decision is to you. Some decisions seem like a major decision to others but they are not important to you. Other decisions could be small decisions but they might be important to you. An example of this could be choosing where to sit at the cinema or deciding what to eat for dinner.

The type, level and impact of the decision, plus how well you make a decision and how well the people around you help you make a decision, all combine to make up your decision making **capability**. The support you need to make decision will consider your capability.

¹²Ramcharan, P, Leighton, D, Moors, R, Laragy, C, Despott, N & Guven, N 2013, its My Choice! Toolkit, Inclusion Melbourne/RMIT University, Melbourne.

5. Opportunities for change

We have the opportunity to drive a change in decision making for people with a disability.

We want to:

- challenge perceptions of decision making capacity
- emphasise an individual's rights for decision making
- identify appropriate safeguards
- build the capability of staff and partners working with you
- encourage greater involvement in decisions
- recognise informal supports and their role
- help all decision supporters to involve you with decisions that impact your life.

A shift is required in the approach used to support you with the transition through life stages. This includes improving our processes. Most importantly, we need to improve how you transition from childhood to adulthood under the NDIS. This should apply to when you are turning 18 when you move from having a child representative to interacting with the NDIS as an adult.

Processes should be in place to identify the decision support needs of all participants before they turn 18 ideally progressively from around 16 years of age. This is especially critical for children in statutory out of home care. It is also critical for moving from a statutory living arrangement into an alternative living arrangement. The primary considerations in these circumstances should be:

- building or maintaining family or social networks
- supporting the move from school to employment of community activities
- support to develop skills to manage their ordinary living costs

In some cases you may have ageing informal supports. Sometimes the informal supports are unable to continue to provide support to you. We want to be pro-active to make sure that you will have ongoing support for decision making if this happens. This might involve some short-term formal support while an informal support network is developed.

We also have the opportunity to put in place strategies to explore alternatives to nominee appointments. This will promote a shift away from the overuse of substitute decision making under the NDIS. When a nominee appointment is required, we have the opportunity to offer better support for nominees. This will help them to recognise and enable your will and preference. It will also help them to provide opportunities to build your capacity for decision making.

We know there are some of you that have no or little informal supports. We want to link you to supports that will develop a sustainable network of support over time. This might include engaging formal decision supporters. It is still important that you are assisted to develop informal supports.

We have the opportunity to increase knowledge and expertise about best practice in support for decision making.

5.1. What will be different for participants and decision supporters?

This policy will lead a positive shift in your experience. There will be more opportunities for you to have more control of decisions that impact your day to day life outside of the NDIS.

We expect as a result of implementing this policy:

- You will have increased ability to exercise choice and control.
- Our staff and partners will have increased understanding of support for decision making best practice. They will be able to support you to be more involved in decision making
- Your capacity to making decisions in day to day life outside of the NDIS will increase
- You will experience increased self-determination and autonomy leading to increased well-being.
- Decision supporters will be able to better support you in your decision making and to build their capacity
- Community inclusion will improve.
- Public perception of people with disability will improve
- You will exercise greater autonomy in decisions about your life.

6. Our timelines and next steps

We appreciate your feedback on this paper. We will use it to help us refine the Support for Decision Making policy. We will also use it to help us develop an implementation plan. We will develop this implementation plan later in 2021.

We have included some proposed actions to implement and evaluate this policy framework at [Appendix C](#). We welcome your feedback on these actions.

There are some actions we will start exploring now. These include:

- Changing how we do things to make sure participants have the opportunity to make decisions for themselves,
- Using plain English to communicate how we make decisions in our Operational Guidelines,
- Updating our Operational Guidelines to improve how nominees or other representatives are appointed,
- Building capability of our staff and partners to support participants with decision making,
- Developing guidance materials for the people that are supporting participants in decision making.

We hope this consultation paper will start a long term, widespread change in how you and future participants are supported by the NDIS. We look forward to your feedback and support in implementation over the coming months and years.

Appendix A - Consultation questions

We welcome your feedback on the policy described in this paper. We have some questions below. You can answer all of them or just a few. You can also provide feedback on anything else in this paper.

1. How can we help people with disability to make decisions for themselves?
2. Who are the best people help you (or a person with disability) to make decisions?
(We call them decision supporters)
3. What should they do to help with decision making?
4. How can they get better at helping?
5. How can we make sure the right people are helping? For example:
that they are building the capacity of the person with disability,
that they are considering what the person with disability wants.
6. What should decision supporters know about so they can help people with disability make decisions?
7. Can you tell us about a time when someone helped you (or a person with disability) to make a big decision? What worked well? What could have been better?
8. What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan.
9. Are there different things to consider for people with different disabilities or cultural backgrounds?

Conflict of interest is when a person or organisation takes advantage of their position for personal or corporate benefit.

10. How can we help reduce conflict of interest?

Undue influence is when a support person makes the person being supported do something they don't want to do by making them feel scare, by being mean or by threatening or lying to them.

11. How can we help reduce undue influence?
12. What are your concerns (if any) around people with disability being more involved in making decisions for themselves?
13. What else could we do to help people with disability to make decisions for themselves? Is there anything missing?
14. Do you have any feedback on our proposed actions in [Appendix C](#) of this paper?

[Return](#)

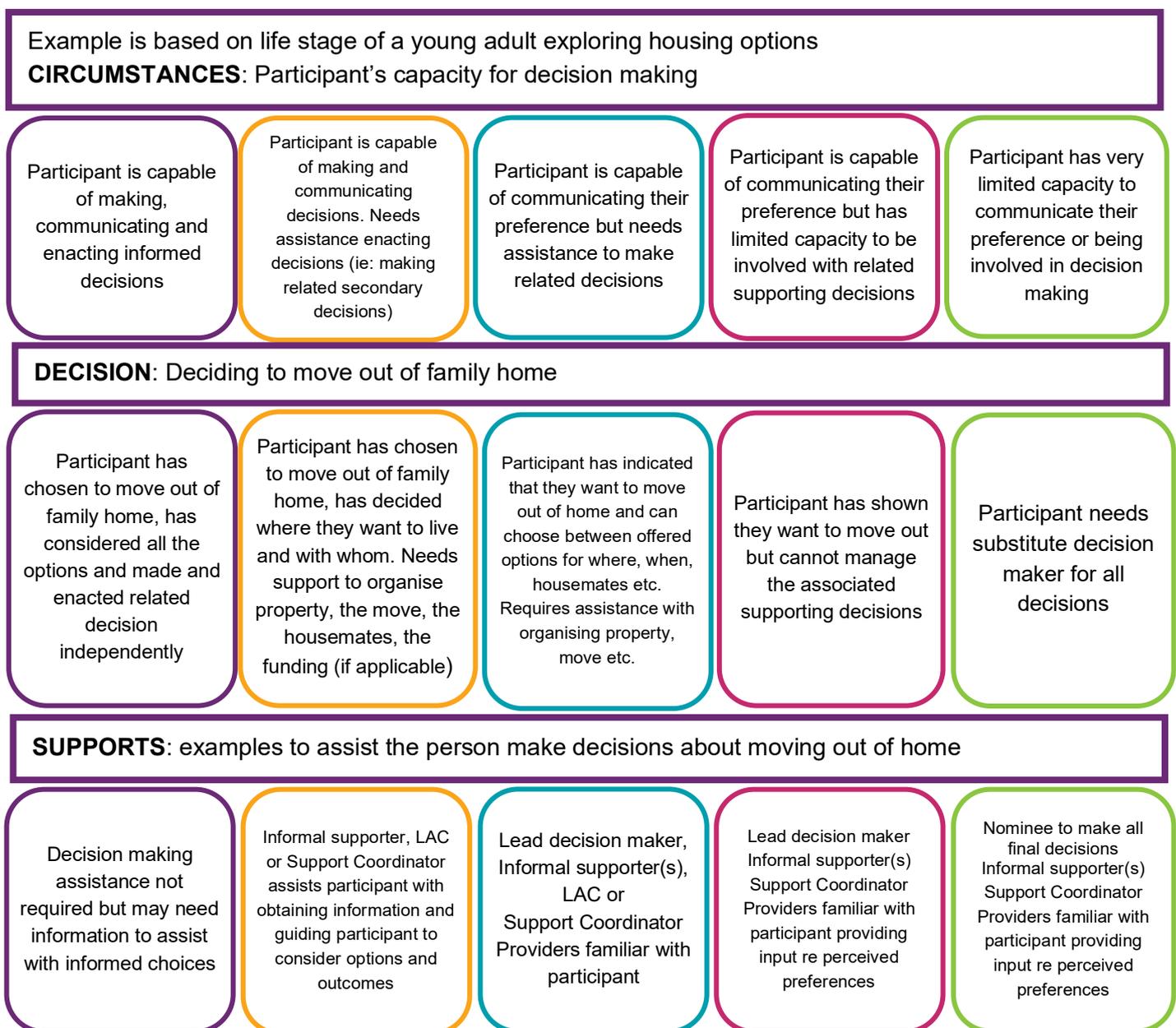
Appendix B - Framework in Action – An Example

By considering all of the things we have talked about, we can get an understanding of what support you need to help you make decisions. This decision making capability framework will describe a clear and deliberate approach to understand the need for support you need for decision making. This will make sure you have an individualised response and access to the right supports at the right time with a focus on long term capability building.

Suggested options to support different levels of decision making capacity

Figure 5 shows how this proposed policy could be used to identify support options.

[Text alternative for figure 5: Suggested options to support different levels of decision making capacity](#)



Roles and Responsibilities

There are many important roles that relate to support for decision making under this proposed decision making capability framework. We have included some of those roles and their responsibilities below. These will guide our thinking on implementation. They will also reinforce the importance of collaboration and the systemic effort required to realise our goals.

Role of the Participant

- To be able to exercise their right to make choices.
- To have the freedom to make mistakes, both large and small, in exercising choice.
- To identify and agree to people being their decision supporters (usually friends, family or peers but sometimes support workers).
- To work with NDIA staff and partners, who will be able to help identify if they have the support they need to make a decisions about things that affect them.

Role of the NDIA

- To recognise the participant's decision making rights. To assist by removing barriers to making decisions. To avoid reliance on substitute decision making wherever possible.
- To work together with the participant and their supporters. To understand the participant's need for support to make decisions. To consider how best to grow the participant's ability to make decisions.
- To make sure there is support available to build the capacity of the participant so they can be included in decisions relating to their lives.
- To document the availability of the participant's decision making supports. To document if the capacity of the participant's decision supporters.
- To ensure connection to other community and mainstream based decision making supports
- To review progress capacity building of decision making skills plan review

Roles of decision making supporters

- To include the participant in decision making. To consider the will and preference of the participant.
- To include people who know the participant best in supporting them to make decisions. Especially people who understand the participant's preference and how they communicate.
- To consider whether there are any potential conflicts of interest with the participant. To declare any potential conflicts of interest. To manage any potential conflicts of interest.
- To help the participant to seek the views of as many people as they want to help them with their decision making.
- To document the decision making support that is being provided if requested.

Role of service providers

- To make the most of opportunities to help the participant to build and keep friendships. To build and maintain and natural community connections.
- To support the participant to practice making decisions in different environments. To support the participant to practice making decisions in everyday interactions. To provide the participant with opportunities to explore other options.
- To include the participant in decisions. To include their decision supporters in decisions to the extent the participant wants. To consider the participant's preferences in the delivery of their services and supports.
- To safeguard the participant against undue influence in making and implementing decisions.

[Return](#)

Appendix C - Proposed next steps

This consultation process will gather the views of support for decision making from people with a disability. It will also gather the views of the people supporting you with decision making. It will help us to make sure the proposed policy will meet your support for decision making needs.

We will develop an Implementation Plan. This will incorporate the feedback we receive to refine the strategies we will deploy to:

- promote,
- encourage, and
- facilitate,

a positive change in access to support for decision making.

A range of proposed actions to achieve our goals are outlined below. We have also included some suggested indicators of success. We will ensure we have solid monitoring and reporting mechanisms to evaluate the outcomes of this framework. This is not a comprehensive list of actions. The actions listed are not the final content for the Implementation Plan. These proposed actions are offered to stimulate discussion and prompt further input.

Goal 1: Increase opportunities for participants

Increase the opportunity for participants to:

- **be actively engaged in making decisions about their life**
- **exercise real choice and control**

Proposed actions:

- Provide increased opportunities for participants to make decisions. This is including through the introduction of any future reforms including home and living by:
 - providing more information that explains the decision making process relevant to these reforms
 - identify key decision making points in the design of the new participant pathway.
 - proactively provide information, support and guidance
 - developing a targeted approach for complex cohorts to provide decision making opportunities. This includes for participants with intellectual disability, cognitive impairment and psychosocial disability.
- Develop a new support for decision making Operational Guideline. This will bring consistency and structure to our approach. This will also bring clarity to participants and families.
- Develop a range of materials that describe the support for decision making process. This will include examples of best practice across different:

- life stages,
- decision levels,
- decision types.

These materials will be available on our website in a variety of formats such as fact sheets and videos.

- Use business intelligence to predict when support for decision making is potentially needed. There will be a specific focus on life stage transitions, i.e. through data driven system alerts.
- Build the capability of our staff and partners by developing internal guidance. This will help them to recognise and support decision making opportunities.
- Develop learning resources for our staff and partners on how to apply the policy framework.
- Review the need for decision making support for participants living in institutions like housing including some group homes.

Indicators of success:

- Participants will have support to understand the NDIS processes.
- Participants will be supported to make decisions that relate to their:
 - personal budgets, and
 - plan flexibility,
 measured through ongoing evaluation and outcomes frameworks.
- Resources and information will be available about best practice evidence based support for:
 - participants,
 - carers,
 - providers, and
 - professionals
- Improved understanding of support for decision making options by our staff and partners. There will be a reduction of substitute decision making e.g.: Nominee appointments.
- We will have a better understanding of:
 - the decision making needs, and
 - existing support arrangements,
 for participants living in institutional arrangements including group homes.
- We will measure this by an action plan for endorsement by the Council.

Goal 2: Support development of participant capability

Support development of participant capability in making decisions (And helping participants to explore and make those decisions).

Proposed Actions:

- Introduce a formal process to identify a participant's decision making capacity that is aligned to the policy framework. We will do this at the beginning of their NDIS journey. We will devise a plan for progressive implementation of the approach for all participants at plan review.
- Improve data capture and recording of participant support networks and relationships
- Develop an inventory of supports for building decision making capability for participants with:
 - no or limited informal supports
 - single service providers

These supports will be in the fixed budget. This means they must be used for this purpose.

- Promote the use of peer support networks and other individual capacity building supports. These are funded through ILC, state and territory governments or mainstream service systems.

Indicators of success:

- We will document conversations about decision making capability. We will identify appropriate supports and document this. This will become a standard part of a participant's NDIS experience.
- Our staff and partners will know the range of supports available to empower participants in decision making.
- Participants will be better supported to access peer support networks.

Goal 3: Build capacity of decision supporters

Build the capacity of decision supporters, agency staff and partners to recognise and enable the will and preference of participants in decision making

Proposed Actions:

- Publish guidance and resources on working with people to support their decision making. These will be for:
 - parents
 - carers
 - providers, and
 - professionals.

These materials will be available in a variety of formats such as fact sheets and videos.

- Clarify through guidance the roles and responsibilities of Nominees (when appointed).
- We will review the current research on support for decision making best practice.
- Use DSS National Disability Advocacy Program and other research to:
 - identify opportunities to develop good practice in supported decision-making,
 - develop formal guidance materials to promote best-practice supported decision-making procedures and practices for:
 - people with disability,
 - their guardians or legal decision-makers
 - families,
 - support workers, and
 - other key parties.
- We will develop an operational framework for Consent and Informed Decision Making. This will assist our staff and partners to make sure:
 - participants,
 - their informal supports, and
 - court appointed decision-makers,

understand their rights and responsibilities about making informed decisions and providing consent.

- We will publish guidance for
 - Support Coordinators,
 - Plan Managers,
 - Support Workers,
 - Providers, and
 - Nominees,to ensure they can support participants with their decision making.
- We will commission the development and delivery of NDIS specific training. This will be for key stakeholders in the support for decision making ecosystem.

Indicators of success:

- Increased capability of decision supporters
- Increased participant involvement in decision making
- Reduction in substitute decision making – e.g.: nominee appointments

Goal 4: Strengthen support for decision making approach - Nominees

Strengthening a support for decision making approach in the appointment of nominees.

Proposed Actions:

- Overhaul of Nominee appointments process including:
 - making sure decision making capability is considered and documented before appointing a nominee
 - providing further information and guidance to clarify rights and responsibilities about:
 - making informed decisions, and
 - providing consent
- Desktop review of nominee appointments and identify the participants decision making capability.
- We will have processes to review existing nominee appointments at:
 - key life stages
 - plan review.

Indicators of success:

- A reduction in Nominee appointments. We will focus on cohorts with disproportionate nominee appointments.

[Return](#)

Appendix D - Glossary

Term	Definition
Advocate	Someone who supports or represents a person (with their consent). Generally, the person being represented is someone who is considered at risk. Advocates promote and safeguard the rights and interest of the people they support.
Capacity Building	<p>Capacity building supports include a range of things to build a participant's independence skills. With capacity building, participants will be more involved in their local community. It could include:</p> <ul style="list-style-type: none">• funding to help a participant find a job or study opportunities,• apply for suitable accommodation, or• learn a range of organisation and self-management skills. <p>For example, a '<i>Core Support</i>' might delivery of meals on a weekly basis. A Capacity Building support would be build the skills of the participant to prepare healthy meals on their own.</p>
Choice	Choices are the opportunities or options in front of a person. A decision is the final selection. Choice reflects the person's capability while decision reflects the final result. Choices are presented to you while you alone make the decision.
Choice and Control	<p>Increased choice and control for participants is a core principle of the NDIS. Around 60 percent of adult NDIS participants have a disability that impacts their cognitive function. This means they might need more support to be more in control of decisions that impact them.</p> <p>Every participant has the right to make their own decisions about what is important to them. They have a right to decide how they would like to receive their supports and from whom.</p> <p>We know that support for decision making is very important in making sure participants have choice and control.</p>
Consent	Consent is when a person gives permission for something to happen. Consent is given explicitly, either verbally or in writing. This could include a handwritten signature, a verbal statement, or use of an electronic medium or voice signature to demonstrate agreement.

Term	Definition
Decision	A decision defines the action a person will take (taking no action may also be a decision). Decision implies there has been a selection from more than one option.
Decision Making	Decision making is the thought process of selecting a choice from the available options. When trying to make decisions, a person must weigh the positives and negatives of each option, and consider the alternatives. A person needs to think about what might happen in the future if they choose each option. Then they can decide which option is best for them.
Decision Supporter	<p>A decision supporter is a person who:</p> <ul style="list-style-type: none"> • helps a participant to practice making decisions • helps them improve their skills, and • builds their capacity to make decisions for themselves. <p>For example family, peer networks, advocates, support workers, LACs and planners.</p>
Dignity of Risk	<p>Dignity of risk refers to the legal right of every person to make choices and take risks. This is how we learn from our experience, grow and have better quality of life. This includes people with a disability.</p> <p>Inherent to the idea of dignity of risk, is that life experiences come with an element of risk. Even the best planning and support cannot avoid. But this is how we learn.</p>
Guardian	<p>A guardian is person who has the authority under the law to manage all or some of a participant's affairs. This can include:</p> <ul style="list-style-type: none"> • legal affairs, • non-legal affairs, • healthcare and medical decisions, and • lifestyle decisions.

Term	Definition
Informal Support	<p>Informal supports are the different types of help people freely give to each other in daily life. This could include the support a person receives from:</p> <ul style="list-style-type: none"> • their parents or siblings, • extended family members, • friends or acquaintances, • colleagues, • neighbours or other people in their community
Nominee	<p>Under the NDIS, a nominee is a person who has authority to act on behalf on the participant. They can make decisions about NDIS matters and supports.</p> <p>Nominees should only be appointed when the participant has very little capacity to make decisions, even with support.</p> <p>Nominees have a duty to involve the participant in decisions that impact them. They also have a duty to build the participant's decision making capacity.</p>
Substitute Decision Making	<p>Substitute decision making is where someone has authority to make decisions of behalf of an adult participant. Both Nominees and Guardians are an example of this.</p>
Support for Decision Making	<p>Support for decision making refers to a range of:</p> <ul style="list-style-type: none"> • informal and formal, • paid or unpaid supports, or • resources, <p>that are available to a person to help them to make a decision.</p>
Supported Decision Making	<p>Supported decision making is the process where a person is supported to make a decision.</p>
Will and preference	<p>Will describes a person's aspirations based on values and beliefs and preference is more immediate wants and desires.</p>

Appendix E –Text Alternatives

Text alternative for Figure 1 Decision Making Capability

Image: A circle with the person in the centre and the following wrapped around.

The Person is at the centre.

Circumstance

- Capacity
- Life Stage
- Options: exposure to choice / previous experience

Supporters

- Informal (Skilled / unskilled)
- Formal
- None

Decision

- Type - Life changing / Life style / everyday
- Level - Primary / Secondary
- Impact - Significant / important / minor)

Return to [Circumstances that influence decision making](#)

Text alternative for Figure 2 Decision making continuum

A continuum from low autonomy to high autonomy:

- Participant has very limited capacity to communicate their preference or be involved in decision making
- Participant is able to communicate their preference but has limited capacity to be involved with related decisions
- Participant is able to communicate their preference but needs support to make related decisions
- Participant is capable of making and communicating decisions. Needs support enacting decisions (i.e.: making related secondary decisions)
- Participant is capable of making, communicating and enacting informed decisions.

Return to [Life stages](#)

Text alternative for Figure 3 Life Stage, decision examples and strategies to build capacity

Life Stage:

Children (<12):

Parents and care givers make decisions

- Child makes choices from available options,
- Learn and experiences consequences of choice

Decision Examples

- Likes/dislikes
- What toy to play with?
- What snack to eat, what clothes to wear.
- Choosing friends, hobbies, games.
- How to spend pocket money
- Exploring behaviour and consequences

Strategies to build capacity

- Develop communication (verbal or alternative)
- Exposure and opportunity for choices through play and daily activities
- Experience safe consequences
- Attend and observe meetings about me
- Building family and carer awareness of choice and decision making support

Young People (13-17):

Increased experiences and opportunity for decision making

- Increased experiences and opportunity
- Greater awareness of consequences
- Family main support, supplemented by peers and other role models, e.g.: teachers, sporting coaches

Decision Examples

- Considering life goals
- Friends, clothing, recreational activities,
- school subjects, sports, after school and weekend jobs,
- exploring relationships and sexuality, pushing boundaries, challenging authority figures, risk taking

Strategies to build capacity

- Enhance and broaden language (verbal or alternative)
- Increase opportunity for day to day decisions
- Guidance to experience safe consequences
- Prepare for transition from school
- Develop strategies for exploring increasingly sophisticated decisions (e.g.: breaking down and staging decisions; commencing early)
- Intentionally develop networks of family and friends

Young Adults (18-25)

Increased decision making opportunities and experiences

- Instigate independent decision making
- Build and utilise a group of trusted and diverse voices in seeking guidance and exploring options

Decision Examples

- Setting life goals
- Social activities, friends, post school options, transport and travel,
- Exploring sexuality and relationships, world views

Strategies to build capacity

- Participate in meetings
- Early and active consideration of lifestyle and decisions that flow
- Explore and increase understanding of personal will & preference
- Increasing awareness of decision making consequences
- Foster deeper and broader networks
- Develop range of peer networks friendships and relationships

Adults (25+)

Assume primary responsibility for decision making for self

- Increasing experiences further inform and shape subsequent decisions
- Greater awareness of trusted sources in decision making including professional advisors and colleagues

Decision Examples

- Career choices
- lifestyle and living arrangements
- friendships, family
- recreational activities
- political and religious beliefs

Strategies to build capacity

- Daily exercising of choice and decision making agency
- Further develop nuance, language and communication of and about personal choice and preference
- Build informal supports into trusted advisors
- Strengthen networks of family and friends into circles of support or Microboards
- Engage in self-advocacy and peer support

Ageing Adults (>55)

Potential for decreasing capacity

- Utilisation of decision making partners
- Sharing of 'will and preference' in the event of inability to make own decisions
- Greater utilisation of substitute decision makers

Decision Examples

- Health, lifestyle and living arrangements,
- care planning,
- recreational pursuits
- family and friends,

Strategies to build capacity:

- Continued enjoyment of decision making and consequences
- Explore and consider 'will and preference'
- Generational change in family supporters
- Increase utilisation of circles of support in anticipating and exploring major life transitions

Return to [Options – Exposure to choice](#)

Text alternative for Figure 4: Informal support capacity and capability continuum

A continuum from low autonomy to high autonomy:

- Concern about ability of informal supporters to recognise the will and preference of the participant and to make decisions in best interest of participant
- Informal supporters need assistance to recognise the will and preference of the participant and need support to enact or implement decisions
- Informal supporters are capable of recognising the participants will and preference but need assistance to support the participant to enact or implement
- Informal supporters are willing and capable of assisting the participant to make decisions but need assistance to recognise the will and preference of the participant
- Informal supporters are able to recognise the participants will & preference and are willing and capable of assisting the participant to make decisions

Return to [Formal Decision Supports](#)

Text alternative for Figure 5:

Suggested options to support different levels of decision making capacity

Example is based on life stage of a young adult exploring housing options

1:

Circumstances: Participant is capable of making, communicating and enacting informed decisions

Decision: Participant has chosen to move out of family home, has considered all the options and made and enacted related decision independently

Supporters: Decision making assistance not required but may need information to assist with informed choice

2:

Circumstances: Participant is capable of making and communicating decisions. Needs assistance enacting decisions (i.e.: making related secondary decisions)

Decision: Participant has chosen to move out of family home and has decided where they want to live and with whom. Needs support to organise property, the move, the housemates, the funding (if applicable)

Supporters: Informal supporter, LAC or Support Coordinator assists participant with obtaining information and guiding participant to consider options and outcomes

3:

Circumstances: Participant is capable of communicating their preference but needs assistance to make related decisions

Decision: Participant has indicated that they want to move out of home and can choose between offered options for where, when, housemates etc. Requires assistance with organising property, move etc.

Supporters: Lead decision maker, Informal supporter, LAC or Support Coordinator, Providers familiar with participant

4:

Circumstances: Participant is capable of communicating their preference but is unable to be involved with related supporting decisions

Decision: Participant has shown they want to move out but cannot manage the associated supporting decisions

Supporters: Lead decision maker, Informal supporter, Support Coordinator, Providers familiar with participant providing input re perceived preferences

5:

Circumstances: Participant has very limited capacity to communicate their preference or being involved in decision making

Decision: Participant needs formal decision maker for all decisions

Supporters: Legally appointed decision maker to make all final decisions, Support Coordinator, Providers familiar with participant providing input re perceived preferences

Return to [Roles and Responsibilities](#)