



Safeguarding People with Disability Supported Decision-Making and Consent Policy

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Issued by:	NDIS Reform, Disability SA
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Policy custodian:	Team Leader, Disability SA
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DCSI strategic objectives:	Support independence and participation Make our communities stronger Provide the best services
SA Strategic Plan:	Safe communities, healthy neighbourhoods

1 Intent

This policy assumes that a person has decision-making capacity unless proven otherwise and acknowledges that a person's capacity varies for each decision and situation.

In instances where a person's decision-making capacity is in doubt, this policy provides direction regarding determining capacity and consent, supporting and facilitating decision-making, and making a decision on behalf of that person where required.

Disability service providers are required to ensure procedures, guidelines and standards comply with this policy.

This policy is to be read in conjunction with the *Safeguarding People with Disability Overarching Policy*.

2 Context

The Department for Communities and Social Inclusion (DCSI) is committed to ensuring people with disability have the same legal rights as others and must have access to appropriate support to fully exercise these rights. Choices and decisions should be made directly by the person. In circumstances where an individual has difficulty making or is unable to make decisions, every effort must be made to facilitate a decision that is most likely to be in line with the person's preferences.

This policy is underpinned by international, national and state obligations in relation to the human rights of people with disability. Article 12 of the *United Nations Convention on the Rights of Persons with Disabilities* is the key driver behind supported decision-making. The Convention states that Parties are to recognise that people with disability enjoy legal capacity on an equal basis with others in all aspects of life and take appropriate measures to provide access by people with disability to the support they may require in exercising their legal capacity.

The principles of *National Disability Strategy 2010-2020* outline the need for people with disability to be involved in the design and delivery of programs and services that impact on them. Specifically Outcome 2 – rights protection, justice and legislation, identifies a need to ensure supported decision-making safeguards are in place for people living with disability who need them, including accountability of legally appointed guardians. Outcome 6 – health and wellbeing also notes the importance of individuals having control over their own lives and the impact such control can have on their quality of life and health and wellbeing.

The *Disability Services Act 1993 (SA)* (the Act) reinforces the right of people with disability to exercise choice and control in relation to decision-making. Following amendments to the Act in 2013, disability service providers delivered or funded by DCSI must have in place appropriate policies and procedures that address supported decision-making and consent.

The *National Standards for Disability Services* promotes active participation in decision-making to safeguard and advance human rights, wellbeing and interests of people with disability.

An objective of the National Disability Insurance Scheme is to enable people with disability to exercise choice and control in pursuit of their goals and the planning and delivery of services.

In South Australia, the implementation of individualised funding is another step to increasing the choice and control people with disability have over their lives.

3 Risk

In the absence of a supported decision-making and consent policy, there is a risk that decisions about a person's life may be made without their involvement or against their actual or anticipated wishes. There is also a risk to disability service providers that without clear direction they may not be aware of, and therefore contravene, the legal requirements relating to consent.

4 Reference Documents

4.1 Directive Documents

- *Advance Care Directives Act 2013 (SA)*
- *Consent to Medical Treatment and Palliative Care Act 1995 (SA)*
- *Disability Discrimination Act 1992 (Cth)*
- *Disability Services Act 1986 (Cth)*
- *Disability Services Act 1993 (SA)*
- *Equal Opportunity Act 1984 (SA)*
- *Freedom of Information Act 1991 (SA)*
- *Guardianship and Administration Act 1993 (SA)*
- *Health and Community Services Complaints Act 2004 (SA)*
- *Mental Health Act 2010 (SA)*
- *Privacy Act 1988 (Cth)*
- *Privacy Amendment (Private Sector) Act 2000 (Cth)*
- *Powers of Attorney and Agency Act 1984 (SA)*

4.2 Supporting Documents

- *DCSI Safeguarding People with Disability – Overarching Policy*

- *DCSI Safeguarding People with Disability – Management of Care Concerns Policy*
- *DCSI Safeguarding People with Disability – Restrictive Practices Policy*
- *HCSCC Charter of Health and Community Services Rights*
- *National Disability Strategy 2010-2020*
- *National Standards for Disability Services*
- *United Nations Convention on the Rights of Persons with Disabilities*
- *United Nations Universal Declaration of Human Rights*

4.3 Related Documents and Resources

- *Office of the Public Advocate Evaluation of the Supported Decision Making Project (November 2012)*
- *Strong Voices – A Blueprint to Enhance Life and Claim the Rights of People with Disability in South Australia (2012-2020)*

5 Scope

This policy applies to all disability services provided by DCSI or funded under the *Disability Services Act 1993*. This includes registered or unregistered health practitioners and therapists providing services to people with disability.

This policy applies to all employees who may be paid staff, volunteers, contractors or people on placements.

This policy is applicable to people with disability who are 18 years of age or over. Parents, guardians or relatives of people under 18 years of age, in most instances, have the right to consent on their behalf. However, disability service providers may choose to apply this policy to people nearing 18 years of age.

This policy operates in conjunction with any mandatory reporting requirements and all relevant legislation, policies, guidelines and standards.

6 Definitions

Definitions specific to the content of this policy are listed below. Further definitions can be found in the *Safeguarding People with Disability – Overarching Policy*.

- **Advance care directive** is a legal form where a person, 18 years of age or over, is able to write down (or where unable to do so have written down on his or her behalf) his or her instructions, wishes and preferences for future health care, accommodation and personal matters and/or to appoint one or more substitute decision makers who can make decisions on the person's behalf in any period of impaired decision making capacity, or as determined by the person. In this policy, it includes Enduring Power of Guardianship, Medical Power of Attorney and Anticipatory Direction made before 1 July 2014.
- **Binding refusal** is a refusal of particular medical treatment outlined in an advance care directive.

- **Impaired decision-making capacity** refers to the inability of a person to make a particular decision at a particular time because he or she is incapable of:
 - understanding any information that may be relevant to the decision; or
 - retaining such information; or
 - using such information in the course of making the decision; or
 - communicating his or her decision in any manner; or
 - by reason of being comatose or otherwise unconscious, is unable to make a particular decision about his or her medical treatment.
- **Informed consent** is the act of agreeing to or giving permission for certain actions affecting one or more aspects of one's life (eg legal, financial, health, lifestyle and social). To be informed a person must be given information about the proposed activity relative to the individual situation including potential for an adverse outcome, other options and the possible results of alternative action or no action. For consent to be effective, the person should be able to communicate an understanding of the proposed activity. Consent can be refused or withdrawn at any time.
- **Lifestyle** – refers to a broad range of activities such as work, leisure, recreation, assistance with daily living, cleaning, mobility, social interactions and friendship and relationships.
- Where there is no substitute decision-maker or relevant instruction, a **person responsible** for a person with impaired decision-making capacity has legal authority to provide or refuse consent to health care and medical treatment for that person (subject to certain legislatively prescribed exceptions), in the following legal order:
 - guardian with health care decision-making powers
 - relative with a close and continuing relationship (an adult spouse or domestic partner or an adult related by blood, marriage, adoption or Aboriginal kinship rules/marriage)
 - an adult friend with a close and continuing relationship
 - someone charged with the day to day care and well-being of the person
 - South Australian Civil and Administrative Tribunal (SACAT) (last resort).
- **Substitute decision-maker** is an adult appointed under an advance care directive who can make decisions about health care, end of life, living arrangements and other personal matters on behalf of a person during a period of impaired decision-making capacity, whether for a short time or permanently. In this document, it includes substitute decision-makers appointed under the former Enduring Power of Guardianship and Medical Power of Attorney.
- **Supported decision-making** is the process of providing information, resources and tools needed to enable a person to make their own decisions.

7 Policy Detail

People with disability have the right to make decisions about their own lives and, regardless of their capacity, must be placed at the centre of any planning or service provision.

This policy acknowledges that a person's ability to make decisions is specific to the situation and will change for each decision.

Supported decision-making is about giving people with disability the tools they need to enable them to make decisions for themselves. It recognises a person's particular goals, aspirations, interests, preferences, strengths and capacities, provides options and consequences, and supports a person to make their own informed decision.

Supported decision-making can lead to increased confidence, improved decision-making skills, strengthened support networks and better engagement with the community. It allows people to exercise their legal right to make their own decisions where possible rather than have their decisions made for them through informal or formal substitute decision-making arrangements.

7.1 General Principles

- People with disability are informed of their inherent human rights and are supported to exercise these rights.
- People with disability have the right to participate in and contribute to the social, cultural, political and economic life of the community on an equal basis with others.
- People with disability have the right to live free from abuse, neglect, intimidation and exploitation.
- People with disability have the right to be respected for their worth, dignity, individuality and privacy.
- People with disability have the right to realise their potential for intellectual, physical, social, emotional, sexual and spiritual development.
- People with disability have the right to take their own chances and make their own mistakes.
- People with disability have the right to have access to appropriate assistance and support that will enable them to maximise their capacity to exercise choice and control, and realise their potential.
- People with disability are empowered to determine their own best interests, including the right to exercise informed choice and take calculated risks.
- The cultural and linguistic diversity of people with disability is respected.
- Intervention in the lives of people with disability occurs in the least intrusive way, with the smallest infringements on the fewest rights.
- Services and supports are based on contemporary evidence-based best practice with a strong focus on person-centred approaches.

7.2 Service Provider Responsibilities

7.2.1 Determining Capacity

A person is presumed to have decision-making capacity unless proven otherwise.

If it has not already been predetermined that a person has impaired decision-making capacity, individuals should have all decisions referred directly to them.

If there are doubts about a person's ability to make a particular decision, efforts must first be made to facilitate supported decision-making.

This policy also acknowledges that capacity is decision specific. That is, a person may have the capacity to make decisions in some circumstances or about some matters but not others. In addition:

- A person will not be taken to be incapable of understanding information merely because the person is not able to understand matters of a technical or trivial nature
- A person will not be taken to be incapable of retaining information merely because the person can only retain the information for a limited time
- A person may fluctuate between having impaired decision-making capacity and full decision-making capacity
- A person's decision-making capacity will not be taken to be impaired merely because a decision made by the person results, or may result in an adverse outcome for the person.

It is the task of disability service providers and, if required, professionals such as psychologists and medical practitioners, to determine a person's capacity. If there is disagreement about a person's decision-making capacity, the Office of the Public Advocate can make a determination.

7.2.2 Dignity of Risk and Duty of Care

People with disability have the right to make informed choices to experience life and take advantage of opportunities for learning, developing competencies and independence and, in doing so, take calculated risks.

If a person isn't allowed to confront a difficult decision or its consequences, their right to be in control of their life is denied. Each individual has the right to take their own chances and make their own mistakes. Making a decision that seems unwise does not mean that a person lacks capacity.

Disability service providers have a duty of care to ensure people with disability are not exposed to unreasonable risk so must work with people to help them strike a balance between achieving their life inspirations and goals and protecting themselves from unreasonable risk and harm.

Disability service providers must ensure that individuals have objective, accurate, and appropriate information in a format that they genuinely understand in order to make the best decisions for themselves.

Disability service providers are to support people to articulate their decision-making arrangements and record these in their individual support plans. This should include consideration of strategies that seek to support individuals to identify and manage risks and live their lives in a way that best suit them.

Where appropriate, disability service providers should maintain ongoing liaison with a person's family, nominated support and/or legally appointed guardian to ensure this.

7.2.3 Decision-Making when a Person has Capacity

For people who do not require support in decision-making, all decisions must be referred to the person. Disability service providers must respect and support the individual's decisions.

For people who require some support in decision-making, disability service providers must facilitate access to appropriate support and information to enable the person to make the decision for themselves as far as is practicable. In doing this, disability service providers should recognise that a person's views may be expressed through body language, behaviour, and/or through a variety of verbal or non-verbal signs. Where needed, augmentative communication aids should be used to assist communication.

Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds are to be supported to make decisions in the context of their culture and heritage.

7.2.4 Decision-Making when a Person is Determined to not have Capacity

In a situation where a person has been assessed as not having the capacity to make his or her own decision, a decision will need to be made on the person's behalf. This is known as substitute decision-making and can be either informal or formal.

7.2.4.1 Informal decision-making on behalf of a person with disability

Informal decision-making is where a person making a decision on behalf of another person has not been legally appointed. People who can make informal decisions include the person's family, friends, carer or nominated support. Most decisions can be made informally, including decisions about who a person wishes to see, their work, leisure, recreation, holidays or accessing services. However, there are certain situations where formal consent is required (refer to 7.2.5).

Disability service providers must ensure all informal decision-making arrangements are clearly recorded and communicated to relevant staff. Decisions can then be pursued through the agreed informal arrangements.

7.2.4.2 Formal decision-making on behalf of a person with disability

In situations where informal decision-making arrangements are considered to be insufficient, formal arrangements will need to be activated. Informal arrangements can be considered insufficient, for example when:

- There is conflict over decisions being made about the person
- The person's safety or the safety of others may be at risk and an order may be required under the *Guardianship and Administration Act 1993*
- Where specific legislative requirements exist (eg consent to medical treatment).

Formal arrangements should take a rights-based approach, and consider the person's individual wishes as much as possible regardless of his or her impaired decision-making capacity.

If no existing formal arrangements are in place, the Office of the Public Advocate can provide advice and mediation. As a last resort, an application can be made to South Australian Civil and Administrative Tribunal (SACAT) to appoint a guardian or place the person under a guardianship or administrative order.

Disability service providers are required to record and maintain any formal decision-making arrangements for a person with disability. Any amendments to person's decision-making arrangements must be clearly recorded and communicated as soon as practicably possible.

7.2.5 Specific Consent Arrangements

Aside from decision-making on everyday issues, some decisions require specific consent from an individual or someone on their behalf.

In all instances, disability service providers must ensure that a person's consent arrangements, including any legal authorisations required to enable consent to be provided, are clearly outlined for, and understood by, direct care staff. Processes should be in place for regular review and updating of these arrangements. Disability service providers must also ensure that a person is offered/provided with information about consent issues in a way they can fully comprehend, and that such information remains readily available.

When appropriate, disability service providers should maintain ongoing liaison with a person's family, nominated support and/or substitute decision-maker on matters of consent to ensure the person's needs and wishes are known and acted upon.

7.2.5.1 Consent to medical treatment

Under the *Consent to Medical Treatment and Palliative Care Act 1995* (SA), it is a medical practitioner's duty to explain to a patient or the patient's representative the nature, consequences and risks of proposed medical treatment, the likely consequences of not undertaking the treatment, and any alternative treatment or courses of action that may be considered in the circumstances.

A person cannot receive medical treatment without their consent. People over 16 years of age can consent to medical treatment as long as they have the decision-making capacity to do so.

If a person has been assessed as having impaired decision-making capacity, alternative consent to receive medical treatment must be sought:

- Where the person has an advance care directive and has not appointed a substitute decision-maker but relevant instruction exists, this instruction is considered to be consent or refusal
- If a substitute decision-maker with health care decision-making powers has been appointed within an advance care directive, the substitute decision-maker can consent or refuse to consent to medical treatment
- Where no advance care directive exists, a 'person responsible', as outlined in the *Consent to Medical Treatment and Palliative Care Act 1995* (SA), has legal authority to provide or refuse consent if that person is willing and available.*

*Subject to certain legislatively prescribed exceptions, refer to the Safeguarding People with Disability Restrictive Practices Policy for guidance around consent to chemical restraint.

In cases where there is a dispute or conflict about the treatment, the Office of the Public Advocate can provide advice and mediation.

Disability service providers are required to record and maintain the consent arrangements for individuals, including if the person has a substitute decision-maker, or has made any binding refusal of consent to treatment. Disability service providers must record these arrangements as soon as practicable.

Disability service providers must take all reasonable steps to ensure a person's consent arrangements are known by medical professionals.

It is recognised that there is a potential conflict of interest in service providers giving consent to some medical decisions, in particular palliative care. Service providers should have in place guidelines that provide appropriate safeguards for both people who require substitute decision-making and staff giving consent.

7.2.5.2 Consent to emergency medical treatment

Under the *Consent of Medical Treatment and Palliative Care Act 1995 (SA)*, a medical practitioner can administer emergency medical treatment to a person without their consent, if they are of the opinion that the treatment is necessary to meet an imminent risk to life or health, and it is not reasonably practicable to obtain consent from a substitute decision-maker or person responsible.

This highlights the importance of maintaining up-to-date records of consent arrangements because it will assist medical practitioners in obtaining consent even in an emergency.

7.2.5.3 Consent in unplanned or emergency (non-medical) situations

At times unforeseen situations occur that result in a person with disability requiring immediate entry to a service or that require a disability service provider to make a critical decision for a person with disability. In these instances, the personal health and safety of the person with disability and the safety of others is the first consideration.

Where practicable, the service provider must determine if there is an advance care directive, personal plan or consent arrangements in place that may guide immediate decision-making.

Following an immediate response, disability service providers must return to usual consenting and planning decision-making procedures outlined in this policy by close of business the next working day.

7.2.5.4 Lifestyle matters

Lifestyle decisions can include decisions about who a person wishes to see, their work, leisure, recreation, holidays, accommodation or accessing services such as assistance with daily living, cleaning and mobility.

Where a person has impaired decision-making capacity, alternative consent to lifestyle decisions must be sought:

- Where the person has an advance care directive and has not appointed a substitute decision-maker but relevant instruction exists, disability service providers must take all reasonable steps to ensure decisions about lifestyle give effect to the person's stated wishes.

- If a substitute decision-maker with relevant decision-making powers has been appointed within an advance care directive, decisions about lifestyle must be referred to the substitute decision-maker.
- Where no advance care directive exists, lifestyle decisions must be referred to the person's family, friends or carer.
- In the absence of the above, service providers may consent to decisions about lifestyle consistent with the person's individual support plan.

In instances where no one is able to assume responsibility, the person resists the decision(s), other interventions have been trialled and/or there are concerns for the safety and wellbeing of the person, the matter is to be referred to South Australian Civil and Administrative Tribunal (SACAT).

Disability service providers must ensure that the person's decision-making arrangements for lifestyle matters, are clearly discussed and documented.

7.2.6 Staff Training and Information

Disability service providers are responsible for ensuring the ongoing training and education of staff. This may include, but is not limited to:

- Disability awareness
- Relevant legislation, policies, procedures and guidelines that may assist them in the direct delivery of support
- Information on determining capacity and consent
- Supported decision-making principles
- Duty of care responsibilities
- Documentation and reporting requirements
- Any individual processes that the disability service provider has in place.

7.2.7 Reporting Requirements

Under this policy, disability service providers are required to comply with any legislative, contractual or organisation-specific monitoring and reporting requirements.

Disability service providers are responsible for maintaining clear and accurate records relating to a person's consent and decision-making arrangements. All consent and decision-making arrangements must be reviewed regularly to ensure changes in capacity or process are captured and recorded.

8 Aboriginal Impact Statement Declaration

The needs and interests of Aboriginal people have been considered in the development of the policy and there is no direct or indirect impact.

9 Approval

Content Author:	Policy Custodian:	Delegated Authority:
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Position: Chief Project Officer NDIS Reform Disability SA	Position: Team Leader Disability SA	Position: Executive Director Disability SA Position: Executive Director Disability and Domiciliary Care Services