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Supported decision making framework

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Document approval

The Supported decision making framework has been endorsed and approved by:

Samantha Taylor
Deputy Chief Executive

Anne Marie Dwyer
Executive Director

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1 Supported decision making framework

1.1 Introduction

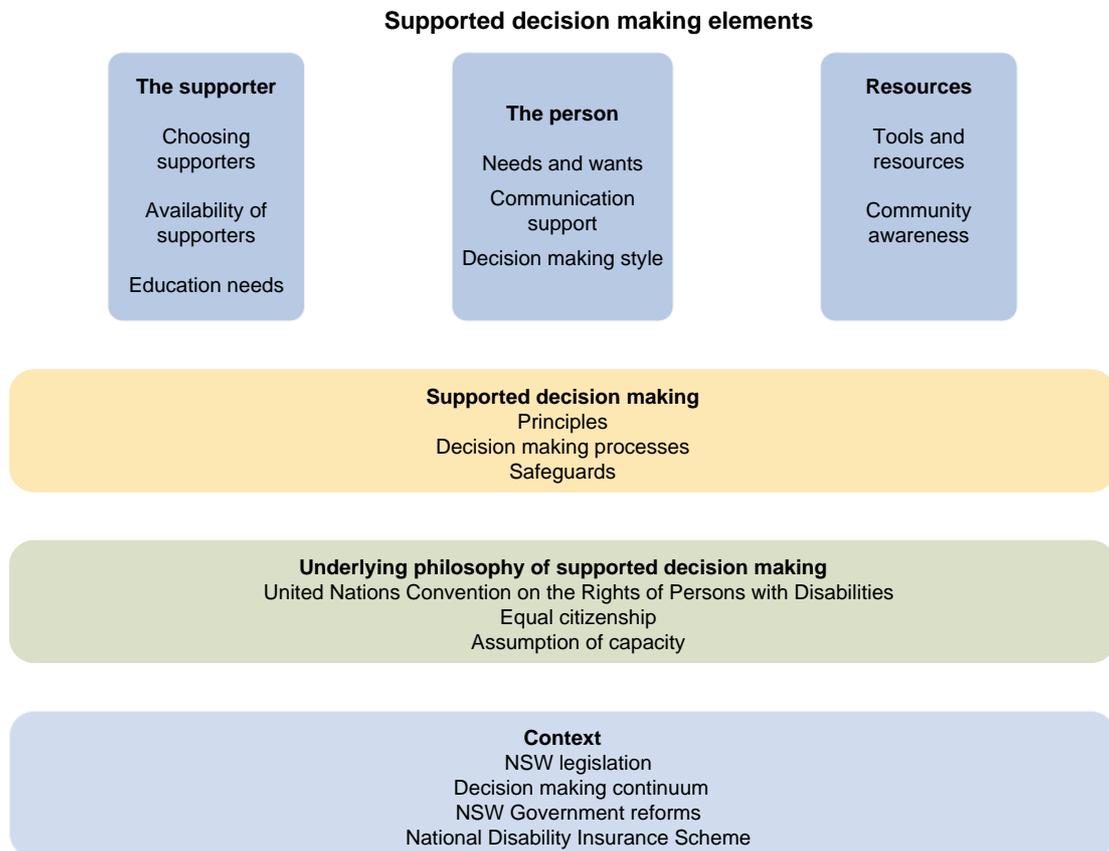
This Framework has been developed for the Supported Decision Making Pilot, a joint project between ADHC, NSW Trustee and Guardian and the Public Guardian in 2013. It is consistent at international level with the United Nations Convention on the Rights of Persons with Disabilities which Australia has signed. Nationally it aligns with action to implement the Convention's principles. At state level the Framework supports the new approach to services for people with disability that puts them at the centre of decisions that concern their lives. This is known as the person centred approach.

Central to the approach is the understanding that people with disability may need support from family, friends, carers and service providers to make choices. They will also need access to clear, relevant information. The whole process is called supported decision making.

The Framework aims to increase the effectiveness of supported decision making for people with disability, empowering them to make a broader range of decisions and work through complex issues. It will also inform policy. At a practical level, the Framework will guide development of tools for people with disability and their supporters.

1.2 Supported decision making elements

There are a number of different elements to supported decision making in NSW as set out in the table below.



2 The person

The person is at the centre of decision making. Each person with disability is unique, and their needs for supported decision making will vary. That is why there can be no 'one size fits all' approach.

A person's need for support with decision making will depend on the complexity of the decision, previous experience, emotional and social factors, the time frame for the decision and preferred decision making style.

2.1 Needs and wants

Each person with disability has their own needs, desires and preferences. Some of their decisions will stem from their own needs and wants and other decisions from external factors, such as having to find new accommodation or lifespan changes like finishing school.

Some people will have clear goals and preferences. Yet others will require support to understand the available choices and come up with decisions that will be the right personal fit. Many people with disability have had limited opportunity to make their own decisions and have not developed experience in this area. Moving to a self-directed approach to services and supports will require varying degrees of education and support.

2.2 Communication support

Communication is a key part of supported decision making. Supporters must clearly understand the communication needs and abilities of the person with disability in order to successfully support their choice and decision making. A person with disability will have individual communication needs. They may require anything from minimal to intensive communication support, perhaps involving the use of communication aids or the help of someone who knows their expressions and communication.

2.3 Decision making style

Every person has their own style of decision making based on a range of factors including personality, culture, values and beliefs, and past experience¹.

Some people will weigh up different factors and opinions before reaching a decision. Other people will prefer to make on-the-spot decisions based on a 'gut feeling' or emotional reaction to a situation. If the decision maker wants to take risks, their supporters can help them assess how harmful such risks could be.

Most people will vary their decision making style depending on the nature of the decision, the time available, and their personal circumstances at the time.

¹ Nicholson, C., 4 April 2012, *Decision making – South Australian Project*, Presentation, DANA Conference, Australian Capital Territory

3 The supporter

A supporter is someone who assists the person with disability to make a decision. The relationship is one of trust, in which the supporter knows and understands the person's wishes, preferences and values. The supporter could be a friend, family member, carer or a service provider. Sometimes the person with disability could have many supporters.

The role of a supporter in decision making can be hard to define. Often a supporter will have other roles in the person's life as a carer, family member or friend. Supporters may change over time or with the type of decision that the person with disability wants to make.

Supporters can assist with decisions by sourcing information, helping the person with disability to consider consequences, weighing up options or communicating the decision. The final decision must always rest with the person with disability and supporters should not make informal substitute decisions. To ensure the person with disability is the one deciding, supporters must put aside their own opinions, values and influences.

Supporters should not unduly influence the person with disability; however, that person has a right to seek the opinion of their supporters and to use their help in decision making.

3.1 Choosing supporters

Support can include one-to-one consultations or circles of support. The person with disability should know and trust their supporters, who may come in and out of their life. Depending on the decision, a person may choose a variety of supporters. Those around them should acknowledge and respect whoever is acting in a support role.

Carers and family members have a significant role in the life of the person with disability, and will usually be involved in supported decision making. Because of the personal relationship, carers and family may be closely affected by decision making support arrangements, such as the choice of a supporter outside the family network.

Sometimes it may not be appropriate for a family member to be involved in supporting decision making because of a history of abuse, neglect or exploitation. In some cases, a family member or carer may have their own needs and issues which make it difficult for them to give the support needed.

There may be times when a person with disability chooses a supporter who is a paid carer or service provider. This could be a personal preference, or due to the lack of other close trusting relationships in their life.

Employing agencies must be clear about the separate roles of service provider and supporter and how these may impact on service provision. Service providers also need to consider any competing interests that might arise.

3.2 Availability of supporters

Not all chosen supporters will be able to carry out their role. Although chosen by the person with disability, they may be reluctant to take on the responsibility for a variety of reasons. The supporter may have his or her own needs and issues and may not have time to provide support.

Many people with disability have had limited opportunities to develop close trusting relationships. In moving towards supported decision making some may need help in developing informal networks, friendships and relationships. Other people may need to be linked to advocates or service providers who are able to offer decision making support.

3.3 Education needs

The role of supporter is unique and differs from the roles of carer, advocate or substitute decision maker. Education and information are essential to help everyone involved understand their respective roles. A range of resources and tools is provided in Section 4 to help supporters understand supported decision making and their role.

4 Resources

Supported decision making is based on a trusting personal relationship between the person with disability and others. A range of tools and resources are available to help develop this relationship, inform decision making and assist communication.

4.1 Some useful resources

Department of Family and Community Services, *Supported Decision Making Handbook*, 2013 (Supported Decision Making Pilot resource)

Department of Family and Community Services, *My life, my decision*, 2013 (Supported Decision Making Pilot resource)

Department of Family and Community Services, *Lifestyle Planning Guidelines*, 2012 www.adhc.nsw.gov.au

Department of Family and Community Services, *Lifestyle Planning Policy*, 2012 www.adhc.nsw.gov.au

Department of Family and Community Services, *Lifestyle Planning Tools*, 2011 www.adhc.nsw.gov.au

NSW Department of Attorney General and Justice, *Capacity Toolkit*, 2008 www.diversityservices.lawlink.nsw.gov.au

Paradigm, *Supported Decision Making: A guide for supporters*, 2008 www.paradigm-uk.org

Victorian Government Department of Human Services, *Supported decision making: A guide to supporting people with a disability to make their own decisions*, 2012 www.dhs.vic.gov.au

4.2 Community awareness

Raising the awareness of services and the general community about supported decision making is important. In addition to resources for people with disability and their supporters, general information on supported decision making, training and website updates is being developed.

5 Supported decision making

While supported decision making is still a developing concept, common principles, processes and safeguards are emerging.

5.1 Principles

The core principles for supported decision making are:

1. Every person can express their will and preferences.
2. A person with disability has the right to make decisions.
3. A person with disability can expect to have access to appropriate support to make decisions.

5.2 Decision making processes

Decision making is unique to the individual, but involves basic steps. Most commonly these are:

1. Considering options.
2. Weighing and judging consequences.
3. Making a choice.
4. Communicating that choice and acting on it.

Because each person approaches decisions differently, there is no standard approach to supported decision making.

Supported decision making applies to everyday decisions. Many people with disability already receive help from their families, carers or support workers to make daily decisions. However, others may not have had the opportunity to develop skills in understanding their choices or making decisions.

Supported decision making is encouraged with all levels of decisions. People with disability should be able to develop their skills and experience by starting with everyday decisions and then building to more significant decisions.

5.3 Safeguards

Despite the focus on enhancing the rights and freedoms of people with disability, supported decision making should not create undue risks for them. Safeguards are needed, as stated in Article 16 of the Convention on the Rights of Persons with Disabilities. The NSW Disability Services Standards require services to provide an environment where people are free from discrimination, abuse, neglect and exploitation. Services are also required to put processes in place to manage these issues if they arise.

Raising awareness of rights and responsibilities is an important safeguard for people with disability. This includes assistance and education for them, their families, carers, advocates and supporters on avoiding, recognising and reporting exploitation, violence and abuse.

6 Underlying philosophy of supported decision making

Current thinking about disability support in NSW reflects international trends upholding the rights of people with disability. In recent years we have moved from the idea that people with disability need protection to recognising they have equal rights to others and capacity to take greater charge of their lives. This thinking is consistent with Australia's ratification of the United Nations Convention on the Rights of Persons with Disabilities.

6.1 United Nations Convention on the Rights of Persons with Disabilities

The articles in the Convention most relevant to supported decision making are:

- Article 5, which states that countries signing the Convention should take all necessary steps to prohibit discrimination and promote equality
- Article 9, which states that people with disability should have access to services, facilities and information
- Article 12, which states that people with disability should have equal access to the law and equal opportunities to exercise their legal rights
- Article 19, which covers the rights of people with disabilities to live in the community and have equal choices to others.

These rights are balanced by Article 16, which requires protection of people with disability from exploitation, violence and abuse.

These Articles set the philosophical basis for the supported decision making framework.

6.2 Equal citizenship

One of the ideas basic to the Convention and the NSW Stronger Together reforms is that people with disability should be able to enjoy equal citizenship with others in our community. In NSW, supported decision making is a way of ensuring that people with disability are given equal choice and control over services and funding by providing additional support and 'reasonable adjustment' in decision making. This may involve use of special tools and resources.

6.3 Assumption of capacity

Capacity is at the heart of discussion about decision making. In NSW, the law presumes that everyone aged 18 years and over has the capacity to make decisions. The United Nations Convention on the Rights of Persons with Disabilities states that people with disability should enjoy legal capacity on an equal basis with others. To exercise their legal capacity, people with disability may need support with aspects of decision making some or all of the time.

7 Context

Supported decision making is an emerging concept in Australia and internationally. A variety of supported decision making arrangements have been developed, each within the context of local laws and policy and the nature of the population. The Supported Decision Making Pilot (SDMP) has been initiated in the context of NSW disability reforms. The United Nations Convention on the Rights of Persons with Disabilities and the Australian Government's disability reforms are also drivers of development in supported decision making.

7.1 NSW legislation

NSW does not have a particular law covering supported decision making. All adults are presumed under common law to have capacity to make decisions.

NSW legislation allows substitute decision making — decisions about lifestyle and finances on behalf of others by trusted people or government officers. The *NSW Guardianship Act 1987*, the *NSW Trustee and Guardian Act 2009* and the *Powers of Attorney Act 2003* plus Supreme Court Rules and associated Regulations cover various substitute decision making arrangements. Sometimes an individual makes these arrangements on their own behalf (powers of attorney or enduring guardianship). Sometimes a court or tribunal does, as in the case of guardianship or financial management orders.

7.2 Decision making continuum

Decision making has been defined as a continuum². Independent decision making is at one end and substitute decision making at the other. In NSW, supported decision making happens every day, either informally or as part of more formal individual planning for people with disability by their family members, advocates and carers. The current context encourages the development and support of these processes.

7.3 NSW Government reforms

The NSW Government's *Stronger Together* disability reforms emphasise a person centred approach to disability services and supports. The vision is a system in which individuals are supported to achieve their full potential and participate in their communities and the economy.

² Office of the Public Advocate South Australia *Supported Decision Making In Australia - Presentation Notes 2009*

Under this approach, the person with disability has more choice and control about services and supports they receive. Supported decision making puts the person at the centre of decision making and is important as many people with disability have not previously made many choices about their lives.

Many aspects of supported decision making have already been built into current NSW Government disability policy. For example, the Department of Family and Community Services, Ageing Disability and Home Care *Decision Making and Consent* and *Lifestyle Planning* policies highlight the right of the person with disability to make decisions and receive appropriate support to do so. These concepts are also part of the NSW Disability Services Standards which guide service providers on meeting the requirements of the NSW *Disability Inclusion Act 2014*. The next step is to establish supported decision making as common practice and raise awareness of it in the wider community.

7.4 National Disability Insurance Scheme

Like the NSW reforms, the National Disability Insurance Scheme (the Scheme) is based on a person centred approach to funding services that meet individual needs. The principles of the Scheme include providing “people with a disability with better information and support to enable them to make informed choices and exercise control and choice over their care and support” (Principle 1)³.

Supported decision making in NSW is compatible with the approaches developed by the Scheme.

³ Council of Australian Governments *High-level Principles for a National Disability Insurance Scheme* 2012