



NATIONAL DISABILITY INSURANCE SCHEME CONSULTATION ON SUPPORTING YOU TO MAKE YOUR OWN DECISIONS

Submission from:
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INTRODUCTION

About Scope

Scope (Aust) Ltd (Scope) is a leading provider of services to people with disability in Victoria, and one of the largest not-for-profit organisations in Australia. Our origins stretch back to 1948, when a group of parents who wanted better lives and opportunities for their children with disability established the Spastic Children's Society of Victoria.

Scope's mission is to enable each person we support to live as an empowered and equal citizen. Scope provides services including Supported Independent Living, Short Term Accommodation, Therapy and Lifestyle options to more than 7,000 people and their families across metropolitan and regional Victoria. Scope also works with corporate and community organisations to improve inclusiveness for people with disability.

Scope welcomes the opportunity to respond to the consultation and has responded to nine questions. Scope has conducted research and developed many resources about decision-making support. Our response to this consultation draws on our own research and resources, research that we have commissioned, as well as other research. Our research and resources are summarised in the Appendix.

Question 1. How can we help people with disability to make decisions for themselves?

People with disability must be provided with the right support to help them make decisions for themselves. Having the right supporters to assist with the process is therefore critical (see response to question 2).

In addition to having the right support and supporters, it is imperative that people with disability are provided with opportunities to practice decision making. Our fact sheet about *Making-decision making part of life* provides some ways in which disability support workers and others can do this and includes:

- Supporters should think about various situations and whether they can do things in a way to give the person an opportunity to make decisions. This way the person will get to practice making decisions and feel encouraged to participate in decision-making.

- Introducing new things for the person to try is an important strategy as it widens peoples' experiences and provides a sense of what is possible. To do this, it might be beneficial to slowly introduce ideas and possibilities that might help the person consider other options for the future. Exploring ways in which the person can have more control in his or her life is also important.
- Encouraging autonomy. As a supporter, it is important to step back, say less and give the person time to participate in decision making. Reflecting on whether or not what is being said and done is interfering with the person making his or her own decisions is important, as is providing positive feedback and encouragement to develop confidence in decision making.

Good communication that is tailored to the individual is essential. Supporters must have the awareness, knowledge and skills to understand and respond to an individual's communication level (i.e., receptive and expressive communication abilities). For example, for an emergent communicator, this may be through observing a person's response to interactions. A context dependent communicator may be able to use some simple hand signs/gestures, vocalisations, single pictures on a card, board or page in a book provided there is familiar context. For novel topics, an additional aid or vocabulary source may be needed (e.g., categories like places, people, body parts, activities, feelings). There are many services that can assist with determining an individual's communication level and develop tailored communication aides.

The barriers that prevent people with disability from making decisions must also be addressed. In our own research, ¹ disability support workers identified a range of barriers to providing decision-making support to adults with cognitive disability. The most common barriers reported was those related to organisational practices and other supporters. Our research results are consistent with previous research that has found structural and systemic issues in an organisation, such as not having easy access to supervisors or others who had relevant expertise, inadequate communication systems and inflexible schedules could have a negative impact on decision-making support. ² Having sufficient time in work schedules and timetables to provide effective support for decision making was also reported to be a barrier by these and other researchers. ³ These results demonstrate a need

¹ Koritsas, S., & Olczyk, A. (2019). *Evaluation of Decision-Making Support Training for Disability Support Workers*. Melbourne: Scope (Aust).

² Bigby, C., Whiteside, M., & Douglas, M. (2015). *Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas*. Melbourne: Living with Disability Research Centre, La Trobe University.

³ Westwood Spice (2015). *My life, my decision: An independent evaluation of the supported decision making pilot for the Department of Family and Community Services (New South Wales)*. NSW: Family & Community Services (Ageing, Disability & Home Care).

to address various organisational level factors that act as barriers to providing support for decision making.

Another barrier to support for decision making is differences in opinions between supporters. There is, therefore, a need for guidance about how to work together and conflict resolution when there are different views. In their research, Bigby et al. (2015) ² reported that supporters held differing views about influencing people they supported. Disability support workers and legal professionals emphasised the necessity to remain neutral. Disability support workers were particularly conscious of remaining neutral and emphasised the need to be aware of how their own values could influence the decision-making support process. In contrast, family members placed less importance to neutrality and tended to actively shape the directions of decisions so they aligned with their overarching goals for the family member with cognitive disability. Differences in supporters' approach often led to conflict. Family members reported that support workers tended to undermine their views and long-term efforts. Some families deliberately hired support staff who shared similar views and, in case of disagreement, stopped employing the support worker. Support workers reported avoiding honest discussion with the family and, at times, openly defied the family's opinions.

Tension between family members and paid staff and how to negotiate differing views was not unique to Bigby et al's. (2015) ² research. Paid carers who acted as supporters in the NSW decision-making support trial acknowledged that they did not feel comfortable with questioning family values and hence found it difficult to provide support for decisions that families disagreed with. ³ These difficulties were also reported by case workers in the ACT trial. ⁴ Case workers in these trials reported that families frequently exerted influence over family members with cognitive disability and, at time, limited support options provided by paid staff. In some cases, staff preferred to not oppose family's wishes because they believed it was not their responsibility or because they felt intimidated by the authority of the family.

Whilst there are some barriers to support for decision making, there are also factors that research has shown can facilitate the provision of support for decision making. The most common facilitators identified through our own research ¹ were knowledge of decision-making support, knowledge and understanding of the person with disability, having empathy, using communication aides, support

⁴ ACT Disability, Aged and Carer Advocacy Service (2013). *Spectrums of support: A report on a project exploring supported decision making in people with disability in the ACT*. Author: Canberra.

from the organisation, legal reform, and additional time. All these facilitators can be leveraged to make support for decision making a reality.

Question 2. Who are the best people to help you (or a person with disability) to make decisions?

Scope has developed a fact sheet about *The role of supporters*. In this fact sheet, we highlight that a supporter can be anyone who:

- Has a trusting relationship with the person.
- Respects the person's independence, sense of worth, and decision-making style.
- Knows the person well and wants to keep learning about the person, or is committed to getting to know the person and understand their will and preferences.
- Is able to spend as long as needed to support decision-making.

Supporters can be family members, service providers, formal and informal carers, friends and those who are formally appointed. It is preferable to have a group of supporters, rather than just one person as different views can be presented and undue influence can be better managed.

In our fact sheet, we note that an effective supporter is someone who:

- Adapts support, including communication style, to the person.
- Focuses on the person's will and preferences.
- Is neutral and does not influence the decision.
- Does not limit the person's options – this means all the different possibilities are explained.
- Respects the person's decision whether or not they agree with it.

It is critical that those who are providing support have a good understanding of the underlying principles of support for decision making (e.g., the United Nations Convention on the Rights of Persons with Disabilities, The NDIS Act, The Australian Law Reform Commission's decision-making principles). Although the consultation paper makes mention of other people making decisions in the best interest of people with disability (e.g., page 34), it should be noted that support for decision making marks a fundamental shift away from decisions being made according to what is seen to be in the best interests of the person with disability to a human rights approach where an individual's will and preference is at the centre of decision-making. The Convention does not include best interests or any similar concept, except in relation to children. Similarly, the Australian Law Reform

Commission's decision-making principles identify a move away from best interest standards. It is strongly recommended that mention of best interest is excluded in the Framework that will be developed. We have created a video that provides information about the key ideas behind support for decision making: <https://vimeo.com/269791487>.

Question 3. What should they do to help with decision making? and

Question 4. How can they get better at helping?

Scope has developed a factsheet about *The role of supporters*, which identifies what supporters need to do to help with decision making. This includes:

- Gathering and understanding information about the decision and presenting this information to the person in a way he or she understands.
- Helping the person work out the options.
- Helping the person to work out the benefits and risks of each option.
- Helping the person to work out and understand the outcomes of a decision.
- Making a plan for turning the decision into a reality.

It is also important for supporters to check-in to see how the decision went in practice. We have created a video that provides an example of one step in support for decision making, weighing up the pros and cons of a decision, and how this might be approached: <https://vimeo.com/269792432>.

Question 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.

The right people are those who focus on the will, preferences and rights of the person with disability, and are providing opportunities for decision making. They will adapt their communication style to what works best for the person and focus on what the person wants rather than what others judge to be in the person's best interests. The right people will not limit the options presented to the person but rather help build awareness of all the options. The right people will be aware of biases

and understand that some people with disability can be influenced by others in a position of power. The right people will respect the decision made irrespective of whether it is perceived as good or sensible.

There are many challenges that can arise when providing decision making support that supporters should be aware of so that they can be addressed and not have a detrimental impact on the person with disability and the support for decision making process. Some of these challenges are outlined in our factsheet *Dealing with challenges in providing decision-making support* and include:

- Remaining neutral. Being neutral means not influencing the person to make one decision over another because of your own beliefs, or because it is the decision you would make if you were in their shoes. To remain neutral, supporters should be aware of their own beliefs and reflect on whether these are influencing how they are providing support. If there is a situation where they feel that they cannot avoid influencing someone, the other supporters should be drawn on to provide support for that decision.
- Supporters may have different opinions that cause conflict or tension. To help work through conflict, supporters should understand each other's roles, motivations and strengths, be respectful of each other's views and opinions, agree to be open and honest with each other, be willing to talk about conflict, and think about how issues will be worked through.
- Managing risk and avoiding the "best interest" approach can be especially challenging, particularly in service environments. There are often risks in making decisions, and everyone has the right to make poor or badly timed decisions. Risk management frameworks and practices can be used to manage or reduce risk. An important component to risk management is ensuring that the person with disability understands what might happen as a result of a particular decision, and that he or she understands this and the risk involved.

Supporters should also know their boundaries. In our *Decision-making support for people with cognitive disability: A guide for disability workers*, we recommend that supporters ask themselves these questions:

- Do you really understand what the person is saying and their intention?
- Are you communicating in a way the person understands?
- Can the person trust you to support their will and preference on this decision?
- Are there others that the person wants support from on this decision?

- Is specialist knowledge (e.g., legal or medical knowledge) required to provide support for the decision?
- Has the person been given the opportunity to change their mind?

Question 6. What should decision supporters know about so they can help people with disability make decisions?

Building knowledge and confidence in support for decision making is required. In a service delivery environment, this should involve training as well as practice leadership and mentoring. It should be noted that there are many existing resources, such as those created by Scope, that can be used to build capacity in disability support workers, families/ carers and legal professionals. There are other resources that have been developed by other groups that should also be considered rather than developing entirely new resources and courses/ training. For example, the NSW Government's Supported Decision Making: A Guide for Facilitators ⁵ and LaTrobe University's learning resource. ⁶

Throughout this response we have highlighted what supporters need to know in order to provide good support. Some of these are highlighted below:

- Decision-making support does not focus on whether a person can or cannot make decisions. Instead, it focuses on ensuring people have access to the right support they need to make decisions.
- People with disability have the same right as everyone else to make their own decisions. They have the right to learn through experience, the right to change their mind, and the right to make decisions that others might not agree with.
- Many decisions involve risk. People with disability should not be prevented from making a certain decision because risk is involved. The focus should be on reducing risk and minimising harm rather than eliminating risk.
- The way they support someone to make a decision will change depending on the person and on the decision that needs to be made.

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<https://www.ideas.org.au/uploads/resources/1392/Supported%20Decision%20Making%20A%20handbook%20for%20Facilitators.pdf>

⁶ <https://www.supportfordecisionmakingresource.com.au/>

- Supporters need to be able to clearly identify the decision that needs to be made. This may not always be straightforward and it is often helpful to break a decision into smaller components.
- Every individual has differences in skills and abilities, whether they have a disability or not but there are some generalities that can be made about the impact of different types of disability on decision-making that should be considered. There are many existing resources available to assist supporters to understand the impact of disability.
- People communicate in different ways. It is important that communication is pitched at a level that is right for the person that is being supported. There are many existing resources that can help with communication including use of plain language or easy English.⁷
- Safeguards must be put in place to ensure that people with disability are not unduly influenced and to prevent abuse.

Supporters should also understand the impacts of co-morbid mental health, trauma and dementia on support for decision making and be familiar with existing resources that might assist in the process (for example, dementia and decision making ⁸).

Question 10. How can we help reduce conflict of interest? and

Question 11. How can we help reduce undue influence?

It is important that supporters know their limits and have a good understanding of their own biases so that they do not influence the person with disability. Remaining neutral is a key tenet of providing support for decision making and is a way to manage undue influence. Having a broad range of supporters, particularly for very significant decisions (e.g., living arrangements, relationships), is useful because it means that more perspectives are presented, and there is greater accountability. Ensuring that there are processes in place to monitor and review how support is being provided increases transparency around the support for decision making process and helps manage the potential for undue influence and conflicts of interest.

⁷ <https://www.scopeaust.org.au/blog/communication-access/plain-language-or-easy-english/>

⁸ <https://www.talkingmats.com/wp-content/uploads/2013/09/Dementia-and-Decision-Making-full-report2.pdf>

Conflicts of interest can often arise and policies and processes must be developed to manage these. Any conflicts of interest must be disclosed and there may be situations where supporters step aside for particular decisions.

Question 13. What else could we do to help people with disability to make decisions for themselves? Is there anything missing?

Investment to build capacity to provide support for decision-making is required. From a disability service provider perspective, this includes funding to help upskill staff. Existing resources that have been developed to build capacity should be reviewed and utilised as far as possible.

In order for support for decision making to become standard practice, societal attitudes towards disability must be also be challenged. For the most part, views about disability can be out-dated and negative, and prevent people with disability from fully engaging in all aspects of life, including decision making. Efforts must also be made to expand the social networks of people with disability. Provision of support for decision making is dependent on having access to trusted people. It is well known that people with disability can be socially isolated and experience poverty in their social networks. Opportunities to increase and nurture their social networks and friendships is therefore critical for support for decision making.

There is also a need to address the tensions between duty of care and risk. In Bigby et al's. (2015) ² research, it was reported that, while support workers demonstrated a strong conviction that people with disability had the right to make their own decisions, they were sometimes reluctant to provide support for decisions they perceived to be risky or dangerous. It was reported that support workers felt they needed to balance the risk of harm to the individual against the duty of care for that individual. The researchers reported that organisations could be risk-averse because of duty of care obligations and the potential reputational and financial damages that could arise if a person was injured or hurt because of a decision that was made. Addressing these tensions will enhance the capacity of disability service providers to provide support for decision making.

Appendix

Scope's research into decision-making support

Scope has conducted research and developed many resources about decision-making support. In 2011, Scope developed a training package titled *Listening to those rarely heard. A Guide for Supporters*. This training package is for those who support people with severe or profound intellectual disability and includes a framework and worksheets about how this group can be supported to make decisions, including communication and managing risk. This resource is typically purchased through Scope.

In 2012, in partnership with Carers Victoria, Scope received funding from the Victorian Legal Services Board Major Grants Program to research the decision-making needs of people with cognitive disabilities and develop practical resources to support best practice decision-making support. Using this funding, Scope and Carers Victoria commissioned researchers from Latrobe University to conduct research that explored the processes and dilemmas associated with supporting people with cognitive disabilities in making decisions. This research included a literature review on processes of decision-making support for people with cognitive disability, and 2) an exploratory study into processes and key dilemmas that are often encountered when providing decision-making support to people with intellectual disability and acquired brain injury².

The funding from the Victorian Legal Services Board and the commissioned research was used by Scope and Carers Victoria to develop resources to build capacity in providing decision-making support to three groups: carers/ families, legal professionals, and disability support workers. The resources are:

- *Sean's decision. Decision-making support for people with cognitive disability. Guidelines for families and carers.*⁹

⁹ Gooding, P., Koritsas, S., Duffield, L., Watson, J., & Hagiliassis, N. (2016). *Sean's decision. Decision-making support for people with cognitive disability: Guidelines for families and carers*. Melbourne: Scope (Aust).

- *Decision-making support: An educational resource for legal professionals working with people with cognitive disability.*¹⁰
- *Decision-making support for people with cognitive disability: A guide for disability workers.*¹¹

Six one-page fact sheets were developed specifically for disability support workers:

- *Introduction to decision-making support.*¹²
- *Key ideas about decision-making support.*¹³
- *The role of supporters.*¹⁴
- *Steps in decision-making support.*¹⁵
- *Making decision-making part of life.*¹⁶
- *Dealing with challenges in decision-making support.*¹⁷

In addition, three video clips were also developed:

- *Decision-making support: An educational resource for legal professionals working with people with cognitive disability – focuses on strategies to use when working with people with cognitive disability.* <https://vimeo.com/269792491>
- *Decision-making support: An educational resource for paid workers and other supporters of people with cognitive disability – focuses on weighing up the pros and cons of a decision.* <https://vimeo.com/269792432>
- *Decision-making support: An educational resource for family members, paid workers and other supporters of people with cognitive disability – focuses on key principles for decision-making support.* <https://vimeo.com/269791487>

¹⁰ Gooding, P., Fleming, L., Watson, J., Koritsas, S., Cuzzillo, C., & Hagiliassis, N. (2016). *Decision-making support: An educational resource for legal professionals working with people with cognitive disability*. Melbourne: Scope (Aust).

¹¹ Duffield, L., Koritsas, S., Watson, J., & Hagiliassis, N. (2016). *Decision-making support for people with cognitive disability: A guide for disability workers*. Melbourne: Scope (Aust).

¹² Duffield, L., Koritsas, S., Watson, J., & Hagiliassis, N. (2016). *Introduction to decision-making support: Information sheet for direct support workers*. Melbourne: Scope (Aust).

¹³ Duffield, L., Koritsas, S., Watson, J., & Hagiliassis, N. (2016). *Key ideas about decision-making support: Information sheet for direct support workers*. Melbourne: Scope (Aust).

¹⁴ Duffield, L., Koritsas, S., Watson, J., & Hagiliassis, N. (2016). *The role of supporters: Information sheet for direct support workers*. Melbourne: Scope (Aust).

¹⁵ Duffield, L., Koritsas, S., Watson, J., & Hagiliassis, N. (2016). *Steps in decision-making support: Information sheet for direct support workers*. Melbourne: Scope (Aust).

¹⁶ Duffield, L., Koritsas, S., Watson, J., & Hagiliassis, N. (2016). *Making decision-making a part of life: Information sheet for direct support workers*. Melbourne: Scope (Aust).

¹⁷ Duffield, L., Koritsas, S., Watson, J., & Hagiliassis, N. (2016). *Dealing with challenges in providing decision-making support: Information sheet for direct support workers*. Melbourne: Scope (Aust).

All these resources are freely available online at <https://www.scopeaust.org.au/news-event/decision-making-support/>.

In 2017, Scope received funding from Perpetual via an Impact Grant to develop and test an online training course for disability support workers about decision-making support. The research aimed to determine whether the online training course improved knowledge and attitudes in relation to decision-making support. Barriers and facilitators to the provision of decision-making support were also explored in the research. As part of this research, six online modules were developed:

1. What is decision-making support?
2. Understanding the person with disability and their needs.
3. What is the role of supporters?
4. What are the steps in the decision-making support process?
5. Making decision-making part of life.
6. What are my challenges and where can I get support?

A summary of the results of this research is available online at

<https://www.scopeaust.org.au/research-projects/evaluation-of-decision-making-support-training-for-disability-support-workers/>.