

# Living My Life

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SAHMRI



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**Front cover picture:**

The front cover of this report shows Lorcan Hopper, an artist from Tutti Arts Inc.  
You can read more about Lorcan and his participation in the project in Section 4 of this report.

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**Acknowledgement of Country**

We acknowledge the traditional Country of the Kaurna people of the Adelaide Plains, where this research was conducted, and pay our respects to Elders past and present. We recognise and respect their cultural heritage, beliefs and relationship with the land, and acknowledge that they are of continuing importance to the Kaurna people living today.



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# Project Team



Above (L-R): Margaret Brown, Jan McConchie, Trish Ferguson, Emily Thwaites, Pat Rix, Ruby Nankivell, Lisette Claridge, Sarah Byrne, Anne Gale, Felicity Crowther.

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Project Reference Group members:

- SA Office of the Public Advocate
- SAHMRI
- SA Government Disability Advocate
- SA Office of Chief Psychiatrist
- SA Mental Health Commissioner
- South Australian Council on Intellectual Disability
- Brain Injury SA
- SA NDIA Local Area Coordinators (Mission Australia and Baptcare)
- National Disability Services
- SA Migrant Resource Centre
- Community Living Options
- Tracey Gibb
- Cecil Camilleri

Supported decision making training was delivered by Michelle Browning together with:

- lived experience representatives, a Wurundjeri man under joint guardianship with OPA and a community elder, his other joint guardian
- Sarah Byrne (community representative, SACID)
- Ruby Nankivell, training videos (community representative, SACID)
- Caroline Smith, training videos (family member)

Supported decision making and/or Be Well Plan training participants came from the following SA Government departments (business units) and organisations:

- SA Office of Public Advocate
- Department for Health and Wellbeing
- Department of Human Services (Accommodation Services)
- Brain Injury SA
- South Australian Council on Intellectual Disability
- SACare
- Community Living Options
- Tutti Arts Inc
- Lutheran Care
- HCO
- Lighthouse
- Flourish Australia
- Mind Australia
- Mission Australia (LAC)
- Baptcare (LAC)
- Ferros Care (LAC)

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Christine Bigby (La Trobe University)

Co-design partners:

South Australian Council on Intellectual Disability  
Purple Orange  
Tutti Arts Inc  
Pat Rix  
Trish Ferguson



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Finally, we thank the people with disability who shared their lived experience, tested the activities, or helped to create the videos within this project, particularly Sarah Byrne, Ruby Nankivell, Jenny Singh, Katrina Webb, Anthony Beazley, Lorcan Hopper and Trish Ferguson.



Above: Sarah Byrne presenting at the SDM training for the OPA

Below: Josh Campton, from the short film, Introduction to Yoga



Grace Lam and Trish Ferguson from the Self Compassion short film (see pg 109)





# Glossary of abbreviations

<b>ACT</b>	Acceptance commitment therapy
<b>ALRC</b>	Australian Law Reform Commission
<b>BISA</b>	Brain Injury SA
<b>CBT</b>	Cognitive behavioural therapy
<b>DSS</b>	Department of Social Services
<b>GAA</b>	Guardianship and Administration Act 1993 (SA)
<b>ID:X</b>	Client number X in the OPA project
<b>JFA</b>	Julia Farr Association Purple Orange
<b>MLMW</b>	My Life, My Wishes document
<b>NDIS</b>	National Disability Insurance Scheme
<b>OPA</b>	South Australian Office of the Public Advocate
<b>PPI</b>	Positive psychology interventions
<b>SACAT</b>	South Australian Civil and Administrative Tribunal
<b>SACID</b>	South Australian Council on Intellectual Disability
<b>SAHMRI</b>	South Australian Health and Medical Research Institute
<b>SAIDHA</b>	South Australian Intellectual Disability Health Service
<b>UNCRPD</b>	United Nations Convention on the Rights of Persons with Disabilities

# Glossary of terms

<b>Disability Royal Commission</b>	The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, which was established in 2019, received almost 8000 submissions, and delivered its final report in 2023.
<b>OPA Staff</b>	A South Australian Public Service employee with delegations by the Public Advocate to perform guardianship functions.
<b>Person with a guardianship order</b>	A person subject to a guardianship order under the GAA.
<b>Supported decision making</b>	A process by which a person is supported to make their own decision(s).

# Executive Summary

## Introduction

The Living My Life Project was conducted by the South Australian Health and Medical Research Institute (SAHMRI) Wellbeing and Resilience Centre in partnership with the South Australian Office of the Public Advocate (OPA) and the Department for Health and Wellbeing. It was funded by the National Disability Insurance Agency through an Information, Linkages and Capacity Building grant awarded in 2020.

The aim was to build on the current delivery of accessible and inclusive services in mainstream service systems to meet the needs of people with disability and their families/carers, with a focus on applying supported decision making principles and building wellbeing and resilience. An overarching goal was to increase the capacity of people with psychosocial disability to access employment opportunities and achieve their life goals. The project involved a number of activities to support people with psychosocial disability and those with impaired decision-making capacity at risk of not being able to express and realise their life goals and exercise choice and control. These included refining a document to help people with psychosocial disability to record their wishes; training for staff from the SA Office of the Public Advocate in visiting clients to help them complete the document; training on supported decision making for the Office of the Public Advocate, health professionals in acute healthcare settings, specialist health services, community-based health professionals and community mental health teams; and mental health and wellbeing training for project participants and their families.

The Living My Life project team understood the inherent challenges of building health sector capacity when staff have limited availability and there is high staff turnover. As such, the project developed resources that are accessible on an ongoing basis including five introductory videos and three e-learning modules.

“increase the capacity of people with psychosocial disability to access employment opportunities and achieve their life goals”

# Supported Decision Making

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In 2008, Australia was one of the first countries to ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD). A key principle of the UNCPRD is the preservation of an individual's legal right to make their own decisions. When someone has a guardianship order due to a 'mental incapacity', their guardian makes decisions for them. While this is done to ensure a person's care and protection, it diminishes that person's decision-making rights.

Supported decision making is an emerging practice whereby a 'supporter' assists the person requiring help with decision making. It sees 'mental capacity' as fluid, rather than static, and recognises that decision-making ability occurs on a spectrum. Studies have shown that when a supporter provides information in a way that is easily understood, takes the time to get to know and understand the person, and facilitates communication that suits the person's needs, the person with a guardianship order can make, or contribute to making, their own decisions. This practice is more closely aligned with the UNCPRD than is 'substitute decision making'. To the greatest extent possible, it upholds an individual's legal decision-making rights and increases participation in their own decision making about their life.

Supported decision making principles challenge the long-held belief that personal autonomy can only be expressed independently. They recognise the interdependent nature of decision making by challenging legal definitions of capacity that cast decision making as primarily a cognitive, rational and independent process.

The UNCPRD, the Australian Law Reform Commission, the National Disability Insurance Agency, and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (among others) have recognised that supported decision making is key to enabling the autonomy of people with disability. Training in supported decision making for people with disability, their families and carers, and health professionals can help achieve this goal.



*"Supported decision making is key to enabling the autonomy of people with disability."*

# Supported Decision Making Project at the Office of the Public Advocate

Since Australia ratified the UNCRPD, the South Australian Office of the Public Advocate (OPA) has sought to enhance its understanding of supported decision making and how it operates. As part of the Living My Life Project, the OPA undertook the Supported Decision Making Project to understand the degree to which it could support clients to make decisions within current constraints. The project explored how supported decision making might operate within the OPA and within the strictures of existing legislation and resources. It was also imperative to consult with people with a guardianship order and their support people, and this was a key focus of the project.

The project had two primary objectives:

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- 1** To pilot supported decision making tools (in particular the document *My Life, My Wishes*) to test their effectiveness in documenting the will and preferences (wishes) of people with a guardianship order and their overall impact upon practice at the OPA; and
- 2** To explore how supported decision making practice at the OPA could be done within the current legal framework and staffing resources to inform future OPA work.

A funding extension was provided in 2023 to further test the resulting tool. This has enabled the OPA to embed the supported decision making tool into practice through training and implementation initiatives. This has led to 475 OPA clients now having a *My Life, My Wishes* record, which far exceeds the project target of 75 records.

Both objectives used the La Trobe Support for Decision-Making Framework (Bigby et al., 2019) as the theoretical and practical model to explore supported decision making practice.

## Recording wishes: *My Life, My Wishes* Document

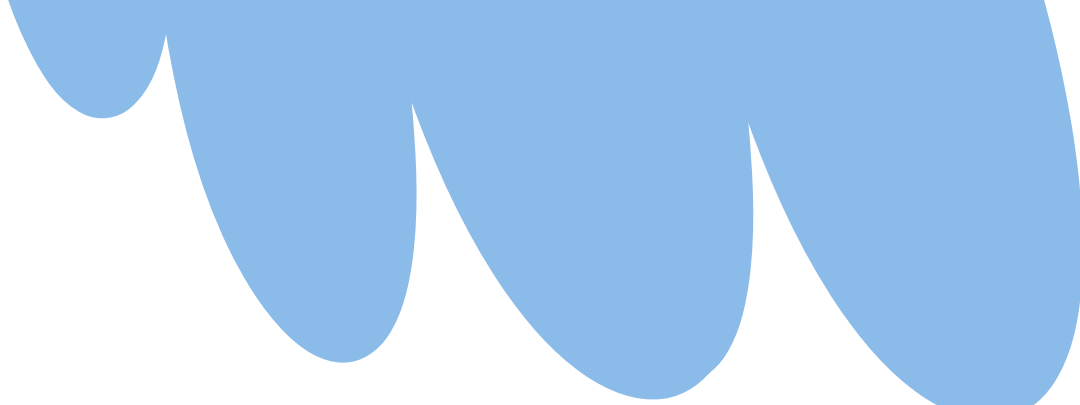
The *My Life, My Wishes* document was developed and piloted with 50 people with a guardianship order. The study found that the document was effective in recording wishes when staff adjusted their practice to the individual's needs, when other appropriate supporters were present and when there was sufficient time for document completion. Fundamental to this process was the client's ability to communicate their wishes, either through complex communication support and/or supporters (formal or informal) who knew them well.

The *My Life My Wishes* document was positively received by people with a guardianship order and their supporters. Most believed the document was useful in the collection of wishes and would be helpful in future decision making. Clients advised that the most important aspect of the research to them was the face-to-face visit by the OPA staff, and support from someone who knew them best. The supporters believed the most important aspect was the involvement of those who knew the person well.

The project also involved consultation with people with disability about broader community use of the *My Life, My Wishes* document. The outcomes were findings to assist community education, campaigns to raise awareness about the document and adjustments to make the document more accessible.

*"the most important aspect of the research to them was the face-to-face visit by the OPA staff, and support from someone who knew them best."*

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## Supported decision making practice at the OPA

While an effective tool for recording client's wishes, the *My Life, My Wishes* document does not replace real-time discussions with clients about important decisions when they need to be made. The OPA explored the extent to which it could implement supported decision making within the current legal framework and resources. It did this through staff training and piloting supported decision making practice.

Prior to commencement, it was assumed that the state's guardianship legislation would present a barrier to supported decision making. While the study confirmed this assumption, it also highlighted that legislative reform alone would be insufficient. Additional external systemic barriers can only be addressed through public policy reform and sector capacity building. Such reforms would support alternatives to guardianship and enable supported decision making to become a community best practice standard.

Staff capacity was another barrier due to the additional time required to undertake supported decision making. It was noted, however, that some internal operational and practice adjustments could assist the OPA to implement supported decision making without changes to resourcing or legislation.

OPA staff noted the limited literature and practice guidance around culturally appropriate approaches to supported decision making with Aboriginal people. The OPA has been successful in securing a Targeted Action Plan grant from the Department of Social Services to specifically research best practice in applying supported decision making for First Nations clients of OPA.

The OPA has now fully implemented *My Life My Wishes* into guardianship practice, aligning the OPA's practice more closely with supported decision making principles. There is now a greater focus on getting to know a person and their wishes to assist in decision making and encouraging the provision of decision support.

*"There is now a greater focus on getting to know a person and their wishes to assist in decision making and encouraging the provision of decision support."*



# Building capacity to practise supported decision making



The Living My Life Project included a program of activities aimed at building capacity within the healthcare sector to practise supported decision making. The project included developing and facilitating specialised supported decision making training to the Office of the Public Advocate, health professionals in acute health care settings (Royal Adelaide Hospital), specialist health services (South Australian Intellectual Disability Health Service), community-based health professionals (general practitioners) and four community mental health teams (including forensic mental health specialists). Specialist training was provided in person to specific groups, and more general information shared online via webinars. Feedback from the events was overwhelmingly positive and highlighted the importance of engaging frontline staff in the important work of culture change.

Given the strong imperative to build greater community knowledge about supported decision making, SAHMRI engaged Dr Michelle Browning, a nationally recognised supported decision making expert, to develop and lead supported decision making work as part of the Living My Life Project.

The resources developed through the project are accessible on an ongoing basis including five short videos and three e-learning modules. The videos are available to the public as well as health professionals, and cover the following topics:

- decision support as a human right,
- guardianship as a last resort,
- good decision-making processes,
- the experiences of a person with disability receiving support with decision making,
- and the experiences of a decision supporter.

The e-learning modules, housed on the Decision Agency website, are intended to facilitate ongoing capacity building across the health sector. They are designed to help decision supporters:

- understand the aims and intention of supported decision making
- explore their role in building the decision-making capability of others
- develop strategies to minimise their influence.

In addition to health professionals, disability advocates, behaviour support practitioners and informal supporters (such as family members) have registered to take advantage of the e-learning modules.

# Be Well Plan: Mental health and wellbeing training

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The transition to a supported decision making process and the barriers that individuals face as part of this change will inevitably influence the general mental health and wellbeing of everyone involved in the decision-making process. As such, it is important to ensure that these stakeholders are able to access services that can safeguard their mental health and wellbeing, both via dedicated services for individuals with disability, as well as via mainstream services that have been designed with the NDIS sector in mind.

As such, this component of the Living My Life Project aimed to assess the effectiveness and suitability of mainstream evidence-based mental health training services for the NDIS sector – specifically individuals who provide services to, or support (formally and informally) people on an NDIS plan – and to explore how the services can be made available to NDIS participants themselves. In this component of the project we:

1. conducted a literature review of psychological wellbeing interventions to determine which approaches to building wellbeing have been tested in populations with a disability, and as such 1) can be used to guide service users who wish to explore mainstream offerings themselves and 2) help inform developers who aim to build on the existing evidence base;
2. tested the impact of an existing universal wellbeing intervention called the Be Well Plan using an uncontrolled pre-post design, comparing change in scientifically validated mental health outcome measures for participants;
3. analysed qualitative feedback on the training from semi-structured interviews and focus groups, and summarised it in a narrative thematic analysis, exploring the suitability for service providers across the sector and determining which changes ought to be implemented to increase accessibility for individuals with a disability; and
4. conducted a co-design process to review what was needed to increase accessibility of the program in response to feedback from service providers who work with individuals with an intellectual disability. This included both a focus on the training and the integrated mental health measurement.

The literature review revealed that there are relatively few studies of interventions to improve the mental health of people with disability, although some of the existing research does suggest that such interventions can be effective.

Our study showed that the Be Well Plan was effective in improving mental wellbeing and decreasing stress and anxiety in a sample of the general population. Additionally, most participants felt engaged in and satisfied with the training and intended to continue using the techniques they had learned. Those who work with people with intellectual disability also felt that the training could be integrated into their work, but would need to be modified for some clients, with clearer explanations, more accessible materials and assistance to become familiar with the software.

SAHMRI staff worked with SACID to draft an easy read version of the Be Well Plan training and the draft was successfully trialled with a person with an intellectual disability from Tutti Arts, with extensive support from a trusted worker. SAHMRI also developed videos and an easy read activity booklet and is exploring further ways to make the content accessible for everyone. One of the next stages of this work is to develop a wellbeing measurement tool suitable for individuals with an intellectual disability.

The results of these activities allowed us to formulate recommendations for pragmatic changes that any mainstream provider can make to improve the accessibility of their services for individuals with a disability.

*"the Be Well Plan  
was effective in  
improving mental  
wellbeing and  
decreasing stress  
and anxiety"*

# Conclusion

The Living My Life Project has built understanding and capacity within the OPA, the SA Department for Health and Wellbeing and disability organisations in supported decision making and related concepts and processes.

Within the OPA, the *My Life, My Wishes* document has been refined, tested and now implemented with hundreds of people with a guardianship order so that their wishes can be understood and supported. OPA staff are now more aware of the time, processes and support people needed to implement supported decision making with their clients. They have identified gaps in their knowledge, such as how to provide culturally appropriate services to Aboriginal people under guardianship, and are working to address those gaps.

Training sessions with OPA and healthcare staff revealed that many staff are already committed to respecting autonomy and human rights, but need more information about how to implement supported decision making in their own context and within their time constraints. One barrier to implementing SDM that was found was high staff turnover. This suggests that it is important to have ongoing training opportunities readily available to new staff. As a result of this project, many SA Health professionals have received training in SDM, and webinars, videos and e-learning modules have been created and made available for the health sector and the public.

The third component of the study found that the Be Well Plan is effective in improving mental wellbeing and decreasing stress and anxiety in people without disability and is likely to be effective for people with disability, although it requires modification for some users. In other words, people with intellectual disability have the capacity to benefit from psychological health and resilience training, but they may need some support to do so. The project team developed easy read versions of the Be Well Plan workbooks and activity booklet, and filmed short training videos. SAHMRI is continuing to test the program with a variety of users, and some organisations who work with people with intellectual disability are delivering Be Well Plan training.

# Recommendations

## Recommendations for legislative reform

The OPA component of the Living My Life Project generated the following recommendations for reform of the Guardianship and Administration Act 1993 (SA).

1. The GAA should require that supported decision making options be exhausted before substitute decision making can occur.
2. The GAA should require that supported decision making practice informs substitute decision making practices.
3. Binary (yes or no) capacity assessments should be replaced with an assessment of decision support needs. Capacity should be recognised as decision specific, rather than by topic area, and be assessed when sufficient decision support is provided.
4. The GAA should include a principle that orders must be as specific as possible, with limited use of orders which confer broad decision-making authority.

## Recommendations for guardianship practice

5. Guidance for implementing supported decision making should enable risk by articulating high thresholds for risk and prioritising the person's wishes.

6. The GAA should be interpreted through a human rights lens, which could reduce SACAT orders. This could also reduce appointments of the Public Advocate as guardian where there are safe and effective informal or formal private alternatives.

## Recommendations for practice in health care

7. Practical training in supported decision making is required in the health sector in all areas and at all levels of each service.

8. Supported decision making principles and processes should be upheld even in the face of urgent external pressure (e.g. hospital discharge decisions).



## Recommendations for NDIS practice

9. The NDIS should fund the provision of decision support.

10. Positive psychology and resilience training should be integrated into service delivery for NDIS clients and made more accessible.

## Recommendations for training providers and developers

This project made it clear that there is a need for mainstream service providers to facilitate better access to services and opportunities for individuals on an NDIS plan. The following recommendations are intended for stakeholders who design, develop, deliver and implement mainstream mental health and wellbeing services. They include changes that mainstream service providers can make to increase the accessibility of existing offerings for people with disability, and considerations that developers need to make when designing new mainstream services or programs.

11. When a service enrolls a new client, the client should have the option to indicate that they need a support person whenever they engage with the service, they need extra assistance from staff of the service, or they need auditory or visual support or modified materials.

12. Ensure all venues are accessible, for example with wheelchair access.

13. When delivering online sessions, make sure a person with a disability is always accompanied by a support person if required.

14. If needed, additional time should be scheduled at the beginning and end of sessions and at regular intervals to ensure clients are comfortable and able to follow the material. Also consider breaking up training into shorter sessions.

15. Prepare different versions of documents for different audiences, such as some with less content, easy read versions, and documents that are suitable for those with vision impairment.

16. Keep the language and content (of documents and of training sessions) as clear as possible. Use examples to clarify difficult concepts.

17. If a program includes measures (e.g. of mental wellbeing), consider whether they are accessible and valid for all people with disability, and whether a support person is needed.

18. Test all documents and programs with people with disability, even if people with disability are not the primary intended audience.

19. When piloting programs (e.g. in a workplace), ask for people with a disability to be included to ensure you get adequate feedback on the content and implementation of the program.



# 1. Introduction


## About this project

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The Living My Life Project was conducted by the South Australian Health and Medical Research Institute (SAHMRI) Wellbeing and Resilience Centre in partnership with the South Australian Office of the Public Advocate (OPA) and the SA Department for Health and Wellbeing. The aim was to build on the current delivery of accessible and inclusive services in mainstream service systems to meet the needs of people with disability and their families/carers, with a focus on applying supported decision making principles and building wellbeing and resilience. An overarching goal was to increase the capacity of people with psychosocial disability to access employment opportunities and achieve life goals. The project involved a number of activities to support people with psychosocial disability and those with impaired decision-making capacity who are at risk of not being able to express and realise their life goals and exercise choice and control.

This report describes and discusses the three main components of the Living My Life Project:

- 1** The project explored how supported decision making might operate within the South Australian Office of the Public Advocate (OPA). This included piloting supported decision making tools to test their effectiveness in documenting the will and preferences (wishes) of people with a guardianship order.
- 2** The project developed and facilitated specialised supported decision making training to the Office of the Public Advocate, health professionals in acute health care settings (Royal Adelaide Hospital), specialist health services (South Australian Intellectual Disability Health Service), community-based health professionals (general practitioners) and four community mental health teams (including forensic mental health specialists). Specialist training was provided in person to specific groups, and more general information shared online via webinars. The resources developed through the project are accessible on an ongoing basis including five introductory videos and three e-learning modules.
- 3** SAHMRI offered 'Be Well' mental health and wellbeing training via Be Well Co to project participants and their families and investigated the feasibility and effectiveness of offering the training to participants of the National Disability Insurance Scheme (NDIS).

The background of the page features a teal color with white, wavy, organic shapes that create a sense of movement and depth. These shapes are layered, with some appearing as if they are floating or flowing over others. On the right side, there are several dark teal, brush-stroke-like marks that add a textured, artistic feel to the design.

The project was funded by the National Disability Insurance Agency through an Information, Linkages and Capacity Building grant awarded in 2020. The NDIS aims to uphold the rights of people with disability through individualised funded plans. It aims to provide people with disability with more choice and control over the support services they receive from mainstream service providers. Supported decision making, where individuals are placed at the centre of the decision-making process, is fundamental to providing agency to individuals on a NDIS plan.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognises that approaches such as supported decision making practices, which set out to empower individuals, are needed to enable people with disabilities to maintain more choice and control over their lives, and achieve their goals and aspirations. This empowerment, while positive, does bring challenges as, for example, ‘people with cognitive disabilities simply do not possess the type of social capital needed to take advantage of opportunities for decision making in individualised systems’ (Bigby & Douglas, 2020, p. 47; see also O’Connor, 2014).

The Living My Life Project set out to build the capacity of individuals with disabilities and impaired decision-making capacity under the guardianship of the Public Advocate. It aimed to assist them to express and obtain their life goals, including future healthcare wishes, using supported decision making practices. It also aimed to build the capacity of professionals who work with individuals with impaired decision-making capacity so that they can support their clients to make decisions about their lives.

# A Personal Experience


The Living My Life overarching project lead, Jan McConchie, is the mother of a son in his mid-30s who lives with Down Syndrome called Eddie. Eddie has never had an IQ test because his mother, a single mother, refused to have him classified in that way. That being said, he is unable to read and it requires time to be clear about what he is saying. Gaining access to his thinking is challenging.

As with a lot of people with Down Syndrome, on becoming an adult, Eddie experienced weight management difficulty, which really affected him. When he became depressed in his early 20s, after realising that life was not going to be as he assumed, that he wasn't going to be able to do the things his big brother did, he became passive but not completely helpless. He found a way to lose weight by vomiting. This became anorexia. He became dangerously thin and continued to struggle with sadness.

His mother approached the Department of Health Eating Disorder Unit, who told her in no uncertain terms that he would not be accepted as a patient as he would not have the capacity to understand the cognitive behaviour interventions part of the program. This was said without a consult and purely based on him having Down Syndrome.



Above: Eddie Jenkinson at Inform Health and Fitness Solutions




His mother persisted with many other approaches, including working with a psychologist who did choose to work with people living with a cognitive disability. It quickly became evident that he was able to understand and work with a cognitive behaviour self-management plan. Once this psychological work was put together with a mainstream – but developed by a smart exercise physiologist – program to help him develop his fitness to experience the self-esteem that flows from it, he had a way to work back to health. It wasn't fast but it was successful.

His mother saw that the combination of psychological and physical exercises worked for him in much the same way as it did for her when she worked on her own resilience to navigate her life. In the decade that followed she saw that he retained the skills he learnt and continued to use them constructively in his life, even though he was living separately from his mother and not always being treated as someone who could manage himself in an independent way. He just sorted out how to manage those people, rather than the other way around.

It is important to note that these experiences occurred some 10 years prior to this project and, while vivid in Eddie's mother's memory, should not be taken as representative of the situation in the South Australian health system either now or even then. What they do exemplify, though, is the challenge that people with a disability have in accessing mainstream services, making it a powerful story to underpin a project that aims to improve accessibility of mainstream wellbeing services for individuals with a disability.

*"In the decade that followed she saw that he retained the skills he learnt and continued to use them constructively in his life"*




# Supported Decision Making

Supported decision making is the process of assisting people to make their own decisions and direct their own lives. It is a practical and legal alternative to substitute decision making, where others make decisions on behalf of a person.

At different times, we all need assistance to make decisions. For many of us receiving good decision support gives us greater confidence that we have successfully weighed up our options and made the right decision. But for many people with disability, good decision support enables their fundamental human rights to autonomy, self-determination and recognition of legal capacity (Browning et al., 2021). Supported decision making is necessary to ensure people with disability have access to information, services and products in a way that suits their needs (Disability Royal Commission, 2023, vol. 6, p. 9). It also helps people work out how they can minimise risks and protect themselves from harm (Bonyhady & Paul, 2023, p. 104).

Supported decision making is an important practice needed to help overcome the systemic neglect and discrimination people with disability experience in the healthcare system in Australia (Disability Royal Commission, 2023, vol. 6, p. 10). Developing the ability of healthcare professionals to provide supported decision making is central to realising the right to equitable access to health care for people with disability (Disability Royal Commission, 2023, vol. 4, Recommendation 4.9(d)).

The page features several teal-colored abstract shapes. A large, irregular shape occupies the bottom right, containing a quote. To its left, a smaller, more circular shape is positioned. A thin, wavy line extends from the left edge of the page towards the bottom right, ending near the large teal shape.

*"Supported decision making is an important practice needed to help overcome the systemic neglect and discrimination people with disability experience in the healthcare system in Australia"*

## History in Canada

Supported decision making has its origins in Canada in the early 1990s. It developed with two important aims: to support people to be self-determining citizens, and to remove the legal barriers created by issues of incompetency which prevented people with intellectual disabilities from receiving individualised funding (Bach, 1998). Supported decision making was developed as a legal alternative to guardianship and formal forms of substitute decision making. Family members of people with significant intellectual disabilities objected to the removal of the legal right of adults with disabilities to make decisions through the appointment of guardians and financial administrators (Gordon, 2000).

*"the road to  
self-determination  
is rarely travelled in  
solitude"*

A parent leader, Audrey Cole, who advocated for legislative reform in Canada, stood before the Ontario Parliamentary Standing Committee on Administration of Justice on 12 February 1992 and explained the imperative for supported decision making in the following way:

*When we start by assuming that certain people are unable to exercise their right to self-determination because of their incapacity, we inevitably look for solutions in the appointment of others to make decisions for them. Mindful of the intrusiveness of that process, we seek to temper it by imposing the least restrictive of a known series of alternatives, such as full or limited guardianship, all of which take away rights to some degree or other.*

*Had we asked how decisions are made rather than who decides, we would perhaps have recognized that the road to self-determination is rarely travelled in solitude. Typically, we make that journey interdependently, in the company of those who care about us. It is not usual for us to make decisions alone and unaided. We make decisions with the affection and support of people we trust – family, friends and others whose opinions we respect. When we enjoy the presumption of competence or capacity, we are never asked to reveal that we had support in making our decisions, nor are we required to prove our capacity to make them independently. To subject others to such requirements on the basis of disability is discriminatory.*



*Had we not concentrated on who decides, we would have seen the need to provide for everyone the same opportunities for support in decision-making that most of us take for granted. In the spirit of equality, we would have recognized the need to validate decisions resulting from such support in the name of the person at the centre of it. Perhaps then we would have looked for the most enabling solutions in an infinite and untapped reservoir of alternatives for empowering those of us who are disadvantaged. Rather than competence, we would have been thinking about accommodation. (Ontario, Legislative Assembly, 1992)*

Supported decision making is based on a set of principles which challenge the long-held belief that personal autonomy can only be expressed independently. It seeks recognition of the interdependent nature of decision making by challenging legal definitions of capacity that cast decision making as primarily a cognitive, rational and independent process (Browning et al., 2014).



## Context in Australia



The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) heard that people with disability face many barriers to being able to exercise their autonomy. These barriers include:

- being unable to access essential information or to communicate effectively because of an absence of reasonable adjustments
- a lack of support for decision making
- not having access to an independent advocate
- systemic neglect and discrimination in the healthcare system
- the overuse of restrictive practices against people with disability (Disability Royal Commission, 2023, vol. 6, p. 10).


These barriers to autonomy can create systemic neglect and make worse the violence, abuse and exploitation experienced by people with disability. The Disability Royal Commission recognised that supported decision making is key to enabling the autonomy of people with disability. The Commissioners reflected:

*Some people with disability are denied the right to make big or even everyday decisions about their lives. What is referred to as ‘substitute decision-making’ can prevent people with disability from exercising their autonomy. Substitute decision-making is decision-making by someone on behalf of another person. It takes place because a person is considered to lack capacity to make decisions themselves. Substitute decisions can be made on personal, financial, property and health matters. People with cognitive or psychosocial disability are disproportionately affected by substitute decision-making. (Disability Royal Commission, 2023, Executive Summary, p. 70)*

The Disability Royal Commission recommended that community attitudes, policies and practice need to better recognise and enable supported decision making (Recommendations 6.13–6.14), and guardianship and administration laws need to be reformed to embed the practice (Recommendations 6.4–6.15).

The evidence put before the Disability Royal Commission demonstrated that people with cognitive disability are subject to systemic neglect in the Australian health system. Health services are not designed for people with disability and health workers do not have sufficient disability knowledge and skills. To change this, we must build the capability of the health workforce to understand and respond to the diverse needs of people with disability (Disability Royal Commission, 2023, vol. 6, p. 321).

One important need is the provision of clear, timely and accessible information and communications, as they can help safeguard people with disability against violence, abuse, neglect and exploitation (Disability Royal Commission, 2023, vol. 6, p. 40). Without appropriate access to support, people are unable to share their views and preferences in conversations on matters that affect them. The Disability Royal Commission recognised people with disability must receive support to be able to access information (Recommendation 6.1), communication (Recommendation 6.32), support for decision making (Recommendation 6.6), health care (Recommendation 4.9), justice (Recommendation 11.11), advocacy (Recommendations 6.21 and 6.15), the services they want from providers (Recommendation 10.6) and alternatives to restrictive practices (Recommendation 6.35).



In addition to the Disability Royal Commission, an independent review into the National Disability Insurance Scheme occurred in Australia in 2023. The review identified similar concerns regarding people with disability not having the support they need to access information and make informed decisions:

*We have identified challenges around access to support for decision-making, including lack of accessible information to inform decision-making, limited opportunities for people to develop decision-making skills, lack of appropriate support for decision-making (including independent support and access to trained decision-supporters), and nominees who do not have clarity about their roles and responsibilities or sufficient knowledge to support participants to be involved in decision-making. (Bonyhady & Paul, 2023, p. 108)*

The NDIS Review panel recommended people with disability and their supporters should be provided with access to high-quality information and training to support them in their roles as decision makers and supporters. This would help NDIS participants access higher quality support for decision making and reduce substitute decision making (Bonyhady & Paul, 2023, p. 112).

## 2. Supported Decision Making Project in the Office of the Public Advocate

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### Setting the Scene

The South Australian Public Advocate is an independent statutory officer empowered by the *Guardianship and Administration Act 1993 (SA)* (GAA) as a guardian when appointed by the South Australian Civil and Administrative Tribunal (SACAT). The Public Advocate is only appointed as guardian if no other suitable person is willing and able to take on this role for the client.

The Public Advocate, and OPA staff acting under delegation of the Public Advocate, must consider the principles in section 5 of the GAA when making decisions about a person with a guardianship order. These are:

### 5 – Principles to be observed

Where a guardian, an administrator, the Public Advocate, the Tribunal or any court or other person, body or authority makes any decision or order in relation to a person or a person's estate pursuant to this Act or pursuant to powers conferred by or under this Act –

(a) consideration (and this will be the paramount consideration) must be given to what would, in the opinion of the decision maker, be the wishes of the person in the matter if he or she were not mentally incapacitated, but only so far as there is reasonably ascertainable evidence on which to base such an opinion; and

(b) the present wishes of the person should, unless it is not possible or reasonably practicable to do so, be sought in respect of the matter and consideration must be given to those wishes; and

(c) consideration must, in the case of the making or affirming of a guardianship or administration order, be given to the adequacy of existing informal arrangements for the care of the person or the management of his or her financial affairs and to the desirability of not disturbing those arrangements; and

(d) the decision or order made must be the one that is the least restrictive of the person's rights and personal autonomy as is consistent with his or her proper care and protection.

Further, the Public Advocate has an important role in protecting the rights of South Australians with a disability generally and has long advocated the alignment of South Australian laws and practices with supported decision making.

Since Australia ratified the UNCRPD, the South Australian Office of the Public Advocate (OPA) has sought to enhance its understanding of supported decision making and how it operates. The OPA has conducted multiple supported decision making projects within the bounds of legal guardianship over several years. One difficulty with these projects has been that supported decision making is technically at odds with the substitute decision making model of guardianship under the *Guardianship and Administration Act 1993 (SA) (GAA)*.

Noting this as a barrier, the OPA undertook the Supported Decision Making Project (as one component of the Living My Life Project) to understand the degree to which it could support clients to make decisions within current constraints. The project explored how supported decision making might operate within the OPA and within the strictures of existing legislation and resources. It was also imperative to consult with people with a guardianship order and their support people, and this was a key focus of the project.

The project had two primary objectives:

1. to pilot supported decision making tools to test their effectiveness in documenting the will and preferences (wishes) of people with a guardianship order and their overall impact upon practice at the OPA; and
2. to explore how supported decision making practice at the OPA could be done within the current legal framework and staffing resources to inform future OPA work.

Both objectives used the La Trobe Support for Decision-Making Framework (Bigby et al., 2019) as the theoretical and practical model to explore supported decision making practice.

A funding extension was provided in 2023 to further test the resulting tool. This has enabled the OPA to embed the supported decision making tool into practice through training and implementation initiatives. This has led to 475 OPA clients now having a *My Life, My Wishes* record, which far exceeds the project target of 75 records.

The purpose of this project was therefore to explore pragmatic ways to implement supported decision making without the need for legislative or resource changes. It also piloted practical support for people with impaired decision-making ability to record their wishes.

# My Life, My Wishes Project

## Purpose

The My Life, My Wishes project involved people with a guardianship order communicating and formally recording their wishes for use in future decision making at the OPA. The study also offered an opportunity to support the development of non-statutory directives completed by people who lack decision-making capacity. This imperative followed the review of the *South Australian Advance Care Directives Act 2013* (see SA Health, 2020), which currently excludes people who lack decision-making capacity from recording their wishes in an Advance Care Directive for use in future decision making.

The project considered how using the My Life, My Wishes document impacted OPA's goal of aligning its practice with supported decision making principles, within the constraints of the *Guardianship and Administration Act 1993*.

## Approach

An action research approach was used to ensure learnings were incorporated into the document throughout the research. The aim was to conclude with a product which could be realistically adopted by the OPA within the current legislative and resourcing context.

The project consisted of the following activities:

1. Develop a purpose-built document (My Life, My Wishes), in consultation with end users.
2. Pilot the use of My Life, My Wishes directly with 50 people with a guardianship order and their supporters.
3. Seek feedback from people with a guardianship order and their supporters on the experience of using My Life My Wishes.
4. Undertake external consultation about community use of the My Life, My Wishes document with people with disability and their supporters.
5. Explore the impact of the My Life, My Wishes document on supported decision making practice at the OPA.



The study used the La Trobe Support for Decision-Making Framework (Figure 1) as the theoretical practice model to train staff and explore supported decision making practice. This framework provides a practical stepped approach, guided by principles and strategies. Given the framework was primarily developed for disability support workers and professionals, the OPA made some adaptations. This included removing Step 5: 'Consider if a formal process is needed', as the OPA is already formally involved in decision making with people with a guardianship order.

### Participant criteria

The criteria for selecting clients with a guardianship order to participate in the project were:

- under the sole or joint guardianship of the Public Advocate, and
- a National Disability Insurance Scheme (NDIS) participant or a client eligible for the scheme.

### Developing My Life, My Wishes

The My Life, My Wishes document was based on two existing documents:

- My Story form developed by the Northern Territory Government, Health and Community Services Complaints Commission
- My Life Decisions<sup>1</sup> form developed by Margaret Brown (Adjunct Research Fellow, University of South Australia) in collaboration with the OPA (see Appendix 16).

The My Life, My Wishes form built upon and combined elements of both forms. The My Life, My Wishes document aligns with Steps 1 and 2 of the La Trobe Support for Decision-Making Framework (Bigby et al., 2019): 'Getting to know the person' and 'Understand the person's will and preference in relation to the decision'. It differs from the La Trobe model, however, to the extent that this model requires direct support for the person to make their own decision on each occasion a decision is needed.



Figure 1: The La Trobe Support for Decision-Making Framework (Bigby et al., 2019)

<sup>1</sup> My Life Decisions is licensed under a Creative Commons License and was developed by Margaret Brown and the Documenting My Life Decisions Committee.



## South Australia Council on Intellectual Disability Consultation

Prior to commencing the study, the OPA engaged the South Australian Council on Intellectual Disability (SACID) to gain feedback on the document from people with intellectual disability. Consultation was undertaken with six inclusion workers who have an intellectual disability. Feedback included:

- Essential amendments to the document and its format are:
  - provide an easy read option,
  - break down questions from broadly asking 'tell your story', to specific answerable questions,
  - include tick-box options along with space to write or draw information,
  - add explanatory information about:
    - why the questions are asked,
    - what the information will be used for,
    - how it will be kept private, and
    - available support to complete the document and for future decision making
  - clarify that the person can choose not to answer any question, and
  - consider whether the document should also collect information about the person's finances.
- Important characteristics, values and practices that are needed from decision supporters when asking people with disability to complete the form are:
  - recognise the importance of relationship building and spend time doing this (see Outcome 5).
  - only collect information that will be used (see Outcome 2).
  - provide emotional support (see Finding 2).
  - regularly update the form (see Finding 2) (SACID, 2021).

## Updated Document

The OPA used the SACID feedback and early project observations (OPA, 2021) to broaden the scope of the *My Life, My Wishes* document to record a person's wishes about all guardianship authority areas. These are accommodation, health, services, access and restrictive practices. It was also updated to include principles of supported decision making, including:

- elements of 'knowing a person' (Bigby et al., 2019)
- decision support needs
- communication needs
- a direction to consult the person when decisions are needed
- the ability for the person to self-complete the document to the greatest extent possible.

Significant duplication between the *My Life, My Wishes* document and internal OPA client documents was identified. As a result, adjustments were made to create a single document that built on the end-of-life planning components of the *My Life Decisions* form and included supported decision making principles.

## Outcome 1:

*My Life, My Wishes* replaced *My Life Decisions* and all OPA internal client documents.

Existing OPA internal client documents (client summary, screening summary, visit record) and the *My Life Decisions* form were combined and replaced with a single *My Life, My Wishes* document to better record the wishes of people with a guardianship order. This has the dual benefit of improving efficiency and the experience of the person with a guardianship order and their supporter. Other procedural efficiencies can be considered at future implementation stages.

### Contextual information

Further adjustments were made to the document following 10 initial pilot visits to include context alongside the person's wishes in each guardianship authority area. In practice, the collection of wishes in the *My Life, My Wishes* document was not useful without individualised context, which makes it easier for supporters to enact the person's wishes or decisions. Without this information, the final step of the La Trobe Framework 'Implementing the decision ...' was not practicable.

*Decision supporters need to be respectful of the person and the information they give. If decision supporters are asking for this information, then they need to make sure they use it. (SACID, 2021, pp. 3–4)*

Context is also important in maintaining a trauma-informed practice, navigating legally enforced restrictions (e.g. orders of the criminal/family court), and validating information provided by the person with a guardianship order.

*I do think there should be space for support people to add information. Some customers' wishes may be unrealistic and, due to lack of capacity, they can't see it. Sometimes extra information from support people could give extra context. This may need to be done separately. (Supporter and Senior Care Coordinator, ID:20)*

Context is essential for wish implementation, maintaining a 'do no harm' approach to interacting with people with a guardianship order, and managing risk. Factual situational information is included alongside wishes to provide a full description of a client's circumstances and to enable decision support.

## Outcome 2:

The OPA has implemented a client profile document that records contextual information integral to knowing the person, their wishes and their decision needs to accompany the *My Life, My Wishes* document.

## Study observations

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### How long it took

The time taken to complete the document at the first attempt was measured, noting that time varied for follow-up attempts or updates. Time taken was measured in four components:

1. preparation (excluding travel and scheduling)
2. interview
3. follow-up
4. administration.

The document took an average of 3.76 hours to complete at the first attempt, inclusive of those instances where the OPA was unable to attempt completion at the visit. These instances occurred on a total of eight out of 50 occasions, with reasons summarised below:

1. A support person was required and not present.
2. The client rejected the OPA staff as an interviewer at the time.
3. The client declined to participate.
4. The client had an extreme objection to the guardianship order.
5. The client was extremely verbally aggressive.
6. The client threatened the safety of OPA staff.
7. The client did not attend.

The resources required to respond to these circumstances were greater than for other clients due to the need to secure collateral information and organise a follow-up.

## Barriers

The barriers to completion of the *My Life, My Wishes* document were identified and grouped under the following themes:

- capacity of the person with a guardianship order
- sensitivity or lack of readiness to discuss end of life
- person with a guardianship order objected to guardianship orders, had behavioural issues or was reluctant to engage
- supporter complexity, e.g. conflict, crisis, burnout, undue influence
- support gaps.

### Capacity of the person with a guardianship order.

The capacity of the person with a guardianship order was the most prevalent barrier. The lower the cognitive capacity of the person, the more complex it was to ascertain their wishes and personal history. This resulted in more time required for follow-up and a higher chance of needing additional visits. This occurred more frequently when there was a lack of support people, or agencies lacked relevant knowledge and rapport with the client to support the completion of the document at the initial visit.

### End-of-life wishes.

The next most common barrier was the person's unwillingness to discuss end-of-life wishes at the initial attempt. In many cases, the project visit was the first occasion the person had been confronted with the notion of end-of-life planning. They required either more time or many discussions with a person of their preference to formulate their wishes in this area. However, this was not an option for people with no trusted supporters (informal or formal). It instead fell to the skill of the OPA staff to discuss end-of-life planning options and to sensitively navigate this topic with a person with impaired decision-making capacity and complex communication needs.

### Outcome 3:

OPA staff have been trained in end-of-life planning discussions with vulnerable people and how to navigate associated documents.

#### Objection to orders and behavioural presentation.

Completion of the *My Life, My Wishes* document was challenging when people with a guardianship order held strong objections to the guardianship orders or presented with significant verbal and physical aggression. In these cases, collateral information from those who knew the person well was essential, including from support providers who had built rapport with the client over time.

#### Supporter and case complexity.

Case complexity can be present in many forms. However, of most relevance to the completion of the *My Life, My Wishes* document was 'supporter complexity'. This included supporters who were essential to the person's ability to communicate their wishes, but who were causing issues (e.g. unduly influencing the person with a guardianship order, in conflict with other supporters, thwarting access to the person, or highly distressed or burnt out). In these instances, both the neutral perspective of OPA staff and provision of a safe environment for the person with a guardianship order to express themselves freely were imperative.

#### Support gaps.

The support needs of clients were identified and themed as follows:

- communication assistance
- needing a support person who knows them well
- needing rapport with a support person.

The client's ability to express their wishes was fundamental to the project. The primary barrier was the absence of appropriate communication support, rather than the presence of a complex communication need. When appropriate communication support was provided, the client was able to express their wishes in most cases. While communication needs complicate the process, they should not exclude a person from being directly consulted on their wishes.

Noting, or determining, a person to be 'non-verbal' or 'unable to express wishes' is consistent with the principles of the GAA; however, it is inconsistent with the La Trobe Framework strategy 'attention to communication' (Bigby et al., 2019). Guardians should prioritise addressing clients' communication needs, such as identifying gaps in the OPA's knowledge of the client and requesting proper assessment and/or appropriate service provision to facilitate communication. This may include training staff about the broad range of communication needs and available support options. This is particularly important in circumstances of severe and profound disability.

#### Outcome 4:

The OPA staff now better understand the individual communication needs of people with a guardianship order when using the *My Life, My Wishes* tool and in any future decision support.

Someone who knows the person well enough to provide information about their personal history and current needs, and has rapport with them, is pivotal to the OPA's dealings with people with a guardianship order. The OPA has limited resources, which means staff have limited time to gain this knowledge and rapport. Consequently, the OPA should prioritise the fostering and maintenance of external 'good support relationships'. Without such relationships, the client is largely unable to communicate their wishes effectively or be supported to make their own decisions.

"Acknowledging and respecting the importance of contributions from constructive supporters is pivotal to the effective completion of the *My Life, My Wishes* document."

*Relationship building is really important; it will help people to feel comfortable answering the questions. Decision supporters should spend some time with the person before asking them to complete this form. (SACID, 2021, p. 3)*

Facilitating multiple parties to spend time with a client to assist in understanding their wishes and supporting them to make their own decisions is called 'orchestration', and it is a key principle of the La Trobe Framework. Acknowledging and respecting the importance of contributions from constructive supporters is pivotal to the effective completion of the *My Life, My Wishes* document.

This helps OPA to know [ID:16]. Can you imagine someone not knowing [ID:16] making decisions for her? Family know her best but OPA filling out [the form] prevents the risk of unknown abuse. (Supporter and family member, ID:21)

If you have good, consistent staff who know the residents, this makes a big difference and people can be supported to make decisions. Best to have a meeting at the time the decision is needed with managers and GPs. (Supporter and accommodation team leader, ID:23)



## Outcome 5:

The OPA now aims to foster 'good support relationships' for people with a guardianship order including engagement with supporters.

## Factors that enable supported decision making

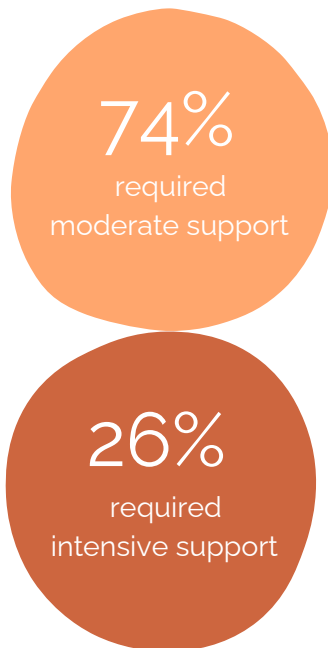
### Essential resources.

For people with a guardianship order to successfully complete the My Life, My Wishes document, what they needed most was support. There were no instances where the person with a guardianship order was able to complete the document independently. During the study, 74% of participants required a moderate level of support, and 26% required intensive support to complete the My Life, My Wishes document.

Social workers or other staff skilled in engaging vulnerable people with challenging behaviour, and who understand the purpose of the My Life, My Wishes document, were also required to ensure completion from a neutral, unbiased perspective.

Thirdly, it was important to ensure there was sufficient time that was specifically allotted to complete each of the following steps:

- Guardian preparation:
  - file review
  - gather collateral information
  - ascertain interested parties required at the interview
  - ascertain client communication requirements (interpreter, complex communication support, augmented communication tools)
  - visit scheduling and arranging.
- Interview with client:
  - face-to-face interview
  - travel time.
- Guardian follow-up:
  - confirming/clarifying information with supporters
  - seeking additional information required to fill gaps in knowledge about the client following the interview
  - responding to safety/welfare concerns, including completing internal escalations as required.
- Guardian administration:
  - completion of documentation related to the client interview (file notes, etc.)
  - finalising electronic version of notes
  - uploading document onto the client record system.



**Finding 1:**  
Skilled staff/supporters require the allocation of sufficient time to assist people with a guardianship order to complete the *My Life, My Wishes* document.

**Additional supportive factors.**

In addition to the essential resources, the following factors (in order of prevalence) assisted in completion of the *My Life, My Wishes* document:

1. a face-to-face interview
2. a support person/agency possessing comprehensive knowledge of the client's current needs
3. a support person/agency possessing comprehensive knowledge of the client's personal history
4. a supporter who had rapport with the client
5. provision of communication support
6. provision of behaviour support
7. the client's own home and paraphernalia
8. a repeat visit by OPA staff
9. an easy read document
10. a pictorial document.

For clients with severe and profound disability, OPA found that it could only gather their wishes by using supporters, individualised communication and behaviour support, and face-to-face interviews. The face-to-face interview enabled supporters to observe subtle elements of a person's circumstances or presentation, which would not have been identifiable by a phone or virtual meeting.

OPA also found that these clients needed a lot of time for staff to build rapport and familiarity with their complex communication needs.

*Unless you meet the person you will have no idea about anything, no matter what you wrote on a form.*  
(Supporter and family member, ID:26)

*See Outcome 4 regarding addressing communication needs and Outcome 5 regarding fostering and maintaining 'good support relationships' for people with a guardianship order.)*

**Aboriginal and Torres Strait Islander considerations**

Of the study participants, 46% identified as Aboriginal. The limited availability of service options specifically for Aboriginal clients, including support to assist clients with information about their own cultural background and family members, posed specific barriers for this group.

*For some communities, people first needed help to achieve their cultural identity before being able to exercise their will, preferences and rights.*  
(Supporter, ID:1)

Further, no avenues existed for OPA staff to seek cultural advice to navigate complex issues, such as end-of-life discussions.

The most prevalent enabler for this group was OPA staff's experience in engaging with vulnerable people with complex needs. This may be explained by the lack of supporters who had rapport with the person at face-to-face interviews, which resulted in the guardian managing this independently at the visit. Overall, however, the most prevalent enablers for this group aligned with enablers 1–3 listed above.

In 2022, the OPA was successful in securing a grant from the federal Department of Social Services (DSS) in order to explore culturally appropriate use of *My Life My Wishes* with First Nations clients. The project work, which aligned with the DSS Targeted Action Plan grants program to further Australia's Disability Strategy, was conducted during 2023 and 2024.

## Outcome 6:

The My Life, My Wishes document is now being piloted as part of a new project in consultation with Aboriginal and Torres Strait Islander people and community representatives.

## Project outcomes

The study demonstrated that the My Life, My Wishes document can be an effective tool for collecting the will and preferences of people with a guardianship order. It should not, however, replace point-in-time discussions with clients about important decisions when they need to be made.

Both participants and supporters provided positive feedback. Most participants reported the document helped them record their wishes, and the majority of supporters believed it would assist in future decision support. The overall findings aligned with the principles and strategies of the La Trobe Framework.

## Impact on supported decision making at the OPA

The My Life, My Wishes document aligns with Steps 1 and 2 of the La Trobe Support for Decision-Making Framework: 'Getting to know the person' and 'Understand the person's will and preference in relation to the decision'. It differs from the La Trobe model, however, to the extent that the La Trobe model requires direct support for the person to make their own decision on each occasion a decision is needed.

*You have given [ID:8] self-respect by not taking everything away from him but showing him he is still capable of making decisions in some areas. Because OPA helped [ID:8] think about all the areas of his life. OPA listened with no judgement and understood that all context is important. (Supporter and family member, ID:19)*



The My Life, My Wishes document should be built on over time and used in conjunction with client consultation when important decisions need to be made. It therefore differs from an Advance Care Directive, which records a person's wishes at a point in time and those wishes are later enacted through a substitute decision process.

*It is important that this information isn't relied on for many years without updating. People change! (SACID, 2021, p. 4)*

Guardians should add to the My Life, My Wishes document over time to account for fluctuations in capacity, the client's changing views and systemic changes.

Strategies from the La Trobe Framework that assisted clients and supporters to complete the My Life, My Wishes document included:

- 'attention to communication'
- 'creating opportunities'
- 'breaking things down'.

Principles of the La Trobe Framework that assisted with document completion included:

- 'commitment to rights'
- 'orchestration'.

These principles require guardians to actively seek the views of people with a guardianship order, explain their rights at a visit, and invite the best-placed supporters to assist with completion of the document.

The success of the My Life, My Wishes document as an assistive tool to support people to record their own wishes varied. In some cases, the easy-read picture elements and transparent recording mode enabled high levels of participation by the client. However, in other cases, these impeded an effective interview, particularly with people who had behavioural or communication complexities. At times, the document caused some behavioural escalation and was, therefore, not used with the person at all. In such instances, the staff's ability to adapt their approaches to the individual needs of the person was more important than the document itself. Here, the document acted as a prompt for completing the information on the person's behalf following the interview.

*There should be some consideration to what emotional support could be provided to people with disability to completing this form. Telling their story could bring up some past trauma or emotions so they need to know where they can go for support if they need it. (SACID, 2021, p. 4)*

## Finding 2:

*My Life, My Wishes* should be enhanced over time, include individual adaptations, be regularly updated and encourage ongoing provision of decision-specific support.

### Participant feedback

The participants (clients with a guardianship order) were asked if they were willing to provide feedback on the *My Life, My Wishes* document following the interview. There were 13 respondents (62% Aboriginal). The participants were asked: 'Who would you like to help you complete the *My Life, My Wishes* document?' The top three responses were (with some clients saying more than one):

- a person who knows me best: 61%
- family/carer (unpaid): 30%
- OPA staff member: 24%.

77% of participants reported that the *My Life, My Wishes* document helped their supporters get to know them better. They also said the document helped both them and their supporters to better understand their wishes. 54% reported the *My Life, My Wishes* document would help them make a decision in the future in the following ways:

- Helps me start to plan for future decisions.
- Encourages me to start to think about what I want.
- Helps me to organise and remember my thoughts.

69% think the document will assist their supporters to help them make decisions:

- My supporters will know what I want if they have to make a decision for me.
- My supporters will know what I am aiming for.
- It will help my supporters know me better.

When the participants were asked 'What do you like about the document?', their replies included:

- a visit from OPA
- completing the document together
- being asked about me
- being asked about my wishes.

The participants told us:

*Help to remember and especially if something happened to Cathy [sister], who organised all life parts.*

*I am happy you came out to see me.*

*I liked it. Thanks for visiting.*

We asked: 'What would make the *My Life, My Wishes* document better?', and the participants replied:

- 'Shorter'
- 'Some questions I don't know how to answer.'

We then asked: 'What else do you need to help you make decisions?' In order of frequency, the participants answered:

1. someone who knows me well
2. help with ideas
3. someone to talk to
4. discussion when a decision is needed
5. someone I trust
6. someone to explain the options
7. support to learn more about how to make decisions.

## Supporter feedback

Supporters were asked if they were willing to provide feedback on the My Life, My Wishes document following an interview with the person with a guardianship order. There were 11 respondents who had assisted with interviews in the following roles:

- carers, e.g. foster parent
- support worker
- Care Coordinator/Accommodation Team Leader
- NDIS Specialist/Support Coordinator
- family member.

All respondents reported the My Life, My Wishes document would help people with a guardianship order to discuss and record their will and preferences (wishes).

*The My Life, My Wishes document ensures that important discussions have been had to give a true reflection of people's wishes. I think it is more official if OPA completes the document with the person so people will feel the information is getting taken seriously and going to the right place. However, support person information/context should be sought also. (Supporter and Care Coordinator, ID:20)*

All respondents reported the My Life, My Wishes document could be helpful for future decision making and decision support. The document was expected to assist decision making in the following ways (in order of prevalence):

- supports informed decision making
- calls for understanding of will and preference
- increases knowledge of the person
- future life planning documentation
- increased understanding of support network (formal and informal)
- understanding of context of wishes.

*It makes [ID:3] feel he has some control over his wishes. It was important to me that OPA has important information on [ID:3]. Also, important that OPA have met the person [ID:3]. The My Life, My Wishes document helps OPA to understand [ID:3] and his likes and dislikes are to help make informed decisions. (Supporter and paid carer, ID:17)*

The top three responses to the question: 'What is helpful about the document?' were:

1. formal OPA recognition of wishes (documenting and filing)
2. supports getting to know the person with a guardianship order
3. prompts the OPA staff to meet the person.

Respondents reported the staff member, or whoever knows the person well, is best placed to help people with a guardianship order complete the document.

We asked the supporters how the document should change:

*I do think there should be space for support people to add information. Some customer's wishes may be unrealistic and, due to lack of capacity, they can't see it. Sometimes extra information from support people could give extra context. This may need to be done separately.*

*Less official wording – simplified for people with disability.*

Finally, we asked: 'What else would improve the OPA decision support for people with a guardianship order?'

1. inclusion of those who know the person best
2. communication support is provided by those who know the person best
3. a supporter who has a trusting relationship with the person
4. gathering information from interested parties
5. visit by the same OPA representative on multiple occasions
6. decision-specific discussions
7. visit from the OPA.



## Julia Farr Association Purple Orange consultation on community use of *My Life, My Wishes*

The Julia Farr Association Purple Orange was engaged to undertake an independent co-designed consultation with end users. The aim was to assess the feasibility of wider community use (those without the Public Advocate appointed as guardian) of the *My Life, My Wishes* document.

The consultants engaged 13 participants including individuals living with intellectual disability (not people with a guardianship order of the Public Advocate), family members who support people with a significant level of disability, and people with a guardianship order living with intellectual disability (JFA Purple Orange, 2022, p. 9).

The most common questions from the participants were:

- Who in the community would use the completed document, outside of public guardianship?
- Who would have the time and skills to support completion of the document?
- Who would benefit from all the information included in the document (JFA Purple Orange, 2022, p. 15)?

The primary findings related to the document's purpose, usability and accessibility. An additional issue considered was how often the document should be reviewed and updated to reflect changes in people's lives, preferences and wishes.

## The JFA made three recommendations to the OPA:

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- JFA Recommendation 1: Scope a strategy and implementation plan to roll out this form in the context of group homes and supported accommodation settings. This should include consultation with residents and staff within these settings.
- JFA Recommendation 2: Consider the role of Support Coordinator and Local Area Coordinator in assisting individuals to be aware of and to complete this form.
- JFA Recommendation 3: Scope and implement a design review of the form in response to the accessibility suggestions made by participants in this consultation. This should include review by an easy English specialist to ensure that questions are short, simple, and accompanied by pictorial icons.

In addition to the JFA recommendations and in line with the SACID consultation (SACID, 2021, p. 3), the OPA added instructions about the purpose and intention of the form for community use. This was to highlight the need for continuous consultation with the person even after they have completed a *My Life, My Wishes* document.

Information should be included at the beginning of the form to explain why these questions are being asked, what the information will be used for, and how it will be kept private. (SACID, 2021, p. 3)

Concerns about maintaining privacy were also raised. This related to the level of personal information collected in the document and associated risks of falsified or inaccurate versions.

The OPA has developed easy read versions of *My Life, My Wishes* (Appendix 5) and the *My Life, My Wishes* user guide (Appendix 6). The other JFA recommendations (1 and 2) are to be pursued in the future, noting that clients receiving support from the Department of Human Services, Disability Services, are included in the general implementation of *My Life, My Wishes* at the OPA.

# Supported decision making practice at the SA OPA

The OPA explored the extent to which it could implement supported decision making within the current legal framework and existing resources. It did this through staff training and an internal practice group that piloted supported decision making.

The training provided to OPA staff is described in Section 3 of this report.

An OPA staff pre-training survey was completed and evaluated. Key findings from the survey were:

- Over 90% of OPA staff reported they believe providing decision-making support to clients is part of the OPA's role.
- There was comprehensive understanding of the meaning of supported decision making amongst staff.
- The majority of staff reported that they often, or sometimes, implement supported decision making in their current practice.
- Getting to know the person was seen as the best way to support people to make their own decisions.
- The reported challenges to implementing supported decision making within the current environment were:
  - time constraints and high workloads
  - risk to clients and/or the OPA
  - capacity of the client to participate in a process
  - conflict within the client's family, resulting in poor support.



## Supported Decision Making Practice Group

Dr Michelle Browning was engaged to assist the facilitation of an internal OPA Supported Decision Making Practice Group. The Practice Group purpose statement was:

*The purpose of the OPA Supported Decision Making Practice Group is to explore the application of the La Trobe Support for Decision-Making Framework (La Trobe Framework) within current legislative and resourcing limitations, and policies/procedures at the OPA with the aim of developing an OPA (SA) specific supported decision making practice guideline and OPA position statement regarding supported decision making. Members of the Practice Group will do this by applying the La Trobe Framework to their current decision-making practice at the OPA and actively contribute to Practice Group discussions with the aim of best aligning OPA practice with the La Trobe Framework.*

The Practice Group sessions ran monthly on a Wednesday morning from 10.00 to 11.30 am, and were face-to-face where possible, and otherwise online. The session topic areas were:

**Session 1:** Introduction to group purpose and method, supported decision making recap

**Session 2:** Decision records and understanding legal tensions

**Session 3:** Developing a supported decision making support tool for OPA and enabling risk

**Session 4:** Enablers and barriers to decision support at OPA

**Session 5:** Supported decision making with Aboriginal and Torres Strait Islander people

**Session 6:** Developing an OPA Supported Decision Making Practice Guide

**Session 7:** Enablers of supported decision making practice at OPA

**Session 8:** Recommendations for an OPA Supported Decision Making Position Statement

**Session 9:** Recap and next steps.

The participants of the Practice Group were:

1. Dr Michelle Browning, Director, Decision Agency, facilitator
2. Emily Thwaites, Project Manager, OPA, co-facilitator
3. Stacey Rowse, Assistant Public Advocate, OPA, OPA advisor
4. Lisette Claridge, Public Sector Project Lead, SAHMRI, SAHMRI project advisor
5. Sage Y, Aboriginal Engagement Consultant, AGD, cultural advisor
6. Angelica N, OPA staff
7. Corinna F, OPA staff
8. Eva G, OPA, OPA staff
9. Emma W, OPA staff
10. Kelly M, OPA staff
11. Leoni K, OPA staff
12. Lauren S, OPA staff
13. Sarah F, OPA staff
14. Tarnia H, OPA staff.

## OPA supported decision making support tools

The Practice Group considered the need for supported decision making support tools for the OPA staff. It recommended a quick reference visual reminder of the La Trobe Framework steps, including descriptions and task examples. A visual guide was drafted to aid the integration of supported decision making practice into all decision-making processes at the OPA (see Appendix 3).

The Practice Group discussed the pros and cons of the tool. Due to the need to vary the approach for each individual, and the fact that the process is not 'linear', a support tool was not considered helpful at this stage of the project. Members agreed to consider it following development of decision-making practice guidance and a position statement.

## Decision records

A Decision Record Template was used to record and analyse decision processes (see Appendix 4). It recorded barriers and enablers for activities included in the La Trobe Framework steps, principles and strategies. Practice Group members were encouraged to attempt the full supported decision making process without additional resources, and while adhering to legislation. Staff recorded the time taken to complete a supported decision making process and the resulting decision types.

## Findings: Barriers and enablers

While OPA staff are highly skilled at ascertaining and considering the wishes of clients in substitute decision making processes, there are both barriers and enablers to implementing supported decision making practice. These barriers and enablers were collected and collated from decision records and Practice Group discussions over nine months, and grouped into four themes:

1. guardianship practice (internal)
2. operational (internal)
3. matter complexity (external)
4. systemic (external).

'Internal' themes refer to OPA policies and procedures for decision-making practice and operations. 'External' themes refer to elements outside of the OPA's control and authority.

### 1. Guardianship practice (internal)

Internal decision-making practice barriers included complexities in understanding, interpreting and recording clients' wishes with the *My Life, My Wishes* document. In addition, the ability to know the person and their situation well is impacted by staff changes, re-allocation of files and system limitations. For example, there was no single file location for recording a client's history, their current situation or their wishes.

Knowing the person is the first step of the La Trobe Framework and is fundamental to supported decision making processes. As the OPA lacks the resources to visit the person often and spend considerable time with them, better processes are needed. The OPA now has effective ways to collect information that is provided by the client, their supporters and through alternative means such as formal assessments (see Outcome 2).

Lack of practice guidance was a barrier to providing supported decision making processes. Staff needed clarification about the importance of supported decision making and its interaction with the current legislation.



## Outcome 7:

The OPA is developing a Decision Making Practice Guide integrating supported decision making principles and practice as far as possible within the GAA and resourcing boundaries.

## 2. Operational (internal)

Internal operational barriers included:

- time
  - Work required *externally* to the person, such as arranging interview times, updating files and travel time
  - Work required *with* the person at interview
- the need for urgent and regular visits with the client
- unallocated decision making (duty and team response decision making) where the client is included in a team response, rather than having a specific guardian to manage their affairs.

Decision records were used to understand the time taken to complete a decision-making process where the guardian has applied the La Trobe Framework. Individual cases varied from 5 to 43 hours, with an average of 23 hours. The timeframe from when an initial decision was needed to the final decision being made ranged from one day to 14 months. Supported decision making was possible sometimes. However, it was heavily reliant upon the client having good knowledge of community services and strong OPA advocacy.

The resourcing required to implement supported decision making as defined by the La Trobe Framework would be significant. However, the study found barriers to the provision of decision support can be addressed through practice adjustments (see 'OPA Supported Decision Making Practice Guide' section below).

## 3. Matter complexity (external)

Barriers to supported decision making included clients being hard to reach or difficult to engage, and/or their supporters causing barriers. This occurred where external parties were in conflict, exerted undue influence, prevented OPA access to the client or obstructed decision support attempts. In these instances, allocating an individual guardian to assist the client resulted in better understanding of the person's circumstances and provided increased opportunities for effective problem solving.

### Finding 3:

Priority support should be provided to highly vulnerable people with a guardianship order, including those who are hard to reach/difficult to engage, have no 'good support relationships', or no-one who knows them well.

### 4. Systemic (external)

Most of the barriers to the OPA providing supported decision making resulted from external systemic factors. These included:

1. service provision gaps
2. external agency/sector conduct
3. decision urgency
4. legal tensions between the GAA and supported decision making.

#### Service provision gaps.

The following service provision gaps impeded OPA's ability to provide, or advocate for, supported decision making:

- appropriate, affordable, available housing options
- quality behaviour support
- communication support
- decision support (supported decision making service provision)
- case management
- overall quality of complex service provision
- crisis response (NDIS model challenges).

Where appropriate external services were available and engaged, the OPA was able to provide the client with a supported decision making process. However, implementing a client's decision was not always possible and depended upon whether their preferred options were available. For example, a client's request for a particular type of housing depended upon the availability of an affordable, appropriate accommodation option in the person's preferred location, coupled with NDIS funding for adequate supports to enable the option. Supporting a person's own decision is only possible to the extent their preferred options are available to them.

#### External agency/sector conduct.

Both limited community awareness about supported decision making and the lack of person-centred practice were barriers. Overall, failing to involve the person or not gathering information about them prior to an application for guardianship orders were noted as barriers. There had often been insufficient attempts to provide decision support prior to a SACAT application, and there was little community awareness of alternatives to guardianship. However, the OPA's awareness of supported decision making and person-centred best practice was an enabler.

#### Finding 4:

The OPA should continue to advocate for funding entitlements for supported decision making from relevant Commonwealth and state agencies, such as the NDIS and My Aged Care. It could request supported decision making as best practice from all providers servicing people with a guardianship order.

#### Finding 5:

The OPA should continue to provide advocacy and sector leadership in supported decision making through community/sector education.

Decision urgency. In situations where a decision was urgently needed, it was difficult to implement a supported decision making process. This occurred due to time pressures significantly limiting the time available to work with the client on their decision making and to put in place services for this purpose. This commonly occurred when the client was in hospital, or an urgent decision was needed.

#### Finding 6:

The OPA should continue to strive to uphold supported decision making processes in the face of urgency and external pressure (e.g. hospital discharge delay, medical treatment) where practicable.



## Legal tensions.

The GAA was enacted prior to widespread recognition for supported decision making as an alternative to guardianship. There are consequently inherent legal tensions in implementing supported decision making into guardianship processes, which are governed by legislation that pre-dates it and gives legal ownership of a decision to the guardian. The following legal tensions arose in attempting supported decision making under the GAA.

The GAA does not require the provision of necessary support to a person with a guardianship order to make their own decisions. The s 5 GAA principles guide the decision-making considerations for guardians. Some of these principles enable guardians to encourage decision making in collaboration with the clients. This is through specifying that the guardian must consider the client's past and present wishes, what they would decide if they had capacity to do so, and making decisions that are *least restrictive of a person's personal autonomy* (GAA s 5(d)). However, on the supported decision making spectrum (Disability Services Division, 2023) this process is understood as 'will and preference-based substitute decision-making'. Despite client participation in the decision-making process, the guardian is the legal decision maker, which means any decision is ultimately a 'substitute decision'. A 'purer' supported decision making approach would involve direct support to the person to enable the person to make their own decision.

Given the legal parameters of guardianship (tensions between substituted and supported decision making), together with time and resource constraints, supported decision making practice is not always possible. The OPA was able to incorporate supported decision making practice where there was an absence of risk, the client had a positive attitude, and their preferred options were available.

Under the GAA, the SACAT grants the guardian either the authority to make *all guardianship decisions* (a full order) or decisions within broad domains (generally accommodation, health, services, access). Alternatively, authority may be limited to a specific decision, e.g. 'authority limited to making decisions and providing consent in relation to cancer treatment'. When broader decision-making authority is granted, the guardian may become accountable for all decisions made in that subject area, including minor or low-risk decisions that could potentially be made by the client (for example, choosing a hairdresser or taking a paracetamol). This is because the GAA does not recognise decision-specific capacity.

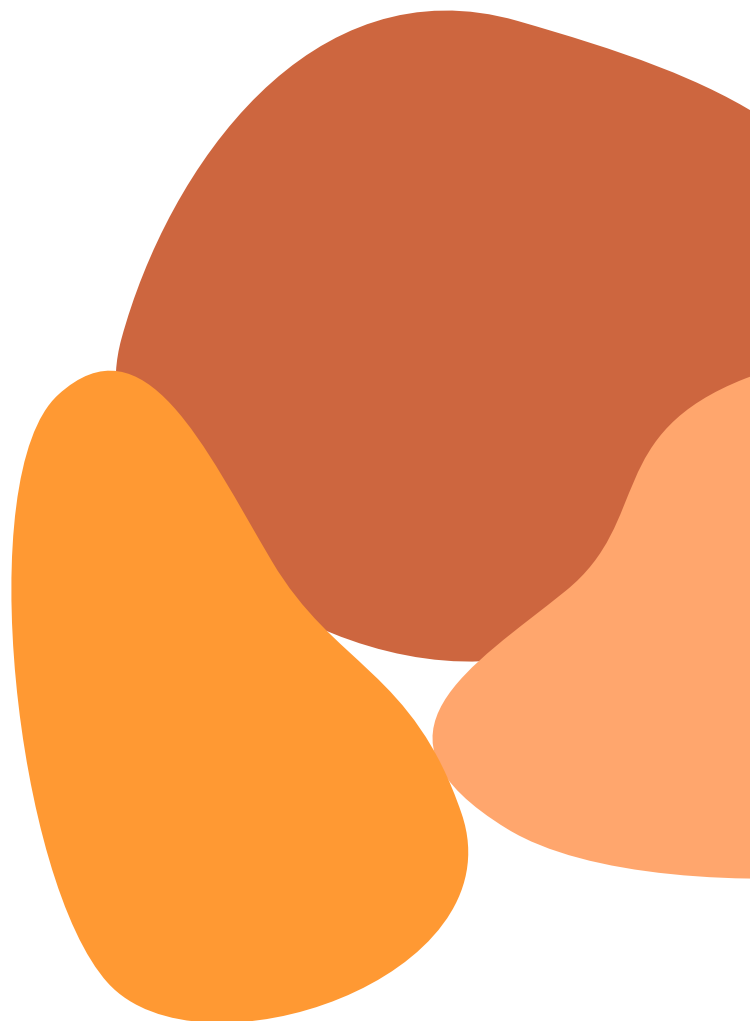
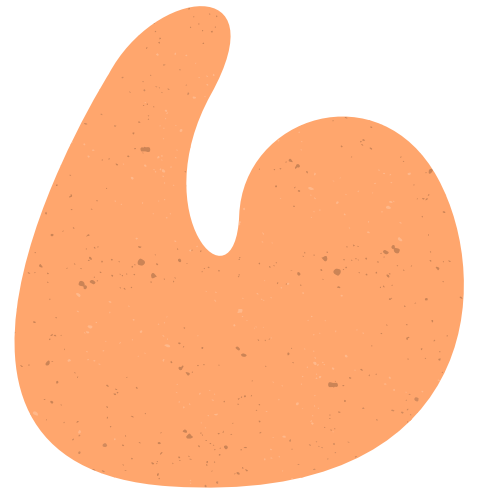
In practice, this means that, even if a supported decision making process is successful and the person can make their *own* decision, the Public Advocate as guardian is the legally responsible decision maker. The legal framework therefore limits the person's capacity and opportunity to make their *own* decisions or to be recognised as having made some of their own decisions.

### Finding 7:

The OPA should continue to promote the legal autonomy of people with a guardianship order by supporting a person's own decision wherever possible, whilst remaining consistent with the GAA and recording processes.

Enabling risk is a key strategy of the La Trobe Support for Decision-Making Framework. This concept recognises the importance of increasing opportunities to support the person's own decision through enabling positive risk, mitigated by appropriate safety mechanisms (Bigby et al., 2019).

The lack of definition in the GAA of risk and of what constitutes 'proper care and protection', and guidance on how this should be weighed against the person's wishes, is problematic. This can limit a guardian's confidence to enable risk whilst working within a 'protective' framework. The lack of a legislative definition and practice guidance on risk enablement created barriers to guardians exploring and enabling risk, resulting in more risk-averse decision-making practices. This was further observed in training sessions and Practice Group discussions, when OPA staff initially stated that supported decision making was only possible in the absence of highly restrictive orders, such as those authorising directed residence, detention and the use of reasonable force. These orders would restrict opportunities to attempt supported decision making for complex and higher risk decisions, due to the potential impact on the individual.



## Finding 8:

The legal autonomy of people with a guardianship order could be promoted by enabling positive risk to the greatest extent possible under the GAA.

Given the range of identified barriers, the project found that amending the GAA will not be sufficient to enable implementation of supported decision making practice at the OPA (see Gooding & Carney, 2023). Changes to associated legislation and public policy, and sector capacity building (including resourcing) are also required to provide viable alternatives to guardianship. The NDIS participants advised the NDIA that they require funding to be supported to make their own decisions (NDIS, 2021).

The identified legislative amendments and/or formal guardianship practice guidance that would best enable supported decision making practice at the OPA include:

- The GAA should require that supported decision making options be exhausted before substitute decision making can occur.
- The GAA should require that supported decision making practice informs substitute decision making practices.
- Binary capacity assessments should be replaced with an assessment of decision support needs.
- If capacity assessment is required, assessment should concern decision-making ability only and be measured when sufficient decision support is provided (measured at the maximum ability of the person) (see ALRC, 2014, Recommendation 3-2).
- Capacity should be recognised as decision specific, rather than by topic area.
- The GAA should include a principle that orders must be as specific as possible, with limited use of orders which confer broad decision-making authority.
- Practice guidance should enable risk by articulating high thresholds for risk and prioritising the person's wishes.



## Recommendation:

Legislative change is required in addition to public policy reform and sector capacity building to promote the legal autonomy of South Australians living with impaired decision-making ability.

### Aboriginal and Torres Strait Islander considerations

Barriers that are particularly relevant for Aboriginal and Torres Strait Islander people were identified and themed into the same areas as above.

#### Systemic (external)

Overall services, including culturally appropriate services, are severely lacking for Aboriginal people with a guardianship order living in regional and remote areas. Decision support examples discussed in the Practice Group showed a lack of an Aboriginal consultant or similar service provider for the person with a guardianship order and OPA staff. The need for such advice is particularly pertinent to people with a guardianship order who are estranged from family and have no informal supports.

Additionally, engagement between the OPA and Aboriginal people with a guardianship order is regularly challenged because of the cultural dissonance between Australian law and the self-determination of Aboriginal peoples. Sensitivities to historical and current socio-economic factors affect the relationship between communities and government/services (Laurens et al., 2021, p. 14). Currently, staff rely on long-term practice experience in responding to cultural sensitivities by acknowledging the cultural dissonance up front and paying particular attention to relationship building with the client and their family/extended family.

### Finding 9:

Consultation with Aboriginal people, communities and representatives should inform best practice approaches to decision making within the guardianship context.

#### Operational (internal).

The difficulty of conducting timely and frequent visits to Aboriginal people who reside in regional and remote locations is a significant barrier to providing or advocating decision support. This is particularly problematic given the importance of rapport building in a population experiencing severe mistrust in government services.

### Finding 10:

Regional and remote partnerships could be explored to provide visitation referrals and cultural advice.

#### Guardianship practice (internal).

The lack of best practice knowledge about culturally sensitive supported decision making practice with Aboriginal people is a barrier to providing this support (see Laurens et al., 2021, pp. 21–22). Not knowing how to do it, and the absence of anyone to ask, meant it either did not occur or the Aboriginal perspective on its success was unmeasured.



## Outcome 8:

Training and/or professional development is being developed for OPA staff on navigating the decision making/support process with Aboriginal people.

### OPA Supported Decision Making Position Statement

A public-facing OPA Position Statement on supported decision making is being developed encompassing findings from this project.

### OPA Supported Decision Making Practice Guide

The Practice Group concluded that an integrated overarching guide would most assist the integration of supported decision making into OPA practice. As a result of this project, the OPA is now developing a Decision Making Practice Guide to achieve this.

In line with Outcome 7, a Decision Making Practice Guide should enable supported decision making practice to the extent possible under the legislation and resourcing. Practice guidance should include the following:

- assessing risk and risk enablement (see Finding 8)
- practice priorities (see Outcomes 4 and 5, and Findings 4 and 6)
- how to justify and record a person's own decisions (see Finding 7)
- how to implement a client profile document aligned with supported decision making (see Outcome 2)
- culturally sensitive practice (see Findings 9 and 10, and Outcome 8).

## Outcome 9:

The OPA is considering future data collection on supported decision making at the OPA for the purposes of evaluating best practice and providing evidence of resourcing needs.

Consideration should be given to how the OPA can evidence supported decision making practice and demonstrate resourcing needs, e.g. document people with a guardianship order who are not receiving decision support or who can be supported to make their own decisions and perhaps remain under SACAT orders unnecessarily.

# Project extension 2023-24

At the conclusion of the Supported Decision Making Project in 2022, the project received an extension due to the impact of the COVID-19 pandemic and limitations on visiting people to undertake the supported decision making process. For the project extension, the OPA set a target of including an additional 25 people under the guardianship of the Public Advocate with a view to embedding the document into decision-making practice at the OPA.

This work was undertaken through an internal 'test and learn' phase, which involved trialling and improving the My Life, My Wishes supported decision making tool. The My Life, My Wishes document is now fully embedded into the decision-making practice at the OPA, with an additional 400+ documents completed with OPA clients.

## Test and Learn

The project extension involved eight guardianship staff conducting additional interviews with 25 people with a guardianship order. Feedback was collected with the aim of ascertaining the following:

1. Where does the MLMW interview best fit within the OPA practice?
2. Does the MLMW deliver on its purpose to collect the wishes of the person, establish good knowledge of them and understand their decision support needs?
3. Is the MLMW document better than current practice?
4. Does it assist decision-making processes?
5. Is it better for people with a guardianship order?

## My Life, My Wishes - 475 Completed

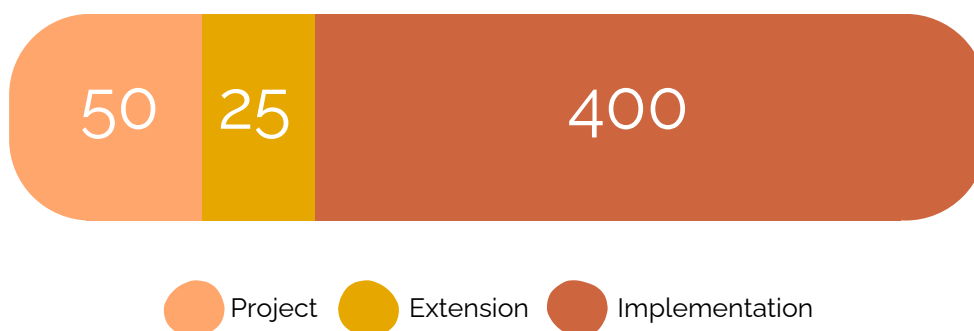


Figure 2: My Life, My Wishes completions

## Test and learn findings

### 1. Where does the MLMW interview best fit within OPA practice?

The form is best completed at a face-to-face visit with the client and supporters. The information collected can then be used in future decision making. Using this document in place of multiple profile and transfer type documents increases the OPA's administrative efficiency and maintains office knowledge of the person.

### 2. Does the MLMW deliver on its purpose to collect the wishes of the person, establish good knowledge of them and understand their decision support needs?

The MLMW form ensures that the wishes of the person with a guardianship order are sought and includes prompts for the guardian to record the client's wishes for each guardianship order domain. It addresses end-of-life wishes through scripted inclusions about future health and treatment planning. Free text elements also allow adaption of the document to meet the needs of everyone. Understanding the person's support needs is addressed in a 'communication needs' section.

### 3. Is the MLMW document better than current practice?

The MLMW document addresses gaps in the collection of information and ensures a file destination for the wishes of people with a guardianship order. The document is an improvement on current practice as it requires a higher standard of information collection and consistent documentation.

### 4. Does it assist decision-making processes?

Easy access to information about a person's wishes, their background, current situation and decision support needs facilitates decision practice that aligns with the person's wishes. In addition, it provides a framework for how to best consult with them or advocate for them to receive support in their decision making. Staff report that they have a much more comprehensive perspective of the person after reading the MLMY document and are better positioned to make more informed decisions. Staff also reported that this is particularly helpful in urgent situations and when working on the after-hours urgent decision-making service.

### 5. Is it better for people with a guardianship order?

The MLMW document was observed to benefit people with a guardianship order through involving them and asking them about their wishes in all life domains. The information requested in the form served well as an interview script and supported the building of rapport with the person. Overall, the document prompted the staff member to consider the person and their wishes and needs in more detail than in previous practice. As a result, the OPA knowledge of the person increased, in turn supporting OPA's decision-making practice. People with a guardianship order who were able to engage in the interview process enjoyed it. David visibly enjoyed it and was quite proud. He wanted to sign it if he could. (OPA Guardian)

## Implementation

Staff training on best practice use of My Life, My Wishes at the OPA was developed and delivered. The training covered:

1. the purpose of the MLMW document
2. best practice
  - adapt to everyone
  - cultural sensitivity
  - address communication needs
  - encourage involvement of the person
  - utilise supporters
  - review and update
3. How to basics (within OPA practice and procedures)
4. MLMW: three components
  - a. file information page
  - b. decision-making profile
  - c. My Life (context) alongside My Wishes (wishes and preferences).

Over six sessions from September to November 2023, 35 guardianship staff attended the training. Following this training, guardianship staff were expected to implement the MLMW document within their practice.

## Next steps

### Community and easy read versions

The OPA is pursuing increased usability of the MLMW document by people with a guardianship order and their supporters in the community. For this purpose, a user guide has been developed and converted to plain English and an easy read version (see Appendix 6).

### Culturally sensitive supported decision making

The OPA received separate project funding to adapt the MLMW form for use with Aboriginal and Torres Strait Islander people. This project adopted a consultative approach with peak bodies, representatives of Aboriginal communities, clients and their supporters. It will result in a widely available video about how to do culturally safe supported decision making, and a written guideline for OPA staff about the importance of cultural nuances when conducting supported decision making with Aboriginal clients.



# 3. Building capacity to practise supported decision making



This section of the report outlines a program of activities conducted by the Living My Life Project aimed at building capacity within the healthcare sector to practise supported decision making. Specialised supported decision making training was provided to the Office of the Public Advocate, health professionals in acute health care settings (Royal Adelaide Hospital), specialist health services (South Australian Intellectual Disability Health Service), community-based health professionals (general practitioners) and four community mental health teams (including forensic mental health specialists). Specialist training was provided in person to specific groups, and more general information shared online via webinars. The resources developed through the project are accessible on an ongoing basis including five introductory videos and three e-learning modules.

## SDM expertise

Given the strong imperative to build greater community knowledge about supported decision making, SAHMRI engaged Dr Michelle Browning to develop and lead supported decision making work as part of the Living My Life Project.

Michelle Browning is a nationally recognised supported decision making expert. In 2010 she explored the emerging concept of supported decision making in the United Kingdom and Canada on a Churchill Fellowship investigation. She went on to conduct doctoral research focused on the practice in Canada, which she completed in 2018. She has been involved in seven projects across Australia (in NSW, Victoria, Queensland, WA and SA) which have explored support for decision making in a range of contexts (e.g. volunteer supporters matched with isolated decision makers, supporting the decision making of people with complex communication access needs) and using different practice frameworks (e.g. La Trobe Support for Decision-Making Framework, WAIIS Framework, CID Framework).

Michelle works with government and non-government organisations to produce supported decision making resources, policy and practice guidelines. She regularly facilitates training, practice groups and supervision for supporters wanting to build their confidence as practitioners. She also provides training for decision makers wanting to understand more about decision making and their rights. For more information about Michelle please visit her website: [www.decisionagency.com.au](http://www.decisionagency.com.au).

## SDM training for the South Australian Office of the Public Advocate

The Office of the Public Advocate in South Australia has led and been involved in a range of supported decision making projects over the last ten years (e.g. Wallace, 2012). OPA sought assistance from SAHMRI and the Living My Life Project to further their supported decision making practice and help inform future practice.

Dr Michelle Browning facilitated two supported decision making training sessions for all OPA guardianship staff. The training explored the La Trobe Support for Decision-Making Practice Framework as its theoretical model. Practical advice was contributed by two presenters with lived experience of guardianship (Anthony Beazley: see Appendix 7) and receiving decision support (Sarah Byrne).

Both sessions ran for 4.5 hours and were face to face for OPA staff and the lived experience presenters. Dr Browning facilitated the sessions online due to COVID-19 travel restrictions. 70% of OPA staff attended both sessions.



### Sarah Byrne, guest speaker

Sarah uses her voice as a person with intellectual disability to support SACID as an Inclusion Worker. This includes developing information and resources that people with intellectual disability and their families really want. In this role, she enjoys helping people to be more informed by sharing her ideas for new workshops and assisting to develop and run these sessions. Sarah has held advocacy roles, such as an Ambassador for Down Syndrome South Australia, where she has shared her experiences and achievements with wide audiences both in Australia and overseas. As the current Our Voice national representative for South Australia, Sarah speaks up about issues that are important to people with intellectual disability. Sarah is involved in her community through participation in dancing, cheerleading and long-term open employment and uses her networks to promote the work of SACID with passion. Sarah believes that it is important for people with intellectual disability to have a voice and be included and valued in the community. This can teach the community how to be inclusive and understand people with intellectual disability – you do this by showing people what you are able to achieve!

## Session 1: 15 October 2021

Session 1 focused on the paradigm shift demanded by the Convention on the Rights of Persons with Disabilities, moving away from substituted to supported decision making. The support paradigm requires us to see that:

- Decision making is a shared process.
- A person's decision-making capacity includes the supports available to them in the decision-making process.
- Legal capacity is a universal human right, irrespective of the amount of support people may require to exercise it.
- Respecting and acting upon the decision makers' will and preferences is the new guiding decision-making principle.

The six decision support strategies outlined in the La Trobe Support for Decision-Making Practice Framework were explored through current guardianship examples. Staff were encouraged to complete the La Trobe Support for Decision-Making e-learning modules prior to the second SDM training session.

Reflections after the first session included:

- Staff were very skilled in executing the La Trobe decision support strategies (e.g. listening, adjusting communication).
- Staff wanted to explore how supported decision making applies to OPA's particular context, roles and responsibilities.
- Further discussion is needed regarding how to apply the framework within the current legislative and resourcing constraints.

See Appendix 8 for the training materials.

## Session 2: 29 October 2021

Session 2 focused on five ways OPA can further the aims of supported decision making (to enable self-determination and support the exercise of legal capacity to the greatest extent possible) in its work:

1. Understanding the process of supported decision making to assist guardians to provide better decision support and, where this is not possible, to advocate for other services to provide this to protected persons.
2. Exploring when staff are able to support protected persons to make their own decisions in the existing legislative context.
3. Applying the principle of orchestration and understanding the importance of building a protected person's decision-making capability.
4. Exploring risk enablement and how small changes to current practice may lead to protected persons feeling they have greater control over their life. Giving 'will and preferences' more primacy when weighing up the potential consequences of risk can start to align substitute decision making more closely to the support paradigm.
5. Championing supported decision making in interactions with others through community education, advocacy for increased practice across sectors and future legislative reform.

Reflections after the second session included:

- OPA applies the s 5 GAA principles and will seek to understand and support the wishes of protected people in circumstances which are consistent with their care and safety.
- Staff are motivated to better implement supported decision making but limited time and workload are major barriers.
- Orchestration (OPA's role identifying and engaging services to enable decision support for protected persons) is largely dependent on NDIA funding. Specific funding is not provided for the provision of decision support.
- An OPA-specific SDM model and decision-making practice guide may be useful for newer staff to learn the decision-making process and move practice further to the support paradigm.
- Many staff do not understand the difference between current practice and SDM-aligned practice, believing that they are already implementing SDM in applying and upholding s 5 principles.

See Appendix 9 for the training materials.

For more information on the findings and recommendations from OPA's involvement in the Living My Life Project see Section 2 of this report.

# SA Health training

The Disability Royal Commission identified the need for health professionals to receive training in a range of topics including supported decision making to enable better quality health care and outcomes for people with cognitive disability (Disability Royal Commission, 2023, vol. 6, p. 353–356).

Following the training sessions for staff from the Office of the Public Advocate, the Living My Life Project turned to providing supported decision making training to members of SA Health. A range of educational strategies were used to connect with the breadth of issues and professionals involved in supporting decision making within healthcare settings including:

- a series of introductory short videos
- two webinars, one for disability liaison clinicians and one for other health professionals
- scenario-based in-person training with the SA Intellectual Disability Health Service (SAIDHS)
- in-person training for all community mental health teams across greater Adelaide
- e-learning modules to facilitate ongoing capacity building across the health sector.

## SDM videos

The Living My Life Project consulted with SA Health to identify the most effective strategies to build understanding of supported decision making for their staff. They identified three key challenges:

- The COVID-19 pandemic limited staff availability and their emotional capacity to take on new approaches;
- Staff burnout and high turnover make retaining knowledge within the sector difficult.
- High workloads in acute settings limits time for educational opportunities.

It was proposed a series of short videos that could be made widely available to staff across all areas of SA Health may be the most effective way of developing knowledge about supported decision making and building sector capacity over time.

It was determined the videos would be housed outside of the Department for Health and Wellbeing, on the [Office of the Public Advocate \(OPA\) website](#), and championed within SA Health by the South Australian Intellectual Disability Health Service (SAIDHS). While developed for health professionals, having the videos in the public domain meant they could have even greater reach and would help to inform the public more broadly about supported decision making as an alternative to guardianship. The videos have been published under creative commons licensing (CC BY-NC-ND 4.0).



## Video production

Frankie Films were engaged to produce the series of short videos on the following topics:

### 1. Decision support as a fundamental human right

- What supported decision making is and why it is important for SA Health.
- It is a process of supporting people with their decision making.
- It is about enabling self-determination and support to exercise legal capacity.
- It is a practical alternative to substitute decision making.
- It responds to a human rights imperative driving some important cultural changes in the health sector.

### 2. Supporting guardianship to become the last resort

- Supported decision making is a legal and practical alternative to substitute decision making.
- It uses specific strategies, tools and forms of accommodation (changes to the decision-making environment) to allow people with disability to remain in control of their decision making.
- OPA promotes supported decision making in an effort to ensure it is only appointed as substitute decision maker of last resort.
- When would SA Health involve OPA? When might substitute decision making be required?

### 3. Supporting good decision-making processes

- Understanding the key aspects of good decision making: identifying the decision, knowing the person's will and preferences, exploring options, considering risks and constraints, making and implementing the decision.
- Tips for supporting a person with their decision making, e.g. taking time, ensuring information is accessible, involving the right people.



Ruby Nankivell being filmed in the grounds of the Royal Adelaide Hospital by Benno Thiel and Rachel Jesse (Frankie Films), supported by Melanie Cheung (SACID)





Video 1: Decision support as a fundamental human right presented by Michelle Browning



Video 2: Supporting guardianship to become the last resort presented by Emily Thwaites



Video 3: Supporting good decision-making processes presented by Michelle Browning

#### 4. The experiences of a decision maker

- A person with disability sharing their personal experiences of being supported with decision making in a healthcare setting.
- Things that were helpful and unhelpful.
- Advice and tips for health professionals.

#### 5. The experiences of a supporter

- Sharing their personal experiences of supporting someone else with their health decision making in a healthcare setting.
- Things that were helpful and unhelpful.
- Advice and tips for health professionals.



Video 4: The experiences of a decision maker presented by Ruby Nankivell



Video 5: The experiences of a supporter presented by Carolyn Smith

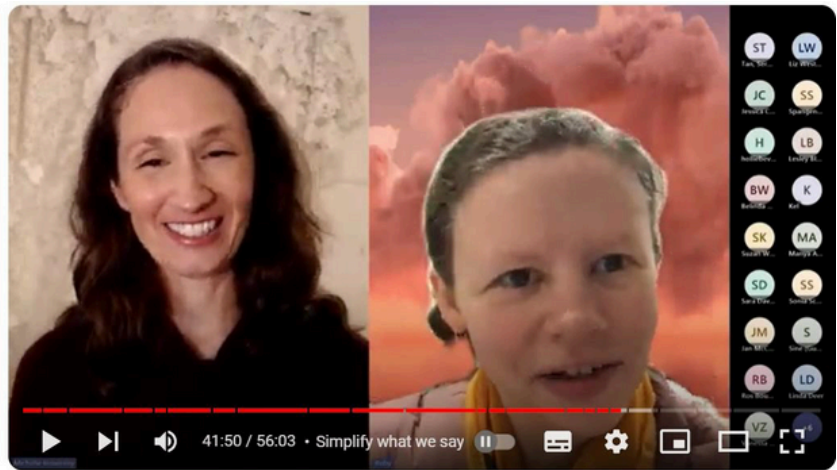
Four presenters contributed to the video content development and delivery:

Ruby Nankivell (decision maker), Carolyn Smith (decision supporter), Emily Thwaites (guardian from OPA) and Michelle Browning (supported decision making expert).

The videos were launched in November 2022 and have been viewed on the [Office of the Public Advocate \(OPA\) website](#) over 742 times as of 8 March 2024.

# Supported decision making webinars

The Living My Life Project offered two webinars to help raise awareness of supported decision making within SA Health. They aimed to build greater understanding of how decision support can be provided to people with disability in acute health care settings. The first webinar was directed towards clinicians with a disability liaison focus and the second to health professionals who work in acute settings more broadly across South Australia.



## Promotion of webinars

The first webinar was promoted to clinicians involved with the NDIS and the Disability Interagency Operational Group, chaired by Wellbeing SA. SAIDHS greatly assisted with championing and promoting the webinar to disability liaison clinicians across South Australia.

The second webinar was promoted through Summit Health, which invited 1881 primary healthcare professionals working in general practices as registrars and nurses. A presentation about the webinar was also made at a Northern Mental Health Alliance meeting and promoted through their newsletter. The alliance membership represents the majority of South Australian mental health service providers, both private and public.

## An introduction for disability liaison clinicians

The first webinar took place on Friday 18 November 2022 at 12.30–1.30 pm. On the advice of SA Health representatives, it was scheduled over lunch time to assist with limited staff availability and kept to only an hour, respecting people's workloads. The free webinar was facilitated by Dr Michelle Browning and Ms Ruby Nankivell, an Inclusion Advisor at the SA Council on Intellectual Disability. The session explored:

- what supported decision making is and why it is important
- its growing importance in the context of the NDIS
- the difference between supported and substitute decision making
- practical advice for clinicians based on real decision-making experiences
- available frameworks and tools for supporting good decision-making processes and
- how they might be useful when you are acting as an advocate and/or decision supporter.

The webinar was attended by 25 disability liaison clinicians, who reported the information was both informative and useful.

## An introduction for health professionals

The second webinar, identical in content to the first, was specifically for health professionals practising in non-acute settings. The event was held outside of work hours to allow busy professionals to participate. The one hour webinar took place on Wednesday 30 August 2023 (6.30–7.30 pm Adelaide time).

Sixty-one health professionals registered for the event including general practitioners, speech pathologists, behaviour support practitioners, radiographers, support workers, social workers, nurses, neuropsychologists, support coordinators, pharmacists, dentists and occupational therapists. All participants received a copy of the webinar recording, which has been viewed 49 times since being uploaded to the [Be Well Co YouTube account](#) on 4 September 2023.

Feedback received after the session included:

*"Thank you both for the presentation tonight. I work as a speech pathologist in an inpatient rehab ward, and we are often asked by the medical team to help decide if patients are able to sign enduring power of attorney forms and appoint someone. We are looking at creating more of a procedure about this and this presentation has given me lots of ideas!"*

*"Thank you for your presentation. It helps to have a process and the reflection exercise is useful for all areas of practice."*

*"This has been such a powerful webinar. Thanks so much, Michelle and Ruby."*

*"Thank you and an excellent presentation."*

# Advanced SDM training for SAIDHS practitioners

SAIDHS is responsible for building the capacity of staff within SA Health to support the unique needs of people with intellectual disability. Supported decision making is an important practice that SAIDHS clinicians need to be able to champion and in doing so ensure the provision of appropriate decision-making support to health service users with intellectual disability.

SAHMRI collaborated with Chris Nelson, Senior Service Manager at SAIDHS, to develop an in-person advanced practitioner training session that enabled SAIDHS clinicians to dive deeper into applying the principles of practice in their unique contexts. In small groups, three highly relevant scenarios were explored and discussed (see Appendix 10). The session also explored available resources for health professionals, decision supporters and tools that can assist with providing decision-making support. A lived experience presenter, Ruby Nankivell, also shared advice from her experience as a person with an intellectual disability having received both good and bad decision support in acute healthcare settings.

The session took place on Friday 18 November 2022 at the Sunset Room, Ingle Farm Recreation Centre from 2.30 to 4.30 pm. While the session was developed for SAIDHS clinicians, there was also strong engagement from staff from the Office of the Public Advocate. Feedback from clinicians who attended the session included:

- Training was well received.
- Use of scenarios was a good way to discuss the how of SDM – these could be adjusted to suit the health service context of future attendees.
- Within health care, there are instances where legal orders need to be implemented (e.g. mental health detention orders). It would be useful to discuss how these legal requirements/processes interact with SDM.
- There may be value in co-presenting future SDM events with a clinician who can help unpack how to engage in SDM in the health service context.



# Training for health professionals in SDM for people with psychosocial disability

People with psychosocial disability have different needs and challenges to people with intellectual disability when making decisions. This was an important reflection to come from the SAIDHS advanced practitioner training. Staff in SA Health who work with people in community and acute mental health settings need more understanding of how supported decision making can be applied in these different legal and practical contexts. SAHMRI wanted to respond to this need by engaging Michelle Browning to develop SDM foundational training for health professionals who support the decision making of people with psychosocial disability.

## Content development

Michelle collaborated with Piers Gooding, Associate Professor at La Trobe Law School, to develop the content for this specialised training. Piers is a leading national and international expert on mental health, and disability law and policy. Claire Hyland, Acting Principal Social Worker in the Northern Adelaide Local Health Network, Division of Mental Health, was invited to co-facilitate the workshops. Claire's rich practice knowledge in supporting people with psychosocial disability was woven throughout the training, illustrating how specific SDM principles and strategies could be used in practice. See Appendix 11 for the challenging decision-making scenario Claire provided, which was explored in small groups towards the end of the training. Lastly, Jenny Singh was invited to provide advice as a person with lived experience of psychosocial disability and supported decision making. Jenny works for the Lived Experience Leadership and Advocacy Network and has a passion for improving mental health services through sharing her experiences with health professionals in forums such as the independent advisory group established by the SA Office of the Chief Psychiatrist.

## Promotion

The opportunity to learn more about supported decision making was promoted through Claire Hyland's connections with the social work teams at each local health network.

## Audience

SAHMRI sought to involve as many frontline mental health professionals as possible in greater Adelaide. Sessions were held across the Northern, Southern, Central and Western local health networks. Health professionals who attended included social workers, nurses, neuropsychologists, clinical nurse specialists, occupational therapists, and a team from James Nash House, the forensic mental health service.





#### Session details and participants' feedback

##### **Session 1: Monday 19 June 2023**

This session was hosted by the Northern Area Local Health Network, Salisbury, SA. 39 people registered. Feedback from the session included:

*Loved hearing from Jenny and her lived experience. Enjoyed the gentle challenging around our personal/professional biases and the need to stick with a good process.*

*A reminder that people can have input even when experiencing significant challenges.*

*I liked learning about enabling risk and giving consumers the opportunity to manage the risks.*

##### **Session 2: Monday 10 July 2023**

This session was hosted by the Central Adelaide Local Health Network and SAHMRI, Adelaide. 30 people registered. Feedback from the session included:

*Brilliant presentation! I welcome the shift in MHS mindset from incapacity to capability. All mental health clinicians and medical staff would benefit from this training.*

*I liked having time to reflect and getting resources to help when in the moment working with people. I can use these in supervision – thank you!*

##### **Session 3: Monday 11 September 2023**

Session 3 was hosted by the Western Adelaide Local Health Network, Woodville, SA. 38 people registered. Feedback from the session included:

*Great to hear from different speakers. Great to place the theoretical concepts in the context of mental health services. Enjoyed the exploration of tension within substitute decision making and supported decision making models.*

*I liked being able to place a label on how I think and work with consumers in community mental health services. We are so stuck in substituted decision making framework, it was refreshing to hear about supported decision making.*

*Got me thinking about how we can increase people's decision-making capacity.*

*I enjoyed listening to Jenny and her lived experience regarding supported decision making.*

*Thought provoking and well aligned with social work principles that often become subjugated in tertiary mental health services. Michelle is clearly extremely well informed in this field and is an articulate and engaging presenter.*

#### Session 4: Tuesday 12 September 2023

Session 4 was hosted by the Southern Adelaide Local Health Network, Daw Park, SA. 30 people registered. Feedback from the session included:

*I liked the engaging discussions and self-reflection to challenge my own practice.*

*Great to do face-to-face training again – to explore questions and thoughts more freely. It was great!*

*I liked hearing the perspective of someone with lived experience.*

*It was informative and challenging.*

*Helped me reflect on my practice and ways to refresh it.*

#### Resources

Each participant who attended the training received a content summary that revised the paradigm shift from substituted to supported decision making and a framework for supporting better decision-making processes. Participants also received a digital resource sheet to further their ongoing learning about supported decision making (see Appendix 12).

#### Reflection from the lived experience presenter

After involvement with the first supported decision making session, Jenny Singh realised that her understanding of supported decision making had been expanded by hearing the workshop content. Jenny explained her experience of support seemed more coercive now she had a greater understanding of supported decision making:

Before I attended the SDM workshop I had thought I had undertaken supported decision making with the treatment team looking after me during a stay at one of the public hospitals in Adelaide. The team helped me to come up with an advance statement for if I needed to return to hospital as well as a safety plan to help me keep on track with my recovery. Although these were both great things to have, the team made it very clear that they would prefer me to stay in hospital and were very vocal about their preference. On reflection, this seems more coercive rather than supported decision making, despite the outcome where I was able to continue my treatment at home.

This insight from Jenny was mirrored in some of the comments shared by workshop attendees who reflected on the importance of minimising their influence as supporters:

Enjoyed reflection as made me aware I was not as supportive as I thought I had been.

I learned how to become a better supporter and have my own emotions and agenda in check.

## Reflection from the mental health professional and training cofacilitator

Claire Hyland, Acting Principal Social Worker for the Northern Region, reflected on her involvement with co-facilitating supported decision making in the following way:

Supported decision making was a new concept for me and provided a framework for work I had been doing for some time, which was very helpful. It appeals to me from a human rights perspective, and I am heartened to see its inclusion in the review of the Mental Health Act in South Australia.

There are very established practices in mental health concerning substituted decision making under the Guardianship and Administration Act; however, supported decision making is a practice that is underdeveloped in the area of mental health. For it to be used and referred to more widely will take more training, its inclusion in policies, procedures and legislation, and a culture shift.

Services under pressure tend to move towards more coercive practices. I think there is genuine concern from clinicians that if we are not taking a directive role in consumers' lives that we are open to criticism and that we will be held accountable if something or someone goes 'wrong'. The harmful impacts of more coercive practices need to be understood better and shape our practice towards a human rights-based model.

Participating in the training was very enjoyable. It provided me with an opportunity to better understand how different groups came to engage in the subject matter, the concerns raised, and comfortability was interesting to observe and reflected the culture I have mentioned. My understanding of SDM was enhanced greatly and I enjoyed working with Michelle immensely. I have had a number of conversations with social workers in particular who now consider SDM in their decision-making matrix with the consumer and their carers. I am no longer in a client-facing role; however, I use supervision to encourage exploration of the use of SDM in practice.

## Reflection from the SDM expert

Many of the health professionals who attended the supported decision making training already had many of the values (e.g. taking a strengths-based approach to working with clients) and principles (e.g. respect for autonomy) that are central to practising supported decision making. However, they lacked a framework and clear strategies to embed supported decision making in their daily work. As such, they reported they found the training uplifting, informative and challenging.

Staff members were overwhelmingly supportive of culture change moving practice away from substitute decision making to supported decision making in the mental health sector. They identified the significant barriers that current approaches to risk present as well as the high prevalence of coercion when supporting client decision making.

It seemed health professionals benefitted from being able to meet with their peers and discuss these complex matters. They recognised the importance of legislative and policy reform in seeking to further embed these practice changes in the mental health sector.

# SDM e-learning modules

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The Living My Life project team consulted with SA Health to test interest in the development of e-learning modules to facilitate ongoing capacity building across the health sector. This was suggested given the ongoing challenges of limited staff availability and high turnover in the health sector. There was strong interest in online learning that could be managed externally and updated by appropriate professionals as needed. SAHMRI believed creating supported decision making modules would additionally contribute to the existing suite of resources produced by the Living My Life Project and increase the impact of its work.

In response to this interest, SAHMRI commissioned Dr Michelle Browning to develop three e-learning modules to make foundational knowledge about supported decision making more widely accessible to decision supporters. The modules are housed on the Decision Agency website (<https://www.decisionagency.com.au/>), allowing them to be in the public domain, freely accessible and monitored by a professional with appropriate expertise to ensure the content remains up to date.

The modules were developed to help decision supporters:

- understand the aims and intention of supported decision making
- explore their role in building the decision-making capability of others
- develop strategies to minimise their influence.

## Module 1: An Introduction to Supported Decision Making

This module explores:

- what supported decision making is
- where it comes from
- why it is important
- how it is different to substitute decision making and
- how it can support people to exercise their legal capacity.

## Module 2: Building Decision-Making Capability

This module explores:

- why we need to think about capacity differently
- how we can improve a person's decision-making environment
- how we can make adjustments to the decision-making process and
- why supported decision making changes the starting point.

## Module 3: Supporter Influence

This module explores:

- why we need to minimise our influence as supporters
- how the approach we take to our role shapes our support
- why we should acknowledge our biases
- how we can work to mitigate our biases and
- why we need to focus on a good process.

Decision Agency engaged [Simply eLearning](#) to help build the e-learning modules. The content of the modules was reviewed by SA Health staff to ensure it was relevant and useful.

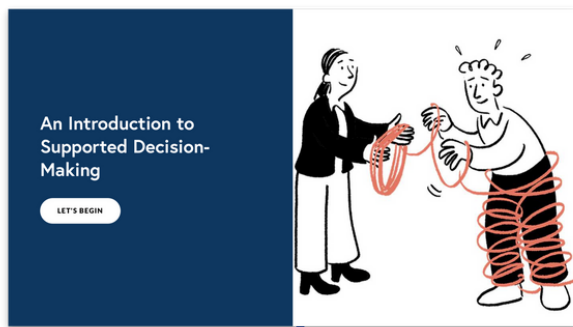
In the future the Department for Health and Wellbeing may choose to make this learning part of mandatory training for health professionals. The South Australian Intellectual Disability Health Service have recommended the completed modules be made mandatory and have promoted their use within the department. They are also promoting improvements in how health professionals support people with disability to communicate their needs and preferences through supporting the use of the My Health Information form.

The Living My Life project team hoped the SDM e-learning modules would also be useful to decision supporters outside the health sector, including those in the disability and ageing sectors. This has proven to be true. The e-learning modules went live on the Decision Agency website on 12 December 2023, and as of 18 April 2024, 90 people had registered with 247 module enrolments. In addition to health professionals, disability advocates, behaviour support practitioners and informal supporters (such as family members) have registered to take advantage of the learning.



# Module 1

# Module 2



### An Introduction to Supported Decision-Making

100% COMPLETE

- What is Supported Decision-Making?
- Where Did Supported Decision-Making Come From?
- Why is Supported Decision-Making Important?
- Turning Substituted Decision-Making on its Head
- Support to Exercise Legal Capacity

People have been helping others to make decisions for as long as time itself.

So, what's the big deal about supported decision-making?

Isn't it just about providing good decision support?

### Building Decision-Making Capability

20% COMPLETE

- What Makes a Good Decision Maker?
- Rethinking Capacity
- Emily's Story
- A Different Starting Point

Decision-making abilities can be turned into

decision-making capabilities with appropriate

decision-making supports and accommodations.

Simply put:

### An Introduction to Supported Decision-Making

100% COMPLETE

- What is Supported Decision-Making?
- Where Did Supported Decision-Making Come From?
- Why is Supported Decision-Making Important?
- Turning Substituted Decision-Making on its Head
- Support to Exercise Legal Capacity

#### SUBSTITUTED DECISION-MAKING

The person's WILL and PREFERENCES are ~~REPLACED~~ <sup>REPRESENTED</sup> ~~IMPOSED~~ <sup>IMPOSED</sup> by the decision-making supporter.

#### SUPPORTED DECISION-MAKING

The person's WILL and PREFERENCES are ~~REPLACED~~ <sup>REPRESENTED</sup> ~~IMPOSED~~ <sup>IMPOSED</sup> by the decision-making supporter.

### Building Decision-Making Capability

20% COMPLETE

- What Makes a Good Decision Maker?
- Rethinking Capacity
- Emily's Story
- A Different Starting Point

We hope in time, our laws will change to reflect this more inclusive way of thinking about decision-making capacity.

But until then it is very important that you recognise the support you provide has the power to change someone's decision-making capability.

### An Introduction to Supported Decision-Making

100% COMPLETE

- What is Supported Decision-Making?
- Where Did Supported Decision-Making Come From?
- Why is Supported Decision-Making Important?
- Turning Substituted Decision-Making on its Head
- Support to Exercise Legal Capacity

Have you ever thought about what it would be like to have your legal capacity removed?

How would it feel to be a legal non-person, with little say over the decisions which shape your life?

### Building Decision-Making Capability

20% COMPLETE

- What Makes a Good Decision Maker?
- Rethinking Capacity
- Emily's Story
- A Different Starting Point

Emily's story is a great example of how you can intentionally build a person's decision-making environment.

Emily's family recognised the importance of Emily being surrounded by people who love her, and who know her well and can support her to live a good life.

While the focus for them in building her network was not specifically building her decision-making capacity, it was an unintended consequence of her rich social capital.

### An Introduction to Supported Decision-Making

100% COMPLETE

- What is Supported Decision-Making?
- Where Did Supported Decision-Making Come From?
- Why is Supported Decision-Making Important?
- Turning Substituted Decision-Making on its Head
- Support to Exercise Legal Capacity

Supported decision-making is about helping others to make decisions, but its vision in many respects is revolutionary.

### Building Decision-Making Capability

20% COMPLETE

- What Makes a Good Decision Maker?
- Rethinking Capacity
- Emily's Story
- A Different Starting Point

When we embrace this different way of thinking about capacity it changes the starting point for us as decision supporters.

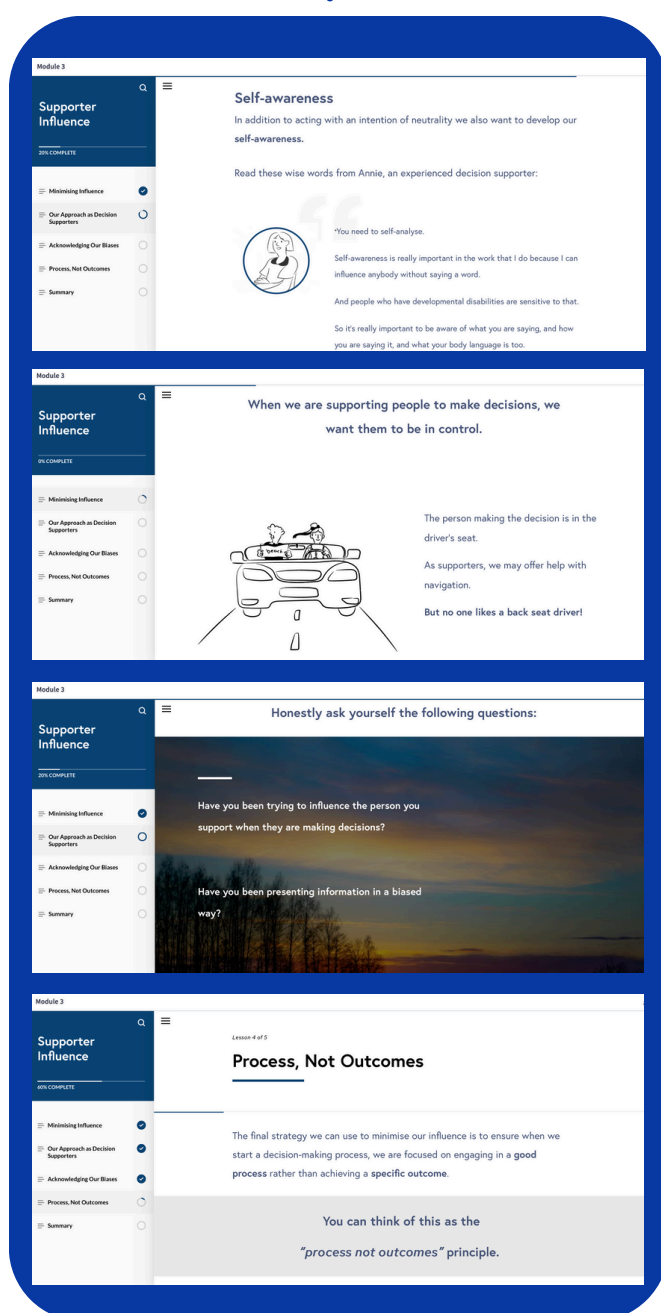
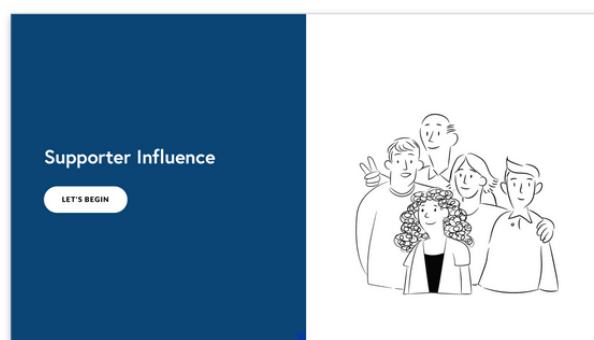
We start by exploring people's abilities and how we can add to them when providing support.

We don't start working with people by assessing their decision-making capacity and focusing on their deficits.

If we choose to think about capacity differently it changes the starting point for us as decision supporters.



# Module 3



## Conclusion

Supported decision making is an important practice needed to enable the human rights of people with disability. In Australia, health professionals need to be able to practise supported decision making to enable equitable access to health care for all Australians (Disability Royal Commission, 2023, vol. 4, Recommendation 4.9(d)).

This section of the report has outlined a program of activities conducted by the Living My Life Project aimed at building sector capacity to practise supported decision making.

The Living My Life Project developed and facilitated specialised supported decision making training to a range of professionals across community, mental health and acute care settings. Feedback from the events was overwhelmingly positive and highlighted the importance of engaging frontline staff in the important work of culture change. The Living My Life Project has also developed a suite of video and e-learning resources that will continue building the capacity of the sector to provide supported decision making well into the future.

## 4. Be Well Plan: Mental health and wellbeing training

### Introduction

This section details the findings of one component of the Living My Life Project, which investigated the feasibility of establishing sustainable wellbeing training capacity for participants of the National Disability Insurance Scheme (NDIS), with a focus on enhancing accessibility of and capacity within mainstream services.

SAHMRI offered the Be Well Plan to a cross-section of individuals who provide services to, or support (formally and informally) people on NDIS plans. We assessed the effectiveness of the program for those cohorts and explored how the program might be made available to NDIS participants themselves. This section of the report is structured in line with these overarching aims. It:

- provides a background to and rationale for the wellbeing training provision
- gives a brief overview of the research methodology
- documents the insights from a rapid review of studies on wellbeing training programs for people with a disability
- analyses the reach and the impact that the wellbeing training has had on participants
- details the insights from interviews and focus groups on future implementation of wellbeing training within the NDIS sector
- documents the findings from co-design sessions to help create an NDIS-friendly version of the program, starting with adaptations for people with intellectual disability
- describes the start of a co-design process to determine what was needed to improve accessibility of mental health measurement tools for individuals with an intellectual disability.



## Team members

This component of the project was conducted largely by SAHMRI and Be Well Co staff members:

- Dr Joep van Agteren, Co-lead, SAHMRI Be Well Co
- Dr Matthew Iasiello, Senior Researcher, SAHMRI Be Well Co
- Laura Lo, Research Assistant, SAHMRI Be Well Co
- Jan McConchie, Living My Life Project lead
- Lisette Claridge, Living My Life Project public sector lead
- Pat Rix, co-design, Tutti (retired founder)
- Trish Ferguson, co-design and lived experience
- Sarah Byrne, co-design and lived experience, SACID
- Tutti Arts Inc, lived experience artists, video production
- SACID lived experience research team, co-design and easy read and testing of measurement
- Training (Be Well Plan)
  - Lou Pyman, training lead, SAHMRI
  - Nicola Otto, training team, SAHMRI
  - Katrina Webb, training team lived experience (Paralympian); Silver 2 Gold High Performance Solutions
  - Stuart Freebairn, training team, SAHMRI
  - Kim Seow, training team SAHMRI.

We would like to sincerely thank a number of brilliant human beings whose input has been instrumental in achieving our project's aims, helping us move one step closer to developing a sustainable wellbeing training capacity for individuals who engage with the NDIS:

- Margaret Brown, UniSA
- Chris Nelson, Manager, SA Intellectual Disability Health Service
- Stephanie Searles, SA Intellectual Disability Health Service
- Liz Forsyth, Brain Injury SA
- Kate Harris, Northern Adelaide Local Health Network
- Laine Dunne-Haynes, SACID
- Suzanne Merral, Tutti Arts Inc
- Kathryn Ayles, Brain Injury SA.

# Background to and rationale for providing wellbeing training to the NDIS sector

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## Supported decision making and the impact on wellbeing

This shift to the new NDIS comes with consequences for the individual as well as their care environment. While empowerment and the building of self-agency is typically associated with increased overall wellbeing (Deci & Ryan, 1995), in reality a number of barriers exist, which might drive downstream issues in wellbeing and mental health. These include:

- barriers to communication and understanding for individuals and their caregivers
- poor knowledge of intellectual disability health needs of carers and professionals
- perceived negative attitudes to disability among health professionals
- failure to identify health issues as distinct from disability issues (diagnostic overshadowing)
- physical inaccessibility, time constraints, lack of knowledge and unhelpful attitudes.

The Living My Life Project set out to directly improve some of these issues by building the capacity of individuals with disabilities and impaired decision-making capacity under the guardianship of the Public Advocate. It aimed to assist them to express and obtain their life goals, including future healthcare wishes, using supported decision making practices.

While the provision of resources and introduction of processes to improve the supported decision making process can aid in overcoming several challenges, the impact of the transition to a supported decision making process and the identified barriers will inevitably flow on to exert an influence on the general mental health and wellbeing of everyone involved in the decision-making process.

By investing in wellbeing supports that can support the sector, the flow-on effects on mental health status of the changes may be reduced, and as such can aid in better implementation of supported decision making, while at the same time helping improve the mental health of a vulnerable population in society.

## Building wellbeing capacity within the NDIS sector as a foundation to supporting the mental health and wellbeing of individuals with a disability

Supporting the community around a person with a disability is understood to positively impact the person (Lancaster et al., 2023; Savage & Bailey, 2004). This community and the disability sector are experiencing a period of rapid change. With this change, be it negative or ultimately positive, comes heightened mental health challenges, e.g. increased levels of stress.

NDIS support workers, given the nature of their work, are exposed to a complex array of personal interactions and the need for independent thinking to address interpersonal dilemmas (Cocker & Joss, 2016; Judd et al., 2017; Ryan et al., 2021). They are exposed to intolerance and prejudice. They are asked to be patient and professional at times when others are not displaying the same. They invariably work without experienced personnel nearby if they find the need to escalate issues. They are at high risk of compassion fatigue and burnout. These factors inevitably impair their ability to regulate their own mental health, which subsequently impacts clients' wellbeing.

Considering the mental health needs of NDIS participants (Emerson et al., 2010; Torr & Davis, 2007; Tough et al., 2017), together with the needs of those that support NDIS participants, not only provides a challenge, but also an opportunity to consider how existing offerings can be optimised to service the sector in general. For example, delivering the same evidence-based wellbeing training to carers and support staff can help create a common language and understanding, and create a foundation for the delivery of services to NDIS participants. Many mainstream services provide opportunities to do so, e.g. many services deliver via peer-support programs or provide train-the-trainer approaches to build capacity within existing organisations. Building this capacity within existing services not only benefits the personal mental health of the trainers and other staff; it provides a crucial

opportunity to determine which contextualisations or adaptations need to be considered to make training offerings suitable for those with a disability.

While the utility of wellbeing programs for the general public is well established (van Agteren, Iasiello, Lo et al., 2021), their feasibility and acceptability in relation to the care environment of persons with a disability is much less established. This lack of knowledge on utility specifically applies to mainstream offerings, that is, offerings that have been developed for the whole population. An opportunity lies in determining how these mainstream offerings can be enhanced to support the NDIS sector, both its staff and NDIS recipients. By doing so, there is the potential to dramatically improve accessibility to services for the sector, as it opens up opportunities beyond specialised services, facilitating more choice for people in the sector who wish to improve their wellbeing.

In line with the wider focus on capacity building in the NDIA Information, Linkages and Capacity Building grants, the project set out to test to what extent a pre-existing universal training program could be utilised to upskill disability services staff, how the outcomes of that training would flow on to their interactions with their clients, and which enhancements and learnings would need to be considered to ensure more access to and use of the training for the disability sector.



### NDIS partner organisations

At the core of the project lies the engagement with existing NDIS service providers and other organisations that are part of the care environment. The following organisations accepted the invitation to be part of the project. They released staff to attend the Be Well Plan training and to participate in post-training focus groups and/or to provide feedback. Some were also involved in specifically targeted co-design work.

- South Australian Office of Public Advocate staff (client services) – guardianship
- South Australian Department for Health and Wellbeing – Northern Adelaide Local Health Network – representatives from all units including frontline staff
- South Australian Office of the Chief Psychiatrist (Lived Experience Advisory Group) – lived experience and family members
- South Australian Council on Intellectual Disability (SACID) (peak body) – training coordinators, NDIS participants and a co-design project partner
- Brain Injury SA (BISA) (peak body) – allied health staff and family and support network
- NDIS Local Area Coordinators – Mission Australia and Baptcare
- members of National Disability Services (industry association): HCO, CLO, Lighthouse and Lutheran Care – workforce
- SA Government Accommodation Services (service providers) – service delivery
- SA Care (private sector service provider) – frontline service delivery
- Tutti Arts (program delivery) – frontline program staff plus NDIS clients
- JFA Purple Orange (training and services provider) – co-design project partner.



# About the training

## Research on interventions to build wellbeing in the disability sector

While individual mainstream service provision by itself may not be optimised to service a wide variety of people with different disabilities, many of their core components and theoretical foundations have – at least to a certain extent – been tested for utility in these populations (Brown et al., 2011; Reichow et al., 2013). For example, for people living with cognitive disabilities research over the years has focused on early intervention and the education system. A 2020 literature review on resilience in adults with an intellectual disability included six studies that focused on promoting resilience in formal and informal social networks (Scheffers et al., 2020). A systematic review of cognitive behavioural therapy for anxiety in adults with intellectual disabilities identified 19 studies reporting cognitive behavioural interventions for people with intellectual disability and anxiety (Dagnan et al., 2018). These studies included core components such as psycho-education (8 studies) and approaches addressing beliefs or self-statements (11 studies), while utilising relaxation (12 studies) and exposure-based approaches (6 studies).

While these studies have merit in advancing our knowledge on the mental health of people with disabilities, it is important to highlight that they overwhelmingly do not focus on states of wellbeing. These interventions tend to target states of pathology and deficits, rather than states of wellbeing or strengths. It is important to understand that states of pathology and states of wellbeing can co-occur; they are functionality independent albeit related (van Agteren & Iasiello, 2020; Iasiello & van Agteren, 2020).

In other words, states of wellbeing are more than the absence of pathology. They require their own assessment methods and dedicated interventions (see the following subsection). This is important as it facilitates a completely different approach to mental health provision, which is applicable to a much wider audience, that is, people with and without symptoms of diagnosable mental illness.

Thankfully, much has been written about how a specific focus on building wellbeing can benefit the disability community. The Oxford handbook of positive psychology and disability edited by Michael Wehmeyer (2013) is a comprehensive resource. Michael Wehmeyer continued his contribution to the disability field as a member of the authoring team of Cambridge University Press's Supported decision making: Theory, research, and practice to enhance self-determination and quality of life (Shogren et al., 2018). He and his colleagues have also published on character strengths for this community (Niemic et al., 2017), and on the importance of self-determination to quality of life of people living with intellectual disability (Wehmeyer, 2020).

This combined body of research – both traditional and that which is focused on wellbeing – shows that the underlying foundations for psychological services are maintained when working with people with disability, providing an important parameter to build a case for improving access to mainstream service provision (as opposed to dedicated services for anyone with a disability). The foundations apply; the question remains what needs to happen to the actual service provision to optimise its accessibility for both staff and individuals within the NDIS sector.

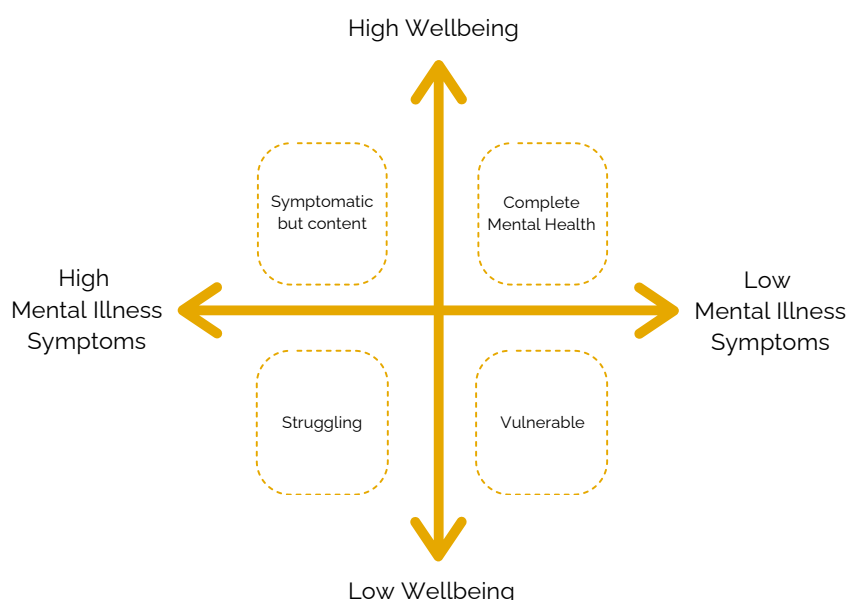


Figure 3: Visual representation of a dual-factor model of mental health, differentiating between states of illness and wellbeing, and allowing for the creation of four distinct quadrants: 'high wellbeing with illness (symptomatic but content)', 'low wellbeing with illness (struggling)', 'low wellbeing without illness (vulnerable)' and 'high wellbeing without illness (complete mental health)'

## Operationalising mental health: Targeting wellbeing in line with dual-factor models

At the core of the Living My Life Project lies capacity building and a focus on tapping into strengths together with combatting any weaknesses. Within mental health care, service provision often defaults to targeting deficits, despite the presence of valid and impactful alternative approaches. This is because many mental health models of care are implicitly underpinned by a bipolar model of mental health, where states of mental illness and mental wellbeing lie on two extremes of the same continuum.

This way of conceptualising mental health is increasingly challenged by contemporary academic research (Iasiello & van Agteren, 2020) showing that states of illness can co-occur with states of wellbeing. For example, someone who is diagnosed with psychosis (a mental illness) can also experience a sense of meaning, autonomy and self-development (states of mental wellbeing). Viewing wellbeing as distinct from illness is also a basic tenet in personal recovery models, which emphasise living a satisfying, hopeful and contributing life, even within the limitations caused by illness (Hurst et al., 2022).

This opens up targeting states of wellbeing as distinct methods<sup>2</sup> to both prevent and recover from states of illness (Iasiello et al., 2019; Wood & Joseph, 2010).

There are a variety of models that support these more nuanced conceptualisations of mental health, wellbeing and illness, the most influential being so-called dual-factor models (Keyes, 2002). These dual-factor models underpin the Be Well Plan and the wider mental health and wellbeing work conducted in this project. In practice this means that there is an emphasis on reducing indicators of distress together with wellbeing, by addressing both the common and unique drivers of each state. It offers a more comprehensive and empowering view of mental health and living with mental health conditions, which is particularly relevant for individuals with more significant intellectual and psychosocial disabilities, who often experience comorbid enduring mental illness.

<sup>2</sup> Distinct from methods of treatment for pathology or illness.



## High-level overview of the Be Well Plan

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Participants throughout the Living My Life Project gained access to a pre-existing group-based psychological skills training called the Be Well Plan, which is a five-session (10.5 hour) program that teaches people to find and master easy-to-use skills to build their mental health and wellbeing. The program was designed to be a universal program that allows individuals to craft a personalised wellbeing strategy. Self-determination and agency lie at the core of the program.

The program was developed and tested by the South Australian Health and Medical Research Institute (SAHMRI) and Flinders University prior to the start of the Living My Life Project, using a rigorous intervention mapping approach and co-design principles (van Agteren, Ali et al., 2021; van Agteren, Iasiello, Ali et al., 2021), with a significant body of underlying evidence informing its development. The design process started with an extensive systematic review and meta-analysis of the most effective ways to improve mental wellbeing (van Agteren, Iasiello, Lo et al., 2021). The review evaluated 419 randomised controlled trials (with a combined sample size of 53,288 participants), to identify activities that are most effective at building mental wellbeing and reducing psychological distress. From this review 30 activities were identified, stemming from evidence-based paradigms such as acceptance and commitment therapy, cognitive behaviour therapy and positive psychology, which form the backbone of the Be Well Plan. The evidence-based activities include mindfulness, thought challenging, self-compassion, strengthening relationships and problem solving, to name a few. An outline of the five sessions is provided in Appendix 13.

The brief activities (5–15 minutes) were designed to be easily completed and implemented daily, allowing participants to embed them into their busy lives as habits to improve their mental health. Throughout the Be Well Plan individuals learn different strategies and experiment with these activities to deal with stress and challenges, and to build strong levels of mental wellbeing and resilience. A core assumption of the Be Well Plan is that everyone is unique and therefore the program is focused on assisting participants to develop a tailored wellbeing plan that suits their individual needs and circumstances and assists them to live a life in line with their own values.

In essence, the Be Well Plan includes the following overarching features:

1. assists individuals to develop their own tailored mental health and wellbeing program by allowing individuals to choose and practise activities that they enjoy and can embed into their daily lives as a habit
2. teaches participants helpful psychological insights, and contrasts these to less helpful psychological pitfalls
3. helps participants to learn more about their mental health and track this across the program, using this information to choose areas they wish to work on, including mental wellbeing, resilience, depression, anxiety or stress
4. encourages habit formation in order to ensure the longer lasting impact of the program.

### A technology-enabled program

The Be Well Plan is a hybrid training which can be taught in person or via teleconferencing software. The training is supported by technology to help improve its impact and engagement. There are two key technology components:

- Integrated within the program is SAHMRI Be Well Co's wellbeing measurement platform, which allows training participants to track their wellbeing over the course of the program, and provides additional mental health and wellbeing articles and resources.
- The training is accompanied by a smartphone application that helps participants put the training into practice. The app is a complementary tool: participants can choose to use the app or not. The usefulness of the app was tested as part of this project in two phases (see below).

This technology component adds a layer of complexity to implementation of the program for individuals with a disability (Roulstone, 2016). Rather than deciding to eliminate the technology component for this specific project, we decided to aim to learn how to make the technology more accessible where possible. Hybrid and technology-assisted programs are becoming more common, partly driven by the COVID-19 pandemic, making it important to provide guidance on accessibility for the disability community when it comes to mainstream service offerings.



## The train-the-trainer process

The program utilises a train-the-trainer framework (Pearce et al., 2012), where the goal is to upskill staff within local organisations, rather than relying on scarce clinical resources and expertise. This not only facilitates scalability, but also ensures that valuable capacity is built within local partner organisations. It improves training delivery as trainers are able to bring in their own contextual expertise, increasing the relevance for the training participants.

This is an essential feature of the program. As individual tailoring lies at the core of the program, the notion is that the Be Well Plan can be utilised across different contexts with minimal need for adaptation. Within the program, trainers have the ability to contextualise information and examples. In higher risk settings or settings where more contextual information is required, the program is book-ended with tailored sessions (as opposed to tailoring the content of the core program). This personalisation feature is especially useful through the lens of accessibility, allowing trainers and individuals to adjust the program to individual needs.

Trainers were recruited via two methods:

1. SAHMRI Be Well Co provided training to a cohort of staff, volunteers or constituents of partner organisations, after which the organisation nominated a potential trainer.
2. The partner organisation selected trainers in advance, who enrolled directly in the train-the-trainer process.

Upskilling local capability within service providers lays the foundation for improving the transfer of wellbeing concepts and training to NDIS participants in the future, both via professional staff and their interactions with their clients and later via peers (Shalaby & Agyapong, 2020). To do so, it is essential to determine which enhancements need to be built to make the training more accessible. In line with empowering NDIS participants to utilise existing services, rather than developing new services which may not be necessary, the aim was to improve an existing evidence-based training, rather than to design a training from scratch for the target population. By doing so, we aimed not only to better service those NDIS participants who directly engage with our partner organisations, but also to ensure additional elements can be added to the generic program, ultimately benefitting individuals with a disability who access the training via another channel (e.g. workforces, community organisations, universities).

The process relied on a staged delivery approach:

- deliver training to staff at NDIS support organisations and selected NDIS participants
- get feedback on the program and gather suggestions for changes for a wide variety of NDIS participants
- upskill a subset of participants into certified trainers who are embedded within the NDIS support network.

The above process resulted in a set of clear recommendations for enhancements to be made to the general training. In order to support the recommendations, a literature review was conducted on existing wellbeing interventions. The aim was to determine the landscape of wellbeing research and draw on its learnings for the future benefit of individuals with a disability.

## Informing a future easy read version of the program

A dedicated co-design objective was included in the project to investigate how the program might be made more accessible to NDIS participants. In this context ‘participants’ includes those on plans and their supporters, paid and unpaid (formal and informal). The parameter that the co-design worked within was the principle of assumed capacity not assumed incapacity, using the concept of supported decision making.

As it has been recognised that pragmatic enhancements to the training may not immediately enable NDIS participants with a more profound learning or cognitive disability to participate, the project set out to conduct co-design work to inform the development of an ‘easy read’ set of tools for the program. While not the core focus of the original program – which focuses on how to optimise mainstream offers without large-scale adaptations – it was deemed important to utilise the expertise of some of the training participants to develop an easier-read version for trialling in the future. This would include developing more accessible ways to include or translate some of the technology components.

For example, a digital tool that is used in the Be Well Plan training provides the individual with a report describing and ranking their ‘character strengths’ or the way values are reflected within the individual’s behaviour. The study of character has emerged within the field of positive psychology as a means of classifying and building on positive traits that reflect universal capacities for thinking, feeling and behaving in ways that benefit oneself and others, and enhance valued life outcomes (Peterson & Seligman, 2004).

To delve into character strengths, the training uses an online tool developed by the VIA Institute at the University of Pennsylvania.<sup>3</sup> Preliminary research suggests that tools to assess character strengths are equally reliable and valid for those with intellectual disabilities, and modifications (e.g. wording changes, cognitive supports) can be used to enable people with intellectual and developmental disabilities to understand character strengths (Niemi et al., 2017). Further, an emphasis on character strengths also has implications for those that support people with intellectual disabilities. For example, researchers have found that promoting mindfulness in support providers using a strengths-based approach can significantly and positively impact the provision of supports (Singh et al., 2010). Co-design work confirmed a good understanding not only of the concept of character strengths but also of how to discuss them with respect to self and others.

The result of the co-design process was the creation of a dedicated easy read version of the program, including a set of videos to be used as support material to help bring core activities to life. Additionally a process was started to test how best to improve the accessibility of the program’s integrated wellbeing measurement approach.

<sup>3</sup> <https://www.viacharacter.org/>



# Study methodology

## Methodology for the rapid review

In order to investigate the current state of scientific research on psychological interventions to build wellbeing in people with a disability, which informed the development of the intervention, a rapid review was conducted, following the Cochrane Rapid Review methodology<sup>4</sup>. Our methods and results were reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Page et al., 2021). Following the Cochrane guide, a key stakeholder group was formed, with four members with roles in academia and government who have lived experience of disability.

### Search

The systematic review was based on a large previous study conducted by the authors, focused on wellbeing interventions in the general population, as well as those with a diagnosed mental or physical illness (van Agteren, Iasiello, Lo et al., 2021). The search strategy was replicated in the current study, with an additional search term of 'disability' and allowing the inclusion of non-randomised controlled studies. The search was conducted in two databases, PubMed and PsycInfo, ensuring high coverage of both the medical and psychological literature.

### Eligibility criteria

Citations were included if they were original studies, available in English, published in peer-reviewed journals, included a psychological or behavioural intervention, were randomised or non-randomised controlled studies, and focused on people with disability. Disability was defined using the NDIS definition: 'A person who has any or all of the following: impairments, activity limitations (difficulties in carrying out usual age-appropriate activities), and participation restrictions (problems a person may have taking part in community, social and family life)'.<sup>5</sup> This definition allows for some grey areas and reviewers erred on the side of including studies if it was unclear whether the participants of the study would be considered disabled by the NDIS.

Studies were excluded if they included pharmacologic or predominantly physical interventions. Interventions that are focused on infants were also excluded, as well as interventions that were principally aimed at improving the wellbeing of parents or caregivers of those with a disability.

### Screening and data extraction

Search data were exported to EndNote for removal of duplicates and screening. Two reviewers individually screened titles and abstracts of the identified records. After downloading the full text, the same two reviewers conducted full-text screening. A third reviewer was used to settle any disputes at the screening stage. Data extraction was conducted on included studies. Extracted data included: year of study, participant characteristics including description of disability, type of intervention (e.g. mindfulness, cognitive behaviour therapy), mode of intervention delivery (face-to-face, online, group-based, with/without guardian/carer), intervention adaptations, and a summary of the primary and additional outcomes.

<sup>4</sup> <https://methods.cochrane.org/rapidreviews/>

<sup>5</sup> <https://www.ndis.gov.au/about-us/glossary>

## Methodology to determine impact of the training

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### Outcome measures

As part of the training, participants' mental health is measured at the start and at the final session. This embedded measuring facilitates an estimate of the impact of the training on mental health and wellbeing outcomes.

- Wellbeing was measured using the Mental Health Continuum Short-Form (MHC-SF) (Iasiello et al., 2022). The MHC-SF is a valid and reliable measure of wellbeing, providing both a continuous measure of three key domains of wellbeing (hedonic, eudaimonic and social wellbeing), as well as a 'diagnosis' of overall wellbeing into 'flourishing' or high wellbeing, moderate wellbeing, and 'languishing' or low wellbeing.
- Psychological distress was measured using the Depression Anxiety and Stress Scale – 21 items (DASS-21) (Henry & Crawford, 2005). The DASS-21 has clear cut-off points for level of severity of symptoms, allowing grouping of scores into 'mild', 'moderate', 'severe' and 'extremely severe' symptoms of psychological distress.
- Finally, the participants' own interpretations of their ability to deal with and bounce back from stress or adversity (or their resilience) were measured using the Brief Resilience Scale (BRS) (Smith et al., 2008). The BRS conceptualises resilience as an outcome and is a well-accepted tool to gain insight into resilience (Windle et al., 2011).

The above combination of scales has been used in a variety of Australian observational and interventional studies, including studies led by SAHMRI, and can therefore, in addition to being used as reliable outcome estimates, be used to establish a benchmark.

### Setting and participants

The project team set up partnerships with NDIS partner organisations to ensure the project reached a diverse group of people with disability. See 'NDIS partner organisations' above for an overview of the organisations that were involved in upskilling their staff and volunteers.

Benchmarking was conducted against other individuals who engaged with the Be Well Tracker and those participating in the Be Well Plan, allowing us to determine any baseline differences between project participants and the general community. Control group members were either members of the general public (i.e. individuals who sought out wellbeing services offered by SAHMRI) or were individuals belonging to an organisation that conducted a wellbeing project with SAHMRI.

### Procedure

Participants were recruited via the partner organisations, with organisations determining who could take part. Participants were sent an information email and an invitation to the first measurement with the outcome measures mentioned above.

Participants continued with the training by following the weekly sessions. If a participant missed a session, they got access to a pre-recorded version provided on a website hosted on the VIMEO platform. This allowed participants to continue with the program even if they missed sessions. At the end of session 4, and before session 5, participants were asked to complete another measure. A subset of participants was invited to focus groups to provide feedback on the training and to deliver suggestions for its improvement (see 'Qualitative study and co-design' section below).

Training was provided online or in person, at SAHMRI or at suitable venues provided by the partner organisations. The use of online training delivery was mainly necessitated due to restrictions in response to the COVID-19 pandemic. Nominated individuals within organisations continued into the train-the-trainer process. Over the course of two months, they took part in 30 hours of additional training, after which they became certified to deliver the training themselves. Information about the train-the-trainer process can be found in Appendix 14.

### Data analysis

The impact of the training was determined by investigating the average difference between the scores on outcomes at the first and the last session. These differences were investigated by a repeated measures Multivariate Analysis of Variance (MANOVA). The technique was chosen as we needed to account for the considerable overlap between the selected outcome measures. Scores generally correlated between 0.5 and 0.8, showing a clear relation between the variables. Effect sizes will be provided where possible to accompany significance tests.<sup>6</sup>

<sup>6</sup> Instead of eta-squared – the default effect size used in MANOVA – we calculated Cohen's *d* as a way to quantify the effect to aid in interpretation by readers.

## Methodology for co-design and qualitative research

### Focus groups and interviews

Training participants were approached to take part in focus groups or individual semi-structured interviews. The goal was to explore various topics related to implementation of the training for the NDIS sector including:

- feedback on the training content and the facilitators for the individual personally
- application of the content in personal and/or work life
- feedback on technology components
- insights on required adaptation for the NDIS sector.

The interviews were semi-structured with questions evolving over time based on inputs received from participants. The interviews and focus groups were conducted by SAHMRI staff.

Focus groups and interviews that were scheduled after training rounds were provided in person, at SAHMRI or at suitable venues provided by the partner organisations. Where required, e.g. in the case of restrictions in response to COVID-19, the training and focus groups were moved online.

Data from the focus groups were analysed using natural thematic analysis. Focus group responses were documented and themed. No transcripts were recorded verbatim. Where recordings were made of interviews, e.g. to aid in analysis, these were destroyed after the interviews or focus groups were completed.

### Co-design methodology for accessibility

SAHMRI project staff partnered with SACID and the recently retired CEO of Tutti Arts Inc Pat Rix to review the Be Well Plan material and training methodology, drawing on the experiences of three participants who have intellectual disability who participated in the plan in its existing form. Pat has worked for over 20 years building wellbeing and resilience for Tutti's clients who are living with disability through the practice of art in all its forms. The project lead, who has a 35-year-old son with Down Syndrome and established, 10 years ago, an independent home for him and six others, now NDIS participants, also brought her experience to the co-design work.

- SACID is the peak body for people with intellectual disability in SA. Two SACID staff (Manager Workshops and lived experience member with Down Syndrome) attended the Be Well Plan training in its usual format face to face, in an open group with two trainers. Due to changing COVID-19 restrictions one of the sessions was delivered online, which therefore brought a different element to training provision for someone with an intellectual disability. A member of the SAHMRI project team joined the SACID participants and documented the lived experience person's response to the training. As part of the project, the team member had previously been trained in easy read (through the SA Council on Intellectual Disability).
- Tutti has been working with disabled artists for 20 years. Tutti's programs are open to all NDIS participants, with many having been with Tutti a long time, leading to a membership growing to 200 artists in 2020. In their work, Tutti considers their artists as having learning difficulties rather than disabilities. They work with a social model of disability (Shakespeare, 2016).



Above: A still from the short film Introduction to yoga, led by V Barratt

Feedback from SACID and Tutti was gathered independently and used to co-design the easy read version. The focus for Stage 2 was to answer the following questions:

1. Was the material accessible (was there assumed knowledge including scientific knowledge)?
2. Did it trigger in a way that was counter-productive in this setting (psychological experiences)?
3. What might be an optimal delivery format?

The activities built into the Be Well Plan were reviewed for

1. the effectiveness of the exercises chosen to demonstrate/have an impact on the principles being taught, and
2. the appropriateness of the exercises given the social constraints experienced due to disability.

Finally, SAHMRI conducted a feedback process via interviews and focus groups on its current measurement methodology together with staff and clients from SACID, gathering insights on the current suitability and accessibility of wellbeing measures, resulting in recommendations for adaptations.

# The insights from the rapid review of studies on wellbeing training programs

Stakeholders who are interested in service provision for people with a disability benefit from developing an understanding of the research landscape surrounding wellbeing interventions that have specifically been tested for people with a disability, e.g. to determine whether a specific therapeutic approach has already been tested in the context of improving mental states of wellbeing (not the alleviation of distress, but rather stimulating positive states of mental health). The below rapid review provides an overview of studies up to August 2022.

## PRISMA statement

The results of the search are displayed in Figure 4. During the screening process, reviewers observed that many studies which aimed to improve the wellbeing of participants used measures of resilience or self-efficacy to evaluate the effectiveness of the intervention. For this reason, these studies were included in the final number of studies included in the review.<sup>7</sup>

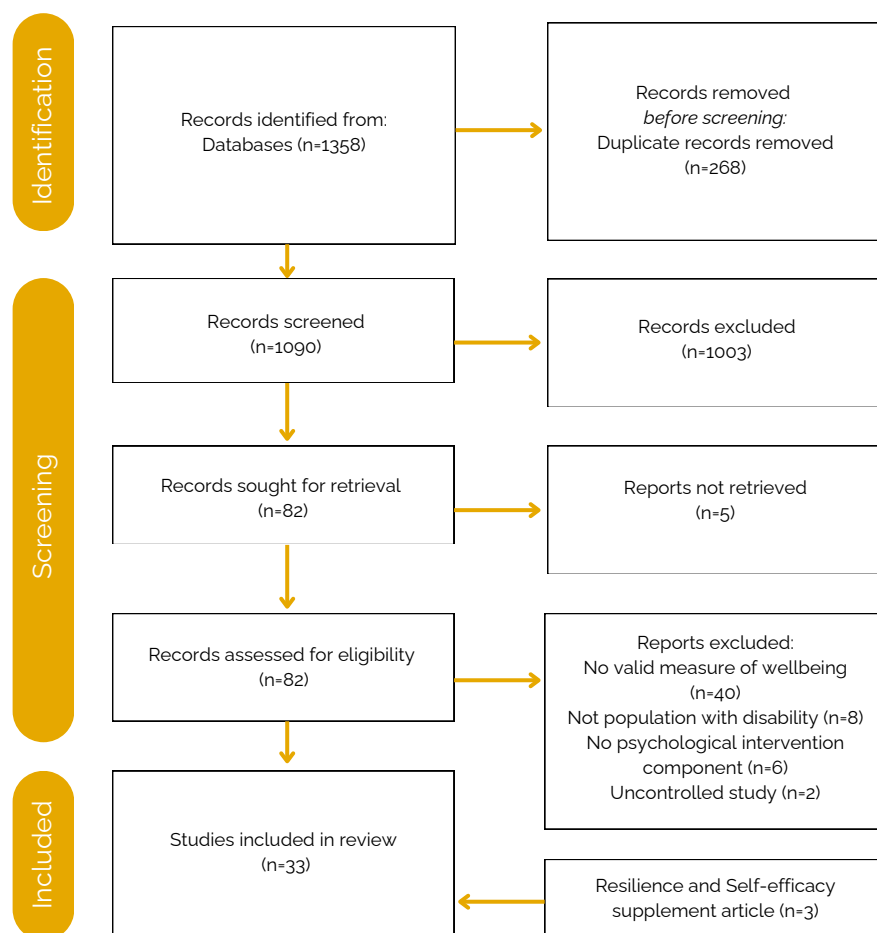


Figure 4: PRISMA statement of the search results

<sup>7</sup> Please note: the outcomes for resilience, self-efficacy and wellbeing are not synonymous with one another. Caution should be exercised when interpreting the results.



## Number of publications

Figure 5 illustrates the rate of publications identified in the current review over time. It demonstrates that studies aimed at improving the mental wellbeing of individuals with a disability grew in the mid-2000s and have steadily increased over time, showing a seemingly linear growth. This growth can be considered relatively small, compared with the exponential growth observed in other fields of wellbeing science (Cebral-Loureda et al., 2022).

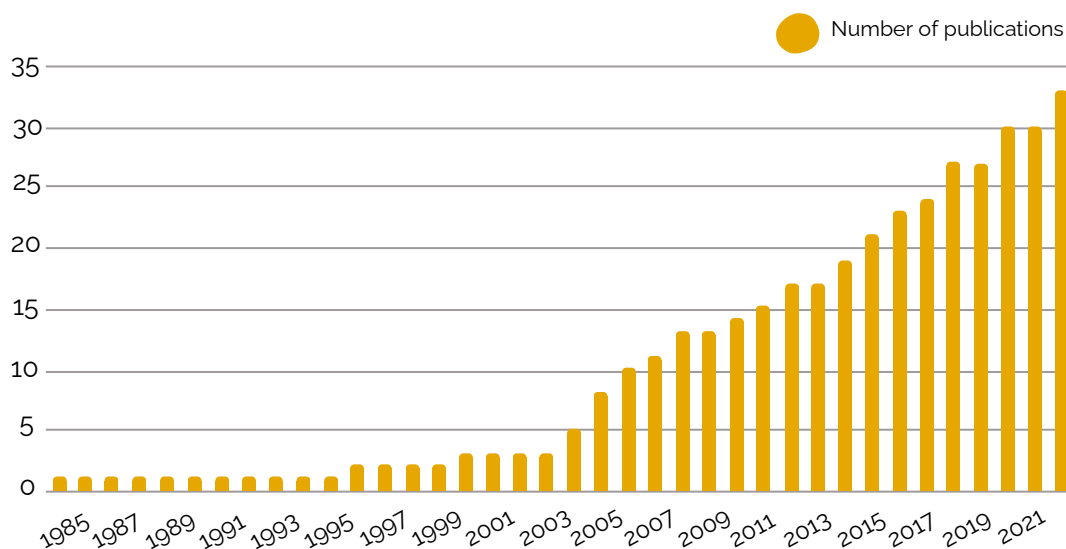


Figure 5: Cumulative number of publications over time

## Conditions

Table 1 shows the breakdown of conditions that were included in the studies identified in the review. Most studies focused on chronic pain (n = 9), multiple sclerosis (n = 4), and tinnitus (n = 3). Four studies included a mix of disabilities.

Table 1. Count of conditions included in the studies identified in the review

Condition	No.
Chronic pain	9
Mixed disabilities	4
Multiple sclerosis	4
Tinnitus	3
Intellectual disabilities	2
Osteoarthritis	2
Panic disorder	1
Parkinson's disease	1
PTSD	1
Rheumatoid arthritis	1
Spina bifida	1
Tourette syndrome	1

Table 2 reports the number of interventions that were included in the studies identified in the review. The large majority of studies included behavioural or cognitive behavioural therapy (CBT; n = 12). Other interventions that were studied more than once included positive psychology interventions (PPI; n = 4), psychotherapy (n = 3), acceptance commitment therapy (ACT; n = 2), and self-management skills (n = 2).

## Intervention types

**Table 2:**  
Count of interventions included in the studies included in the review

Intervention	No.
Behavioural or cognitive behavioural therapy (CBT)	12
Positive psychology intervention (PPI)	4
Psychotherapy	3
Acceptance commitment therapy (ACT)	2
Self-management skills	2
Case-management skills	1
Coping skills	1
Expressive art	1
Music therapy	1
Resilience training	1
Service dogs	1
Stress management	1
Motivational interviewing	1
Written emotional disclosure	1
Yoga	1

## Mode of Delivery

The count of intervention modes of delivery is reported in Table 3. Interventions were most commonly delivered in person (n = 22) or online (n = 6).

**Table 3:**  
Count of the intervention mode of delivery

Mode of delivery	No.
In person	22
Online	6
Telephone	2

## Adaptations

Of the identified studies in the current review, the large majority of interventions were not adapted or designed for the specific population included (n = 30). Only five studies included adaptation for the specific population being studied.

## Interpretation of results

The primary and secondary outcomes, including study results, are reported in Table 4. This review aimed to search academic literature for studies focused on improving the mental wellbeing of individuals with a disability. Academic literature rarely defines the study populations by eligibility for disability support (i.e. NDIS), rather by diagnoses and severity of conditions. As a result, we included an intentionally broad set of conditions that could be considered disabilities, i.e., we accepted any study where the authors indicated that they targeted populations of disability. Despite this broad search, a major result of this review was that only a modest number of studies could be identified. The rate of publication of studies focused on interventions to improve the wellbeing of people with disabilities is much slower than the rate that can be seen for the rest of the field (Cebral-Loureda et al., 2022). In other words, it appears that the increasing importance placed on promoting wellbeing is not yet reflected in scientific studies on populations with disability.

As mentioned above, the current review adopted a broad definition of disability, and it was difficult to distinguish which studies were conducted in populations that would be classified as disabled as per NDIS guidelines. A comparison of the NDIS (2022) guidelines demonstrates that many of the conditions identified in the review are unlikely to meet the NDIS disability requirements, particularly chronic pain (the most commonly identified condition).

Many common types of psychological interventions were included in the identified studies; however, few intervention types were studied more than once, making it impossible to make claims about the impact of sub-types of interventions. One noteworthy absence in the included studies were mindfulness-based interventions, which have been demonstrated to be highly efficacious in improving the wellbeing of the general community and in the context of disability (Chapman et al., 2013; van Agteren, Iasiello, Lo et al., 2021).

Surprisingly the overall effectiveness of the interventions remained despite the apparent lack of adaptation of the interventions. This is an interesting finding considering the fact that typically contextualisation and adaptation are thought to be necessary to increase engagement and lead to meaningful interventions for people with disability (Susanty et al., 2021). It is promising that these psychological interventions demonstrate some effectiveness in people with disability, a finding which is supported by other reviews in the literature.

The ability of this rapid review to draw firm conclusions on the effectiveness of interventions at improving mental wellbeing of people with disability is unfortunately limited. Primarily this was limited by the modest number of studies identified, and the types of conditions identified. The majority of studies demonstrated positive outcomes for participants, with only  $n = 6$  (16%) reporting no effect. Most of the ineffective interventions were in the context of chronic pain, although one study was in intellectual disability with art therapy.<sup>8</sup>

It should be noted that this review set a high bar for inclusion of studies, limiting the included studies to those which used a controlled or randomised controlled study design. Previous studies have commented on this issue, finding that the intervention literature in disability is often methodologically weaker and that future high-quality studies are required (Chapman et al., 2013; Maes et al., 2021). Previous reviews on the effectiveness of interventions for people with disability have commented on the methodological weaknesses of the literature, mainly that controlled or randomised controlled studies have rarely been conducted. Future research should utilise rigorous research methodologies to test the impact of interventions on individuals with disability. For the sake of disability insurance schemes, it may be worthwhile using populations who are already on said schemes, rather than defining populations by conditions and severity.

<sup>8</sup> Previous uncontrolled studies have shown that art therapy can result in positive changes for people with intellectual disability (Burns & Waite, 2019), again pointing to the limitation of the current review and the lack of high-quality studies.

Table 4:  
Description of studies

Study	Condition	Type of intervention	Mode of delivery	Intervention adaptations	Primary outcomes	Secondary outcomes	Main result
Allen & Blascovich, 1996	'Severe and chronic ambulatory disabilities – muscular dystrophy – multiple sclerosis – traumatic brain injury – spinal cord injury'	Service dogs	In person	Extra training for dogs to suit each disability patient	Affect	NA	All participants showed substantial improvements in psychological wellbeing
Beukes, Andersson et al., 2018	Tinnitus	CBT	Online	Adapted from Swedish into English	Not wellbeing related	Anxiety, life satisfaction	Anxiety and life satisfaction only significant for within group time effect
Beukes, Baguley et al. 2018	Tinnitus	CBT	Online	'This content was redeveloped into an interactive e-learning version, to ensure it was visually stimulating and engaging'	Not wellbeing related	Anxiety, life satisfaction	'Anxiety significant (within groups only). Clinical significance (score change > 6.3) was reached by 14% of the intervention group.'
Boselie et al., 2018	Chronic pain	PPI	Online	NA	Depression, anxiety, happiness, affect	NA	Patients in the PPI condition scored higher on happiness, positive affect, and scored lower on depression and anxiety
Deckersbach et al., 2006	Tourette syndrome	Psychotherapy	In person	NA	Not wellbeing related	Life satisfaction, depression	Both groups improved in life satisfaction (even at 6 month follow-up) – active control?
Glombiewski et al., 2010	Chronic back pain	CBT	In person	NA	Life satisfaction, depression	NA	Significant improvements for life satisfaction and depression
Graziano et al., 2014	Multiple sclerosis	CBT	In person	NA	Depression, quality of life, affect	NA	Only quality of life had a significant improvement at 6-month follow-up
Hart et al., 2008	Multiple sclerosis	Psychotherapy	Telephone	NA	Affect, depression	NA	Fixed effects for time show significant improvements in affect and depression
Hausmann et al., 2017	Osteoarthritis	PPI	Hybrid	NA	Not wellbeing related	Affect, life satisfaction	Significant improvements in negative affect and life satisfaction
Heutink et al., 2012	Chronic neuropathic pain	CBT	In person	NA	Not wellbeing related	Life satisfaction, depression, anxiety	Anxiety significantly improved. Depression and life satisfaction remained stable
Ho et al., 2020	Intellectual disabilities	Expressive art	In person	NA	Wellbeing, mood	NA	No significant overall improvements for mood or wellbeing
Kahan et al., 2006	'Disabilities – polio – rheumatoid arthritis – cerebral palsy – SCI – stroke – other musculoskeletal, central nervous system or peripheral nervous system impairments'	Psychotherapy	In person	NA	Life satisfaction, depression	NA	Significantly improved life satisfaction and depression
King et al., 2011	Panic disorder	CBT	In person	Adaptations according to the characteristics of the sample of patients treated.	Wellbeing, anxiety	NA	'Overall wellbeing increased from 60.8% to 72.5% among the patients in the group with therapy, thus differing from the group without therapy. Significant reductions in anxiety'
Lindert et al., 2022	Musculoskeletal Disorders	'Case management interventions'	In person	NA	Psychological wellbeing	NA	Changes over time, significant improvements in psychological wellbeing
Magnussen et al., 2007	Back pain	'Vocational oriented – motivational interviewing, etc'	In person	NA	Not wellbeing related	Life satisfaction	Only minimal changes in secondary outcomes were registered between groups from baseline to 1-year follow-up. An exception was life satisfaction which improved significantly more in the control group.

Study	Condition	Type of intervention	Mode of delivery	Intervention adaptations	Primary outcomes	Secondary outcomes	Main result
Mohr et al., 2005	Multiple sclerosis	CBT	Telephone	Only for control group	Affect, depression	NA	There were significant improvements during treatment on all-outcome measures and an increase in Positive Affect Scale score.
Müller et al., 2016	'Chronic pain + physical disability – spinal cord injury – multiple sclerosis – neuromuscular disease – postpolio syndrome'	PPI	Online	Tailored which intervention activities participants got by scores on a questionnaire	Life satisfaction, affect, depression	NA	Significant improvements in life satisfaction, positive affect and depression
Norman et al., 2004	Chronic pelvic pain	Written emotional disclosure	Home	NA	Affect	NA	No main effect group comparisons on affect. Moderate group effects, with increased positive affect among women with higher baseline negative affect.
Pacchetti et al., 2000	Parkinson's disease	Music therapy	In person	NA	Happiness, quality of life	NA	'Over time, changes on the Happiness Measure confirmed a beneficial effect of MT on emotional functions. Improvements in in quality of life were also documented in the MT group.'
Paikkatt et al., 2012	Chronic schizophrenia	Yoga	In person	NA	Wellbeing	NA	At the end of 1 month experimental group showed better rating in comparison to control group in wellbeing.
Rini et al., 2015	Osteoarthritis	Coping skills	Online	NA	Affect	NA	Smaller effects were observed for negative affect and positive affect.
Shearn & Fireman, 1985	Rheumatoid arthritis	Stress management	In person	NA	Depression, life satisfaction	NA	No significant changes
Wicksell et al., 2008	Chronic pain and whiplash-associated disorders	ACT	In person	NA	Life satisfaction, depression, anxiety	NA	'Significant differences in favor of the treatment group were seen in life satisfaction and depression. Although an improvement could be seen for the treatment group in HADS-Anxiety, neither the difference between the groups, nor the analysis of the treatment group over time, reached significance.'
Yang et al., 2023	'Autism without intellectual disability'	CBT	Online	NA	Anxiety, affect	NA	Significant decrease in anxiety and increase in positive affect.
Zachriat & Kröner-Herwig, 2004	Chronic tinnitus	CBT	In person	NA	Wellbeing	NA	Improvement in general wellbeing is greater in tinnitus coping training than habituation-based treatment.
Zemestani 2020	Physical disability	ACT	In person	NA	Psychological wellbeing, depression	NA	Significant changes in depression and psychological wellbeing
Davidson et al., 2005	PTSD	CBT	In person	NA	Resilience	NA	Changes in resilience following treatment were statistically significant.
Roeden et al., 2014	Intellectual disabilities	Behaviour therapy	In person	NA	Quality of life, resilience	NA	Significant changes for quality of life. Resilience has two sub-scales, only 1 (social optimism) showed significant changes
Giovannetti et al., 2020	Multiple sclerosis	Resilience training	In person	NA	Quality of life	Depression, anxiety, stress, resilience	Only significant changes in secondary outcomes at 3rd timepoint follow-up measure
Janevic et al., 2022	Chronic pain	PPI	Hybrid	Cultural adaptations	Not wellbeing related	Resilience	No significant changes in resilience
Taylor et al., 2017	Chronic pain	Self-management	In person	NA	Not wellbeing related	Depression, anxiety, self-efficacy, quality of life	Self-efficacy, anxiety and depression all improved more in the intervention group at 6 months
Khan et al., 2015	Spina bifida	CBT	In person	NA	Depression, anxiety, stress, quality of life, self-efficacy	NA	Significant improvements in all outcomes
Haas et al., 2005	Back pain	Self-management	In person	NA	Self-efficacy	NA	No differences in self-efficacy

# Analysis of the reach and the impact of the training on current participants

## Overview

This report includes the insights from 228 training participants who provided consent to be included in the research and completed a baseline survey. From these, 101 participants provided a measurement at the end of the training. The first group (n = 228) will be used to report insights into the mental health and wellbeing of the sector. The second group (N = 101) will be used to report the impact of the training.

## Mental health insights compared to norms

The average age of the training participants was 42 years, with 63% being female, 11% being male and 26% choosing not to indicate their gender to the researchers. Other gender options (e.g. transgender) were also available as answer options, but were not provided as answers by any participants. No other demographics (e.g. educational status or socio-economic status) was asked as part of the study as it was not deemed to be the core focus of the research.

There were no significant meaningful differences at baseline between the study participants and our general population norms (n = 6,068) for any of the key mental health variables (see Figure 6). There were no differences in mental wellbeing outcomes or resilience, i.e. the positive and adaptive mental health outcomes. Similarly, there were no significant differences between any of the distress outcomes or on levels of burnout for those participants who were employed.

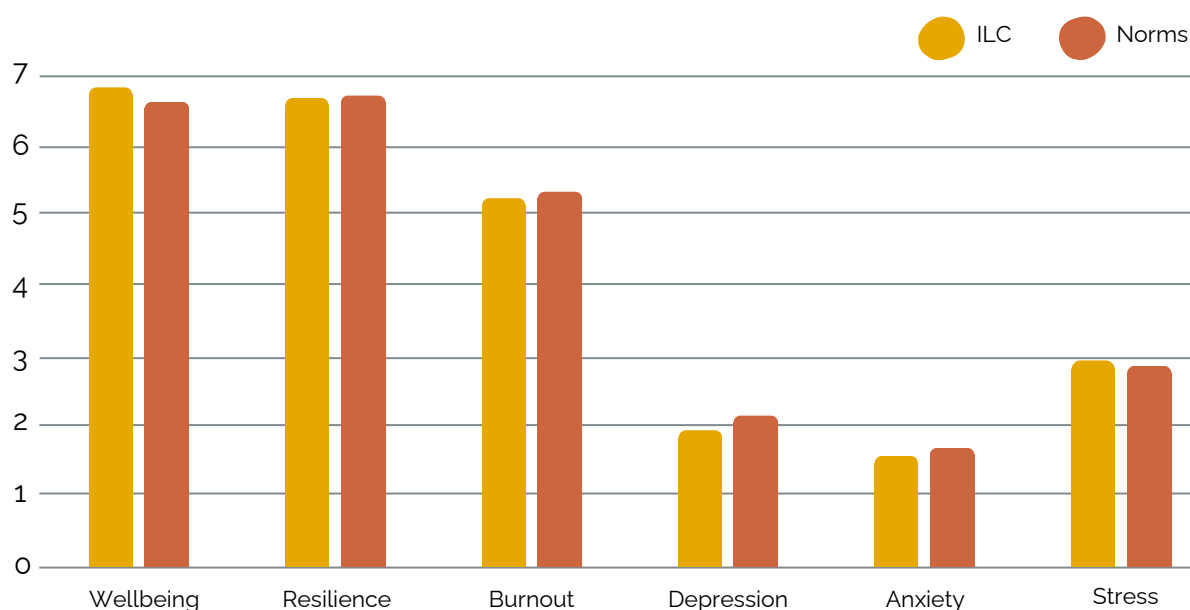


Figure 6: Baseline comparison for participants compared to general population norms for each of the measured outcomes



What the averages do not show is a clear indication of risk within the participant group. The outcome measures that were used also facilitate grouping into risk categories, as shown in Figure 7. The baseline scores show a population that is resilient, with 4 in 5 people showing high resilience. The group also shows typical rates of distress comparable to the norms.

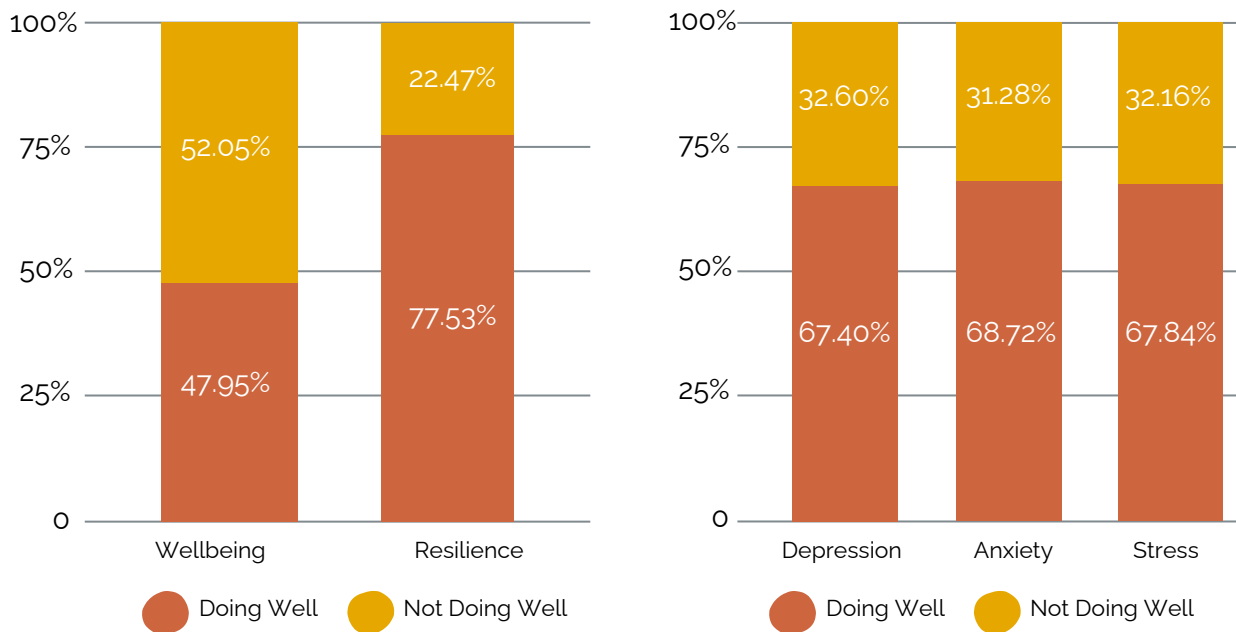


Figure 7: Baseline risk groups for positive and adaptive states (7a) and distress states (7b)

### Impact of the training

At baseline, the respondents who completed both a pre- and a post-measure trended a bit 'healthier' compared to our general population norms. This indicates that there was a difference between those respondents who completed both measures and respondents who only completed one measure, which is worth noting. While this can point to a source of bias in the sample, people with worse baseline scores tend to respond better to psychological interventions. As such it is likely that it means that the effect sizes below are conservative, i.e., they are underestimated, rather than inflated.

On the total sample, significant and meaningful improvements could be noted for all outcomes, being mental wellbeing, resilience, depression, stress and anxiety, generally displaying small but meaningful effect sizes, comparable to those found in other studies. The test statistics are displayed in Table 5.

Table 5:  
Overall statistics for mental health outcomes comparing change from beginning (pre) to end (post) of training

	Pre		Post		Sign.	Effect size
	Mean	SD	Mean	SD	p	d
Mental wellbeing	6.69	1.79	7.27	1.65	<.001	.33
Resilience	6.58	1.40	6.88	1.35	.01	.22
Depression	2.01	2.14	1.53	1.68	.03	.24
Anxiety	1.56	1.78	1.15	1.39	.02	.25
Stress	3.18	1.91	2.72	1.63	.005	.26

At the end of the training the number of people who crossed a risk cut-off was reduced, particularly for mental wellbeing. The number of people with a risky wellbeing score reduced by approximately 17%. The movement in distress scores occurred largely in the higher distress tiers, with those with severe and extremely severe distress reducing their distress levels most, explaining the lack of a change in cut-offs in the general graphs. While resilience showed a modest decrease of 4%, the lack of a more profound effect for resilience can be explained by the high baseline resilience at the start of the training

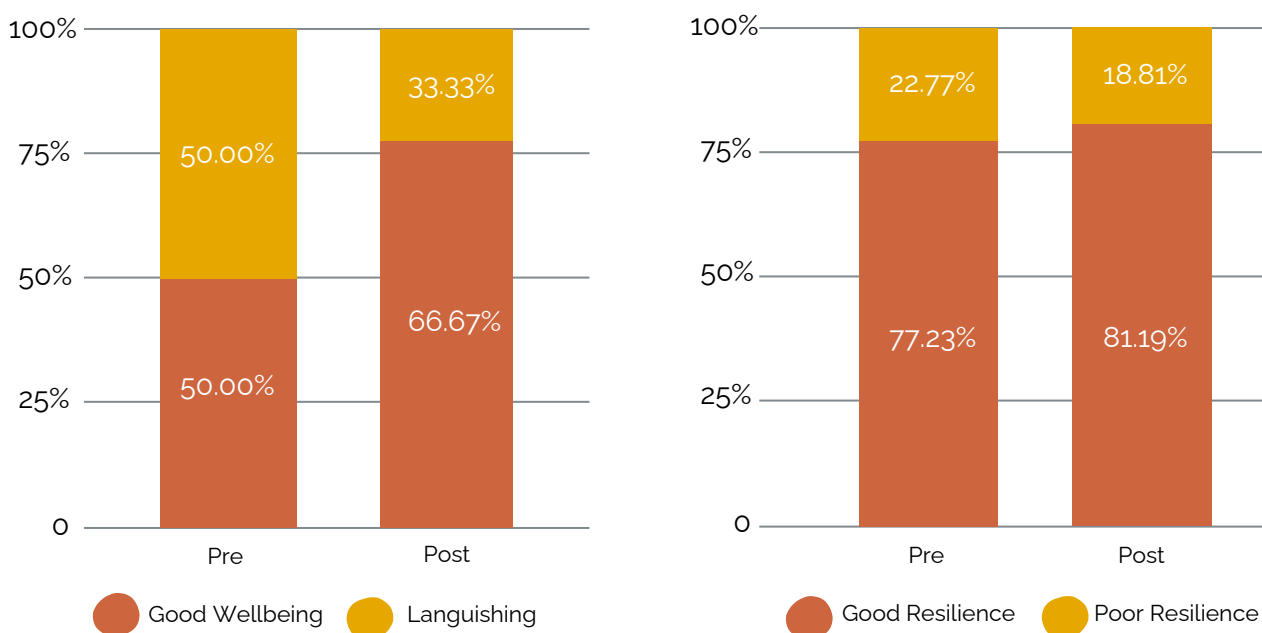


Figure 8. Change in risk groups from beginning to end of training for wellbeing (8a) and resilience (8b)

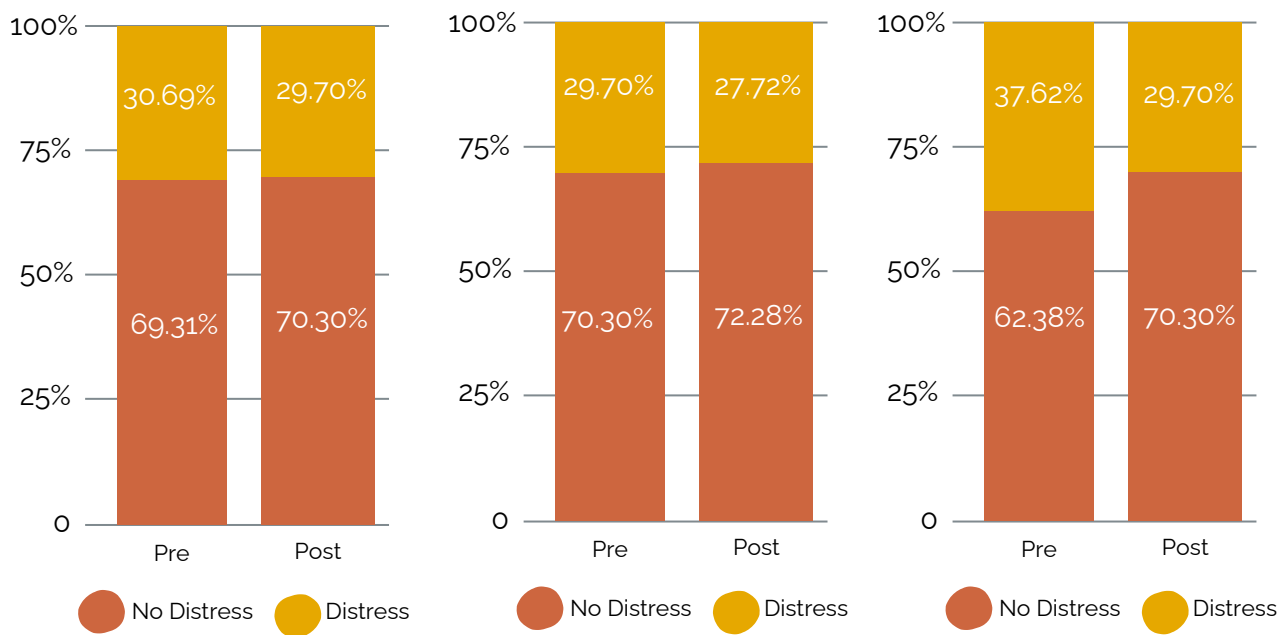


Figure 9. Change in risk groups from beginning to end of training for depression (9a), anxiety (9b) and stress (9c)

When further looking at those with problematic mental health at the start, significant moderate to large effect sizes can be noted for all mental health outcomes, including stress (see Table 6). These effects show the large impact of that the training on improving mental health outcomes for participants. This is important to demonstrate as it points to the training having the ability to reach people when they are vulnerable. The significant effect on people with active distress points to the fact that the training will have benefit for symptoms that typically warrant engagement of a professional.

Table 6:

Statistics for mental health outcomes comparing change from beginning (pre) to end (post) of training for individuals with risk scores

		Low pre		Low post		Sign.	Effect size <i>d</i>
	N	Mean	SD	Mean	SD		
Mental wellbeing	48	5.18	1.35	6.27	1.66	0.000	.61
Resilience	23	4.74	0.88	5.81	1.01	0.000	.95
Depression	31	4.70	1.85	2.88	1.87	0.000	.80
Anxiety	30	3.68	1.91	2.35	1.76	0.000	.59
Stress	38	5.09	1.38	3.87	1.49	0.000	.70

## Training satisfaction data

In addition to testing the impact of the training on improving mental health outcomes, participants were asked to reflect on their satisfaction with the training content. At the end of the training:

- 90% of participants felt engaged throughout the training.
- 82% of participants were satisfied with the training.
- 87% of participants were confident they would use the learnings in the future.
- 93% found the Be Well Plan Workbook to be a helpful learning tool.

These percentages are fairly comparable to ratings that are typically received for the Be Well Plan in other settings. When looking at the structure of the training and resources, larger discrepancies with typical ratings could be found:

- 76% found the five-session format helpful in allowing time to practise.
- 46% found the timing and pace of the five Be Well Plan sessions to be appropriate to the level of complexity and/or importance of the concepts and skills.

An easy explanation could be found for some of the disagreement across the five-session format, with most of the participants who indicated disagreement across the qualitative feedback coming from the organisation that provides arts therapy, with a strong focus on unstructured therapy provision.

The lower rates of agreement with timing and pace related to the complexity of the topics is a novel finding and will need to be incorporated in recommendations for the future, to ensure that there is an appropriate match with the target population, particularly for individuals with a disability who would typically require more support.

When invited to provide free text comments on the training, many participants voiced their appreciation of having been part of the training, as can be seen from some of the responses:

- ‘It was valuable and great our organisation supported it and is concerned with wellbeing.’
- ‘I enjoyed having the time and space to think about my own wellbeing.’
- ‘Participating in the program helped create a safe space to open up dialogue between peers/colleagues about shared experiences and struggles or challenges. Also helps to not feel alone in our challenges.’
- ‘I really enjoyed the training each week and learning new wellbeing strategies.’
- ‘It really is a wonderful course. I am so bogged down with work after time off with illness and I really didn’t want to “waste time” that I could have been using catching up with plans. But it has really helped me cope with the overwhelm of it all.’

While most participants enjoyed the program, some said the format was challenging, particularly when it came to sharing personal experiences with work colleagues. This feedback, voiced by a few participants, counters feedback from other participants who appreciated the group format and learning more about colleagues. This contradiction is a normal finding, as group-based mental health programs are not always the optimal format for people to work on their mental health and wellbeing.

Further responses to questions on improvements to the program are incorporated into the section on Stage 1 of the co-design.

## Qualitative study and co-design sessions to help create a NDIS useful version of the program

This work builds on the key principles set out in 'Policies and practices to support preference, choice, and self-determination: An ecological understanding' by Stancliffe et al. (2020). The underlying principles of the more recent developments in literacy theory contribute to our work on wellbeing literacy. Keefe and Copeland (2011, p. 97) summarised five core principles of literacy, which we follow in our conceptualising of wellbeing literacy:

1. All people are capable of acquiring literacy.
2. Literacy is a human right and is a fundamental part of the human experience.
3. Literacy is not a trait that resides solely in the individual person. It requires and creates a connection (relationship) with others.
4. Literacy includes communication, contact and the expectation that interaction is possible for all individuals; literacy has the potential to lead to empowerment.
5. Literacy is the collective responsibility of every individual in the community; that is, to develop meaning making with all human modes of communication to transmit and receive information.

### Co-design Stage 1: Insights from interviews and focus groups on implementation within the sector

#### Description of participants

As mentioned in the methods section, the participants for the focus groups and interviews were selected from a diverse subset of the partner organisations, aiming to ensure coverage across the disability sector. The groups trained included a cross-section of disability service staff, family members and guardians. They were surveyed post-training and detailed post-training focus groups were also held with the SA Office of Public Advocate, SACID, BISA, SA Government Accommodation Services (government accommodation and support services provider), SA Care (private sector accommodation and support services provider), Mission Australia (Local Area Coordinator plan management service provider) and Tutti Arts (disability service provider – activities).

#### Feedback on the facilitators and training content

Mirroring the general participant feedback mentioned above, participants in the focus groups and interviews were generally very positive about the training. Many participants pointed to the positive effects they noted in themselves, as reflected in the following quotation: 'I'm feeling less stressed at work with the use of my individualised wellbeing plan.'

*"I think [having the training available for the sector] would make my workplace a more happy and productive workplace."*

A lot of participants indicated that they were familiar with the program content and the techniques used, either because they were taught to them professionally or because they had encountered them in other training programs. That said, the respondents often said that they have not come across a program that was set up like the Be Well Plan, highlighting the academic credibility, integration with technology, the high personalisation element, and the engaging and pragmatic format as stand outs. While some participants indicated that they had programs with a similar focus, e.g. SACID, participants commented that 'that is nothing like [the Be Well Plan] in the sector'.

Participants liked the train-the-trainer format, and felt very satisfied with the SAHMRI trainers. They felt that they were approachable, and were well versed to teach the concepts at the heart of the training.

Participants commented on the clear changes they could already note in their colleagues. For example, in one organisation, a participant commented on the fact that almost all staff took up the training and, while some were ambivalent, many felt clear benefits, particularly younger staff.

#### Utility for the sector

Respondents could see a clear benefit for the sector, both for staff and for clients (see below): 'I think [having the training available for the sector] would make my workplace a more happy and productive workplace.' Participants noted how difficult it was to work in the sector and that it takes a toll on them. The issue participants identified was that staff didn't put their own wellbeing first. This meant that a lot of staff would not engage with such a program unless it for example came in the form of an employer-supplied training offering.

Participants felt that the program allowed them to address their mental health using a different angle. The program had a strong focus on the self, which made it different from many other offerings which are more workplace specific. They liked the pragmatic nature of the program, and the fact that they could take elements and embed them within their own routine: 'We have embedded mindful activities within our regular work catch-up meeting with great benefits.'

Staff commented on the benefit of being able to reflect on their own mental health and wellbeing in a safe environment. The fact that the program focused on strengths and not just deficits meant that participants felt safer to participate. As one participant noted: 'It was great to do this as a group – I feel more connected to my colleagues and less isolated in general.' Some participants did note that there may be a potential issue with disclosing experiences in a professional setting:

*I found it challenging to concentrate as I am a support worker and felt myself being distracted by wanting to support artists with a disability to understand the content instead of concentrating on myself. I also found sharing such intimate things in a work environment and particularly in front of artists with disabilities that may not understand professional boundaries and confidentiality hard and made me hesitant to share information.*



This opinion was not universally voiced, but would have to be taken into account for specific settings where boundaries are difficult to maintain and/or where there is a higher likelihood of more challenging and traumatic experiences, as it is important to avoid iatrogenesis.

When it comes to integration for professional staff, most staff found a weekly format worked for them, but they did feel that more time was needed. The session times were already extended, which was appreciated by some: 'I found that extra half hour in the session perfect. 2.5 hour sessions I think just give that extra wiggle room for getting [one's] head around everything.' That being said, others still felt that the material needed to be simplified and that more time needed to be given to reflect and work through the content: 'Some of the sessions would've benefited from being 2.5–3 hours to allow for more discussion.'

#### Utility for clients

Participants clearly noted that the program would have benefits for clients:

*I think the Be Well Plan could be adapted to suit all needs – particularly those with learning disabilities – to simplify the process and use it as a way of building tools for resilience and wellbeing, rather as a scientific tool of measurement.*

While most participants pointed out the benefits they personally received, some noted that it helped them improve their professional conduct, both to colleagues and clients. Some mentioned that they took concepts from the Be Well Plan and integrated them into their day-to-day work, which they had done with other trainings before, taking helpful concepts and contextualising them for the benefit of their clients.

Participants were quick to indicate that the program would need adaptation if the program was embedded within services. This was particularly the case for services that work with people with more severe disability. As one of the respondents said:

*Some participants [with an intellectual disability] can't read and are afraid to pick up a pen. They feel terrible for not being able to do their part. A big focus of our work is to drive their motivation. You don't want to undo that.*

The program in its current form is highly structured, which may be OK for some individuals, but is problematic for others. For example, for many clients with more severe disability the session duration of two hours is too long. As such, participants were quick to focus on finding a way to integrate the training within their existing practice rather than seeing it as standalone training.

Others did see the merit in having distinct training sessions, particularly for those with less severe disability, either embedded within services or as mainstream services. This would allow for dedicated practice. If this were the case, there were however clear recommendations:

- Keep slides and material as clear and simple as possible.
- Ensure that the materials are accessible and are developed with potential visual and auditory impairment in mind.
- Provide additional time for reflection and build in overflow time that allows trainers to interact with people who need a bit more assistance.

While this may speak for itself, materials created by mainstream providers are typically not developed with disability in mind.

Some participants voiced concerns over the integration of technology in the training, indicating that technology could form a barrier for those with more severe disability. This is particularly the case if no assistance is provided to help engage with the technology. Other participants indicated that the sector has seen a lot of change towards adoption of technology, voicing a more optimistic note for those individuals who do feel comfortable navigating it.

Regardless of the technology components, participants indicated that the resources were highly appreciated and many wanted to get their hands on more printed hardcopy materials, as voiced by this participant:

*'[I'd like to get] a spare book to take home to rewrite after further reflection.'*

There were also recommendations regarding the way individuals gain access to the training. If the training is a mainstream training, participants indicated that it would be good to make it easy for individuals to indicate they need assistance. The key recommendation was to allow for the inclusion of a support person or buddy for those who need it, to provide assistance along the way. If trainers knew there was a participant who needed more support, it would be appreciated if they could stay on for a bit longer to help them through any issues.

## Co-design Stage 2: Development of an easy read NDIS-friendly version

Early in the project, the need to explore the development of an easy read version of the program was noted. While the overall focus and purpose was universally accepted as needed for the sector<sup>9</sup> it became apparent that individuals with more severe disability, particularly those with an intellectual disability, would benefit from a highly adapted format that was easier to implement within services. While Section 5 of this report will therefore largely focus on recommendations for mainstream wellbeing deliverers, this section speaks to preliminary work that was conducted to create an easy read version based on intensive participant feedback.

As a first step, SAHMRI staff in consultation with the SACID staff members created a first draft easy read format, which included:

- an opportunity to change the sequence of the training and to spread it out over a longer timeframe
- introduction of a support person at the beginning of the program
- creating an easy read version of the booklet informed by some of the explanatory conversations with the SACID inclusion staff member during the training.

Separately, the CEO from Tutti Arts attended the face-to-face training in its standard form while it was delivered to her Tutti staff. By arrangement Pat brought with her a Tutti artist and supported him through the training, again observing responses, comprehension and tolerance of the workshop structure.

<sup>9</sup>The format of the training is for one or two trainers to introduce the material supported by slides and video, using a combination of a lecture, small group discussion and an introduction to activities that the participant may choose to do in their own time. The participants are encouraged to build a bank of activities of their own and introduce them into an ongoing practice to support their mental health beyond the life of the training. The booklet and the app detail the activities, whilst explaining what aspect of psychological health each activity supports. The intention is that take-away tools will support a personal practice.

Day three of the training introduces the research on the positive results that have been achieved through practising regularly what is called mindfulness. The group had been set homework to consider which of the mindfulness techniques introduced in the session most suited their lifestyle and personality. The Tutti artist Lorcan had found some of the material made him emotional or he found the concepts at times overwhelming and so for part of Session 3 one of the trainers had spent time outside with him kicking a football. The trainers were not sure how useful that session had been to him. The trainers convened as usual for Session 4 and, as they would normally, they talked about the homework activity. One of the trainers sent the following in an email to the team:

*Just letting you know about something that happened at Tutti today. Firstly, Stuart and I had an initial chat with Lorcan who explained how he has been using dance to help him relax and doing mindful breathing over the last week as his homework for the course. Then during the presentation break one of the [Tutti] artists advised that he had written a song about his feelings and had made an mp3 with a video of the words for the projector. Stuart put it on just before the break and as the music started Lorcan said, 'I'd like to dance to this', so we urged him to go ahead. Anyway, I think everyone in the room was blown away by the song, the lyrics, and the way Lorcan danced to it like a professional dancer. It was a very special moment and the Manager, Linda, said, 'That's what I call a "Tutti moment".'*




Above: Lorcan Hopper dances during day three of the Tutti training

Lorcan has had a long history of high anxiety, at times finding it too hard to come out of it; everyone needing to wait its course. After the training Lorcan's mother reported that Lorcan had explained to them what they should do when he became anxious in this now familiar way. He seemed to have found a way through the training to become sufficiently in control of what was happening for him to work with it and usefully draw on his parents' support. The roles were reversed: instead of them explaining to him how to cope, he was explaining to them what we wanted them to do to help him. His mother also reported that, at least in what is now only a few weeks, his anxiety was much reduced. We learnt that the program in its current form already had benefit at least to Lorcan. While the focus of the training is mental health, wellbeing and resilience, the outcome not only reduced anxiety in Lorcan; it is an example of supported decision making in practice.

It important to note that Tutti has a strong successful focus on supporting the resilience of their artists (NDIS clients). Lorcan, the primary focus of this story, has been supported by Tutti for a number of years and his parents have been closely involved with the team at Tutti and supportive of their work. We assume the change is most likely built on that foundation rather than coming out of the blue. Nonetheless Lorcan was able to assimilate the training into his life, communicate to his parents what he was doing, and be more able to take the lead in self-management of these overwhelming emotional periods.

*"The roles were reversed: instead of them explaining to him how to cope, he was explaining to them what we wanted them to do to help him."*



As a second step, the draft document was used in a series of fortnightly two-hour workshops (eight sessions in total) with the CEO of Tutti and one of her artists with an intellectual disability who had not been part of the training before. She was a long-time member of Tutti and has a close, trusting relationship with Pat. The two have worked together in many group workshops, some of which evolved to be professional public performances.

Pat led her colleague through the Be Well Plan program. The two SAHMRI project team members participated, asked questions and took notes. The documentation of the sessions also included edits from an easy read discussion, which was also considered during the session. The easy read aspect was approached as a secondary component to the workshops and more work on this will be required down the track as the material is worked on with more people. The primary objective was to review the intention of the work and the approach to the content rather than the format of the document. The sessions were recorded. The process was thorough and meticulous. Significant time was spent at the beginning of each session checking what our person with a disability had retained from the previous session and doing a recap. A significant amount of time was also spent talking about other Tutti artists well known to them both, about what in their experience might work or not work for them, and issues that they at times have had to deal with.

Most of the Be Well Plan could be worked through using this approach. What is important to note is that the easy read version of the program in the suggested structure is not a diluted program, but simply a program that is more accessible for those who need more assistance. In other words, at the core of the easy read version lies the important notion that it does not view the person with disability as differently capable of working on their mental health than the general population.

The integrity of the program was maintained in the easy read version, with the following changes made:

- The training was broken up into shorter sections and more prompts and examples were introduced.
- The flow of the program was changed to introduce a support person at the start and to add prompts on managing loneliness for those who do not have ready support available.<sup>10</sup> The name 'buddy' worked well. This should not come as any surprise. The role described in the training is one of the foundation stones of supported decision making.
- Different escalation points and support services were introduced.
- More accessible versions of the activities were created (see Appendix 15), taking into consideration social context.
- Where needed, nuance was provided on what is malleable (e.g. mental health) and what is not (their disability).

<sup>10</sup> A note was made on security clearances for buddies, which would have to be taken into account, but checking these was not deemed to be the responsibility of the training provider.



## Next steps

The Stage 2 process resulted in an easy read booklet that will be made available with the current booklet according to the participant's preference.<sup>11</sup> Indeed, there could be different delivery approaches. The initial thought that the principles might be productively embedded in service delivery practices was supported through the consultation stage. That it could be part of other practices such as performance is also supported by the success already shown in Tutti's work. To support that approach some additional assets have been produced.

SAHMRI is currently exploring a new mode of delivery of the program using the methodology of the 'flipped classroom', whereby material is presented in video format for self-paced learning followed by five weekly one-hour group sessions. This model would easily accommodate a facilitated approach to the video section. Trainers familiar with the learning needs of a group could work with the material at whatever pace they wanted. The videos to support this program are still in development. As part of the project, based on information gathered in the co-design work, a number of videos were refilmed working with Tutti artists. While they will be an integral part of the new training, they will also be available in the public domain for anyone to use and be available as part of any other service delivery for the NDIS sector.

The following short videos were produced by workshopping with artists with disability. That process in itself confirmed the proposition that the concepts are accessible to people with learning disability. The group had no difficulty understanding the concepts and were able to workshop how they would choose to communicate them and then be filmed doing so.

1. Mindful breathing
2. Focusing your mind 5, 4, 3, 2, 1
3. Mindful walking
4. Introduction to yoga led by yoga instructor V Barratt
5. What's good in my life? – Gratitude
6. Self-compassion
7. Resources you already have: meaningful pictures
8. What is stress?

<sup>11</sup> There is conflicting literature on the merit of using easy read formats versus tailored education, which needs to be explored in subsequent testing (see Sutherland & Isherwood, 2016).



Caite Moloney (with photo of her father Rob Smith) from the video, Resources you already have: meaningful pictures



Further, an important part of the program is a set of activities published together as an activity booklet. As part of the project, the activity booklet has also been rewritten as an easy read publication (Appendix 15). This booklet can be offered as an alternative within the training itself. As with the videos, a number of the original activities have been omitted so that it too can be made available in the public domain as a standalone resource that can also be used in any other program.

The content of the easy read activity booklet covers:

1. **Mindful breathing:** use breathing techniques to ground yourself during moments of stress.
2. **Progressive muscle relaxation:** release tense muscles to relax your mind.
3. **Mindful walking:** be present when you walk and take a moment to ground yourself.
4. **Online mindfulness:** find one of many apps that can help instil mindfulness in your life.
5. **Mindful eating:** appreciate the food you eat by practising being present.
6. **Yoga:** use physical activity combined with mindfulness to de-stress your mind and body.
7. **Mindful 5-4-3-2-1:** a mindfulness activity to help notice what's around you.
8. **Cultivating gratitude:** find moments of gratitude in your day-to-day life to build positivity.
9. **Three funny things:** find moments of laughter and joy to boost your mood.
10. **Re-thinking thinking traps:** reflect on common thinking traps to avoid them in the future.
11. **Expressive writing:** reflect on emotional experiences to reduce feelings of distress.
12. **Self-compassion:** use the power of self-compassion to achieve personal growth.
13. **Acceptance of your experience:** mindfully accept emotional reactions as passing states.
14. **Getting in touch with your values:** identify your values and how they add to your wellbeing.
15. **Goals and my values:** set goals in line with your values.
16. **Thought defusion:** teach yourself that thoughts come and go; you do not need to react to them.
17. **Gratitude letter:** express gratitude to the people you care for.
18. **Improving communication skills:** learn how to listen better and respond constructively.
19. **Assert yourself:** practise assertiveness skills.
20. **Goal setting:** learn simple behaviours that make it easier to reach a goal and succeed in life.
21. **Meaningful pictures:** use images to identify sources of meaning in your life.
22. **Finding flow:** find the ultimate mindful state when performing tasks.
23. **Problem solving:** learn to solve life's problems effectively using simple steps.
24. **My character strengths:** identify your values and virtues and put them into action to build wellbeing.



Left: Annalisse Truong from the Mindful Walking short film

The team has furthermore commenced a co-design process that mirrors the above process for the integrated wellbeing measurement. SAHMRI Be Well Co staff will work together with SACID staff throughout 2024 and 2025 to conduct interviews and focus groups with staff and clients, resulting in an NDIS-friendly wellbeing measurement tool. It is one of the phases in a larger project focused on developing an item bank for measuring positive mental health (see Iasiello et al., 2023). By working with SACID, the team will be able to test whether the item bank in its original form is sufficiently accessible for individuals with an intellectual disability and which changes should be considered to improve accessibility.

# 5. Conclusions and recommendations



## Findings from this research

### Findings about the OPA's practice

The OPA's study found that the My Life, My Wishes document is an effective tool for recording the wishes of people with a guardianship order, although it should not replace point-in-time discussions with clients about important decisions. It found that it is most effective if trusted support people assist to fill it in, if contextual information about the person is included, and if it is updated regularly.

Most clients responded positively to the document, and thought it helped them and their supporters understand their wishes better, although some found it too long and some found it triggered difficult emotions. All of the support people who participated in this research thought the document would be useful in the future.

The document could not always be completed in a single visit, especially if the person had complex needs or insufficient support to communicate, or were opposed to the guardianship order, or their support person obstructed the process. With many clients, the presence of a support person who knows the client well, understands them and can assist with their communication needs is essential. As well as suitable support people, ample time is required to prepare for a visit, to discuss the form with the client and seek additional information from family/supporters. Face-to-face visits (rather than phone or online) were found to be most useful, and were essential for clients with more severe disability.

The project found that some Aboriginal clients need support to learn about their background and cultural identity before they can identify their wishes. Also, OPA staff lacked information and sources of advice on supporting Aboriginal clients, especially with complex decisions such as end-of-life discussions. Culturally appropriate services are particularly important for Aboriginal clients who lack family support, who do not have an existing relationship with any OPA staff, or who live in regional and remote locations.

*"Culturally appropriate services are particularly important for Aboriginal clients"*



OPA staff found that some clients who are difficult to engage or whose supporters are uncooperative need additional support from an individual guardian. The OPA also found that limited awareness in the community and in other services is a barrier to supported decision making. The OPA will continue to advocate for SDM and to educate other service providers. Another finding is that SDM can be more difficult to implement when a decision is urgent, such as when a client is in hospital, although the OPA still encourages SDM whenever possible.

The guardianship legislation gives power to guardians to undertake substitute decision making, and guardians often receive decision-making authority over even minor daily decisions. This limits the person's capacity and opportunity to make their own decisions. The OPA will continue to promote the legal autonomy of people with a guardianship order by supporting a person's own decision wherever possible, including by enabling positive risk.

A consultation by the Julia Farr Association Purple Orange concluded that the document could be used by people with intellectual disability who are not under a guardianship order. The consultation recommended an easy read version of the form. It suggested that the form should be used in group homes and supported accommodation settings, with assistance from support coordinators.

## Findings on building capacity within the healthcare sector

Training sessions with OPA and healthcare staff revealed that many staff are already committed to respecting autonomy and human rights, but need more information about how to implement supported decision making in their own context and within their time constraints. Some staff were unaware of the difference between SDM and substitute decision making before the training. One barrier to implementing SDM that was found was high staff turnover. This suggests that it is important to have ongoing training opportunities available to new staff, such as the short videos and e-learning modules created through this project.

The experience of providing and reviewing SDM training also led to new understandings, for example of the different decision support needs of people with intellectual disability and people with psychosocial disability. The process also highlighted the need for legislative and policy reform to embed SDM into the health and mental health sectors.

## Findings on mental health and wellbeing training

The third component of the project investigated the feasibility of establishing sustainable wellbeing training capacity for NDIS participants. It aimed to counter the possible mental health and wellbeing impacts of the transition to a supported decision making model for NDIS participants and their families and supporters. One focus was considering whether mainstream wellbeing programs can be adopted or modified for the NDIS sector.

The literature on the mental health of people with disability highlights that mental wellbeing is not just the absence of a mental illness. Mental wellbeing should be assessed and promoted separately to the treatment of diagnosed illnesses. Research has also found that a focus on building wellbeing can have significant benefits for the disability community.

The literature review of studies on wellbeing interventions found that the number of studies aimed at improving the mental wellbeing of individuals with a disability has grown recently, but is still small compared with studies on the wellbeing of those without a disability. Some studies support the effectiveness of psychological interventions for people with disability.

*"The Be Well Plan was effective in improving mental wellbeing and decreasing stress and anxiety"*

Our study showed that the Be Well Plan was effective in improving mental wellbeing and decreasing stress and anxiety in a sample of the general population. Additionally, most participants felt engaged in and satisfied with the training and intended to continue using the techniques they had learned. The participants recognised that working in the NDIS sector can be very stressful and that programs like this are needed for staff, although some would prefer to work through the program on their own, not with work colleagues. Those who work with people with intellectual disability also felt that the training could be integrated into their work, but would need to be modified for some clients, with clearer explanations, shorter sessions but more of them, more accessible materials and assistance to become familiar with the software.

The testing of the Be Well Plan revealed that the concepts and activities are appropriate for everyone, but some enhancements needed to be made to make the program more accessible for some people with intellectual disability. These included an easy read version of the program, short videos, shorter training sessions, using it with a support person or buddy, and more accessible ways to present some of the technology components.

## Outcomes of the Living My Life Project

### Outcomes within the OPA

- The previous OPA internal client documents (client summary, screening summary, visit record) and the *My Life Decisions* form have been combined and replaced with a single *My Life, My Wishes* document to better record the wishes of people with a guardianship order.
- All new clients of the OPA now have the opportunity to discuss and have their will and preferences documented, and this also being implemented with existing clients. At time of writing more than 450 people under guardianship have had their wishes documented in this way.
- OPA now collects contextual information on each client to help understand their needs and wishes.
- OPA staff are now better trained to understand supported decision making, to understand the communication needs of people with a guardianship order, and to support end-of-life planning with vulnerable people. It will develop staff training on decision-making support with Aboriginal people.
- The OPA now aims to foster good support relationships for people with a guardianship order.
- The OPA received a further grant to study how to use the *My Life, My Wishes* document with Aboriginal and Torres Strait Islander people. The OPA plans to engage in further discussions and consultation with Aboriginal communities on best practice approaches to decision making for Aboriginal people within the guardianship context.
- The OPA has made *My Life, My Wishes* more accessible to the community by adding instructions about the purpose of the document and drafting an easy read version and an easy read user guide.
- The OPA is developing a Position Statement on supported decision making.
- The OPA is developing a Decision Making Practice Guide for use by OPA staff.
- The OPA will collect data on its SDM practice to aid future evaluations and to provide evidence of resourcing needs.

*"more than 450 people  
under guardianship  
have had their wishes  
documented"*



### Outcomes in the health sector

- Specialist staff in the Department for Health and Wellbeing in partnership with their hospital-based social work teams have received training in supported decision making. Training resources were left with the teams for future work.
- All SDM training was developed and delivered with people with lived experience together with academic experts.
- SDM training was made available to health professionals via a webinar, which was promoted broadly across the sector. It is published online as a free resource.
- Videos explaining supported decision making in the context of guardianship were created, including the perspectives of persons with lived experience. They are used by OPA in their information sessions for hospitals and are also available in the public domain.
- E-learning modules on supported decision making in the health environment were created for internal training of health staff and are also available to the public.

### Outcomes in the disability sector

- Training in the Be Well Plan was delivered to more than 250 disability sector staff including support and allied health workers, family members and NDIS participants.
- Easy read versions of the Be Well Plan's workbooks have been developed to increase the program's accessibility.
- The Be Well Plan activity booklet has been written in easy read for use in the training and is also published online as a free resource for the public.
- Several of the Be Well Plan training videos have been refilmed using artists with disability. These are also both available for the commercial program and available free for use by the public.
- Co-design with specialist disability organisations working with people with lived experience was used to review, evaluate and create these bodies of work.
- A number of staff from disability sector organisations have been trained as Be Well Plan trainers, including staff of SACID, BISA, OPA, SA Health and Tutti Arts.
- Brain Injury SA won a grant to continue delivering training to family members, friends and clients.
- SACID is enhancing its current training programs, which include Healthy Minds, My Life My Choices and Relationship-wise as they continue to strengthen their sector contributions.

# Recommendations



## Recommendations for legislative reform

The OPA component of the Living My Life Project generated the following recommendations for reform of the Guardianship and Administration Act 1993 (SA).

1. The GAA should require that supported decision making options be exhausted before substitute decision making can occur.
2. The GAA should require that supported decision making practice informs substitute decision making practices.
3. Binary (yes or no) capacity assessments should be replaced with an assessment of decision support needs. Capacity should be recognised as decision specific, rather than by topic area, and be assessed when sufficient decision support is provided.
4. The GAA should include a principle that orders must be as specific as possible, with limited use of orders which confer broad decision-making authority.

## Recommendations for guardianship practice

5. Guidance for implementing supported decision making should enable risk by articulating high thresholds for risk and prioritising the person's wishes.
6. The GAA should be interpreted through a human rights lens, which could reduce SACAT orders. This could also reduce appointments of the Public Advocate as guardian where there are safe and effective informal or formal private alternatives.

## Recommendations for practice in health care

7. Practical training in supported decision making is required in the health sector in all areas and at all levels of each service.
8. Supported decision making principles and processes should be upheld even in the face of urgent external pressure (e.g. hospital discharge decisions).

## Recommendations for NDIS practice

9. The NDIS should fund the provision of decision support.
10. Positive psychology and resilience training should be integrated into service delivery for NDIS clients and made more accessible.



## Recommendations for training providers and developers

This project made it clear that there is a need for mainstream service providers to facilitate better access to services and opportunities for individuals on an NDIS plan. The following recommendations are intended for stakeholders who design, develop, deliver and implement mainstream mental health and wellbeing services. They include changes that mainstream service providers can make to increase the accessibility of existing offerings for people with disability, and considerations that developers need to make when designing new mainstream services or programs.

11. When a service enrolls a new client, the client should have the option to indicate that they need a support person whenever they engage with the service, they need extra assistance from staff of the service, or they need auditory or visual support or modified materials.

12. Ensure all venues are accessible, for example with wheelchair access.

13. When delivering online sessions, make sure a person with a disability is always accompanied by a support person if required.

14. If needed, additional time should be scheduled at the beginning and end of sessions and at regular intervals to ensure clients are comfortable and able to follow the material. Also consider breaking up training into shorter sessions.

15. Prepare different versions of documents for different audiences, such as some with less content, easy read versions, and documents that are suitable for those with vision impairment.

16. Keep the language and content (of documents and of training sessions) as clear as possible. Use examples to clarify difficult concepts.

17. If a program includes measures (e.g. of mental wellbeing), consider whether they are accessible and valid for all people with disability, and whether a support person is needed.

18. Test all documents and programs with people with disability, even if people with disability are not the primary intended audience.

19. When piloting programs (e.g. in a workplace), ask for people with a disability to be included to ensure you get adequate feedback on the content and implementation of the program.

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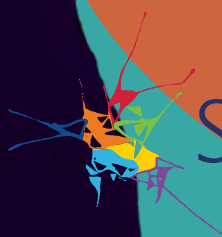
# Living My Life

Volume 2

June 2024



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SAHMRI

OPA

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**Front cover picture:**

The front cover of this report shows Lorcan Hopper, an artist from Tutti Arts Inc.  
You can read more about Lorcan and his participation in the project in Section 4 of this report.

**Authors:** Anne Gale, Michelle Browning, Joep van Agteren,  
Matthew Iasiello and Jan McConchie

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**Photos:** Tutti Arts Inc and Jan McConchie

**Acknowledgement of Country**

We acknowledge the traditional Country of the Kaurna people of the Adelaide Plains, where this research was conducted, and pay our respects to Elders past and present. We recognise and respect their cultural heritage, beliefs and relationship with the land, and acknowledge that they are of continuing importance to the Kaurna people living today.



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# Appendix 1:

## Online resources related to this project

### **Supported decision making video resources**

Created for this project by SAHMRI and SA Health

<https://www.opa.sa.gov.au/guardianship/supported-decision-making/supported-decision-making-video-resources>

### **Supported decision making e-learning modules**

Created for this project by Michelle Browning

<https://www.decisionagency.com.au/e-learning>

### **Be Well activities videos**

These short videos were created by Tutti in collaboration with artists with disability

<https://www.bewellco.io/living-my-life-project>

### **My Health Information**

An easy read form for people with intellectual disability to fill out before they go to hospital

<https://www.sahealth.sa.gov.au/wps/wcm/connect/d933364d-3114-46e3-9cc0-cf0c5e532028/20030.2+My+Health+Information-online+form.pdf>

### **Be Well Certified Trainer Program**

An information pack for those interested in becoming Be Well trainers

[https://www.bewellco.io/\\_files/ugd/508c8d\\_44af4ba8fa294a238b00086f9238853a.pdf](https://www.bewellco.io/_files/ugd/508c8d_44af4ba8fa294a238b00086f9238853a.pdf)

### **Be Well Plan background research**

Joep van Agteren, & Matthew Iasiello (2020). Advancing our understanding of mental wellbeing and mental health: The call to embrace complexity over simplification. *Australian Psychologist*, 55(4), 307–316. <https://doi.org/10.1111/ap.12440>

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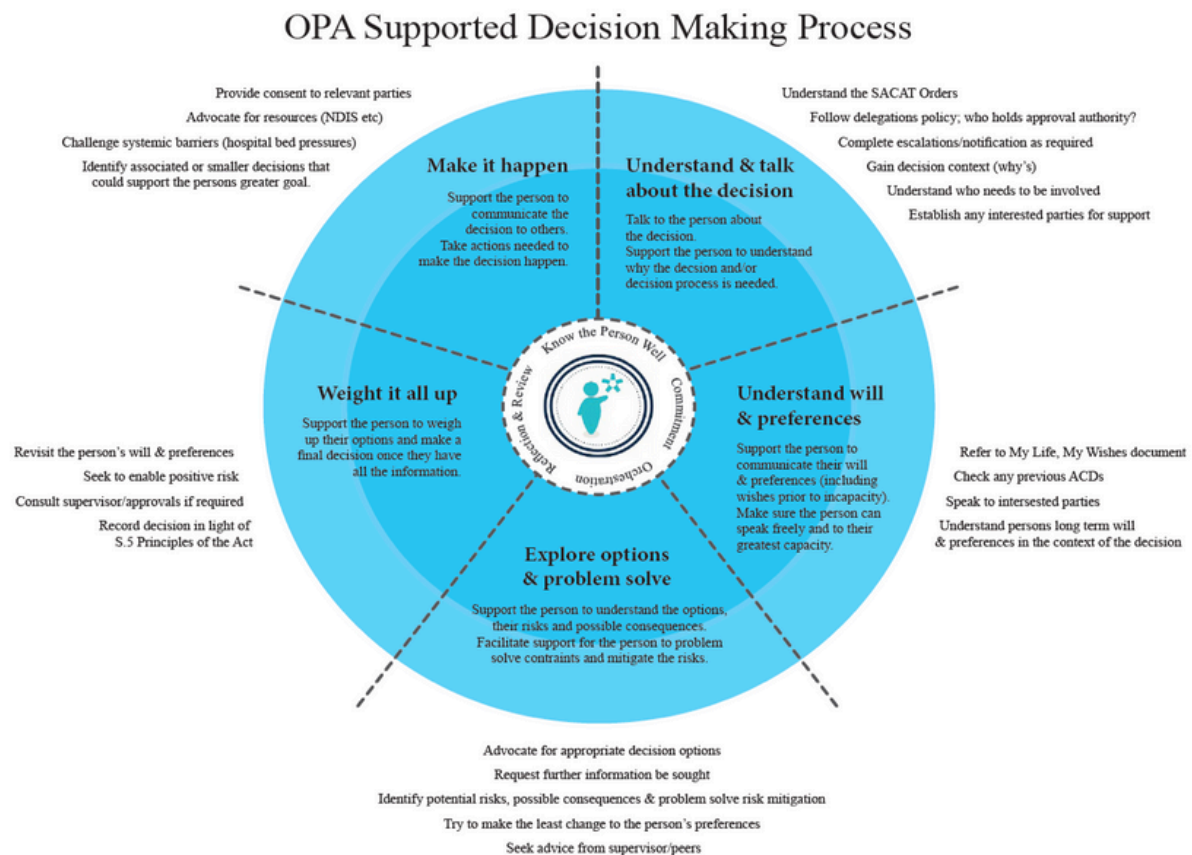
## Appendix 2:

# OPA supported decision making project history

Date	Type	Title	Funders/Partners	Aim
2009	Presentation	'Supported decision making in Australia' Presentation to Vic OPA and Vic Law Reform Commission	John Brayley (OPA SA)	An introduction to supported decision making policy and practice issues
2010	Submission	Submission to the Productivity Commission Inquiry into Disability Care and Support	Prepared by John Brayley and Dianne Chartres	A submission on the links between supported decision making, individualised funding and self-managed funding
2010-2012	Project	The Supported Decision Making Project (inc. Supported Decision Making Trial)	Cher Nicholson (OPA SA), Julia Farr MS McLeod Benevolent Fund, Margaret Wallace and Associates – independent evaluator	Assist people with a disability to set up supported decision making agreements to maximise their autonomy to exercise their legal decision-making rights. To study supported decision making when it is offered to people who have had a brain injury, stroke, intellectual disability, or a neurological condition affecting decision making. Trial an approach to supported decision making, in which a person nominates one or more people whom they know to act as a supporter. An extra person, a 'monitor', helps with the process and identifies problems if they occur.
2012	Presentation	'Supported decision making: Australian perspectives' Presentation to World Congress on Guardianship	Cher Nicholson (OPA SA)	An overview of results from the trial.
2012	Presentation	'The future of supported decision making' Presentation to World Congress on Guardianship	John Brayley (OPA SA)	Question exploration: can supported decision making replace substitute decision making?
2013	Website	What is supported decision making?	Cher Nicholson (OPA SA)	Info added to OPA website
2013	Presentation	'SA work on supported decision making' Presentation in Ireland	Cher Nicholson (OPA SA)	Presented the SA work in a session as part of a program on 'Supported decision-making in theory and practice: Ireland's Capacity Bill'
2013	Presentation	SA Supported Decision Making Project outcomes. Presented to David Bowen, CE, NDIS Launch Transition Agency, and Nick Hartland, senior executive at the DFHCSIA	John Brayley (OPA SA)	
2013	Presentation	'Supported decision making: A case for change' Presentation to the Supported Decision Making Forum (QLD Advocacy Inc and QUT)	John Brayley (OPA SA)	This case for change considered both cultural change and the need for law reform. A population-based model was introduced.
2014	Response paper	Response to the ALRC Issues Paper, 'Equality and disability in Commonwealth laws'	John Brayley (OPA SA)	Responded to questions raised by the ALRC related to equal recognition before the law for people with disabilities.
2014	Response paper	Joint response to ALRC Discussion Paper, 'Equality and disability in Commonwealth laws'	OPA Vic	The discussion included commentary on proposed National Decision-Making Principles, and the role of state-based tribunals and the NDIS.

2015	Presentation	'Promoting the dignity and worth of peoples' Presented to the Annual World Social Work Day Breakfast	John Brayley (OPA SA)	This general presentation had a section on the harm to individuals caused by avoidable substitute decision making, linked to the need to provide supported decision making.
2017	Project	Implementing Supported Decision Making for Adults with a Guardianship Order in South Australia	Law Foundation, Margaret Brown (UniSA), Anne Gale, PA	To identify opportunities, barriers and best practice for implementing supported decision making in guardianship practice in South Australia, and to make recommendations for legislative and practice reform to enable supported decision making for adults with mental incapacity living in South Australia.
2018	Project	The law and policy on decision making by, for and with clients in SA guardianship practice	Law Foundation, Margaret Brown (UniSA), Anne Gale, PA	Further research from above project to: develop a practice and policy guide in relation to supported decision making for OPA staff as well as other health and legal professionals, and identify areas for law reform in GAA.
2018	Project	Supported Decision Making for the Lifetime Support Authority	Lifetime Support Authority, Anne Gale, PA	To produce a policy and practice framework to implement supported decision making principles for Lifetime Support Scheme clients with an acquired brain injury.
2019	Project	Supported Decision Making and My Life Decisions in DHS Accommodation	Anne Gale, PA, Margaret Brown (UniSA), Disability SA	Implement supported decision making utilising the My Life Decisions plan for residents of DHS accommodation services, particularly those under the guardianship of the Public Advocate. Utilise the supported decision making model developed by the Office of the Public Advocate to complete the My Life Decisions plan so residents can plan ahead and maximise their NDIS plans. Train and skill the DHS capacity building and service coordinator staff in supported decision making for implementation and utilisation of the My Life Decisions plan.
2021	Response	Updated GAA 'exposure draft'	Anne Gale, PA	Provide comment on 'exposure draft'
2020–22	Project	OPA Supported Decision Making Project (a component of Living My Life)	OPA, NDIS (ILC), SAHMRI, SA Health and Wellbeing Consultant s: Decision Agency Julia Farr Purple Orange South Australian Council on Intellectual Disability	To trial the use of available and purpose-developed tools to seek and record the wishes of people with a guardianship order and consider application of supported decision making practice at OPA within legislative and resourcing constraints. Co-design with people with disability the My Life, My Wishes and My Health Information forms Recommendations for an OPA Advisory Group of people with disability. Develop OPA Supported Decision Making Position Statement and Practice Guide
2022	Response (attendance at Royal Commission)	Policy Roundtable – Best Practice Models of Guardianship, Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability	Anne Gale, PA	Provide response regarding options for reform to guardianship and administration regimes in Australia and how supported decision making can be incorporated within guardianship and administrative regimes.

# Appendix 3: OPA supported decision making process visual guide – draft



# Appendix 4: OPA decision record template

SUPPORT FOR DECISION MAKING RECORD						
Completed by name	Date					
Person name	Age	Broad Diagnosis	Behavioural support needs	Complex communication needs	Cultural	GTR
Order: Choose an item.			Special Powers: Choose an item.			
The decision needed: Click or tap here to enter text.				Decision area: Choose an item.		
Decision context or case background:						
any useful background or context info not included in the above or below						
I HAVE...	I DID THIS BY...	THIS WAS EASY BECAUSE...	THIS WAS DIFFICULT BECAUSE...	I WAS NOT ABLE TO DO THIS BECAUSE...	Case detail	TIME (hrs)
<b>Followed the Steps:</b>						
Found ways to know the person	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Identified & described the decision	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Understood the person's will & preferences in relation to the decision	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Refined the decision with constraints & consequences considered	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Reached a final decision & associated decision	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Advocacy needed to implement the decisions	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
<b>Applied the Principles:</b>						
Commitment	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Orchestration	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Reflection & Review	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
<b>Used the Strategies:</b>						
Attention to communication	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Educated about consequences	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Listened & engaged	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Created opportunities	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
Enabled positive risk taking	Choose an item.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.	0
				<b>TOTAL TIME</b>		0
				<b>Resulting decision type:</b> Choose an item.		
				<b>Resulting decision date:</b> Click or tap to enter a date.		
<b>General feedback/notes on trying to implement the framework in practice:</b>						
e.g. time taken, difficulty of engaging in the process and workload pressure...						

Appendix 5:  
*My Life, My Wishes* form – easy read





Easy Read



# My Life My Wishes Form

My wishes for me.

How to help me with decision making.



OFFICE OF THE PUBLIC ADVOCATE SOUTH AUSTRALIA

This is the My Life My Wishes Form.



This form will help to tell people:

- Your **wishes**.  
Wishes are the things that you really want.
- How to help you with decision making.
- Information to get to know you.



It was made by the Office of the Public Advocate.

The Office of the Public Advocate are also known as OPA.

When you see we or us that means OPA.



You can ask someone you trust to help you fill out this form.

Look at the User Guide for help on how to fill out this form.

## What is in this form

About you .....	4
Part A: My decision-making profile .....	5
Help you need to make decisions.....	5
Your communication needs .....	6
Your culture and faith .....	7
Your values and beliefs .....	8
Personal history .....	9
Your supporters .....	10
Part B: My life, my wishes .....	12
Where you live – Your life now .....	13
Where you live – Your wishes .....	17
Services – Your life now .....	20
Services – Your wishes .....	22
Health – Your life now.....	24
Health – Your wishes.....	26
Access – Your life now.....	29
Access – Your wishes .....	32
Other – Your life now .....	35
Other – Your wishes.....	37
Agreement.....	38

About you



Name



Date of Birth



Address

Suburb

Postcode

## Part A: My decision-making profile



Part A is about your decision-making profile.



This is information to help people who support you understand what help you need to make decisions.

It is about you.

### Help you need to make decisions

What is your disability?



What help do you need to make decisions about your life?

## Your communication needs



What help do you need to talk to others?



Where and when is it easier for you to speak to others?



What languages do you speak? Do you need an interpreter?





## Your culture and faith



**Culture** is the behaviours and beliefs that people follow together.

**Faith** is the trust in something outside of yourself, for example God.



What culture do you connect with?

How do you make decisions in your culture?



Who do you need to include?

## Your values and beliefs



**Values** are what you think is important in your life.

**Beliefs** are the strong thoughts that something is true.



What is most important to you in your life?

A large, empty rectangular box with a thin blue border, intended for a person to write their response to the question above.

## Personal history




What do you want people who support you to know about what has happened in your life?


## Your supporters





Who do you want to help you make decisions?

	Name	
	Organisation	
	Relationship	




  

	Name	
	Organisation	
	Relationship	

	Name	
	Organisation	
	Relationship	

	Name	
	Organisation	
	Relationship	

	Name	
	Organisation	
	Relationship	

	Name	
	Organisation	
	Relationship	

	Name	
	Organisation	
	Relationship	

	Name	
	Organisation	
	Relationship	

	Name	
	Organisation	
	Relationship	

## Part B: My life, my wishes



Part B is about your life and wishes.

There will be questions about:

- Where you live.
- The services you use.
- Your health.
- Access to the community,
- Other things in your life.

There will also be questions about how you wish these things could be.



## Where you live – Your life now



Answer these questions by thinking about where you live now.



What type of house do you live in?

- ☐ Own my home.
- ☐ Live with family.
- ☐ Rental.
- ☐ Housing trust.
- ☐ Supported Independent Living.
- ☐ Specialist Disability Accommodation.
- ☐ Group home.
- ☐ Aged care.
- ☐ Other.



Other information about my home.



When did you move in?



What supports do you have at home?



How much support do you have?

For example, how many staff per person living in the home with disability.



Describe your home.



Who do you live with?



Do you have any worries or problems with your home?



Where have you lived in the past?



Does your guardianship order say that your Guardian needs to agree to where you live?



☐ Yes



☐ No



☐ Not sure



Does your guardianship order say you cannot leave your house without your support staff for your safety?



☐ Yes



☐ No



☐ Not sure

Does your team use **Restrictive Practices** with you?

Restrictive Practices are things in place that stop someone with disability doing something.



☐ Yes



☐ No



☐ Not sure

## Where you live – Your wishes



Answer the next questions by thinking about how you wish you could live.



What do you think about where you live?



What do you like about where you live?



What do you **not** like about where you live?



Where do you want to live?



Who do you want to live with?





What should your home be like?

A large empty rectangular box with a blue border, intended for a response.



What home supports should you have?

A large empty rectangular box with a blue border, intended for a response.

## Services – Your life now



Answer these questions by thinking the services and supports that you use.



What supports do you use?



What activities do you do?



What job do you have?



Do you have any problems or worries about your supports?

---

## Services – Your wishes



Answer this question by thinking about the services and supports you want in your life.



What supports do you want?



What activities do you want to do?



What job do you want?

## Health – Your life now



Answer the next questions by thinking about the support you have to look after your health.



What are your main **health conditions**?

Health conditions are things that affect how you live your life.  
For example sickness or injury.



Who helps you with your health?

This might be:

- Taking you to appointments.
- Explaining things to you in a way you can understand.
- Helping you with your medication.
- Other health things.



## Health – Your wishes



Answer the next questions by thinking about the support you want to look after your health.



What health care do you want in your life?



### Dying wishes

Dying wishes are things that you want when you come to the end of your life.



Who do you want to be told when you die?



Where do you want to be when you pass away?

What do you want to happen when you come to the end of your life?



- ☐ I want to be comfortable and pain free at my home.
- ☐ I want doctors to do anything they can to keep me alive.  
This includes starting my heart again if it stops.



- ☐ I want a tube in my throat if I cannot breathe by myself.
- ☐ I want to go to a hospital room for very sick people.



- ☐ I want treatment that the doctor recommends.  
This might be

- Medicine, food or drink through a needle.
- Tablets.
- Surgery.
- Blood cleaning.



Is there anything that you do **not** want to happen at the end of your life?

## Access – Your life now



Answer the next questions by thinking about the **informal people** in your life.

Informal people are people who are not paid to be in your life, for example:

- Friends.
- Family.



Who do you see?



How often do you get to see these people?



Where do you usually see these people?



What support do you need to be able to see these people?



Do you have any problems or worries about seeing these people?

## Access – Your wishes



Answer the next questions by thinking about the people that you do and do not want to see.



Who do you want to see?



Why do you want to see these people?





How often do you want to see these people?



Where do you want to see these people?



Who do you **not** want to see?



Why do you not want to see these people?

A large, empty rectangular box with a blue border, intended for a written response.

## Other – Your life now



What is your money situation?

A large, empty rectangular box with a blue border, intended for a handwritten response to the question about money situation.

What is your legal situation?

A large, empty rectangular box with a blue border, intended for a handwritten response to the question about legal situation.



Do you have any other problems or worries in your life?

## Other – Your wishes



Do you have any other wishes in your life?

## Agreement



The information in this form:

- Has come from you.
- Is true.

The person who this form is about:



Name

---



Signature

---



Date

---



The supporter agrees that the information in this form is true to the best of what they know at the time it was filled out.

The person responsible or substitute decision maker:



Name

---



Signature

---



Date

---

**Other supporter:**



**Name**

---



**Signature**

---



**Date**

---

**Other people who helped you to fill out this form:**



**Relationship**

---



**Name**

---



**Signature**

---



**Date**

---



**Relationship**

---



**Name**

---



**Signature**

---



**Date**

---





**1800 066 969**



**[opa@agd.sa.gov.au](mailto:opa@agd.sa.gov.au)**



**[www.opa.sa.gov.au](http://www.opa.sa.gov.au)**

This resource was funded by the Australian Government Department of Social Services and the South Australian Health & Medical Research Institute.



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Appendix 6:  
*My Life, My Wishes* form user guide  
– easy read



Easy Read



# My Life My Wishes Form

User Guide.



OFFICE OF THE PUBLIC ADVOCATE SOUTH AUSTRALIA

This is the My Life My Wishes Form User Guide.



This user guide will help you to know how to fill out the My Life My Wishes form.



This was made by the Office of the Public Advocate.

The Office of the Public Advocate is also known as OPA.

When you see we or us that means OPA.



You can ask someone you trust to help you go through this user guide.

## What is in this user guide

My Life My Wishes form.....	4
Principles .....	6
How to complete this form .....	7
Part A. My Decision Making Profile .....	8
Part B: My Life, My Wishes .....	9
Signing the My Life My Wishes form.....	10
Who is your supporter? .....	11
Know your rights .....	14
Consent.....	14
Capacity .....	15

## My Life My Wishes form



The My Life My Wishes form is a form to write down things about:

- Your life now.
- Your wishes for the future.
- Help you need to make decisions.



This form can help you to make choices about what you want in your life.



You can use the form to share with your supporters your choices around:

- What you want or need.
- What you want for your future.
- Important information about you.



Supporters are people in your life, they could be:

- Family.
- Friends.
- Support workers.
- Guardian.
- Other important people.



You can fill in this form if:

- ☐ You need support to make decisions in your life.
- ☐ You live in South Australia.
- ☐ You cannot make an **Advance Care Directive**.



An Advance Care Directive is a legal document that tells others about:

- Your health care in the future.
- End of life wishes.
- Where you would like to live in the future.
- Anything else that is important.



You can only make an Advance Care Directive if you:

- Are over 18 years old.
- Have decision making capacity.



The My Life My Wishes form is NOT:

- A legal document.
- An Advance Care Directive.

## Principles



The My Life My Wishes form was made for everyone to:

- Be involved with making decisions about their life.
- Be supported to make decision and choices.
- Tell your supporters your choices about your life.
- Have supporters to ask and listen to what you want in your life.
- Have supporters to make decisions that include your decisions and choices.



## How to complete the form



You can have a supporter to help you to fill out the form.



In the form, write or draw:

- Your wishes for the future.
- Your life now.
- As much information as you want.  
This could be a lot or only a small amount.

You can take your time to fill out the form.



You do not have to answer every question.



## Part A. My Decision Making Profile

Your decision making profile is where you write what you want your supporters to know about you.



You might be asked questions about:



- What support you need to make decisions.
- Your culture and faith.
- Your history.
- How you tell people what you want or need.
- Who you want your supporters to be.



## Part B: My Life, My Wishes

The My Life, My Wishes part is where you write:



- Your wishes for your health.



- Your wishes for where you live.



- Your wishes for other areas of your life.
- What type of support you need to make decisions and choices.



- Any other information that your supporters should know to help you.

## Signing the My Life My Wishes form



The My Life, My Wishes form can be signed by:

- You.
- Your supporters.

## Who is your supporter?



A supporter is someone who can help you to complete your My Life My Wishes form.



If you need support to make decisions, you can ask someone to help you.



The supporter might be able to make some decisions for you if you are not able to.



Supporters can be different types of people.



Your supporter could be an **informal support** like a:

- Family member.
- Friend.

An informal support is someone who is not paid to support you.



Your supporter could be a **guardian**.

A guardian is someone who can make decisions for you about:

- Your health.
- Where you live.
- Who you live with.
- Other personal decisions.



Your supporter could be a **substitute decision-maker**.

A substitute decision maker is someone who makes decisions for you.





Your supporter could be a **person responsible**.

This is someone who makes decisions about your health care.



You can get more information about decision making and supporters on the OPA website.

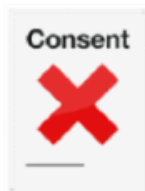
[www.opa.sa.gov.au](http://www.opa.sa.gov.au)

## Know your rights

### Consent



Consent means you say it is ok for someone to do something.



The form does not mean you have agreed to any decision.

You should be asked each time there is a decision to made about you or your life.



You can get more information about consent to medical treatment here

[www.opa.sa.gov.au](http://www.opa.sa.gov.au)

## Capacity



When you are over 18 years old there are life decisions that you need to make.

These decisions might be:



- Signing legal documents.
- Agreeing to a service.
- Giving consent to medical treatment.



If you can make decisions, you have decision making capacity.

You can still make decisions if you:



- Do not understand all the information.
- Can only remember the information for a short time.
- Make a decision that does not have a good outcome.
- Can make some of the decision.



Some people need support to make some decisions.

You might be able to make some decisions but need support to make other decisions.

Some people might need support to make decisions if they:



- Have a disability.
- Are really sick.
- Have an injury.



You might need support to make a decision if you do not understand:

- All of the information about a decision.
- What might happen after a decision is made.



**1800 066 969**



**[opa@agd.sa.gov.au](mailto:opa@agd.sa.gov.au)**



**[www.opa.sa.gov.au](http://www.opa.sa.gov.au)**

This resource was funded by the Australian Government Department of Social Services and the South Australian Health & Medical Research Institute.



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# Appendix 7:

## Presentation by Anthony Beazley

**Hi Brian (not real name<sup>1</sup>). Can you tell everyone here a little bit about yourself?**

I am from Wagga. From a broken home. A Wurundjeri man.

**Can you tell us about how you met your guardian Lois (not real name)?**

I met Lois at the Aboriginal hospital where Lois was working. Flinders Hospital. I was living in a drain at the time. Lois saw me and said I'll find some accommodation. First, I lived in two different motels short term. Then I ended up at the Department of Human Services Disability.

**How long have you known Lois?**

I have known Lois for 10 years.

**Why did Lois become your guardian?**

I was living in a drain and wanted Lois to be guardian because she brought up my past about family. Lois contacted my auntie for me. Lois accepted me into her family.

**What type of decisions does Lois make for you?**

Lois makes medical decisions such as go to hospital or any other medical concerns. Lois will ring and speak to me if I have concerns. She will talk to me and resolve the situation.

**Can you tell us, Brian, about a decision Lois has made for you?**

Lois sent me to hospital for drugs. She made the decision for me. It was the right decision at the time. Also Lois helped have a zoom meeting with Department of Humans Services. She was present for support.

**Do you like having a guardian? Why or why not?**

I love my guardian, Lois. I bounce ideas off her. When we talk, she listens. She is caring.

**Brian, what do you like when you are helped to make decisions?**

I must have a caring person help with making decisions.

**What don't you like when you are helped to make decisions?**

I don't like being told what to do and especially ignored as well.

**What difference has having a guardian made for you?**

Lois has made a difference in my life by being caring, showing respect to me, having empathy, a good heart and listening to me. She saved me from having nowhere to go or live.

**What advice would you give to guardians or people supporting others to make decisions?**

They must be caring, understanding, show empathy, not to belittle, have respect, not rush anyone when making decisions or talk over the person. And have a good heart.

<sup>1</sup> The OPA has received permission to use Andrew's actual name in this report, but a pseudonym was used in the training materials.



# Appendix 8:

## Training materials from OPA training session 1 on supported decision making



### Exploring will and preferences

#### Example story: Samantha

Samantha is a 46-year-old woman with an intellectual disability. Samantha's verbal communication is limited. Samantha has been in hospital for approximately 4 months after being relinquished from an aged care facility. Staff at the aged care facility reported that they are unable to manage Samantha's needs, and have evicted her from the facility.

Prior to the hospital admission, Samantha's cousin Beth was her guardian and administrator. Social work staff at the hospital made an application to VCAT for independent guardianship and administration after reports from Samantha's mother that Beth was not acting in the best interests of Samantha. In addition, Beth had refused Samantha's access to NDIS and had reported to staff that she 'would only consider Samantha living with me or in aged care'.

At the VCAT hearing, OPA was appointed as guardian with accommodation and access to services authority. Beth retained her role as administrator for Samantha. When the guardian initially met with Samantha, she reported that she wants to 'live with Beth'. When the guardian asked if she would consider any other accommodation options, she repeated that she wants to live with Beth. When the guardian asked Samantha if she was happy for Beth to be involved in managing her money, Samantha did not respond and looked down at the floor nervously.

At the end of the meeting, Beth arrived and told Samantha, 'Don't worry, you will be coming to live with me. No one else can take care of you like I do.' The guardian observed that Samantha did not respond and again appeared to look down at the floor anxiously in response to this comment.

Hospital staff have indicated that they will soon be ready to discharge Samantha, and that they believe they have found an SRS that would be suitable with NDIS supports in place. Hospital staff have reported that they would have serious concerns about Samantha residing with Beth, as they do not believe that she would be able to provide Samantha with an appropriate level of care.

**Question:** How would you go about clarifying Samantha's will and preferences?

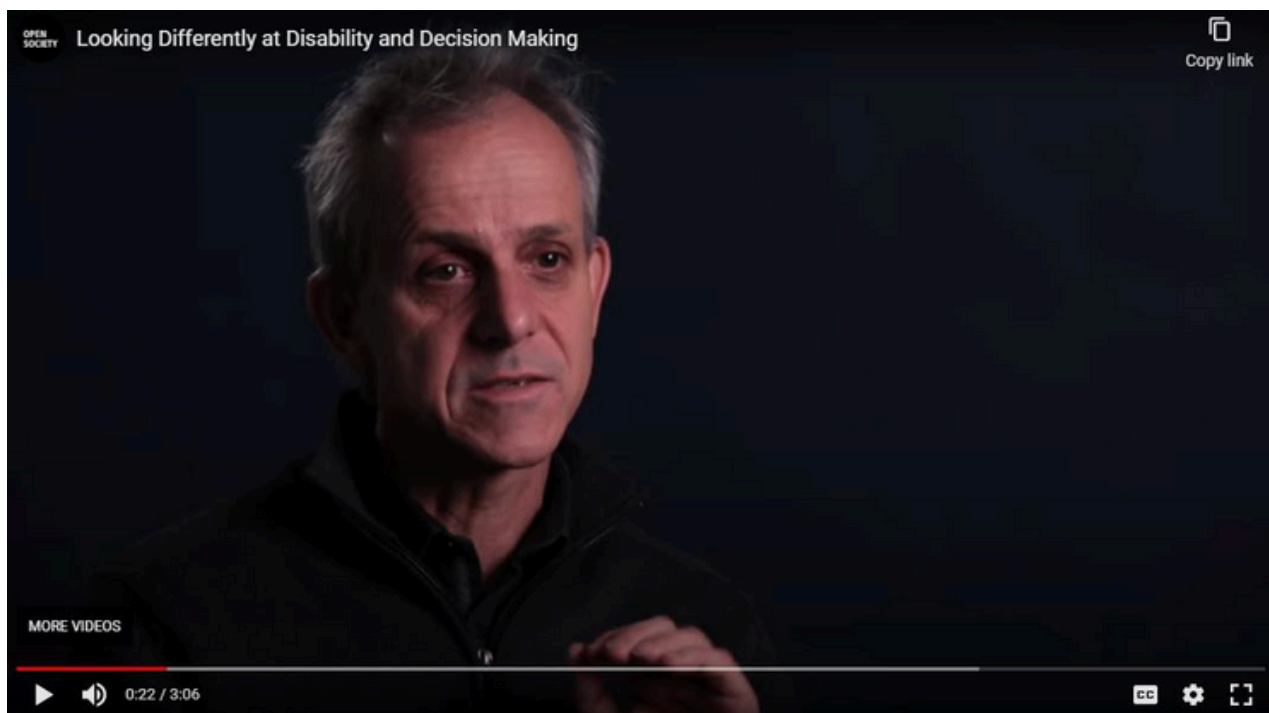
## Supported decision-making Resource summary, October 2021

### **Dr Michael Bach discussing legal capacity and supported decision-making**

Resource Type: Video on YouTube

Focus: A three-minute video explaining the importance of legal capacity and how it can be realised for people with disability through the practice of supported decision making. Michael Bach is a Canadian researcher and leader in the Community Living movement.

He was one of the champions of supported decision making at the drafting of the United Nations Convention on the Rights of Persons with Disabilities. Press control and click on the image below to watch Dr Bach's video.



# La Trobe University Support for Decision Making Practice Framework

Resource type: Online learning resource including videos and downloadable tools

Focus: An evidence-based supported decision making practice framework designed primarily for professional decision supporters including frontline managers, disability support workers, clinicians and case managers.

The e-learning resource developed by La Trobe University's Living with Disability Research Centre is an evidence-based framework designed to guide supporters through the process of assisting someone with cognitive disability to make decisions. The framework consists of six modules which outline specific steps, principles and strategies supporters can use to develop their skills as a decision supporter. Press control and click on the image below to explore the La Trobe Support for Decision Making Practice Framework.



## Enabling risk: Putting positives first

Resource type: Online learning resource, videos and tools

Focus: This e-learning resource provides information about enabling people to take risks as an integral part of disability support work.

The resource developed by La Trobe University is based on a review of research about risk and from piloting materials with disability support workers and people with intellectual disability. There are five e-learning modules which define risk, its types of outcomes and the factors that influence risk taking behaviour. The resource describes the four essentials of risk enablement, the process for supporting people with cognitive disabilities, as well as how to apply the process in different situations. It also describes the benefits of working in a way that enables choices that involve risk. Press control and click on the image below to explore Enabling Risk: Putting Positives First.

### **Enabling Risk** *Putting Positives First*

## A process of decision-making support: Exploring supported decision-making practice in Canada

Resource type: Academic journal article (open access)

Focus: This journal article explores research into the practice of supported decision making conducted in Canada. It compares the decision-making processes of two people with intellectual disability who were supported by paid professionals and the range of factors which influenced the processes and outcomes. Press control and click on the image below to explore the article online.

The screenshot shows the top portion of a journal article page. At the top left, there is a 'Listen' button with a speaker icon. Below this, the text 'Original Article' is visible. The main title of the article is 'A process of decision-making support: Exploring supported decision-making practice in Canada'. The authors are listed as Michelle Browning, Christine Bigby, and Jacinta Douglas. Below the authors, it says 'Published online: 05 Aug 2020'. There is a 'Download citation' button and a DOI link: <https://doi.org/10.3109/13668250.2020.1789269>. A 'Check for updates' button is also present. At the bottom, there is a navigation bar with several options: 'Full Article' (highlighted in blue), 'Figures & data', 'References', 'Citations', 'Metrics', 'Licensing', 'Reprints & Permissions', and a 'PDF' button (highlighted in green).

## Dr Joanne Watson discussing autonomy and supported decision-making

Resource type: Video on YouTube

Focus: A twelve-minute video explaining the importance of autonomy and the right of people with complex disabilities to receive the support they need to make decisions and determine their own lives. Dr Watson explains this work is difficult, time and resource intensive and yet necessary as Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities.

The video provides a powerful example story about Tom and the way his decision supporters identify a decision opportunity, help Tom to explore his options and use video to collectively interpret his expressions of preference. The actions of his supporters enable him to decide how he wants to spend his time and money. Press control and click on the image below to view Dr Watson's video.



# Appendix 9:

## Supported decision making training case studies



Supporting protected persons to make their own decisions

### **Example stories**

#### **Access decision**

Jack is a 20-year-old who lives alone in a unit and is supported by staff. He enjoys talking with others and meeting new people. Jack has a mild intellectual disability and autism spectrum disorder. Sometimes he has difficulty understanding the consequences of his actions and there have been times when he has been negatively influenced and exploited by others.

Jack has a consistent care team who know him well and have worked with him for some years. He is in contact with his mother daily via phone, visits her regularly and when he stays at her home gets to see his extended family.

Jack's mother and father separated 10 years ago and since this time his father moved interstate and they see each other approximately once per year. Visits and phone calls from Jack's father are unpredictable and unplanned.

Jack's father applied to SACAT to become his guardian as he felt that his mother was blocking his ability to see Jack. SACAT appointed the Public Advocate joint guardianship with the mother to support a mutual decision-making approach to access decisions.

The delegated guardian initially spoke with Jack to understand his views on seeing people involved in his life. He was able to clearly describe arrangements with his mother as well as concerns he had about his father. Jack reported that he loved his father but was unable to problem solve the pressure from his father for access with the concerns he had about spending time with him.

The delegated guardian had further conversations with Jack. Jack reported his father didn't understand him and didn't allow him to do things that made him feel better, for example playing with toys or bringing a toy with him to visits. It was clear Jack loved his father and being able to have contact with him. The delegated guardian gathered information on the current arrangements, risks to Jack and his susceptibility to being influenced. There were reports after calls from Jack's father he would contradict his previously expressed wishes saying he wanted access to occur.

Jack was supported to explore a range of access options. He requested the care team handle his mobile phone if his father calls too often and becomes heightened. He wanted access to be arranged on a case-by-case basis. Doing this would allow Jack to be involved in deciding whether he wants to see the person and be involved in shaping the circumstances.

The delegated guardian made an open-ended decision which will allow Jack to be supported to decide when he sees his family members and in what circumstances.

## Health decision

Fernanda is a 43-year-old woman who lives in supported accommodation with 24-hour support. She has a mild intellectual disability, schizoaffective disorder and a range of chronic health conditions including epilepsy, chronic pain syndrome, obesity and chronic respiratory disease.

Fernanda was admitted to Lyell McEwin Hospital for pneumonia, a urinary tract infection and a leg infection. After resolving the acute health issues Fernanda was discharged from hospital with a 7 Step Pathway document that had not been explained to her. The document notified that there was medical consensus between two respiratory specialists on limitations of future treatment for Fernanda's future hospital admissions. The limitations were:

- Not for CPR due to medically ineffectual and medical inconsolable.
- Intubation will not be considered if found to be required ongoing due to obesity, poor lung stability and any further disability would lead to a life not worth living.

The delegated guardian visited Fernanda at home and she was able to easily engage in conversation and express a clear view. The delegated guardian explained the form to Fernanda. She offered clear end-of-life wishes for all care to be provided and remarked 'so they are just going to leave me to die'. The delegated guardian followed up with doctor for further explanation but was given no additional information as the doctor did not need guardian consent before it was made active.

The delegated guardian discussed the document with the NDIS Coordinator who was also concerned. The coordinator explained Fernanda has complex behaviour and extreme sensitivity to pain, which can lead to behaviour escalation when she presents in hospital. The delegated guardian took this information back to the doctor. Fernanda was not in support of the document and presented very differently now to when she was in acute pain in hospital. A review was requested. The doctor maintained his position on no CPR and no intubation. His justifications were: low probability of meaningful quality of life; psychological and emotional intolerance given ID; prospect of not being able to speak.

The delegated guardian escalated the matter to the Department Heads of ICU and Respiratory Medicine and wrote to the Lyell McEwin Hospital for impartial review of the document via letter. The Director of ICU emailed to confirm the 7 Step Pathway document had been cancelled and the OPA letter had been included in Fernanda's medical file.

## Discussion questions

- Do you believe there is a legislative context that allows delegated guardians to be able to support protected persons to make their own decisions? For example, principle 5(d) of the GAA.
- Reflecting on these two recent decision-making scenarios, please discuss when you have been able to support a protected person to make their own decision in your work as a delegated guardian. Please explore as a group whether there are commonalities between your experiences. For example, were there particular types of decisions that lent themselves towards a supported decision making approach?
- Please discuss how you record decisions when the protected person is supported to make their own decision. Do you feel confident in how to document a supported decision?



## Exploring La Trobe Practice Framework

The La Trobe Support for Decision Making Practice Framework centres around three practice principles: commitment to the person and their rights; orchestration of others involved in the person's life; and reflection and review on your own values, influence and support. It promotes the use of six key decision support strategies:

- 1.attention to communication
- 2.education about consequences and practicalities
- 3.listening and engaging to ensure all options are considered
- 4.creating opportunities
- 5.breaking things down and
- 6.enabling risk.

And the six steps of the decision-making process relevant to OPA's work are:

- 1.knowing the person
- 2.identifying and describing the decision
- 3.understanding the person's will and preferences
- 4.refining the decision and taking account of constraints
- 5.reaching the decision and associated decisions and
- 6.implementing the decision and advocating if necessary.

### Example stories

Elizabeth is a 72-year-old woman who is a retired school principal and who has been described as 'fiercely independent, opinionated' and 'likes her own way'. She is well educated and articulate; however, she lacks insight into her physical and cognitive disabilities. Elizabeth has been diagnosed with bipolar-schizoaffective disorder with an underlying neurological condition Lui body dementia. Elizabeth has been a long-term client of geriatric mental health services and has been very difficult to engage, refusing to let people into her home. There is a history of Elizabeth's home being squalid, of her not taking medication, not getting out of bed as a result of depression, and losing weight from not eating.

Elizabeth has had several admissions to hospital for biopsychosocial reasons. She is always resistant to admission; however greatly improves physically and mentally after a few weeks of 'respite' in an aged care facility. At the last admission, the hospital considered her unsafe to return home. During respite she insisted on returning to where she has lived for the last 30 years.

The delegated guardian met with Elizabeth to discuss her accommodation options. They discussed that, if she wanted to return home, she would need to accept increased services at home including an L4 package, daily nursing visits for medication, assistance with getting up and dressed and Meals on Wheels. The staff where Elizabeth was on respite reported she was in good spirits, albeit still insistent on returning home. The geriatric mental health team were not supportive of Elizabeth returning home even for a four-week trial.

Elizabeth had challenged the need for the guardianship order and disputed her diagnoses in detailed medical reports and evidence to the contrary. She expressed a strong will and preference to return home. The delegated guardian spent time speaking with Elizabeth at the guardianship and administration hearings, providing accurate information, building trust and discussing the risks and barriers openly with Elizabeth.

The delegated guardian thoroughly explored the option to return home, liaising with services in readiness for discharge and reported back what was being put in place. The delegated guardian identified the key constraint to being able to return home was the need to accept services. After some discussion Elizabeth agreed to services coming into the home.

The delegated guardian considered the possible risks involved with returning home (evidence of previous decline of supports into the home, and her care needs becoming higher than support levels) and determined it was appropriate to enable the risk at the very least for a trial period, given there had been some improvement while Elizabeth had been in respite. The delegated guardian had the support of their line manager to do so.

The delegated guardian returned to Elizabeth to confirm the decision, discuss the daily contributions required and sign the service agreement. At this meeting Elizabeth said she had changed her mind. Over time she had come to realise returning home was beyond her ability to manage even with the highest level of in-home supports. She expressed if she couldn't move home, she wanted to move to a retirement village and the delegated guardian explored this option with Elizabeth further.

The delegated guardian engaged in deep listening. She supported Elizabeth to gradually build a realistic picture of this alternative option. In doing so, it increasingly became apparent to Elizabeth that she did not have the ability to view retirement village options, sell her property and physically move. Through conversations Elizabeth came to realise her preference to move to a retirement village was outside her capacity and remaining in an aged care facility was the best option and her preference.

At Elizabeth's request, the delegated guardian went on to advocate for her to be offered a place in an aged care facility in the same area as her home, close to the shops, with a larger room that would also allow a bird to be brought from home. The delegated guardian resisted significant pressure from the hospital to accept the first available bed. Elizabeth is now settled in an aged care facility that reflects her will and preferences.

### **Discussion questions**

- Does this example story illustrate all six steps of the La Trobe Practice Framework?
- Can you identify any specific decision support strategies that are used?
- Do you think this Practice Framework might be useful to you when you have the opportunity to support the decision making of protected persons?

Decision making is often a shared task and there can be a range of people who are needed to support someone to be able to make decisions well. The concept of orchestration recognises that supported decision making processes often require one person to lead or orchestrate the process by drawing in other supporters from various parts of the person's life as well as mediating any differences between supporters or others potentially affected by the decision.

Orchestration is an important aspect of the work you do as delegated guardians. You identify supports and services that are missing in the lives of protected persons and advocate strongly for them to be realised. You work to improve the networks of support that are in place for people, often mediating conflict, and this can have a significant impact on the protected person's ability to be supported to make decisions.

### **Example Story: Nicole**

Nicole was a 23-year-old woman with borderline personality disorder and an intellectual disability. She had made allegations of sexual abuse by her father and brother, and police took out Family Violence Intervention Orders on her behalf. The Public Advocate was appointed to make accommodation and access to persons decisions for Nicole.

At the commencement of the order Nicole was completely unable to articulate her will and preferences. She was in a state of trauma and her personality disorder was florid. She didn't have adequate structure and support in her life generally and as a result 'things were in chaos'. The advocate guardian took over decision making in relation to Nicole's family visits because Nicole was at risk of self-harming and there was a significant concern that she would be sexually assaulted by her father.

The advocate guardian sought to put appropriate supports in place for Nicole. This required obtaining a significant amount of funding from the National Disability Insurance Scheme as Nicole needed ongoing support from a psychologist, psychiatrist, support workers (24/7) and the advocate guardian. The advocate guardian established a care team for Nicole that met regularly (six weekly) and was responsible for supporting her with decision making. How the care team engaged with Nicole was directed by a Behaviour Support Plan developed by her personality disorder specialist.

It took two years for Nicole to fully engage with the care team meetings. Having this structure in place changed Nicole's decision making. With a greater level of support, she was able to clarify and express her will and preferences. Decisions were no longer made on the run, and she was able to set boundaries with respect to seeing her family. Nicole sought the support of the care team with her decision making, specifically her key worker and psychologist. Nicole's guardianship order was reviewed recently and was revoked given the robust decision-making support that was in place which enabled her to have decision-making capacity.

### **Discussion questions**

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- Does the concept of orchestration resonate for you and your experience as a delegated guardian?
- What are the activities you do that build the decision-making ability of protected persons?
- What are the challenges you face to orchestrating good decision support in the lives of protected persons? Do you have any ideas as to how they might be overcome?

## Exploring risk

Supported decision making asks us to take a risk enablement approach when exploring risk as an important constraint in the decision-making process. There are a few key features of a risk enablement approach. Firstly, it is collaborative and involves the person in the whole consideration of risk. Secondly, it approaches risk from a positive standpoint. Thirdly, it invests time and energy assisting the decision maker to be able to understand the nature and consequences of the risks. Fourthly, when harm minimisation is necessary it asks us to explore alternative ways to reach the same goal for the person that have the least change to their will and preferences.

### Example story: Sally

Sally is a 70-year-old woman with early onset dementia. She has lived with her partner and 2 dogs on a rural farm for the past 6 years. Her capacity has only recently declined. Sally's partner is retired and provides full-time care to Sally at home. This includes providing medication management, transport assistance, meal preparation and general prompting and supervision as a result of Sally's memory difficulties. Sally has no difficulties with her mobility and is able to shower and toilet independently. She is content where she is living.

Sally's brother Ronald and her long-term friend Margaret were appointed as substitute decision makers under an Advance Care Directive and her brother was appointed as attorney under an Enduring Power of Attorney. Ronald and Margaret made an application to SACAT to appoint 2 of Sally's daughters as guardian and administrator due to difficulties fulfilling their role in the face of significant conflict with Sally's partner. Shortly after, further applications were put to the SACAT by the 2 daughters (guardian and administrator) recommending appointment of the Public Advocate due to their roles also becoming unworkable due to conflict with Sally's partner.

At the hearing, it was reported that the 2 daughters, brother and best friend had been prevented from accessing Sally and as a result had concerns about her wellbeing and the state of her care. A full guardianship order was made appointing the Public Advocate including special powers (S32(1).A) in the event that Sally required alternative accommodation.

The delegated guardian visited Sally at her partner's home. Strong rapport was witnessed between Sally and her partner, and no care concerns were noted. The home was well kept and Sally presented as well cared for. Sally was spoken to away from the company of her partner. She reported that she loves where she is living, specifically she loves the peace and quiet, the expanse of the land she looks onto from her lounge room window, and living with her partner and his two dogs. She reported that it would be her 'worst nightmare' to move from her partner's home or to be separated from him. She explained she was aware that some of her family do not visit because her partner can get 'aggro', but she is happy to visit them at their homes. She also reported she was visiting her family regularly and would wish to continue doing this; however this was not in fact the case – she had not seen her family for many months. Sally also reported that 1 of her daughters resides in her privately owned home, and she wishes this arrangement to continue as this daughter has always needed more support than the others and Sally would like to provide this support.

The 2 other daughters requested OPA make a decision to place Sally in an aged care facility as, according to them, Sally is not adequately cared for by the partner in addition to him preventing contact with the family. The guardian sought further information on Sally's care needs and health status via an ACAT assessment and Sally's regular GP. The GP reported that the partner supports Sally to see the GP regularly, she has presented at required assessments and the partner is managing Sally's medication adequately. The guardian spent significant time arranging an ACAT assessment on behalf of Sally as the partner objected due to fears it would result in placement in an aged care facility. ACAT advised that Sally's partner was obstructive to assessments; however with a home visit and collateral was able to complete the assessment. Sally became eligible for a low-level home care package and respite.

Excluding the daughter residing in Sally's home, the family continued to pressure the delegated guardian for a decision about transfer to an aged care facility. The delegated guardian discussed the option of using special powers with the family, who advised it would be too 'heavy handed' but wanted resolution from the delegated guardian about access between the family and Sally. The delegated guardian contacted Sally to discuss with her the concerns from her family and the options, with intention to start short-term respite and devise a plan agreeable to Sally for when her partner was unable to care for her. Sally advised, again, that she did not want to move to an aged care facility or take up respite. If she needed to, she would like to return to her own home with supports in that home. At this point in the conversation the partner took the phone and became angry and verbally abusive towards the delegated guardian. The partner reported he would refuse home care package supports entry to the home.

### **Discussion questions**

- What are the risks involved in this situation? Please consider the positive and negative benefits of these risks to Sally.
- What strategies could be used to mitigate each of these risks?
- Do you think it would be possible to develop a plan for mitigating the risks with Sally (and her partner)?
- How could you minimise harm by making the least modifications to her will and preferences?

# Appendix 10:

## Worksheet from SAIDHS advanced SDM training for practitioners

### Decision making scenario 1

Ted is a 35-year-old male with mild intellectual disability, autism, ADHD and anxiety. He resides in a house with three other people and is supported by two carers. Ted has a history of challenging behaviour and property damage. He has a Positive Behaviour Support Plan and is prescribed 3 types of antipsychotic medications, which he has been taking since his early 20s. Ted was referred to SAIDHS due to increasing incidents of physical aggression. SAIDHS clinicians are concerned about the impact of multiple high-risk medications on Ted's long-term health. Ted's carers have voiced concerns about reducing any medications.

#### Reflection questions

- What are the range of factors that might be influencing the use of high-risk medications for Ted?
- How could we explore more deeply what Ted is expressing through his behaviour? From your experience with others what are some possible reasons he may become physically aggressive?
- What options, strategies and supports might address these reasons (other than medication)?
- How could we better understand Ted's will and preferences around his current medication use? How could we be more directed by Ted's will and preferences when exploring future medication use?

### Decision making scenario 2

Sasha is a 42-year-old female with severe intellectual disability and barriers to communication. She lives in supported accommodation with one-to-one supports and is under the guardianship of the OPA. Sasha was referred to SAIDHS due to concerns about weight loss of unknown cause. SAIDHS clinicians completed a medical assessment and recommend a blood test and MRI to investigate; however the carers reported this would be traumatic, and she would not be able to tolerate the tests.

#### Reflection questions

- What communication support might Sasha need to be able to understand the concerns about her weight loss? Consider approaches, tools and resources.
- If the key barrier to having the blood test and MRI is fear because of a lack of understanding, what creative strategies could be explored to help Sasha understand what is involved? How might you go about trying to reduce her fears and the possibility of trauma?
- If after exploration and reflection the blood test and MRI are not appropriate investigative strategies (e.g., there is history of trauma and a strong likelihood of re- traumatisation), what alternative investigative options could be explored with Sasha?
- After communication support is provided, and options are explored, how might you work with OPA and her carers to clarify and act on Sasha's will and preferences about the blood test and MRI?
- How might you advocate for Sasha's will and preferences to direct decisions about her future health?

## Decision making scenario 3

Harry is a 22-year-old male with moderate intellectual disability and Down syndrome. He lives with both parents and has 2 younger siblings. He was referred to SAIDHS due to his parents' concerns about his oppositional attitude at home towards his parents' requests and day option coordinators indicating he is becoming verbally 'aggressive' with other participants and can no longer attend the program. SAIDHS clinicians completed a mental health assessment and identified no mental health conditions; however his frustration is likely relating to seeking more independence as a young adult. Harry indicated to SAIDHS clinicians that he wanted to move out of home, but his parents were reluctant to agree to this idea.

### Reflection questions

- How could we explore more deeply what Harry is expressing through his behaviour? How can we understand his will and preferences?
- Are there any decision opportunities presenting themselves?
- What role might SAIDHS clinicians have in supporting Harry to communicate more effectively what he wants (his will and preferences)?
- What role might SAIDHS clinicians have in supporting Harry's parents to become more open to hearing and acting on his communication (will and preferences)?
- What organisations and groups might be able to offer Harry support? What organisations or groups might be able to offer support his parents?



## Appendix 11: Supporting the decision making of people with psychosocial disability: A challenging decision-making scenario

Kevin is a 61-year-old single man, living alone with chronic schizophrenia. He has been admitted to an inpatient psychiatric ward with a relapse of psychotic symptoms following a period of non-concordance with treatment. He is an NDIS participant and lives alone in private rental; he receives 10 hours of support per week and a recent review of his support plan with assistance from the community mental health team has concluded he would be safer and optimally supported in supported independent living accommodation. Kevin has been reluctant thus far to engage with this plan.

Since coming onto the ward, a number of other psycho-social issues have come to light; Kevin is in arrears with his rent, the property is becoming squalid and he is at risk of losing his accommodation. His mother, who acts as his carer but has no formal decision-making responsibilities, is very worried and upset about her son's future. She has expressed concerns that, when she passes away, he will have no one to 'bail him out' and advocate on his behalf. She is of the view he shouldn't be making independent decisions and he needs to be in supported care with someone taking care of his finances for him.

Kevin's cognition is somewhat impaired based on previous assessments; likely secondary to a dozen or more episodes of psychosis resulting in admission over the last 30 years. He has also used illicit substances in the past to dangerous levels. However, Kevin has been assessed as having decision-making capacity in relation to his accommodation and support choices. There has been some doubt cast on his ability to make more complex decisions regarding finances.

What role might you play in assisting Kevin to make an informed decision about his support and accommodation in readiness for planning his discharge from hospital?

### Reflection questions

#### 1. Looking into and understanding the decision

- Why is the decision important?
- What might it mean for Kevin?
- What might it mean for other people in Kevin's life?
- Who needs to be involved in making this decision?
- What might help the process (e.g. involving the right people, supporting communication)?
- What might hinder the process (e.g. available time, money, resources)?

#### 2. Understanding the person's will and preferences

- What are Kevin's preferences?
- How does this decision align with Kevin's vision for his life?
- How does the decision relate to his values, beliefs and prior experiences? (If we don't know, how could we find out?)

### 3. Gathering information and exploring options

- How could you support Kevin to explore his options?
- How could you present information to Kevin that would work best for him?
- How could you explore the good and bad things that could come from each option with him?

### 4. Working through barriers and risks

- What are the barriers to acting on Kevin's will and preferences?
- How could the barriers be overcome?
- What are the risks (positive and negative)?
- How could the negative risks be reduced and managed?

### 5. Weighing it all up and making the decision

- How could you help Kevin weigh up the benefits and risks?
- How would you know what Kevin's final decision is?
- What support would Kevin need to communicate his decision to others?

### 6. Reflecting on the decision and what happens

- Do you need to advocate alongside Kevin for the decision to be acted on?
- Are there more decisions to be made as a result of the decision?
- What has the impact of the decision been on Kevin and others?



## Reflecting on your influence

Think about a time when you helped someone to make a decision. I would like you to consider three questions.

- Were you trying to influence the person's decision?
- Can you identify the biases you brought to the decision-making process? (For example, you thought the person was too unwell to decide, some options were too risky, you value relationships more than personal autonomy.)
- Did you approach the decision-making process with a specific outcome in mind? (For example, you felt one option was the best for the person, you needed to get the person to agree to something.)

# Appendix 12:

## Supporting the decision making of people with psychosocial disability training: Content summary and digital resources

### What is supported decision making?

- Supported decision making is the process of providing practical assistance with decision making. It offers people with disability a broad range of supports to be able to make their own decisions and stay in control of their lives.
- Practical assistance can be ensuring the person knows there is a decision to be made. Explaining and clarifying information and creating opportunities to try new things. It can involve helping the person identify and weigh up their options, solve problems and minimise their stress and anxiety.
- Practical assistance can also involve identifying possible risks, developing an understanding of consequences and helping the person implement their decision.
- For people with psychosocial disability it can also involve removing distractions in the environment, simplifying information and conversations so as to not overwhelm people, building trust and providing a safe space, using diaries lists and photographs to help remember important conversations, and encouraging people to take time and not act impulsively.

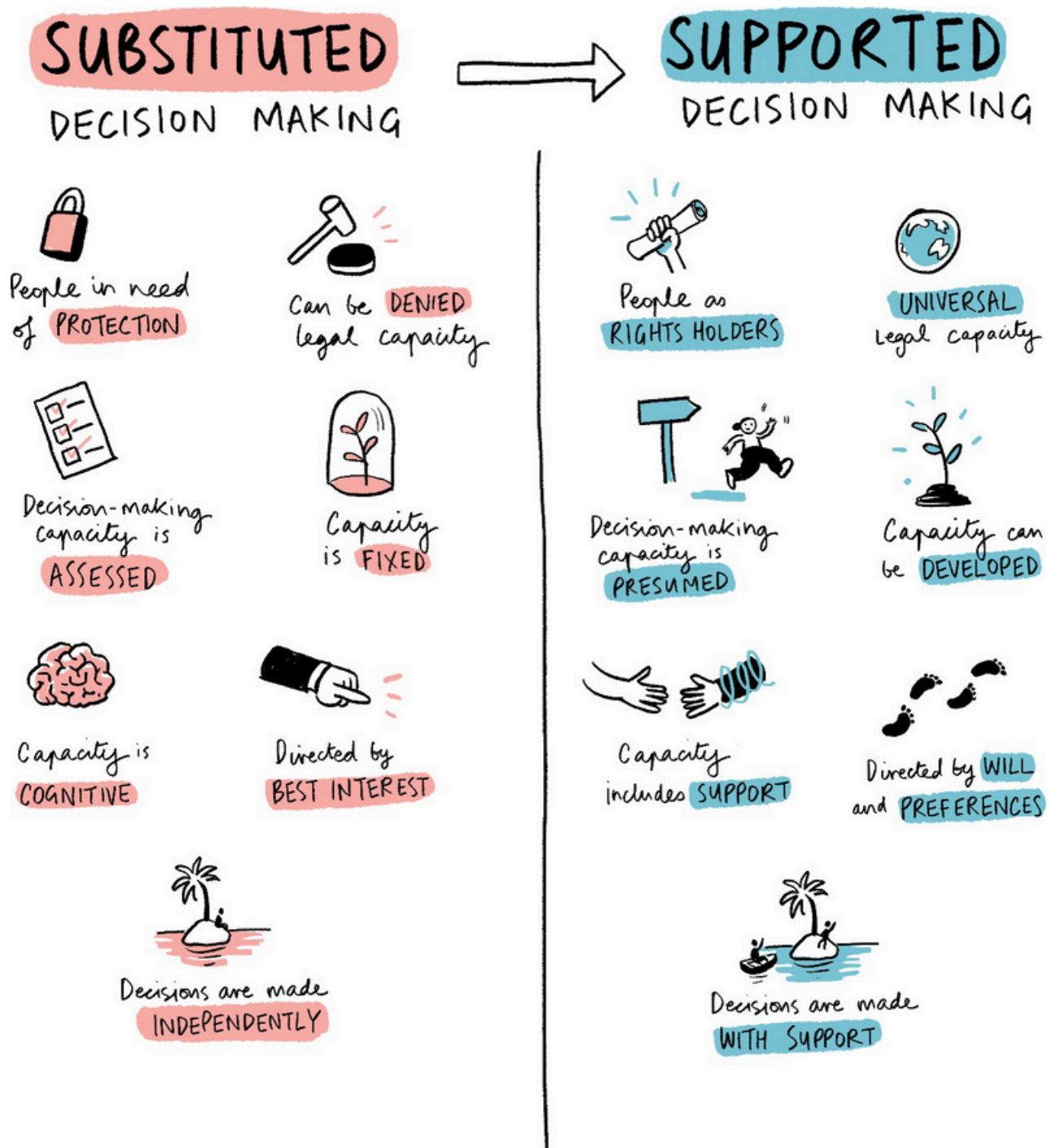
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Why is it important?

- The Convention on the Rights of Persons with Disabilities states we must provide people with disability with the support they need to exercise their legal decision-making rights.
- Supported decision making is a practical and legal alternative to substitute decision making.
- Substitute decision making is when someone else makes decisions for you. This can be informally or formally through mechanisms like guardianship and financial management.
- Supported decision making recognises we all need support to make decisions in our lives at different times, and we draw on the support of people we know and trust.
- Our ability to make decisions is shaped not only by our skills and experience as individuals but also by our context and the quality of support available to us.

Ability + supports and accommodations = decision-making capability

- The support you provide has the power to change a person's decision-making capability. What you do or don't do can have a big impact.

How is supported decision making different to substitute decision making?

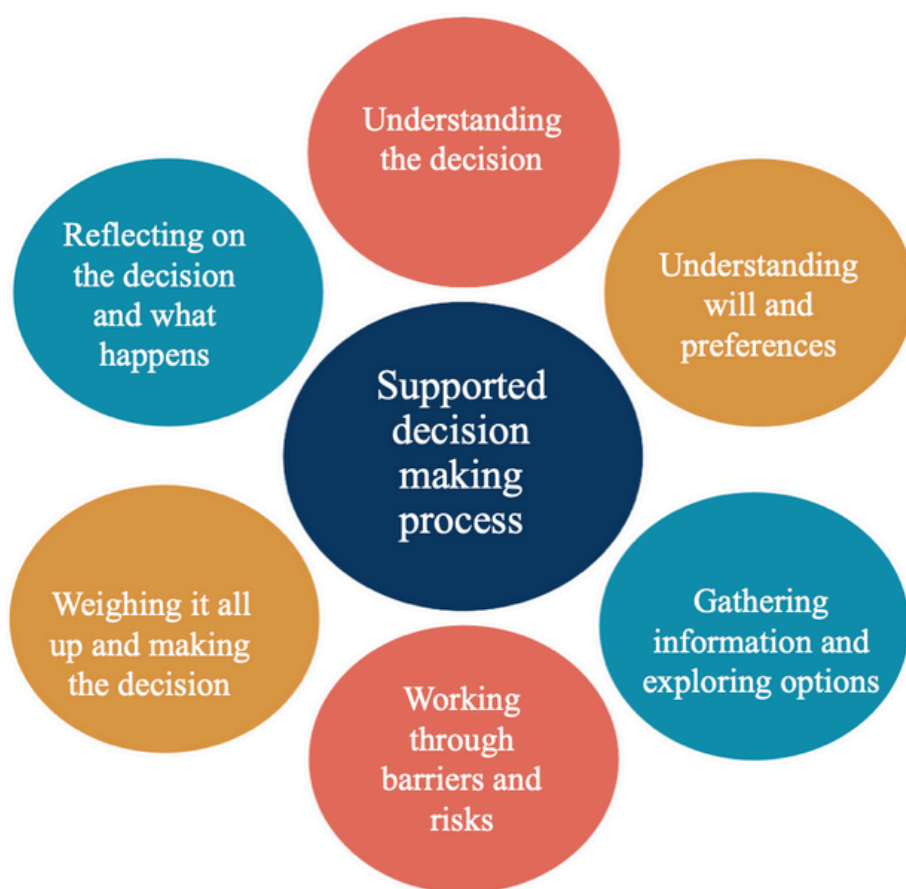


To read more about this go to:  
[www.decisionagency.com.au/resources](http://www.decisionagency.com.au/resources)

## Three important decision support strategies

1. Strengthening relationships: we develop the quality of our relationships with decision makers including mutual knowledge, respect and trust. We also foster the relationships the decision maker has with others.
2. Minimising your influence: we approach the decision-making process from a neutral standpoint, acknowledging and working to minimise our biases. We need to focus on a good process rather than achieving a specific outcome.
3. Enabling risk: we see risk as something that is not inherently negative, collaborating with people to identify possible harm, and find ways to reduce the harm that respect their will and preferences.

## A process to help guide practice



To access a tool which guides you through this process go to:

[www.belongingmatters.org/product-page/supported-decision-making-guide](http://www.belongingmatters.org/product-page/supported-decision-making-guide)

## Supported decision making digital resources

### What is SDM?

[An animation exploring supporting decision-making in practice.](#)  
[A series of five videos explaining what it is and why it's important in the health context.](#)

### Why is SDM important?

[Supported decision-making is about enabling the exercise of legal capacity.](#)  
[Stories from people who have experienced severe mental health problems and been supported with their decision making in health contexts.](#)  
[Autonomy can be realised for people with complex communication support needs through decision-making support.](#)

### How do you provide support?

[Factsheet on supporting decision making in the health context.](#)  
[A research-based support for decision-making practice framework.](#)  
[A research-based approach to supporting decisions involving risk.](#)  
[Journal article exploring the range of factors which influence the supported decision-making process.](#)

### What tools can you use to better support communication?

[Practical tips on communicating with people with disability in the health context.](#)  
[Using tools such as My Health Information.](#)  
[Using tools such as Talking Mats.](#)  
[Providing information in Easy Read.](#)  
[Understanding the importance of communication partnering for people with complex communication support needs.](#)

### What tools can you use to talk about decision making?

[WaiS SDM plain language and Easy Read resources.](#)  
[ADACAS online decision-making toolkit.](#)  
[My Rights Matter SDM Hub including resources such as SDM Conversation Cards.](#)

# Appendix 13:

## Overview of the Be Well Plan sessions

### **Session 1: Getting on the same page**

- Introduction to facilitators and the group norms. If presented online, particular focus will be placed on explaining the software.
- Participants self-reflect on the reasons for participating in the program and reflect on their personal drivers. Facilitators provide insight into their own drivers to work on their mental health by sharing them with the group.
- Participants share their personal drivers with other group members in small groups.
- Participants acquire basic knowledge on mental health and definitions for key concepts such as mental health and resilience to create a common language and understanding.
- Facilitators delineate scope of the program: focus on building mental health not treating mental illness.
- Participants explore importance of believing in malleability of mental health and the need to have a growth mindset. Evidence on malleability is presented.
- Participants are asked to reflect on most surprising thing they learned so far. Participants do a small group sharing exercise where they discuss their choice
- The evidence for different psychological interventions is presented. Participants learn that finding activities that work for their specific situation is key.
- Participants are introduced to a number of easy mindfulness activities and are asked to choose one to practice during the week.
- Participants are asked to set a goal and are introduced to the concept of tiny habits/implementation intentions as a technique to improve the chance of goal attainment.

Homework: complete measurement if participants have not completed it before the training.

### **Session 2: Using your mental health profile**

- Participants reflect on their first week of using their plan and how their mindfulness activity worked during the past week. They reflect on whether they need to adjust their plan. Participants share reflections in small groups.
- Participants get familiar with the concept of self-compassion (as opposed to self-criticism) and how it can be used to learn from failure and shape our thinking patterns.
- Participants practice a self-compassion activity and share their reflections in small groups.
- Participants interrogate their measurement result stemming from the integrated measurement. Facilitators can share their own results with the group.
- They identify areas they can improve on and select one outcome (wellbeing, resilience, mood, anxiety, stress) they want to focus on for this session.
- Participants share their outcome of focus.
- Participants are introduced to activity finders: flow charts that map evidence-based activities to each of the activities.
- Participants use the activity finders to explore activities they can add to their plan focused on their outcome of choice.
- Participants pick one activity from the activity bank to add to their Be Well Plan and set new goals for the week.
- Participants are introduced to the use of prompts and reminders as another method to increase goal attainment.

Homework: complete a survey that allows participants to identify their own values.



### **Session 3: Your resources and challenges**

- Participants reflect on week 2 and make changes to their plan if needed. Participants share reflections in small groups.
- Participants work with (and are reminded of) existing resources to their own mental health via two practical activities.
- The first activity gets participants to choose pictures that display sources of meaning in their life. Participants share the pictures in small groups. Facilitators show their own pictures to start the activity.
- The second activity gets participants to identify core values that can be used to guide their life decision and their goals. Participants share which values are important to them. Facilitators share their own values.
- Participants then use a custom questionnaire to identify a key resource or challenge they want to work on for the next week. These resources and challenges can be psychological, health behavioural or external.
- Participants are introduced to a second activity finder that maps evidence-based activities to each of the challenges and resources.
- Participants explore new activities mapped to the resources and challenges and pick one new activity from the activity bank to add to the Be Well Plan.
- Participants finish the session by adjusting their Be Well Plan and are reminded of the importance of celebrating small wins related to their mental health (i.e. when they practise activities in line with their Be Well Plan).

Homework: Participants are asked to choose and reach out to a social supporter as part of their weekly activities.

### **Session 4: Stress, coping and resilience**

- Participants reflect on week 3, adjust their plan if needed and share their reflections in small groups.
- The concept of stress and eustress is introduced and participants learn the effect of stress on our mind and body.
- Participants learn about coping strategies (avoidance-focused coping versus more helpful ways, e.g. problem-focused coping). They complete an activity where they reflect on when they used different coping strategies and what impact it had on them.
- Participants are then walked through various ways of effective coping using psychological techniques, including identification of cognitive traps, positive reframing and the use of thought defusion.
- Participants complete example activities related to cognitive traps, positive reframing and thought defusion in their own life. They share their reflections with other participants in small groups. Facilitators provide examples of their own life.
- Participants learn about the importance of asking for help, both from their social support network and professional services.
- Participants then choose one new activity specifically focusing on stress and resilience. They add this to their Be Well Plan.

Homework: participants are asked to complete another measurement, the results of which will be used during the next session.

## **Session 5: Future proofing your Be Well Plan**

- The participants reflect on the past 4 weeks, what has worked and what has not. Participants share reflections in small groups.
- Participants are asked to investigate how their measurement results have changed over the four weeks.
- The facilitator will introduce the concept of realistic optimism, growth, the fact that progress comes with ups and downs and that it is a slow and gradual process to see change.
- Participants will then build their final Be Well Plan, which aims to summarise key learnings from the previous weeks into a standalone plan.
- Participants summarise what their best possible mental health looks like. They share their best possible mental health with group members.
- Participants highlight their unique drivers and motivations, and existing resources and challenges in their life. They write down the values that are important to them.
- Participants set a longer-term mental health goal.
- Participants choose the activities they wish to add to their 'final' Be Well Plan. They identify their key supporters and reflect on what support services they need in case of emergency.

## Appendix 14: Train the trainer description

The project has left the sector with a number of Be Well Plan train the trainers. Those trained through the grant are based in South Australian disability sector peak body organisations SACID and BISA, central government agencies SA OPA and SA Health (Centre for Disability Health and Division of Palliative Care which oversees hospital long-term stay discharge) and exemplar disability organisation Tutti Arts, among others.

These organisations give good coverage to the sector:

- Guardianship/substitute decision makers: Office of Public Advocate
- NDIS peak bodies and community training and program providers: Brain Injury SA (BISA), South Australian Council on Intellectual Disability (SACID) and Tutti Arts
- Department for Health: long-stay transition and disability health services unit SA Intellectual Disability Health Service (SAIDHS), mental health nurse training unit and Northern Adelaide Local Health Network People and Culture training unit.

Even before the completion of the project on the basis of having an accredited trainer from the program BISA won a grant to continue the work. Beyond the project they will continue to deliver training to family members and friends network and to extend the work with funding from their grant for a new train the trainer from their lived experience cohort.

SACID will enhance their current training programs which include Healthy Minds, My Life My Choices and Relationship-wise as they continue to strength their sector contributions.

Tutti Arts programs will be enhanced by the skills inhouse.

SA Government will continue to deliver the program internally and to family members.

Appendix 15:

My Be Well Plan activity book –  
easy read



**Easy Read**



# My Be Well Plan

## Activity Book

Find an activity that works best for you.



**Flinders  
University**

## What is mindfulness?



Lots of the activities in this book talk about **Mindfulness**.



Mindfulness is:

- Thinking about what you are doing now.
- Not worrying about anything else that is happening.
- Not being distracted by anything else.

Mindfulness helps you feel **grounded**.



Being grounded means distracting yourself from emotions, such as

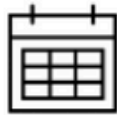
- fear,
- sadness,
- anger.

This book will have different mindfulness activities that can help you feel grounded.

Each activity will tell you:



- How long to do it.



- How often to do it.



- How **difficult** it is.

This will tell you if the activity is:

- Easy.
- Medium.
- Hard.



It will also tell you what areas it can have a positive impact on.

You can choose an activity that works best for you.






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# 1. Mindful Breathing



Different ways to breathe that can help if you are feeling stressed.

How long	How often	Difficulty
 10 minutes	 1 a day	 Easy



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

## What is Mindful Breathing?



We all breathe every day, all day.

Sometimes we do not notice we are breathing.

If you think about your breathing for a minute, it can help you to feel calm.

## Why I should do Mindful Breathing



This can help you to **ground** yourself.

This means to distract yourself from emotions, such as

- fear,
- sadness,
- anger.

## How to do Mindful Breathing



1. Breathe slowly in through your nose.



2. Breathe slowly out through your mouth.



6

3. Breathe in through your nose for 6 seconds.



6

4. Breathe out through your mouth for 6 seconds.



5. Try to focus just on your breathing.

6. Think about how your breathing feels as you breathe in and out.



7. Do this for 1 minute.

## 2. Progressive Muscle Relaxation



Relaxing different muscles in your body.

How long	How often	Difficulty
 15 minutes	 1 a day	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

## What is Progressive Muscle Relaxation?



This is a mindfulness activity for your muscles.



You will **tense** different muscles.

Tense means to squeeze different muscles.



Then you will relax different muscles.



Think about your muscles when they are tense and when you relax them.



You can tense and relax all your muscles in your body.

## Why I should do Progressive Muscle Relaxation



Sometimes your muscles may tense because you feel anxious or stressed.

This can help you to relax your muscles.



## How to do Progressive Muscle Relaxation



1. Find a space you can lie down or sit.



2. Breathe slowly in through your mouth.



3. Breathe slowly out through your mouth.



4. Choose 1 body part of your body.



5. Tense this body part for 30 seconds.

6. Relax this body part for 15 seconds.



7. Repeat with other body parts.

## How to tense different muscles in your body



**Feet:** curl your toes downwards.



**Lower leg:** Pull your toes towards you to stretch your calf muscle.



**Upper leg:** Tighten your thigh muscle.



**Bottom:** Squeeze your bottom muscles.



**Hands:** Make a fist.



**Upper arm:** Bend your arm up and make a fist.



**Jaw:** clench your jaw.



**Eyes:** squeeze your eyes shut.



**Forehead:** raise your eyebrows and hold them high.

### 3. Mindful walking



Think about your walking and how it makes you feel.

How long	How often	Difficulty
 10 minutes	 1 a day	 Easy



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Health.
- Mood.
- Anxiety.
- Stress.

## What is Mindful Walking?



Sometimes when you walk you think about

- What you are doing that day.
- What problems you have.
- Stress in your life.



Mindful walking is when you just think about the steps you are taking.

You do not think about other things.

## Why I should do Mindful Walking



Mindful walking can help you:

- Reduce stress.
- Concentrate.
- Regulate your emotions.

## How to do Mindful Walking



1. As you walk think about how your body is feeling.

Think about the feelings you feel in your:

- Legs.
- Feet.
- Arms.

2. Think about how your body moves as you take a step.



3. If you start to think about something else, stop and think about your next step again.



4. Use your nose and smell what is around you.



5. Use your mouth and see if there is anything you can taste around you.






6. Think about your feet touching the ground and how it feels.

## 4. Online Mindfulness



You can use an app or website to practice Mindfulness.

How long	How often	Difficulty
		
Depends on the activity you choose.		



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

## What is Online Mindfulness?



There are different mindfulness activities you can find on:

- Websites.
- Mobile apps.

It is important to find one that works on the device that you want to use.

## Why I should do Online Mindfulness



Online mindfulness can help you find ways to practice:

- Meditation.
- Deep breathing.

## How to do Online Mindfulness



1. Go on the internet or app store.



2. Type in the word mindfulness.

3. Different videos, instructions will show up.



4. Click on 1 to try.

5. Try it!

Keep going if you like it.

If you do not like it, try a something else.



Here are some free apps you can try:




- Smiling Mind.
- Insight Timer.
- Headspace.



## 5. Mindful Eating



How does it feel when you eat?

How long	How often	Difficulty
 10 minutes	 1x a day	 Easy



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

## What is Mindful Eating?



Sometimes when you eat you think about:

- What you are doing today.
- What makes you sad and angry.



Mindful eating is when you think about what you are eating.

- How the food smells.
- How the food feels in your mouth.
- How the food tastes.



## Why I should do Mindful Eating



Mindful eating can help you to think about the yummy food you eat.

## How to do Mindful Eating



1. Eat your food slowly.

2. Are you still feeling hungry or are you full?



3. Think about the food.

- How does it smell.
- How does it taste.
- How does it feel.



4. Do not do anything else when eating.

Do not look at your phone or the TV.



5. Did you cook your food or need to get it ready to eat?



You do not have to do this with every meal.

Start with 1 day and see how you go.

## 6. Yoga



Connecting the breath, mind and body.

How long	How often	Difficulty
 15 minutes	 1 a day	 Easy



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Health.
- Mood.
- Anxiety.
- Stress.

## What is Yoga?



Yoga helps you think about:

- Your breathing.
- How your body feels.

## Why you should do Yoga

Yoga can help your body in different ways:



- Stronger heart.
- Stronger muscles.
- Stronger spine.
- Staying healthy.
- Blood flow.
- Relaxation.
- Sleep.
- Reduce stress.

## How to do Yoga



You can join a Yoga Studio.



Search for Yoga Studio's online.

You can ask for help to do this.



You can also do yoga at home.



Search for home yoga exercise online.

You can find some beginner Yoga exercises at:




[www.yogidia.com](http://www.yogidia.com)

## 7. Mindful Attention



5 – 4 – 3 – 2 – 1

Focus on what is happening around you.

How long	How often	Difficulty
 5 minutes	 1x a day	 Easy



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

## What is Mindful Attention?



Mindful attention is knowing what is happening around you.

## Why I should do Mindful Attention



Mindful attention can help when you feel:

- Stressed.
- Anxious.
- Overwhelmed.



## How to do Mindful Attention



Think about where you are right now.



Find 5 things you can see.



Find 4 things you can hear.



Find 3 things you can feel.



Find 2 things you can smell.



Find 1 thing you can taste.




Take a deep breath in between each activity.

## 8. Being Grateful



Think about what you are grateful for.

Think about the good things in your life.

How long	How often	Difficulty
 15 minutes	 1x a day	 Easy



This activity can have a positive impact on:

- Wellbeing.

## What is being grateful?



Being grateful is thinking about all of the good things in your life.



This could be things like:

- Family.
- Friends.
- Holidays.
- Pets.



It is thinking about things that go right and well for you.

It is not thinking about what has gone wrong.

## Why you should think about being grateful



Being grateful helps you to feel:

- Positive.
- Happy.

It can help you to focus on something good when things are hard for you.

## How to think about being grateful



1. Think about yesterday.



2. Think of 3 things you are grateful for.

3. Why did these things go well for you?






4. Who helped these to go well?

## 9. 3 Funny Things



Thinking about the good and funny things that have happened.

Life is better when you are laughing.

How long	How often	Difficulty
 10 minutes	 1x a day	 Easy



**This activity can have a positive impact on:**

- Wellbeing.
- Mood.

## What is 3 Funny Things?



Sometimes life can be hard.



This activity asks you to think about good and funny things that have happened.

## Why should I think of 3 Funny Things



It can help you forget sad and hard things.



It can make you feel happy.

## How to think about 3 Funny Things



1. Write down 3 funny things that happened today.



2. How did they make you feel?




3. Why were they funny?

## 10. Re-thinking Thinking Traps



Stopping yourself from using **thinking traps**.

Thinking traps are negative ways of thinking.

How long	How often	Difficulty
 20 minutes	 3x a week	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Mood.
- Anxiety.



## What is a Re-thinking Thinking Traps?



Sometimes we might think about things in a negative way.



That is thinking something bad will always happen.

Sometimes our brain will make us think what happens is worse than what really happened.

This is called a thinking trap.

## Why I should use re-thinking Thinking Traps



Changing how you think can change it from a bad to good thought.

This can help with how you are feeling.

It can help your anxiety.

## How to Re-Think Thinking Traps



1. Think of something that happened recently where you did not leave feeling good.



2. Stop thinking.



3. Think about what happened again.

4. Try to think about the real events that happened.

Do not think about how what happened made you feel.



5. How else could you have thought about the event?

### Example of Re-thinking Thinking Traps



My partner did not come to an event with me. This means my partner does not care about me.




Think of other reasons why your partner could not come.

For example, they were busy or sick.

## 11. Expressive Writing



Write thing down when you have had a hard time.

How long	How often	Difficulty
 20 minutes	 1x a day	 Medium



This activity can have a positive impact on:

- Mood.
- Anxiety.
- Stress.

## What is Expressive Writing?



Everyone has things happen that are hard.



Expressive writing is writing what you are thinking down.



You can write about how you were feeling.

## Why you should do Expressive Writing



When something is hard you may not want to talk about how you feel.



You can write down all of your feelings.

This can help you to

- Work through your feelings.
- Not feel as worried or stressed.

## How to do Expressive Writing



1. Think about a hard time in your life.



2. Write down how you feel about this hard time.



3. Write down the thoughts you had in this hard time.

4. Write down how this hard time has made life for you now.

When you are doing Expressive Writing, remember:



- You can write anything you want.
- Do not worry about spelling.
- Focus on times that you can work through on your own.



- Get professional help with really hard times.



- It is OK if you are not ready to write about the hard time.  
Choose a different time in your life.






- You do not need to show anyone what you have written if you do not want to.

## 12. Self-Compassion



Looking after yourself when you are having a hard time.

How long	How often	Difficulty
 20 minutes	 1x a week	 Medium



This activity can have a positive impact on:

- Resilience
- Mood.
- Anxiety.
- Stress.

## What is Self-Compassion?



**Self-compassion** is being kind and helping yourself during a hard time.



You might try to help other people when they are having a hard time.

But when you are going through a hard time, you might not give yourself the same amount of help.

## Why you should use Self-Compassion



Self-compassion can help you to feel better.

It helps you to not judge yourself.



## How to do Self-Compassion



1. Think about a friend who had a hard time.



2. What would you say to help your friend?



3. How would you feel if this was you?






4. Think about what you would say to yourself if you were in the hard time.

5. Could you help yourself the same as you would help a friend?

## 13. Acceptance of Your Experience



Thinking about the feelings you had during an event.

How long	How often	Difficulty
 20 minutes	 1x a day	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Resilience
- Mood.
- Anxiety.
- Stress.

## What is Acceptance of your Experience?



You will feel lots of different emotions in your life.



It is important to let yourself feel the emotions you have.



Do not ignore the hard emotions.

Think about how the hard emotions make you feel.

## Why I should do Acceptance of your Experience



Accepting your experience can help you deal with emotions such as:

- Anger.
- Sadness.
- Anxiety.
- Frustration.

## How to do Acceptance of Your Experience



1. Think of an emotion you feel that can be hard.



2. How does it make your body feel?

3. It is ok to feel this emotion.

This emotion will only last for a short time.



4. After feeling that way, how does your body and mind feel?



5. Your body is going to feel different emotions every day.




6. Why do you think you felt this emotion?

7. Did something happen that made you feel this emotion?

## 14. Getting in Touch with your Values



Think about what is important to you in your life.

How long	How often	Difficulty
 20 minutes	 1x a week	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Resilience.

## What are values?



Values are things that are important to you.

It is good to know what kind of values you want in your life.

Different types of values in life can include:



- Teamwork.
- Love.
- Kindness.
- Honesty.
- Forgiveness.
- Family.
- Friends.
- Creativity.
- Learning.
- Gratitude.
- Hope.
- Humour.

## What are your values in life?



1. Think about a time that was very important in your life.



2. What happened at that time that made it important?

- Your friends or family were there.
- You won something.
- You got a new job.
- Something else important to you.



3. What are 3 important values in your life?

4. How can you add your values in your life every day?






Knowing our strengths can help us to think about what our values might be.

Go to [www.viacharacter.org/](http://www.viacharacter.org/) to find out your strengths.

## 15. My Goals and Values



Thinking about your goals and what is important to you in your life.

How long	How often	Difficulty
 15 minutes	 1x a day	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Resilience.



## What are your goals and values?



Setting a goal can help you get something you really want.

Values are things that are important to you.



You might have a life goal. This could be:

- To get a job.
- To be a good partner.
- To get fit and healthy.



If your goals and your values in life are similar it makes it easier to achieve them.

## Why I should think about my goals and values



Thinking about your goals and values at the same time can help you choose personal goals you want to have.



Choosing a goal that connects to your values will help you reach your goal.

## How to choose goals with your values

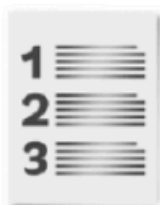


1. What are your top values?



2. What life goal do you want to achieve?

3. How can you use your top values to reach your goal?



4. How can you break down your big goal into smaller goals?

## 16. Thought Defusion



The way you think can make you feel different emotions.

How long	How often	Difficulty
 15 minutes	 1x a day	 Hard



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

## What is Thought Defusion?



What you think can make you feel different emotions.

You might feel:

- Sad.
- Happy.
- Angry.



Thought defusion is knowing that what you think can be true or not true.

You do not have to agree or believe what you are thinking.



Listen to what you are thinking if it will help you.

## Why I should use Thought Defusion



Thought defusion can help when you are feeling sad or upset.

It can help you try and solve a problem.

## How to use Thought Defusion



1. Think of a time when you felt sad or upset in the past week.

2. Do you think you would feel this again another time?  
Think about how you could change how you think.



3. Write down what you were thinking when you were sad or upset.



4. Try to change how you talk about what you are thinking.

Instead of saying, 'I am going to fail.'

Try to say, 'I am having the thought I am going to fail.'

5. Think of a time when you could practice this.

## 17. Thank you letter



Writing a letter to someone to say thank you.

How long	How often	Difficulty
 20 minutes	 1 time	 Medium



This activity can have a positive impact on:

- Wellbeing.

## What is it?



Write a letter to someone you know to say thank you.

The letter can tell the person how they helped you feel happy.

## What can I use it for?

It can help you:



- Make your relationships stronger with people.
- Feel happy and healthy.
- Focus on good things that happen in your life.
- Know that other people care for you.



## How to write a thank you letter



1. Think about a person who you want to thank.

Write their name down.



2. Write a letter to the person about:

- How they helped you.
- How their help made you feel.



3. Give the person the letter to say thank you.



## 18. Reflective and active listening






**Reflective** means to think back on things.

**Active listening** is when you give the person talking all your attention.



Reflective and active listening is listening to other people and thinking about the conversation.

How long	How often	Difficulty
 5 minutes	 4x a day	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Resilience.

## What is reflective and active listening?



Reflective and active listening is a good conversation.

It is about giving the person talking all your attention and thinking about what they are saying.

Learn how to be a good listener and how to talk to other people.

## What can I use it for?



Reflective and active listening can help you to build relationships with other people.

It can help you improve:



- Your communication skills.
- Relationships.
- How you feel.

## How to do Reflection and Active Listening



When someone is talking to you:



1. Listen to the other person.

2. Look interested in the other person.



3. Ask questions about what the other person is talking about.

4. Try not to talk too much about yourself.

5. Try this with someone you know.

When you are active listening, try to listen and not talk about a holiday that you have been on.

### Example of reflective and active listening



**Person 1:** I went on a holiday on the weekend.

**Person 2:** That sounds fun. Where did you go?



**Person 1:** I went to Queensland with my family.

**Person 2:** What did you like most about Queensland?





**Person 1:** It was good to just relax with my family and go on some rides.

**Person 2:** That sounds really great, glad you got to have a rest and do something fun with your family.

## 19. Assert Yourself



Telling other people what you think.

How long	How often	Difficulty
 15 minutes	 2x a day	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Resilience.

## What is Assert Yourself?



**Assertiveness** is to tell other people what you think and how you feel in a nice way.

It can be used when needing to deal with tricky situations.

## What can I use it for?

It can help to:



- Reduce conflict.
- Reduce anger.
- Tell others how you feel.
- Have positive conversations with others.

## How to assert yourself



1. Practice the **broken record technique**.

The broken record technique is when you keep saying the same thing if someone keeps asking you something.

For example, when someone does not listen to you when you say 'no', you keep saying 'no' every time they ask.



2. Write down when you practiced this.

3. What was the situation?



4. How did you use the broken record technique?

5. What could you do different next time?

## Example of how to assert yourself



Someone wants you to buy something, but you do not want to.



You can say 'No thank you I do not want to buy anything.'



The person keeps asking you.



You say again 'No thank you I do not want to buy anything.'




Stay calm and repeat the same thing each time.



## 20. Goal Setting



Working towards something you want.

How long	How often	Difficulty
 15 minutes	 1 time	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Health.
- Mood.
- Anxiety.
- Stress.

## What is Goal Setting?



Goal setting is working towards something that you want.

Think of something you really want that is a big goal.



Then think of small steps that you can do to reach your bigger goal.

## What can I use it for?

You can use goal setting to:



- Try and do something you want to do.
- Help you feel good if you reach a goal.
- Help you make a plan to reach a goal.

## How to set a goal?



1. Write down a goal you want to do in the next couple of weeks.



2. Why do you want to reach this goal?



3. Break down the goal into smaller steps.



4. Is there anything that might make the goal hard to do?

5. Write a **SMART** goal.

A SMART goal is:



- **Specific.**

Make the goal clear.



- **Measurable.**

Think about how you will know if you have reached your goal.



- **Achievable.**

Is your goal possible to do.



- **Realistic.**

Is it a goal that will work for you in your life.





- **Timely.**

When will you do the goal.

## 21. Meaningful Pictures



Think about pictures or photos that are important to you.

How long	How often	Difficulty
 5 minutes	 3x a day	 Easy



This activity can have a positive impact on:

- Wellbeing.
- Resilience.

## What is it?

Meaningful pictures is thinking about:



- Things that are important to you each day.
- Why those things are important in your life.

## What can you use it for?

You can use meaningful pictures to:



- Think of things that are important in your life.



- Help you feel happier in life.

## How to do this?



1. Take photos of 3 things that are important to you.



2. Write or draw why the photos are important to you.



3. Print out or post these photos online to look at them again.

This can remind you why they are important things in your life.



Some ideas of things that could be important to you is:

- Your job.
- Your pets.
- Your friends.
- Your family.
- Going for walks.





**Write or draw about each photo.**




What is photo 1 of?	Why is it important to you?
What is photo 2 of?	Why is it important to you?
What is photo 3 of?	Why is it important to you?



## 22. Finding Flow



Doing something you enjoy and not thinking about anything else.

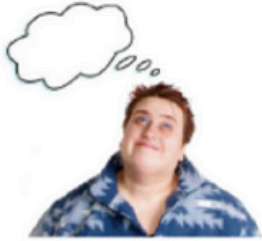
How long	How often	Difficulty
 10 minutes	 1x a day	 Easy



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Mood.
- Anxiety.
- Stress.

## What is Finding Flow?



Flow is when you are doing something you enjoy and forget about everything else.

## What can I use it for?



When you find your flow it helps you to be focussed on something you like.

It can help you to forget about things that may be hard.



It can help you to feel happy.

## How to Find Flow



1. Think of an activity that you love.



2. Make sure this activity is a bit hard for you.



3. Think of a time of the day that is quiet.



4. Remove anything that stop you from doing your activity.  
This could be your phone.

5. Begin your activity.

You might need to change your activity if what you chose does not get you into the flow.

## 23. Problem Solving



Feel more in control of your life.

How long	How often	Difficulty
 15 minutes	 1 time	 Medium



This activity can have a positive impact on:

- Wellbeing.
- Resilience.
- Health.
- Mood.
- Anxiety.
- Stress.

## What is it?



Sometimes you will have problems.

It is good to know different ways to solve problems that you have.

## What can you use it for?

Problem solving can be helpful all parts of your life.

It can help when you have:



- Negative feelings, like stressed or angry.
- Relationship problems.
- Problems at work.

Being able to problem solve is important.

It means you can do something to try and make things better.

## How to do it?



1. Think about a problem you have.



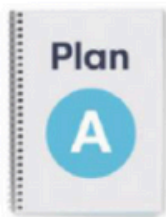
2. Think of some ways you could solve the problem.



3. What are some good and bad things about the way you could solve the problem.



4. Choose the best way to solve the problem.



5. Make a plan to solve the problem.






6. Check if the plan is working.  
If it is not working, change the plan.

## 24. My Character Strengths



Find your strengths and what you like about yourself.

How long	How often	Difficulty
 15 minutes	 Ongoing	 Medium



This activity can have a positive impact on:

- Wellbeing.

## What is it?



Your character strengths are the good things about you as a person.



Some character strengths are:

- Creativity.
- Honesty.
- Humour.
- Kindness.
- Leadership.
- Teamwork.



## What can you use it for?



It is important to use your strengths every day.

This can help you to reach your goals and make you feel happy.



## How to do it



1. Do the Signature Strengths test on [www.viacharacter.org/](http://www.viacharacter.org/)



2. Choose 1 strength to use.



3. Think about different ways that you could use the strength you have chosen.



4. Think about how you could use the strength to reach a goal.

5. Write a SMART goal.

A SMART goal is:



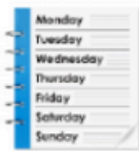
- **Specific.**  
Make the goal clear.



- **Measurable.**  
Think about how you will know if you have reached your goal.



- **Achievable.**  
Is your goal possible to do.



- **Realistic.**  
Is it a goal that will work for you in your life.



- **Timely.**  
When will you do the goal

**Notes:**

This resource was funded by the Australian Government Department of Social Services.

Go to [www.dss.gov.au](http://www.dss.gov.au) for more information. The development of the original Be Well Plan resources was supported by a grant by the James & Diana Ramsay Foundation.



This document has been made in an easy-to-read way by the South Australian Council on Intellectual Disability using images from Microsoft 365 and Photosymbols. Images cannot be used without permission. This document was tested by people with intellectual disability.

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Appendix 16:  
*My Life Decisions*

# My Life Decisions

A form for people who are unable to make a legal document but want to have their goals and wishes written down so that it can guide their future supported decision making.

1. This form is for people in South Australia who are unable to complete the legal **Advance Care Directive** and require support.
2. This document **does not** replace an **existing legally binding Advance Care Directive**, which should be completed by people who have legal capacity.
3. This document is intended **to replace** all other **advance care planning forms** in South Australia for people who require support to make decisions or who lack decision-making capacity, including the Palliative Care Plan, the Statement of Choices and specific aged care facility forms or plans.

This document has been developed by the Documenting My Life Decisions Committee in collaboration with the Office of the Public Advocate SA. It is based on the principles of the South Australian *Advance Care Directives Act 2013* and the United Nations Convention on the Rights of Persons with Disabilities 2006.

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ver 1.0

# Introduction

## Principles

This form provides a supportive framework to establish the goals of care which will guide future decision making for those people who require support and are unable to make their own decisions about their future health care, residential and accommodation arrangements and personal affairs near the end of their lives.

It incorporates principles from the following South Australian legislation:

*Advance Care Directives Act 2013*

*Consent to Medical Treatment and Palliative Care Act 1995*

*Guardianship and Administration Act 1993*

It also draws on the important guiding principles of the United Nations Convention on the Rights of Persons with Disabilities and in particular Article 12: Equal recognition before the Law. This includes the right to make decisions with support. This convention was ratified by the Australian Government in July 2013.

The SA *Advance Care Directives Act* at s 10(d) is consistent with the convention when it states:

*A person must be allowed to make their own decisions about their health care, residential and accommodation arrangements and personal affairs to the extent that they are able, and be supported to enable them to make such decisions for as long as they can.*

***This is known as the principle of supported decision making.***

## Planning documents in South Australia

**Advance Care Directive.** If a person is competent, they should complete a legally binding Advance Care Directive. Copies of the South Australian *Advanced Care Directive DIY Kit* are online at [www.advancecaredirectives.sa.gov.au](http://www.advancecaredirectives.sa.gov.au) or available at Services SA.

**My Life Decisions.** This document does not override an existing Advance Care Directive. This document is for people who require support to make decisions or who lack decision-making capacity

**Resuscitation Plan – 7 Step Pathway.** Medical practitioners developing a clinical care plan involving resuscitation and end-of-life care should take an Advance Care Directive or My Life Decisions Plan into account when completing a Resuscitation Plan – 7 Step Pathway. (If a Resuscitation Plan is later found to have been completed prior to this form, it is advisable to check if the instructions on the plan are consistent with those on this form.)



## Definitions

1. **Consent to medical treatment:** This My Life Decisions Plan **does not give legal consent to medical treatment**. It provides guidance for future decision making. A medical professional can only provide medical treatment to a person if the person consents (if they have capacity to do so), they have previously given consent through an Advance Care Directive, a parent or guardian consents (if the person is a child), a substitute decision maker or person responsible consents, or if it is an emergency.
2. **Capacity:** The *Advance Care Directives Act 2013 (SA)* **presumes** all adults have full legal capacity to make decisions about their health care, residential and accommodation arrangements and personal affairs. However, a person has impaired decision-making capacity in relation to a decision if they are not capable of:
  - a) understanding information that may be relevant to the decision (including the consequences of making the decision)
  - b) retaining this information
  - c) using this information in the course of making the decision, and
  - d) communicating his/her decisions in any manner (*ACD Act s 7*).

People are presumed to have decision-making capacity unless there is clear evidence that they don't. They can still have decision-making capacity if they do not understand some technical information, or if they do not retain information for long, or if they fluctuate between impaired and full capacity, or even if they make decisions that others may believe are not in their own best interests (*ACD Act s 7(2)*).

3. **A substitute decision maker** is a person who has been legally appointed as a substitute decision maker in an Advance Care Directive or under a previous legal document (*ACD Act s 21*).
4. **A person responsible** is:
  - a) a guardian (if one has been legally appointed)
  - b) if there is no guardian, then a spouse, domestic partner or adult relative who continues to have a close and continuing relationship with the person (including someone related by adoption or by Aboriginal or Torres Strait Islander kinship rules)
  - c) if no guardian, spouse, domestic partner or relative is available, an adult friend who has a close and continuing relationship with the person
  - d) if none of the above are available, an adult who oversees the day-to-day supervision, care and wellbeing of the person (*Consent to Medical Treatment and Palliative Care Act s 14(1)*).

*The concept of 'person responsible' replaces the concept of 'next of kin'.*

# How to use this form

## Who should be involved?

It is important to have a meeting to discuss the wishes and goals of care for the person concerned which are then documented on this form. The meeting should include the person concerned if he/she can understand the conversation and express their own wishes (with support if necessary), those close to the person and also those responsible for the ongoing care of the person. These people may include the responsible doctor, the **substitute decision maker** (if one has been appointed), the person's family or carers (**person responsible** – see definition) and (if the person is a resident of an aged care facility) a nursing professional.

The **My Life Decisions** form should be completed as soon as possible after the meeting and signed by:

- 1) the person concerned if possible;
- 2) the **substitute decision maker** or **person responsible**; and
- 3) the **health professional** involved in the ongoing care of the person such as a doctor or nursing professional.

## Role of health professionals

All health professionals assisting clients in completing this **My Life Decisions** form should:

- a) have some training in how to introduce the conversation with the client, the person responsible and those who care for and support the person. It is important to understand the concept of supported decision making, that is, 'stepping into the person's shoes' or 'being the person', when the client does not have capacity or is non-verbal.
- b) be familiar with the prompts provided in the *Advance Care Directive DIY Kit* (part 3: ***What is important to me – my values and wishes***)
- c) arrange a suitable time to meet and notify the relevant people who will be involved in the meeting.
- d) take notes on a separate sheet of paper, in order to complete the plan so that it will capture the person's wishes clearly and be legible.
- e) tick each decision box according to the supported decision-making framework (below)
- f) once the plan is completed, make sure all the relevant people sign the document.

**Does the person have a doctor who is available and willing to complete a *Resuscitation Plan – 7 Step Pathway*?** If 'Yes', a Resuscitation Plan – 7 Step Pathway should be completed by the person's doctor and informed by the person's wishes expressed in this My Life Decisions Plan.

### Points to remember

This My Life Decisions Plan should:

- a) reflect the wishes of the person so far as they are known
- b) reflect the decisions they would have made in these circumstances if they were able to fully express their own wishes (stepping into the person's shoes)
- c) protect the person's interests as they would currently understand them
- d) avoid restricting the basic rights and freedoms of the person, as far as possible.

### Types of decisions in a supported decision-making framework

To assist future decision making based on this document, it will be helpful if each category of decision is marked as one of the following.

**Self-determined decisions (green)** reflect the expressed wishes of the person with minimal intervention from supporters (substitute decision makers or persons responsible).

**Collaborative decisions (amber)** involve collaboration and negotiation between the person and their supporters.

**Substitute decisions (red)** are made by the person's supporters on behalf of the person.

# A Plan for 'My Life Decisions' – Including End of Life

Date this form was completed:

Name of person: .....

Date of birth: .....

Address: .....

## 1) Making an Advance Care Directive

Is the person competent to complete an Advance Care Directive?

If 'Yes' he or she should complete an Advance Care Directive.

If 'No' proceed with completion of this form.

## 2) Values and wishes

### 2.1 What I want:

---

---

---

---

Type of decision made:



Self-determined



Collaborative



Substitute

### 2.2 What I don't want:

---

---

---

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Type of decision made:



Self-determined



Collaborative



Substitute

### 2.3 Health care I want:

---

---

---

---

Type of decision made:



Self-determined



Collaborative



Substitute

## A Plan for 'My Life Decisions' – Including End of Life

### 2.4 Where I want to live and what care I want:

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---

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---

Type of decision made:

☒

Self-determined

☐

Collaborative

☐

Substitute

### 2.5 Other personal arrangements:

---

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---

Type of decision made:

☒

Self-determined

☐

Collaborative

☐

Substitute

### 2.6 My dying wishes:

---

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---

Type of decision made:

☒

Self-determined

☐

Collaborative

☐

Substitute

3) ☐ Mark this box if it is agreed that the person would NOT WANT TRANSFER TO HOSPITAL if palliative care measures can be provided that are adequate to maintain their comfort and dignity in their place of residence (which may be a residential care facility).

Type of decision made:

☒

Self-determined

☐

Collaborative

☐

Substitute



## A Plan for 'My Life Decisions' – Including End of Life

4) These are the people who agreed that the goals of care recorded in this 'My life Decisions' form are what .....would have wanted  
(insert resident's name).

List names:

Relationship to the person

_____	_____
_____	_____
_____	_____
_____	_____

### 5) Signed by

a) If the person is able to understand (with support if necessary) they may sign here:

Signature: \_\_\_\_\_ Date:    /    /

b) Person responsible or substitute decision maker

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Signature: \_\_\_\_\_ Date:    /    /

c) Health or other professional\*

Name: \_\_\_\_\_ Profession: \_\_\_\_\_

Signature: \_\_\_\_\_

*\* such as doctor responsible, nursing professional or other responsible professional*

