South Australian Health and Medical Research Institute and Office of the Public Advocate

Living My Life

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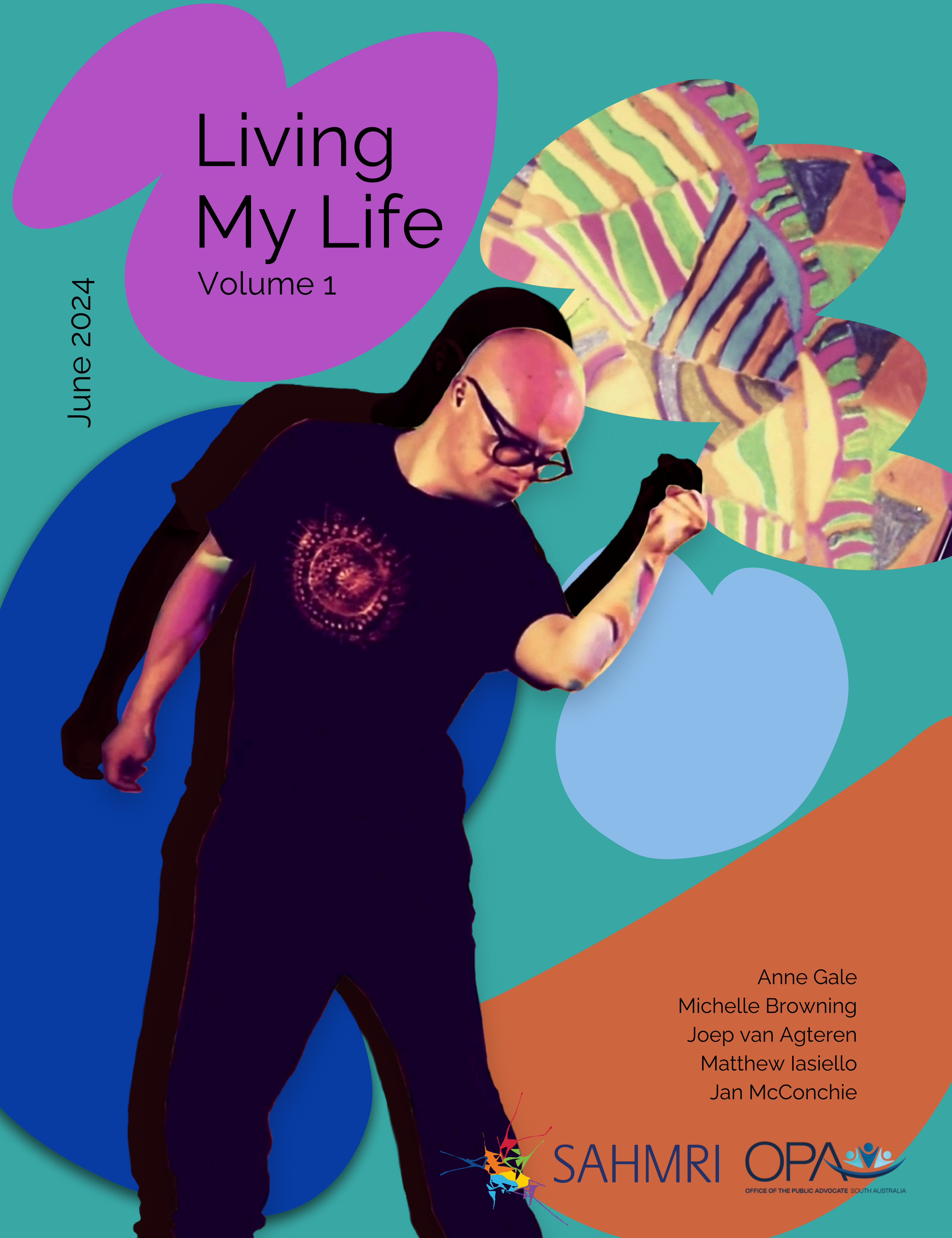

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Front cover picture:
The front cover of this report shows Lorcan Hopper, an artist from Tutti Arts Inc.
You can read more about Lorcan and his participation in the project in Section 4 of this report.

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Designer: Lilian Choo
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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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.

Team lead: Jan McConchie, SAHMRI

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- 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)

Academics/experts who provided input to the project:

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Michelle Browning (Decision Agency)
Margaret Brown (University of SA)
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Co-design partners:

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

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We also acknowledge Pat Rix, who brought her twenty-plus years of experience working with artists with disability to the co-design component of this project.

We want to thank Margaret Brown, who has spent many decades educating South Australian health workers and service providers to respect the autonomy of all decision makers, and who generously contributed her wisdom and guidance to this project.

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

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

Glossary of terms

Disability Royal Commission	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.
OPA Staff	A South Australian Public Service employee with delegations by the Public Advocate to perform guardianship functions.
Person with a guardianship order	A person subject to a guardianship order under the GAA.
Supported decision making	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.

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

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.

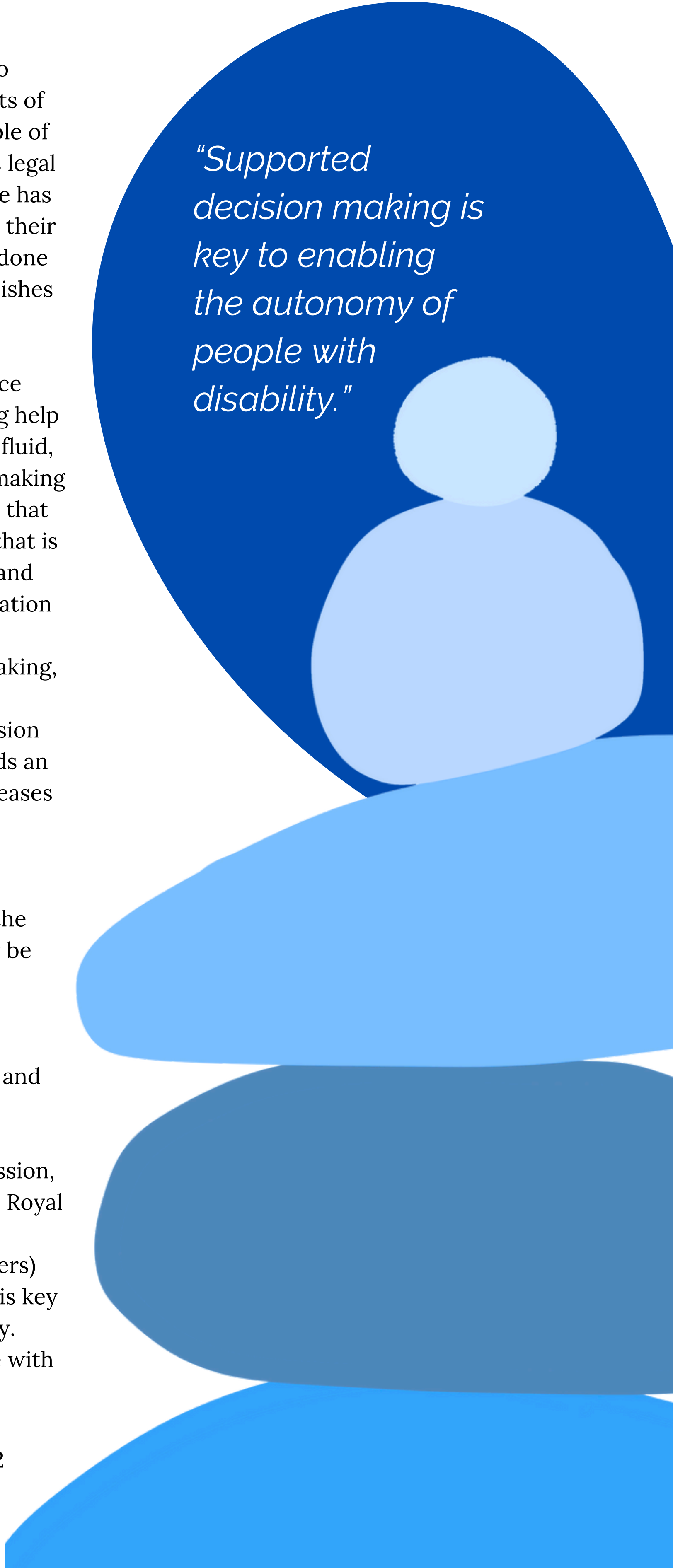
Supported Decision Making

In 2008, Australia was one of the first countries to ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). A key principle of the UNCRPD 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 UNCRPD 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:

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."*

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

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.

"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. 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.

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 enrols 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

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 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.

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

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.

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)).

"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

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*[1] form developed by Margaret Brown (Adjunct Research Fellow, University of South Australia) in collaboration with the OPA (see Appendix 16).

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

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.

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[1] *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

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.

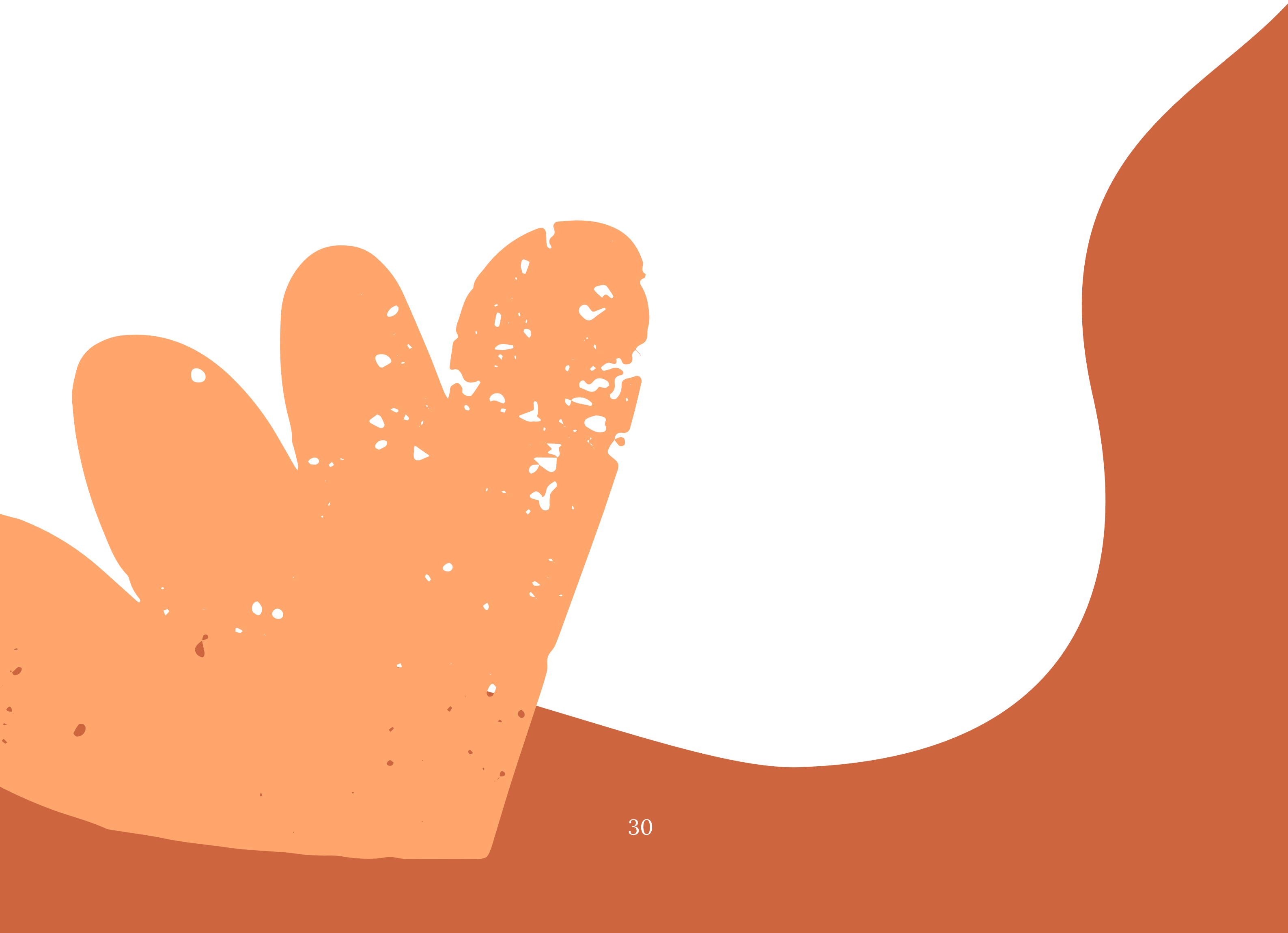
Support gaps.

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.

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.

"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.

74%
required
moderate support

26%
required
intensive support

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:

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.

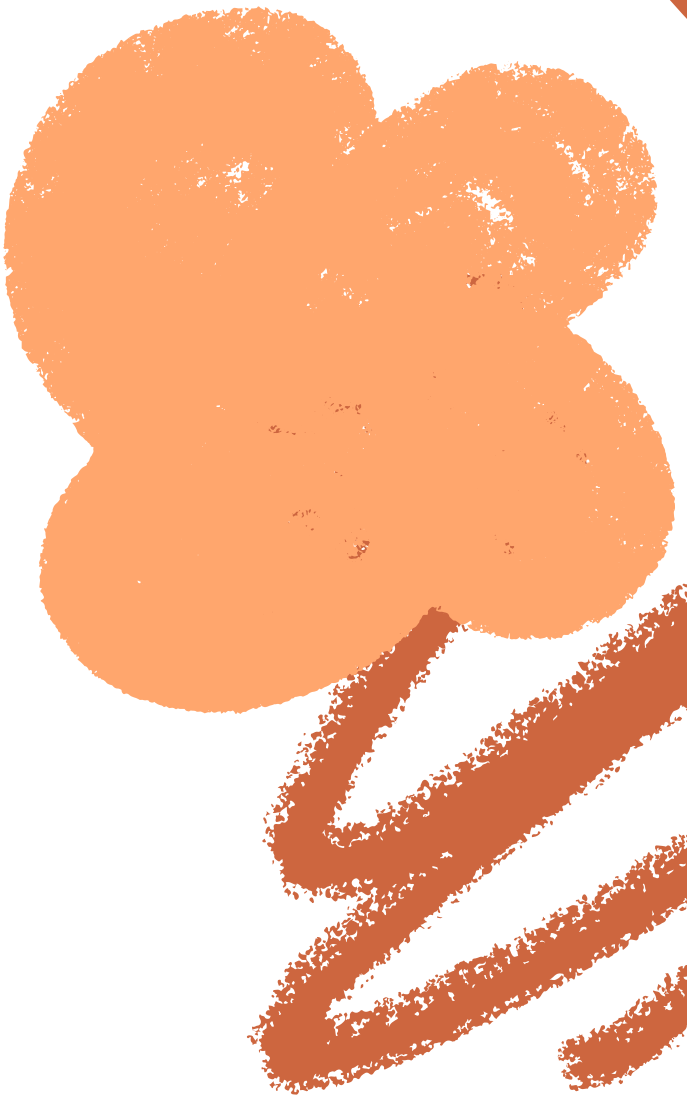
Finding 4:

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?

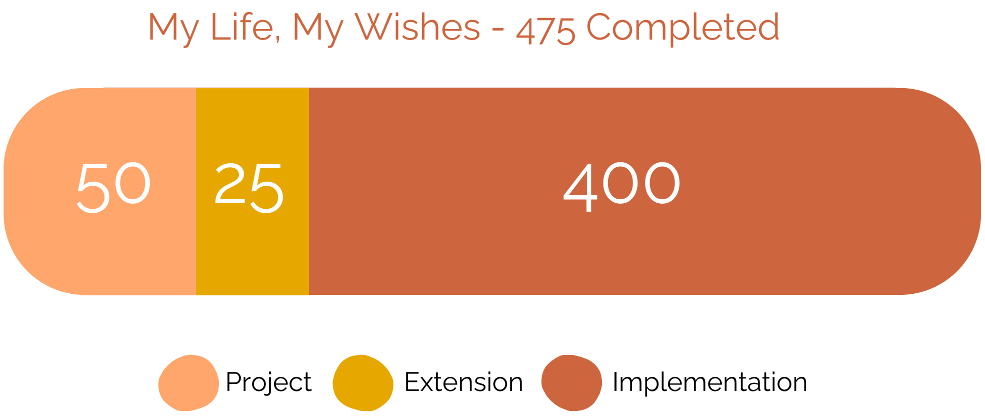


Figure 2: My Life, My Wishes completions

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, WAiS 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.

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.

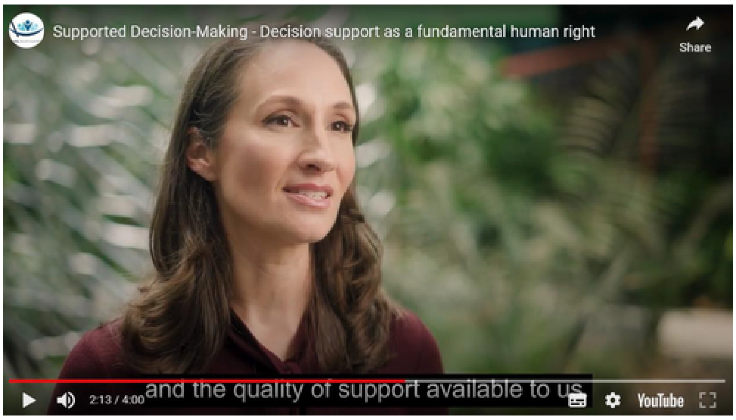
2. Supporting guardianship to become the last resort

- 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?

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)

3. Supporting good decision-making processes

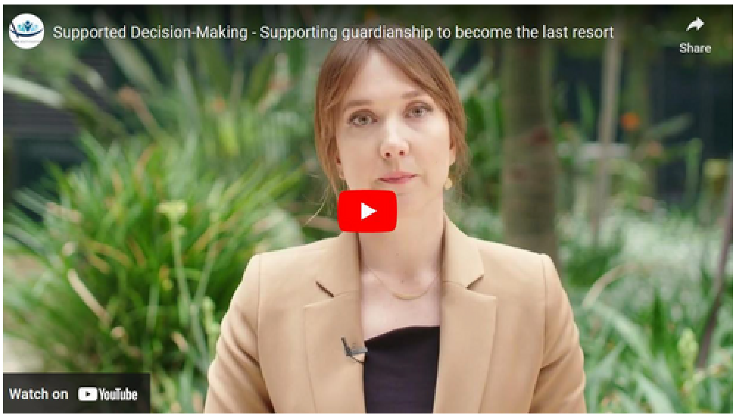
- Understanding the key aspects of good decision making: identifying the decision, knowing the person's will and preferences, exploring options, considering risks and constraints, making and implementing the decision.
- Tips for supporting a person with their decision making, e.g. taking time, ensuring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



Supported Decision-Making - Decision support as a fundamental human right

and the quality of support available to us

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



Supported Decision-Making - Supporting guardianship to become the last resort

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

Supported Decision-Making - Supporting good decision making processes

and provide support too.

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

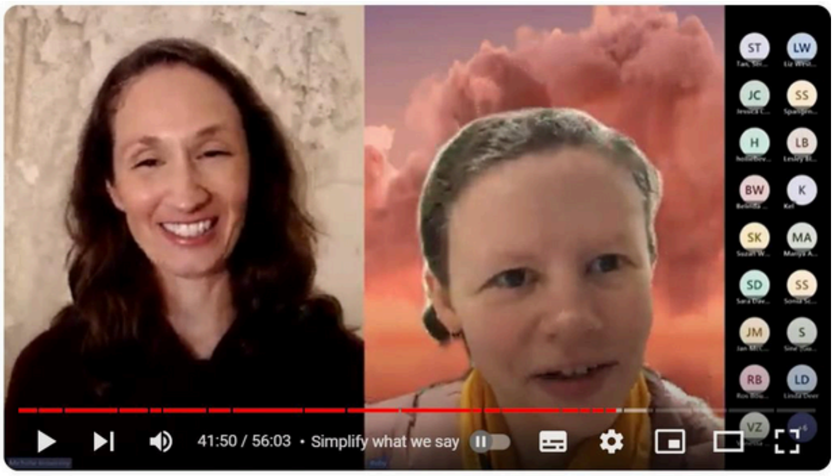
Four presenters contributed to the video content development and delivery:

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

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:

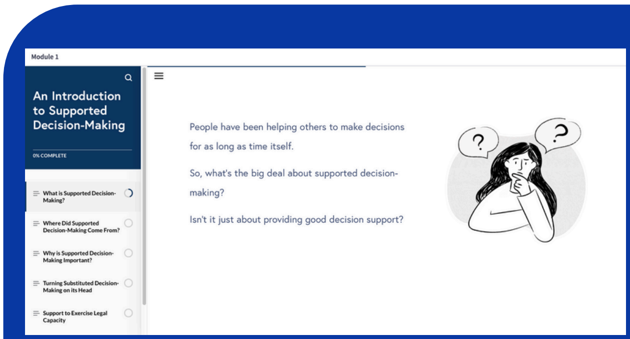
- why we need to minimise our influence as supporters
- how the approach we take to our role shapes our support
- why we should acknowledge our biases
- how we can work to mitigate our biases and
- why we need to focus on a good process.

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.

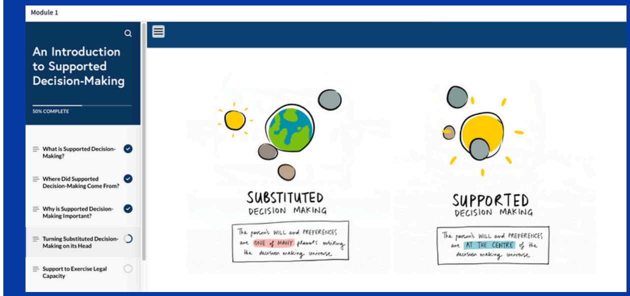
Module 1

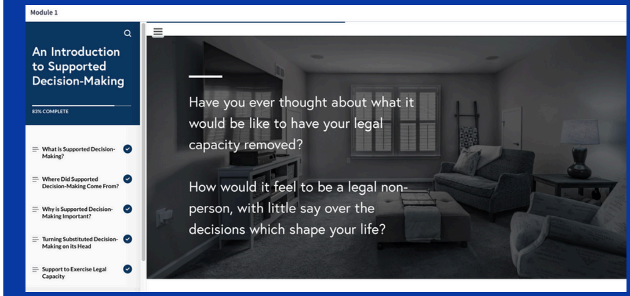


People have been helping others to make decisions for as long as time itself.

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

Isn't it just about providing good decision support?



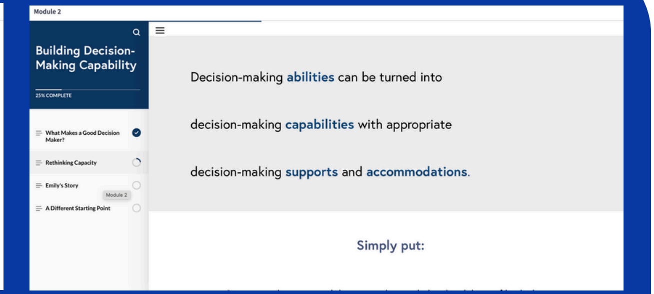


Have you ever thought about what it would be like to have your legal capacity removed?

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

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

Module 2

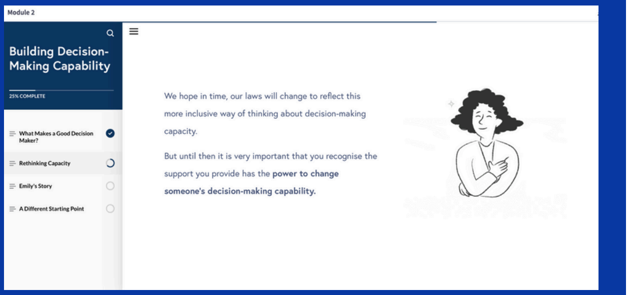


Decision-making **abilities** can be turned into

decision-making **capabilities** with appropriate

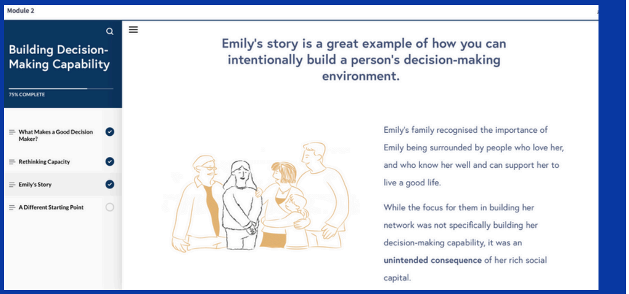
decision-making **supports** and **accommodations**.

Simply put:



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.**



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 capability, it was an **unintended consequence** of her rich social capital.

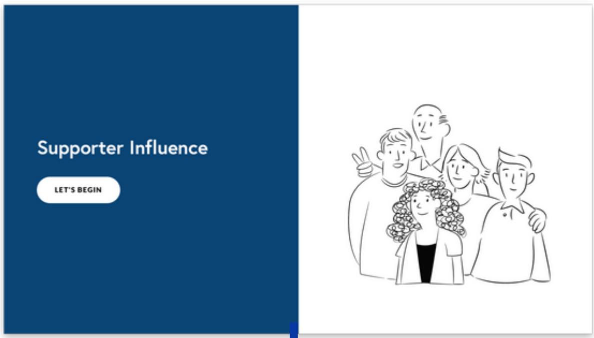
When we embrace this different way of thinking about capacity it changes the starting point for **us as decision supporters.**

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 a decision supporters.

Module 3



Self-awareness

In addition to acting with an intention of neutrality we also want to develop our **self-awareness.**

Read these wise words from Annie, an experienced decision supporter:

"You need to self-analyse.

Self-awareness is really important in the work that I do because I can influence anybody without saying a word.

And people who have developmental disabilities are sensitive to that.

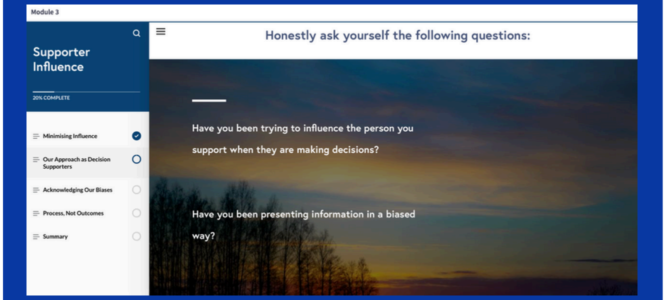
So it's really important to be aware of what you are saying, and how you are saying it, and what your body language is too.

When we are supporting people to make decisions, we want them to be in control.

The person making the decision is in the driver's seat.

As supporters, we may offer help with navigation.

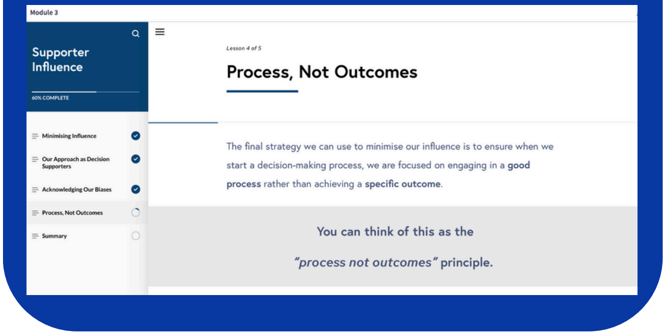
But no one likes a back seat driver!



Honestly ask yourself the following questions:

Have you been trying to influence the person you support when they are making decisions?

Have you been presenting information in a biased way?



Lesson 4 of 5

Process, Not Outcomes

The final strategy we can use to minimise our influence is to ensure when we start a decision-making process, we are focused on engaging in a **good process** rather than achieving a **specific outcome**.

You can think of this as the *"process not outcomes"* principle.

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

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 (Niemiec 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.

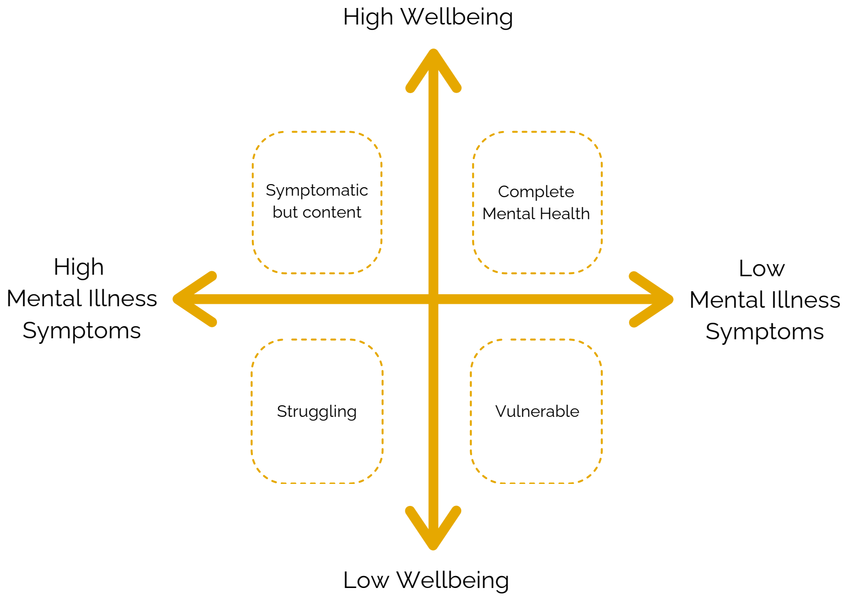


Figure 3: Visual representation of a dual-factor model of mental health, differentiating between states of illness and wellbeing, and allowing for the creation of four distinct quadrants: 'high wellbeing with illness (symptomatic but content)', 'low wellbeing with illness (struggling)', 'low wellbeing 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[2] 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.

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[2] Distinct from methods of treatment for pathology or illness.

High-level overview of the Be Well Plan

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.[3] 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 (Niemiec 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.

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[3] 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[4]. 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)'.[5] 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.

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[4] https://methods.cochrane.org/rapidreviews/

[5] https://www.ndis.gov.au/about-us/glossary

Methodology to determine impact of the training

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.[6]

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[6] 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.[7]

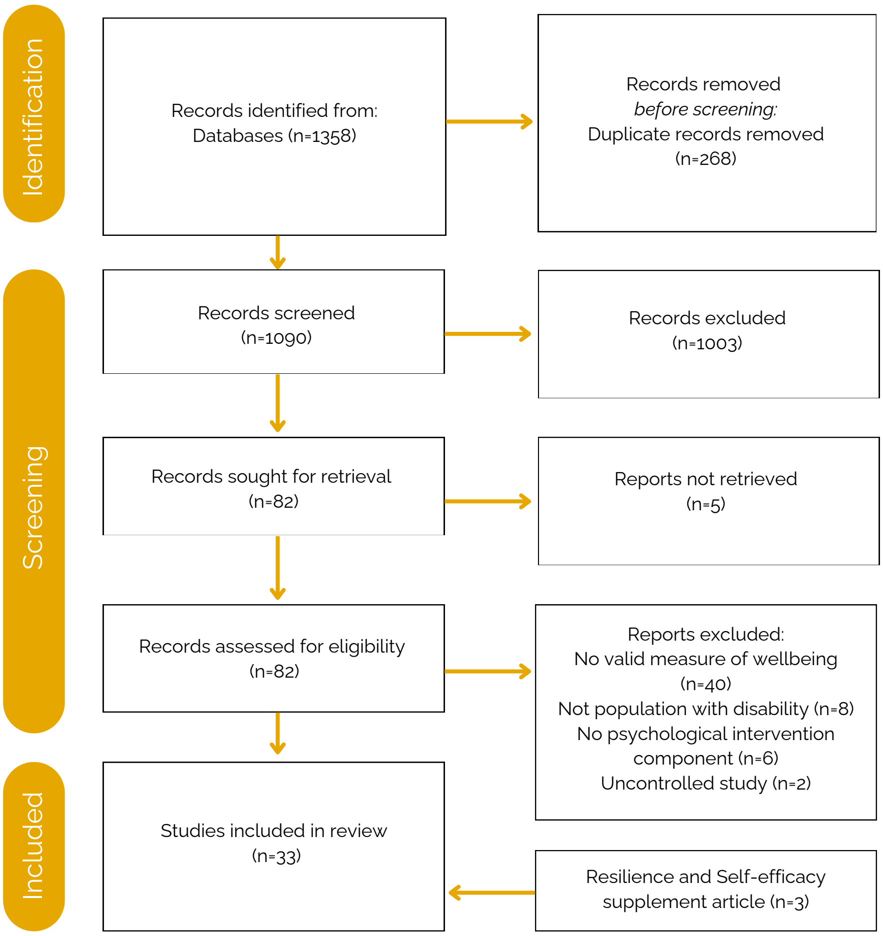

Figure 4: PRISMA statement of the search results

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[7] 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).

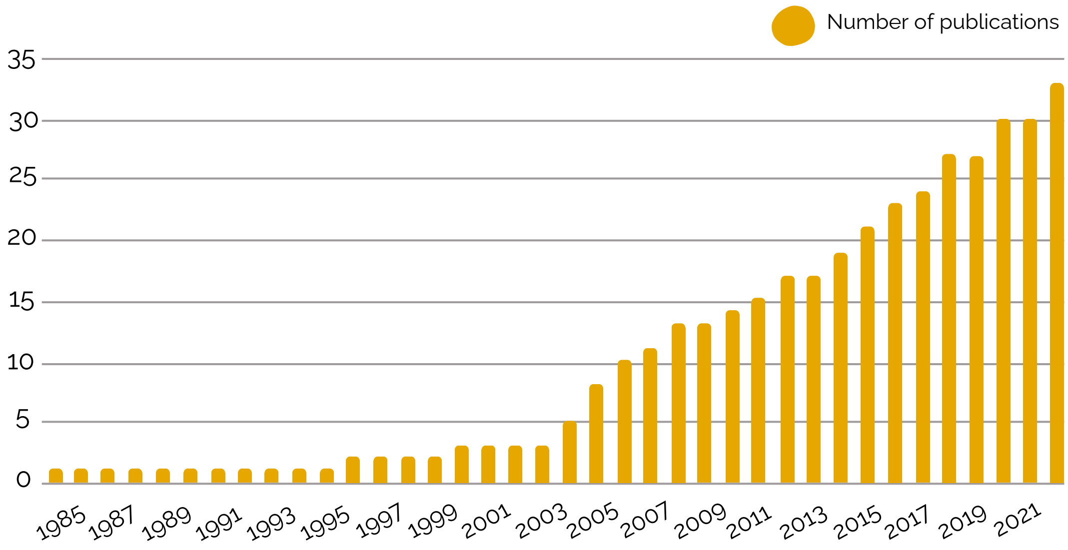

Figure 5: Cumulative number of publications over time

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.[8]

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.

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[8] 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.

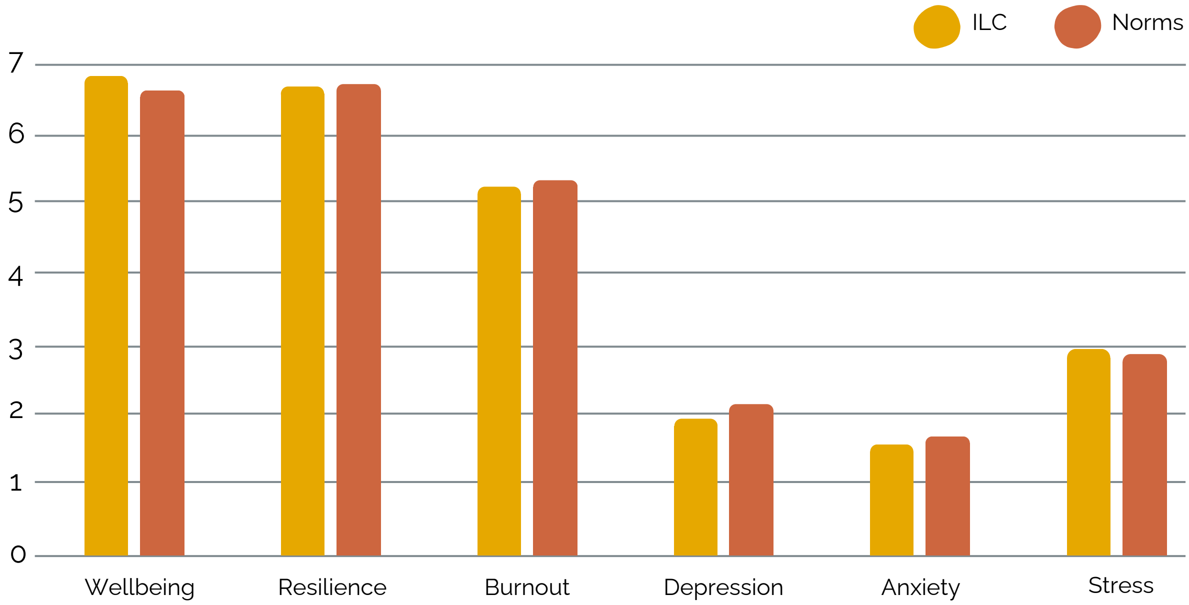

Figure 6: Baseline comparison for participants compared to general population norms for each of the measured outcomes

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.

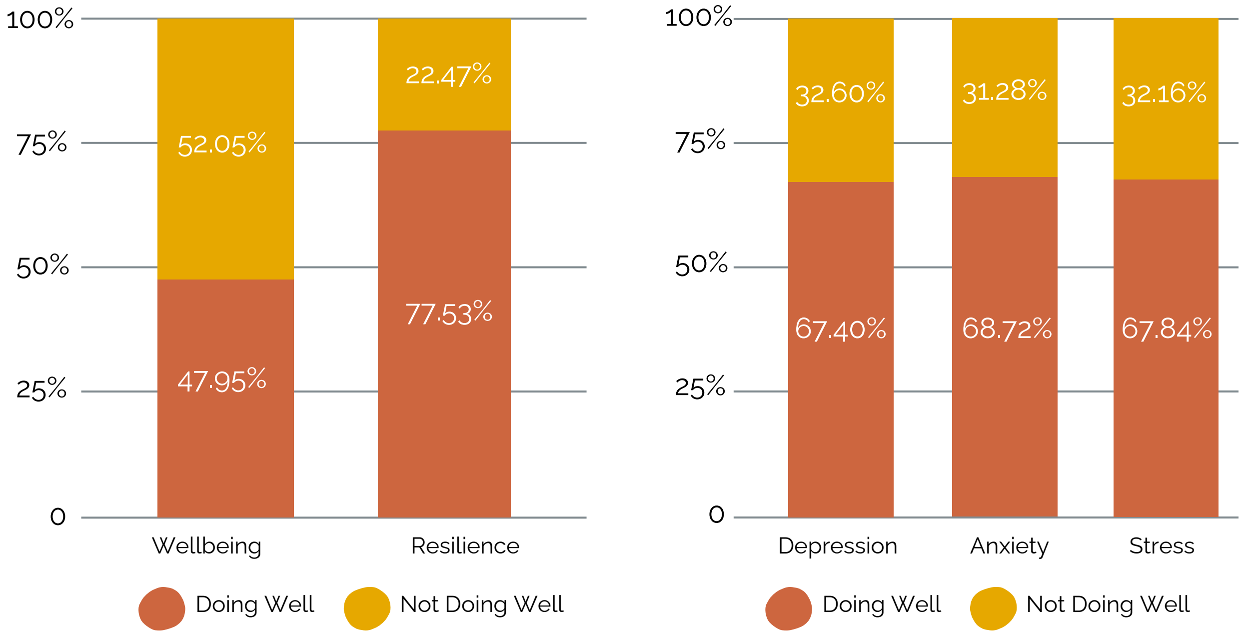

Figure 7: Baseline risk groups for positive and adaptive states (7a) and distress states (7b)

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

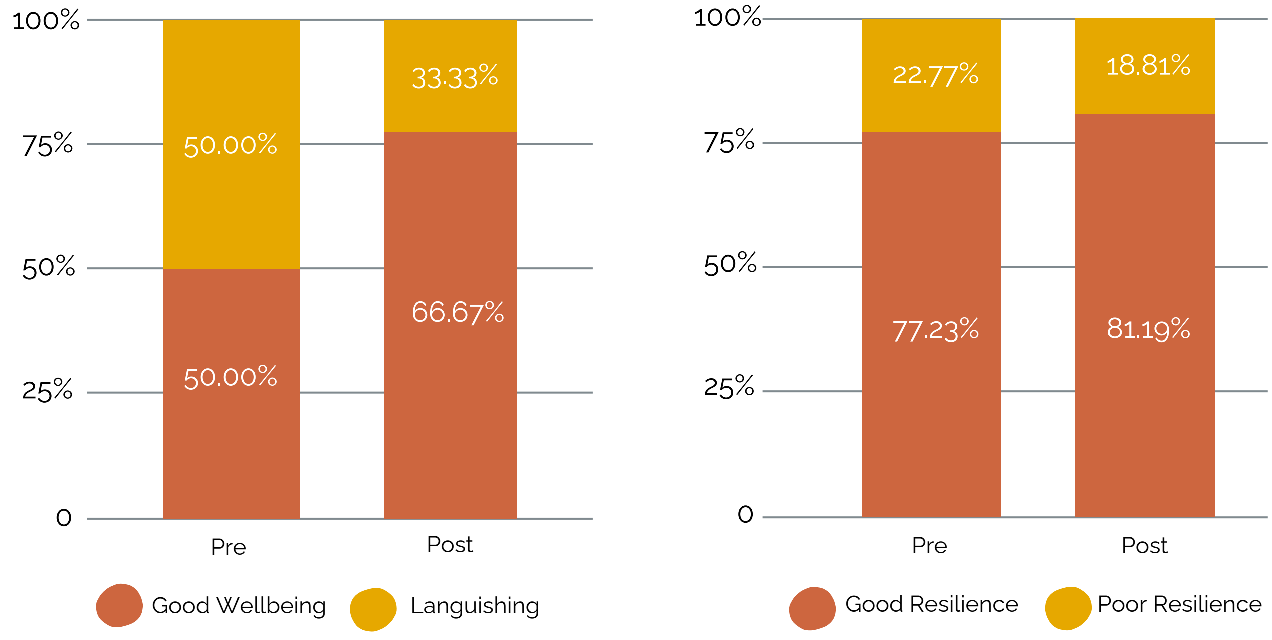

Figure 8. Change in risk groups from beginning to end of training for wellbeing (8a) and resilience (8b)

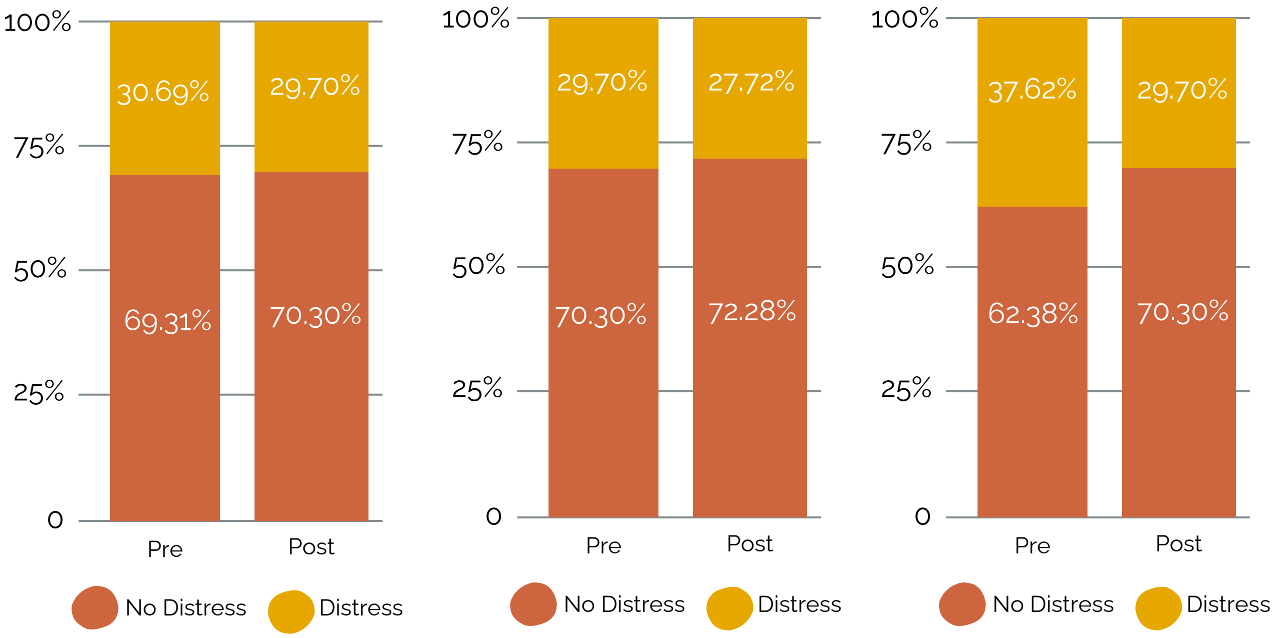

Figure 9. Change in risk groups from beginning to end of training for depression (9a), anxiety (9b) and stress (9c)

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 *d*
	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.

n 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 first 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[9] 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.

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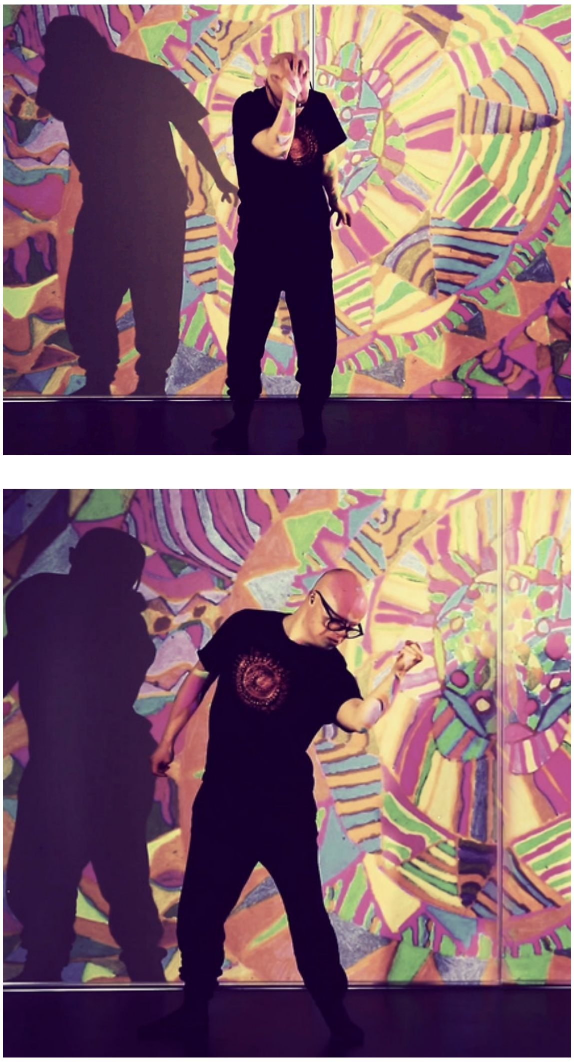
[9] The format of the training is for one or two trainers to introduce the material supported by slides and video, using a combination of a lecture, small group discussion and an introduction to activities that the participant may choose to do in their own time. The participants are encouraged to build 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.[10] 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).

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[10] 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.[11] 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?


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

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[11] 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).

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 enrols 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.

References

Allen, K., & Blascovich, J. (1996). The value of service dogs for people with severe ambulatory disabilities: A randomized controlled trial. JAMA, 275(13), 1001–1006.

Australian Law Reform Commission (ALRC). (2014). Equality, capacity and disability in Commonwealth laws: Final report. Commonwealth of Australia. https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/

Bach, M. (1998). Securing self-determination: Building the agenda in Canada. TASH Newsletter, 24(6/7), 8–10.

Bach, M., & Kerzner, L. (2010). A new paradigm for protecting autonomy and the right to legal capacity: Advancing substantive equality for persons with disabilities through law, policy and practice. Law Commission of Ontario. https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf

Beukes, E. W., Andersson, G., Allen, P. M., Manchaiah, V., & Baguley, D. M. (2018). Effectiveness of guided internet-based cognitive behavioral therapy vs face-to-face clinical care for treatment of tinnitus: A randomized clinical trial. JAMA Otolaryngology – Head & Neck Surgery, 144(12), 1126–1133.

Beukes, E. W., Baguley, D. M., Allen, P. M., Manchaiah, V., & Andersson, G. (2018). Audiologist-guided internet-based cognitive behavior therapy for adults with tinnitus in the United Kingdom: A randomized controlled trial. Ear and Hearing, 39(3), 423–433.

Bigby, C. (2008). Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community. Journal of Intellectual and Developmental Disability, 33(2), 148–157.

Bigby, C., & Douglas, J. (2020). Supported decision making. In R. J. Stancliffe, M. L. Wehmeyer, K. A. Shogren, & B. H. Abery (Eds.), Choice, preference, and disability: Promoting self-determination across the lifespan (pp. 45–66). Springer.

Bigby, C., Douglas, J., & Vassallo, S. (2019). The La Trobe Support for Decision Making Practice Framework learning resource. La Trobe University. www.supportfordecisionmakingresource.com.au

Bigby, C., Knox, M., Beadle-Brown, J., & Bould, E. (2014). Identifying good group homes: Qualitative indicators using a quality of life framework. Intellectual and Developmental Disabilities, 52(5), 348–366.

Bonyhady, B., & Paul, L. (2023). Working together to deliver the NDIS: Independent Review into the National Disability Insurance Scheme final report. Commonwealth of Australia. https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf

Boselie, J. J. L. M., Vancleef, L. M. G., & Peters, M. L. (2018). Filling the glass: Effects of a positive psychology intervention on executive task performance in chronic pain patients. European Journal of Pain, 22(7), 1268–1280.\

Brown, M., Duff, H., Karatzias, T., & Horsburgh, D. (2011). A review of the literature relating to psychological interventions and people with intellectual disabilities: Issues for research, policy, education and clinical practice. Journal of Intellectual Disabilities, 15(1), 31–45.

Browning, M., Bigby, C., & Douglas, J. (2014). Supported decision-making: Understanding how its conceptual link to legal capacity is influencing the development of practice. Research and Practice in Intellectual and Developmental Disabilities, 1(1), 34–45.

Browning, M., Bigby, C., & Douglas, J. (2021). A process of decision-making support: Exploring supported decision-making practice in Canada. Journal of Intellectual & Developmental Disability, 46(2), 138–149.

Burns, S., & Waite, M. (2019). Building resilience: a pilot study of an art therapy and mindfulness group in a community learning disability team. International Journal of Art Therapy, 24(2), 88–96.

Cebral-Loureda, M., Tamés-Muñoz, E., & Hernández-Baqueiro, A. (2022). The fertility of a concept: A bibliometric review of human flourishing. International Journal of Environmental Research and Public Health, 19(5), Article 2586.

Chapman, M. J., Hare, D. J., Caton, S., Donalds, D., McInnis, E., & Mitchell, D. (2013). The use of mindfulness with people with intellectual disabilities: A systematic review and narrative analysis. Mindfulness, 4(2), 179–189.

Cocker, F., & Joss, N. (2016). Compassion fatigue among healthcare, emergency and community service workers: A systematic review. International Journal of Environmental Research and Public Health, 13(6), Article 618.

Dagnan, D., Jackson, I., & Eastlake, L. (2018). A systematic review of cognitive behavioural therapy for anxiety in adults with intellectual disabilities. Journal of Intellectual Disability Research, 62(11), 974–991.

Davidson, J. R., Payne, V. M., Connor, K. M., Foa, E. B., Rothbaum, B. O., Hertzberg, M. A., & Weisler, R. H. (2005). Trauma, resilience and saliostasis: Effects of treatment in post-traumatic stress disorder. International Clinical Psychopharmacology, 20(1), 43–48.

Deci, E. L., & Ryan, R. M. (1995). Human autonomy. In M. H. Kernis (Ed.), Efficacy, agency, and self-esteem (pp. 31–49). Springer.

Deckersbach, T., Rauch, S., Buhlmann, U., & Wilhelm, S. (2006). Habit reversal versus supportive psychotherapy in Tourette's disorder: A randomized controlled trial and predictors of treatment response. Behaviour Research and Therapy, 44(8), 1079–1090.

Diener, E. D., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. Journal of Personality Assessment, 49(1), 71–75.

Disability Services Division, Victorian Government Department of Human Services. (2023). Supporting decision making: A guide to supporting people with a disability to make their own decisions. Department of Human Services. https://supporteddecisionmaking.com.au/resource/supporting-decision-making-a-guide-to-supporting-people-with-a-disability-to-make-their-own-decisions/

Douglas, J., & Bigby, C. (2020). Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability. Disability and Rehabilitation, 42(3), 434–441.

Emerson, E., Einfeld, S., & Stancliffe, R. J. (2010). The mental health of young children with intellectual disabilities or borderline intellectual functioning. Social Psychiatry and Psychiatric Epidemiology, 45(5), 579–587.

Fassnacht, D. B., Ali, K., van Agteren, J., Iasiello, M., Mavrangelos, T., Furber, G., & Kyrios, M. (2022). A group-facilitated, internet-based intervention to promote mental health and well-being in a vulnerable population of university students: Randomized controlled trial of the Be Well Plan program. JMIR Mental Health, 9(5), Article e37292.

Giovannetti, A. M., Quintas, R., Tramacere, I., Giordano, A., Confalonieri, P., Messmer Uccelli, M., Solari, A., & Pakenham, K. I. (2020). A resilience group training program for people with multiple sclerosis: Results of a pilot single-blind randomized controlled trial and nested qualitative study. PLoS One, 15(4), Article e0231380.

Glombiewski, J. A., Hartwich-Tersek, J., & Rief, W. (2010). Two psychological interventions are effective in severely disabled, chronic back pain patients: A randomised controlled trial. International Journal of Behavioral Medicine, 17, 97–107.

Gooding, P. (2017). A new era for mental health law and policy: Supported decision-making and the UN Convention on the Rights of Persons with Disabilities. Cambridge University Press.

Gooding, P. (2015). Navigating the 'flashing amber lights' of the right to legal capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to major concerns. Human Rights Law Review, 15(1), 45–71.

Gooding, P., & Carney, T. (2023). Lessons from a reformist path to supported decision-making in Australia. In M. Bach & N. E. Yaksic (Eds.), Legal capacity, disability and human rights: Towards a comprehensive approach (pp. 255–276). Intersentia.

Gordon, R. M. (2000). The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making. International Journal of Law and Psychiatry, 23(1), 61–77.

Graziano, F., Calandri, E., Borghi, M., & Bonino, S. (2014). The effects of a group-based cognitive behavioral therapy on people with multiple sclerosis: A randomized controlled trial. Clinical Rehabilitation, 28(3), 264–274.

Haas, M., Groupp, E., Muench, J., Kraemer, D., Brummel-Smith, K., Sharma, R., Ganger, B., Attwood, M., & Fairweather, A. (2005). Chronic disease self-management program for low back pain in the elderly. Journal of Manipulative and Physiological Therapeutics, 28(4), 228–237.

Hart, S. L., Vella, L., & Mohr, D. C. (2008). Relationships among depressive symptoms, benefit-finding, optimism, and positive affect in multiple sclerosis patients after psychotherapy for depression. Health Psychology, 27(2), 230–238.

Hausmann, L. R., Youk, A., Kwoh, C. K., Ibrahim, S. A., Hannon, M. J., Weiner, D. K., ... & Parks, A. (2017). Testing a positive psychological intervention for osteoarthritis. Pain Medicine, 18(10), 1908–1920.

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. British Journal of Clinical Psychology, 44(2), 227–239.

Heutink, M., Post, M. W., Bongers-Janssen, H. M., Dijkstra, C. A., Snoek, G. J., Spijkerman, D. C., & Lindeman, E. (2012). The CONECSI trial: Results of a randomized controlled trial of a multidisciplinary cognitive behavioral program for coping with chronic neuropathic pain after spinal cord injury. Pain, 153(1), 120–128.

Ho, R. T. H., Chan, C. K. P., Fong, T. C. T., Lee, P. H. T., Lum, D. S. Y., & Suen, S. H. (2020). Effects of expressive arts-based interventions on adults with intellectual disabilities: A stratified randomized controlled trial. Frontiers in Psychology, 11, Article 1286.

Hurst, R., Carson, J., Shahama, A., Kay, H., Nabb, C., & Prescott, J. (2022). Remarkable recoveries: An interpretation of recovery narratives using the CHIME model. Mental Health and Social Inclusion, 26(2), 175–190.

Iasiello, M., Ali, K., van Agteren, J., Kolovos, E., Kyrios, M., Kashdan, T. B., & Fassnacht, D. B. (2023). What's the difference between measures of wellbeing, quality of life, resilience, and coping? An umbrella review and concept map of 155 measures of positive mental health. PsyArXiv Preprint. https://osf.io/preprints/psyarxiv/s96mr

Iasiello, M., & van Agteren, J. (2020). Mental health and/or mental illness: A scoping review of the evidence and implications of the dual-continua model of mental health. Evidence Base: A Journal of Evidence Reviews in Key Policy Areas, 1, 1–45.

Iasiello, M., van Agteren, J., Keyes, C. L. M., & Cochrane, E. M. (2019). Positive mental health as a predictor of recovery from mental illness. Journal of Affective Disorders, 251, 227–230.

Iasiello, M., van Agteren, J., Schotanus-Dijkstra, M., Lo, L., Fassnacht, D. B., & Westerhof, G. J. (2022). Assessing mental wellbeing using the Mental Health Continuum – Short Form: A systematic review and meta-analytic structural equation modelling. Clinical Psychology: Science and Practice, 29(4), 442–456.

Jacobson, N. S., & Truax, P. (1992). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. In A. E. Kazdin (Ed.), Methodological issues and strategies in clinical research(pp. 631–648). American Psychological Association.

Janevic, M., Robinson-Lane, S. G., Courser, R., Brines, E., & Hassett, A. L. (2022). A community health worker-led positive psychology intervention for African American older adults with chronic pain. Gerontologist, 62(9), 1369–1380.

JFA Purple Orange. (2022). Final report:Advice to the Office of the Public Advocate relating to supported decision-making forms.

Judd, M. J., Dorozenko, K. P., & Breen, L. J. (2017). Workplace stress, burnout and coping: A qualitative study of the experiences of Australian disability support workers. Health & Social Care in the Community,25(3), 1109–1117.

Kahan, J. S., Mitchell, J. M., Kemp, B. J., & Adkins, R. H. (2006). The results of a 6-month treatment for depression on symptoms, life satisfaction, and community activities among individuals aging with a disability. Rehabilitation Psychology, 51(1), 13–22.

Khan, F., Amatya, B., Ng, L., & Galea, M. (2015). Rehabilitation outcomes in persons with spina bifida: A randomised controlled trial. Journal of Rehabilitation Medicine, 47, 734–740.

Keefe, E. B., & Copeland, S. R. (2011). What is literacy? The power of adefinition. Research and Practice for Persons with Severe Disabilities, 36(3–4), 92–99.

Keyes, C. L. M. (2002). The mental health continuum: From languishing to flourishing in life. Journal of Health and Social Behavior, 43, 207–222.

King, A. L. S., Valença, A. M., Melo-Neto, V. L. D., Freire, R. C., Mezzasalma, M. A., & Nardi, A. E. (2011). Efficacy of a specific model for cognitive-behavioral therapy among panic disorder patients with agoraphobia: A randomized clinical trial. São Paulo Medical Journal, 129, 325–334.

Lancaster, K., Bhopti, A., Kern, M. L., Taylor, R., Janson, A., & Harding, K. (2023). Effectiveness of peer support programmes for improving well-being and quality of life in parents/carers of children with disability or chronic illness: A systematic review. Child: Care, Health and Development, 49(3), 485–496.

Laurens, J.,Bates, S., Kayess, R., & Fisher, K. R.(2021).Good practice in supported decision-making for people with disability: Final report. Social Policy Research Centre, UNSW.https://apo.org.au/sites/default/files/resource-files/2021-06/apo-nid313465.pdf

Lindert, L., Schlomann, L., Pfaff, H., & Choi, K. E. (2022). The role of psychological wellbeing in a cross-provider worksite healthcare management program for employees with musculoskeletal disorders. International Journal of Environmental Research and Public Health, 19(9), Article 5452.

Maes, B., Nijs, S., Vandesande, S., Van Keer, I., Arthur-Kelly, M., Dind, J., Goldbart, J., Petitpierre, G., & Van der Putten, A. (2021). Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities. Journal of Applied Research in Intellectual Disabilities,34(1), 250–262.

Magnussen, L., Strand, L. I., Skouen, J. S., & Eriksen, H. R. (2007). Motivating disability pensioners with back pain to return to work –A randomized controlled trial. Journal of Rehabilitation Medicine, 39(1), 81–87.

McIntyre,H., Loughhead,M., Hayes,L., Procter,N. G.(2021).National Disability Insurance Scheme and lived experience of people presenting to the emergency department: Protocol for a mixed methods study.JMIR ResearchProtocols,10(11), Article e33268

Mohr, D. C., Hart, S. L., Julian, L., Catledge, C., Honos-Webb, L., Vella, L., & Tasch, E. T. (2005). Telephone-administered psychotherapy for depression. Archives of General Psychiatry, 62(9), 1007–1014.

Müller, R., Gertz, K. J., Molton, I. R., Terrill, A. L., Bombardier, C. H., Ehde, D. M., & Jensen, M. P. (2016). Effects of a tailored positive psychology intervention on well-being and pain in individuals with chronic pain and a physical disability: A feasibility trial. Clinical Journal of Pain, 32(1), 32–44.

National Disability Insurance Scheme (NDIS). (2021). Consultation summary: Supporting you to make your own decisions.

National Disability Insurance Scheme (NDIS). (2022). List A: Conditions that are likely to meet the disability requirements. https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/list-conditions-are-likely-meet-disability-requirements

Niemiec, R. M., Shogren, K. A., & Wehmeyer, M. L. (2017). Character strengths and intellectual and developmental disability: A strengths-based approach from positive psychology. Education and Training in Autism and Developmental Disabilities,52(1), 13–25.

Norman, S. A., Lumley, M. A., Dooley, J. A., & Diamond, M. P. (2004). For whom does it work? Moderators of the effects of written emotional disclosure in a randomized trial among women with chronic pelvic pain. Psychosomatic Medicine, 66(2), 174–183.

O'Connor, M. (2014). The National Disability Insurance Scheme and people with mild intellectual disability: Potential pitfalls for consideration. Research and Practice in Intellectual and Developmental Disabilities,1(1), 17–23.

Office of the Public Advocate (OPA). (2021). Supported Decision Making Project:Interim report.

Ontario, Legislative Assembly. (1992, February 12). Transcript of Standing Committee on Administration of Justice: Official Hansard.https://www.ola.org/en/legislative-business/committees/administration-justice/parliament-35/transcript/committee-transcript-1992-feb-12

Pacchetti, C., Mancini, F., Aglieri, R., Fundarò, C., Martignoni, E., & Nappi, G. (2000). Active music therapy in Parkinson's disease: An integrative method for motor and emotional rehabilitation. Psychosomatic Medicine, 62(3), 386–393.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., & Brennan, S. E. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. Systematic Reviews, 10(1), 1–11.

Paikkatt, B., Singh, A. R., Singh, P. K., & Jahan, M. (2012). Efficacy of yoga therapy on subjective well-being and basic living skills of patients having chronic schizophrenia. Industrial Psychiatry Journal, 21(2), 109–114.

Pearce, J., Mann, M. K., Jones, C., Van Buschbach, S., Olff, M., & Bisson, J. I. (2012). The most effective way of delivering a train-the-trainers program: A systematic review. Journal of Continuing Education in the Health Professions, 32(3), 215–226.

Peterson, C., & Seligman, M. E. P. (2004). Character strengths and virtues: A handbook and classification. Oxford University Press.

Reichow, B., Servili, C., Yasamy, M. T., Barbui, C., & Saxena, S. (2013). Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower-functioning autism spectrum disorders: A systematic review. PLoS Medicine, 10(12), Article e1001572.

Rini, C., Porter, L. S., Somers, T. J., McKee, D. C., DeVellis, R. F., Smith, M., ... & Keefe, F. J. (2015). Automated internet-based pain coping skills training to manage osteoarthritis pain: A randomized controlled trial. Pain, 156(5), 837–848.

Roeden, J. M., Maaskant, M. A., & Curfs, L. M. (2014). Processes and effects of solution-focused brief therapy in people with intellectual disabilities: A controlled study. Journal of Intellectual Disability Research, 58(4), 307–320.

Roulstone, A. (2016). Disability and technology: An interdisciplinary and international approach. Springer.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission). (2023). Final report. Commonwealth of Australia. https://disability.royalcommission.gov.au/publications/final-report

Ryan, C., Bergin, M., & Wells, J. S. G. (2021). Work-related stress and well-being of direct care workers in intellectual disability services: A scoping review of the literature. International Journal of Developmental Disabilities, 67(1), 1–22.

SA Health. (2020). South Australian Government Response to the Review of the Advance Care Directives Act 2013. South Australian Government.

Savage, S., & Bailey, S. (2004). The impact of caring on caregivers' mental health: A review of the literature. Australian Health Review, 27(1), 111–117.

Scheffers, F., van Vugt, E., & Moonen, X. (2020). Resilience in the face of adversity in adults with an intellectual disability: A literature review. Journal of Applied Research in Intellectual Disabilities, 33(5), 828–838.

Shakespeare, T. (2016). The social model of disability. In L. J. Davis (Ed.), The disability studies reader (5th ed., pp. 195–203). Routledge.

Shalaby, R. A. H., & Agyapong, V. I. O. (2020). Peer support in mental health: Literature review. JMIR Mental Health, 7(6), Article e15572.

Shearn, M. A., & Fireman, B. H. (1985). Stress management and mutual support groups in rheumatoid arthritis. American Journal of Medicine, 78(5), 771–775.

Shogren, K. A., Wehmeyer, M. L., Martinis, J., & Blanck, P. (2018). Supported decision-making: Theory, research, and practice to enhance self-determination and quality of life. Cambridge University Press.

Singh, N. N., Singh, A. N., Lancioni, G. E., Singh, J., Winton, A. S. W., & Adkins, A. D. (2010). Mindfulness training for parents and their children with ADHD increases the children's compliance. Journal of Child and Family Studies, 19(2), 157–166.

Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: Assessing the ability to bounce back. International Journal of Behavioral Medicine, 15(3), 194–200.

South Australian Council on Intellectual Disability (SACID). (2021). My life my story: Consultation report.

Stancliffe, R. J., Shogren, K. A., Wehmeyer, M. L., & Abery, B. H. (2020). Policies and practices to support preference, choice, and self-determination: An ecological understanding. In R. J. Stancliffe, M. L. Wehmeyer, K. A. Shogren, & B. H. Abery (Eds.), Choice, preference, and disability: Promoting self-determination across the lifespan (pp. 339–354). Springer.

Susanty, D., Noel, P., Sabeh, M. S., & Jahoda, A. (2021). Benefits and cultural adaptations of psychosocial interventions for parents and their children with intellectual disabilities in low-and middle-income countries: A systematic review. Journal of Applied Research in Intellectual Disabilities, 34(2), 421–445.

Sutherland, R. J., & Isherwood, T. (2016). The evidence for easy-read for people with intellectual disabilities: A systematic literature review. Journal of Policy and Practice in Intellectual Disabilities, 13(4), 297–310.

Taylor, C. T., Lyubomirsky, S., & Stein, M. B. (2017). Upregulating the positive affect system in anxiety and depression: Outcomes of a positive activity intervention. Depression and Anxiety, 34, 267–280.

Torr, J., & Davis, R. (2007). Ageing and mental health problems in people with intellectual disability. Current Opinion in Psychiatry, 20(5), 467–471.

Tough, H., Siegrist, J., & Fekete, C. (2017). Social relationships, mental health and wellbeing in physical disability: A systematic review. BMC Public Health, 17(1), 1–18.

Van Agteren, J., Ali, K., Fassnacht, D. B., Iasiello, M., Furber, G., Howard, A., Woodyatt, L., Musker, M., & Kyrios, M. (2021). Testing the differential impact of an internet-based mental health intervention on outcomes of well-being and psychological distress during COVID-19: Uncontrolled intervention study. JMIR Mental Health, 8(9), Article e28044.

Van Agteren, J., & Iasiello, M. (2020). Advancing our understanding of mental wellbeing and mental health: The call to embrace complexity over simplification. Australian Psychologist, 55(4), 307–316.

Van Agteren, J., Iasiello, M., Ali, K., Fassnacht, D. B., Furber, G., Woodyatt, L., Howard, A., & Kyrios, M. (2021). Using the intervention mapping approach to develop a mental health intervention: A case study on improving the reporting standards for developing psychological interventions. Frontiers in Psychology, 12, Article 648678.

Van Agteren, J., Iasiello, M., & Lo, L. (2023). A guide to what works for mental wellbeing: An evidence review of interventions. Beyond Blue.

Van Agteren, J., Iasiello, M., Lo, L., Bartholomaeus, J., Kopsaftis, Z., Carey, M., & Kyrios, M. (2021). A systematic review and meta-analysis of psychological interventions to improve mental wellbeing. Nature Human Behaviour, 5(5), 631–652.

Wallace, M. (2012). Evaluation of the supported decision making project. Office of the Public Advocate. https://supporteddecisionmaking.com.au/wp-content/uploads/sites/4/2021/03/OPA-SA-2012_final_supported_decision_making_evaluation.pdf

Wehmeyer, M. L. (2013). The Oxford handbook of positive psychology and disability. Oxford University Press.

Wehmeyer, M. L. (2020). The importance of self-determination to the quality of life of people with intellectual disability: A perspective. International Journal of Environmental Research and Public Health, 17(19), Article 7121.

Wicksell, R. K., Ahlqvist, J., Bring, A., Melin, L., & Olsson, G. L. (2008). Can exposure and acceptance strategies improve functioning and life satisfaction in people with chronic pain and whiplash-associated disorders (WAD)? A randomized controlled trial. Cognitive Behaviour Therapy, 37(3), 169–182.

Windle, G., Bennett, K. M., & Noyes, J. (2011). A methodological review of resilience measurement scales. Health and Quality of Life Outcomes, 9(1), Article 8.

Wood, A. M., & Joseph, S. (2010). The absence of positive psychological (eudemonic) well-being as a risk factor for depression: A ten year cohort study. Journal of Affective Disorders, 122(3), 213–217.

Yang, Y. J., & Chung, K. M. (2023). Pilot randomized control trial of an app-based CBT program for reducing anxiety in individuals with ASD without intellectual disability. Journal of Autism and Developmental Disorders, 53(4), 1331–1346.

Zachriat, C., & Kröner-Herwig, B. (2004). Treating chronic tinnitus: Comparison of cognitive-behavioural and habituation-based treatments. Cognitive Behavior Therapy, 33(4), 187–198.

Zemestani, M., & Fazeli Nikoo, Z. (2020). Effectiveness of mindfulness-based cognitive therapy for comorbid depression and anxiety in pregnancy: A randomized controlled trial. Archives of Women’s Mental Health, 23, 207–214.