

CoMHWA



Consumers of Mental Health WA (Inc)

Feedback to:

National Disability Insurance Agency (NDIA)

PO Box 6100 Parliament House, Canberra ACT 260022

RESPONSE TO: Consultation Paper: Supporting you to make your own decisions

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Consumers of Mental Health WA

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1. Preliminaries

About the Respondents

Consumers of Mental Health WA (CoMHWA) is Western Australia's peak body for and by mental health consumers (people with a past or present lived experience of mental health issues, psychological or emotional distress). We strengthen and advance the voice, leadership and expertise of people with lived experience of mental health issues. We work collaboratively with other user-led organisations and a diversity of stakeholders to advance our rights, equality, recovery, and wellbeing.

Language

CoMHWA uses the term 'mental health consumer' throughout this submission. Mental health consumers to refer to people who identify as having a past or present lived experience of psychological or emotional distress, irrespective of whether they have received a diagnosis of mental illness or accessed services. Other ways people may choose to describe themselves include "peer", "survivor", "person with a lived experience" and "expert by experience".

This definition is based on consumers' call for respect, dignity, and choice in how we choose to individually identify.

2. Introduction

Impairments resulting from mental health conditions can be difficult to recognise and are less apparent than those who live with physical or intellectual disability. Systemic and cultural stigma in Australia has meant that many people with mental health conditions may try to manage or ignore any impairments, often in isolation. This can often exacerbate issues and cause the need for support for people with psychosocial disability to be overlooked¹.

CoMHWA and the consumer community regularly hear and acknowledge the life-changing ability of NDIS funding for individuals who live with permanent physical and psychosocial disabilities. While the psychosocial disability community is grateful, there are still many systemic barriers that impact access to and management of the NDIS.

As the peak body for people with psychosocial disabilities in WA, for several years we have delivered support for decision-making projects and have collected feedback regarding what works and what doesn't with regard to supported decision-making helping people receive fair and informed access to the NDIS, housing and other areas of support throughout the community.

The implementation of the recommendations in this submission, and the recommendations of other consumer organisations and alliances is seen as pertinent to the success of supported decision-making, and the mental health and well-being of society's most vulnerable individuals².

Furthermore, CoMHWA has coordinated the following supported decision-making projects (external links to CoMHWA website):

- [NDIS Access Project](#)
- [Individualised Community Living Strategy](#)
- [Peer Choices \(NDIS supports\)](#)
- [M3Q: My Medicines and Me](#)
- [Paths2Wellbeing](#)
- [Peers4Wellbeing](#)
- [Peer Hostels Project](#)

¹ https://nmhccf.org.au/sites/default/files/docs/nmhccf_psychosocial_disability_booklet_web_version_27oct11.pdf

² https://nmhccf.org.au/sites/default/files/docs/nmhccf_psychosocial_disability_booklet_web_version_27oct11.pdf

3. Consultation questions

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

Supported Decision Making is based on the belief that people who have disabilities including psychosocial disabilities and other disabilities that may impact (or be seen as impacting) their ability to make their own decisions have the right to make their own decisions. Supported Decision Making enables individuals to be actively involved in the decision-making process to the maximum extent possible, with the appropriate supports³.

Supported decision-making is a way of supporting a person to make decisions without the person losing ownership of their decisions and invites caregivers, peers, professionals, and clinicians to support, but not take over, the decisions of people in mental health crises or those with ongoing disabilities. The Office of the High Commissioner for Human Rights describes this distinction as:

“With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person explains the issues when necessary and interprets the signs and preferences of the individual.”

The types of support an individual may require in the decision-making process need to be individualized to the person’s competencies and the demands of the decisions faced⁴. The individualized nature of Supported Decision Making emphasizes why a “one-size-fits-all” approach to decision making not only limits the agency and self-determination of capable individuals but is inappropriate for addressing the complexities of decision-making demands across contexts and over the life span⁵.

³ Blanck, P., & Martinis, J. G. (2015). “The right to make choices”: The national resource center for supported decision-making. *Inclusion*, 3(1), 24-33.

⁴ Schalock, R. L., Keith, K. D., Verdugo, M. Á., & Gómez, L. E. (2010). Quality of life model development and use in the field of intellectual disability. In *Enhancing the quality of life of people with intellectual disabilities* (pp. 17-32). Springer, Dordrecht.

⁵ Shogren, K. A., Shaw, L. A., Raley, S. K., & Wehmeyer, M. L. (2018). Exploring the effect of disability, race-ethnicity, and socioeconomic status on scores on the self-determination inventory: Student report. *Exceptional Children*, 85(1), 10-27.

2 Who are the best people to help a person with disability to make decisions?

A person may appoint whoever they want as their Supporter and may appoint more than one. A person may also appoint, or revoke their appointment of, a Supporter at any time⁶.

A person may appoint a family member, friend or carer. Family members may experience difficulties in separating their own needs; or an appointed Guardian may be in place who may not know or understand the person deeply and may be influenced by professional rules about duty of care. These situations may lead to **substitute decision making** where other people make decisions for the person.

Clinicians and service providers may engage people in **Shared Decision Making** to help decisions to be informed by evidence and consumer preferences⁷. One of the concerns with Shared Decision Making is that professionals often misjudge deficits or inabilities in a consumer's capacity to make autonomous decisions.⁸ As a consequence, staff can engage in what is termed '**provider directiveness**' where they attempt to influence a consumer's choices or preferences to align with those deemed appropriate by the clinician/provider.⁹

Advocacy organisations, which may not be directly paid by the person, but receive funding from government or other sources, may be appropriately appointed as a Supporter.

Peer Support is provided between two or more people who have similar or shared experiences, and who recognise each other as Peers, it involves sharing experiences with a focus on personal strengths and mutuality.

The evidence suggests that peer support contributes to improvements in mental health service responsiveness, safety, effectiveness, efficiency, and in making services more person-centred¹⁰. Moreover, Peer Support Workers are better than professionally qualified staff at promoting recovery outcomes such as hope, empowerment, self-esteem and self-efficacy, social inclusion, and engagement¹¹.

⁶ <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/4-supported-decision-making-in-commonwealth-laws-2/supporters-3/>

⁷ Headspace. (2011). *Evidence Summary: Shared decision making (SDM) for mental health – what is the evidence?* [Fact sheet]. <https://headspace.org.au/assets/download-cards/sdm-evidence-summary.pdf>

⁸ Simmons, M. B., Batchelor, S., Dimopoulos-Bick, T., & Howe, D. (2017). The choice project: peer workers promoting shared decision making at a youth mental health service. *Psychiatric services*, 68(8), 764-770.

⁹ Simmons, M. B., Coates, D., Batchelor, S., Dimopoulos-Bick, T., & Howe, D. (2018). The CHOICE pilot project: Challenges of implementing a combined peer work and shared decision-making programme in an early intervention service. *Early intervention in psychiatry*, 12(5), 964-971.

¹⁰ Repper J and Carter T. A review of the literature on peer support in mental health services. *J Ment Health*. 2011; 20(4): 392–411. DOI: 10.3109/09638237.2011.583947

¹¹ Pitt V, Lowe D, Hill S, et al. Consumer-providers of care for adult clients of statutory mental health services. *Cochrane Database Syst Rev*. 2013; 3: CD004807 DOI: 10.1002/14651858.CD004807.pub2

The research literature has demonstrated a positive impact of Peer Support Workers in aiding decision-making. This includes challenging negative assumptions, countering behaviours or language that may work against patient empowerment and assisting people to negotiate and communicate their decision.

Obstacles for people with psychosocial disabilities to decision making relate to; inability to source evidence of impairment of decision making, consumers' pre-existing relationships within mental health rather than disability services, assessments conducted and planning by people without/with reduced skills and understanding of people with psychosocial needs in decision making.

The Australian CHOICE pilot study combined Peer Work and Shared Decision Making models. It found that Peer Workers' involvement in Shared Decision Making resulted in consumers feeling more involved in their assessment and that this led to greater client satisfaction. Although this study primarily focussed on using a Shared Decision Making Tool, it demonstrated the strengths of combining the principles of evidence-based practice, technology-friendly clinical encounters, and both client-centred and recovery-oriented Shared Decision Making. This work was inspired by and replicated many of the positive findings of the CommonGround program; combining a web-based Shared Decision Making tool that was administered and implemented by Peer Workers.

Consumers of Mental Health WA (CoMHWA) provides Peer Supported Decision Making for people with psychosocial disabilities. As the peak body for mental health consumers, CoMHWA provides Peer Supported Decision Making to support the selection of service providers and for individuals to decide whether to apply for entry into NDIS. that is independent of service providers which helps to reduce actual and perceived conflict of interest. CoMHWA has drawn on the expertise of consumers eligible/enrolled in the NDIS to develop a successful model of support for people with psychosocial disabilities to facilitate effective engagement in decision making.

Peer Workers and Peer Mentors provide a platform of trust and mutuality with the person to help build their decision-making skills that are transferable to other parts of their life to support their self-advocacy and build their independence. The CoMHWA Supported Decision Making model provides cost-saving, expert, time-limited, independent peer-based decision making support for people with psychosocial disabilities.

3 What should they do to help with decision making?

Although there exist a wide range of frameworks describing recommended processes for implementing Supported Decision Making¹², most can be synthesised into the three stages outlines below.

1. Two-way Information Sharing

A two-way exchange of information occurs between the consumer and the supporter.

The information shared includes but is not limited to:

- The nature of the decision at hand, what its purpose, stakes and consequences are, and what this decision means to the consumer
- The self-identified decision-making strengths and competencies of the consumer
- The degree and nature of the support the consumer needs to best make an informed decision that aligns with their values and preferences
- How the supporter will provide the support the consumer needs and whether the supporter is the right person to provide the support
- The different decision options and potential risks/benefits associated with them
- The consumer's values and preferences

2. Deliberation on Information

The supporter and the consumer discuss together the information that was shared in the first stage. This discussion may include:

- Further elaboration on or exploration of the consumers values and preferences
- Answering any further questions or clarifying any confusion the consumer may have about the decision, decision-options and the possible outcomes associated with the decision.
- The extent to which various decision-options align with the consumers values and preferences

3. Decision and communication

The consumer reaches a decision that is most consistent with their values and preferences. The role of the supporter is then to:

- Aid the consumer in the effective and assertive communication of this decision
- Support the consumer to act on the decision if appropriate
- Advocate for the consumer's right and capacity to reach a supported decision if the decision is challenged

¹² Beyth-Marom et al., 1991; Furby & Beyth-Marom, 1992; Hickson & Khemka, 2013; Shogren, Wehmeyer & Palmer, 2017; Australian Supported Decision Making Network, 2016; WA's Individualised Services, 2013.

The role of the support person in Supported Decision Making is first and foremost to enable the individual to exercise their decision-making capacity to the greatest extent possible, according to the wishes of the person with the disability. This support not only encompasses supporting the consumer (who remains the primary decision maker) to reach an informed decision, but also includes supporting the consumer to communicate their decision to others and, communicating to others on behalf of the consumer if/when a decision results in resistance that, regardless of the degree of disability, the consumer is a person with a history, interests and aims in life, and is capable of, and entitled to, exercise their capacity for decision making¹³.

5. How can we make sure the right people are helping? For example: that they are building the capacity of the person with disability, that they are considering what the person with disability wants.

Supported Decision Making requires funded Supporters to have high level interpersonal skills and attributes to achieve their role. Recruitment processes, training and Peer Supporter Supervision should be provided to help reduce the risk of undue influence.

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

Decision Supporters need to understand and operate in accordance with the following principles and philosophy that underpin Supported Decision Making are summarized below¹⁴:

- Supporting and strengthening self-determination, regardless of a person's apparent level of psychosocial disability or mental health distress.
- Viewing decision-making as relational, interdependent and changeable, (and recalling that no person, regardless of disability or distress, makes choices in a purely autonomous or individualistic manner).
- Understanding capacity as context related and decision-specific; different strengths and capacities will be relevant for different decisions.

¹³ Pathare, S, Shields, LS (2012). Supported decision-making for persons with mental illness: a review. Public Health Reviews 34, 15.

¹⁴ ADACAS Advocacy, 2016; ADACAS Advocacy, n.d.; Australian Supported Decision Making Network, 2016; WA's Individualised Services, 2013

- Respecting the 'dignity of risk' such that consumers have the right to take risks and go against professional, clinical or caregiver advice, as this is part of respecting their inherent dignity as an autonomous human being.
- Providing an alternative to **substituted decision-making** and instead, being driven by the rights, will, and preferences of consumers.
- Upholding principles of equality and non-discrimination.

8 What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan.

CoMHWA has received feedback from people with psychosocial disabilities, including direct requests, demonstrating a need for Peer Support to assist the consumer to make their own decisions in regards the selection of services they require and the providers they see as best placed to deliver those services.

Efficiency benefits of supported decision making include reduced risk of unplanned change of providers and/or plan reviews. Peer Supported Decision Making accords with the NDIS insurance model as it helps consumers to select services that will assist their recovery and builds their self-advocacy (and work readiness) skills.

9. Are there different things to consider for people with different disabilities or cultural backgrounds?

To gain the most benefit from Supported Decision Making the person with the disability should be able to participate in the process and to select their Supporter. A selection of genders, cultures and lived experience can help build trust and support a successful outcome for the individual to increase their decision making skills.

10. How can we help reduce conflict of interest? Conflict of interest is when a person or organisation takes advantage of their position for personal or corporate benefit.

Conflict of interest or perceived conflict of interest can be raised when Supported Decision Making is provided by someone with a vested interest in the outcome of a decision, including staff or consultants of NDIS or other service providers.

Conflict of interest can be difficult to identify and counteract. It is critical that NDIS has appropriate safeguards to reduce the risk of the decisions of individuals being adversely influenced.

- 11. How can we help reduce undue influence? Undue influence is when a support person makes the person being supported do something they don't want to do by making them feel scared, by being mean or by threatening or lying to them.**

Supported Decision Making requires Supporters to have high level interpersonal skills and attributes to achieve their role. Recruitment processes, training and Peer Supporter Supervision should be provided to help reduce the risk of undue influence.