

Mental Health Carers NSW Inc.

Supported Decision-Making for Adults with Disability and Older People in NSW.

Focus: Psychosocial Disability and Mental Health Contexts

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About Mental Health Carers NSW (MHCN)

Mental Health Carers NSW (MHCN) is the peak body for carers of people who experience mental health challenges in NSW. MHCN is a community managed organisation that provides systemic advocacy, capacity development and education for the carers, family, friends, and kin of those experiencing mental health challenges across NSW.

In Australia, there are approximately 354,000 mental health carers who, each year, provide 186 million hours of unpaid support.¹ Due to the demands of their caring role, carers are at a high risk of developing mental health issues, as well as experiencing loneliness and social isolation. MHCN supports mental health carers and advocates for services and systems that support them in their caring role. MHCN ensures the voices of mental health carers in NSW, and the people they care for, are represented in policy and service reform processes. We work to uphold the rights of carers and consumers to equitable, accessible, and adequately funded mental health services.

MHCN empowers mental health carers to become champions for mental health reform and advocacy. We engage regularly with carers so they can inform our policy priorities and advocacy; for example, every month we convene the *Carers of Forensic and Corrections Patients Network* meetings, and peer led *Mental Health Carer Connection* meetings.

MHCN also provides the Disability Advocacy Futures Program. This program engages in systemic advocacy on behalf of those who experience psychosocial disability. In this role MHCN advocates to non-Health state government services under the Disability Advocacy Futures Program.

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¹ Diminic, S., Lee, Y. Y., Hielscher, E., Harris, M. G., Keadon, J., & Whiteford, H. A. (2021). Quantifying the size of the informal care sector for Australian adults with mental illness: Caring hours and replacement cost. *Social Psychiatry and Psychiatric Epidemiology*, 56(3), 387–400.

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Executive Summary

Mental Health Carers NSW (MHCN) welcomes the opportunity to make this submission into supported decision-making for adults with disability and older people in NSW, with particular attention to psychosocial disability and mental health settings. Our submission draws on lived experience, from people with psychosocial disability, and from the families, carers, and kin who provide informal support when decisions need to be made. The process of supporting decision-making is complex and relational. People can make the right decisions with the right support.

Day to day, families and carers are involved when a loved one experiences distress or crisis, yet they are frequently excluded decisions and support that involve the people they are directly providing care for. Information about the person and proposed decisions or treatment may be withheld, and recognition of the carer or family member as a partner in care who supports the person's decision-making is low to non-existent. Professional guidance regarding treatment is thin and there is little protection for those providing support.

The approach can put a person's autonomy and safety at risk because families and carers have valuable historical knowledge. They intricately understand the views and preferences of the person receiving service. They understand the fluctuations in the person's decision-making and what 'good' can look like for them. They remember which decision supports have worked before and know what early warning signs for decision-making impacts can look like.

The central point of our submission is that supported decision-making should be the default across NSW systems. Substitute decision-making should be used only as a genuine last resort in tightly limited and proportionate situations, and only with regular review and independent oversight.

Decision-making is a relational and interdependent process shaped by other people, their responsibilities, and the circumstances around a person. This submission rests on the human rights of individuals as reflected in the United Nations Convention on the Rights of Persons with Disability (UNCRPD).² Article 12 outlines that 'people with disabilities have the right to *equal recognition before the law*. It states that people with disabilities have the right to make decisions and choices for themselves. This is the right to legal capacity. This article also recognizes that, when it is challenging for people to make decisions on their own, they have a right to receive support if they wish, from whom they wish to receive it. The requirement to make, communicate, and participate in decision-making is emphasized by

²<https://humanrights.gov.au/know-your-rights/rights-of-individuals/disability-rights/disability-rights/international-opportunities-and-the-cprd/united-nations-convention-rights-persons-disabilities-uncrpd>

the 4 *Decision-Making Principles* to guide legal frameworks proposed by the Australian Law Reform Commission in 2014. These are:

- I. Equal right to make decisions.
- II. Access to support.
- III. Will and preferences drive decisions.
- IV. Safeguards against abuse.

The UNCRPD recognizes that it is a human right for people to make decisions and get appropriate support. These human rights also exist for families, carers, and loved ones. A person's freedom to make decisions, to choose their treatment and make lifestyle choices are critical to the UNCRPD, including the freedom to take risks. These decisions, however, can impact those who support their, their families, and carers through harm, unreasonable burden, or financial risk.

If supported decision-making is the chosen mechanism for the freedom and autonomy of people's rights, its frameworks and implementation must address the reciprocal dynamic of relationships to recognise and protect everyone's rights, rather than separating consumers and carers, decision makers and their supporters, into isolated policy categories.³

The words that systems use matter. The term 'supported decision-making' might sound like a clear process but does not always capture how complex this work is in implementation, particularly when relationships are at the centre. Supporting someone with decision-making is not just sitting alongside a decision; it is about open discussion, encouragement, and capacity building for all parties. It also means setting in motion the actions and steps that enable a decision, which is where families and carers carry a large share of responsibility, emotional and or pastoral care.

Yet, policy implementation has not yet properly acknowledged the time involved, the repeated conversations, and the trial and error that comes with turning a decision into action. The practical steps are not optional extras, they are a part of ensuring autonomy, responsibility, and the human rights of all involved. People need time, clear information, and genuine opportunity to choose, and they need to develop safeguards that offer guidance and protection along the way. Systems that treat decision-making as a binary state risk unjustified removal or autonomy, which may escalate distress.

Support with decision-making allows individuals to exercise legal capacity with assistance rather than losing it entirely. It also enables families, carers, and loved one to contribute appropriately within clear ethical and legal frameworks. Right now, supported decision-making is currently not the norm, largely because NSW systems do not reflect its purpose in their design. The barriers include legislative settings that enable a default to substitute decision-making, the absence of formal recognition of nominated supporters, and the

³ [Mental Health Carers NSW, \(2019\). *Australia's Approach to Human Rights and Mental Health*. Submission 139.](#)

complicated and expensive court and tribunal processes undertaken in the appointment of formal and statutory decision makers.

Capacity is too often assessed with no support in place, and mental health responses can be driven by crisis, with limited accountability for quality-of-life outcomes. Financial and trustee systems can be hard to scrutinise.

Access to appropriate and accessible alternate communication, such as interpreters, is inconsistent and some practices could be viewed as culturally unsafe. Service coordination appears often fragmented, while staff shortages and limited training result in limited understanding or implementation of supported decision-making.

When supported decision-making is implemented properly by skilled supporters and with consideration and education of the potential outcomes of decisions, it can change the course of people's lives. The recognition of shared family decision-making where appropriate is the foundation of supported decision-making. It understands the interrelationships and intersectionality of the impact of decisions, considering the human rights of all involved.

Key Recommendations

The recommendations in this submission point to the need for reform across multiple systems so supported decision-making can operate as intended.

1. Implement the principles of the Australian Law Reform Commission's Decision-Making Recommendations.
 - a. Adults must be presumed to have the capacity to make decisions unless proven otherwise, and this capacity should be assessed specifically for the decision at hand rather than in a general sense.
 - b. If a person has difficulty with some steps of a decision, they must be provided with the necessary help to make the decision themselves or by the person of their choice.
 - c. Any intervention of appointment of a decision-maker must be the least restrictive option possible to protect the person's autonomy.
 - d. A person's ability to make decisions may change over time or depending on the complexity of the decision.
2. Put the recommendations from the DRC report into effect and develop a supported decision-making framework that protects the human rights of people with disabilities.
3. Create a statutory duty to attempt, and to document, reasonably supported decision-making processes improving the capability of supporters, before any substitute mechanism is considered.
4. Provide legal recognition for nominated supporters, including family and carers, where chosen by the person.



5. Amend confidentiality provisions that deter transparency and accountability in trustee and guardianship arrangements.
6. Expand access to independent advocacy and peer support, including decision-support frameworks that include carers.
7. Provide dedicated funding for culturally safe, Aboriginal-led, and CALD community decision-support initiatives that address intersectional barriers.
8. Commit across government to supported decision-making standards, including workforce training.

The Ageing and Disability Commission is well placed to advance supported decision-making as a safeguard. Still, its legislative framework and operating remit must clearly state the promotion of supported decision-making as the first option and accepted best practice across systems, as they must support monitoring and oversight.

Understood as a living, relational process, supported decision-making can be the backbone of a system that respects and protects rights and dignity. In mental health settings, fluctuating capacity is too often read as sustained incapacity. When the episodic and changing nature of mental health conditions and psychosocial disability is not understood, systems slide into substitute decision-making as the default. The result is compounded harm, eroded trust in self, family, and services, and rising long-term demand for crisis support. That does not have to be where NSW lands. With legislative changes and clear government leadership, NSW can lead nationally and deliver a system that respects dignity while handling responsibility and risk in a fair and transparent way.

Scope of this Submission

This submission addresses the following terms of references as published by the Committee on Ageing and Disability regarding:

That, pursuant to section 28B(1)(e) of the Ageing and Disability Commissioner Act 2019 (the Act), the Committee conduct an inquiry into and report on supported decision-making for adults with disability and older people in NSW, with particular reference to:

- a. the lived experience of people seeking to access appropriate support to make decisions for themselves
- b. barriers to implementing models for supported decision-making across legal, financial, health, education, employment and care systems in NSW
- c. the distinct experiences of and challenges faced by Aboriginal people and people from culturally and linguistically diverse backgrounds
- d. the role and functions of the Ageing and Disability Commission (the Commission) in relation to supported decision-making
- e. possible changes to the functions of the Commission, including legislative amendments to the Act, to enhance supported decision-making

- f. measures to ensure that substitute decision-making is an alternative approach that is employed in appropriate and limited circumstances
- g. other related matters

Response to the Terms of Reference

(a) *The lived experience of people seeking to access appropriate support to make decisions for themselves.*

What is happening

People with psychosocial disability, their families, carers, and loved ones consistently report the same pattern in decision-making within health, legislative, and service systems: that decisions occur around them and are made about them, not with them.⁴ Evidence gathered by MHCN points to consumers experiencing exclusion from decisions that directly affect their lives, their treatment, and the supports they use. What they commonly report includes:

- Being spoken about in clinical and service settings rather than being engaged in discussions about their own care.
- In crisis situations, decisions are made rapidly without proper explanation or opportunity to participate.
- Some describe feeling pressure to consent to treatment or service arrangements while already under stress.
- Others describe the exclusion of their chosen supporters, such as family members, carers, or trusted friends, from discussions and planning.
- A recurring concern is that services do not recognize how varied decision-making ability can be across people with psychosocial disability, and that this gap can lead to coercive or substitute practices.
- The fear that being honest and open about what is happening, how they feel, what they are thinking will cost them their autonomy or cause misrepresentations of their capacity.

Decision-making ability does not stay the same from one moment to the next, and this is true of all people regardless of diagnosis. For people with psychosocial disability, it shifts with many influences, and those influences can shape how someone presents, which then

⁴ Kavanagh et al., (2023). 'A scoping review of the barriers and facilitators to accessing and utilising mental health services across regional, rural, and remote Australia', *BMC Health Services Research* 23(1):1060; Allen et al., (2022). 'Informal carers' support needs, facilitators and barriers in the transitional care of older adults: a qualitative study', *Health Expectations* 25(6): 2876-2892.

affects how a provider or assessor judges their abilities. Capacity is also tied to the specific decision at hand and is not a single, fixed label that applies to everything.

Families, carers, and loved ones have described parallel experiences of exclusion.⁵ They experience:

- Being relied upon to provide support and intervention during periods of crisis but will be excluded from care planning and decision-making processes.
- Refused access to the information that they need to provide safe support.
- Fear and distress that their loved one is being stigmatized and not treated with dignity or awareness of their unique circumstances.
- Expectations that they must manage risk and provide ongoing care without the appropriate authority, guidance, or recognition that would make the role more workable.
- Receiving blame for outcomes in circumstances where they were not permitted to meaningfully contribute to the decisions.

For consumers and carers alike, this mix of exclusion and expectation can lead to major stress, trauma, and fear. This undermines trust in health and service systems, which can delay seeking help and increase the likelihood of crisis and presentations in emergency settings. When people anticipate stigma or poor understanding of their disability and believe they could end up in a loss of autonomy, they are far less likely to raise early concerns when there is still time to respond well.⁶

Carers' roles and their own human rights cannot be sidelined in this process. The care and support carers provide can bring risks to their own health, wellbeing, and financial sustainability, especially when these 'replacement costs' should sit with and be supported by policies and social care systems, not individual households.⁷ Carers also matters to the relational aspect of supported decision-making because they add support, perspective, background information, and safeguards that can protect the person and strengthen decisions.

Why this happens

For MHCN's stakeholders, the presenting problem is not that people with psychosocial disability, along with their families, carers, and loved ones, lack the ability to make decisions. The difficulty is that decision-making capability shifts with the situation and whatever

⁵ Additional examples can be found in Kokanovic et al., (2018). 'Supported decision-making from the perspectives of mental health service users, family members supporting them, and mental health practitioners', *Australian & New Zealand Journal of Psychiatry* 52(9): 826-833.

⁶ Klink et al., (2019). 'Toward understanding mental illness stigma and help-seeking: a social identity perspective', *Social Science and Medicine* 222: 35-43.

⁷ Deloitte Access Economic, (2020). *The Value of Informal Care in 2020*.

support or pressures are present. Current research argues for a departure from a binary and legalistic view of 'capacity/incapacity', emphasizing that capability is not fixed but can be built or enhanced through tailored support. This bolsters the person's existing ability and allows them to reach a necessary threshold for decision-making rather than immediately resorting to a substitute decision-maker.⁸

Decision making capability therefore is not fixed, it can change over time, over a day, and can be affected by trauma, medication, stress, surroundings, service treatment and culture. Because psychosocial disability is intersectional and personal, it does not look the same from one person to the next, yet communication gaps, limited understanding, and stigma can lead others to misread it. Still, many systems treat capacity through a binary capacity lens. This means that, when distress or a dip in capacity is noticeable, the person's authority to decide is more likely to be taken away altogether.⁹

What must change

Supported decision-making comes with practical, day-to-day interactions, discussions, and patience. The real starting point is tougher and more fundamental: changing the ingrained assumptions about whether a person with psychosocial disability can choose for themselves. This mindset must move away from treating mental health conditions and psychosocial disability as precursors to limited decision capacity. Instead, the default should be that people can make their own decisions, and when they need help, they can do so with as much support as they need.

Strengthening supported decision-making and ensuring that consumers and carers can meaningfully and fairly participate in care and service planning is critical to rebuilding trust in systems, reducing presentations to crisis services, improving autonomy, and bettering mental health outcomes. This requires looking closely at what support, and how much of it a person needs to make choices that reflect their preferences and rights while also respecting the rights of their carers and loved ones.

Supported decision-making also cannot be treated as something services attempt only when the conditions are perfect. It needs to sit at the centre of relationships and routine service delivery as the normal way of interacting, so that practices shift from substitute consent as the reflex, and toward supported participation as the standard.

When positive approaches are used, the following is possible:

- Improved trust with loved ones.

⁸ Browning et al., (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: 34-45.

⁹ Mertens et al., (2025). 'Navigating power imbalances and stigma in mental healthcare. Patient-reported barriers and facilitators to participation in shared decision-making in mental health care: a qualitative meta-study', *Health Expectations* 28(2): e70239.

- Improved trust in clinicians and services.
- Greater willingness to disclose concerns early.
- Improved treatment adherence when options are explained clearly and are chosen by the person with proper informed consent.
- Stronger recovery pathways.
- Improve dignity, sense of autonomy, and believe in oneself.

Accordingly, MHCN recommends that:

- NSW Government services adopt mandatory training in psychosocial disability, fluctuating decision-making ability, and supported decision-making principles and methods.
- Services adopt a presumption of supported decision-making in practice standards.
- Capacity assessments are not conducted in unsupported crisis conditions but involve documented reasonable support.
- Services must document all efforts to identify and include nominated supporters unless demonstrably inappropriate or at the individual's request.

(b) *Barriers to implementing supported decision-making across legal, financial, health, education, employment, and care systems.*

Effective uses of supported decision-making do not fail because people cannot decide what they want or need. The more common problem is structural: our systems are not set up to provide the right resources for person-centred practice, deep listening, or the time required for supported decision-making processes to unfold properly.

MHCN notes that this ToR item sets a high bar, since it requests information spanning several service areas. Each one comes with their own unique operational and implementation realities. With that in mind, MHCN has tried to speak to as many of these as possible, with an emphasis on core concerns our stakeholders have raised with us. As ever, MHCN welcomes the opportunity to facilitate consultation between our stakeholders and relevant departments and services.

Legal barriers

Under the UNCRPD, legal capacity is a person's right to make their own decisions about their lives, on an equal basis with everyone else. In this way, supported decision-making means that people keep their right to legal capacity *regardless* of how much support they need to make decisions. Other people may dislike, question, or disagree with the choice that is

made, but this does not mean that the individual does not retain their right to the choice just as others have the right to raise their concerns.

Guardianship and trustee systems can function as the default mechanisms for complex and crisis situations. In these cases, the risk is that 'capacity' can be assessed before proper support or service linkages have been arranged. Moreover, confidentiality provisions can also prevent transparency and accountability.¹⁰ In that context, the Guardianship Act contains certain provisions that differ from the Mental Health Act 2007 (NSW), particularly around voluntary versus involuntary status and delayed access to care outside of the acute system.

In cases where a service provider undertakes a supporter role, conflicts of interest can be hard to avoid. These frameworks can shrink a person's autonomy in a broad, blanket way instead of limiting restrictions only as far as needed and only for the decision in front of them. That approach sidelines the aim of returning decision-making authority to the individual.

Even when a substitute decision-maker is legally empowered to decide, that does not remove the duty to talk decisions through with the individual, and it does not mean that authority must be exercised at every opportunity. The same logic carries across treatment orders; being subject to an order does not automatically mean a consumer cannot grasp what is being decided, or that they do not need to know what decisions are being made. Lastly, if legal constraints on providers are reduced, fear of personal liability may decrease, which may in turn reduce the tendency to treat substitute decision-making as the default.

When families and carers are not formally recognized, they can be blocked from making sure their loved one has the support, information, and care required to make decisions in the first place. Stakeholders consulted by MHCN from the *Mental Health Carer Connections* group raised the specific concern that eradicating substitute decision-making without a clear recognition of the role of carers risks leaving carers with responsibility but no standing. Supporting a loved one means sometimes dealing with messy, complex, and high stakes situations and feeling that they must step in when a decision could bring serious consequences.

MHCN's position is that supported decision-making is a genuinely relational practice that is central to the wellbeing of consumers and carers alike. Yet, when carers are excluded, their capacity to offer practical support is weakened, even when they are trying to help without intruding on the person's right to decide.

What is needed, then, are provisions that recognize the value of carers and allow supported decision-making to work as intended, meaning it is supportive in practice, not only in principle.

¹⁰ Mental Health Carers NSW, (2019). *Review of the Guardianship Act and Safeguards for NDIS Participants*.

Health and mental health systems barriers

Acute health environments are usually organised around clinical deadlines, limited resources, and managing risk. This structure makes substitute consent more common. Clinicians and staff may fear liability for themselves, their employer, and other patients when risk is present. As a result, they may choose containment over collaborating with the person. In a risk-averse culture, the motivation and practical capacity to use supported decision-making during crisis shrinks, even where advance preferences are already in place.¹¹ The result is predictable: distress rises, and people are less likely to stay engaged over the long term.

MHCN's stakeholders have reported several design barriers across health and mental health care design:

- Time pressure in acute settings.
- Too few interpreters and other communication support.
- Lack of person-centred practice.
- Complex and dense clinical language.
- Limited recognition or respect for family-led decision-making.
- Poor continuity of staff relationships.
- Inaccessible information formats along with a shortage of independent advocacy services.
- Cognitive impacts of medication and or distress.
- Confidentiality rules are applied in ways that exclude carers even when consent exists or could be supported.

More time is needed within these settings to identify and consider a person's preferences, values, and support networks. Psychosocial disability can involve fluctuating symptoms, with decision-making capability shifting alongside the person's mental health. Yet services often treat capacity as fixed because the immediate goal is to reduce risk and resolve the situation quickly. That approach sidelines the person's prior preferences. It also perpetuates the stigma that a mental health diagnosis and disability automatically mean incapacity. Moreover, health and mental health services are also not funded or staffed appropriately to maintain the tools required to support and uplift people during periods when their ability is reduced.

¹¹ Hamer et al., (2026). 'Risk redux? Therapeutic risk taking and the role of supported decision-making in mental health settings', *International Journal of Mental Health Nursing* 35(1): e70234.

Support should make participation possible, so a diagnosis is not treated as proof that someone's preferences or directives are less credible.

Service system barriers

A range of barriers exist across NSW services. While supported decision-making may be supported in policy and theory, it must be implemented in practice.

NSW Housing runs on heavy bureaucracy and a strong systems-first approach, which is notoriously difficult for people with psychosocial disability to navigate. The result is that people are often shut out of real involvement in housing decisions because protocols are not clearly explained, and the approach is neither trauma-informed nor grounded in mental health literacy.¹²

In this setting, barriers to supported decision-making include the complex eligibility criteria and application processes that require significant support and explanation, limited transparency about waitlists, allocation zones, limited availability of housing, and frequent 'wrong door' experiences when people reach out for help but end up with the wrong service.¹³ People with psychosocial disability require support to interpret complex documents and applications to understand the processes and make informed decisions about the housing options they have.

Supported decision-making in housing relies on trusted supporters, carers, and advocates, who understand the person, their potential challenges, and the necessary support and safeguards required for a successful tenancy. Yet they are often left out when key choices are being made. Several barriers occur: too few funded peer workers and housing navigators, tight resourcing for individual advocacy organisations to support housing decisions, and families and carers not having sufficient information to assist meaningfully.

Psychosocial disability is often approached as an 'invisible' disability. That assumption breeds confusion and, at times, dismissal of a person's capacity and the support they need. The impact is that staff may not recognize what support is needed to help the person decide, reducing the credibility of tenants with mental health diagnoses, and housing allocation being influenced by stigma or lack of awareness rather than preference and need. This can only lead to greater disengagement from services.¹⁴

A major barrier is the severe shortage of social and affordable housing in NSW, which shifts the system towards crisis allocation instead of a collaborative decision-making process. This context results in limited choice about where a dwelling is located, increased pressure to accept unsuitable or unsafe housing, and reduced ability to choose preferences and

¹² Nguyen et al., (2021). 'Housing-related delayed discharge from inpatient mental health units: magnitude and contributors in a metropolitan mental health service', *Australian Journal of Social Issues* 57(1): 144-163.

¹³ [Mental Health Carers NSW, \(2024\). *Housing and Psychosocial Disability in NSW*.](#)

¹⁴ Devine et al., (2020). "'If I had stable housing, I would be a bit more receptive to having a job': Factors influencing the effectiveness of Disability Employment Services reform", *Work* 65(4): 775-787.

support. This serious deficit means that the decision-making capacity of a person with psychosocial disability is restricted by availability rather than guided by their preferences and needs.

In employment, people with psychosocial disability report that employment services and disability programs do not have the requisite understanding of supported decision-making to enact it.¹⁵ This includes staff not being properly trained to understand how to facilitate employment, an understanding of what has worked in the past and environments that are triggering, or they lack the structures to mitigate psychosocial risks.¹⁶

This can lead to employment planning being conducted through substitute decision-making and professional judgement over the person's preferences. This dynamic can create power imbalances where the person might be expected to commit to longer term employment or tasks during times of distress or engage in employment that does not have the mental health flexibility that they need.¹⁷ When stigma is anticipated in workplace and employment settings, people may fear that employers or services will question their capacity as a whole and that disclosing their mental health and/or disability might affect their job opportunities, performance, and promotion.¹⁸ To promote psychosocial safety, employment services need to be flexible, responsive, and empathetic to changing capacity. An open-minded and supportive work environment will help people with psychosocial disability to maintain employment.

Additional barriers to supported decision-making in employment include the omission of trusted supporters, such as families, carers, peers, and advocates, from employment discussions and planning processes, particularly when the person requests it. Trusted supporters must be seen as assets to employment discussions because they can help the person unpack and navigate complex employment requirements and planning, navigating the NDIS and DES, and can help them advocate for workplace adjustments.

(c) The distinct experiences of and challenges faced by Aboriginal people and people from culturally and linguistically diverse backgrounds.

Much like ToR item (b), this point presents some concerns. The primary concern is simply: Aboriginal people and CALD communities have distinct experiences, and they should be addressed in separate, standalone items. Policy conversations sometimes bundle

¹⁵ Devine et al., (2024). 'Experiences of young Australians with intellectual and/or psychosocial disability sharing disability-related information to gain workforce adjustments', *Disabilities* 5(1): 1.

¹⁶ Devine et al., (2021). "I don't think they trust the choices I will make": Narrative analysis of choice and control for people with psychosocial disability within reform of the Australian Disability Employment Services Program', *Public Management Review* 21(1): 10-30.

¹⁷ Meltzer et al., (2020). 'Barriers to finding and maintaining open employment for people with intellectual disability in Australia', *Social Policy & Administration* 54(1): 88-101.

¹⁸ Litvinenko, I.L., & Timokhin, D., (2025). 'Psychosocial barriers and ways to improve employment of persons with disability', *Problems of Social Hygiene, Public Health, and History of Medicine* 33: 857-862.

Aboriginal and CALD perspectives together, but can blur out the differences, and we end up mixing issues, experiences, and histories that are not the same.

Barriers to supported decision-making in these distinct areas relate to how our services interact with colonial histories and cultural differences in decision-making, on top of structural inequities. The *Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability* documented key barriers for First Nations people with disability. These include the lack of cultural and historically safe practices and services, excluding community and family from decisions, poor access to culturally appropriate advocacy, and long-standing mistrust of government due to historical trauma. Forced guardianship is a trauma and an environment prone to developing psychosocial disability. Forced guardianship of First Nations peoples is a legacy of colonialism, which inherently lacks cultural sensitivity and is fundamentally culturally unsafe.

First Peoples Disability Network have emphasised the need to address historical abuse and for better oversight of people with disability in and out of home care, while highlighting that ‘pervasive intersectional discrimination means they are less likely to be believed...’ when reporting incidents.¹⁹ In their ‘Our Lives, Our Decisions’ submission, *People with Disability Australia* demonstrated that substitute decision-making remains widespread, partly because these approaches do not acknowledge or engage meaningfully in cultural diversity in their policy design.²⁰ Through consultation with First Nations organisations and communities, the Committee can learn about the importance of family and kinship networks and their importance to decision-making and commit to genuine cultural safety.

For supported decision-making to emerge as the benchmark, we must change the culture of negating different experiences, beliefs, and identities. This includes understanding and treating the intersectional differences between First Nations and CALD communities as separate policy categories to ensure that neither is overlooked or conflated.

(d) The role and functions of the Ageing and Disability Commission (the Commission) in relation to supported decision-making.

The Commission is in a strong position to take a leading role in strengthening supported decision-making across NSW. Created under the Ageing and Disability Commissioner Act 2019 (NSW), The Commission promotes the rights of older people and adults with disability, responds to allegations of abuse, neglect and exploitation, and raises awareness to systemic problems that risk the safety and wellbeing of already vulnerable people.

Those responsibilities sit naturally alongside supported decision-making. The simplest proposition is that people with disabilities have a right to make decisions about their own

¹⁹ First Peoples Disability Network Australia, (2022). *The Experiences of First Nations People with Disability and their Families in Contact with Child Protection Systems*.

²⁰ People With Disability Australia, (2022). *Our Lives, Our Decisions: Submission to the Disability Royal Commission on Guardianship, Substituted and Supported Decision-Making*.

lives and, where they need support, it must be provided in ways that respect their rights, will, and preferences. Article 12 of the UNCRPD reflects this because it recognises the legal capacity of people with disability and places a duty on governments to ensure they access what they need to exercise it.

The *Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability* reinforced supported decision-making as a human right and a practical safeguard. It pointed to the harm caused by sustained reliance on substitute decision-making including guardianship, which often restricts autonomy. Similar issues are being addressed by the NSW Law Reform Commission to acknowledge that decision-making laws need to do better to reflect the will, preferences, and rights of people with disabilities.²¹ The Commission's own review raised similar concerns, especially the ongoing dependence on substitute decision-making and the need for strengthened supported processes.²² Because of the wider policy and legal context, the Commission is well-positioned to act as a steward in the system for supported decision-making, enacting its safeguarding functions, its role in public awareness, and its oversight and reporting responsibilities. These can include but are not limited to:

Public awareness

Evidence provided to the DRC showed that awareness of supported decision-making is still low across community and service systems. Many people with disability, families, carers, and service providers do not have a clear understanding of the principles or what those principles look like in day-to-day practice.

The Commission already runs community education and online training aimed at preventing abuse of older people and adults with disabilities. Building supported decision-making rights and practices into existing education would help raise understanding of how people can be assisted in making their own decisions without losing the protections that are meant to keep them safe.

Sector guidance

Although supported decision-making is increasingly referenced in policy discussions, services need practical guidance on how to do it well. Submissions to the DRC and the NSW Law Reform Commission highlighted the consistent problem that workers often do not know how to support a person's decisions while also meeting legal, clinical, and organisational policies and duties.

This is a clear opportunity for The Commission to support the development of practice guidance, standards, and useable tools to ensure it is applied consistently and safely across services.

²¹ NSW Law Reform Commission, (2018). *Report 145 – Review of the Guardianship Act 1987 (NSW)*.

²² NSW Government, (2022). *Independent Review of the Ageing and Disability Commissioner Act 2019*.

The DRC treated supported decision-making as a way to reduce risks of abuse, neglect, and exploitation. When a person is genuinely involved in decisions about their life, they are more able to notice risks, raise concerns, and keep control over their circumstances. The Commission can thus promote supported decision-making not only as a rights-based reform, but also a preventative, risk management and harm reduction strategy.

Monitoring and reporting

The Commission receives and investigates reports of abuse, neglect, and exploitation and thus has clear visibility of systemic and service level issues that jeopardize autonomy and rights. It could build supported decision-making into its monitoring and reporting processes, with reference to recurring patterns, such as when substitute decision-making is being used readily or inappropriately and practical barriers to recognising trusted supporters. Routine reporting would strengthen the evidence base for reform and identify opportunities for better safeguards.

Supporting workforces and family and carer capability

Disability advocacy organisations have consistently raised the issue that supporters are often unsure what their role is meant to be in the decision process.²³ Workers, families, carers, and trusted supporters can struggle with how to help someone express and reach a decision without taking over or encroaching on their rights.²⁴

The Commission could strengthen capability across the workforce, in the household, and in the community by promoting training, guidance materials, and resources that clarify responsibilities and good practices. This could include guidance around safely including supporters, because even though many people with disability depend on trusted supporters, services often face uncertainty about how to involve them in a way that respects privacy and meets expectations. The Commission could develop guidance materials that explain how supporters can be recognised and included safely, so that services are better prepared to include them without weakening their safeguards or responsibilities.

Families and carers often play a major part in decision support, especially when someone has a psychosocial disability. This can involve having frank, honest, and sometimes difficult discussions, and providing emotional, practical, and financial support. Still, our stakeholders have pointed to ongoing confusion among providers about privacy, consent, and what informal supporters are allowed to do.

²³ Maybery et al., (2021). 'Mental health service engagement with family and carers: what practices are fundamental?', *BMC Health Services Research* 21(1): 1073.

²⁴ David et al., (2024). 'Setting priorities for mental health family carer research and advocacy in Australia', *International Journal of Care and Caring* 8(4): 765-771.

Clear, practical guidance from the Commission could help service manage privacy duties while still acknowledging the legitimate role that families and carers may have. This can reduce conflict and make collaboration easier.

(e) Possible changes to the functions of the Commission, including legislative amendments to the Act, to enhance supported decision-making.

While this submission focuses largely on the cultural change necessary to embed supported decision-making across the many systems that people with psychosocial disability, their families, carers, and supported encounter, MHCN notes the following possible legislative changes:

- i. Implementing improved terminology such as replacing outdated terms such ‘decision-making capacity’ to ‘decision-making ability’, and ‘administrator’ to ‘representative’ to reflect relational dynamics of the decision process.
- ii. Introduce statutory recognition of supporters and support persons so that they can formally assist individuals without losing their autonomy.
- iii. Introduce a statutory obligation to attempt supports before substitute mechanisms. Including time limits, regular review, and enhanced access to independent advocacy.
- iv. Legislate that clear, accessible information and guidance about supported decision-making be made available to all parties including information-sharing, privacy, and the circumstances in which information may be shared without a person’s consent.
- v. Review of the gag laws under the Trustee and Guardianship Act to support accountability, and amendment of the Civil and Administrative Tribunal Act 2013, section 65 to require the consent of the individual or tribunal for the publication or broadcasting of their name under item 2.²⁵
- vi. Expand The Commission’s authority to issue sector standards, practice guidance, and compliance, as well as mandatory reporting on substitute decision-making usage.

(f) Measures to ensure that substitute decision-making is an alternative approach that is employed in appropriate and limited circumstances.

From the outset, there must be clear guidelines and examples for what ‘appropriate and limited circumstances’ entail. Often, perception of risk alone may justify the use of restrictive practices and substitute decision-making. The Commission needs to work closely with

²⁵<https://attwoodmarshall.com.au/public-trustee-continues-to-flourish-under-cloak-of-secrecy-and-gag-laws/>

services and providers to identify what their perceptions of risk are, whether they align with risk management policies, and if they restrict the rights of the person. This will inform the development of frameworks and resources to counter misinterpretations of risk and over-reliance on restrictive processes.

An emphasis on consistent terminology, and mandatory reporting and audits can help make substitute decision-making a last resort that is only ever proportionate, measured, and regularly reviewed and subjected to independent oversight. Measures should include documented evidence that supported decision-making was attempted, restoration planning aimed at returning decision authority to the person, independent advocacy access, inclusion of chosen supporters unless demonstrably inappropriate.

Conclusion

Supported decision-making can be a crucial piece of infrastructure in any service system that aims to respect human rights and keep people safe. This is critical in mental health and disability, where a person's ability to decide can shift over time and is too often misread or prejudged because of stigma. If a system reaches too quickly for substitute decision-making, the damage compounds, and creates more harm and less trust between people and services. This can only ever result in a heavier demand later for health and crisis responses.

People with psychosocial disability must have the same access to supported decision-making as anyone else because their right to make choices about their lives, treatment, and support does not disappear. Changes in mental health do not cancel autonomy. Rather, they point to what the system should be doing to put the right support in place so people can access information, express what they want, and take part in decisions that shape their life. Making supported decision-making available and enshrined in the law affirms dignity and legal rights.

In practice, families and carers already do a lot of this type of work and support. When they are properly recognised and included, they can help people weigh their options, navigate complicated systems, and communicate preferences in ways that services and providers can understand. Treating families and carers as part of the decision-making support and giving them tools to do it safely and well, can strengthen autonomy, make decisions safer, and less adversarial.

Getting there takes coordinated work. Legislative reforms matter, but so does leadership inside institutions and investing in workforce capability. When supported decision-making is woven through policy, law, and day-to-day service delivery and is monitored by The Commission, NSW can move closer to an inclusive, rights-based system where people with psychosocial disability can exercise real choice, control, and dignity.