



# **Submission to Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability**

## **Respecting human rights: the role of supported decision making and self-determination as a safeguard against violence**

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## 1. Who we are

NSW Council for Intellectual Disability (CID) is a systemic advocacy organisation that works to ensure all people with intellectual disability are valued members of the community. CID has been a leader in disability rights for more than 65 years.

People with disability are at the front and centre of everything we do – they are decision makers, staff members, board members and spokespeople. We work to build a community that protects rights, includes everyone and supports people well. We focus on issues that people with disability tell us are important, such as the NDIS, health, jobs, education, transport and safety.

CID promotes human rights. We help people with disability to be heard, we speak up on the big issues and campaign for change. We advise on how to be more inclusive so that our society is equal and accessible.

We believe people with disability should have the same opportunities as everyone else. Through CID all people with disability and their families and supporters can learn, build skills, and actively participate in the community. We provide information, hold workshops and develop useful resources. We go to community events, share our stories and connect with peers.

## 2. Summary

This submission highlights the potential of Supported Decision Making (SDM) principles and practices to influence a wider range of human services agencies in the common goal of inclusion. Embedding SDM principles and practices across settings would help move human rights concepts into practice and provide opportunities for better interagency collaboration.

When systems are aligned and working toward a common goal, people with intellectual disability are supported in consistent ways that enable them to live their best lives. As Alex Elliot, CID Project Worker with lived experience says: 'One unsupported decision and your entire world is challenged'.

Through the increased leadership of people with intellectual disability, CID delivers advocacy and projects that aim to advance the practice development of Supported

Decision Making across Australia to positively impact the self-determination of people with intellectual disability.

The Disability Royal Commission should consider CID's recommendations to Government in its report.

### 3. Self-determination

This submission talks about people with intellectual disability, but the concepts apply to everyone. Promoting a universal perspective sets an inclusive foundation by uniting people as human beings with rights to a self-determined life.

Self-determination means to 'self-govern'. It means to lead one's own life, to have agency, to take volitional action on something we want to do.

The theory of self-determination encompasses three ideas of human personhood: autonomy, competence and relatedness that drives action (Shogren et al., 2015).

**Autonomy** means to act on one's own self-interest. When someone has autonomy over their own life they plan, set goals, solve problems, and make choices and decisions.

**Competence** means a feeling of accomplishment, a sense of mastery and self-efficacy. When someone feels competent, they self-manage, attain goals, and plan and solve problems.

**Relatedness** means connection to others, typically a feeling of inclusion, belonging and connectedness through relationships and self-identity. When someone relates well to others, they are self-aware, have self-knowledge and manage themselves.

When someone chooses their own pathways across their lifespan as children, youth, adults and as elders, they are living a self-determining life.

*Some leadership advice I would give to others is that you are the boss of your own life. You can be taught to lead and take part in a way that is easy and welcoming to you. You come first. Alex Elliot, CID Project Worker with lived experience*

## 4. Nurturing self-determination across the lifespan

### 4.1 Schooling and education

Developing self-determination in children from a young age is critical for progressing the practice of supported decision making across communities.

Educators prepare children for a thriving life as an adult post-school. Children may grow to enjoy higher education, employment, and flourish at home and socially in the community.

There is opportunity for children moving through an inclusive education system to learn to seek support for their own decision making and to learn to give support to others.

When children develop self-determination from a young age, it increases the likelihood of them having the skills, confidence, and self-esteem to make determined decisions during transition when they progress to post-school pathways.

The promotion of self-determination by educators can be achieved through:

- skill development
- opportunities to practice
- building and using supports.

Children can learn critical self-advocacy skills from a young age to seek the supports and implement the strategies they need that enables connection, inclusion, belonging and self-identity in the world.

When children of all backgrounds with varying needs receive the same opportunities for skill development, opportunities to practice and to build and use supports, then all children are realising their rights as humans to develop agency over their own lives from a young age and to capitalise on natural supports available to them across their lifespan.

Barriers to achieving this include:

- segregated schooling
- insufficient pre-service teacher training

- insufficient delivery models of professional development and not enough access to on-the-job feedback and coaching
- lack of accountability for the implementation of Individual Education Plans
- layering of social community complexities, particularly in regional and remote communities resulting in overcrowded classrooms with teachers receiving overflow students from absent teaching staff, leaving teachers in impossible supervision situations
- students' needs not being met due to environmental conditions, including situations of violence and neglect
- government expectations to implement new initiatives on an ongoing basis, resulting in schools being overwhelmed with competing initiatives.

Additional barriers for students with intellectual disability include:

- lack of belief from teachers that they can learn
- lack of access to functional communication systems
- lack of direct instruction from teacher; too much time with support staff
- variability in instruction practice received by teachers from year to year
- lack of involvement in their own individualised planning
- inaccessible Individual Education Plans and student documentation
- lack of correct provision of the educational adjustments and supports they need.

At a systemic level, more can be done to review educational policy and strategic reform design and delivery. Major reform programs need to consider if they meet the needs of students with intellectual disability. If there are targeted initiatives that could be complementary to improving outcomes for students with disability, then these need to be intentionally and strategically coordinated from design to delivery.

*Good support in school builds confidence for decision making in future.*

Alex Elliot, CID Project Worker with lived experience

## 4.2 Post-school transition

Many young people with intellectual disability are leaving school with low reading and literacy skills, and without functional communication systems. With no links to higher education, employment or other community activities, it is these people who are likely to rely on supported decision making across their lifespan. With supported decision making being an under-developed practice in Australia, these people may be at higher risk of abuse, neglect, violence and exploitation.

Australia's post-school transition system and supports available for youth with disability are underdeveloped. There is also limited Australian research available regarding post school transition, and there is a gap in formal education that specifically targets post-school transition leadership to develop the policy and practices that are required to make improvements.

In comparison, the USA's Institute for Community Inclusion at the University of Massachusetts Boston delivers an 18-month graduate certificate specifically focused on Transition Leadership for Youth with Disability, which centres around self-determination, career development and competitive employment, inclusive higher education programs, transition leadership for systems change and other transition topics such as interagency collaboration, supported decision making, and guardianship.

Australia's investment in similar coursework would produce graduates knowledgeable and skilled to lead evidence-based transition services that promote positive post-school outcomes for young people with disability.

There are also opportunities for Australia to lead by including people with intellectual disability in the educational delivery of this coursework.

Transition services could include evidence-based practices such as those identified from effective programs and research literature outlined in The Taxonomy for Transition Programming 2.0 (Kohler, Gothberg, Fowler, and Coyle, 2016). The model outlines five main categories:

- student-focused planning
- student-focused development

- interagency collaboration
- family engagement
- program structure.

Enhanced transition services and practices would bridge a gap between inclusive education and community inclusion outcomes for adults with disability by:

- nurturing self-determination and decision-making skills from an early age within the schooling system
- implementing strategies to keep young people in school until graduation and reduce dropout
- increasing access to predictors for post-school success such as engaging in paid work experience during schooling
- enforcing schools to deliver quality transition practices such as formal transition assessment and planning programs
- enforcing the education system to collaborate with external agencies to foster successful transition of youth with disability to higher education and employment.

### 4.3 Higher education

There is little formal or informal education and training that exists for Australian workforces that promotes:

- the understanding of self-determination theory and how it can be applied practically to nurture someone's self-determination and decision-making skills across their lifespan
- best practice in the provision of support for decision-making.

Supported Decision Making fits within the broader framework of self-determination theory. It is an under-developed practice that has potential to release the over-reliance on substitute decision making practices such as guardianship and financial management. This can only occur if it is resourced, and adopted into strategy, policy and workforce capability plans across sectors, and legislated.



Higher education plays a critical role in the development of our future workforces across sectors and systems.

Young people move through their school years and grow to become our practising lawyers, bankers, health workers, support workers, community workers, teachers and service assistants. These are the same adults we will rely on to provide the supports and adjustments to the people with intellectual disability they encounter in the community in their everyday lives, across their lifespan.

Higher education plays a critical role in the development of teacher workforces who are vital to the development of children. They can have direct influence on the schooling experiences of children with disability.

Educating teachers in human rights frameworks and instructional strategies that facilitate the development of a young person's self-determination has the potential to positively affect their outcomes for the trajectory of the young person's life.

*If you don't believe that everyone has the right to make their own decisions then it would mean lack of freedom, lack of choice and being able to have your own mind and be in part of how you want to be involved in the community.*

Ricky Kremer, CID Project Worker with lived experience

#### **4.4 National Disability Insurance Scheme**

The National Disability Insurance Scheme (NDIS) was initiated as a major reform of disability support in Australia to provide individualised support and links to community for people with disability throughout their lifespan (Commonwealth of Australia, 2013). The objective of the NDIS is to provide people with greater choice and control over the services and supports they receive.

In theory, the NDIS is an enabling structure to foster self-determination in people with disability. However, the lack of mandated Individual Education Plans for students with disability (Cumming et al., 2014) eliminates opportunities for students to develop self-determination skills (Wagner, et al., 2012) and for schools to deliver evidence-based, student-centred transition practices (Kohler et al., 2016).

When used effectively, the NDIS can be an enabler to decision making skill development for people with disability. It can provide opportunities for people with disability and their supporters to try and practice new things and take steps toward their own goals for their best life.

There is opportunity for the National Disability Insurance Agency (NDIA) to model the practice of promoting self-determination development across the lifespan to services to adopt.

An effective NDIS human rights strategy would be person-centred with the individual's will and preference directing the entire individualised process. It would include an expectation that the individual has meaningful presence in meetings; that they are engaged and supported to participate, provided with the people they select as supporters; and have access to the decision making accommodations and reasonable adjustments to set, attain and evaluate their goals.

For individuals without supporters, there would be an obligation from rights-based legislation, human rights policy and practice guidance to build support networks for individuals. Having higher expectations of workforces across sectors to provide good decision making supports and adjustments across settings (i.e. health, employment etc.), would help build natural support networks for individuals to benefit.

Enabling this, is the important role of education in helping children build, use and provide supports from an early age. Enhancing the knowledge, skills and confidence of teachers across Australian education systems to intentionally set conditions for self-determination would enable other sectors and systems, such as the NDIS, carry forward the nurturing of decision making across the lifespan.

*Decision making is a human right. Human rights means that everyone in the world has value. They are rules about what a person can do, or have, or not.*

Ricky Kremer, CID Project Worker with lived experience

## **4.5 Community Inclusion**

Community has a duty to reasonably accommodate people with intellectual disability to thrive. There is a need for real and constant application for disability inclusive practices in communities. There is a need for real and constant application of the social

model of disability in communities. Government agencies and communities have responsibility to uphold their legal obligations to provide reasonable adjustments and support, including support for decision making.

When we increase someone's self-determination and provide them with the supports and adjustments they need to achieve things across the sectors they engage with daily across their lifespan, then it provides alternatives to substitute decision making practices such as guardianship and financial management orders.

*If you make decisions for yourself – that's it you're free... It will be hard for some because they don't know how to do it before. They don't know how to stick up for their rights... Their supporters can help them. Good supporters help people make decisions by themselves.* Len Robinson, CID Project Worker with lived experience

## 5. CID's Supported Decision Making strategy

CID's contribution to the advancement of Supported Decision Making includes systemic advocacy, project implementation, strategic relationships, and sector engagement. We also model supported decision making through our inclusive governance.

CID's approach is through the direct leadership of people with intellectual disability. All of CID's Supported Decision-Making project work has been co-produced with people with lived experience of intellectual disability. People with intellectual disability have been involved in our strategic engagement with academic researchers, practitioners, public servants and family members. CID has emerged with an informed strategy to lead systemic advocacy recommendations. These strategies introduce new ways of thinking, acting and working together.

CID's Supported Decision Making presents a model that aims to assess the environment around a person to determine what supports and adjustments could be provided by close and paid supporters to enable them to make more of their own decisions.

## **5.1 New assumptions to replace old beliefs**

CID wants government and providers of services in all sectors to adopt a new assumption and belief that everyone has decision making capability. Decision making capability is when the people with disability are involved in their own decisions and can include supports and adjustments.

Moving away from a medical model of assessing whether a person has capacity to make decisions towards a concept that responds to the social model of disability: assessing the provision of environmental supports instead of the person.

This concept lines up with recent education system reforms that have moved away from resourcing allocation models based on the diagnoses of students with disability, to resourcing allocation models that are designed on providing educational adjustments based on the functional learning needs of the child. It also respects the importance of culture and community in shaping and supporting decision making.

## **5.2 A co-produced Supported Decision Making framework**

CID has co-produced a Supported Decision-Making framework that is drawn from the principles outlined in the Australian Law Reform Commission (ALRC) report recommendations (Equality, Capacity and Disability in Commonwealth Laws, ALRC Report 124), and enhanced by the perspectives of people with intellectual disability. The four principles embedded in CID's SDM framework that will drive advocacy and project implementation, include:

1. Everyone has decision making capability
2. Everyone must get the support they need
3. Will and preferences must be respected
4. Enable risk and balance duty of care.

CID's reference to the language of 'decision making capability' in Principle 1 is an extension of the ALRC's mere statement of the right to make decisions. It is re-framed to assert a new assumption and belief that is aligned with a social model view of disability, assessing the environmental supports and adjustments around a person to explicitly move away from assessing the decision making capacity of an individual,

which is often viewed as inherent to the person with intellectual disability and entrenched in medical model attitudes and practices.

CID's Principle 4 also has a stronger representation of risk enablement than the ALRC's recommended principle relevant to safeguarding. CID acknowledges that services and sectors will need systemic and localised support to achieve a balance between enabling risk and maintaining duty of care to prevent circumstances of abuse, violence, neglect and exploitation. CID promotes high expectations for risk enablement, noting with the right mitigation strategies in place, people with intellectual disability can maintain the dignity to risk without experiencing safeguarding as a restriction on human rights.

*Supported decision making means someone with disability can make their own decisions but getting support while doing it and being in control.*

Ricky Kremer, CID Project Worker with lived experience

### **5.3 Defined Representative Decision-Making framework**

CID acknowledges that in some circumstances, a small number of people may require decision making support in the form of substitute decision making. This is sometimes called 'fully supported' decision making. It involves another person interpreting the person's wishes and determining the decision to be made. In this case, CID uses the term 'Representative Decision Making' and emphasises that:

1. alternatives to Representative Decision Making must first be considered before resorting to this practice
2. evidence of a Supported Decision-Making approach implemented with integrity must be expected and moderated
3. in circumstances where Representative Decision Making is used the process must
  - be led by will and preferences of the person the best they can be ascertained
  - uphold the person's rights if their will and preferences cannot be ascertained or would result in undue risk or harm

- follow the least restrictive path
- include regular review of the requirement for Representative Decision Making
- remain decision specific.

## 6. Interagency collaboration to advance practice development

CID leads advocacy relationally, building trust and confidence. We aim to share resources and information that will lead to broader impact and sustained social change. This has resulted in strategic partnerships that lead to opportunities to progress advocacy in a way that demonstrates cohesion and collaboration between governments and community groups.

Through this strategic engagement, CID has produced a list of actions that could be taken by the guardianship divisions within civil and administrative tribunals to enhance the practice development of Supported Decision Making even in the absence of guardianship law reform. These include:

- requiring substantial information about attempts to support a person to make their own decisions about relevant issues to be included in any application form
- requiring tribunal staff to work with applicants to do more before setting a hearing date
- requiring tribunal staff to talk to the person more actively about supported decision making and link people to with community advocates where appropriate
- requiring tribunal staff to take action to identify an independent, trusted person who will help the person with disability to look at the paperwork and form and express their views to the tribunal
- removing separate representatives as the default option: great efforts should first be made to support a person to give instructions

- requiring a separate representative to consider and comment on whether they should apply to have their role changed to direct representation
- training tribunal members to develop skills to consider whether more could be done to support a person's decision making or need for community assistance, before making orders.

## 7. Workforce capability improvements across sectors

Workforces across sectors need to be explicitly trained in human rights frameworks and supported decision-making practices that nurture self-determination across a lifespan.

With the advancement of disability advocacy, research, and policies that reflect raised expectations for individuals with intellectual disability, existing professional development and training must be retooled to reflect the workforce practices that we want to see across sectors.

Pre-service and in-service teacher education training must be centred around human rights, self-determination, inclusive education, integrated and competitive paid work, supported decision making and supported community living.

There is need for workforces in legal, health, banking and other sectors and fields to be trained on the same human rights concepts, self-determination and supported decision making for them to know and understand how they can best play their role in delivering an inclusive community.

The critical improvement required is the need for all supporters - family, friends, direct workers, professionals and organisations - to be operating from the same belief system. This would involve the use of consistent supportive practices, guided by overarching legislation and policy that reflect the same rights-based principles at national, state and local organisation levels.

*What's important is for people with disability to have their own freedom to choose what they want to do*

Ricky Kremer, CID Project Worker with lived experience

## 8. Recommendations

The Disability Royal Commission should consider the following recommendations to Government in its report.

1. People with intellectual disability should be supported to lead and influence the systemic advocacy that strives for better outcomes in their own lives. Support should mean the creation of advisory and other decision making opportunities, employment, consultation and co-production as well as individualised inclusive practice.
2. The NSW Government should respond to the 2018 NSW Law Reform Commission report recommendations to progress guardianship law reform in NSW, in consultation with people with intellectual disability.
3. The concept of decision making capability should be promoted in place of capacity assessment. Decision making capability asserts that everyone can make decisions: people must be involved in their own decision making and this can include the supports and adjustments they want and need.
4. Commonwealth and State governments should introduce a model of Supported Decision Making that is drawn from the principles outlined by the Australian Law Reform Commission and enhanced by the perspectives of people with intellectual disability. The four principles embedded in CID's SDM framework that will drive advocacy and project implementation, include:
  - Everyone has decision making capability
  - Everyone must get the support they need
  - Will and preferences must be respected
  - Enable risk and balance duty of care.
5. Commonwealth and State policy and laws should be reformed to introduce a new framework that embeds supported decision making in the day-to-day practice of government and non-government agencies.
6. A new framework should include strategies on
  - the inclusion of people with complex communication and support needs



- supporting people who do not have anyone suitable or available to support them with decisions
  - culturally appropriate support, including that determined by First Peoples
  - advice, education and training that reaches across sectors
  - evaluation and learning from practice and review.
7. Communities should be encouraged and supported around their duty to accommodate people with intellectual disability by way of reasonable adjustment.
8. State education departments should take action to:
- ensure the pre-service and in-service teachers receive the training and education they require on rights-based practices that nurture the development of decision making skills in young people with disability from an early age
  - contribute to the development of post-school transition systems that include the embedding of Supported Decision Making practices during transition from school to employment, higher education and the community.
9. Higher education institutions should develop further coursework that promotes information, education and training on human rights frameworks, self-determination and supported decision making, post-school transition pathways and practices and community inclusive practices. This coursework should be co-produced and co-delivered by people with lived experience.
10. The National Disability Insurance Agency and NDIS Quality and Safeguards Commission should lead in the promotion and upholding of best practice in supported decision making through:
- appropriately resourced plans
  - practice standards that uphold the rights of people with disability
  - ongoing professional development on evidence-based practices
  - ongoing accountability through quality standards
  - ongoing co-production with people with lived experience of disability.

## Citations

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