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## **Submission (2) to Australian Law Reform Commission Equality, Capacity and Disability in Commonwealth Laws**

### **Background**

The NSW Council for Intellectual Disability is a systemic advocacy and information agency. It is the peak body representing people with intellectual disability in NSW. The lived experiences of people who have intellectual disability have primacy in the organisation's ability to legitimately speak in partnership, and on behalf of people with intellectual disability in this state, and on matters affecting people throughout Australia.

With a governing structure that incorporates a majority of people with intellectual disability on the NSW CID Board, who are also very active in the roles of policy and community education, we have the benefit of expert witnesses influencing all our work.

The Speak Out Reach Out subcommittee (SORO), is comprised entirely of people with intellectual disability, and is supported to investigate issues from their own lives and of those from further afield. Their work focuses on NSW CID advocacy priorities as well as interests brought to the table during regular meetings.

Many conversations around the table, as well as focussed, extended work on research, policy submissions, and in community consultation, reveal a greatly engaged and engaging, thoughtful, insightful, compassionate, humorous and diverse population. What we learn from our Members' stories and attitudes, we see reflected time and time again in our wider consultation work.

There are several major themes that always arise somewhere in this work:

- The desire to be seen, to be treated, and to *feel* like a sentient, credible, powerful people rather than dependent, incapable, and undeserving of successfully 'ordinary' lives;

- The yearning for a variety of meaningful, mutually supportive relationships. Relationships interact with self-determination for us all, but have special dominion in the lives of people with intellectual disability.
- The lack of connection with society's fast-paced and largely inaccessible information stream, which would normally empower people without intellectual disability to make choices and changes to their personal circumstances;
- Ongoing, skilful support to develop technical/practical aspects of day-to-day-living, with a view to gain independence, or to *share responsibility* for day-to-day living.

This submission will address broadly the idea of the right to make decisions of one's own that set the course for the day or indeed of one's life. It will also address what we believe should be contained in legislation to protect the process of *developing* capacity for self-determination, with an emphasis on the features of supportive decision-making relationships, as communicated by people with intellectual disability themselves.

### **Legal capacity**

Legal capacity has a technical sense, but it originates in having the confidence in yourself and from others, that you need in order to be able to set your own direction with or without the assistance of others.

Many people have lived lives devoid of opportunities to develop and strengthen their decision-making identity and skills. It is not uncommon for people to be embedded in a loving and protective family who do their utmost to shield their family member from difficulties and harm, and consequently can unintentionally restrict some aspects of human growth. Others are embedded in a heavily risk-averse and resource-deficient environment in supported accommodation services. Still others have developed distrust and resistance to support for decisions (interpreted rightly or wrongly as interference and control) and all the details that follow, because of previous negative experiences of personal and systemic abuse. This has very significant effects on motivation, processes and outcomes for individuals.

SORO wishes for themselves and for others, the opportunities such as those described below:

“People can still make their decisions as good as people without intellectual disability. We believe we must empower ourselves about what we would like to happen in our lives, to grow up in the world and to do good things. For example, I did not like working in a sheltered workshop. I say to myself, I have enough knowledge, now it is time to brighten myself up. I have had the opportunity to go into open employment, to see the sky, to open my

knowledge of what I need to know in my life to be able to have a job. I will have motivation to go to work, without someone looking over my shoulder all the time. People can rely on me and trust me to do my daily task” (A SORO member, living independently - SORO report to NSW CID AGM 2013).

At a recent SORO forum, a person with intellectual disability who lives in an institution said that it was “too much trouble” making even a relatively insignificant decision. Making and carrying out decisions revolves around external factors that were seen as insurmountable, such as conflict arising from other residents’ wants and needs, and staffing timetables ( “Able to decide” - forum for people with intellectual disability, 31 October 2013).

Still others felt under pressure to please family, friends, and authority figures, so are quiet or revoke their decisions in order to “keep the peace”. “People think my decision is wrong and try to change it”. In some peer examination of this situation, it was suggested that perhaps people around the person can see that they have not explored enough options. Other people said they don’t have people to “talk things through with”.

At a consultation about the review of the NSW Disability Services Act in 2013, NSW CID heard comments from a participant about his struggles with his finances. The primary reason he felt he was not “learning from my mistakes (with money)” was that he would forget he had made the mistakes, and forget the consequences of those mistakes. His telling of his situation revealed impressive insight into his dilemma, a factor which may help exempt him from being placed under financial guardianship should he have the wherewithal during assessment pressure to remember it.

His situation begs the provision of support strategies that would consolidate his learning, provide practical strategies to support memory and tailor careful management processes. Some unobtrusive back-up would not go astray. It is isolation, damaged self-esteem and lack of access to trusted and skilled supporters that may lead to serious money problems, rather than total incapacity in decisions about finances.

### **The Law**

In discussing the assessment and removal of a person’s right to make legal decisions, (legal incapacity), SORO were very concerned about the processes leading to this. They said that the Law must state and protect a process that invests lengthy time and resources into developing and enhancing a person’s abilities to address the issues that have brought their capacity under the microscope. This process must be enacted *before* a final assessment of capacity, and then subsequent appointment of a substitute decision maker if needed.

“You must support and train people to grow their skills to do it confidently. Then assess if they can do it.”

They were not content to leave the consequences of a legal capacity assessment entirely to the authorities. A more collaborative approach was preferred:

“Then *negotiate* the next step (with the person). Make the decision together. Working together. Working out another solution.” This step continues to uphold the human rights approach by leaving open the provision of the least restrictive alternative to a substitute decision-maker.

SORO were anxious that a capacity bias, rather than an incapacity bias, be dominant, and that if they were in the situation they would “need the opportunity to show myself, prove myself.”

These provisions appear to lead to, in effect, a version of supported decision-making which would delay and quite probably negate the need for the appointment of a substitute decision-maker in many cases, and fulfilling article 12.

Furthermore, SORO said that

“You should get *any support you need (access to whatever service you require)*” that would help you to avoid being put under guardianship. One member cited the example of the types of support that can be provided under the Community Justice Program in NSW, which aims to address the individual factors which have led to incarceration of persons with intellectual disability in the past, and therefore breaking the cycle of repeated law-breaking behaviour and loss of liberty.

In applying a legal capacity assessment process, SORO were adamant that the law must recognise that:

“Every situation is different, every person is different”, therefore a blanket, inflexible process that assesses in only one way, is not appropriate. The person’s situation must be “handled sensitively. They should look at the whole story, not half.”

The assessment should include opportunities for assessors to see you in real life situations, “watch how you do it”, and in context, “in with other people”. A person should also have access to an advocate.

There was agreement that the concept and language of ‘assessment’ could actually impact negatively on attitudes and performance, as they are associated with experiences of being labelled as deficient and have often resulted in profound life course change. “You could clam up!”.

In the event that you are having a bad day for whatever reason, the law should allow the opportunity to “postpone until you are feeling better”.

If a person was declared to have legal incapacity, and appointed a guardian, SORO said that the law should state that “You should be asked about who can be your guardian”. They expressed shock and disbelief at the difference between the process of selecting someone to have power of attorney, versus the Tribunal’s appointment of their choice of legal guardian.

“You must have a chance to say what you want!”

“They need to explain why you need a substitute decision-maker”.

SORO said that all communication about this must be in ways that suit the person involved, so at the very least the use of appropriate language (non-legal, non-jargon) is essential. They were also concerned that there is an extra barrier to accurate assessment for people who require an interpreter, especially one who is unfamiliar with the often unique aspects of an individual’s communication. This is relevant across all life scenarios where informed decisions for self-direction are needed.

They went on to say that the law must provide for a person to challenge the decision both to appoint a guardian, and also to challenge who is appointed.

### **Family, carers and support people**

SORO and NSW CID have looked into how support relationships can work effectively in the eyes of the person with intellectual disability. Much of what people recommend requires a flexible approach which adapts to the individual and their potential as well as actual developing capacity, and responds positively to the subtleties of changing power dynamics.

People said in supported decision-making, indeed any type of training, “They take the lead, and then you step up to lead”.

Factors such as “how you were brought up” can affect whether training in decision-making will be effective, and indeed, who may be the most appropriate person to be in a supporting role.

“We want to grow and get strong. We want to be nourished and challenged from time to time. Like changes. Like mistakes. If we are not, we get used to our comfort zone. We can’t mature” (SORO member presentation to “Able to decide” forum).

Throughout our work on the Productivity Commission Inquiry into the Care and Support of People with Disability, and in further consultations across the state, it is abundantly clear that negotiating through the power dynamics in any relationship as a key challenge for people with intellectual disability.

People are very sensitive to the attitudes and beliefs of those supporting them.

“To make decisions, they want people who they trust to support them. They want them to be able to be really positive about their abilities and decisions. To be able to make suggestions that they might not have thought of.” (SORO report to NSW CID AGM 2013)

Supports are urged not to “give up on you” and “not to “take over”.

“It’s important for anyone to have a go, even if they can’t at least they *had a go*. And the advocate can help that person.....if the person can’t do it, it means they’ve had a go, they should not feel a failure. All they’ve got to do is “OK, let’s try it another way, and work out...I’ll do half of it, and you do half of it. And we can work, do it together”. (Robert Strike, “Speak Out Reach Out DVD presentation on self managed support packages, 2012”)

These points strongly suggest support for an ongoing capacity development framework in decision-making, incorporating a focus on both self-development and also the skills and attitudes of those in relationships with people with intellectual disability. This is in preference to a limiting, black-and-white interpretation of legal capacity that does not also address the strengthening of personal and social capacities.

Thank you for the opportunity to participate in this submission process.

Regards

The Speak Out Reach Out Committee and staff of NSW Council for Intellectual Disability.  
January 2014