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**Implementing Article 12 Now!
By Christina Ryan**

Self-determination has a wide range of benefits and is a key safeguard for all people. Yet supporting the will and preferences of people with cognitive and communication impairments is a relatively new and contentious field of practice. Debate continues over whether a full shift away from a best interests approach is even possible.

Advocacy for Inclusion supports people with disabilities to make decisions about their own lives, and to articulate their will and preferences, as outlined in Article 12 of the [Convention on the Rights of Persons with Disabilities](#) (the CRPD).

In addition to our frontline practice, Advocacy for Inclusion has participated in the Australian Law Reform Commission [Inquiry](#) into equality before the law by sitting on the Inquiry's advisory group, and more recently we provided substantial advice and support to the ACT Law Reform Advisory Committee's [inquiry](#) into the ACT Guardianship Act. We succeeded in having this review undertaken after many many years of lobbying.

The majority of our consumers, members and self-advocates are highly marginalised and isolated people with disabilities. Most have cognitive disabilities and/or significant communication barriers. Close to 100 per cent are NDIS recipients.

We use a systems approach to transition people with disabilities and their support networks to the new "will and preferences" landscape and we are confident that it is not only possible to implement Article 12 now, but that the biggest barrier to success is attitudes rather than the decision making ability of the people with disabilities that we work with.

We work in a multifaceted way across our entire organisation through:

1. Individual Self-advocacy skill building via our Self-advocacy program and support to use the world's first [supported decision-making App](#). This simple app takes the user through a decision making process to make their own decision. It can be used independently or with a decision supporter. It also recognises that there may be a guardian involved for some domains.
2. We use access to Individual Advocacy support to address service and social barriers. We use a will and preferences model of advocacy so that we are only working with the express consent of the consumer, and in accordance with their directions. Our work is human rights based which means we do not operate without the knowledge of the person or an understanding of their desired outcome. Our consumers consistently report to independent auditors that they know their rights are our first consideration.
3. As a systemic advocacy organisation we lift the voice of our consumers, members and self-advocates to the systemic level. Recently Advocacy for Inclusion officially became a Disabled People's Organisation, despite operating this way for some years. We did this to make a clear statement that the voice and rights of people with disabilities are central to our work, and that our work is undertaken by the people who we represent. We are a representative organisation which does advocacy. Without this level of commitment by advocacy organisations we believe that people with disabilities will never achieve equality and self-determination. Our systemic

advocacy has included significant research projects including our landmark report [“Ask me. I make my own decisions”](#) which examined the experience of control and choice in highly marginalised people.

4. We have also developed Supporting Self-advocacy skill building for carers and service providers, to improve the ongoing self-advocacy of disabled people. Its one thing to make a decision, but it won't go far unless the person is also able to self-advocate that decision. Some years ago we recognised that there was little point in self-advocacy skill building if the people around a person with disability didn't continue to support those self-advocacy skills in daily practice. So, we developed Supporting Self-advocacy training.
5. We see self-determination as a combination of decision making and self-advocacy. The go hand in hand and are unable to operate independent of each other.

So, this multifaceted approach to our frontline work has placed us in the unique position of observing the decision making abilities of many people with disabilities.

We've made a few observations, but first I'd like to say something:

This is a bucket. It has a 10 litre capacity. Capacity is appropriate for buckets, but not for people. People are neurodiverse and everyone thinks and responds a bit differently to everyone else. When referring to people we think in terms of decision making ability, or even just that they are neurodiverse and operate in their own way. The recent report from the ACT Law Reform Advisory Committee recommends that we get rid of the term capacity as it simply doesn't work in law and causes confusion.

As frontline advocates we have never worked with someone who is not able to express their will and preferences to us. Sure there are people who need more support than others to work through their preferences and desired outcome/s, but not a single person has failed to indicate to us what they would prefer and whether they are comfortable with something.

When undertaking research for our Ask Me report we also discovered that nobody bothers asking people with disabilities what they actually want. People with disabilities are assumed to be unable to understand or be involved in discussions and information sharing, so others just express decisions for them. In fact, for the Ask Me study we were told that some people would not be able to communicate with us, even though we had a history of communicating with them and they had agreed to participate in the research.

This is indicative of the level of interference experienced by neurodiverse people and those with significant communication barriers. It is an active and ever present wall between them and their right to make their own decisions. In the end we named the report Ask Me, because this is what our research participants kept saying. They knew whether they wanted to have a cup of tea now, they knew what colour tshirt they wanted to wear today, they knew whether they preferred one support worker over another, they knew whether they felt safe or not, and they certainly knew who they wanted to live with. They were able to provide us with consistent responses over time about many aspects of their lives, yet the majority were not afforded the respect of being allowed to make their day to day decisions, far less their major life decisions.

Over many years we have also observed a highly inconsistent application of substitute decision making or guardianship. It appears that there is some kind of lottery as to whether or not someone is subjected to a substitute decision making order. It depends almost entirely on whether other people decide one is needed, rather than on whether the person is “unable” to make their own decisions. In our experience, unfortunately, many service

providers and lawyers insist on an order to assist their organisational bureaucracy to be easier and faster.

It is quite possible to acquire the skills to communicate with anyone, providing you have a commitment to do so, understand that they are equal to you by respecting their neurodiversity, and give them the necessary time to communicate in the way that best suits them.

Of the many many people we have worked with there has been no consistency as to who has an order and who does not. It does not seem to bear any relationship to their actual decision making ability, or their diagnosed disability. Rather it seems to be based on who they encounter and what level of prejudice about their decision making arises from that encounter, and then it's the luck of the draw. For one person a guardianship order is sought, for another similarly neurodiverse person an order is never considered. Sometimes it's their communication barrier and the lack of preparedness to understand their particular accent or support them to communicate effectively.

We have not been able to ascertain any consistency about who ends up with orders, but it is clear that once someone with cognitive disability comes to the attention of the Tribunal it is more than likely that they will end up with some form of guardianship. That is simply how the law currently stands.

Difficult question:

Is it the case that we have constructed such a large industry around notions of "capacity" and the imposition of substitute decision making regimes that we have a vested interest in seeing this industry continue? There is a huge amount invested in medical, academic, and legal systems around "capacity" with many people working their entire careers researching, policing or assessing it.

Yet, at the frontline we fail to see the need for such an investment, rather we see a desperate need for decision making support, for training across community, legal, academic, medical and government systems, and for law reform to recognise that support is legitimate.

What would happen if we invested the same level of time, resources, research and money to supporting decision making? Its time to see decision making support as an everyday matter, like cleaning teeth or catching a bus?

Is the greatest barrier to implementing Article 12 really just our own prejudice and vested interest?

Imagine if there was a strong level of decision support available today, equivalent to the current level of resources applied to imposing, researching, and reviewing substitute decision making?

We would potentially see a huge reduction in case load across a wide range of areas such as:

- The numbers of people with disabilities in Australia's prisons.
- People being unhappy about their disability supports including who they live with.
- The number of parents with disabilities in the child protection system.
- The work of Civil and Administrative Tribunals.
- The work of complaints handling bodies like Human Rights Commissions and advocacy organisations.
- Etc.

This would take us a long way towards implementing article 12 now, but it's going to take courage from many of us, and the willingness to flip an entire culture built over several centuries.

Are you up for the challenge?

Are you up for equality with people with disabilities?

Thank you