Submission to the NDIA on the Consultation Paper: Supporting you to make your own decisions

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Overview

Family Advocacy aims to advance and protect the rights and interests of people with developmental disability[1] (hereinafter disability) so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. We do this by building the capacity of the family by providing advice and support so they can advocate with or on behalf of their family member with developmental disability.

Family Advocacy was founded by and continues to be governed by families that support a person with disability in their lives. We also have an initiative called Resourcing Inclusive Communities, which aims to assist people with disability, their families and the broader community to develop skills and confidence so that they can support the person with a

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[1] Developmental disability is a disability that occurs in the developmental period of a person’s life (in the period from conception to adulthood) and includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida, and any combination of physical, intellectual or sensory disability.

disability to have more choice and control over decisions and supports that facilitate individualised and normative lifestyles.

In this way, we believe our purview lies in alignment with the overall objectives of the NDIS, with a similar aim to provide transformational benefits to the lives of people with disability. Putting the person with disability at the centre of the decision making with regard to arrangements and supports is a critical component of this.

Family Advocacy appreciates the opportunity to provide input to the NDIA on its Consultation Paper on Supporting you to make your own decisions. This submission is shaped by the accumulated knowledge of families' experience that spans 30 years in advocating for supports, enhanced policies and practices that value the lives of people with disability, as well as the foundational work in utilising the theory and practice of Social Role Valorization in the much of the work we undertake. This notion of socially valued roles and its impact ties in to the concerns and caveats we express in regards to the NDIA progressing and implementing the proposed Supported Decision Making (SDM) Policy.

Our main concerns

For the most part, we support the vision, key principles and goals of the Supported Decision making Framework and Policy. Everyone has a right to participate in decisions about their own lives. Australia, as a signatory to the UNCRPD, has an obligation to ensure this happens for everyone with a disability too (including those with developmental disability). But we do have some concerns and caveats, which are outlined below. Whatever SDM Policy is adopted, it must have integrity, moral coherence, and provide adequate safeguards to reduce the vulnerabilities of people with disability. In moving from SDM policy to practice, it will be crucial for the NDIA to remain faithful to its original intention.

The limitations of valuing choice and individualisation over interdependence

The word choice has come into fashionable use in services and politics but deserves more thought to question the way it is being used. In recent decades, with the promotion of consumerism and individualism, the notion of exercising choice has obtained ascendency over many other long held and important qualities for citizens to exercise. The exercise of "choice" is often seen as more important than the content or quality of the choice. The illusion of autonomy can easily be met by the action of choosing, irrespective of its impact (Armstrong, 2007).[2] Many people with disability are merely offered service options to choose from: which day program or group home would you like to attend; a kind of pseudo choice into service bondage operating in an otherwise vacuum of choice.[3]

Thus, the exaggerated emphasis given to choice making is almost wholly driven by ideology rather than a considered examination of its likely result. Devalued people who are given choices sometimes take an option which is not socially valued. And many supporters may be afraid of imposing their values on someone else rather than give feedback. For example, in the case of a supporter, paid or unpaid, allowing an adult to dress as they like, regardless of social mores, or what is culturally appropriate and valued such as wearing clothes that are much older or much younger for their same aged peers. The poor imagery associated will mean that with the person with disability can be perceived as childish, dependent and incompetent, factors which lead to devaluation.

In this way, there are limitations on concentrating exclusively on individualisation and self-determination, highlighting the crucial role of interdependence and relationships, knowing someone well and working together to make a decision that best suits their preferences. Further to this, a certain level of obligation should be felt by the 'supporters' in relation to guiding and supporting a person with disability that may need sound advice if their image in the eyes of others is at risk. Important decisions are hardly ever made by any of us in a social vacuum but in consultation with those who share in our lives most closely. This is especially the case for people with severe to profound intellectual disability.[4] Certainly, for many people with disability, there is a greater risk due to the many societal negative assumptions held about this group.

People with disabilities often miss the crucial developmental experience of receiving "feedback". We recommend the SDM Policy acknowledges the value of strong and trusting social connection/ the right relationships to allows for the scenario whereby the decision supporter will not simply "provide choices" but also mentoring, feedback, guidance and role modelling in order to provide the best chance for the person with disability to be seen with positive imagery. In this way, they are providing the platform to develop both in choice

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[2] John Armstrong, *Making the Most of Autonomy and Choice*, Crucial Times, June 2007

[3] John Armstrong, *Thinking about decision making,* Belonging Matters – Thinking about…Decision Making, Issue 16, August 2013

[4] Jo Watson, *Listening to those rarely heard: Supporting people with severe to profound intellectual disability to participate in decisions about their lives,* Belonging Matters – Thinking about…Decision Making, Issue 16, August 2013

making ability and age appropriateness. For example, saying a decision supporter could say "people might think you're not an adult if you go out looking like that and how would that make you feel?". This approach can allow the opportunity to share the connection between the act of choosing and its consequence and the person considering how they would like to be perceived.

Choice and placing too much weight on "consequence" as a potent learning strategy

There are a number of factors that are relevant for a person to understand the potency of consequence as a learning strategy, and factors that a person with developmental disability may not possess. For example:

- **Having knowledge versus believing knowledge** – a range of social problems are couched in terms of awareness: 'With proper information, people will be informed and become responsible'. But there is often a gap between knowledge and belief. For example, after learning the negative outcomes of smoking, few smokers believe these consequences will actually occur for them.[5]
- **The delayed development of the forebrain** – until the forebrain develops by the mid-20s, a young person finds it difficult to predict the consequences of their own decisions. For example, binge drinking, reckless driving, staying up all night, being wrongly dressed for certain types of weather.
- **The ability to delay gratification** – real satisfaction comes from fulfilling a deeper purpose which almost always involves sacrificing cravings, comfort and wants. Often, when shopping a person can succumb to the desire to have something now versus the long term pain of endless payments with money one does not have.
- **The affect transfer of the amygdala** – the amygdala is a major controlling structure for emotion and motivation, forming part of the brains limbic system, and conveys such feelings as euphoria and pleasure. Even the anticipation of a sought after event can activate the limbic systematic. Advertising uses a technique called "affect transfer" which is powerful, where our emotions/desire is linked to a product and used to encourage people to purchase the product, For example, the McDonalds Happy Meal associates the emotion of happiness to a linked menu choice.
- **Consequences can be denied** – the power of desire can overcome rational thought. For example, people know that not exercising and eating fatty foods increases weight

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[5] Elliot, Dr. 2002 "Stop Smoking Program", *Today's Chiropractic*, September 03, 2002

but may continue to do so. Calculated risks can be unconsciously distorted to satisfy the urge for instant gratification. Such as the desire to go shopping overcomes the conscious knowledge we cannot afford to pay for the products.

These 5 factors affect us all including people with a developmental disability, in terms of diminishing the impact of using consequence as a learning strategy. The dilemma for a person with a cognitive disability is that they may not connect an event and its consequence (cause and effect) especially if there is some distance in time and space from its consequence. For example, a fine, or being sent to court or jail. There may be an inability to predict the consequence. For example, obtaining Netflix will bring expensive monthly bills later in time.

An added dilemma is the social situation where through their isolation, people agree to many things they do not understand as a means of seeking approval such as signing a contract or service agreement.[6]

Many support workers of people with disabilities still believe that just permitting people to experience the consequences of actions will teach and modify the behaviour of the people. However, the danger here is that experiencing natural consequences as a useful learning strategy without extensive advice and guidance and even role modelling, results in their decisions being left to receive the full brunt of a disapproving society. For example, allowing a person without advice or guidance to wear clothing that is not culturally appropriate for their age group or the occasion can lead to that person being judged as “childlike” or othered. Another example is allowing a person to eat whatever and whenever they like even if they have health issues. Certainly, these choices can be made by the person, however, the focus ought to be on supporting the person to deepen their learning around the consequences of this.

Choice and the dignity of risk

Another perversion in learning strategy is the misuse of the dignity of risk. When it comes to making choices for a person with a cognitive impairment, safeguarding is necessary. It is important to weigh up in what way can the person with disability be involved in a respectful

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[6] Wolfensberger, W. (2004) TIPS, August

way without taking over or overstepping whilst allowing for the dignity of risk where this is properly considered[7].

The dignity of risk is very conditional. It assumes that people will learn and grow from experiencing the consequences of their choices, positive or negative. And this risk “is taken only to the level at which we can predict that a person can cope, without endangering themselves or others and/or losing their ’dignity’. There is little dignity in repeated failure and punishment for things one cannot connect”,[8] or know why these awful things are happening.

In the real world, learning that our actions and decisions have consequences can be exciting but it can also be painful. For example, a young child that touches a hot stove and feels its sting. As young children, our parents would guide us in a graduated way to match our experience to our capacity to predict and respond to the consequences of our actions. And to avoid serious danger such as being run over by a car, our parents would sometimes say ‘no’. But through this process, we became responsible adults, able to understand the value of delayed gratification (for the most part), adaptive in our interactions and relationships, and capable of extended periods of work and effort.

It is fair to say, people who are devalued members of our community such as people with disability, have rarely had this kind of graduated individual tutelage, particularly if the person has a cognitive disability. It is not uncommon for them to have been “done to” by the formal and informal supports in all aspects of their life.

Some people with developmental disabilities have not had this individual tutelage or exposure to positive or negative learning experiences. It is about time they did, however, and this needs to be a considered approach.

Choice and the promotion of assertiveness

Learning about and understanding one’s rights is important, especially for a devalued person as often these are not naturally attained. But there is a danger here where the opportunity for empowerment or self-advocacy, is not matched with the capacity needed to realise those rights and balance them out in and amongst other rights that exist and this can have detrimental effects. Such approaches can cause an adversarial attitude or an obsession with

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[7] John Armstrong, *The Potential Use and Misuse of Natural Consequences, What makes us really sit up and notice?,* Community Resource Unit Inc. Occasional Paper No.2 May 2005
[8] Ibid.

rights and entitlements, rather than encouraging a person to become openly friendly or unselfish or place community above individual needs: qualities that are much more endearing to others and ones broader acceptance.[9] This can create further wounding and a lost opportunity for developing real capacity and successful relationships.

Informed choice needs opportunity and capacity

Society typically values a person that has the capacity to foresee consequences well into the future and take appropriate pre-emptive action. This is seen as wisdom. When wisdom is combined with good conduct, this leads to mastery of the self and self-restraint. A devalued person requires a concerted effort to be assisted to progress these concepts. Without it, people with disability are being given the opportunity to make choices without the investment in capacity. To do so, is neglectful, and a true expression of devaluation as when supporters fail to respond to the misery that poor decision making creates in people's lives.

Choice, when carefully considered, requires opportunity and capacity where each is dependent on the other for beneficial life outcomes. If one fails, so does the other. A lack of opportunity has pervasive long term impacts such as lack of confidence, competence, fear of the unknown, little knowledge of the broader culture, continued dependency on others, fear of failure and insecurity. Without opportunity, one cannot develop capacity.

A lack of capacity refers to the inability or difficulty to perceive the true nature of the options and accurately predict the consequences of one selection over another. The cause and effect distinction is not always appreciated or understood, especially where there are abstract concepts such as time and space involved. This can lead to faulty problem solving and judgement.

Opportunity without capacity building often leads people to either select what they have always chosen, select what make others happy or select the last option offered. This can produce an illusion of choice making that many observers are fooled by, but this, unfortunately, keeps people locked into a very narrow range of experience. Further to this, if choices have been limited within someone's life, the broader knowledge of options cannot be accessed.

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[9] John Armstrong, *Making the Most of Autonomy and Choice*, Crucial Times, June 2007

One important trait when looking at capacity is responsibility for the implications of one's decisions, positive or negative. Responsibility suggests a person is mature, has purpose and self-discipline, as they can make the choice to do such things as delay gratification and have self-control. For example, the decision to control the urge to eat junk food so that the long lasting benefit of good health continues.

When these qualities are missing, which can often be the case for people with developmental disability, falling for the illusion of choice is tantamount to abandoning people and conveniently blaming them for the results they produce, often with the mistaken assumption that the "consequences will teach them" (as discussed).

The most important skills used in Supported Decision Making are actually values based qualities

Objectivity, care, concern, knowing the person really well, having a good relationship, respecting a person's right to make decisions, respecting and honouring all forms of communication. These qualities can best be described as a duty of care; the concept that genuine care and concern is the willingness to assist people see things they may not realise are there; a requirement to act with good intention towards those in our care. In respect of the SDM Policy, we believe a decision supporter has a "duty of care" to ensure people with disability receive the same type of opportunity *and* investment in capacity to make good choices and decisions. One without the others should be seen as neglect.

One example of the value of having these qualities or the right relationships in supported decision making is the scenario where a man who would not let anyone into his house as he would get very upset if anyone sat on the couch or touched the cups in the kitchen etc. Staff would often end up sitting in the car outside of the house until the man had calmed down and he could call them if he needed them. This was also the case when family wanted to visit. This was a learned response for various reasons, which continued for 12 years.

One day, a new support worker arrived, who respectfully took the time to get to know the man deeply and understand why this was happening. He discovered the man thought all of his stuff was going to be stolen and he was bothered that he had no privacy. The support worker taught the man that he could have total privacy and make his own decision in his bedroom, but that the common area was for all of the rest of us to share and make decisions about together and reassured him that all of his stuff would be safe. Once he accepted this different way of thinking about his space, this behaviour disappeared and he was able to let family and staff enter the common areas of his house and even touch things. This shows the importance of right relationship and taking the time to get to know the person, their passions, interests, motivations and dislikes and importantly, not react as a supporter on mere choice as a means to support the person well.

The power and safety of personal relationships

Quote from 2 parents:

"Input from people associated with the person at a frequent level, both family and ancillary, should be taken into account."

"…no one else knows better about the participant than the family."

When anyone offers support to a person with a disability in the context of decision making, there must be a concern about safeguards to make sure the supporter acts appropriately. It must be understood that the support arrangement includes a commitment by the person offering the support to act to promote the autonomy, the dignity, and the interests of the person being supported. In effect, the decision supporter acts in good faith to make all reasonable efforts to assist in achieving the outcomes that best combine the person with disability's wishes, personal security and wellbeing within the range of possible choices and outcomes.[10]

The families' experiences we hear highlight the importance of the NDIA recognising that the family is the natural authority for their family member and they are best placed to be the decision supporter for a significant cohort of people with developmental disability.[11] Families ought to be recognised as having credibility and experience in understanding the impact of their family member's disability has on their everyday life, as well as the most optimal support arrangements, the ability to challenge stereotypes, and provide the proper decision making assistance which place the person with the disability in the "driver's seat". Indeed,

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[10] Orville Endicott, *Inclusion in Decision Making,* Belonging Matters – Thinking about…Decision Making, Issue 16, August 2013
[11] https://www.family-advocacy.com/assets/Uploads/Downloadables/453f2744d5/10753-The-Natural-Authority-of-Families-MKendrick-CT06.pdf

the acknowledgement and respect of the role of family in the lives of people with disability is one of the general principles listed to guide the actions of the NDIA.

In regards to a person with developmental disability, it is most important to have a family member involved and present in any meeting with supported decision making, as in many cases, a tremendous amount of support will be needed in a delicate and respectful way.[12]

In the common scenario where the service sector dominates the life of a person with disability, it is important to arm the family member in order that they may be able to rebalance the power dynamic. Also, other informal effective decision support structures such as circles of support and microboards are more often than not, set up by the family.

Informed choice assumes you have had the opportunity to practice choice making over time. This starts with families and young children. Did we have the chance as a youngster to make small choices and then with practice expand the choices you were allowed to make? With time, you are making greater and more complex choices. You cannot assume people can make major choices after years of making no choices at all. People need practice, coaching and opportunity.[13] And so do the families that support them to do so.

Accordingly, it is vital that the NDIA focuses on capacity building with families, their duty of care and that they be supported to be aware of any potential conflicts of interest. Investment in families forms a critical component to this, as often families are told by professionals that their child has no or limited decision making skills and hence may potentially not be geared towards gradual choice as the child develops. This can be overcome by capacity building.

Communications and accessibility

Any communication should be in Easy Read English and be available to be translated into multiple languages, including Braille. The person with disability should have the option to choose their preferred form of communication and have their accessibility needs taken into account.

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[12] We do acknowledge the view that in some cases, the family can be the cause of neglect, abuse, violence and exploitation and make decisions which are in their own interests rather than what is in the best interests for the person with disability.

[13] Jeffrey I. Strully, *Authentic Choice: Myths, Excuses and a Deepening Understanding of Choice*, Belonging Matters – Thinking about…Decision Making, Issue 16, August 2013

The NDIA culture and building trust

Unfortunately, from the experiences shared by our families, there appears to be a significant disconnect between policy and practice within the NDIA. In addition, the recent battle in relation to independent assessments has caused a great deal of mistrust for families with the NDIA. Significant consideration and thinking around the NDIA's approach will be required in order to address these trust issues when raising awareness and implementing the proposed SDM Policy. It would go a long way to building this trust if the implementation of the SDM Policy was done with integrity and moral coherency.

The need for independent advocacy

We must highlight the absolute necessity of advocacy in any new NDIS process, particularly in a post COVID-19 era. The introduction of the NDIS created significant change in the sector and for people with disability and as a result, the current problems resulted in a greater need for independent disability advocacy.

Our families have expressed shock that so much advocacy is required on their part. Families want to be heard in relation to these systemic issues, but are frustrated and exhausted, hence the need for independent advocacy's organisations.

On an individual level, our advocacy, representation and information has provided essential supports to enable people with disability (and their family representative) to fully participate in the NDIS and to be included in the community. At a systems level, this consultation is one of many where we, and other disability advocacy organisations, have provided submissions to State and Federal governments as well as directly to the National Disability Insurance Agency (NDIA).

Systemic advocacy can provide an alarm bell to warn where there are significant issues to enable the NDIA to respond to failures in the new SDM Framework process should it be implemented, prevent unnecessary cost, time wasting, and avoid problems before they blow up into preventable tragedies. Most importantly, it brings to the forefront the significant implications that current processes and practices are having directly on the people whom the system is there to support - the person with disability.

State and Federal Governments have a clear responsibility for ongoing funding to ensure that people with a disability will always be able to turn to local, independent advocate when they need them. Should the NDIA introduce the SDM Policy, they must also provide extra funding for independent advocacy in order to support people with disability to navigate this new system, to assist those who “fall through the cracks” and to feedback to the NDIA any unintended consequences that may follow.

Family Advocacy calls on the NDIA, to make a recommendation that Federal, State and Territory governments provide funding in perpetuity for disability advocacy, representation and information services for people with disability, and that a boost of funding be specifically injected to advocates to help inform and support participants with the SDM process.

Conclusion

This submission has illustrated that whilst SDM is an important right for people with disability need to exercise, significant safeguarding is necessary through natural relationships, usually through the family unit. Good decisions are made when people receive good support with a clear understanding around the nuances involved for a person with developmental disability.

People with disability need to be given not only the opportunity to make decisions but also the investment in their capacity to do so. The NDIA should support the capacity building of the person with disability and their decision supporter to understand the pitfalls around the illusion of choice, of placing too much weight on consequence as a learning strategy, with the dignity of risk.

The need for advocacy has never been greater. Family Advocacy wants the NDIS to be a success but independent advocacy funding is required in perpetuity to always be there as a safety net.

We hope the NDIA take notes of our concerns, is prepared to listen to the feedback from families and their family member with a disability regarding the direct impact and concerns with the current Supported Decision Masking policy and implement our recommendations.