

10th September 2021

Submission for the consultation paper "Support for Decision Making".

To whom it may concern

I am writing this submission to the NDIS Support for **Decision Making consultation** on behalf of the people and families that Community Living Project (CLP) support.

CLP has worked in close partnership with families since 1984 to build opportunities for a good life for their family member who is living with a disability. We believe people with disability should belong to and participate in community life. This means their interests are best served when they are supported to grow up in a family, go to their local school, participate in community activities with their peers, as adults - have a home of their own, maintain strong relationships with family and friends, work and participate in community life and have their rights as citizens protected.

People with disability are highly vulnerable to being excluded from ordinary community life. This happens through segregated experiences, which deprive people of opportunities to have the rich range of relationships and experiences that most people take for granted, and congregated activities that stifle opportunities for the individual to have meaningful choice and control and be included in everyday life.

CLP supports people with disabilities and their families to exercise meaningful choice and control through building family leadership, and also supporting each person to make decisions around who works with them and to self-direct their day-to-day support. Self-directed support is about helping the person to identify what's important to them when recruiting their workers. It's the person and their families who then manage their day-to-day support, with CLP as coaches and facilitators.

Building family leadership is essential in building a community in which everyone is valued. Traditional models of 'care' generally reflect an organisation's needs rather than the individual's needs. Family leadership requires a different mindset and moves towards inclusion and creating a real sense of purpose in people's lives. Family leadership safeguards vulnerable people for the future through locating the control where it belongs - with the person, their family and their informal network. Family leadership fits well into the context of the National Disability Insurance Scheme (NDIS) as it:

- strengthens opportunities to create more effective and sustainable support
- enables a focus on goals which are meaningful (eg working in a real job)
- enables people with disability to have greater choice and control over their support
- reflects the NDIS objectives of choice, autonomy and control.



There are barriers that get in the way of people and families taking leadership roles. These barriers arise from a long history of traditional models of 'care', where being 'done to' by powerful services with imposing bureaucratic structures and systems is often the norm. Many people have come to accept that agency needs often drive service decisions rather than the needs of the vulnerable person at the centre of the support. For many years in human services, one size fits all solutions have been offered to families through a menu of services based on the availability of specific 'programs' and a shared pool of workers. While this has generally been seen as the most efficient way to offer services, the impersonality of this approach has meant that individual outcomes have been highly variable and individual needs have not been met.

The NDIS is doing a lot to break down this power imbalance and is seeking to provide people with opportunities for greater choice and autonomy. Family leadership requires the right information, skills, support and opportunity to build the necessary self-confidence and knowledge. Many vulnerable people lack informal support to help work through problems and may not believe it is possible to make their own decisions and be heard. Negative community assumptions can further undermine people's confidence and families may feel weighed down by a sense of burden. Health crises and broader family issues can mean that short term pressures drive service delivery and a more standardised approach might be the preferred option for a family that is feeling under siege.

CLP has developed a model of Self-directed Support that embraces Family Leadership. This model uses the 'Seven Steps to self-direction' developed by Griffith University under the Innovative Workforce Fund (see <http://pearl.staffingoptions.com.au/Article/GetResourceFile/327>) The Self-directed Support model coaches people with disability, their families and informal network to build their capacity and confidence to create a personal life vision and to understand and articulate the person's needs. Self-directed Support builds the capacity and confidence of the group of workers to engage with and support the natural authority and wisdom of the family. This is the 'right relationship' and working culture between the person, family and agencies to facilitate support for decision making that is acting in the person's best interest, thus safeguarding the person from harm.

Specific feedback that CLP families would like to raise regarding support for decision making with the current arrangements under the NDIS is outlined below

- **Guardianship**
 - A parent shared that if there is no formal guardianship arrangement in place, then often that parent's decisions are then not respected by the NDIA.
 - Guardianship should take into consideration all views and perspectives before decisions are made. The guardian should represent the best interest of the person when making any decision. Sometimes families have conflicting interests which can make it difficult for decision making.

- **Family and decision-making (general feedback)**
 - Families would like to see more information provided in accessible formats so that the person can have a better understanding of the information to aid decision making processes.
 - Complexity of NDIS plans and the planning process is a major constraint to decision making for the person/family. It is an extremely difficult process for an inarticulate family to navigate the system or to advocate for themselves.

- **Removing the word “disability” in the process**
 - The person’s ability to be supported with decision-making should not be about the disability. That is limiting and there will be a ‘power-over’ influence in the process. It is more important to believe in the person’s ability and to have a positive understanding of the person. The supporter has to find the way to assist the person with better understanding the process.
 - In some instances ‘disability’ has been used as an excuse for the person’s poor decisions vs a person being unjustly wronged due to their disability.

- **The nature of the decision**
 - Important to take note of the differences if the support for decision making process is between two people (the supporter and the person with disability) or 3 or more people (supporter, person and any external party (eg lawyer) who may not know the person at all/well). If the process involves more people, it will be harder. It may take more meetings or sessions with the third party to better observe/understand the person better.

- **Supported decision-making should be a developmental life skill**
 - Opportunities need to be facilitated to practice that skill from a young age eg: options to make decisions, to make choices and to experience those options being taken, time to deliberate and then make the decision/choice and experience the natural outcome of that decision. The learning builds with repetition and further exposure to help the child generalise the concept of decision-making.
 - Therefore in addition to a therapy focus approach for young people to build up their physical functioning capacity, there also needs to be opportunities to develop the decision-making skills of young people in their environment (child care, schools etc) – not only 1:1 sessions with a therapist.
 - Need a different approach with adults who have missed many skills in engaging in decision-making processes in their everyday lives due to a lack of understanding and appropriate support or education.

- **Choice versus best interest concerns**
 - Families raised concerns around decision supporters who:
 - do not know the vulnerable person well;
 - do not know what the future vision is that the person and their allies are pursuing;
 - are not going to be around for long to see or support the impact of the decision;
 - have their own personal agenda or interests at heart;
 - are support workers or paid providers in the person’s life and are not clear about the vision that the vulnerable person and their allies are working towards;
 - offer a ‘program’ or limited choices of segregated service rather than typical options that people without a disability can expect to have choices around.
 - Others who make decisions for and with the vulnerable person need to:
 - Know the person well, over time;
 - Be discerning about the choices or decisions made;
 - Understand the responsibility that comes with making decisions for and with a vulnerable person;
 - Talk to the person extensively about the issues;
 - Consult with friends and allies about the likely consequences of a particular decision/choice;
 - Be there to support the person with the decision that has been made and the consequence.

- **Risk taking and safeguards**

- It is important to ensure that there are appropriate safeguards in place for all the decisions made. Every decision has an element of risk. Safeguards need to look at what is in place and who will implement them.
- It is important to ensure that the person has a concept of right and wrong and is able to apply the concept to different situations. That is crucial to supported decision-making.
- Does the person understand the risk involved in the wrong decision?
- Safeguards include:
 - Surround the vulnerable person with good people who know them well and are prepared to hang around for some time in their lives.
 - Have a vision with the person of what a great life is and will be, know their dreams for the future.
 - Consciously assist the person to make as many decisions as they are capable of making and in a way that extends their capabilities.
 - If you have been the person to help make a decision for and with someone, stick around and be ready to support them with that decision and the consequences.
 - If a risky decision has been made, rally as many friends and allies around the person to support them through and to deal with any not so good consequences as well as celebrate with them the good outcomes.
 - Seek out and engage as many friends and allies to the vulnerable person as possible to struggle with the decisions and choices at issue, try not to be the only one advising / assisting the person with their choices.

- **Impact of consequences**

- How does a person relate to the consequences of their own actions? Do they have to be responsible for their own actions? Do they learn from the consequences of their own actions? If there is no consequence for their own action, do they actually learn the ability to manipulate situations to get what they want without regard to others/consequences?
- Reference to the diverging paths of a typical life for a person with a disability (options across the lifespan often are limited to disability-related services) vs a person without disability (options in the community) will have huge impact on genuine opportunities to supported decision-making.

People with disability flourish when enabled to make decisions for themselves, or when supported by their family and close friends to make decisions about their lives.



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