

Belonging Matters' Submission to the NDIA

Support for Decision Making Consultation, September, 2021

Part 1: Summary

In this submission, we have provided a brief overview of Belonging Matters, our work, insight into some of the barriers to decision making (gained from nearly 20 years of supporting people with intellectual disability and Autism), some reflections from a recent consultation with people with intellectual disability and family members as well as some recommendations for enabling more effective support for decision-making. These include:

- Support for decision making that is understood in context - informed by inclusion, valued roles and opportunities, human rights, and wellbeing and thriving.
- Positive, trusted and enhancing relationships and support mechanisms for decision-making that empower a person with a disability to have a voice e.g. Circles Of Support and independent facilitation, advocacy, mentoring, trusted friends.
- The importance of informal supporters and helping people to develop networks so that they can have more typical decision-making support e.g. from a friend, colleague or mentor.
- The importance of long-term relationships and knowing the person's preferences, passions and needs.
- More opportunities for the person to practice and reflect on decision making throughout their lifespan e.g. making smaller decisions that led to making large decisions
- Concrete examples and experiences to broaden people's understanding of what is possible, so they can genuinely choose, rather than choosing from a limited menu of service or provider options.
- Capacity building support for people with a disability to develop their decision making knowledge, skills and confidence to enact decisions and pursue meaningful goals.
- Ensuring that planning and decisions about what is possible for someone's life is not just tied to funding or short-term work.
- Enabling risks, while compensating where needed, with appropriate supports or safeguards that do not stifle a person's life opportunities.
- Understanding a person's decision-making experience and tailoring decision-making supports to uniquely build their capacity.
- Bringing attention to often neglected life areas. For example, sexuality and relationships.

- Support for decision making capacity building, coaching and mentoring for families and informal supporters of people with a disability.
- Reform and capacity building around the role of nominees.

Part 2: About Belonging Matters

Belonging Matters is a not-for-profit capacity enhancing service that provides education, resources, mentoring and advice about social inclusion and belonging. It was developed in 2003 by people with disabilities and families who have a passion for social inclusion! We are people friendly and value driven.

Supports we provide

Belonging Matters undertakes a range of activities and produces a range of resources that aim to inspire and build the knowledge and skills of people predominantly with intellectual disability and Autism, their families and allies to enable people with a disability to have opportunities and pathways typical of other citizens in the community - lives that are personally fulfilling, unique, socially inclusive and empowering.

We also provide personalised mentoring to enable people to create a vision for a good life in the community and plan for what might be needed to make it a reality. We are available to people over the long term as life changes, but by building the capacity of people themselves, this becomes less frequent.

Belonging Matters also invests in the leadership of people with a disability to mentor others and share their story. This is often a key to others creating change as they can see it can be done.

What informs our work with people with a disability and families

Our work is informed by the lived experience of people with a disability and families through our board membership, feedback mechanisms and Belonging Matters Advisory Council and consultation work. The work of Belonging Matters has been informed by many leaders both nationally and internationally. Our organisation is a member of the National Alliance of Capacity Building Organisations (NACBO). At its foundation, Belonging Matters is guided by Social Role Valorisation (SRV). This informs us about why and how people are marginalised in society and what means we can use to address devaluation and marginalisation. A key means is through affording people with a disability access to the same opportunities and valued roles as everyone such as a home of their own and paid employment.

Contact

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Part 3: Legislation

People's right to make their own decisions and experience the control over their own lives is outlined in legislation and policy, including the:

- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) – Including principles such as:
 - Individual autonomy - including the freedom to make one's own choices.
 - Respect for difference.
 - Non-discrimination.
 - Full and effective participation and inclusion in society.
 - Respect - for evolving capacities.
 - Equality - of opportunity. (Ramcharan, et al. 2013)
- NDIS Rules 2018 (Provider Registration and Practice Standards) which state “Each participant is supported by the provider to make informed choices, exercise control and maximise their independence in relation to the supports provided.” (NDIS 2018, cited in National Disability Services 2019)

Part 4: Some reflections on barriers to decision making

The material below is drawn from our experiences and a consultation with Belonging Matters' staff and a small number of people with a disability and family members who were able to contribute to our submission.

Barriers experienced by people with a disability in relation to their decision-making can be many, just a few of these might include:

- Gate-keeping and 'best interest' decisions by professionals.
- Pathologising people's attempts to communicate and make decisions.
- Poor practice, tokenistic or 'cynical' decision-making support.
- The costs of chronic disempowerment; people giving up on voicing their preferences and passions for life.

Gate-keeping and 'best interests' decisions by professionals

Often professionals will make decisions based on the perceived 'best interests' of the person. This can include people's choices and options being ignored or 'shut down' by professionals around them. This can be due to stereotypical assumptions about what people with a disability can and can't do, lack of vision, time, energy knowledge or commitment to alternatives.

Recently an advocate engaged Belonging Matters in regard to a man with intellectual disability who was very keen to move into his own home away from a group home. The staff of the group home were adamantly opposed to this idea and enlisted the opinion of a GP, who determined that the person was not suited to a living option outside of congregate care, without even having a conversation about individualised supported living.

"The doctor doesn't have experience around how moving out of home can work....it's all medical model thinking... one reason put forward was you can't get health care in your own home, you can only get it in a group home."

This is not to say that there is not a role for some professional opinions in the lives of all of us, however, for people with a disability these opinions can almost become like a law, governing the whole extent of what is seen as possible for the person and their whole life.

"I really agree about just the sheer, just how dominating some services can be, they have clear conflict of interests, as well making decisions supposedly in the best interests of a person...we were basically told that my brother would end up in a group by almost every service provider, It really just took kind of seeing alternative models like proposed by Belonging Matters. And then, one of his family members, me, just advocating and advocating and pushing back against this dominant best interest approach that they sort of pretend is neutral and comes from a place of professional, you know, evaluation, but is actually just an opinion that's really just based in in very negative messages about people with disabilities."

Pathologising peoples' attempts to communicate and make decisions

While good positive behavior support practice understands all behavior as a means to communicate, there is still a tendency for the self expression of people with a disability to be dismissed or pathologised, when this is in fact a communication about a preference.

"So, someone who might be labelled as non-compliant or who has a 'behavior of concern', is actually trying to tell us something."

“So, then people just sort of succumb, don't they, they become, they just give in to the system.”

“It wasn't until I got a bit mad” (that people started listening to me.)

Poor practice or ‘cynical’ decision-making support.

There are costs to people with a disability when decision making is practiced poorly, or as one family member described as ‘cynically’. “Choice” is often used as an excuse for inaction or genuinely assisting a person to explore their options, try various options and then make an informed decision.

“A service might say well that's support for decision making because ultimately we're respecting what they want. You know they want to stay inside all day and just watch telly, that's what they want to do, and so therefore we're supporting someone to make that decision. Well, how many good choices have they been offered you know? Are they aware of alternatives?”

The costs of chronic disempowerment and lack of typical or valued choices; people giving up on voicing their preferences and passions for life.

Many people with an intellectual disability are given a menu of segregated options to choose from that are not options available to other citizens. When leaving school, one person commented on his experiences and how he gave into the system.

“I went to my supported employment, all we did was hammer nails and we got paid \$1.50 a day..and it was boring. Then I left and went to an adult day activity centre, but that was repetitious.”

“So I kind of thought, this is the option I've got. So, Yeah, I just have to make the best of it.”

In their guide to supported decision making, National Disability Services (2019) states that *“Having the right to make decisions is not the same as being able to make them.”* (p10). Some people with a disability will need support, often specific and tailored, to be able to make the most of their skills and abilities to make and/or participate in decisions.

A number of ‘ingredients’ might be used to support the decision-making capacity of people with a disability. Some are explored below.

Part 5: Recommendations for support for decision making

Support for decision making that is understood in context - informed by inclusion, valued roles and opportunities, human rights, and wellbeing and thriving.

Support for decision-making should not just be about people making more choices, particularly choices amongst mediocre options. The practice needs to be understood and informed by human rights principles, (such as equality of opportunity) as well as principles such as inclusion, valued roles and contribution and what we know universally contributes to wellbeing and thriving for people. This includes things like having social relationships, having purpose, seeing good in the future and opportunities for growth and learning, for example. (Brown, Arnold, Fletcher, Standage, 2017). Without being informed by what truly enriches and enables a good life for someone, we risk having no underlying compass to guide our work. This kind of compass will also enable people with disabilities and families to better create or distinguish great options for people's lives - and when they are offered, dismiss the substandard ones in favour of something better.

“The reality of many of the lives of people with disabilities with higher support needs is that they look very different from the average person, this just should not be the case, it seems as if on some level we just accept this. We need to continue to challenge it. Alongside families and people with disabilities, friends and supporters, good disability services can lead this challenge too.”

Well executed support mechanisms (for example, Circles of Support). Independent facilitation. Someone with exceptional communication skills and who has a high level of trust with the person with a disability and their supporters.

We have found that Circles of Support, that bring together a group of people who know and genuinely care about a person with a disability, without payment or a service agenda, can assist to expand people's choices and provide a rich environment for supported decision making. Well facilitated Circles of Support not only assist the individual with a disability to make decisions and explore what makes a good life but also encourages Circle members to listen and engage the person in all decisions relevant to their life. Circles of Support, if facilitated well, can keep the focus on a good life for the person and act as a mechanism for capacity building.

“When I'm facilitating a circle, I'm often not just holding space for people but I'm providing information and advice to them about what I know, based on years and years of experience working with other people in the context of making a particular decision. I share lots of

stories with families and people with disabilities about how other people have taken that journey and how they've all come to make decisions.

“You need to have exceptional communication skills, to keep drawing the focus back to the person's preferences and their ideas about what they think is important in their life, while also respecting the views of others who have a stake, like family and so on....”

Someone to support the person with a disability to have a voice – an advocate, mentor, or friend.

There are many ways in which the voices of people with a disability can remain unheard or be silenced. People may be used to, or feel compelled to default to others to make decisions, may feel dominated or may not want to create disharmony or challenge others. Families or others may struggle to enact support roles without ‘taking over’ to make decisions for the person. Having someone to support with decision making whose role is exclusively to help the person be heard and express their preferences can be a key factor for success, and an important safeguard.

“Sometimes it's hard to have a say, because everyone, you know, is putting in their two cents worth or, you know, telling you what to do and to have someone who can really hold your voice is really important, that might be an advocate or a friend or a facilitator.”

The importance of informal supporters and helping people to develop networks.

Many of us have a range of people to turn to for advice and support; mentors, extended family, friends, colleagues, well known neighbours, peers etc. Because the lives of people with intellectual disability and Autism so often exist wholly or mostly in services, these informal networks are missing. A key strategy to enable better support for decision making (as well as life satisfaction!) is to support people to build informal networks and to enable them to draw on those networks for support and advice.

“So, if everyone else's voice is in the mix too, you know, because people that know that person well might have lots of thoughts about a decision. And then the individual can make a decision based on all of that support around them.”

“None of us makes decisions alone.”

The importance of long-term relationships and knowing the person's preferences, passions and needs.

People may experience many barriers to understanding and expressing their needs, wants, options, etc. Therefore, it is generally helpful to have people involved in support for decision-making who have had a long-term relationship with the person. However, in our

experience, this can sometimes lead to a fixed or limited sense of what is possible for the person. Facilitation, capacity building or support to maintain a sense of possibility for someone and a willingness to try new things, or consider again what has already begun to be explored before, is important.

“Really getting to know the person, if you're going to help someone to make decisions, you really need to know that well and you need to know how they make decisions, how they communicate. (For many people it's not going to be as simple as asking them) where do you want to live? It's knowing people well how they make decisions and what would it take for them to be as fully informed about that decision as they can be?”

“The long-term nature of the relationship to the person has been really beneficial in helping them make decisions.”

More opportunities for the person to practice and reflect on decision making throughout their lifespan e.g. making smaller decisions that led to making large decisions.

Belonging Matters supports the focus within the current Support for Decision Making strategy on enabling people with disabilities to make more decisions across more areas of their life, more often. This is a key foundation to capacity building. Currently people with a disability are denied these everyday opportunities. More opportunities throughout life for decision making will naturally build people's capacity, so that when a more significant decision has to be made, people will have some skills, experience and importantly some sense of autonomy and self-determination to draw on.

“When given the opportunity to make a decision, that's often really hard, especially big decisions because (people are) not afforded the opportunity to make lots of little decisions in their life previously, there's often very limited experience to draw on.”

Concrete examples and experiences to broaden people's understanding of what is possible.

Many people with disabilities, particularly in congregate settings have limited types of experiences - limited to certain places, groups of people or types of activities or routines. To support people's ability to make informed choices, they need to be able to experience different opportunities, including a wide range of places, spaces and roles in community. For some people, decision making will only be possible once things are actually experienced.

“So part of decision making is about creating opportunities for people to trial, to test, to experience life - to get a sense of what all those possibilities are, and to do it for the people we're talking about, (those with higher support needs) is to do it in a concrete (manner).”

“It's very hard to make decisions unless you have experience. And this is a big thing that we see a big gap in a lot of people's lives, where their experience is quite limited or limited to a certain type of experience.”

Support for people to enact decisions, and to pursue meaningful goals.

People may have very clear ideas about what their goals are ‘I want to move out of home’ or ‘I want to get a job’ but are often less clear about how to make a particular goal a reality, or even to speak up about it. Unless people have support that has the wisdom and ability to uncover and harness their interests and dreams, many hours of paid support can be wasted on endless life wasting activities. Good supports will start with someone's interests, skills and passions and assist someone to think about, design, trial, test various opportunities towards the things that mean the most to them. There is a stronger focus on goal attainment under NDIS and the need for accountability by services as to what is being done to help people achieve goals, however this will not guard against ‘goals’ ‘goal achievement’ which is tokenistic.

“We have previously worked with people who had been supported to ‘volunteer’ within their day service, others where they had had long-held passions for a particular activity (sometimes decades) but family had not known how to support the person to take this opportunity forward, and the service, somehow, had not seen it as part of their job.”

Ensuring that planning and decisions about what is possible for someone's life is not just tied to funding or short-term work.

Planning, including helping people ‘taste’ life options and experiences needs to occur over time. Many people with disabilities and families who have been assisted by Belonging Matters have done so over a number of years. This period of time was needed to help in supporting people in the various stages of developing a good and rich life. In our work we include a strong focus on the value of informal supports. Often funding may be needed, but if used well it can assist people to harness existing informal networks, or build new ones.

“Just as a dearth of supports can limit people's lives, When planning is just thought about too closely tied to funding, “we can do X only if we have funding” this also hasn't got the balance right. Money might well be part of the foundation, but it's only as good as the vision, the creativity, the skill, the enthusiasm and persistence of those involved.”

Enabling risks, while compensating where needed, with appropriate supports.

Decision making support needs to enable risks for people, but a significant part of that may be putting safeguards in place so that taking these 'risks' becomes possible, and wherever possible, empowering. We are doing a disservice to people with disabilities by assuming they can't do something because it's too risky. With the right supports in place people can be afforded a dignity of risk and learn the skills that might reduce any perceived risk.

"We don't want people to just put in a layer of cotton wool, and another, and another, but people do (also) have vulnerabilities. And so, it's about really looking at what would the safeguards be around a person to help them take some risks. And that might be putting some support in place, or, you know, teaching people about that particular experience."

Understanding decision making capacity and tailoring decision-making supports.

It's good that many organisations and government departments are producing Easy English information. However, it's vital that we understand how each person makes a decision and what supports a person might need to make an informed decisions. For example, simply asking a person verbally if they want to move into their own home may not be understood. The person may need to see pictures or to actually visit different styles of homes. This might not even be enough. Recently when looking at a few rentals, a man with Autism kept saying he didn't want to move into any of the places. It took someone who knew him well to realise that he didn't understand that he could bring his own furniture with him and the current tenant would remove their furniture out. Once this was understood, he became very excited.

Helping bring attention to often neglected life areas. For example, sexuality and relationships.

Some areas, such as sexuality and relationships are common facets of life which are denied, dismissed or minimised for people with a disability. This may be due to cultures in services, insufficient support, the absence of positive or supportive conversations, fears or controlling behaviours of family, as well as underlying negative societal beliefs about people with a disability in relation to sexuality. A whole spectrum of relationship types, from friendships to sexual and romantic relationships are areas where people with disabilities have a right to greater control and autonomy and often where people could benefit from a range of further supports, including supports for decision-making.

"How heavily (people's intimate relationships are) controlled, particularly for people in group homes, you know, just so many examples of parents being able to exert so much control too. (Supervisors would say) any kind of intimate relationships need to be fully

supervised, at all times. The people can't be left alone. They could be in this relationship for 10 years and never been alone with that person. And it's just taken for granted that people are unable to understand a depth of relationship...Everything's always assumed that there's going to be poor repercussions. Of all the controls that people have in their lives, this is just such a big one.

The expression 'support for decision making' as it is understood in the consultation paper highlights the need for a focus on not only the capacity building needs of the person with a disability, but also those around them. Below are some capacity building strategies which have supported families and those around a person with a disability, in the context of Belonging Matters' work.

Support for decision making capacity building, coaching and mentoring for families and informal supporters of people with a disability.

Capacity building is core to the work of Belonging Matters. We know, from many years of experience, that parents and supporters of people with a disability often need support to imagine what might be possible for their family member.

"Parents are hesitant. Well, family members, like me, are hesitant because, you know, we've been told these messages about disability our whole life that are wrong. Just gently supporting and guiding them, coaching and mentorship, to sort of assist everyone, including the person themselves, to have that vision that they are a decision maker and...how they want to live their life...to hold on to that. It requires that kind of support and mentorship and coaching from maybe outside the immediate context."

"So it was really important for someone to come in with those ideas so that you could move out, and, and get the conversation started, and keep it going."

Reform and capacity building around the role of nominees

Belonging Matters supports the focus of the current strategy on reforming the NDIA plan nominee process and further support and guidance around the role. One family member who was a nominee expressed concerns about the role currently.

"I'm not a supported decision maker in that role formally. I'm a substitute decision maker, I can make my own decisions, for my brother. I try to support him to make his own decisions, but it's only because I know about this stuff because I've interacted with (a capacity building agency like) Belonging Matters." "I think that the current nominee system is really poorly designed to support decision making. I'm a nominee, there's probably a few siblings who are nominees And I'm shocked by how much power I have. I have a huge amount of

power. I can essentially exclude my brother from the (planning) meeting. I can basically dictate things. I could focus solely on trying to get him day program access, even if he doesn't want that or has never had an opportunity to explore an alternative. There's a problem with the policy, it's not, it's not right, it doesn't fit with the values and principles in the legislation. there needs to be some attention to how that nominee system works."

"I barely remember the day that I was made a nominee, there was that little information shared with me. I just made that nominee and then I didn't receive a phone call being like, so how's your nominee role going? What kind of support do you feel like you would need? Here are some videos of how nominees have assisted their people, nothing, nothing. I'm sure some those resources might be out there, and I know that the NDIA is doing some work on trying to look at the nominee role and how they can support them, but up till this point there's been no monitoring and capacity building, and I know it's been identified as a big issue."

References

National Disability Services (2019) People with Disability and Supported Decision-Making: SDM - A guide for NDIS providers in NSW.

Brown, D.J., Arnold, R, Fletcher, D, Standage, M (2017) Human Thriving a Conceptual Debate and Literature Review. *European Psychologist* 22(3) 167-179. Cited in you need these 7 things to thrive, Research says. Niemiec, R 2017

Ramcharan, P, Leighton, D, Moors, R, Laragy, C, Despott, N & Guven, N 2013, It's My Choice! Toolkit, Inclusion Melbourne/RMIT University, Melbourne.