

Witness statement to the Senate Standing Committee on the NDIS.

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We see in our advocacy work that the NDIS is often inaccessible to people who are most-likely eligible, such as people with ID, FASD, ASD and other DDs. What we observe is that due to the working memory and executive functioning required for this level of application, planning/evidence gathering, many people are unable to participate without full assistance.

People are telling us that there is no-one to sit with them and help them understand how to draft a plan that will ensure that their needs are met. Generic guidebooks are no help if you can barely read. The role of LAC's are unclear to the participants as they seem more able to assist once you have a plan formulated but people tell us that 'they don't know what they don't know.' They need time to be 'understood' and build relationships for their needs and goals to be fully addressed. People don't want to spill their deepest distress to a stranger.

We are being told repeatedly that the process of application, planning an evidence gathering is not accessible to people with disabilities and does not provide support for people who are unable to articulate their needs, are isolated, without informal support from family who have solid capacity themselves, challenged by mental ill-health and those who are overwhelmed by the gravity of the process.

In our position as Advocates for people with intellectual or developmental disability who are endeavouring to apply to enter the NDIS scheme, or to co-ordinate the rigorous process of requesting a review on the outcome of a plan which they feel is insufficiently funded for their circumstances. Frequently the professional reports and therapy recommendations have been not recognised or when the lack the funding to obtain these Allied Health specialist reports means that they cannot 'prove' their need to the level required. Waitlists for advocacy services are now so 'competitive' that timely response for review assistance is often unavailable when they need it, for participants who need help to appeal.

The whole system is so complex. One example is a young Aboriginal man who was referred for Advocacy after an appearance at the Magistrates court, as it was likely apparent that he was a person for whom an NDIS plan would be appropriate. When we contacted the local partner in the community to ask for assistance in Access planning to be told that he would likely due to the complexity of his situation would be referred directly to NDIA planner, but it was unclear who could help him or his guardian Aunty who herself had such complex disabling health issues that she herself needed to apply for NDIS plan., to understand how to understand what a positive behaviour support plan is or how funding could help him towards finding a suitable job or training and ultimately stay out of the justice system.

Another planning meeting with a man with complex mental health distress challenges since his youth was told by a planner that his ASD primary diagnosis meant that he was not eligible for Psychology services and that for NDIS to fund this for people with his diagnosis could put at risk the future sustainability of the scheme.

To put this onus on a person who is struggling to survive each day is just not a humane approach.

Anne Livingston – Support Coordination Manager - Developmental Disability WA

Independent Assessments - Core concerns for support coordination perspective.

There has never been a time when Disability has been more about Funding. People cannot even get a response unless they have funding in a plan and share their plans with providers.

1. Relationships - it takes time to build relationships to really understand what a person requires and develop a plan that meets their needs. Many individuals and families are barely coping on a daily level to manage with the thoughts of spilling their whole life to a complete stranger. People are traumatised, feel judged, isolated, battling each day with other departments like education, housing, health.
It takes time to work through a plan that reflects goals and needs of complex people. This cannot happen in 1.5hrs/3hrs in a planning meeting. People need to pre-plan with someone who can support them and not feel overwhelmed and pressured on the day to try and justify the supports that are required while being questioned by a stranger.
2. Informal supports - Supporting informal supports like family and friends is completely not considered. There is an assumption that people have family or friends who can support them through the process. This is not the case. Many people are isolated or have not got family who have capacity to support them.
The NDIS is a complex scheme that people in general who are middle class struggle to navigate so people with Aboriginal, CALD or low-income families are completely at a loss without support. Advocacy agencies such as DDWA are completely overwhelmed with the requests for support.
3. Community - The focus is on the person a person's disability however there should be a focus on the functional impact and how the supports are there to help the person to have a normal life bedded in community. People with disabilities are more isolated from community than they have ever been. Plans focus on paid supports and seldom is there even a goal that supports connection to community in an informal way. Building community connection needs to be done on a case-by-case basis with the person with the disability not general information
4. Families with multiple people in their family home with NDIS funding More and more families have multiple people with disabilities in the family home. The multiple levels coordination needed to ensure all members have the support they need on an individual level is complex and needs a high level of skill. Preparing for planning meetings, coordination with services providers and other agencies is extensive and overwhelming for families. Families are falling through the cracks and not utilising their plans because they just don't know how to navigate the systems.

Example

Brown family Single parent family. Five family members living in the same house. All have autism including the mother. Mother has seizures, eldest daughter has high anxiety, 2 younger children have autism, and stoma care and one is also nasal gastric fed 5 times per day.

1. Complex planner without any plan review meeting reduced the plans by 50%/ RORD competed decision stood/ AAT now

2. Result - reduction in care / children not attending activities in the community/ isolation/increase in behaviours for younger children/school suspension/weight loss for one of the children due to stress/increase in seizures for mum.
3. Over the past 6 months this family has experienced increased stress/ anxiety/social isolation.
4. Hours of SC have been over the SC allocation and 40 hours of Advocacy from DDWA has been provided

Recommendations

1. People need support and time to develop relationships and build a trust that will help them to develop a plan that will reflect their needs looking at the functional impact of the disability and other community/family supports. Each plan should have a minimum of 20 hours per year to do this. If this is done well it should reduce over time depending in the complexity
2. NDIS recognition of complexity when families have multiple members with a disability or people have no informal supports. Additional supports are required to build relationships, connections and community. This needs to be intentional and purposeful. Each plan in this category should have additional supports to build those connections that reflect this gap.
3. People need consistency in their lives and not have re-tell their story to multiple parties. Having one person to walk alongside them during this process is imperative to provide the support, respect, dignity and control that each participant deserves in the NDIS system. This can only be provided if resources are provided in a person plan. Advocacy agencies are at capacity, NDIS partners are limited in their role and capacity to provide this level of support.

Mary Butterworth - CEO - Developmental Disability WA

1. I want to talk to you today about people with developmental disability, those with high support needs, in particular who have complex communication needs ie. those who have little or no spoken language and little or no signed language either, as well as those who are unable to rely on the spoken and/or signed language that they do have at all times, in all situations due to their disability. Many of these children and adults are also reported to demonstrate behaviours that concern or challenge other people.
2. Lot of time and money is poured into behaviour plans yet if there was a greater focus on supporting the person to communicate and connect with others as well as to convey their needs then a lot of *the so-called* “behaviours of concern” - behaviours which would be better understood if described more appropriately as *stress and distress behaviours* - would reduce. They say all behaviour is communication.
3. Having said this, we are not suggesting there is a quick fix to the very real and complex communication difficulties experienced. Simply funding expensive alternative or augmentative communication devices (AAC devices) is simplistic and likely to fail unless there is also funding provided to allow for the long term, ongoing and essential support and coaching - over years - of both the unpaid and paid support people in the life of someone with communication disability. Indeed, there is a very high redundancy / abandonment rate for communication devices, often because the devices are used by others as a tool to control the person with disability ie. do this now, stop doing that, stand up, sit down. To be effective, these devices and AAC systems need to be used to support connection, not compliance. They need to be tools that increase the choice, control and autonomy of the person with disability, not the people around that person. The tools need to be modelled, used in fun, engaging ways that support mutually enjoyable interaction and connection, so that meaningful relationships can develop through small talk, telling jokes, sharing ideas, chatting about shared pleasurable activities, building language, understanding connection and importantly, increasing the person's sense of self, and real choice, control and autonomy in their life.
4. I know a man at a group home and the staff just don't take his communication device seriously, don't bother to use it, except to tell him what to do - no wonder he gets so frustrated and explodes every so often. Imagine if I taped your mouth closed and taped your hands to the chair how long you would last before you “did your lolly” in complete frustration. It is a major breach of the international rights around communication for PWD not to be supported to communicate.

5. In my view support workers assisting people with complex communication needs, need to have their job title changed to 'Communication Partner' as this is their main purpose, and it is essential that not only the job title but their job description and training reflects that. Currently, in our experience, it does not, yet the quality of life the person with developmental disability's access to real choice and control depends on it.
6. More broadly this widespread lack of focus and skill is not helped by recent changes to university fees. At Edith Cowan University they are offering a 4 unit post grad course in Complex Communication and Challenging Behaviour to teachers, therapists, Psychologists and family members however this highly contemporary course has become unaffordable for many, increasing from roughly \$800 to \$2300 per unit. One of the few courses in Australia which is critically needed and is now beyond the reach.
7. One of our greatest concerns is the lack of belief in what is possible. Recently a man in his fifties left long term institutional care and his family said he could not communicate. However, our communication consultant met him and within an hour she was able to show that he did in fact already have a way of communicating a clear yes/ no response, and he began engaging with two different robust alternative communication apps on an iPad.

Similarly, a young woman in her 20s who was also thought to have no way of communicating, was - in less than hour - engaging with a number of different AAC apps and using eye gaze, gesture, and symbol-based voice-output devices to interact with our communication consultant. She gave clear and definite yes/no responses to several questions as well as initiating her own messages with the device.

That is not to say either of these adults had begun to communicate independently, but they showed they had the ability to learn to use alternative and augmentative communication systems.

Why have NDIS planners not realised that the only pre-requisite for learning to use a robust AAC system is breathing?

Why are children and adults with complex communication needs not being afforded plans that allow time for well supported AAC system trials with adequate funding for families and others supporting the child or adult to be coached in how to use the AAC systems, to model how to use them so that the trials are as effective as possible?

Why is there not funding allocated for long term coaching and capacity building of the person's support networks so that the rate of device abandonment is reduced?

It takes training to be an effective communication partner for people learning to use AAC, and even to support people who use AAC competently. It doesn't come naturally, but it can be learnt given the appropriate training, time to practice, and

time for ongoing coaching feedback. Skilled communication partners are the most important support people with complex communication needs can have, yet this is simply not recognised in NDIS plans. Independent assessments will never be able to determine the precise form of communication support a person with developmental disability and CCN requires however, recognising that every person with developmental disability and CCN requires lengthy ongoing communication support and access to an appropriate, robust AAC system would be a start.

It's important to recognise that the support needs to be provided during any and all AAC device trials to, recognising that for most people with developmental disability will have great difficulty "proving" they have the ability to learn how to use a device within a 4-8 week period, and especially if adequate - most likely intensive - support during this time frame is not provided.

8. So what I am saying is if we are serious about reducing "behaviours of concern" and giving people with complex communication needs a voice then we need to train the NDIS planners in what they need to be funding, not just the device, but proper support over a long period of time to embed communication with the person and all of those who are connected with them....having a device on loan to trial for one month as is current practice is totally ineffective in many cases.