

Submission to NDIS Review

Date: 1 September 2023
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Background

I am the sister and advocate of a man with a disability.

Our family is thankful for the NDIS, especially for the option to self-manage after having had the experience of block funding and inflexible service provider/s and supports.

I also work as an independent support worker, with a strong commitment to best practices in business and person-centred care. My qualifications and experience, including lived experience and related advocacy, Bachelor of Business, Graduate Diploma in Counselling, Certificate IV in Small Business Management, NDIS working knowledge as an LAC, and self-management skills, allow me to provide services to a professional standard.

As an independent, I believe it is my responsibility to provide everything (as is practicable) that a registered organisation would provide including having a working knowledge of NDIS and the confidence and ability to communicate with other providers, support coordinators, therapists and family members.

Continuous Improvement and Regulation

Suggestion: A submittable signed check-list for non-registered providers could ensure a minimum level of skill, understanding of / adherence to legal and tax requirements, service agreements, restrictive practice, and a commitment to strengths-based practice.

As an independent, I believe in continuous improvement and staying informed about NDIS. I continue to attend conferences and do short courses to increase my knowledge and understanding and have membership to a few relevant bodies. However, there's a concern about inexperienced and unknowledgeable individuals working as independents, leading to issues like boundary violations and lack of adherence to tax rules relating to GST and having service agreements in place, and potential work health and safety for worker and individual, as well as contributing to an unsustainable scheme with poor outcomes.

Sometimes, independents without knowledge, experience and capacity are supporting families to keep the family member/individual in a vulnerable state, as the eternal child, and not building strengths. I have also seen many questions from family members / individuals on Facebook asking questions about how a worker should do something that is clearly the worker's responsibility.

Direct Employment and Funding

Direct employment can save the NDIS significant amounts. It puts pressure on families however it also alleviates pressure as it gives the most control and best outcomes. In our case, it means not having to micromanage an organisation.

There is a fear, however, of losing funding in future plans, by saving the NDIS money. It is a relief to know there is sufficient funding available for my brother's needs by employing directly. Spending is based on need and funds will be under-utilised come review. For some, the thinking is, having money available, means it needs to be spent or lost in the next plan.

Suggestion: NDIA to be understanding of this and have a standard that provides funding based on the hourly requirement at the hourly capped rate. Reassure families they will not lose funding.

Focus on Capacity Building

Suggestion: Place a greater capacity building focus on all funding categories

Core funding should have a greater focus on "Capacity Building" to move away from a culture of dependence. It is often easier to 'do for' than to 'do with' or have hands off. There are many examples of individuals becoming more reliant and dependent and have support workers as 'friends'. There needs to be a clear distinction between informal and formal supports. NDIS should act as a "gap-filler," not replace informal and community support networks.

Payment to Informal Supports

Suggestion: Independent workers should sign a Statutory Declaration to confirm no personal relationships (blood / defacto) with the individuals they support or the parent / self-manager.

The presence of money, in some cases, enables families to abdicate responsibility. I have seen families that are less present because there is a paid option. Families / people with close relationships are also taking on these paid roles. This is extremely detrimental for relationships and for the care of the individual. I saw a Facebook post where support workers had lost work because the mother of the individual gave her boyfriend work and directed other workers to do things in a different way so as not to upset the boyfriend. This doesn't sound like it's about the individual. I have also heard of in-laws, cousins, step-family providing 'support' in areas where qualified support is available and accessible.

Support for Individuals with Limited Informal Support

Suggestion: Establish an accepted mechanism for community members, friends, support workers, or service providers to advise and flag potential shortcomings in funding for individuals with limited informal support.

I know a situation where an adult is living with a parent who is in his 80s. His other parent is in nursing home care. This individual has 5 hours support per fortnight. The parent says nothing is needed but this is not the consensus of other people who have known him for many years. The service provider has not been active in advocating.

Funding for Equipment

Suggestion: Consider longer trial periods for new assistive technology devices (to allow for other barriers to be dealt with eg mental health) and implement a no-penalty return policy for unused, surplus equipment to a third-party that can manage receipt and redeployment.

I am aware of several expensive AT devices & home mods that have had very little use (or are not fit for purpose) and are justified in an OT report but not in reality due to danger or other restrictions to use. I believe there needs to be great consideration given to how and when items will be used and the process for transition and implementation.

Distinction between holiday and respite

Suggestion: Implement a process for NDIA to directly approve or disapprove large one-off claims. Have queries bypass the plan manager to be directly approved / disapproved by NDIA prior to spend.

I'm sure this is not new information to hear of individuals claiming a supported holiday as respite, with the household attending respite together. There is a disparity when one support coordinator will support this, and plan manager will process as reasonable and necessary, but another won't. This is perhaps due to the tenacity of the individual.

A Focus on Strengths and 'A Good Life'

Suggestion: Shift the focus from deficits to strengths and promote the idea of 'A Good Life' as the ultimate goal. Encourage families to define what their loved ones need, without fear, emphasizing culturally valued ways of skill development or alternate ways of expression.

Suggestion: Allow families or individuals to present their vision of a 'good life' for funding consideration. Provide funding support for visioning and holistic planning beyond paid supports.

Suggestion: Encourage case managers (rather than support coordinators) to look outside of paid supports and typical services, incentivizing this approach.

Goals are OK, but often written by the planner / LAC and to my view, not a big enough picture. NDIS should support 'normal' and 'typical' avenues for outcome achievement rather than over-therapising. Families that have the capacity and knowledge and desire need to be able to work with a framework they choose (ie Social Role Valorisation) with funding support from the scheme without fear of 'am I doing the right thing because I'm thinking outside the box'; 'will I lose self-management because an LAC doesn't like what I'm doing'.

Ending Sharp Practices

Suggestion: Clearly define that support coordination and service provision cannot occur within the same organization or closely linked entities.

In areas where there has been a monopoly or duopoly of support providers, organisations are protecting their patch. In rural areas there are many more options now. The sharp practice of Support Coordination and service provision is not necessary and not in individual's interest.

Societal Change

Suggestion: Advocate for societal change that normalizes and includes everyone, focusing on the person, not the disability. Eliminate practices that congregate and segregate individuals with disabilities (no time to go into it, but please eradicate Supported Employment and encourage open employment). Encourage services to employ staff for the individual, not the service.

Eliminate big signs on the sides of vehicles telling the world that 'the people in the vehicle are needy and dependent' and 'I am wonderful for providing this service'.

Change the marketing. 'I love NDIS' on service provider presence feels focussed on the financial outcomes for the organisation. NDIS has moved on. The market is more mature and this statement also adds to the devaluation of individuals with NDIS funding. It's saying 'People who enter the door of a place with an 'I love NDIS sticker' are different, they are less than, they are needy, they are a burden, they require help and funding'.

If I could urge anything, it would be for people in leadership of NDIA to look at current models of thinking around supporting individuals to be included and appreciated in our communities. Social Role Valorisation is, in my opinion, an excellent model which ultimately is about supporting people to have the good things in life. It has two core strategies - assisting individuals to improve their social image and to build competencies.

Talk to *Australian Social Role Valorisation Association, Values in Action Association, Community Resource Unit, Belonging Matters* and La Trobe University's *Living with Disability Research Centre* and look at the great work being done by these and other organisations in contemporary thinking and practice. Traditional thinking is not encouraging Australia toward better outcomes and equality. The sector needs a shake-up and it needs to think differently about how to assist individuals to have the good life.