

Tune Review of NDIS ACT and Rules
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Intellectual Disability Rights Service Inc (IDRS) is a disability advocacy service and community legal centre working to 'Make Rights Real' for people with intellectual disability in NSW since 1986

Our response is informed by the experience of the people with intellectual disability we work with providing non-legal and legal advocacy including assisting people with NDIS Appeals since mid-2017.

We would like to note our support for the excellent submission made by The National Legal Aid in September to the Standing Committee about the NDIS. This submission was extremely thorough and we agree with all the points referenced in that document.

This is a response specifically about the:

The experiences of people with disability, their families and carers with the Scheme's administration and decision-making, including: access, planning, review and appeal processes. In particular the experiences of people with intellectual disability and their carers.

Regarding access

People with undiagnosed cognitive impairments and other difficulties with learning and understanding documentation, would benefit from nationwide access to experienced assistance to complete an access form. This assistance could be provided to the person themselves or a support person or carer.

The NDIS has made provision for Local Area Coordinators to assist people to complete access requests. Our experience is there are gaps in knowledge about the impact of intellectual disability and these forms being completed without capturing an accurate picture of the person's functional day to day capacity.

Providing assistance to people with intellectual and cognitive impairments to make a thorough first access request would reduce the need for reviews of decisions and people with disability having to repeatedly apply for access when they are not to have met the criteria.

Regarding the planning experience for people with intellectual disability

- It is our experience that NDIA staff do not understand impact of intellectual disability on participant's functional capacity– in particular:
 - that it takes longer to learn things for a person with an intellectual disability
 - functional capacity can usually be improved by direct support

- When the support is arbitrarily reduced/removed a person's functional capacity will almost always be reduced.
- Finally that a person's capacity to commence a review or make a complaint is hampered by when they cannot speak to the person who can give them answers.
- Further NDIA planners make decisions, at odds with the evidence provided to them regarding capability of the person and the reliance /access to supports. In some cases family members who are older or unwell are forced to provide "informal support" for adults in direct contradiction of the Supports for Participant's Rules 2013.
- Spending the funding in the plans to access appropriate supports is negatively impacted by:
 - Lack of support coordination - Often people with intellectual disability are provided with support coordination only once in their plan with support coordination being removed or reduced in later plans. This decision can result in disengagement in supports by participants because they are not capable to navigate the complexity of engagement of services themselves. Most people with intellectual disability will need on-going support co-ordination.
 - NDIS plans are not provided in formats accessible to people with intellectual disability. The categories, and individual subheadings in the plan itself are very confusing and people with intellectual disability do not understand how to use their funding. Many of the people IDRS works with have no-one in their lives who can assist them to understand their plan
 - The goals in the plans frequently bear no relation to the allocation of funds in the plan. This is at odds with the principles underlying the scheme that the NDIA regard the goals as relevant to the funding.



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