**Consultation by the Department of Social Services on proposed improvements and legislative changes to implement the recommendations from the review**

[**Implementing the recommendations of the 2019 NDIS Act review**](https://engage.dss.gov.au/?page_id=12697)

**SUBMISSION BY THE TELETHON KIDS INSTITUTE**

The Telethon Kids Institute welcomes the changes proposed to give participants to the NDIS more choice and flexibility, fix parts of the legislation that are not clear or are out of date, and to give better support to people with more complex or unique needs, such as people with psychosocial disability, and children and families.

The Telethon Kids Institute is highly supportive of the introduction of the Participant Service Guarantee to set standards for how long NDIS processes such as approving or amending a plan will take and how the NDIA will work with people with disability.

We are particularly pleased to see this work progress to this stage as one of our key researchers, Professor Andrew Whitehouse, who has worked with DSS and the NDIA for some time, sat on the formal consultative committee for this review.

With this in mind, we are pleased to provide support for the proposed changes. However, in doing so we offer additional commentary, as provided below, against 2 of the 14 recommended changes (Recommendations 12 and 13) where research undertaken by the Telethon Kids Institute can further inform your review process.

Should you require any further clarification or wish to discuss these comments, we would be pleased to meet with you to discuss. Pls contact A/Professor Jenny Downs, Principal Research Fellow, on 08 63191763 or me on the phone numbers below.

Thank you again for the opportunity to provide a submission.

Fiona Roche

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**TELETHON KIDS INSTITUTE – COMMENTS AGAINST 2 OF THE 14 RECOMMENDATIONS**

**Recommendation 12**

12. The NDIS Rules are amended to reinforce that the determination of reasonable and necessary supports for children with disability will:

a) recognise the additional informal supports provided by their families and carers, when compared to children without disability

b) provide families and carers with access to supports in the home and other forms of respite

c) build the capacity of families and carers to support children with disability in natural settings such as the home and community.

**Response to the three components of Recommendation 12 by the Telethon Kids Institute is as follows:**

1. The recommendation to expand the NDIS to recognise the additional informal supports provided by the child’s families and carers, is strongly supported. Reasonable and necessary supports are essential for children with disability, irrespective of any funded supports that are provided for the child, families and carers deliver substantial care and support themselves. This is a critical part of parenting, but for parents with a child with a disability, parenting can be associated with strain, stress, and threats to their mental health.
2. The recommendation to provide parents with supports in the home and other forms of respite, to minimise threats to their mental health by providing breaks in their caring is also strongly supported. The Telethon Kids Institute has studied the mental health of parents with a child with intellectual disability or a neurogenetic disorder associated with intellectual disability for many years. Across all diagnostic groups, mental health is poorer for parents with a child with intellectual disability compared to parents in the general population whose children do not have intellectual disability.

A recent study led by Telethon Kids Institute investigated the mental health of 447 caregivers with a child with intellectual disability who reported their psychological distress using the Kessler Psychological Distress Scale. The minority of caregivers had scores classified as no psychological distress (n=21, 27.1%), mild distress was reported by 135 (30.2%) caregivers, moderate distress by 121 (27.1%), and high distress by 70 (15.7%) of caregivers. High levels of psychological distress reported in earlier studies remain in the current day.

There were flow on implications from poor parent mental health for the child’s quality of life: poorer parental mental health was associated with lower child quality of life scores (coeff -0.47, 95%CI -0.61, -0.32).

Parent caregivers with a child or adolescent with intellectual disability are extremely vulnerable to psychological strain and distress, illustrated by our data where 27.1% reported no distress compared with approximately 70% in the general population. Poorer mental health has been attributed to the child’s sleep and behavioural problems, recurring grief and challenges navigating the complex care pathways for their child’s necessary supports.

Greater caregiver support is strongly supported. Additional to the provision of new supports, we recommend that the additional step should be made of collecting data to evaluate the merits of providing respite/carer supports in order to understand effects on parental mental health and any flow on effects for family wellbeing and parental productivity. We feel this is critical to guide future initiatives in this important domain.

*See: Whitehouse A, Jacoby P, Reddihough D, Leonard H, Williams K, Downs J. The effect of functioning on Quality of Life Inventory-Disability measured quality of life in children with intellectual disability is not mediated or moderated by parental psychological distress. Quality of Life Research. doi: 10.1007/s11136-021-02855-9.*

1. The recommendation to build the capacity of families and carers to support children with disability in natural settings such as the home and community is strongly supported. The Telethon Kids Institute recently investigated relationships between the child’s functioning, participation in the community and quality of life in children with intellectual disability. More impaired functioning was associated with poorer quality of life, and more frequent community participation was associated with higher quality of life, irrespective of the child’s level of functioning.

Engaging in community participation is an important modifiable factor that can improve how well the child lives. Participation in the community such as social and recreational experiences that are fun and interesting can contribute to the development of emotional wellbeing and social networks and are particularly important to counter social isolation. Participation interventions that are tailored appropriately for a child’s interests and level of disability might include sport, recreation or arts-based activities and would also include opportunities for the child’s choice, control, and personal engagement.

The Telethon Kids Institute further supports additional social and community opportunities being made available for children with disabilities. This can be a problematic area for parents to advocate for when planning supports with the NDIS as it can be difficult for them to identify goals for their child, that will assist them to live productively in the community. We suggest that the NDIS document how these goals are achieved by children and their families to enable experiences of healthy living to help families visualise this for their child, and thereafter identify and implement strategies that would suit them.

*See: Williams K, Jacoby P, Whitehouse A, Kim R, Epstein A, Murphy N, Reid S, Leonard H, Reddihough D, Downs J. Functioning, participation and quality of life in children with intellectual disability: An observational study. Developmental Medicine and Child Neurology. Doi: 10.1111/(ISSN)1469-8749.*

**Recommendation 13**

13. The NDIS Act is amended to provide more flexibility for the NDIA to fund early intervention support for children under the age of seven years outside a NDIS plan, in order to develop family capacity and ability to exercise informed choice and control.

**Response to Recommendation 13 by the Telethon Kids Institute is as follows:**

This recommendation is strongly supported, with the additional suggestion that there is a need for further equity in this arena. The burden of disability is greatest in families who live with disadvantage, yet those are the families who are less likely to access services and supports. We recommend that the NDIS consider the following:

1. The collection of data on how to engage with difficult to reach families, and then evaluate the merits and effectiveness of any identified strategies.
2. The development of a range of intensities of support with light touch interventions available as needed that can increase to greater intensities as needed by the developmental needs of the child.
3. The inclusion of child and parent mental health support interventions to promote positive and strengths-based attachment with the child.
4. The provision of early interventions that reduce social isolations and promote peer supports.
5. The inclusion of a health literacy focus to build family capacity to understand, access and implement health information according to what they need.

7 October 2021