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## Mental Health of Young People with Developmental Disabilities

A National Health Medical Research Council  
(NHMRC) funded research project

Joint Standing Committee on the National Disability  
Insurance Scheme Inquiry – ***Market Readiness***

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# Joint Standing Committee on the National Disability Insurance Scheme Inquiry - Market Readiness

## Terms of Reference

*As part of the committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on market readiness for provision of services under the NDIS, with particular reference to:*

- a) the transition to a market based system for service providers;*
- b) participant readiness to navigate new markets;*
- c) the development of the disability workforce to support the emerging market;*
- d) the impact of pricing on the development of the market;*
- e) the role of the NDIA as a market steward;*
- f) market intervention options to address thin markets, including in remote Indigenous communities;*
- g) the provision of housing options for people with disability, with particular reference to the impact of Specialist Disability Accommodation (SDA) supports on the disability housing market;*
- h) the impact of the Quality and Safeguarding Framework on the development of the market;*
- i) provider of last resort arrangements, including for crisis accommodation; and*
- j) any other related matters.*

## MHYPEDD Comments

We are the Chief Investigators of the five-year NHMRC-funded 'Mental Health of Young People with Developmental Disabilities' (MHYPEDD) research program. The participants in this research project are parents and carers of children with developmental disabilities aged 2-12 years and practitioners who work with families with children with developmental disabilities.

We ask the Joint Standing Committee on the NDIS Inquiry into Market Readiness to consider the following:

### Regarding TORs:

- a) the transition to a market based system for service providers;**
- b) participant readiness to navigate new markets;**
- c) the development of the disability workforce to support the emerging market;**
- d) the impact of pricing on the development of the market;**
- e) the role of the NDIA as a market steward;**

NDIS Participants with a child with a recent diagnosis of a developmental disability are unlikely to be ready to ask for what their child needs. Submission to previous Joint Standing Committee Inquiries into the NDIS provide extensive evidence that planners are also not ready to advise parents and participants on the most suitable services and supports. If those creating the 'demand' in the market based economy are not demanding appropriate services and supports, the market will not provide them.

When a child is diagnosed with a hearing impairment, a clear pathway is provided to parents for how to help their child. As it is for a diagnosis of diabetes or spinal cord injury. No such pathway is available for parents of a child with a developmental disability. The child, their family and the wider community are suffering as a result.

Further, it is impossible to determine the degree of 'market readiness' of the disability sector for NDIS participants with developmental disabilities when there are no key reference points. Those reference points being appropriate and effective services and supports. If the appropriate and effective services and supports are not defined, it cannot be measured if they are in adequate supply.

**Recommendation 1** - The NDIA take responsibility for developing and implementing a pathway for NDIS participants with developmental disabilities with particular reference to:

1. The NDIA undertake and/or oversee research into determining the most appropriate proven-to-be-effective, evidence-based services and supports to be part of such a pathway, in line with international best practice.
2. If cost-effective service delivery is best achieved via group delivery of services - the NDIA take the necessary steps to enable group delivery of services. Even if that entails setting aside a portion of the budget for block funding of services, supports and interventions.

**Regarding TORs: a) the transition to a market based system for service providers and c) the development of the disability workforce to support the emerging market**

To ensure the financial sustainability of the NDIA it is imperative that NDIS and NDIS ECEI Approach participants have access to evidenced-based proven-to-be-effective services and supports that will reduce long term NDIS expenditure. That is, services and supports that do not just alleviate current challenges in living for the person or child with a disability and their carers. Services and supports are needed that increase the person with disabilities' independence and ability to participate in the community, thereby reducing required services and supports.

Such services and supports might involve greater cost in their initial set up. Additional costs for evidenced-based programs can arise from systemised methods of staff training, data collection, evaluation and resource production. However, over the course of the life of the NDIS participant, effective services and supports would prove to be highly cost-effective.

For the NDIA, initial set-up and maintenance costs of proven-to-be-effective programs would be outweighed by the enormous potential cost savings of providing fewer and less intensive services and supports over the lifetime of a NDIS participant. However, initial set-up and maintenance costs do not fall to the NDIA. They fall to the service provider. Despite the benefits of such services and supports for the NDIA participant and the wider community, there is currently no financial reason for the service provider to deliver these programs as the cost benefit goes to the NDIA.

**Recommendation 2** – close the economics loop between the entity that benefits from cost-effective services (the NDIA) and the entities that would incur the additional costs of delivering cost-effective services (the service provider).

**By way of an example...**

Our area of expertise is in the area of developmental disability (including but not limited to autism, Down syndrome etc). Our 5-year NHMRC funded research project adds to an enormous body of evidence showing the value of effective parenting programs delivered at a timely stage in a child's development. Such program delivery can have a significant impact on the child's social functioning throughout childhood and into adulthood. This positive impact comes from reducing the child's emotional and behavioural problems and improving their mental health. As a result, the level of services and supports a child needs through their life is greatly reduced as a result.

Research shows that as well as costs to government funded services and supports, there is a significant cost burden to the family of the person with the developmental disability both in direct costs and opportunity (time) costs. Preliminary data from our research indicates that financial cost burdens to the family can be reduced with effective parenting programs. In addition, there is emotional benefits to the family, including siblings, resulting from such appropriately timed intervention. Not to mention the potential happiness of the child themselves if they are no longer displaying emotional and behavioural problems.

**We draw the Committees attention to the following:**

**The program that we delivered in this MHYPEDD research project – Stepping Stones Triple P – can be very cost-effective to deliver and would reduce costs to the NDIA over the lifetime of a participant. It can be delivered in a group setting and by practitioners already working with families. But there are initial cost in staff training and ensuring fidelity of program delivery and**

costs associated with coordinating group program delivery. Given the current structure of the NDIS which does not facilitate group program delivery, this effective program is no longer offered by most of the Stepping Stones trained practitioners and service providers.

**Regarding TOR: b) participant readiness to navigate new markets;**

**Recommendation 3** – The ability of parents and carers of newly diagnosed children with disabilities to navigate markets, must be facilitated by the NDIA.

It is an incredibly stressful and emotional experience for parents when they discover that their child has a disability. Adding to the stress of realising your child will not have a typically developing future, is the stress of the overwhelming onslaught of new information to be absorbed, agencies to interface with and decisions to make that can have a significant impact on the child's future. Or worse, a lack of information and guidance.

It is too much to expect parents in such situations to be immediately fully equipped to know what is best for their child and to navigate markets for disability services and supports. The NDIA has a pivotal role in assisting parents and carers in becoming market ready, educating parents on the value of evidenced-based proven-to-be-effective supports and the kinds of supports that are most suitable for their child.

**Recommendation 4** – NDIS Planners and ECEI Partners need to be trained in the value of evidenced-based effective services and supports to enable them to communicate this value to parents and carers.

In the case of young children with developmental delays, early *AND* effective intervention is critical. The information the parents require at this time needs to be robust, accurate and easy to understand. It would be time consuming for parents to 're-invent the wheel' and research the best interventions for their children. Delays in selecting and implementing interventions is highly counterproductive for the child, the family, the wider community and the sustainability of the NDIS. To enable NDIS participants to be ready to navigate new markets - NDIA has an important dual role to play as:

- Researcher – to filter information on services and supports to determine the most effective and those that have a robust evidence base
  - Large organisations may have enough resources to research effective interventions and supports and assess the robustness of their evidence base, but small and medium size entities will not.
  - It would be a wasteful duplication of activities if individual service provider organisations are conducting this research. It would be far more effective if the NDIA undertook this research and disseminated its findings to service providers and NDIS participants and their parents and carers.
- Educator – educate parents not only about suitable effective supports for their child but also of the value of evidenced-based proven-to-be-effective interventions

Professor Stewart Einfeld, Professor Matthew Sanders, and Emeritus Professor Bruce Tonge are available to the Joint Senate Committee for further input on this matter. They can be reached by emailing [fhs.steppingstones@sydney.edu.au](mailto:fhs.steppingstones@sydney.edu.au)

## ***Mental Health of Young People with Developmental Disabilities* Chief Investigators**

### **Professor Stewart Einfeld, University of Sydney**

Chair of Mental Health, Disability and Group, Health Sciences Faculty Research Group

Faculty of Health Sciences Senior Scientist, Brain and Mind Centre

Co-developer of the Developmental Behaviour Checklist

Co-chief Investigator of the NHMRC and National Institutes of Health funded Australian Child to Adult Development (ACAD) Study (now in its 20th year)

World Health Organisation Travelling Fellow

Australian Society for Psychiatric *Research Junior Travel Award*

*National Research Prize* from the Australian Society for Study of Intellectual Deficiency

### **Emeritus Professor Bruce Tonge, Monash University**

Foundation Head, School of Psychology and Psychiatry, Monash University

Head, Discipline of Psychological Medicine, Monash University

Senior Clinical Advisor of the Mental Health Program of Southern Health, Monash Medical Centre

Establishing founder, Monash University Centre for Developmental Psychiatry and Psychology

Minister of Mental Health Victorian Public Healthcare Award for *Outstanding Individual Achievement in Mental Healthcare* in 2009

RANZCP 2010 Meritorious Award for *Outstanding contribution to Victorian Psychiatry over many years*

2010 ASPR Founder's Medal for *Contribution of significance to psychiatric research throughout career*

2010 Monash University David de Kretser Medal for *Exceptional contribution to the Faculty of Medicine, Nursing and Health Sciences over a significant period of time*

Award for *Distinguished Service to the Profession of Child and Adolescent Psychotherapists in Victoria*, VCPA, July 2015

### **Professor Matthew Sanders, University of Queensland**

Fellow of the Australian Association for Cognitive and Behaviour Therapy (2016)

Fellow of the Academy of the Social Sciences in Australia (2016)

*University of Queensland's Top 5 Innovators* (2013)

The Australian Psychological Society's President's Award for *Distinguished Contribution to Psychology* (2007)

*Queenslander of the Year* (2007)

Founder of the Triple P-Positive Parenting Program