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Mental Health of Young People with Developmental Disabilities

A National Health Medical Research Council
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Joint Standing Committee on the National Disability
Insurance Scheme Inquiry - ***Provision of services under the
NDIS Early Childhood Early Intervention Approach***

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Submission to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry - *Provision of services under the NDIS Early Childhood Early Intervention Approach*

The following submission is based on the extensive Disability Sector experience of the Chief Investigators of the NHMRC-funded research project '*Mental Health of Young People with Developmental Disabilities*' (MHYPEDD) Professor Stewart Einfeld, The University of Sydney, Professor Matthew Sanders, The University of Queensland and Emeritus Professor Bruce Tonge, Monash University.

Introduction

The NDIS is a ground-breaking social reform that is to be commended and supported. We welcome the opportunity to contribute to the Joint Standing Committee on the *National Disability Insurance Scheme (NDIS) Inquiry - Provision of services under the NDIS Early Childhood Early Intervention Approach* and to offer our experience and knowledge in this area, during this important early operational stage of the NDIS Early Childhood Early Intervention (ECEI) Approach. Our response speaks to the following terms of reference for this Inquiry:

- b. the service needs of NDIS participants receiving support under the ECEI pathway;*
- d. the adequacy of funding for services under the ECEI pathway;*
- f. the evidence of the effectiveness of the ECEI Approach;*
- g. the robustness of the data required to identify and deliver services to participants under the ECEI;*
- h. the adequacy of information for potential ECEI participants and other stakeholders;*
- j. the principle of choice of ECEI providers;*

Evidenced-based, cost-effective programs

The National Disability Insurance Agency (NDIA) has a duty of care to current and future participants of the NDIS to ensure participants of ECEI services have access to services and supports that provide the most benefit to each NDIS ECEI participant, their family and the wider community for the proportional cost-of-delivery. In other words, the effectiveness and future sustainability of the NDIS will rely on the availability of services and supports that are the most cost-effective, but not necessarily the cheapest.

The design of the NDIS to rely on market forces to shape the services available to parents of children with developmental disabilities presents a quality assurance issue for NDIA and the ECEI Approach component of the NDIS. As international and Australian experience shows, service providers will opt for cheaper programs when there is no incentive to deliver a more expensive program. The issue that is of consequence to the NDIA is that cheaper programs, services and supports may not be the most cost-effective and beneficial over the lifetime of the ECEI participant.

We are the Chief Investigators of the five-year NHMRC-funded 'Mental Health of Young People with Developmental Disabilities' (MHYPEDD) Program Grant. The participants of this research project are parents and carers of children with developmental disabilities aged 2-12 years. We ask the Joint Standing Committee on the NDIS Inquiry into *The provision of services under the NDIS Early Childhood Early Intervention Approach* to consider the following:

The data that is being gathered in the final stages of the MHYPEDD project adds to the extensive body of evidence of the efficacy and value of evidenced-based parenting intervention programs designed to prevent and reduce child behaviour and emotional problems as well as improve children's social adjustment.

The Joint Standing Committee should be aware that the strongest determinant of community participation for people with developmental disabilities is the extent of their behaviour problems. The extent of behaviour-related problems is a much greater indicator of a person's potential social isolation than the severity of the impairment causing their disability.^{1 2 3 4}

The evidence is also clear that, for parents and carers as well as children with a disability, behavioural problems can be addressed and prevented by evidence-based parenting program tailored to the needs of a child with a developmental disability.

Once parents have more confidence in their ability to cope with their child's behaviour, the benefits flow throughout the entire family. Small everyday events, which once seemed impossible to participate in, become possible again. Parents become less stressed and depressed and children and families are able to participate more fully in community life.⁵

Many families who have difficulty managing their child's behaviours have not experienced the benefits of early intervention services and parenting training, and only seek help when they reach crisis point. The ECEI approach offers a chance to address this by offering families of young children support or referral to services that can help.

Offering evidence-based parenting programs to every family of a child under six with a developmental disability under the ECEI approach presents the potential for enormous cost savings to the NDIA, particularly in the area of families experiencing crises and, in some cases, relinquishment. These cost benefits would logically flow to the wider community.

¹ Einfeld S, Piccinin A, Mackinnon A, et al. Psychopathology in Young People with Intellectual Disability. *JAMA*. 2006;296:1981-1989

² Bruininks R, Hill BK, Morreau LE. Prevalence and implications of maladaptive behaviours and dual diagnosis in residential and other service programs. In: J. A. Stark, F. J. Menolascino, Albarelli MH, Gray VC, eds. *Mental retardation and mental health*. New York: Springer-Verlag; 1988

³ Anderson D, Lakin K, Hill B, Chen T. Social integration of older persons with mental retardation in residential facilities. *Am J Ment Retard*. 1992;96:488-501.

⁴ Parmenter TR, Einfeld SL, Tonge BJ, Dempster JA. Behavioural and emotional problems in the classroom of children and adolescents with intellectual disability. *JIDD*. 1998;23:71-77.

⁵ Tellegen C. and Sanders M. Stepping Stones Triple P-Positive Parenting Program for children with disability: A systematic review and meta-analysis. *Research in Developmental Disabilities*, 2013;34(5):1556-1571.

More importantly, the delivery of these programs greatly improves the ability of ECEI services and the NDIS to deliver on its core aim of improving life for people with disabilities while increasing their community participation.

However, despite the logic of this approach, as chief investigators of MHYPEDD, we are concerned the influence of market forces in the design of the NDIS will only act to undermine delivery of evidenced-based programs. We see the reason for this occurring to be the following:

a. Many service providers associate evidence-based programs with greater initial costs of delivery.

These costs arise from the need to ensure fidelity of program delivery to produce outcomes demonstrated in clinical trials and involve systemised methods of staff training, data collection, evaluation and resource production.

It should be noted that many evidenced-based programs are *not* more expensive to deliver than non-evidence-based programs. However, there is also a cost to the individual service provider to research and assess services and supports to ensure they are evidenced-based, and which programs have the strongest body of evidence behind them.

b. Despite the cost-effectiveness of evidenced-based programs for the wider community, there is no direct financial benefit for the service provider to deliver these programs.

Any potential costs in the delivery of evidence-based programs will be mitigated by the savings that the person with the disability, their family, the NDIA and the wider economic community would receive as a result of timely and early effective intervention for families of children with disabilities.

However, whilst the service provider must bear any additional delivery costs of evidence-based programs, they will not be the recipient of the cost-benefit.

Consequently, designing the NDIS around market forces runs the risk of producing market failure which will leave many ECEI-connected families with little to no evidence-based support.

This has been illustrated by the MHYPEDD research project which has been investigating delivery of an evidence-based parenting program for parents of children with a developmental disability (aged 2-12 years). In this research project, the Stepping Stones Triple P program was used.

Evidence clearly shows that the cost-benefit to the NDIA of ensuring availability of evidence-based parenting programs as a core component of the ECEI is potentially extraordinary. However, already the new arrangements of the NDIS have resulted in several organisations which successfully delivered Stepping Stones Triple P programs in the past no longer continuing to offer the program.

We therefore recommend that mechanisms incentivising the delivery of evidence-based programs be considered.

Benefits of delivering an effective parenting program as part of the ECEI approach include:

The cost savings to the NDIA:

- Reduced rates of families experiencing crises and requiring intensive supports to sustain their parenting role.
- Reduced service requirements by the person with the disability in adolescence and adulthood.
- Reduced chances of the person with developmental disability developing complex psycho-social issues, such as anxiety, which place a significant cost burden on the NDIS.

The benefit to the child with a developmental disability:

- Improved mental health and well-being throughout childhood and into adulthood.
- Dramatically reduced behavioural and emotional problems.
- Improved social adjustment and community participation skills.
- Improved participation in school.
- Dramatically increased chances of living a fully engaged life within the community in the longer term.
- Increased likelihood of the child remaining with the family until adulthood, and beyond if desired.

The benefit to the family of the child with a developmental disability:

- Once parents learn parenting skills and confidence, and understand their child's behaviour, they are set up to be able to deal with the child's behaviour for life.
 - Please review parent testimonial from Amanda Bates, mother of five (three with a learning or developmental disability), in the clip [Changing Lives "My house is very chaotic"](#)
- Reduced behavioural and emotional problems in the child with the developmental disability reduces the stress and burden on parents and siblings.
- Reduced behavioural and emotional problems in the child reduces family isolation and enables community participation.
 - Please review parent testimonials in the clip [Changing Lives "We can now go out together as a family"](#)
- Improved family economic circumstances.
- Improved parental work participation with substantial reductions in paid and unpaid absences from the workforce.

The benefit to the wider community:

- The person with a developmental disability is more likely to be able to engage with and participate in their community, thereby contributing to the richness of community life for all in the community, including workforce participation.
- Reduced chances of the person with developmental disability developing complex psycho-social issues that place a significant cost burden on various community services: NDIA, housing, health, welfare, justice etc.
- Improved parental work participation with substantial reductions in paid and unpaid absences creating economic benefit to the community.

The criteria used by ECEI plan developers to recommend services and supports needs to be 'interventions that are the most efficacious and the most cost-effective'. But plan developers can only recommend services and supports that they are aware of, and that are being provided in a way that is accessible for the family of the child with the disability.

Conclusion

Market forces alone will not provide the most efficacious, cost-effective, evidence-based programs for parents of children with developmental disabilities. Not enabling the widespread delivery of evidenced-based, cost-effective services and supports would result in a missed opportunity to reduce cost pressures on NDIA downstream and maximise potential community participation and life-fulfilment of children with developmental disabilities and their families.

Due to the enormous potential benefit to the person with disability and their family, as well as the extensive and significant cost savings for the NDIS, it would be negligent of the ECEI to fail to enable and/or incentivise service providers to deliver cost-effective evidence-based programs to children with developmental disabilities. It is also the duty of the NDIA to ensure such programs are included in the plans of participants of the ECEI Approach.

Professor Stewart Einfeld, Professor Matthew Sanders, and Emeritus Professor Bruce Tonge are available to the Joint Senate Inquiry for further input on this matter and can be reached by emailing fhs.steppingstones@sydney.edu.au

Issue:

Market forces will not respond to the cost-effectiveness of evidence-based programs as the entity that may incur greater costs outlay (the service provider) is not the entity receiving the cost benefit (the NDIA).

Recommendation:

Entity receiving the bulk of cost benefit of evidence-based services (the NDIA) provide incentives to entities that may incur the greater costs of delivering evidence-based services (the service provider).

Suggested actions with service providers:

- NDIA undertakes the responsibility for researching and assessing best options of cost-effective evidenced-based services and supports suitable for NDSI ECEI participants and provide this information to service providers.
- Provide funding for service providers for staff training and accreditation to deliver evidence-based programs
- Provide funding for service providers to enable cost-effective group delivery of evidence-based parenting programs for children with developmental disabilities

Suggested action with ECEI plan developers:

- Provide training for ECEI plan developers to educate parents of the value of cost-effective evidenced-based services and supports
- Provide training for ECEI plan developers on available cost-effective evidenced-based services and supports to recommend to the family of the ECEI approach participant.