Mental Health of Young People with Developmental Disabilities

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

Submission to the Productivity Commission's Review of the NDIS Costs

12 July 2017

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> 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.

The NDIS is a ground-breaking social reform that is to be commended and supported. Such an immense shift in service delivery can expect a challenging transition to full operational capacity. Designing the NDIS as an insurance scheme with benefits paid to individuals is an empowering move. For too long people with disabilities have not been able to exercise control over their lives as able-bodied and minded Australians do. 'Choice and control' is the right of every person with disabilities and that of their primary carers.

However, simply acknowledging someone has a right does not mean that right has been enabled. There is mounting evidence the NDIS structure of benefits paid exclusively to individuals is inadvertently disadvantaging the community it seeks to support and those most at need within that community.

Our field of expertise is children with developmental disabilities and their families and carers. However, we know that the issues addressed in this submission will apply to many other participants of the NDIS. We request that the Productivity Commission consider the applicability of recommendations within this statement to people with other disabilities and in other age groups.

We note with extreme concern that, since the introduction of the NDIS, delivery of evidence-based, proven-to-be-effective, community building group services has declined and almost ceased in some areas. We see this as happening for two reasons:

- Those developing NDIS plans with participants and their families do not know of the existence or efficacy of evidence-based programs
- Individual funding arrangements dis-enable the delivery of services and supports in cost-effective and community-building group-settings

Recommendation 1: Promote evidenced-based services and interventions

The impact for children with developmental disabilities as case study with wider relevance for the NDIS

Childhood is a crucial stage of development for all children, particularly so for children with developmental disabilities. The quality of support received early in life has a direct impact on the amount of care and support a person with developmental disabilities will require in adulthood. The quality of support will have an unequivocal impact on their capacity, and that of their family, to participate in community life.

Behavioural problems associated with developmental disability are a major cause of:

- Decisions by parents to seek out of home placement for a child with developmental disabilities
- Failure of group residential placement
- Restrictions in participation in recreational and educational programs
- Reduced occupational opportunity in the post-school period
- Social isolation for the entire family as well as the child with developmental disabilities
- High levels of parental stress
- Impaired parental capacity to interact optimally with their child
- Paid and unpaid absences from work for the parent

Non-evidence based interventions, even if delivered by well-meaning therapists and service providers, have significant potential to do more harm than good, advance behavioural and emotional problems and limit a child's ability to develop. The ability of a child with developmental disabilities to participate in community life and parental mental health is more closely linked to the severity of the child's mental health and behavioural problems than it is to the severity of the child's disability.

As a case in point: delivery of the evidence-based Stepping Stones Triple P Parenting Program as part of the NHMRC-funded MHYPEDD project has added to the body of research that shows evidence-based parenting programs benefit children with developmental disability in the following ways:

- Dramatically reduces behavioural and emotional problems
- Improves their mental health
- Improves their adjustment and participation
- Reduces the stress and burden on parents in the longer term
- Reduces family isolation and enable community participation
- Improves family economic circumstances
- Improves parental work participation with substantial reductions in paid and unpaid absences

A 'population-health' system of delivery that combines group programs with one-to-one interventions is the most cost-effective and community-building method of service delivery. Given this evidence, we would argue that facilitation of evidence-based interventions and supports in a group setting is a duty of care of the NDIA. It is also sound practice to ensure the economic viability of the NDIS.

It is imperative the NDIA has a mechanism to ensure that all stakeholders of the NDIS - participants and their families and carers, professional staff developing plans with participants, and practitioners and organisations delivering services - receive clear and empowering information regarding the high value of evidenced-based interventions, supports and programs. It is also crucial that parents of children with developmental disabilities know how to negotiate with the NDIS case manager for such programs to be included in the support package for their child.

Recommendation 2: Facilitate cost-effective and community-building group service delivery

Already the new arrangements of the NDIS mean that several organisations which have successfully delivered Stepping Stones Triple P programs in the past are no longer able to do so. Stepping Stones Triple P is just one example of a group-based service able to reach large numbers of clients at scale. A mechanism is required to enable organisations to provide evidence-based programs in a group or community setting.

Choice and Control

We recognise that NDIS participants are free to pool funds and thereby, theoretically, arrange group delivery of services. However, this only works when there are a number of participants who live near each other who have the necessary skills to negotiate with other participants and who also have the project management skills required to facilitate the delivery of a group service.

NDIS participants' facilitation of group-based initiatives would be highly unlikely in less affluent areas, areas of significant cultural and language diversity and entirely impossible in remote and rural locations.

Moreover, without detailed knowledge about childhood developmental disorders and evidence-based interventions, families would also have limited knowledge about the degree to which programs can support them or how to differentiate between evidence-based and non-evidence-based programs.

'Choice and control' for individuals under the NDIS is only possible if there is a choice. "*Exercising choice*", in the words of the NDIS Issues Paper, is only possible if there are two or more service providers of the same service or if there are two or more services that could provide benefit to the participant.

When there is only one service provider, or only one service or no service providers, or no group-based or evidenced-based services and no information about the efficacy of services available, individuals do not have choice and control simply because they can pay for services on receipt of an invoice.

All NDIS participants deserve a choice of high-quality services, not just those living in high density areas, living in high socio-economic areas, with high functioning life skills, education, social and professional networks and agency. When families are not able to organise and facilitate group delivery of services it is the duty of the NDIA to provide a mechanism to facilitate agencies to provide group programs for parents.

Conclusion

The empowering nature of enabling NDIS participants to exert financial control over their arrangements with service providers is commendable and should be supported. However, individual control of allocated government spending of disability supports does not, by itself, enable choice. In fact, the current funding structure is removing a level of choice from families of children with disabilities.

This matter is an equity issue. The current structure of the NDIS further disadvantages those who are already disadvantaged, families of children with developmental disabilities and, in particular, families of low socio-economic status, people with low education, people with mental health and psychosocial issues, people of culturally and linguistically diverse backgrounds and people living in remote and rural areas.

We strongly argue that a percentage of the NDIS budget must be spent on:

- Promotion of evidenced-based services and interventions
- Provision of clear and empowering information
- Facilitation of cost-effective and community-building group service delivery
- Enabling organisations to advocate for evidence-based, proven-to-be-effective services and supports

If the market cannot support provision of a choice of evidenced-based cost-effective services, it is the duty of the government to enable such a provision of services. Given the evidence of the returns on investment that evidence-based group-delivered interventions for children with developmental disabilities can bring, as well as the benefits to individual children and their families, there is a moral as well as economic imperative to ensure these families will have access to high-quality, cost-effective support.

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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

Professor Matthew Sanders, The 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

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Foundation Head, School of Psychology and Psychiatry, Monash University

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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