SUBMISSION TO PARLIAMENTARY INQUIRY ON NDIS PLANNING

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Organisation Information.

ISADD was founded in Western Australia in 1994, as the first service in Australia (and possibly the Southern Hemisphere) dedicated to delivering Early Intensive Behavioural Intervention (EIBI) for young Children with Autism. This therapy is based on the Applied Behavioural Analysis (ABA) approach pioneered by Ivar Lovaas at UCLA. Since then, ISADD has expanded to offer services in South Australia and Victoria. It also has links with associated organisations overseas. It has also expanded to provide services to all age-groups

It has been an approved provider with the Western Australian Disability Services Commission since 1998 when Autism-specific funding was introduced in that State. It is also an approved provider with the federally-funded (through DSS) Helping Children With Autism program.

Currently the organisation employs around 50 staff, and provides services to over 300 clients across Australia.

I would like to make five suggestions to the inquiry.

1. As a dedicated provider of Early Intensive Behavioural Intervention (EIBI), particularly in the early years we encountered many instances of scepticism and even hostility towards our approach. While over the past 30 or more years, the body of research has grown, and consistently shown superiority of outcomes of behaviourally-based programs compared with other therapy approaches, there remain some professionals who are reluctant to accept the evidence, and continue to promote/offer inferior (and some actually ineffective) treatments.

This reluctance to accept the evidence seems apparent in some NDIS planners, as is also ignorance of the research evidence. As long ago as 2011, a review commissioned by the then Department of Families Housing Community Services and Indigenous Affairs concluded that the only programs that were demonstrated to be effective for young children with an ASD, based on the research evidence were those that are behaviourally-based. (*Prior and Roberts 2011*). More recently, a study funded by the NDIS also identified behaviourally – based therapies as those with strong evidence of efficacy (*Roberts et al. 2016*). It is disappointing therefore to have heard of planners stating that "NDIS does not support ABA" and of others refusing to fund sufficient hours of therapy.

My first suggestion is:

> **Planners who are required to work with families with a child with Autism should be properly informed regarding evidence-based therapies, and the costs associated with funding these.**

2.It is well established that for maximum effectiveness, an EIBI should provide 20 or more hours per week of one-to-one intervention (*Roberts et.al*). As a properly implemented EIBI program, supervised by trained professionals and carried out by well-trained therapists can then easily cost more than $50,000 per annum, I am concerned that there have been numerous cases where funding for EIBI has been as little as $10,000 for one year. At the same time, I am also aware of a few families who have received in excess of $60,000 – a more appropriate figure. This discrepancy between funding amounts cannot be attributed to different levels of need; while research indicates children with autism respond to therapy at different rates, all need an initially high rate of treatment for optimal results.

My second suggestion is:

> **As a matter of policy, families should be provided with sufficient funding to cover the costs of a professionally-supervised EIBI program as indicated by the research evidence (20+ hours per week).**

3.The research on EIBI also indicates that the earlier therapy commences, the better the outcomes are likely to be. Also achievement of therapy goals occurs over shorter time spans the earlier the age at which therapy commences. No doubt the inquiry has had many submissions regarding delays in approval/receipt of funding, thus I will not add to this further other than to note that delays to receipt of funds in the case of young children with Autism have serious consequences in terms of the long-term outcomes of the therapy, and are also likely to result in higher costs as therapy will need to be continued for longer. (over 20 years ago, a U.S.A. study suggested savings of well over $1million over an individual's lifetime (Jacobson, J.W., Mulick, J.A. and Green, G. (1998) *Cost Benefit estimates for intensive behavioral intervention for young children with autism - general model and single state case.* Behavioural Interventions Vol. 13 (4) Nov. 201-226)

My third suggestion is:

> **Every effort should be made to make funds available to families as soon as possible after an Autism diagnosis.**

4. On a related matter, the NDIA has introduced a requirement for registered providers to be quality assessed/audited as a condition of registration. These audits are expensive, and beyond the financial reach of many smaller service providers. Anecdotally, I have heard that many of these providers have decided to withdraw – resulting in a reduction of already scarce resources available to NDIS participants.

For many years, the Western Australian Disability Services Commission has audited their approved Service Providers under a scheme known as "Standards Monitoring", under which the Providers are assessed against a set of Service Standards. This monitoring was paid for by the Commission, using independent Monitors.

My fourth suggestion is:

> **Consideration should be given to the NDIS funding the assessment/auditing of Service Providers, and a scheme similar to W.A.'s Standards Monitoring be examined as a potential model for audits.**

5. I am also concerned that that audits are focussed on *process*, and little or no consideration is given to *outcomes*. Achieving desired outcomes, and participant family satisfaction with the service provided, should outweigh process considerations in any evaluation of an organisations suitability to be a registered provider.

My fifth suggestion is:

> **Audits of Service Providers should focus on outcomes rather than processes.**

Thank you for receiving my submission

G. D. Cooper

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