

**Feedback from the Australian Advisory Board on Autism Spectrum Disorders
on:
The National Disability Insurance Scheme
*COAG Consultation Regulation Impact Statement***

Date: January, 2013

Feedback on Option 1 – choice limited to government funded providers

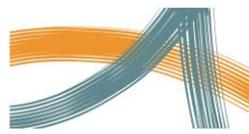
The Australian Advisory Board on Autism Spectrum Disorders acknowledges that Option 1 closely aligns with the way much of the current disability system is currently organised in Australia where service providers are block funded to provide services for people with a disability.

The COAG document clearly indicates this option is unlikely to be implemented as it does not align with the personalisation agenda of a NDIS based on individual funding packages for people with a disability. This option supports the existing service provider system and provides relative certainty in planning from that perspective. Notwithstanding the advantage this gives providers and the services that can be given to people with a disability, Option 1 is inconsistent with the fundamental aim of the NDIS, which is to give people with disabilities and their families' greater choice and control over the services they receive.

Feedback on Option 2 - Choice is limited to providers (including new providers) that meet regulatory standards

The Australian Advisory Board on Autism Spectrum Disorders proposes that Option 2 is the preferred approach even though it is more costly. It safeguards the human rights of people with a disability by ensuring there is a quality framework underpinning the services provided to people with a disability. The Board's experience of what happened through the implementation of the HCWA package confirms that this option should be implemented.

With the advent of individual funding packages (*Helping Children with Autism Packages*), service providers with specialisation in Autism initially had a large increase in demand for services, followed by a rapid decline in demand, as private practices began to offer therapy services at a reduced rate. These rapid changes in demand made service planning very challenging. Many private practices are able to offer cheaper services because they often do not pay for professional development of their staff or senior therapists to supervise their staff. The quality of services provided by clinicians can therefore be variable, as many therapists have entered the field with limited autism-specific experience and with little access to professional development or supervision. Non-government organisations with a track record for expertise in Autism have extensive disability-specific experience and knowledge. If these organisations ceased to provide services because disability-specific interventions are offered



by cheaper, generic service providers, the subsequent loss of expertise to the disability sector would ultimately have a negative impact on the quality of services.

As an Advisory Board that was closely involved in the consultations and scoping of the Helping Children with Autism Package, we recommend the need for regulatory standards. As mentioned above, the introduction of new government money in the form of individual funding packages resulted in many new service providers entering the market, some of whom offer therapy approaches that are unsupported by evidence. These services can be attractive to families because they are often cheaper (due to the lack of training and supervision of staff) and are cleverly marketed.

When FaHCSIA (Department of Families, Housing, community Services and Indigenous Affairs) became aware that some service providers were providing therapy which was unlikely to be effective and therefore were an inappropriate use of taxpayer money, regulations about whether specific types of therapy were eligible or ineligible for the *Helping Children with Autism* funding were developed (5 years after the commencement of the *Helping Children with Autism* programme). FaHCSIA commissioned a review of research to identify the most effective models of practice in early intervention of children with autism spectrum disorders (Prior, Roberts, Rodger, William & Sutherland, 2011) and the eligibility of interventions was based on this review. However, we are aware that some service providers have continued to use therapy approaches that are not evidence-based under a different name, in order to comply with the service eligibility standards. Regulatory standards should therefore include: (a) regular auditing of case files; (b) mandatory attendance by professional staff at approved professional development, and (c) mandatory regular supervision of professional staff by experienced clinicians.

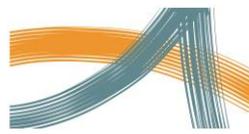
The NDIS Regulations Impact Statement implies that services are high-risk if the participants have a cognitive impairment, or are socially isolated. However, in our experience, services that require a high level of expertise are also high-risk. For example, speech pathology services that aim to develop a means of communication for a child who is non-verbal require a high level of expertise. If these services are provided by therapist without appropriate expertise, tax-payer investment into these services is likely to be wasted.

Ongoing benefits:

Option 2 would offer consumer choice, with safeguards to prevent service providers being funded for ineffective interventions. It would also enable service providers to deliver services according to need, as there would be greater flexibility to provide services where they are needed, rather than in the locations and in the form specified under block funding arrangements.

Ongoing costs:

Although the need to comply with regulations is time-consuming, the benefits outweigh the risks of providing unregulated services.



Impact financially and otherwise in transition:

Quality providers are accustomed to adhering to regulations, the change will be minimal. The cost would be in imposing the quality framework but this would be a better result for the person with a disability.

Feedback on Option 3 - Choice is unrestricted, except for higher risk circumstances defined by service type (personal care, for example) and the cognitive capacity of the consumer.

It is likely that many of the services would fall into the higher risk category. This includes therapy for young children with ASD that requires a high level of expertise, and respite and accommodation services for children and adults with ASD, due to the high prevalence of challenging behaviours in this population. These challenging behaviours necessitate extensive training in functional behaviour assessment and positive behaviour support. It is therefore recommended that all services meet regulatory standards as suggested in Option 2.

The issue is that federal government has in fact applied Option 3 to HCWA and although it has generated many more providers the level of service is very variable as we have highlighted above. Option 3 would lead to a further diminution of high quality services for people with a disability at the very time when the NDIS rhetoric is saying that things will be better for a person with a disability under this new framework. Quality service provision will only occur if it is regulated and safeguarded as proposed under Option 2.

Some services would be regulated and therefore quality assured.

Ongoing costs:

Those services that are not regulated will continue to be risky.

Feedback on Option 4 - There are no limits to consumer choice.

Ongoing benefits:

Option cannot be a serious consideration. The benefits of Option 4 are outweighed by the costs (see below).

Ongoing costs:

Following our experience with individual funding packages for families of children with autism resulting from the *Helping Children with Autism* Programme, this option is highly risky.

Conclusion

For the reasons indicated above, Option 2 is our preferred option.

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