



AUTISM BEHAVIOURAL INTERVENTION NSW

SUBMISSION TO THE PRODUCTIVITY COMMISSION INQUIRY ON DISABILITY CARE AND SUPPORT

16 August 2010

Background to ABI

Autism Behavioural Intervention NSW (ABI) is a charitable organisation that provides autism specific early intervention services for families with children that have an Autism Spectrum Disorder (ASD, referred to hereafter simply as autism).

ABI's programs are designed to empower families with the ideas and strategies to successfully support their child's learning and development and as importantly, the integration of the child into family and community settings.

ABI was first established in 2006 to fill a gap in the ability for families to access services in the outer suburbs of Sydney and more specifically, access services that were based on Applied Behaviour Analysis (ABA). At the time of ABI's establishment, ABA was only available through private service providers at a high cost to families.

ABA is based on well researched principles of behaviour and learning. Broadly, ABA refers to the application of the principles of behaviour to produce change. It is currently the best known method for teaching socially appropriate and functional behaviour and reducing problematic behaviours in children with autism.

ABI's Footprints – Stepping into Learning Program pioneered affordable ABA.

ABI is largely funded by the NSW Government through the Department of Human Services - Ageing Disability and Home Care (ADHC) for children under the age of 6 years. Through ADHC's funding, ABI has provided over 250 families with the Footprints program since 2006 and have increased our capacity to be able to provide over 100 families a year access to the service across Metropolitan Sydney and in Wollongong.

ABI's services are also available through the Federal Government's Helping Children with Autism package (HCWA). Through HCWA, ABI provides the Footprints Program, Behavioural Intervention services, Literacy Programs (MULTILIT), Occupational Therapy and Speech Therapy for children up to the age of 7 years old.

Autism Behavioural Intervention Association of NSW Limited
ABN 26 111 342 833

Suite 202/35 Doody Street, Alexandria NSW 2015
Phone 02 9669 2250 Fax 02 9669 2240
info@abinsw.org.au www.abinsw.org.au



What is the Footprints program?

ABI's Footprints program has developed a reputation as one of the most cost effective and outcome focused early intervention programs for children with autism. It is for this reason that it is also one of the most funded autism specific early intervention programs by the NSW Government.

The Footprints program is a home based (a cross setting based as opposed to a centre based) program for families over a 20 week period. It provides for theoretical and practical training for families and any other person that a child may interact with, the development of an individualized assessment and behaviour plan and then the implementation of that plan to achieve the family and child's goals. The individualised assessment and planning is done in collaboration with the child's family and may cover any of the following target areas: reduction of challenging behaviour, communication skills, increasing attention, pre-academics and academics, school skills, play skills, socialisation and relationship building, gross and fine motor skills, self help/independent living skills and community access skills

Hookway Family:

"It has been the best thing I have done with my daughter...my consultant has given me the confidence as a mum...it has been a life saver...ABI has changed my life"

Le Family:

"We believe anyone with a child with ASD should be given the ABI opportunity ASAP!"

Spaven Family:

"Life changing...it has given us the skills to move onto the next step. I now have him enrolled into preschool and he's doing really well, he couldn't have done this without ABI"

Leong Family:

"The program exceeded our expectations, we have used many programs and this one transformed our son"

Barrett Family:

"ABI has changed our lives, ABI made us realise it was not only Patrick that needed to change, we all needed to change so we could understand and help support him better. Within the first 2 weeks everything changed and I had a new son! ABI has given us the best gift of gift, our precious little boy...we were living a nightmare and we would still be there today if it wasn't for ABI"

Context of ABI's submission

As noted above, ABI provides early intervention services for children with autism. Our comments set out below have been deliberately limited only to those areas of disability services that we have had specific experience, i.e. autism and early intervention.

ABI offers the following comments in relation to the key questions raised by the Productivity Commission.

Who should be eligible?

Who should be in the scheme and how could they be practically and reliably identified?

- All people with a disability who need assistance with daily living tasks, including self care, communication and mobility should be eligible to ensure that all people with a disability and their families receive the support they require to be active, engaged, productive and participating members of the community.
- People with a diagnosis of an Autism Spectrum Disorder (ASD) as defined in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (known as DSM IV) should be considered as meeting the eligibility criteria. The three disorders usually referred to as ASD (hereafter referred to simply as autism) include Autistic Disorder, Asperger's Disorder and Pervasive Development Disorder not otherwise specified (PDD-NOS).

Autism is a distinct set of disabilities and all involve "severe and pervasive impairment". Autism is not "severe", "mild" or "moderate" autism, although parents, health professionals, journalists and politicians often describe autism in this way. For the avoidance of doubt, a person with an autism diagnosis under DSM IV should be eligible.

Autism is a life long disorder. While early intervention is crucial when a child is first diagnosed, intervention and assistance will be required for the life of a person with autism. A person with autism should therefore be eligible for life.

- A formal disability diagnosis (whether autism or another form of disability) is often difficult to obtain amongst indigenous and other cultural backgrounds. A formal diagnosis is often avoided or delayed to the detriment of the person with a disability. Such indigenous and other cultural backgrounds should be identified and a safety net should be introduced to ensure that the lack of a formal diagnosis does not prevent appropriate intervention and assistance being provided.

Which groups are most in need of additional support and help?

- All people with autism require additional support. Certain minimum levels of support should be established across the life of a person with autism, National Minimum Standard of Care.

These minimums are in some cases already established. In respect of early intervention, it is recognised that any child with autism requires a minimum of 20 hours a week of early intervention [refer Prior, M & Roberts, J. M. A. (2006). *Early intervention for children with autism spectrum disorders: guidelines for best practice. Australian Government Department of Health and Aging, Australia*].

Minimum levels of support will need to be established in respect of school age children and older people with autism. ABI offers no comment at this time in relation what these minimums should be.

- As discussed further below, the following groups of people are more likely to "miss out" on services and should be afforded a priority focus under an NDIS in any transition:
 - those living in outer metropolitan areas, regional, rural and remote areas; and
 - those from an indigenous or other cultural and linguistically diverse background.

What can be done about reducing unfairness?

- Through non-government (privately funded) services many children with autism receive the required minimum levels of support. For example, there are many families that pay in excess of \$60,000 per year for up to 40 hours a week of early intervention for their child. As a result of such a high cost certain social demographics necessarily miss out as they are unable to provide this level of intervention under the current system. This is clearly unfair for the families that cannot afford the private services. It is also unfair for the families that can privately fund the services, with many having additional mortgages or even accessing their superannuation to fund the services.

With an NDIS and a resulting National Minimum Standard of Care all families, regardless of their social demographic would be guaranteed a minimum level of support.

- There are challenges, however, in relation to implementation of an NDIS. There is a significant lack of capacity in the areas of early intervention, such that the availability of additional funding does not necessarily translate to an increase in services, as there are insufficient allied health professionals to deliver the newly funded services.

By way example, under the Helping Children with Autism package, additional Government funding often simply subsidises existing privately funded services.

Further, families in the outer suburbs of Sydney and families in regional and rural areas have continued to “miss out” on services, notwithstanding that they have funding available to them. Available services are concentrated in the inner city areas, rather than the hard to get to places.

With funding under the Helping Children with Autism package expiring in a 12 month period, many families end up spending their money on services they don't really want or need because the money is lost otherwise.

- Families from various social demographics, such as those from indigenous and other cultural and linguistically diverse backgrounds also continue to “miss out” as they find it harder to navigate the complicated systems in place.

The families that succeed best in the existing bureaucratic system are those that have the ability to advocate for themselves.

- It is imperative that in any transitional phase of implementing an NDIS that the families that have traditionally “missed out” are identified and given an appropriate level of priority.

Who gets the power?

How could people with disabilities or carer's have more power?

- A significant component of any NDIS must involve an individualised funding model. As a general comment, families are in the best position to decide the type and level of intervention required.
- Various safety nets must be put in place to ensure that appropriate choice is made available to all families and that families who are in need of assistance with choice have that assistance provided to them.

- While ABI supports individual choice, there are many early intervention programs that are experimental, are not evidence based and do not capture adequate data to demonstrate the outcomes of their programs. Consideration will need to be given as to whether individual choice should be extended as far as allowing individuals the right to choose such programs.
- To ensure the required significant increase in capacity is achieved, direct funding must be provided to organisations in early years. The success of an NDIS will depend on their being sufficient capacity and capacity building funding should be provided in the short term of an NDIS scheme. Overtime, such direct funding should be reduced or eliminated.

How should the amount of financial support and service entitlements of people be decided (and by whom)

- As discussed above, certain minimum levels of support must be guaranteed, a National Minimum Standard of Care. These minimum levels should be set by relevant professionals not the bureaucracy. In the context of early intervention for people with autism, this would be a panel of independent clinical psychologists and developmental pediatricians.

The cost of the National Minimum Standard of Care should then determine the minimum amount of financial support that is provided.

- A child and family's needs, however, do not stop with early intervention alone. Depending of family circumstances, additional support may need to be provided by way of respite or some other relevant service.
- The crucial point is that under the NDIS, the amount of financial support should not be set at a fixed dollar amount per person with a disability. The amount of financial support should be set by reference to the cost of the early intervention, respite or other services the person with a disability or the family of that person needs.
- While a review of funding is obviously necessary, a child with autism does not generally lose his or her diagnosis, so any review of funding should occur at relevant intervals not on an annual basis. Families must be afforded the comfort of knowing that the services are guaranteed at a particular level for 2 to 3 years.

What services are needed and how should they be delivered?

What kinds of services particularly need to be increased or created?

- ABI believes that the most effective intervention programs are those that are
 1. evidenced based;
 2. individualised (in that they are flexible in their approach and focus on the specific needs of the person with a disability and their family, rather than a predefined curriculum);
 3. trans-disciplinary (in that they focus across all areas of need, rather than limited to a single developmental focus, such as speech or sensory issues);
 4. cross setting focused (in that the intervention is considered in light of all the areas that a person is expected to interact, rather than focus singularly on the success of a child in say the school environment); and
 5. outcome driven/focused.

Any increase in services must meet these crucial criteria but above all must be evidence based.

- Early intervention services must be increased. As noted above, many families still “miss out” and moreover, most families do not access the recognised minimum level of services.
- Most government funded models of intervention are not funded to these required minimum levels and so existing models will need to be adapted and/or new models of early intervention and service delivery will need to be developed.
- The needs of a person with autism, however, do not end after early intervention. Additional services will therefore be required from a “whole of life” perspective – this means early intervention, at school, specific adolescent services, transition to work, at work (if possible), community participation (whether at work or not), supported accommodation (and support in accommodation) and ultimately retirement.
- Finally, interpretation services are crucial for families from CALD communities. The effectiveness of early intervention services is often reduced by lack of funding for interpretation services.

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

- Coordination: ABI has no specific comment in relation to the coordination of services, other than noting the inefficiency arising from the duplicity of function by Federal and State Governments and across the multiple departments that deal with certain aspects of a disability services.
- Cost (and quality): The key question to be asked is not the cost of any services but its effectiveness in the context of its cost. Too often issues of cost, and how much a Government is prepared to fund, drive down the quality of services.

Unfortunately, in NSW, ADHC monitor the cost of programs, the number of programs, waiting list lengths and times, locations of where services are provided and the social demographic of clients but they do not evaluate or measure the outcomes of the interventions provided. This has been equally the case for services provided under the Helping Children with Autism package. Greater evaluation and accountability is required in relation to the effectiveness of programs under an NDIS.

This evaluation must extend beyond a mere client satisfaction survey, as in an under funded industry that is suffering from a lack of capacity, often individuals and families are grateful for anything. This is not to say client satisfaction surveys should not be carried out and relied upon. However, independent professional clinical evaluations must also be made to ensure that individuals and families are receiving best practice services.

- Innovation: Often the best innovation in the disability industry occurs in the small community based organisations, these organisations (yes, such as ABI) grow out of parental discontent and dissatisfaction and adapt more readily to changing community needs and ideas. The preservation of such small organisations is important to maintain quality, responsiveness and innovation in the industry. Often, this necessarily comes at a higher cost but it is submitted with better cost effectiveness where clinical outcomes and client satisfaction is taken into account.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

- In the context of autism, an early diagnosis and early intervention is considered to give rise to the best possible outcomes for a person in life. This issue is considered in detail in *Early intervention for children with autism spectrum disorders: guidelines for best practice*. Australian Government Department of Health and Aging, Australia Prior, M & Roberts, J. M. A. (2006).

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

- As noted above, the NDIS must have a whole of life approach to the person with a disability. It is only through a planned whole of life approach that a person can appropriately transition from early intervention to primary school to high school and to work and so forth.

How can a new system ensure that any good aspects of current approaches are preserved?

- ABI has no comment at this stage. This is not to say that the current system has nothing worth preserving. The existing system has generated a number of incredible disability organizations, both large and small, and this knowledge, experience, enthusiasm and goodwill must above all be preserved.

What should be done in rural and remote areas where it is harder to get services?

- Services in rural and remote areas are often driven by chance, the chance that a person with relevant skills has chosen to settle in a particular area.

For ABI to operate in a rural or remote area, versus operating in a metropolitan or regional area is largely one of cost. To hire an individual, requires some certainty of demand, such demand is guaranteed in larger populated areas but more difficult in rural and remote areas. To this end, block funding or alternatively, the specific funding of positions is required, rather than reliance solely on a personalised service delivery model.

As a minimum, additional funding could be provided to compensate for travel costs and travel time.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

- ABI understands family's frustrations of duplicated assessments and questionnaires. That said, in the delivery of clinical service it is often paramount that the clinician make their own assessment of a persons strengths and needs, it is not possible to simply rely on assessments made by others. Obviously, an assessment of an autism diagnosis can, in most circumstances, be accepted but individual strengths and needs must often be assessed and understand separately before intervention strategies can be and should be implemented.

Funding

How should a new scheme be financed?

ABI has no comment at this time

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

ABI has no comment at this time.

Organising and implementing a new disability policy

What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?

ABI has no comment at this time

How long would be needed to start a new scheme, and what should happen in the interim?

- A national register for people with Autism should be established.
- Additional research should be undertaken in relation to the effectiveness of the various interventions that are being provided.
- As noted above, in the area of early intervention, ABI has concerns as to the level of capacity in the industry to meet additional demand.

Accordingly, in the interim, it is imperative that capacity building initiatives be implemented to ensure that organizations such as ABI and so many of our organisational colleagues in the industry are in a position to respond to the resulting increase in demand.

- Consideration should also be given to various industrial relation challenges, for example the disability industry competes for the employment of allied health professionals with the health industry but the health industry enjoys better award conditions than the disability industry. Improved award conditions may be required to entice people to the industry and/or maintain their employment in the industry.



Sam Lo Ricco

Director, Autism Behavioural Intervention NSW