

Parent Support Network



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24 February 2016

Submission S051

Received 03/04/2016

Family and Community Development Committee

Family & Community Development Committee
Parliament House
Spring Street
EAST MELBOURNE VIC 3002

Dear Inquiry Committee,

Terms of Reference: B: The availability and adequacy of services, and C: The adequacy of services under the NDIS.

I write on behalf of Victorian parents who are part of the Applied Behaviour Analysis (ABA) Parent Support Network. The ABA Parent Network is a community of parents who are all carers of children with autism and have implemented an ABA program with their child.

While we are a diverse group of parents caring for diverse children on the spectrum, we all agree that ABA is the most rigorous and most effective autism treatment. We further believe it should be available and accessible to all ASD children.

Health

Many of us have been frustrated with the response of General Practitioners and pediatricians who do not recommend ABA as an intervention. Our experience is they do not on-refer ABA for fear that parents cannot afford it, or because they are simply ill-informed about the positive, proven and documented life outcomes possible through ABA.

It is simply unacceptable that parents do not learn about ABA at diagnosis. Every parent wants access to the best available treatment, and every Victorian child has the right to the same. If parents were informed up-front about ABA we could prevent families from investing great amounts of time, money and effort into ineffective second-rate treatments that have no supporting evidence and no outcomes. Furthermore, uninformed parents are not able to advocate for ABA which creates a vicious circle of wasted time, money and life opportunity.

Education

The ability to access quality education for children with autism means that many of us have taken drastic actions. We've moved house to be closer to services, we've written letters to local and state

"Applied Behavior Analysis is the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, *and to demonstrate that the interventions employed are responsible for the improvement in behavior*" (Baer, Wolf & Risley 1968).

In regard to autism, ABA therapists and Service Providers seek to improve behaviour across three developmental domains: communication, social, and behavioural. Globally, hundreds of thousands of families use ABA as their preferred autism intervention.



members to get
begged school

Autism Behavioural Intervention
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support, and we've
principals to help us
help our children. In regard to schooling, finding a school that will not only accept ASD kids but help them learn and thrive is extremely difficult.

We parents of ASD children want private schools to be mandated to accept children with disabilities. We want public schools to welcome children with autism rather than provide excuses to parents on why our children can't attend or won't be well-supported. Schools that support children with ASD have far too few places and they rarely understand ABA practices or allow ABA therapists in the classroom. These schools should be provided with ABA training so they can be the change agent for creating better outcomes for ASD children.

In addition to access and training, teachers and aides are generally untrained in autism. They do not understand ABA's effectiveness, evidence-base, and the huge uptake rates (and mainstream acceptance of the therapy) in other western nations. As parents of children with autism, we hear (all too often) of our children being excluded from the classroom, or being coerced into engaging in accommodating practices that prevent learning. Rather than intentional, we know this is a result of teachers' uncertainty about autism and their lack of effective strategies and skills to deal with ASD behaviours. Imagine if all teachers were 'autism proficient'. This would benefit all children because class teachers would have more time and energy to help everyone as disruptive behaviours were eliminated or minimized.

Disability Services

Parents have mixed feelings and experiences about the quality of disability services. Public services—whether local, state or federal—are confusing and disjointed which makes it difficult to know how to access services or even what is available. The simple act of accessing Medicare and Centerlink services requires multiple forms, hours of writing and box-ticking, a tax accountant, and a degree in English!

Autism families need simple, plain English forms that outline all available services and connect the sectors. We have children with autism! We don't have the time or energy to complete a dozen different forms, and read service booklets and pamphlets written in jargonistic language and bureaucratese.

Our experience as autism parents also shows that private ABA Service Providers are generally excellent, however, the intensity of ABA makes it extremely expensive. This expense prevents many families from being able to do any ABA hours, or it forces them to implement their own [second-rate] ABA program which is rarely successful.

"Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning and appropriate social behavior" (Mental Health, A Report of the Surgeon, 1999).

Within our own network we have parents that have moved from regional areas to the city to access better-quality ABA services. Other parents have sold their home, taken a second job, or accessed their superannuation in order to afford ABA. **Please note: We do not regret these measures.** The outcomes are worth the sacrifice 100%. However, in a wealthy, developed country like Australia is it simply not fair that wealthy families can access an effective and known intervention but poorer families cannot. Nor is it fair that parents with a special needs child correspondingly face massive financial consequences. While we have personally incurred these financial costs, we have saved the government money because ABA is an effective early intervention measure and most of our children will not require lifelong welfare support. Additionally, most of us [parents] have been able to regain employment and taxpayer status.



Sport

Inclusive sports providers, and those that accept children with autism, get inundated because parents want their children to have access to the same sporting opportunities as any other child. For reasons of convenience and community, many of us would like to access a local sport but we are turned away because organisations do not have the resources or training to include our children. Providers of these extra-curricular are rarely (if ever) trained in ABA so they are unable to apply the principles which would make their programs more inclusive.

Employment & Housing

As parents of young children this category does not yet apply to us. However, we worry constantly about our children's future, about their employment opportunities, their place in society, how they will be housed and cared for when we are no longer around. And while ABA provides us with confidence because it has taught our children independence, we know that adults with autism are predominantly unemployed or under-employed. They are often forced to remain at home well into adulthood. Services that help adults with autism find meaningful work, programs that help ASD adults continually grow their independence will be a significant need in the next decade.

Conclusion

ABA breaks tasks down into microscopic details (discrete trial training). It doesn't just teach the child to cross the road, or sit quietly; it teaches the child how to learn, and how to apply this learning to a variety of real-life situations. ABA also teaches the family how to deal with the daily challenges inherent in autism.

ABA gives children with autism the ability to access mainstream schools and the chance to learn. It gives families a more comfortable home life, and parents the opportunity to return to their profession and make a meaningful social contribution beyond the family home.

In summary, we are extremely grateful that we somehow (and seemingly against the odds) gained access to ABA. Without ABA many of us would be caring for a dependent child; to the detriment of the child, our families, and society at large.

We believe, despite the incredible financial costs that we have borne, that ABA is the best possible intervention for our children, for our families, for our communities, and for ourselves. Please help all families with autism by providing access to ABA. Money spent early on ABA therapy will alleviate lifelong care for many, and additional taxes for you and I and other Australians.

I am most eager to speak at the public hearing to share my own ABA/autism story, and to relay the stories and experiences of other ABA/Autism parents.

Regards

Sarah Wilson

CONVENOR - ABA PARENT SUPPORT NETWORK

ABIA PRESIDENT

AUTISM BEHAVIOURAL INTERVENTION ASSOCIATION