

Submission S096

Received 22/04/2016

Family and Community Development Committee

Dr Anna Middleton

28/02/2016

Submission to the Inquiry into Services for people with Autism Spectrum Disorder

SUMMARY

Early Intensive Behavioural Intervention (EIBI) using methods such as Applied Behaviour Analysis (ABA) is recommended best practice for autistic children. Access to ABA for pre-school and primary school children with autism should be made available through adequate funding. The Helping Children With Autism package, in particular the \$12000 grant and the Autism-Specific Early Learning Centre (ASELCC) are grossly inadequate to meet the needs of Victorian autistic children. The government-funded Early Childhood Intervention Services (ECIS) should not be seen as a form of therapy or a substitution of EIBI. My submission is based on my experience as the parent of a 4-year-old autistic child and a General Practitioner.

Dear Sir/Madam,

I am the parent of a 4-year-old child with autism who is enrolled in an intensive early intervention program.

OUR EXPERIENCE OF ABA THERAPY

When my son was diagnosed at age 2 and 10 months, my husband and I received little guidance on how to help him. We were told to try the usual triad of speech therapy, occupational therapy and psychology, however after a few months of this approach we could not see much improvement in his challenging behaviours and communication difficulties.

We then commenced an intensive behavioural program (based on ABA) and immediately saw positive changes. ABA involves formulating specific goals and working towards them with clearly defined steps until they are attained. Over the last few years, via an ABA approach, my son has succeeded in many areas including communication skills (such as holding a conversation), social skills (joining in games with other children), daily living skills (toilet training, dressing) and fine motor skills (such as drawing and writing).

Intensive early intervention consisting of 20-40 hours per week has been recommended as best practice.

FUNDING AND AVAILABILITY OF ABA

The annual cost of my son's therapy program (accessed through a private provider) is \$65,000 - \$70,000. We drive an hour each way to access this therapy. The Helping Children with Autism (HCWA) Package has contributed a total of \$12000. The remainder of the cost is covered by my husband and I and our extended family.

Given this, I see the offering of \$12000 to be grossly inadequate.

The ASELCC, which was also set up as part of the package, is a subsidised childcare and therapy centre offering intensive behavioural intervention. This would have been an ideal setting for my son, and is located close by. Given the extremely limited number of places available, my son was never offered a spot despite being on the waitlist for 2 years. We received an email from the ASELCC late in 2015 stating that they would now be prioritising children under 4 (as their therapy model targets very young children), so my son would never be granted a spot. In fact, the longer a child is on the waitlist, the less likely they are to secure a position there.

Thus, while the ASELCC is a fantastic centre, it does not help more than a handful of autistic children and their families. In addition, given that the particular branch of intervention is targeted at very young children (so older preschoolers, particularly those preparing for school entry, are denied enrollment) I do not believe that this particular centre is inclusive enough to be provided with the entirety of government funding for centre-based therapy.

INADEQUACY OF ECIS AS A SUBSTITUTE FOR THERAPY

The other government-funded service available to young children with autism is the Early Childhood Intervention Service (ECIS), which sends a 'key worker' around on a regular basis (fortnightly or so) to the family's home. These visits are supposed to be spent developing goals with the family and brainstorming strategies on how to implement them. We were involved in ECIS for a term. During that term, we came up with 3 goals (relating mainly to improving my son's behaviour). By the end of the ten-week term there were no strategies or ideas provided on how to work on these goals. In contrast, our (then home-based) ABA program in the same time period had set over twenty goals, with a clear pathway of how they were to be achieved, and some of the most challenging behaviours had been conquered (for example, escaping onto the road).

For some families, ECIS may be very helpful in generating ideas and getting help to navigate the system of trying to get help for autistic children. However it should not be seen as equivalent to therapy, and especially not as comparable to intensive early intervention such as ABA.

UNAVAILABILITY OF BEHAVIOURAL INTERVENTION IN SCHOOL

ABA is a therapy that can be used in the school setting. Moomba Park Primary School in Fawkner utilises ABA therapists in classrooms and the playground to facilitate appropriate behaviour, engagement in the classroom, and social interactions. I have spoken to the principal about enrolling my son there; however we do not live in the catchment zone. I have visited around 6 local schools regarding enrolling my son for next year and the only way we can access ABA in the classroom is by employing a private therapist; this option

was only offered to us at a private school which did not otherwise seem very inclusive of children with disabilities. The school we have chosen to send my son to will not permit a private therapist, but was the only school (amongst those I visited) which I felt openly welcomes students with disabilities rather than seeing them as a burden.

RECOMMENDATIONS

In my opinion, the future of autistic children and the wellbeing of their families would be vastly improved if the following were offered:

1. Funding for each child diagnosed with autism to receive 20 hours per week of Early Intensive Behavioural Intervention (or similar) until primary school (particularly the provision of this in a daycare setting similar to the current ASELCC); and
2. Funding for each primary school child with a diagnosis of autism to participate in a school-based ABA program, such as that offered at Moomba Park Primary.

Regards,

Anna Middleton

Dr Anna Middleton