

Inquiry into services, support and life outcomes for autistic people in Australia

Terms of reference addressed by submission:

Productive and meaningful ways to improve services and support for autistic people in the areas of education.

Specific focus for submission:

Early-life education to enhance learning, social development, and emotional resilience in children with autism. This submission recognises that effective early education will also impact healthcare in relation to mental health and minimisation of 'challenging' behaviours which are known to limit child age-appropriate activity participation and inclusion in wider learning communities.

It is important to emphasize that, despite the focus on early education, a solid programme holds promise for creating life long benefit to protect the child from later adverse mental health and social experiences.

1. Receiving the diagnosis and beginning the search for effective therapy and intervention;

There are not enough early intervention programs.

Our son, Ashton, was diagnosed in 2016 at two years old.

At the time of diagnosis, our son couldn't tell you he was hungry, thirsty, tired, or sad. He couldn't tell you if he was hot or cold or even if he was happy. Ashton couldn't look at us, recognise us, or even his twin sister.

It took 18months from when I first raised my concerns to when he was officially diagnosed. This is far too long.

We were told Ashton had an autism disorder. "Early intervention is the key."

These were the words we heard repeatedly. We were told that 15 to 25 hours of intensive intervention each week is needed for a positive outcome. Ashton may need speech therapy, occupational therapy, and psychologists.

We just had to do it; there was no thought that we could not or would not. From a financial perspective we could fund his treatment, there are many who cannot. We needed to ensure Ashton was on the best pathway he could be on. He needed to find HIS 'place' in the world.

We have learnt a great deal and from this experience has come a clear understanding that parents of autistic children and the children do not have enough support and help with access to funding, namely the inadequacies of the NDIS and Inclusion support Qld.

My heart is heavy when I think of the struggles for the families in the local ASD community. My husband and I were compelled to do something that will give these children a chance to find their place in this world. Thus we started a foundation to support children with Autism.

Lack of proven early intervention programmes backed by ongoing research

2. We realised that Ashton's opportunities for help (because we had the means to pay for it, if it was available, which it was not!) were not reflected in the lives of other young autistic children who were receiving inadequate intervention or placed in general childcare/preschool programmes where educators' understanding of autism and capacity for meaningful assistance were low. This situation causes adverse consequence not only for the child (e.g., restriction, isolation) but also families who were often asked to remove their child because they found it difficult to cope with the stress of continued complaints and negative feedback on their child;

For point 2 above, parents of autistic children experience greater levels of anxiety, depression, and stress than parents of children with Down Syndrome and behavioural disorder (Dumas, Wolf, Fisman & Culligan, 1991).

In a study of parents in Australia, mothers and fathers reported clinically significant anxiety and depression between three and five times the rate reported in the normal adult population (Bitsika, Sharpley & Bell, 2013)

During my research after my sons Autism diagnosis I found there was only one programme on the Gold Coast that would be available that was inclusive, this had places for 16 Autistic children and often had a wait list they ran an "ABA" (applied behaviour analysis) programme, their practices did not suit my child.

There was one other and that was AEIOU, which was a non inclusive programme which again was not suitable as I wanted my child to be in an inclusive programme so he could be with his peers when the opportunity was there and when he was able to cope.

In 2012, the authors of the Australian Government Guidelines for Good Practice noted:

"Only a small number of autism treatment programs have direct research evidence supporting their effectiveness, and there is continuing need for further research. Most interventions have not been evaluated adequately and many have not been evaluated at all.

Several years later, the situation is unfortunately not a whole lot better.

Until recently, families received limited early intervention funding through the Federal Government's Helping Children with Autism (HCWA) package, which could be used to access services provided by HCWA-registered providers. Now, as the National Disability Insurance Scheme (NDIS) is rolled out throughout the country, most families are transitioning to this scheme. More information on the transition process is available on the Department of Social Services website."

There's no getting around it — intensive early intervention is expensive. For it to be effective the therapist: child ratio should ideally be 1:1 but at minimum 1:3. These teachers, therapists, and child-care personnel should be specifically trained in working with children with autism, have knowledge and skills required for their special needs

(Early Intervention for Children with Autism Spectrum Disorder: 'Guidelines for Good Practice' 2012. Margot Prior and Jacqueline Roberts)

Unfortunately, many providers are still not offering families anywhere near the recommended 20 hours a week of high quality, autism-specific early intervention.

Previously, the cost of intensive early intervention meant it was beyond the reach of many Australian families. It was hoped that the introduction of the NDIS would mean that all young children with autism would be able to have access to fully-funded early intervention programs.

Regrettably, this is not proving to be the case, with many families still finding they have to fight for their entitlements. (Autism Awareness Australia. 2018, www.autismawareness.com.au/therapies/early-intervention/)

What we have introduced, as individuals, being Ashton's Place, a not for profit organisation that supports children with Autism, needs support and research and should be a collaborative approach with Government participation.

Because of the lack of programmes on the Gold Coast, I decided, with the support of my husband that we needed to develop a programme that was inclusive and was in mainstream early childhood education and care services and that also had the ability to train staff and highlight the awareness of Autism.

Ashton's Place is a foundation that supports children with Autism. ACE (Autism Connect Early) is the early intervention programme, funded by the foundation that is backed by the University of New England to ensure ongoing research into the programme.

The Autism Connect Early (ACE) programme is focused on using research evidence to develop innovative educational approaches for children with autism. To achieve this, we have partnered with the University of New England (UNE) to embed continued review and evaluation across ACE activities so that we obtain an objective measure of how children are developing and growing. UNE will also be involved in professional development of all staff to ensure they have intensive early intervention training that gives them the resources required to be informed educators delivering a proven outcomes based programme.

The ACE programme was implemented in an early childhood education and care service on the Gold Coast in July 2019.

ACE aims:

- a. Meaningful inclusion based on autistic children's' competencies, interests, and tolerances with a focus on 'whole child' and 'whole world' learning experiences;
- b. Skill-building across key domains such as physical, sensory, social by exposing children to a range of age-level and developmental-level experiences involving play, movement, pre-academics; and
- c. Learning via social connection and relationships with educators and peers.

NDIS obstacles; Cost of ASD

Results from Australian Research -----"The median family cost of ASD was estimated to be AUD \$34,900 per annum with almost 90% of the sum (\$29,200) due to loss of income from employment. For each additional symptom reported, approximately \$1,400 cost for the family per annum was added. While there was little direct influence on costs associated with a delay in the diagnosis, the delay was associated with a modest increase in the number of ASD symptoms, indirectly impacting the cost of ASD.

Conclusion of the study. A delay in diagnosis was associated with an indirect increased financial burden to families. Early and appropriate access to early intervention is known to improve a child's long-term outcomes and reduce lifetime costs to the individual, family and society. Consequently, a per symptom dollar value may assist in allocation of individualised funding amounts for interventions rather than a nominal amount allocated to all children below a certain age, regardless of symptom presentation, as is the case in Western Australia." 1

1 Results from Australian research. Published online 2014 Sep 5 . doi: 10.1371/journal.pone.0106552 Cost of Autism Spectrum Disorders Chiara Horlin, 1 Marita Falkmer, 1 , 2 Richard Parsons, 1 Matthew A. Albrecht, 3 and Torbjorn Falkmer 1 , 4 , 5 , * Jennifer Gladys Mülle, Editor

We were told from an NDIS representative that because the service comes under the education sector and that it gets its own funding from that department that parents are not entitled to funding in the service for the extra care that is required for an autistic child.

If we are to support families so they may work while their child has access to what they require for an effective early intervention programme then we need to provide, speech therapy- occupational therapy - psychologist –extra staff for 1-1 or 1-2 ratios - sensory areas and programmes that meet their sensory needs and that cater to their ability to process information once they have learned it and to also meet their individual developmental needs.

Further investigation into what is available through the NDIS has revealed there is availability of funds, but that NDIS representatives do not provide the information. Even when parents are trying to complete the plans there is no guiding of what they can claim for or what they can access. Ashton's Place has provided funding to a person with knowledge of what is required to complete the plans and what they are entitled to, to ensure they get what they should for their child's education.

This is most distressing to see the lack of consideration for families from NDIS representatives.

Inclusion support programme QLD – putting up barriers to the service and the ACE Programme.

(Even if you are approved for support then it doesn't matter whether you have 4 or 8 children with a disability, in our case Autism, then you can only have one support person paid for to cater to the needs of these children who require 1/1 or 1/2 ratios for support. So unfortunately even with this Government initiative it is not possible for Early childcare centres to enrol these children. These children and their families have nowhere to go if we do not support them. Imagine Nerang already has a waitlist.

Australian government department of education, skills and employment state;

"The Inclusion Support Program is designed to assist child care services to include children with additional needs by providing tailored inclusion advice and support from contracted Inclusion Agencies as well as funding to address more challenging inclusion barriers.

It funds providers to **build** their ability to include children with additional needs in mainstream services so that these children can learn and develop alongside their peers."

Imagine childcare and kindergarten Nerang is an early childhood education and care service that has a goal to " build our ability to include children with additional needs in mainstream services so that these children can learn and develop alongside their peers" (as stated by the Australian Government department of education, skills and employment.) with the support of Ashton's Place and the introduction of the ACE (autism connect early) programme which is an early intervention programme for children on the autism spectrum, developed in partnership with The University of New England.

Lack of funds or support from existing Government initiatives that are not successful!

Nerang has been trying to get access to funding for one extra staff person in a room where we have 8 autistic children with the majority at level 3. The service only wanted one extra person to assist in meeting this goal. The service has put on extra staff at its own cost. The service has 4-5 staff at any one time for 8 autistic children, running an early intervention programme in partnership with the UNE research department, following the eylf guidelines, the kindergarten guidelines the governments recommended inclusion policy for children with a disability by offering a 1-2 and sometimes 1-1 ratio to be able to help these children and their families.

Why we need this!

An autistic child was in a service (one of many) with 30 typically developing children and was unable to cope because of sensory issues, developmental delays. One child of many across Australia. Most of the parents enrolled in the ACE programme had the same experience. The Imagine Nerang service enrolled the child and many others to ensure that they were cared for in a service that could ensure best practice was implemented.

An inclusion programme was established that allows these children to gently assimilate into a typically developing kindergarten programme thus ensuring positive outcomes for children allowing them to be able to have the skills necessary to enter mainstream school.

Inclusion for a full day in a typically developing children's room with typically developing peers is not possible in the beginning for some children and never for others. They need areas where they can be in their own environment to be able to regulate themselves to then be ready to go into the typically developing children's classroom and the ISS(Qld) funding representative wanted the service to take away their carers or their 1-2 or 1-1 ratio and put the children with autism in a typically developing children's room so they could be assessed for a few hours, (to see how they coped, when it is very evident they cannot!) one of them was my son. He was taken from his one on one carer/educator and expected to be placed into a room in a child care service where the ratio is 1/12 - I observed him climbing on furniture, trying to get out windows, trying to open doors, pulling equipment out and climbing up book shelves, all of this anxiety and distress placed on him and others by the ISS representative just so he could be observed in a typically developing room so she could confirm whether he and the other children could cope or not. She did not consider safety of these children and because we had already hired extra staff to care for these children it was deemed that no extra funding was approved because we already had it?????

Just to be sure we had all staff watching the children from outside to ensure their safety and we stepped in if we felt that it was necessary.

It has taken months of discussion and we still have no answer of support from Inclusion Support QLD. If the government's representative is unable to interpret the guidelines then while we wait we are causing serious harm to these children if we don't step in and fund their care.

The ISSQLD reasons for so far not giving funds for a support person are that the Autistic children are not in a typically developing children's room with typically developing children all day!! Not possible if you know anything about autistic children.!

Be clear these parents have nowhere to go!!

I have read some of the submissions and have seen a pattern emerging that points to depression, anxiety, mental health issues as these children become adults because not enough emphasis has been placed on offering appropriate programmes for these children at an early age. The Cost to society is great and the cost to the individual even greater.

3. We have been prompted by the lack of funding and resources available to early childhood education and care services to set up Ashton's Place and develop the ACE Programme. The latter in partnership with researchers from the UNE, Dr Vicki Bitsika, Professor in Biomedical Sciences and Dr Christopher Sharpley, Professor in Neuroscience to embed continued evaluation and refinement to processes.

There is a huge need for more proven early intervention programmes (we use proven early intervention models as well as partnering with UNE to do research so we may implement best practise and proven programmes for these children.

**Reasons why NDIS is not supporting these children's needs and their families!
Things need to change!**

Environments are inadequate in early childhood education and care services.

Autistic children need very specific environments to be able to learn adequately. Early childhood education and care services are not equipped to be able to provide care for these children in a typically developing children's classroom. The children have sensory issues, they need clear spaces they need quiet spaces they need areas where they can regulate themselves. A typically developing children's classroom in an early childhood setting is not equipped to be able to cater to the needs of these children. Autistic children need to be able to be in an environment that is conducive to their way of learning. Once they have accomplished certain tasks or activities they then need to have those activities or tasks introduced into typically developing children's classroom environments and with typically developing children. This assimilation needs to be over time, regular intervals repeated each day so that they can become familiar with the surroundings thus ensuring the goal and that is to be able to have inclusive classrooms. It's important that as you introduce the autistic children into a typically developing children's classroom with typically developing children that you have also been able to educate the typically developing children in this class to be able to be understanding of the autistic children and so our goal and our hope is that by the end of kindergarten year or preschool year that both groups of children are able to work together in an environment that is conducive to learning and with empathy and understanding from both parties. But inclusion can't just happen immediately when an autistic child is enrolled into an early childhood education and care service they need time, they need space they need one on one attention.

If there isn't any help, if there isn't any funding available then this is not possible. a child going into a typically developing children's classroom just cannot cope, they are unable to complete activities, they need one on one help to be able to assimilate into the classroom, they need one on one help until they are able to accomplish activities with their peers and they also need to have had the experience of being able to accomplish cognitive activities and physical activities etc. before they are able to be inclusively involved in a typical classroom for the full day.

The ACE program aims to be able to introduce these children into a typically developing children's environment on a regular basis but then being able to go back to the familiar environment to be able to process the information that they have been involved in and then continue again the next day through repetition, doing the same process but changing it up a little bit each time to ensure that when children go into any area that they're able to generalize and understand that they can do those things in a number of environments.

The ACE Programme has had negativity and pushback from the education department QLD where representatives who were called in to review the programme, which mapped to all the required guidelines, for assessment and ratings, advised the service that it would be best if we build a building next door and bring them (being the autistic children) on excursions to the service then we could implement any programme we liked!! How is that following the Governments set inclusion support policy!?

Early childhood education and care services need to change.. The physical space needs to change .. The education for staff needs to change for these children and others with disabilities.

Governments need to be proactive and make change happen. How many inquiries does it take?

Ashton's Place is providing a programme in partnership with UNE that will work on implementing proven outcomes for early intervention programmes. The findings will be based on research conducted over an initial five-year period and hopefully beyond.

A strategy ;

What would make a difference?, A Framework to guide programmes.

I believe we have to have a framework, so that's what we have to put in place, the framework and then we need to have documentation that identifies how much money is spent now on health issues, the key to it is a economic assessment so the government can see that by spending the money now they will save the money in the future. There is research that has already been done!!

There are already research papers available (Synergies Economic Consulting Pty Ltd www.synergies.com.au : Australian Government Australian institute of family studies.)

We need to translate that research into cost of Autistic children in an early childhood education and care services re actual service fees and the government can understand that because we already have the funding within the service we just need a new category, instead of just ISS funding there should be a funding category for children on the spectrum as long as they're working within the approved new framework and the "Early Intervention for children with autism spectrum disorders: Guidelines for Good Practice" (Prior and Roberts 2012) focusing on interventions for children under seven years old and then what's the cost that families would need to pay and what would government contribute to for that particular arm of that particular funding..

Approved framework for autism

We need to have an approved framework that can be in place in early childhood education and care services across Australia so that much needed early intervention can be implemented across these services giving consistency.

Until that can be approved through the National disability insurance agency (NDIA) and ACECQA then we need to be able to be guided by the approved frameworks that exist and the "Early Intervention for children with autism spectrum disorders: Guidelines for Good Practice" (Prior and Roberts 2012) focus on interventions for children under seven years old

Training

Professional development training. This needs to be conducted for all staff, to bring awareness and to be able to provide children in care the necessary resources and implementation and understanding of these resources.

Ashton's Place a not for profit organisation is already in the process of doing these things but it needs to be wider spread. We can only achieve a fraction of what could be achieved by an understanding and a call to action by the relevant Government departments.

Look at the research that has already been done and still those recommendations go unheeded.

BENEFITS OF EARLY INTERVENTION

There is increasing recognition that the first few years of a child's life are a particularly sensitive period in the process of development, laying a foundation in childhood and beyond for cognitive functioning; behavioural, social, and self-regulatory capacities; and physical health. Yet many children face various stressors during these years that can impair their healthy development. Early childhood intervention programs are designed to mitigate the factors that place children at risk of poor outcomes. Such programs provide supports for the parents, the children, or the family as a whole. These supports may be in the form of learning activities or other structured experiences that affect a child directly or that have indirect effects through training parents or otherwise enhancing the care-giving environment.

As part of a recent study, RAND researchers synthesized what is known from the scientifically sound research literature about the short- and long-term benefits from early intervention programs, the features that are associated with more-effective programs, and the economic gains that accrue from investing additional resources in early childhood. We summarize those findings here.

Key findings:

- Early childhood intervention programs have been shown to yield benefits in academic achievement, behavior, educational progression and attainment, reduction in delinquency and criminality, and improved labor market success, among other domains.
- Interventions with better-trained caregivers and smaller child-to-staff ratios appear to offer more favorable results.
- Well-designed early childhood interventions have been found to generate a return to society ranging from \$1.80 to \$17.07 for each dollar spent on the program.

This research brief describes work for RAND (Research And Development) Labor and Population documented in *Early Childhood Interventions: Proven Results, Future Promise* by Lynn A. Karoly, M. Rebecca Kilburn, and Jill S. Cannon, MG-341-PNC, 2005, 200 pages, ISBN: 0-8330-3836-2 ([Research Brief](#)) is also available from RAND Distribution Services (phone: [310-451-7002](tel:310-451-7002); toll free [877-584-8642](tel:877-584-8642); or [email us](#)).

Guralnick posts a set of early intervention principles that in his opinion, appear to have achieved international consensus:³²

1. a developmental framework informs all components of the early intervention system and centres on families
2. integration and coordination at all levels of the early intervention system are essential
3. the inclusion and participation of children and families in typical community programs and activities are maximised
4. early detection and identification procedures are in place
5. surveillance and monitoring are an integral part of the system
6. all parts of the system are individualised
7. a strong evaluation and feedback process is evident
8. true partnerships with families cannot occur without sensitivity to cultural differences and an understanding of their developmental implications
9. recommendations to families and practices must be evidence based
10. a systems perspective is maintained, recognising interrelationships among all components.

(Synergies Economic Consulting Pty Ltd www.synergies.com.au)

We need money now for research into autism and resources to be able to support those in need ...

Synergies Economic Consulting Pty Ltd suggests;

Investment in strategies that could potentially alter the outcomes for at least some children with ASD, such as best practice early intervention. In particular, if this improves educational and employment outcomes for even a small number of people, the benefits (via reductions in costs and improvements in quality of life outcomes) will be sizeable.

(Economic Costs of Autism Spectrum Disorder in Australia (updated study) April 2011 Synergies Economic Consulting Pty Ltd www.synergies.com.au)

The information below is what Ashton's Place has presented to the University of New England. This proposal is now in place and I believe a model of this nature is what is needed to bring about societal change for the better for Autistic children and their families for a positive future, so their children may grow up with the foundations set.

The research aims will be to:

Develop an early intervention model/programme, ACE _ Autism Connect early _
The model/programme must take all areas of development into consideration providing a strong Individual profile taking into account the child's interest areas so all involved understand the children's needs and those of the family however, this model will have a focus on;

- Arousal – anxiety levels

- Social aspects with peers and key staff

- Connections importance of key staff

- Structure and routine that has a focus on change to ensure adaptation of the environment and social aspects that a child is faced with

- Environments carefully planned to ensure balance in all sensory areas

- We plan to implement effective models of practice to ensure we have a programme that is relevant and one that meets the needs of the individual child and their families.

- Strong links with home and the ACE model so parents are able to build a supportive network. Key to successful early intervention is to give parents effective tools to be able to manage at home

- It must have a practical focus – the outcomes of the research must be able to be practically applied to ensure the greatest impact on these children, and those into the future, it must focus on preparing them to be functioning members of society.

- The outcome of the study must be able to be written into Policies and procedures for Centres to ensure ongoing consistent and effective implementation of the ACE model/programme.

- The Study will then need to be expanded to ensure there is an effective transition to school and then ongoing support in the school system.
Further on from this, future research into school models must be done and written into school policies.

This impact study will have far reaching positive impacts on society and will have the ability to be ongoing therefore providing data for longitudinal studies thus ensuring the effectiveness of the model, as it will be able to be adapted as necessary based on positive outcomes of the research.

The ACE (Autism Connect Early) model/programme will be implemented in specific services that will cater to children on the Autism spectrum.

The services will run the model/programme ensuring that the program content is relevant to the individual child.

Research has identified that "... no one program will suit all children with Autism and their families ...research has identified there is growing evidence that intensive developmental and combined programs are also effective."
(Good Practice Guidelines 2012)

As per the GPG 2012.. We can define key elements, which are necessary for effective intervention.

- "An Autism specific curriculum content focusing on attention, compliance, imitation, language, and social skills.
- Highly supportive teaching environments, which deal with the need for predictability and routine, and with challenging behaviours, obsessions, and ritual behaviours.
- Support for children in their transition from the preschool program
- Support for family members via partnerships with professionals involved in treatments."
- Teachers who are appropriately trained to deliver these programs
- Professionals who are appropriately trained to deliver quality programs

Research development and implementation

Please note - Ashton's Place will be guided by the Impact study requirements.

Establishing a staffing model that is effective in implementing the ACE model to ensure the delivery of positive outcomes for families and children.

E.g. number of children in a room in total and what number of Autistic children and typically developing children is best practice and then how many staff required for this and the qualification level of the staff. Speech therapist, Occupational therapist, behavioral therapist, psychologist, lead educators and assistants..

Staff Training program aimed at developing an environment that supports Autistic children. Both physical aspects as well as program ideas for supporting these children. Trainers can be brought in to train staff in the initial stages as well as employment of appropriately experienced qualified staff. Environmental follow up to ensure training session ideas have been implemented where possible any further suggestions welcomed.
Identified staff to have ongoing training in the ACE model be it by further smaller specific training sessions or personalised training

Establishing when and how one on one session will be or can be implemented.

On going consultation with Ashton's Place to give advice and guidance on the implementation of the ACE model in the Centres that have been identified for delivering the program.

The ACE Programme is a living programme that has direct research evidence from the UNE that will support it.

Ongoing research to identify areas of improvement or adaptation.

GOVERNMENT SUPPORT IS NEEDED

