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Submission to the Select Committee on Autism

July 2020

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SUBMISSION TO THE SELECT COMMITTEE ON AUTISM

1. Executive Summary

This submission from SDN Children’s Services is based on our experience as a provider of inclusive early learning, NDIS therapies and other support to families, as well as feedback from 63 families of children with a diagnosis of autism spectrum disorder (ASD) engaged in our services.

Families were emailed a link to an online survey with questions based on the terms of reference. We encouraged them to share their experiences with us in order to contribute to our submission. The families who received the survey had one or more children with a diagnosis of ASD and were engaged with our early learning or NDIS children’s therapies, on a waitlist, or were previously engaged with our services.

We were heartened to receive so many responses from families covering a broad range of perspectives and experiences. Despite this variation, the following issues resonated strongly with a large number of respondents:

- The need for improved access to and consistency of diagnosis
- Waiting times for services
- Isolation and barriers to inclusion.

Some parents kept their comments brief while others shared more details about the challenges they have faced. Some of the comments, particularly regarding isolation and lack of inclusion, were deeply moving, and we hope these will inform efforts to improve support to families.

The feedback from families aligns with the evidence available in literature, and the experience and insights that SDN itself has gained over a number of years as a provider of early childhood interventions for children with autism spectrum disorders.

2. About the SDN Group (SDN)

SDN Children’s Services is a not-for-profit organisation established in 1905 and is one of Australia’s most experienced and trusted leaders in mainstream early education and childcare, disability services for children, and family support. The SDN Group includes a wholly-owned subsidiary, SDN Child and Family Services Pty Ltd.

Our purpose is to promote and enhance children’s wellbeing, learning and development in inclusive environments. We provide high-quality children’s therapies and inclusive early childhood education and ensure our services are safe, affordable, inclusive and as inspiring as possible. We build strong connections within communities, challenge discrimination and help remove barriers to full inclusion.

We believe in the rights of children as articulated in the United Nations Convention on the Rights of the Child and are committed to social and educational inclusion. Through our strategy we seek to enhance the wellbeing of children and to make sure that children facing challenges have a place in the services we operate, support and advocate for.

We operate an integrated model of service delivery using our Pathways Approach that brings together our expertise in mainstream and specialised service delivery. In all, around 5,000 children, families and other service providers benefit from SDN's work each year.

We have many years of experience partnering with families with children with Autism Spectrum Disorder. We are a registered NDIS Provider and offer therapies for children from early childhood until transition to high school, with a focus on children with autism.

SDN welcomes children with disability into our mainstream early learning centres and preschools, with a strong focus on inclusive education. We also operate SDN Beranga Autism Specific Preschool in Rooty Hill, NSW, supporting families to engage in early learning and therapy for children with a diagnosis of autism. There is a high demand for the service and vulnerable families and children at risk are prioritised for access.

SDN was selected by the NDIA to trial the Early Childhood Early intervention (ECEI) approach in the Nepean Blue Mountains in NSW, and provided transitional services funded by the NSW Government across metropolitan Sydney from 2017 to 2018. The NDIA also selected SDN as one of two ECEI Transition Advisors to mentor and coach early intervention organisations across NSW.

More information about SDN is available at: www.sdn.org.au

3. Families' experiences: the literature

Parents of children with an Autism Spectrum Disorder (ASD) often report high levels of stress and mental health issues associated with the challenges of raising a child with complex needs (Weiss, Wingsiong & Lunsky 2014[1]). These issues are often compounded by having to navigate multiple service sectors to address the specific needs of their children. Many parents have difficulty sustaining regular work due to problems with accessing and sustaining quality childcare. Mothers of children with ASD report greater emotional problems compared with mothers of children with intellectual disability without ASD, and compared with mothers of typically developing children (Totsika et al., 2011[2]). Evidence also suggests that elevated stress and related impact on parent and child psychological wellbeing indirectly affect parenting behaviour and child outcomes.

The stressors families with a child with an ASD face include:

- Being asked to remove their child from an early childhood education and care or school situation because the educators could no longer manage (White et al. 2012[3]);
- Being told frequently that their child has lost control, threatened or hurt someone (White et al. 2012);
- Receiving frequent phone calls from school or early childhood education and care (White et al. 2012);

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[1] Weiss, J.A., Wingsiong, A., & Lunsky, Y. (2014). Defining crisis in families of individuals with autism spectrum disorders. *Autism.* Nov; 18(8): 985-995.

[2] Totsika, V., Hastings, R.P., Emerson, E., Lancaster, G.A., Berridge, et al. (2013). Is there a bidirectional relationship between maternal wellbeing and child behavior problems in autism spectrum disorders? Longitudinal al=analysis of a population-defined sample of young children. *Autism Research.* June 6(3):201-211

[3] White, S.E., McMorris, C., Weiss, J.A., et al. (2012). The experience of crisis I families of individuals with autism spectrum disorder across the lifespan. *Journal of Child and Family Studies* 21(3): 457-465.

- Higher medical expenses compared to children without an ASD due to high comorbidity of psychiatric and behavioural disorders in children with an ASD (McArthy, 2007[4]);
- The added strain of day-to-day care responsibilities and the time required to attend health appointments;
- Having difficulty accessing or sustaining work as work is dependent on the availability of appropriate and affordable early childhood education and care and after school care (Loynes, 2001[5]);
- Lack of financial resources due to inconsistency of work and then the compounding stressors that result from poverty including unsustainable housing, poor nutrition and compromised safety and wellbeing.

Studies that have examined the experience of crisis in families of people with an ASD found that child behaviour was the most frequent subtheme (Weiss, Wingsiong & Lunsky 2014[6]) and are the most consistent predictor of parental stress, marital breakdown and decisions to seek out of home care (Novita Children's Services, 2014[7]; Nankervis et al 2011[8]).

4. Families' experiences: family voices

SDN also sought feedback from families engaged in our services so that their voices could be heard as part of this inquiry.

We heard from 63 families who have a child or children with an ASD via an anonymous survey. The families were current or former clients of SDN in any of our service types, or were on a waiting list for an SDN service.

The responses from families have been organised under the key elements from the inquiry terms of reference. SDN received so many comments from families in relation to some elements of the terms of reference that we included a selection of comments in the body of the submission, with the full range of responses in the appendix.

> *Having our son diagnosed turned our world around. It filled us initially with so much worry, so many questions. We suddenly became afraid of the future. We began worrying about whether he will fit in and whether he will be accepted by his peers or will he live a life of being bullied? We scrambled to find the right therapies for him, and worried about the cost, not only financially, but we needed to invest our emotions, strength and time in it. We had to dedicate our lives to helping him overcome his struggles.*

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[4] McArthy, J. (2007). Children with Autism Spectrum Disorders and intellectual disability: current opinion. *Psychiatry* 20(5): 472-476

[5] Loynes, F. (2001) *The impact of autism: a report compiled for the All Party Parliamentary Group on Autism*.

[6] Weiss, J.A., Wingsiong, A., & Lunsky, Y. (2014). Defining crisis in families of individuals with autism spectrum disorders. *Autism*. Nov; 18(8): 985-995.

[7] Novita Children's Services (2014). *Supporting families: factors contributing to children and young people with disability living in voluntary out-of-home care*. The Department of Communities and Social Inclusion, South Australia.

[8] Nankervis,K., Rosewarne, A. & Vassos, M. (2011). Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care. *Journal of Intellectual Disability Research*. Vol. 55(4). 422-433.

a. current approaches and barriers to consistent, timely and best practice autism diagnosis;

SDN asked families about their experience with diagnosis of autism. While 22% of survey respondents reported an 'OK' experience of diagnosis, and 12% made no comment, 48% of respondents commented on the length of time to access diagnosis, the out of pocket cost for diagnosis; and the stress and feelings of being overwhelmed.

Comments suggest that:

- **wait times are long for both private and publicly funded diagnosis;**
- **there are significant differences between methods of diagnosis, with some taking one visit to a paediatrician and others requiring multiple assessments and consultations;**
- **many families find the diagnosis process to be more stressful than they believe it should be, and for some it is traumatic, with the process putting strain on families with no clearly identified services that can support the family through the process.**

Families said:

We paid for a private clinic to complete the testing required for diagnosis as the public waitlist was 18 months long.

Took close to a year as I needed reports from speech, OT, psych and paediatrician. There were waits to see all the specialists, waits to get the reports. The visits and the reports were quite expensive, and I had to space them out to afford them.

We were looking at a waiting list time of between 6-11 months. The diagnosis cost also varied between paediatricians/those qualified to provide the diagnosis. We understand that the diagnosis can range in Sydney from $960 to $1400 per hour.

Our diagnosis journey took almost three years and cost well over $5,000.

It was long, expensive and difficult.

The wait was excruciatingly long.

The experience was long but thorough and went over 2 years.

It took a number of years before she underwent formal assessment.

It took a long time and we went private that cost $2000.

It took 2 years to get funding for it or anyone to listen that he needed a diagnosis.

The process was very long because at the time my son wasn't even 2 and it was so hard to get a Dr to listen especially because of his age group.

I feel that the assessment that is done with a child to diagnose them with autism is not appropriate. I attended my child's assessment was not happy with how they conducted it. I *believe that while doing the assessment they should consider the child's strength and weaknesses rather than giving them things to do which they have never done before. It should also be culturally appropriate to the child and family.*

e. the demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages;

Families were asked about the availability and quality of the autism services and the professionals they have interacted with. Responses reflect the high demand for services and concerns regarding the adequacy of these, including government services and those provided through the private and NGO sectors.

While 11% of respondents commented positively, 89% commented on long waiting times and difficulties with the process to access services. Some also commented on the quality of the services accessed.

Families said:

NDIS has helped us tremendously. The therapists we've gotten for our son have worked well with us, and in conjunction with one another. Sometimes it can be difficult to avail of services right away as there is a long queue and wait list

There are not enough services available, waiting times are too long leaving children to continue to regress and families not knowing the tools and strategies to implement at home.

For the last two years I have had no therapy for my son. I have called around, been given numbers and places from paediatrician and still unsuccessful.

The autism services were quite hard to find in our area. We mostly rely on information provided by other families. Finding therapists was quite a work. We struggled; we did research online. There were lots of information online, but no one could help us directly. In my experience, finding right therapist and what services we need were confusing.

The availability of services available is good, however I feel the quality could improve. The NDIS has been amazing in terms of services as our family would not be able to afford current therapies our son is receiving, the issue is particularly with psychologists they are new to the field and do not have the experience that you gain over the years to provide proper support. The psychologists that are experienced with autism have long waiting lists. I also felt there was lack of information and support around children who have Autism with intellectual disability

It is very hard to find a very professional service provider for autism even in Sydney, we tried many different service providers in last two years. The service price is too high for parents to pay even with NDIS funding. There's half year we ran out of the funding.

f. the interaction between services provided by the Commonwealth, state and local governments.

Some families also commented specifically on the interaction of services funded by different levels or areas of government.

Families said:

More contact and communication with each other. I found we are always relaying messages from one to the other.

I feel it is also important to note the huge difficulties with the department of education and therapy services working together. My son is in a specialist support class and is unable to have therapist attend school which means all therapy has to be completed after school or he has the day off. Both these scenarios are not ideal, one of my son's main issues is routine and having the routine broken it takes time for him to adjust if there is a slight change. The lack of communication between the school and therapists is also poor. Considering children with ASD attend school 5 days a week for 7 hours each day, it would be expected school, therapists and families are a team. Sadly, this isn't the case, it feels as though they are separate entities which makes it extremely difficult to make progress, there is no consistency in what is being taught at school and home in terms of regulation and behaviour management strategies.

h. the adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people.

More than half of respondents commented on issues they had with the NDIS and the NDIA, including difficult experiences working with the NDIA and the variation in the skills and knowledge of the planners, inadequate levels of funding and long waiting times to access funding or services.

Families said:

I have had a few problems with NDIS but once I got the right person to help I found the NDIS to be very understanding.

My plan manager is extremely supportive, she suggested an intensive plan as I'm a single mother of twins with autism and she understands the level of stress that comes with that.

My child has suddenly come up with risky behaviours 6 months into my plan. I don't have enough funding for more therapy and was told to just cancel therapy. I'm already doing and put that to a new service even though current therapy is helping and small progress is being made. NDIS was unable to give me an expected wait time for a review and my child's behaviour is affecting our everyday lives to the point we can no longer access the community or family.

Waiting 9 months for funding after diagnosis. Early intervention is extremely important. Making a child wait that long and a family hanging off the edge just waiting is crazy. The funding is always cut short the following year but if they understood disability, they would know things can change and children require additional treatments that weren't discussed in the planning meeting

We were unable to get a psychologist for the 12 months and NDIS reduced our funding down as we hadn't been able to use the services. The next year when we were able to get a psychologist, but we are limited to how many sessions we can have as we don't have enough funding now

Family responses indicate general satisfaction with their ECEI provider but concerns with the length of time taken to go through the process. There is some indication that ECEI is not delivering the short-term intervention that the program is intended to provide.

It was the worst aspect of my engagement with NDIS. To get my daughter even the initial appointment I had to ring 3-4 times a fortnight for 6 months, when my understanding is children are meant to be seen in 2 weeks. Every time I rang, I was told someone would be in contact in the next 2 weeks to make an appointment. In the end I only got an appointment by threatening to complain to the NDIA. In the meantime we were desperately trying to self -fund treatment, which created huge financial stress for us. Even with that, we missed valuable intervention time because of [the] awful service. The stress it created was incredible.

ECEI was all about NDIS, sometimes we felt all they want is our NDIS money. It was never about your kid and what problems we are facing.

Very appreciative and grateful that they go above and beyond for what your child needs

We are grateful for it allowing us to get our diagnosis, but it was a slow, confusing process that changed twice during the process.

k. the social inclusion and participation of autistic people within the economy and community.

We asked families to tell us about their experience of inclusion and/or participation in their community. While 23% commented on increasing awareness of Autism in the community and personal connections with specific community activities, an overwhelming 77% of respondents told us about not being included, limited opportunities for their child, and feeling isolated due to having a child with an ASD.

Families said:

We have found it difficult, not a lot of "normal families" would understand us on a day to day basis. Its quite stressful at times when there are certain things we can go to because of loud noises, the crowded spaces.

Therapy sucks a lot of time that others would spend on connection. All the costs not covered by NDIS take the money that others would spend on community activities. We spend as much on that as most families do on their housing costs. NDIS' insistence they will only fund "disability specific" programs means our kids miss therapeutic opportunities that would also help them build social connections in the community. Any attempt to raise issues with the NDIS makes us feel voiceless and powerless. If the aim was to design a system to isolate families with disabilities, undermine their mental health and disempower them the NDIS is doing a bang-up job.

Going to my daughter's school assembly with my autistic son was very painful because he would just have melt downs and nothing I could do to keep him calm not even noise cancelling headphones I had other mums always saying something to me about the noise I even had a teacher complain to me about the noise going out on the bus train or shopping centres. I have the same problem. People are not understanding.

We struggle to access community supports as my child is showing undesirable behaviours to others. This is leaving us exhausted as parents and secluded.

We had called over 72 daycares

It is very important to educate childcare centre with autism. There are not many childcare understand on how to help children with autism. Childcare is very important because it is like the safe place for parents to put their kids in their care while they are able to have a break, respite or even working.

5. Families' experiences: case study of the benefits of an integrated service

The inquiry terms of reference also include the social and economic cost of failing to provide adequate and appropriate services, and something which is evident throughout this submission is the stress and hardship faced by families.

The feedback from families identifies many challenges and criticisms of the services and support available. However, innovative wrap-around services to support families with a wholistic approach have been very effective in addressing families' needs.

In 2011, SDN was funded by the NSW Government to establish SDN Beranga as an Autism Early Years Demonstration Service with two parts:

1. A long day care centre for 24 children aged between 2-6 years with ASD per day (Lighthouse Centre). The centre prioritised children at risk and vulnerable families.
2. Outreach services to 13 childcare centres operated by a range of providers (Satellite Centres) that were supported to develop autism-specific practices.

Our model was built on 3 layers of practice:

- high quality early childhood education and care practices
- best practice early childhood intervention strategies, and
- combined autism-specific approaches.

SDN contracted an external consultant to build and test a model for monetising the benefits of SDN Beranga in the long day care and satellite program format. The modelling used publicly available costing information and SDN estimates of out of home care conversions and escalations from our experience in working with children at Beranga.

This analysis showed that the long day care and satellite program model yielded benefits in three areas which it was possible to "monetise" in the short-medium term:

1. Reduced need for special education in favour of education in a supported environment in a mainstream school.

2. Reductions in child safety investigations and child removals into OOHC.

3. For children already in OOHC when arriving at SDN Beranga, a cessation of escalation into higher intensity out-of-home care costs.

The projected possible financial payback to the state government for these three areas was estimated at over $15.2 million per year. This demonstrated the clear economic and social benefits of operating such a service for families, the community and governments.

The cessation of NSW funding for SDN's Beranga at the end of the 2017/2018 financial year created a significant shortfall in funds available to sustainably operate and necessitated a transition to a community preschool for 3-5 year old children with ASD without a satellite program. The change to the model meant that the level of support we could provide to families was reduced, and therefore the potential financial benefits to governments were also reduced.

6. Conclusion

SDN Children's Services hope that the voices of families of children with autism shared in this submission will inform the Senate Select Committee about the challenges they face, particularly regarding access to diagnosis and services, and the barriers to, or lack of, inclusion in the community.

SDN intends to use these insights to improve the experience of children with ASD and their families as they enter and take part in our own services. However there are many parts of the family journey that providers such as SDN are not able to influence, and require system changes at a national level.

We thank the Select Committee for this opportunity to contribute to the inquiry and are willing to provide any further advice.

SDN will continue working with children with autism and their families and will keep them informed of any developments with this inquiry, including providing a copy of this submission.

7. For further information:

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8. Appendix: further responses from families

a. current approaches and barriers to consistent, timely and best practice autism diagnosis;

We paid for a private clinic to complete the testing required for diagnosis as the public waitlist was 18 months long.

Took close to a year as I needed reports from speech, OT, psych and paediatrician. There were waits to see all the specialists, waits to get the reports. The visits and the reports were quite expensive, and I had to space them out to afford them.

We were looking at a waiting list time of between 6-11 months. The diagnosis cost also varied between paediatricians/those qualified to provide the diagnosis. We understand that the diagnosis can range in Sydney from $960 to $1400 per hour.

The referrals, the booking in appointments which some are up to 3 month wait list, the tests, the waiting of the test results, the lack of paediatrician available during the week, booking in for when the paediatrician is available and accessing and the diagnostic [sic].

Fairly complicated, uncertain & stressful. Deficits only focus. Nothing positive about our child's strengths at all. Nothing positive about Autism at all. Only seen as a problem rather than a difference!

Our diagnosis journey took almost three years and cost well over $5,000.

Occupational therapy x6 Speech x6 Psych visits around 8 times then to a [paediatrician] to show reports where he was diagnosed.

Very traumatic.

It is very difficult. Time consuming. Takes lots of energy and fight

It was long, expensive and difficult.

The wait was excruciatingly long.

The experience was long but thorough and went over 2 years.

It took a number of years before she underwent formal assessment.

It took a long time and we went private that cost $2000.

Long process. Lots of different tests with different professionals.

The price for her to get a diagnosis report was approximately $1,500.

Lengthy. Took more than 6 months for the wait. Depressing!

I do believe the cost involved is sometimes exorbitant

It took 2 years to get funding for it or anyone to listen that he needed a diagnosis.

Very slow and long waiting. Children should get faster one stop support rather than running different services with long waiting.

The process was very long because at the time my son wasn't even 2 and it was so hard to get a Dr to listen especially because of his age group.

I feel that the assessment that is done with a child to diagnose them with autism is not appropriate. I attended my child's assessment was not happy with how they conducted it. I believe that while doing the assessment they should consider the child's strength and weaknesses rather than giving them things to do which they have never done before. It should also be culturally appropriate to the child and family.

e. the demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages;

Not enough around. Lack of knowledge

There are not enough professionals to provide services. There is a very long wait to receive services.

Once my eldest was diagnosed we were not directed to any services, other than the paediatrician, to assist us with what the diagnosis meant and what services we can access. 2 years down the track I am still learning about what services are available to my son and our family.

As an autism professional I expect them to be able to help me with the challenges that I face with my child however I feel like they have very little education and experience on how to deal with it. Some professionals are there only for money.

It's very hard when families are placed on waiting lists, we have been very lucky to have services we have for our daughter

I had to be on long wait lists as well as sift thru all the different philosophy styles of therapy especially towards Autism to find a child led & family led therapist!

NDIS has helped us tremendously. The therapists we've gotten for our son have worked well with us, and in conjunction with one another. Sometimes it can be difficult to avail of services right away as there is a long queue and wait list

There is a waitlist everywhere with Autism services that is my only concern, you end up with a spot it's just a matter of when and where.

There are not enough services available, waiting times are too long leaving children to continue to regress and families not knowing the tools and strategies to implement at home.

There needs to be more available allied health and also support for families that NDIS can cover such as home domestic help

Not enough services especially psychs

We always see high waiting times for services We are getting serviced, but the effectiveness and results are at very slow pace

Very difficult to find and long waiting time. Very expensive as well

Very less professionals available and they are in full demand. Very hard to get an OT or Speech pathologist for the session. Also, very difficult to get behavioural therapist.

For the last two years I have had no therapy for my son. I have called around, been given numbers and places from paediatrician and still unsuccessful.

I have found there are long waiting lists for services. My children have ADHD as well which means many ASD approaches don't work for them.

Overall, I would say it was been a good experience. The LENGTHY wait periods for services however override any good experience. There are few professionals available that is ready when you need it most.

All the specialists that we went and talked to are very nice and very friendly and professional. The availability of other services is a bit low; you will be on waiting list so there is no assurance that you'll get a spot.

Parents with first ASD diagnosis getting difficulties to find the right therapist and intervention program for their children. Sometimes we need to try for couple of months to find out whether the therapy works well or not before finding another therapy or provider. Long waiting list to get therapy and funding is a problem as family struggling day to day to survive.

The lack of continuity between them and the understanding of autism themselves

The autism services were quite hard to find in our area. We mostly rely on information provided by other families. Finding therapists was quite a work. We struggled; we did research online. There were lots of information online, but no one could help us directly. In my experience, finding right therapist and what services we need were confusing.

There are insufficient autism specialists in my area. The psychologist whom my child is seeing doesn't exactly make us feel comfortable.

Availability is less but quality is good.

The availability of services available is good, however I feel the quality could improve. The NDIS has been amazing in terms of services as our family would not be able to afford current therapies our son is receiving, the issue is particularly with psychologists they are new to the field and do not have the experience that you gain over the years to provide proper support. The psychologists that are experienced with autism have long waiting lists. I also felt there was lack of information and support around children who have Autism with intellectual disability

Quite lacking. The waiting list for community centre is long so we had to go private, which was a long wait list as way but still slightly faster

Just everywhere you go it’s all waiting list

The availability of transition to school and specialist schooling options seems to be limited.

For me I do hope they'll expand their autism services/professionals. I hope they're more accessible therapists around in different area that can have an easy access to.

My son has always been put to waiting list. Not enough funds to increase frequency of therapy. Lack of support from the school in terms of a support worker. Some providers are far from my home

This is very frustrating that I am waiting from August last year for speech therapist...still didn't get any responses from them...thank god only getting to after waiting for 5 months!!

Some providers take money without providing the service,

There is none in my area, the closest one is 45 minutes away

Availability is not enough, quality is fine.

Living in western Sydney there is not allot of services available, but we have been in contact with the autism advisory service and they have helped significantly we also found SDN to be a great preschool for my son and he's needs

So far all of them have been supportive and I've learned a lot from them through which I can help my child.

It is very hard to find a very professional service provider for autism even in Sydney, we tried many different service providers in last two years. The service price is too high for parents to pay even with NDIS funding. There's half year we ran out of the funding.

I have had many support workers call in sick and or not respond so we have not been able to get into the community in the way I hoped. I have also been trying to find a speech therapist that can work with us at the school but I'm also still on a waiting list for those

Some of the service providers are only behind the funds that NDIS provided, some do religiously. It's hard for parents to find the right one and their availability. There should be a rating and assessments done on the centres.

I feel everyone who has been involved with autism services has been supportive.

Limited availability of services. Especially services that can go into school environment Long wait lists We have used an OT that was quite aggressive with my son who ended up being so scared of her he would run away when she would turn up

Most Autism services have lengthy waitlists. We see a speech pathologist, physiotherapist and an occupational therapist. We have been told we are not funded by NDIS for my daughter to attend a psychologist as she has high anxiety, so we may need to self-fund this in future. The therapists are mixed- there are brilliant ones out there, but it takes a lot of trial and error to find them. There is no handholding after an Autism diagnosis, nor are there government-funded support groups available. I rely heavily on other parents. Not enough autism services/professionals.

Lack of autism services around the area, I think it needs more autism services that's accessible in every suburb

I did also find that there were not a lot of available Child Psychologists in my local area that were taking new patients.

The lack of services in my area

Long waiting for every service.

Regional NSW not many therapists and long waiting lists.

We were unable to get a psychologist for the first 2 years

Much greater need for availability in the area, lots are on long waiting lists.

Once the professionals are located (a process which can take weeks (if not months) and literally almost 100 or more phone calls in total), they have been great and wonderful therapists and clinicians. However, because they have such good reputations, or the quality of the facilities they run have good reputations, there can be long waiting lists for most of them and then quite prohibitive costs to sustain ongoing care on a private basis or outside of NDIS.

I have found since NDIS there are longer waits to see services. There are a lot of good services but also some dodgy ones They don't care about family individual needs or cultural needs

There are plenty of private therapies, but they are expensive

The waiting lists are crazy long. Some therapists are not equipped or don't want to deal with the more severe or challenging cases of ASD.

h. the adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people.

I have had a few problems with NDIS but once I got the right person to help I found the NDIS to be very understanding.

The plan took a little longer to process than normal but did not impact on access to therapy. When we phoned the NDIS they remedied this situation quickly.

I filed a review for my son due to funding cuts, I explained why extra funds were needed with detail. Although the actual review took 5 months, the plan was renewed for 12 months and NDIS did listen and adequate funding was provided.

The service provider/contact for the NDIS plan this year has demonstrated in her communication and information provision that she understands the complexity of having a child with autism.

My plan manager is extremely supportive, she suggested an intensive plan as I'm a single mother of twins with autism and she understands the level of stress that comes with that.

I don't think the NDIS really understand everyone's needs.

My new contact from NDIS was most helpful. Way more helpful that the lady we have had for the past 3 or 4 years. I think they know you and become a bit complacent and a bit dismissive.

Our current NDIS support person seems to OK but the one we had last year left and they didn't advise us. We had been waiting for some assistance and keep leaving messages, emails etc but we didn't know til about 6 months later she had left her job. She was trying to sort some plan issues out for us that never got sorted. They don't have the time to always assist

NDIA show some understanding but not the full understanding. Therapy budgets are cut every year. I think NDIA have a mentality of "one size fits all"

Delayed response in order to provide NDIS assessment and funding.

When having NDIS plan reviews with different providers each time and having no consistency in contact people makes the process very difficult. Each time there is contact you have to explain your child's circumstances as it is either not recorded anywhere the staff member can access or they do not read it. Some NDIA staff/providers have an understanding of healthcare and/or disabilities and some very clearly do not. This is evident in their communication and provision or not of information.

NDIS should be able to provide you with a manager straight away or at least help you secure one to help from there. A lot of working mums do not have the time to find another agency, I understand the future for our kids get that part but think of the stress it causes??

My child has suddenly come up with risky behaviours 6 months into my plan. I don't have enough funding for more therapy and was told to just cancel therapy. I'm already doing and put that to a new service even though current therapy is helping and small progress is being made. NDIS was unable to give me an expected wait time for a review and my child's behaviour is affecting our everyday lives to the point we can no longer access the community or family.

Funding is always issue. Feels like you need to fight for it.

Not enough funds to support.

They seem to have no understanding of the huge impact it had on the whole family system, getting to all the appointments, doing the therapy, jumping through all the hoops on top of coping with how hard every little bit of life is when your kids are in the spectrum. Their systems place no value on the parent as an expert in their child, everything I know about my child had to be written in a report by a health professional for it to be counted. They are slow, unresponsive and there is no transparency about what will and won't be funded.

Waiting 9 months for funding after diagnosis. Early intervention is extremely important. Making a child wait that long and a family hanging off the edge just waiting is crazy. The funding is always cut short the following year but if they understood disability, they would know things can change and children require additional treatments that weren't discussed in the planning meeting

Accessing NDIS was long and tiring process. Some information were confusing, it wasn't clear cut.

They don't help to provide funding for what the therapist and paediatrics told us to give him.

Insufficient funding is given for support work for the child, which comes under Community Participation. Fees for support workers and events vary quite a bit, and very often the funding runs out way before the 12 months are up.

They don't understand anything, how hard it is to live with a child They don't read the reports They don't care They don't do everything correctly They don't listen They think we are a number Every 3months when they do reviews it's not fair. Some things take a long slow process. They should do reviews every 2-3years.

NDIA is not understanding parents with autism. Parents know better than NDIA how can help the kid achieve his best, but NDIA doesn't listen to parent. Also, NDIA is not understanding Autism kids.

If your funding isn't used, they cut it but it might not be used as your waiting for services. This may come in the next year, but you can access this because the funding has been cut

We were unable to get a psychologist for the 12 months and NDIS reduced our funding down as we hadn't been able to use the services. The next year when we were able to get a psychologist, but we are limited to how many sessions we can have as we don't have enough funding now

The NDIS service is a great tool and certainly the availability of it is why we've moved to Australia (and taking advantage of our existing Australian citizenship). However the number of hoops to jump through that the NDIA insists on such as levels of reports (all at great cost and personal expense) and then even after providing reports from the experts who all say that intensive 25hrs plus of help or therapy is recommended each week for any progress, and then still have NDIA only give a 'standard' plan which at most funds a third of those costs is demoralising.

Comments regarding ECEI:

Mostly it was a positive experience that assisted my son to change his behaviour and teach me how to help my son. In the end it has helped him cope better with his diagnosis and provided firm foundations to continue growing/learning. Parts were very frustrating in the communications with NDIS/NDIA and some service providers being rigid in their care provision model.

If it wasn't for them I would have not done a lot for my child and also helping me find the right school for her.

It has helped us get the initial therapies that our son needed

So far so good, I have no complaints at the moment and hope to not get any in the near future and if so I hope that it is something that can be resolved professionally.

Good but need more home help

It was the worst aspect of my engagement with NDIS. To get my daughter even the initial appointment I had to ring 3-4 times a fortnight for 6 months, when my understanding is children are meant to be seen in 2 weeks. Every time I rang, I was told someone would be in contact in the next 2 weeks to make an appointment. In the end I only got an appointment by threatening to complain to the NDIA. In the meantime we were desperately trying to self -fund treatment, which created huge financial stress for us. Even *with that, we missed valuable intervention time because of {the} awful service. The stress it created was incredible.*

ECEI was all about NDIS, sometimes we felt all they want is our NDIS money. It was never about your kid and what problems we are facing.

Our NDIA manager is part of this scheme and has been excellent. The only suggestion I have is more programs aimed at transition to school both in the disability provider and primary school space. My daughter was only able to attend one program before she started school and the public school she attends was not able to offer assistance as their ECEI program filled up 12 months prior. More funding is needed in this space.

Didn't change much

Very appreciative and grateful that they go above and beyond for what your child needs

We are grateful for it allowing us to get our diagnosis, but it was a slow, confusing process that changed twice during the process.

k. the social inclusion and participation of autistic people within the economy and community.

Therapy sucks a lot of time that others would spend on connection. All the costs not covered by NDIS take the money that others would spend on community activities. We spend as much on that as most families do on their housing costs. NDIS' insistence they will only fund "disability specific" programs means our kids miss therapeutic opportunities that would also help them build social connections in the community. Any attempt to raise issues with the NDIS makes us feel voiceless and powerless. If the aim was to design a system to isolate families with disabilities, undermine their mental health and disempower them the NDIS is doing a bang-up job.

Going to my daughter's school assembly with my autistic son was very painful because he would just have melt downs and nothing I could do to keep him calm not even noise cancelling headphones I had other mums always saying something to me about the noise I even had a teacher complain to me about the noise going out on the bus train or shopping centres. I have the same problem. People are not understanding.

We are in desperate need in Canberra of more inclusive sports and social groups. My daughter, 6, currently attends swimming but was denied by many clubs as she needs almost one-on-one support. If we do find a group, they are usually expensive and have wait lists.

We feel very fortunate with our son's daycare as they have been very accepting and inclusive of our son. But apart from that, we haven't had that much experience with inclusion from the community.

We have found it difficult, not a lot of "normal families" would understand us on a day to day basis. Its quite stressful at times when there are certain things we can go to because of loud noises, the crowded spaces.

We struggle to access community supports as my child is showing undesirable behaviours to others. This is leaving us exhausted as parents and secluded.

None at all. Terrible public school.

Not always, because any training sessions like swimming and other sports don't have funds support / concessions.

It has been quite difficult. Lucky my son goes to a great school that is very supportive and he attends a social group fortnightly.

When we first received diagnosis, we were grieving and stay low. Then we realised that our child has sensory issues and overwhelmed in busy environment. We are slowly retrieving from busy environment and only meet several persons that our child comfortable with. In times, we didn't realise that we gradually getting isolated and have no one. Even close friend does not understand what it means having child with autism. There are not many people understand our struggles as the child will appear normal in their place. That's why people said autism is an invisible disability and parents normally struggle in silent. Especially for us that have no parents and relatives to help.

We attend swimming. My son is tolerated.

We don't feel included in the community. We have to go to therapy in weekend. It mostly take up our time. We hardly have time to go in community.

It is difficult to participate in the community, Autism I don't feel has awareness raised correctly, the lack of people who do not understand that half the child with ASD also have intellectual disabilities astounds me. They think of autism as something that is portrayed in shows like the good doctor or atypical so when you have a child who has autism and is 6.5 years old but has the mental age of a 4 year old, it becomes difficult to explain. There is also lack of community sports which are mainstream with staff experienced enough to manage children with special needs. Therefore the children with special needs are again isolated to participate in activities with children who are at the same level as they are, which I don't think give the children the opportunity to grow and build their skills.

Here and there. But there isn't much help around when you have other children and you are a single parent

Son starts screaming in a gathering!!

None of the above quite the opposite.

There's still some people in the community don't know what is autism. Still discrimination for autism happened in the community.

Right now we are busy with therapies and interventions. Not much participating in the community. Though my son goes to regular daycare as well where he is supported. But I feel the neurotypical or regular community is still not much aware of autism and its struggles.

General community events don't cater to autistic children. There is an isolation

Hardly any inclusion.

By community I am going to say School firstly. I think that Schools also become quite complacent and think they have heard it all, when in fact as we know, we are all different and have different needs. I do feel like we are all lumped together, and an Autism diagnosis is seen as an excuse for bad behaviour and that they are not given the same goals and expectations as other children.

Not enough services such as sport and recreation for children with disabilities

We had called over 72 daycares

It is very important to educate childcare centre with autism. There are not many childcare understand on how to help children with autism. Childcare is very important because it is like the safe place for parents to put their kids in their care while they are able to have a break, respite or even working.

There should be more awareness especially in childcare centres. They are mostly clueless about how to deal with autistic kids. They are mostly left on their own, there should be more training and awareness programs.

More teachers need to be trained to help children with ASD, and employers need to be educated about people with ASD and be encouraged to make provisions for their employment.

Lack of inclusion in the area especially sports. My son was not welcomed into the team, got seriously hurt, missed over a week of school and no one from the team bothered to check he was ok or even respond to a Facebook post in our soccer group from me.

Included in the community in the places we attend, now. But my son has been stripped of opportunities to participate so many times in local preschools due to severe bullying. It's something that he hasn't been given the opportunity to participate in many things because he "Is different" which to an adult makes no sense.

Not really feeling included

Community inclusion has been difficult