ABOUT THIS SURVEY

In August 2014, Autism Awareness Australia launched a survey targeting parents and carers of children and young adults on the autism spectrum. With the national rollout of NDIS fast approaching, we wanted to get a clearer picture of what autism support services look like in Australia so that we can continue to effectively advocate for the needs of autism families.

We are excited that 1,500 parents and carers in total – from all eight states and territories in Australia – took part in our survey and that so many of them expanded upon their answers with heartfelt, candid comments in the free text sections. We have read and reflected upon every single response.
While many issues and ideas were raised through the survey responses, three core themes rose to the forefront:

1. People on the autism spectrum, and those who provide their care, have a **life cycle of needs and deserve meaningful support in order to achieve best possible outcomes.**

2. Parents and carers are frustrated by the **level of support available** and difficulty accessing much-needed services. They fear that disability services will continue to be **underfunded** or further cut back under austerity budget measures.

3. There is **confusion and scepticism about how NDIS will play out in real life** and how it will impact autism families.

The following pages highlight some key findings from the survey results. The complete data report will be shared on our web site in the coming months. We are also developing complementary key findings summaries that are specifically geared toward the government and healthcare / education professionals.

**One important final note:** Given Autism Awareness Australia’s experience base and credibility in supporting families with young and school-aged children, we are well-positioned to capture their impressions. However, there are other critical voices from the autism community - especially those of autistic adults - that need to be heard as the NDIS is shaped and implemented. We urge the government to listen to all of our voices as this historic program takes form.

We’d like to thank all respondents for taking the time to complete our survey. Your experiences and input have been pivotal in helping us better understand the needs of autism families across Australia and how we can best support you.

We hope you will find the summary results as valuable as we have, and we encourage you to share the report with all your networks.
Most children and young adults on the autism spectrum are being cared for by a parent/carer. However, the majority of respondents also indicated that more than one person or service provider is involved in the weekly care of their child:

- 26% of respondents involve the child’s grandparents in providing care.
- 16.5% of respondents involve the child’s siblings in providing care.
- 78% of those respondents whose children on the autism spectrum are young adults (18 years+), 78% indicate that their child does not provide his/her own care.
- Only 4% of respondents are currently accessing government-provided respite services.

**COMMENTS**

“The financial burden placed on families where there is a family member with a disability is huge. Governmental agencies have no appreciation of the financial, emotional and social toll this takes. Disability greatly impacts on parents’ ability to work and find suitable employment.”

“Individuals with autism, their siblings, and parents would all participate more successfully in our community with the right support. The support always is a financial strain on the family without government assistance.”

“After dealing with autism since my youngest was diagnosed at 18 months, I don’t know how many times I’ve applied for respite...as a single parent working part-time with two children on the spectrum, I still don’t receive any assistance. Is it because I don’t yell, scream, cry, or beg enough for help?”

**WHAT DOES THIS MEAN?**

Autism can have a significant impact on both the individual and their entire family unit. Current funding and support services provided by the government are grossly inadequate, which in turn can place families under tremendous financial strain to meet the needs of their loved ones over the course of a lifetime. Parents/carers often have to rely upon extended family and local community for that support... or go without it.
More than one-third of the children covered in this survey have an additional diagnosis beyond autism, with ADHD/ADD (54%) being the most common condition cited by their parents/carers.

In 2006, the Australian government issued Best Practice/Good Practice Guidelines for Early Intervention, which were reaffirmed in 2012. Fewer than 18% of eligible families were directed to these guidelines by a professional at the time of their child's diagnosis.

“Saw a paediatrician when [our] child was younger and was told to wait and see, only to be diagnosed 12 months later.”

“My experience as the parent of a daughter with ASD was that the GP and paediatrician brushed off my concerns as an anxious parent with poor parenting skills.”

“The only reason diagnosis was so quick was because I pushed and wouldn’t take no for an answer.”

“After diagnosis it was extremely disappointing to walk out of the paediatrician’s office not knowing what to do. There was a lack of information and available options.”

The timely diagnosis of autism is still a huge challenge in Australia, with 28% of all respondents indicating that their children were not properly diagnosed until after the age of six. This is currently above the age limit to qualify for federal funding under the “Helping Children With Autism” (HCWA) package or to take full advantage of intensive early intervention. Despite the cost of private assessments, an overwhelming 73% of respondents used private services to have their child diagnosed.

How long did it take to receive their child's diagnosis?

- 58% of respondents waited at least 6 months
- 34% waited more than one year
- 19% waited more than two years

What are the top 3 reasons for this lag?

- 75% Reluctance of health care professionals to refer on/make a diagnosis
- 51% Lengthy waiting times
- 28% Financial considerations
EARLY INTERVENTION (EI)

An overwhelming percentage of young children with autism in Australia are not receiving anywhere near the government-recommended level of 20 hours per week of quality early intervention.

How many hours of EI per week are they receiving?

- **40%** of children are receiving only 1-2 hours per week.
- **84%** of children are receiving 10 hours or less per week.

Capped at $12,000 in total, the HCWA funding package does not come close to covering government-recommended best practice levels of EI or to even meeting the current therapy levels of an overwhelming majority of autism families with young children.

Of those respondents whose children are receiving 10+ hours of EI per week, 83% expect to have **out-of-pocket costs of at least $10,000** per year.

How are families funding EI for their children?

- **74%** are using income / savings.
- **22%** receive family support / loan.
- **11%** have taken out a second mortgage / line of credit.

The 3 most common forms of EI that respondents are accessing for their children

- **75%** Speech therapy
- **69%** Occupational Therapy (OT)
- **30%** Applied Behavioural Analysis (ABA)
Of great concern

38% of families surveyed expressed uncertainty on how they will actually fund or continue to fund their child’s EI program.

WHAT DOES THIS MEAN?
The government knows what constitutes best practice for early intervention yet isn’t funding it to adequate levels. Children on the autism spectrum are being short changed during a pivotal developmental period, and many parents/carers are being forced to choose between family basics and funding an early intervention program...if they even have that choice.

“We are struggling. Some weeks, we’ve had to choose between intervention or food. It’s a tough decision, but we have to put our children first.”

“We will have to cut down on intervention services in order to continue to afford therapy.”

“We sold our house, investments, and have used saving and income.”

“It’s great to have best practice guidelines, but they just make parents feel awfully guilty when they can’t afford it or go broke trying to pay for it.”
The lack of sufficient support that parents/carers and their children experience during the diagnosis period and early intervention years is even more pronounced once children reach school age. Almost across the board, respondents shared the same message: Our children are not getting the support they need and deserve at school.

Where do our respondents’ children attend school?

- 52% of children attend a mainstream public school
- 21% attend a mainstream private school (including Catholic schools)
- 20% attend an autism-specific school or a school for children with disabilities
- 4% of children are being home schooled

What funded support are these children receiving at school?

- 31% of children are receiving no school-funded support
- 26% of children are receiving less than 10 hours per week of school-funded support
- 20% of parents/carers do not know whether the child is receiving school-funded support
- 14% of children are receiving full time support

How many hours do they need?

- 35% of respondents indicate their child requires at least 20 hours per week or full-time support
- 25% of respondents indicate their child requires between 10-20 hours per week

According to parents/carers, the 4 biggest challenges for their children in the school setting are:

- 70% Social interactions
- 40% Finding a suitable peer group
- 34% Bullying
- 34% Suitable academic goals and curriculum
Many children spend most of their time at mainstream schools and have little support or understanding. It can be a battlefield for students with autism both socially and intellectually.

A lot more support is needed for children with ASD at school. So many children miss out on any funding due to the ludicrous funding criteria requiring low levels of speech and language.

All teachers should be trained to assist autistic kids, and curriculums be modified more to suit these kids so that they can succeed, rather than keep falling further behind.

The top 4 ways parents/carers would like to improve their child’s school?

- Autism-specific training for teacher’s aides: 74%
- Extra training for teachers: 70%
- Increased classroom support: 66%
- Facilitated social inclusion/play: 62%

WHAT DOES THIS MEAN?

Funding to support integration of students and adaptation of curriculum is severely lacking and in many cases, absent. Parents are often not informed about whether their child receives funding, and if they do, how the funding is used to support their child. There appears to be a direct relationship between a parent/carer’s ability to advocate for their child and the level of support the child receives, rather than all children having appropriate support on a needs basis. The education system gives little consideration to the importance of children establishing meaningful and caring social relationships.

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“All teachers should be trained to assist autistic kids, and curriculums be modified more to suit these kids so that they can succeed, rather than keep falling further behind.”
Parents and carers feel vastly under supported in helping their children on the autism spectrum navigate the post school years, be it gaining meaningful employment, living as independently as possible, or planning for their long term care.

Employment status of our respondents’ children (post school or 18+ years old)

- 18% are currently employed
- 32% are unemployed, with an additional 20% being underemployed
- 22% are taking part in community access programs

The main reasons for unemployment are:

- 54% struggle to cope in a work environment
- 40% don’t have the required skills or training
- 38% can’t find suitable work that leverages abilities / interests

Navigating post school options:

- 40% of respondents identified “School” as being the most useful source of information for post school options.
  However, the majority of respondents undertook their own research in order to access valuable information about post school options.

The top 4 concerns parents/carers have for their child’s future:

- Their happiness/fulfilment
- Who will care for my child when I’m gone?
- Their personal safety
- Their independence
An inability to cope in a work environment may be a result of insufficient support, and inadequate adjustments and modifications to accommodate people who could otherwise make a significant contribution. A focus by employers on disability rather than capability limits opportunities for those seeking employment. Parents are dependent on their own resourcefulness to identify suitable opportunities rather than receiving the much-needed support and guidance from skilled advisors.

"It’s] extremely difficult finding and funding inclusion into the general community either employment or essential activities."

“I have grave concerns for my child being able to gain stable employment once he finishes school, or to be adequately supported whilst he searches for a job, particularly given the punitive restrictions currently being brought in around Centrelink payments related to young job seekers.”

“We focus on early childhood but need to also map adequate programs to extend to our young adults and adults. People are on the spectrum for life, and they deserve the support of the community.”
What do parents and carers across Australia think about the NDIS?

- Over half of our respondents don’t believe that the NDIS will be delivered on time, in full or will meet most/all of their child’s needs.
- When it comes to having the choice of how their NDIS funding package can be spent, respondents are evenly split: one-third believe they will have a choice, one-third believe that they won’t have a choice and one-third remain neutral.
- Over half of our respondents are concerned that there will be issues around ensuring the quality of service providers once the NDIS is rolled out.

The most common services that respondents would like to see funded under the NDIS include:

- Allied health: 73%
- Educational resources: 63%
- Support outside of school hours: 47%
- Home behaviour management support: 43%
- Respite services: 38%

How do respondents in the current NDIS trial sites rate their overall impressions/experiences?

- More respondents have negative perceptions (33%) than positive ones (26%) regarding their experience with the planning and assessment process for their child.
- 42% of respondents feel that their child’s current NDIS funding package is insufficient to meet most of their needs, while 26% feel that their child’s funding package is adequate.
- 43% of respondents are not satisfied with the accessibility and calibre of service providers in their area, while 26% are satisfied.
- 33% of respondents were satisfied with the knowledge and experience of their NDIS planner, while 25% were not.
"The NDIS scares me at the moment because of the unknown."

"[The biggest challenge is the] difficulty accessing respite and therapy support providers. The rate at which the NDIS is funding support is not high enough."

"I don’t know anything about NDIS and how it could potentially affect us."

"We see NDIS as a positive step."

"The ‘My Way’ funding has not been as flexible as promised and the administration cumbersome."

"There are some brilliant service providers, but they are closing their doors to new clients as they simply cannot cope with the numbers coming to them."

According to their parents/carers, how many hours of NDIS-funded support are children in the trial sites receiving?

- 51% are only receiving 1-2 hours of funded support
- 29% are receiving 3-5 hours of funded support
- 2% are receiving 15+ hours of funded support

62% of respondents believe that more hours of funded support are needed to meet their child’s needs.

WHAT DOES THIS MEAN?
There seems to be a huge gap between the level of funded support that parents/carers in the trial sites need for their children and what is actually being delivered. In most cases, young children are receiving no more than what they would have received from the current, underfunded “Helping Children With Autism” package, while school-age children and young adults on the spectrum continue to be underfunded.
IN CLOSING

While the results of this survey highlight a system that underdelivers against the needs of autism families across Australia, there are glimmers of what meaningful support and best outcomes look like. Amid the hundreds of free text comments, there are a few bright spots:

- Front line medical professionals and specialists who take parent/carer concerns seriously and have the depth of expertise to accurately diagnose autism in a timely fashion
- Quality, intensive early intervention programs that are helping children develop core life skills
- Schools that are inclusive, flexible, and sufficiently resourced to meet the needs of students with disabilities
- Employers who recognise the value that autistic employees can bring to the workplace and programs that help adults live as independently as possible

We firmly believe that these bright spots should be the norm, not the exception, across Australia.

We are currently a long way from realising these levels of support consistently across the country. It is our hope that the NDIS will deliver upon its great promise, and we stand ready to work with everyone within the broader autism community to fight for what our loved ones deserve. Thank you for your support.

EXPLANATORY NOTES

1. This publication presents results from #autism2014 A national survey of autism parents and carers conducted throughout Australia by Autism Awareness Australia.
2. Responses to some questions in the survey total more than 100%. In these instances respondents had the option of choosing multiple answers to these questions.
3. All data in this survey was collected anonymously.