

**INQUIRY INTO FOUNDATIONAL AND DISABILITY  
SUPPORTS AVAILABLE FOR CHILDREN AND YOUNG  
PEOPLE IN NEW SOUTH WALES**

**Name:** Name suppressed  
**Date Received:** 27 April 2025

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Partially  
Confidential

Dear Secretariat & Select Committee,

### Our Gratitude and Thanks

Firstly I would like to sincerely take this opportunity to thank the bipartisan approach and interest the committee has taken in relation to 'Foundational & Disability supports for Children and Young People' in New South Wales. I would also like to extend this gratitude and consideration the committee has taken, in seeking consultation with parents and carers who care for young people and children with permanent life long disabilities. Through this process, we as parents along with many other families not only hope that we work with this government (as well as future governments), by providing some insight into some of our challenges. But also hope through this initial process provide the potential to set up a system or approach in New South Wales that stands to be best in class in both Australia and globally.

### Our Story

#### Dealing with Early Diagnosis

**We as parents are proud parents to a beautiful 4.5 year old by named born in July 2020. has been diagnosed with Autism Spectrum Disorder – Level 3 (ASD3) with global development delay** with sensory processing disorder back in March 2022. Our most recent and updated diagnosis in February 2025, still has confirmed his ASD3 diagnosis and sensory processing disorder, but the **Children's Development Unit (Westmead Hospital) has upgraded his development delay to an Intellectual Development Disability (categorised as Moderate to Severe).**

As first time parents and giving birth to during the peak period of Covid we started to notice some unusual mannerisms and delayed milestones or goals with early development. As first time parents – we didn't know what the norm was.

He didn't roll and do "tummy time" some of the first occupational and physical aspects of an infant child that is critical in developing neck strength and motor planning. He skipped crawling and went straight to standing and walking. He was infatuated with textures and rubbing his saliva on textures, which led to many rounds of sickness. Did not take to toys (and still doesn't know how to play with toys nor show an interest). **We made the decision early on when he was 8 months to send him to a mainstream childcare at Strathfield One Stop Child Care Services (SOCCS) to begin his early childhood development – and even the educators at SOCCS also found it difficult to teach, engage and aide in the development of through the early childhood path.**

is navigating through his life currently with limited speech and still quite non verbal. Poor physical and weak muscle tone. Significant fine and gross motor delay. Is quite rigid and structured with every small and high level of detail. Is expressing behavioural challenges. **He is unable to "play" as cognitively he doesn't understand play.** Refer to the next page in comparison to a neurotypical child his age.

As mentioned is a 4.5 year old boy who will turn 5 years old in July 2025 this year. The below basic table of support needs outlines the gap between a neurotypical child at the same age in relation to everyday basic activities such as communication, self care, and independence (including the level of support he requires from ourselves).

<b>Task or Skill</b>	<b>What a Normal 5 Year Old Child can do</b>	<b>What is restricted to perform - due to his impairments</b>
Waking up from bed	Anywhere between 5-7am. Possibly in their own bed or parents bed with one parent awake.	Will wake up at 4am in the morning in parents bed. Both parents need to be awake or meltdown will occur. If father is away for work travel, will result in intense meltdown
Eating breakfast or meals in general with or without utensils	Independently eat cereal from a bowl possibly at the dining table unassisted with spoons/utensils – including drinking from an open cup. Can eat finger food – unassisted	Needs to eat in the high chair. Only recently in April 2025 started using a spoon to eat independently and scoop his food but due to his poor motor planning is still mastering this skill. Prior to this he required a fully loaded spoon.. Wont drink from an open cup. If mum leaves to attend to other items, will end in a meltdown and flip his bowl of food onto the floor. Can eat finger food – unassisted
Brushing teeth	Independently brush teeth with children's fluoride toothpaste sometimes assisted with a parent in the bathroom, spits toothpaste / water rinse into the bathroom sink.	Wont tolerate brushing teeth except on the leather lounge in the living room. Needs to be held down. Can only tolerate an electric toddler's toothbrush due to oral sensory input from the vibration. Cannot use toothpaste doesn't know how to use the mouth/tongue muscles to spit even water. Which also rules out mouthwash. Flossing impossible to do.
Dressing / undressing	Independently undress and dress into one or two piece clothing provided by the parent. Including socks on feet and shoes that have no laces. Can tolerate and wear head gear (such as hats, swimming caps, goggles/glasses or ear plugs/headphones)	Needs parents to assist in removing clothes does not possess the coordination or cognitive ability to understand how to remove sleeved tops. Has poor balance to stand one foot to put on shorts/trousers. Needs to wear a tight fitted sensory vest over the top (eg shirt, jacket or jumper) as he then will chew through the neckline – leaving tops drenched in saliva, holes in tops and this has led to his teeth enamel eroding. Stopped wearing a hat since the age of 2, cannot tolerate swimming caps or any ear wear. Will not wear noise cancelling headphones
Playing socially or independently with toys	Can independently play with toys (pretend play, cause and effect, etc) playing collaboratively with other children in a natural setting (home, daycare). Possibly advanced play with toys emulating story lines from movies, cartoons or pretend play with figurines	Shows no interest in toys (figurines, dolls, cars, blocks etc). Doesn't understand the concept or show interest in cause and effect toys (push and pop toys). Doesn't engage in toy play with other children. Much rather pace up and down and stim.
Physical play (ball games, playground equipment)	Can independently without assistance climb up a childreans' ladder, go down a slide. Ride a pedal driven tricycle. Kick and catch a ball. Put a ball through a hoop. Jump on a trampoline. Go on a swing (not a baby swing). Enjoys swimming	Has recently with the aide of physiotherapy in clinic has climbed up a vertical ladder (max 3 rungs), starting to transition this to a park equipment at but inconsistent. Still requires help from a physio to pedal a tricycle but only in the clinic environment. Can now

		<p>kick a ball and put a ball in a hoop, and transition this to his natural environments. Enjoys the trampoline and can jump. Only allows to be in the baby swing on park equipment. We feel some of these skills will regress as NDIS have cut his physio funding. We will be ceasing physio July 2025 due to our funding level. Enjoys swimming at (children with disability – funded by parents/outside of NDIS)</p>
Toileting	Can urinate or defecate into a potty or toilet independently and understand the concept that urine/faeces goes in the toilet or request verbally to a carer (parent or educator) the need to go to the toilet. May require assistance with toilet paper/self cleaning upon finish.	<p>Cannot verbally or non verbally communicate the need to urinate/defecate. Still insists on wearing nappies. If presented to go to the toilet, this will result in intense meltdowns – headbanging on floor tiles, glass shower screens, sink basins etc. Tried the potty in an external environment to the toilet – also ends in meltdowns.</p>
Showering / bathing	Can independently undress and turn on taps, shower underneath a shower head. Apply soap and shampoo. Also bathe in a bathtub possibly with some assistance for the bath. Can with some assistance dry themselves with a towel	<p>Only tolerates the bath. Shower/Shower head leads to intense meltdowns due to the sensation of water droplets onto his head at pressure. Does not tolerate any headgear such as shower caps or even shampoo on hair. Will only comply with the bath and prefers father to assist in bath routine in the tub, but does not tolerate shampoo on hair. Taps for the bathroom need to be running – or will lead to headbanging onto objects in the tub.</p>
Car Rides and general outings	<p>Will tolerate sitting in the rear seat/booster seat. Will tolerate music. Will tolerate any route taken to multiple destinations. Will engage in eating outside of home (cafes, restaurants, visiting friends and family).</p> <p>Can walk holding parents hands or unassisted whilst still following instructions and direction</p>	<p>Will tolerate sitting in the rear seat/booster seat. Will tolerate music. Will not tolerate any route other than going to grandparents house and has recently (March 2025) tolerated going to day care, and therapy clinic. Any alternative route to these 3x locations than the usual route (due to road closures, traffic/congestion etc) will result in an intense meltdown with high pitch screaming. Any destinations other than his grandparents, day care, or therapy will also result in intense meltdowns. Cannot go shopping as a family, cannot go for walks in the neighbourhood. Visits to the doctors, hospital will be an intense meltdown – and has developed a fear of these venues.</p> <p>will not walk in public, still in a toddler pram (which he has outgrown), does not follow instructions or direction. Will collapse onto the floor if taken out of the pram. Will insist on being back in the pram – or being carried by only his mum (he weighs 17kg)</p>

### Our perception in relation to : Society's perception of Autism

Back during 2021-2022 Covid also made aspects of both [redacted] and our struggles as parents even more challenging. Covid was a very lonely period for us as parents. Being in a Local Area Government of concern (Strathfield/Homebush West), lockdowns forced [redacted] out of his early childhood setting for almost 5 months. Having to continue to pay for his place in child care while not attending, but importantly not exposing him to any developmental focus was difficult especially considering we as parents work full time in rewarding but stressful and elevated career paths [redacted].

[redacted]. Covid lockdowns also prevented [redacted] from celebrating his 1<sup>st</sup> Birthday with his extended family and family friends. There was very little social exposure to [redacted] with familiar faces outside of our home circle

**As the months would pass. We would started to realise the significant disconnect and delay [redacted] had with children his own age at 20 months old. This is when through our paediatrician we immediately sought after a developmental assessment with a developmental paeditrician at Norwest, as there were 24 month waiting periods with NSW Health or the public pathway.** We suspected autism, but not at a staggering ASD level 3. The level 3 assessment shook our world upside down.

**As we started to research what we could do for our son, it was very apparent the lack of knowledge, advisory and pathway for support there was outside. It was very much left to our own accord to find therapy clinics, techniques and specialists to help us aid in giving [redacted] the best Early Childhood Intervention** as possible at 20 months old.

Dealing with some of the Early Childhood Partners (ECP) through the NDIS, as well as some Health Professionals (such as GPs), day care educators and even some of the initial therapists (Occupational or Speech) at the time – was very frustrating. Often we heard the phrase:

- "oh he's still young",
- he has "plenty of time ahead of him to turn it around before schooling",
- he will "Definitely come down a level from Level 3",
- we "have seen worse".

Were the common phrases – looking back at this now, we realise how much education Australian society really needs when coming to grips with [redacted] level of Autism (ASD3). These were just messages of positive reinforcement with no substance or strategies in how.

We would later realise, that not only people working in Early Childhood (day care, our NDIS ECP) but society as a whole, would play down the scenario we were dealing with as parents with an infant with ASD3. Society very much included family members of our extended circle who actually work in Early Childhood such as [redacted] grandmother

and Aunty ( who unfortunately are now estranged from and us as parents – due to embarrassment of his disability as the years went on.

Even some of our closest friends often would misinterpret his level of ASD3 – with “popular culture”. Often would hear of comments such as “oh but Steve Jobs, Greta Thornberg Elon Musk have autism – this must be ultra smart and has a hidden talent”. This is true for those individuals – but these are individuals who suffered from Aspergers, or Level 1 – mild Autism on the low end of the spectrum. **People around us had no understanding at all regarding the varying levels of Autism and the differentiation with an individual with ASD Level 3.**

When ventures into the public domain, it becomes quite irrational and unpredictable at times. Having Sensory Processing Disorder – as part of his Autism is a “Sensory seeker” as opposed to being a “Sensory avoider”. There was a moment which still sticks out to us today (probably for the rest of our lives), when was 2 years old – we took him to Castle Towers for Brunch at “the Shed”. being nonverbal, was very experimental with his emotions through his voice. He took a liking to food such as chicken nuggets and would often high pitch “shriek” in pure happiness and excitement. This became all too much for a neurotypical family sitting next to us (Father around the age of 50-60, Mother 45-55, their daughter and son both aged between 18-25). The father had abused us as parents, and told us parents to shut our child up. When we explained he was autistic, the son then shockingly mocked his autism disability. We packed his brunch to go and tried to hastily pay our bill and disappear. We just wanted to sink into the confines of the earth and disappear. Our son was confused and became distraught, which even made the situation even more difficult to navigate. Plenty of others silent around us, looked on (none coming to our defence, none coming to our aide). We could feel the judgement even though it was silent. We have had countless situations like this in public in the last 2.5 years. Should become audible to the point where he would shriek in excitement or rage in a meltdown. We packed up, jumped in the car and would escape back home. Leaving any errand, shopping trip, or simple family day out prematurely cancelled. We will be honest, currently these day’s are a lot more fewer rather than constant – but they still do happen, with weight and size though does it become difficult more physically when you are trying to navigate through a crowd in a pram that has outgrown, or when you are trying to carry him back to the car when he is pulling strands of hair out of your scalp while onlookers pass by.

We see an autistic child. Society see’s a spoilt brat with a tantrum and a set of parents who are failing the child.

### relationships

We as parents consider ourselves our safety net and ‘go to’ in terms of primary care but also implementers of his therapy strategies and mentors, trainers to others, but in addition to us – has currently in his life:

- His Parents
  - o works 4 days a week, but during those 4 days is juggling admin, therapy sessions with in clinic at
- His Grandparents on side
  - o Grandfather is 74 years old. Retired from a stroke and has been on the disability pension since 52 years old. grandmother is 67 years old and is the full time carer for Grandfather.
- educators at
  - o He has been attending the centre since Term 3 in 2023. The staff although have the best intentions are struggling with disability and therapy execution from both parents and therapists, as well as therapy aides.
  - o He has a couple of neurotypical friends who welcome him when he arrives at the centre but struggle to play and bond with due to inability to understand the meaning of play.
- Therapists
  - o has been seeing the same Occupational Therapist since late 2022 at . He has been seeing his Physiotherapist for almost a year until NDIS funding cuts recently made this untenable. was seeing a Speech therapist since early 2023 – however this therapist has now left in October 2024 and he has struggled to bond with other speech therapists since.

has occasionally the following relationships once a month.
- best friend and her two neurotypical children
  - o A little girl aged 4, who is unable to form a relationship with due to his limited speech and inability to play. Her younger brother is only an infant.
- Therapist
  - o Due to current behavioural issues, we are seeing a Psychologist at Due to NDIS cuts, we are paying for this out of pocket once a month.
- Occasional visits from uncles
  - o This could be once a month to once every two months.

It is important to note that [redacted] also no longer has relationships with the following:

- [redacted] estranged side (since December 2023).
  - o [redacted] parents (both mother and father)
    - Have wished to no longer be part of Sebastian's life. They found it hard to integrate Sebastian into their communal events such as birthday parties, get togethers, events – they live a very social life and have said that they cannot accommodate for both Sebastian's sensory needs and see his disability as a curse on the family. This is despite [redacted] mother being a director of a [redacted] (having had autistic children come through her centre).
  - o [redacted] sister, her husband and their daughter
    - Have also chosen to align with both the decision of [redacted] parents. They have a daughter 9 months younger than [redacted] who formed a close bond with [redacted] in the early years, but as she grew older – she far out developed [redacted] (who is still operating at a 1 year old's level). [redacted] sister also decided that [redacted] would be a negative influence on her daughter's development going forward and agreed with the decision [redacted] parents.

There are no other relatives that [redacted] and [redacted] have in Australia other than those named above. It is important to also note that due to the high level of needs for [redacted] – [redacted] and [redacted] are unable to fulfil their previous relationships with other friends and so rarely meet or interact with those individuals, potentially only once or twice every six months.

Therefore with our personal experience, its quite evident that society as a whole, is struggling to come to grips with understanding the seriousness of ASD Level 3. It is not the same as ASD levels 1-2. It is an entirely different disability altogether.

Rejection of people with ASD3 is not only those in the amongst the community, but also from their extended family members. This leads to wider family separation and isolation of primary caregivers, such as us parents, having to march on with little to no respite. Fortunately in our case, our employers are very understanding of the situation of [redacted] and [redacted] Flexible work hours as well as working from home arrangements for [redacted] courtesy of her employer are in place. [redacted] working environment requires him to travel in his national role with his employer to various factories and facilities, with some working from arrangements also arranged due to the situation at home.



## Our Goal for

Despite some of the experiences in the previous sections. If anyone were to ask us as parents, **if we had our chance again – would we do it differently. If given a choice between [redacted] and a normal neurotypical child – would we make a different choice. Our answer 10 times out of 10 would be no. We are proud of [redacted] – we would choose this same path every single time – even the same level of autism being ASD3**

Despite the challenges we have with extended family leaving us, day care educators not knowing how to support us, people playing down his disability and even the NDIS recently (January 2025) cutting his disability funding by 30% – we will persevere and stride on.

[redacted] has come a long way. Being parents of an autistic child is surprisingly very rewarding and over filled with pride. Want to know why? It's the little things we all take for granted such as:

- holding our hands as parents and walking for the first time in public out of his pram at 3.5 years old (on a Wollongong Trip in 2024).
- Jumping on a trampoline for the first time elevating two feet off the ground at 3.5 years old at home.
- Learnt how to shuffle up a flight of stairs when was 3 years old at home
- Starting to speak, and expanding his vocabulary all throughout 2024 at the age of 3 to the point where [redacted] can request some of his needs, say hi and buy. Call his grandparents ([redacted] /father's side) as grandma and grandpa.
- Starting to show signs of independent eating with a utensil (spoon) recently in April 2025 at home with his mother.
- Performing 8 out of 8 urinations in the toilet in a single day in December 2024 when we invested in a toilet training specialist during the Summer holidays. Although this skill has regressed, this highlights his potential.
- When [redacted] was 3.5, he even memorised words (January–December), and some basic adjectives or nouns (which were often found in his Spot books). Again although this skill has also regressed, as he no longer shows an interest in Spot the Dog and books, shows again his potential.
- Knows how to kick a ball at age 4. Which is a massive 'proud-dad' moment for [redacted] being a massive football fan.
- Learnt how to climb up a vertical ladder with his physiotherapist at 4.5 years old and transfer this skill to the playground.
- Recently learnt how to climb
- Navigate those days through a busy shopping mall in the pram or venture out of the pram occasionally despite the significant sensory overload

We feel these milestones outweigh anything such as an HSC or ATAR achievement, an athletic award, his wedding day, the day he becomes a father. Much of these milestones [redacted] being ASD3 will never go through. But it's the small things [redacted] achieves which are huge wins. It reminds us parents to be grateful and be humble in life.

We as parents have a lot to be proud of personally:

- being one of the youngest in the Finance industry in Sydney as a 'Certified Financial Planner' before her mid 20s'
- career progression in in various National Engineering roles.
- Knocking down and rebuilding our previous run down investment property in Wentworthville into a safe and nurturing home for

But is the pinnacle of that pride. **So our goal as parents from the day he was diagnosed at 20 months old, was to never give up and try to give as normal life as possible, with the hope that he would never have to go through life alone**, even till the day when we both exited.

You read and hear frightening facts such as the average life expectancy of an ASD3 person being 35-40 years old. When you are Level 2 this pushes out to 45-55 and Level 1 being 50-60. The General population is 79 to 82. The reasons for such a low expectancy – is the fact that ASD3 individuals suffer from chronic conditions or health complications unfortunately they have no means of communicating because of the non verbal or limited verbal nature of their life. Which is quite the experience for us as parents – as one day contracted a serious ear infection but despite displaying no distress, or elevated temperature – we noticed he was bleeding through his ear. never complains of pains or aches, which makes us concerned about his gut and organ health. It wasn't until 6 months ago (late 2024), he had contracted a parasite.

We are accepting of the fact that will never be able to achieve the same level of achievements we as parents have gone through:

- Completing year 12 and receiving a HSC
- Going to University
- Having a successful career
- Even having a family of his own

He may have had a chance if he was ASD1 or ASD2, but with his ASD3 and now his Intellectual disability, we know that will need potentially someone looking out for him for the rest of his lives.

This further stresses the need to appreciate ASD3 as an entirely separate disability away from the Autism spectrum.

We as parents are happy to fulfil the role of permanent and lifetime caregivers. We are trying to expand our family, to provide a sibling, but we are aware of the risks. Chances of a male sibling potentially having also autism (increased risk of 50%) and a female sibling having autism (increased risk of 20%) when the first child being a boy is autistic. These statistics were provided to us by in April 2025 on a recent visit to discuss the possibility of IVF, but understand some of the genetic screening and results (2022-2024), we as parents sought after, in an attempt to understand some form of explanation for autism. These statistics are supported on page 491 by Ozonoff et al (2011), Recurrence Risk for Autism Spectrum Disorders: A Baby Siblings

### **Our Experience in so called non existent 'Early Childhood Intervention'**

Even with our pursuit to seek answers, to understand the current impact with and potential impact with a recurring child with ASD, **it takes almost 12 plus months through the current NSW health system, to understand the full genetic make up through myriad testing and screening. This is beyond basic tests for fragile X and other genetic tests for common disorders.**

Although this has been a journey of:

- Diagnosis and acceptance
- Working alone to find and research the right form of early intervention
- Juggling full time working roles while implementing therapy strategies
- Trying to identify why us? What caused his autism?

**We as hardworking parents and citizens, although have as a participant on the NDIS. Know fulling that this is not the long term solution for autism.**

**Nor do we believe that any State driven foundational or disability supports for children or young people will also be 'the all and end all' solution for children like**

We do not see these schemes, strategies, funding or investment as long term strategies. Throwing infinite and more taxpayer funding at each disabled person on a case by case will not work, we've come to this understanding now. But early childhood intervention needs to be seen as an investment.

Strategies need to be developed to identify how can Early Intervention:

- Be integrated into the curriculum of new diploma in childhood education courses, and how can current persons working in early child hood be retrained, refreshed in effective Early Intervention – especially for those in ASD3.
- How can the same be translated to future and current Primary and then later Secondary teachers.
- Specialised schools in NSW are extremely limited. The Department of Education through the public systems, have only 3-7 spots annually for Kindergarten enrolments for a specialised SSP for a moderate to severe intellectual disability child (like You have potentially 100 of these children fighting for a spot.
- Support units are not set up to deal with ASD1 to ASD3 children especially those with moderate to severe intellectual disability.
- Mainstream environments are not supportive environments. Yes it is great to integrate children for their development – but it puts mainstream teachers under enormous pressure to navigate the special and individual needs of the child with the disability as well as the needs of the rest of the neurotypical class. Mainstream environments are already a hotspot for bullying within neurotypical environments.

We need to have an honest look at the education system and say hand on heart – this cannot work for a child with severe disabilities.

With utmost respect, those bullet points listed above are credible and realistic challenges a parent with an ASD3 child. We cannot expect the government to immediately build more SSPs but there needs to be more down the pathway within the next 5-10 years. Autism is a disability growing exponentially at a rapid pace. There will be no cure, but the therapy and integration of autistic individuals need to be considered. We have attached an appendix/attachment of a statement from \_\_\_\_\_ educators who are struggling to care for him.

#### Experience with NDIS and strategies outside funding

We were unaware of so called “disability specialised” day care centres, who primarily take neurotypical children with extra therapy staff and aides for children with special needs. Centres apparently amongst the Good Start Early Learning centres and Only About Children specialise in these. **When we spoke to our NDIS ECP from**

**regarding if there were any centres that specialised in Autism – we were told there were none back in 2021-2022, we later found out in 2025 that this was false and that they were. Which shows how unreliable the NDIS system is in relation to Early Childhood Intervention and education.** Those external third parties such as ECPs are ill informed, uninterested or basically are working off a federal level, not interested in Early childhood educational requirements that are usually governed at the State Department of Education level.

We were initially on \$17,459.10 in NDIS funding just prior to his formal diagnosis in 2022. This later got increased to \$38,895.00 in December 2022. Which has been beneficial at the time with \_\_\_\_\_ receiving weekly Speech and Occupational with Physiotherapy on the odd occasion. With \_\_\_\_\_ lagging behind physically in both stature and development, we increased the frequency of Physiotherapy, (where he started to then achieve some of the physical milestones as mentioned previously on page 4). \_\_\_\_\_ since the age of 4 though, has started to develop aggression and behavioural challenges. We believe a lot of the behavioural challenges are due to the fact he isn't able to associate with his peers in the mainstream day care setting. We firmly believe when \_\_\_\_\_ starts schooling next year this will translate to his primary school environment. With this said – we are only looking at a couple of Public SSPs, some support units and Catholic school's specialising in children with Intellectual Disability moderate to severe – like

Intellectual disability is another disability that \_\_\_\_\_ has – but is unrecognised or appreciated by the NDIS as a disability. They only recognise his ASD3 and the associated impairments related to this. However Intellectual Disability – is what the NSW schooling system (for disability specialised schools) consider for placement within either a disability school that is :

- Mild to moderate
- Moderate to severe

With this said – this degree of uncertainty and appreciation of “intellectual disability” needs to be looked into as its quite clear at the Federal level through the NDIS, they do not recognise intellectual disability as a form of disability. Refer to our appendix item regarding [redacted] most recent formal diagnosis from the Children’s Developmental Unit (Westmead Children’s Hospital) who go onto to detail the impairments of Intellectual disability, particularly children with a moderate to severe case. This cognitively affects [redacted] every second of the day. It is an extension of his ASD3 which further illustrates why ASD3 needs to be considered as an outlier outside of the full Autism spectrum. [redacted] as a child should be playing. Knowing how to play. Knowing how play is both educational and is a tool for forming relationships with his peers and others.

Play helps both motor planning but also cognitively develop as well as improve verbal communication. Unfortunately because of [redacted] ASD3 and Intellectual Disability disorder (Moderate to Severe), he doesn’t understand the concept of playing. So during daycare and at home – will not play with his toys.

His playroom (which we first intended to be a home theatre), is very bland and basic. More physical movement based. The any toys he does have (such as the spot the dog and cars), are not played the conventional way, instead need to be neatly stacked. Any deviation from this ends up in a significant meltdown sometimes resulting to self harm. Refer to figure 1.

His conventional toys we bought throughout the years, and gifted by others – unfortunately are locked away in a linen cupboard refer to figure 2. We haven't discarded this. Mainly in the hope that he will like many other children his age or at the age he is operating at (1-2 year old), he will one day enjoy. We, our therapists and day care have tried to integrate toy playing or general play with \_\_\_\_\_ for his entirety now as a child under the age of 5, its been unsuccessful apart from recently kicking a ball and jumping on a trampoline.

Most parents with a child at the age of 4 coming towards 5, are hoping for school readiness and expanding on skills they already are mastering such as basic number counting, their alphabet etc. We are just hoping our son learns how to play.

### Day Care's (Early Childhood) struggles with

We recognise and appreciate the pivotal role we play as parents and caregivers as long term strategic "implementers" as well as those in early childhood environments (such as day care educators and primary school teachers). So the goal for must be that all those caring for in his childhood environments are brought up to speed with how they can help succeed and bridge the gap between those basic support needs listed in the table of comparison on page 2 earlier.

We do acknowledge though that:

- Awareness and knowledge of hidden disabilities such as ASD is not advocated very well by those typical Autism not for profits (we wont name them all but Autism Awareness Australia, Amaze, Reframing Autism etc), we've reached out a couple of times with no luck.
- We have received excellent advocacy and advisory from the likes of Family Advocacy (<https://family-advocacy.com/>) and from Hireup (<https://hireup.com.au/resources/ndis>) – free services I would recommend any parents with a young autistic children to reach out to these groups. They have a fountain of strategies to navigate inside the NDIS and strategies outside the NDIS. We would very much recommend the Select Committee reach out to these groups as opposed to the typical "Autism not for profits"
- Acknowledge additionally that there is a massive disconnect with Early Childhood environments such as Day Care centres and pre schools. Educators are quite simply not equipped to deal with ASD3. We need to stop treating ASD under the one brush – lot of these centres have success with ASD1 and some ASD2 children when mixed with mainstream neurotypical children. It doesn't work for ASD3.  
in both his previous daycare (SOCCS) and his current daycare

You would think a child even with ASD3 (with recent intellectual disability diagnosis) would learn basic motor planning, self care, some communication or cognitive functionality – if they were attending at an ultra young age of 8 months. Sadly for this isn't the case.

as mother during her working days – will take to almost 3-5 hours of therapy a week up until January 2025 (when this got cut to 2 hours due to NDIS funding cuts). We as parents then spend almost 20 hours a week mastering therapy strategies and learnings during weekday afternoons and on the weekends in home.

Should a develop or show signs of mastering a skill (verbal/non verbal, cognitive through play, feeding, self care etc), we as parents then provide visual aides, instructions or videos to educators in his day care environment, much like fig 3 on the next page, through the day care app

*Figure 3 - Therapy strategies mastered at home, passed onto daycare*

Quite often no acknowledgment or comments are sent from his day care environment. When we do follow up at both drop off and pick up – we are usually met with the staff explaining that they are overwhelmed, but have tried but not able to implement the same learnings or with minor level of success. We are not sure if it's a language barrier, but do understand that staff are not only overwhelmed with the needs of mainstream neurotypical children, but the demand \_\_\_\_\_ has on them. This reiterates our observation or recommendations listed in the bullet points on pages 10-11. Again we point towards the appendix item – statement form daycare where they personally acknowledge the challenges with a child with ASD3.

This is not just a reflection of Sebastian's current experience in an early childhood setting like his current day care. But it is a window into his short to mid term future when he enters schooling next year – potentially in a mainstream school or support unit. \_\_\_\_\_ like many other ASD3 children will struggle. Although \_\_\_\_\_ has missed his opportunity in relation to 'Early Intervention', we hope other children with ASD3 and moderate to severe intellectual disabilities – do not go through his journey.



## Conclusion and Recommendations

We understand the committee would be receiving an abundance of submissions from parents and many other caregivers. Should our statement and submissions be considered and also read – **we are truly grateful for your time and effort in reading our submission, hearing our story, understanding our struggles and considering our suggestions.**

We would like to summarise and highlight again some key points.

- Autism is a spectrum, but **children with ASD3 (most severe autism) combined with moderate to severe intellectual disability – should be treated as an outlier outside the spectrum. They are almost an entirely significant and severe disability**
- Parents or primary care givers of these children or young people – are isolated. They have no time to invest in previous friendships, it is a given that family members and even friends will disown, abandon and estrange themselves. We as parents of \_\_\_\_\_ are a resilient pair, we do wonder if one day the need for respite will catch up on us healthwise – as we sometimes have 4 hours of sleep a night – but we are **deeply concerned regarding other parents in a similar situation if not worse such as single parents navigating this alone.**
- **Early childhood intervention is non existent. Sadly we have to admit this** – as politicians, parents, educators and an entire society. **Early childhood intervention starts with Early childhood education – for ASD3 children this is non existent.** Their needs are not being met. Individuals in certain positions such as Early Childhood Partners (like in our example) aren't even aware of day care's that specialise or assist with autistic children. **ECPs like \_\_\_\_\_ are the examples \_\_\_\_\_ have been involved – honestly from a parental point of view are just wasting NDIS funding to the tune of \$20 million a year. We sincerely hope the State government do not adopt this model in their Foundational supports.**
- **Further on with Early Childhood educational environments, diplomas and degrees for both Early Childhood, Primary education need to consider training and courses that are autism specific.** \_\_\_\_\_ enrolled himself in a DIR Floor time course that helped identify the 6 key strategies in working with autistic children in a 101 course, but there are further courses for practitioners, therapists etc (that Australian Speech, OT and physiotherapists) that are attending. Please refer to the following URL <https://www.icdl.com/courses>

- Although the previous point states primary education, **this needs to continue though into secondary education, with that said secondary teachers in their degrees to also look into autism specific education and strategies.**
- SSPs (Schools for Specific Purposes), need to be included in a medium to longer term investment by the NSW Department of Education. NSW has the potential to be best in class within both Australia and globally – for Autistic children with a moderate to severe intellectual disability, if they can replicate more schools like the Hills School in Northmead. **Honestly some parents like us would even be open for paying schooling fees to maintain the operation and ongoing sustainability of these type of SSP schools.** They are an investment into the disabled, teaching life long self care and self supporting skills, to assist the disabled (particularly those with ASD3) to go into vocational employment and be integrated into society.
- Reiterating again that children with severe disabilities like ASD3 and moderate to severe intellectual disability, are not suitable for mainstream schooling environments even with a support unit. These children struggle in these environments, also exerts significant pressure on educators to navigate both a large mainstream or support unit class with children with severe disabilities.

The one recommendation or ‘solution’ we do not have – is how do fix Society’s perception of autistic individuals, particularly ASD3 individuals in the community. Reverting back to the family who abused us at the café at Castle Towers. There’s unfortunately no fix for this. Again as I reiterate on page 14, some of the traditional not for profit Autism Awareness bodies are not doing enough in this space for families, carers or parents of Autistic people, let alone those with ASD3. With that in mind – I do recognise the efforts that those such as :

- from Family Advocacy (<https://family-advocacy.com/>) and
- from Hireup (<https://hireup.com.au/resources/ndis>)

Are doing in this space and urge that they be consulted in any foundational supports framework and execution going forward, as they have been helpful in identifying solutions outside of the NDIS recently for us (in a time where we had a 30% funding cut to funding).

Lastly – please do not hesitate to contact us as parents. We are more than happy to be both consulted, explain our story even more. We don’t believe more personalised targeted funding is the fix like what the NDIS does. It needs to be a more universal collective investment aimed at Early Childhood education – such as the course and competency of day care workers as well as primary and secondary school teachers. Building of more SSPs – basically an approach that benefits all, not just a specific individual

Kind Regards