

Submission  
No 64

**INQUIRY INTO CHILDREN AND YOUNG PEOPLE WITH  
DISABILITY IN NEW SOUTH WALES EDUCATIONAL  
SETTINGS**

**Name:** Name suppressed  
**Date Received:** 15 March 2024

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Partially  
Confidential

# Submission to Parliamentary Inquiry

## Prelude:

I would like to thank you for the opportunity to put forward my experiences and ideas in order to move things forward in the right direction - not just for education but for societal attitudes towards disability and inclusion, as a whole.

A changed attitude towards people with disabilities will not happen overnight. It will take one or two generations at least to get things to where they need to be, and it will be slow.

I would very much like the opportunity to speak at the inquiry. However, I would like to remain anonymous and the name of my daughter's school also. I am fearful about retributions for her and her sibling who is still at the school, should this be made public.

As such I have changed my daughter's name to Jessica in this piece, and would appreciate your thoughts as to how our experiences could still be shared and our views heard without ramifications for us personally in the future.

Jessica's first support teacher at preschool for the first 2 years of her educational life is an amazing, driven human being who has set the bar, for her future educational life. Whilst in recent years, this has not been met by any stretch, unfortunately, it gave us inexperienced parents a template of what we need to work towards and how things can work when they work best.

She recently told me that people fall into 3 categories (and I would agree with this based on very many, daily personal experiences over the last 7 years):

- 1) the people who just naturally "get it" and are unable to see any difference when they meet someone with a disability. Some of these include people who grew up with disability in their families or close community. The even more amazing people are those who didn't and are just born with that gift!
- 2) People who don't naturally "get it" but are open (to varying degrees) and can learn. These can sometimes include the people who openly stare at my daughter in public or who avoid a person with a disability because they are afraid of what they don't understand. The vast majority of the population fall into this bracket: most overtly, children aged 8 to adulthood and some adults.

My husband and I fell into this bracket until our daughter, who was born with no signs of disability other than she was developing a bit slower from a gross motor perspective, regressed rapidly within a matter of weeks aged 17 months – and was diagnosed a couple of months later with a severe neurological condition, which meant she was no longer verbal or able to use her hands properly, and she was going to find it difficult to walk, if ever at all.

- 3) People who don't and never will "get it", and will do all they can to shut out disability from their day-to-day lives.

We feel truly lucky and blessed to be in the situation that we are in with our daughter, despite the fact that it is very hard work, all of the time, and impacts ourselves and the rest of our family

significantly. I feel I have a whole new, enlightened perspective on the world. And that the pro's outweigh con's for her siblings in the way that they will always see the world.

We often say that Jessica "sorts the wheat from the chaff" in terms of who she warms to and doesn't when she meets people. And from the reaction we see people having to her. As it happens, none of our wide group of friends fall in to category 3, and we love even some of them more for having realised that they are in category 1.

Times have moved on from the Victorian era where people with disabilities were taken from their families at birth and institutionalised away from society's eyes, for life.

And equally, even in the last 10-20 years, it is not considered socially acceptable to overtly show your distaste or dislike of someone just because they have a disability and may look or act differently.

However, sadly times have not moved on enough when you consider the subliminal segregation that special schools represent. The idea that it is somehow "better for them" to be receiving "special" care in a segregated setting is a way of people in category 2 or 3, feeling more comfortable about their view of the world.

Having been very much a category 2 person prior to Jessica's regression and diagnosis, I can appreciate that it is difficult to see things from this side of the fence, unless you are in it.

My daughter is now 10 and sometimes feels lonely and excluded at school and in the community when kids say things or adults overtly stare at her.

Whilst this can be upsetting for all parties concerned, I truly believe that my daughter is an ambassador for future generations' attitudes towards disability. On the odd, rare occasion I have met an adult who was at school with someone with a disability, I have been amazed by their warmth and with how normally they treat Jessica. Something she gets overjoyed about.

## Background:

On diagnosis, the national UK charity told us she would have to go to special school, something I just accepted, and we were already linked in with a special school while we were there, which was something I didn't have any issues with.

However, I had already had confirmed what my gut instinct was telling me: that \_\_\_\_\_ is not a cognitive or intellectual disability, despite looking very much like this, and is in fact just a severe apraxia of the voice, hands and body.

Aged 3, I felt that despite all the therapy we were doing, there was something missing and we needed to address the educational / social interaction piece. There were no real special school pre-school options that I could find and I ended up enrolling in our local community pre-school.

This, with the help of her support teacher mentioned above, was the making of her. The difference being in a mainstream educational and social pre-school environment was phenomenal: it was as if the lights suddenly came on, and her communication, social, emotional and physical skills came on leaps and bounds almost overnight.

This to me, showed me the benefits of including my disabled daughter in her mainstream community and educational setting, and she has continued to flourish since. She has way, way surpassed all the expectations and limitations put upon her by many of the allied health and medical experts that we came into contact with during the first 5-7 years of her life.

And I have seen with my own eyes that the biggest reason for this positive change has been inclusion in a mainstream educational setting.

I often think what would happen to a mainstream child with no disability at all, if you were to expose them to a limited, segregated, social and educational setting, and speak to them and treat them as such for the whole of their developmental years.

I think you would find that there would be a very negative outcome for them, so why would you do this to someone who is already so challenged, through no fault of their own?

### **Jessica's disability**

My daughter needs 24/7 support for every transition, to eat, drink, go to the toilet.

On regression she lost the words that she had and became non-verbal. She has looked at us for yes, looked away for no since aged 20 months, and started using an e-tran frame to look at symbols as a precursor to using an eye gaze which she started using aged 3. Following many hours of physio at home and in clinics, and with the help of Ankle Foot Orthoses and the prescription of a walking frame, she suddenly walked independently from one end of the house to the other aged 4: because her older brother was having a birthday party and she wanted to impress the older able-bodied boys who were watching her trying to take one step at a time.

She learnt her letters and numbers at pre-school age and tapped on cards to tell us which ones she knew.

When it came to primary school, I looked at all 6 special schools within a 25 km radius of our house, and disappointingly, none of them came close to fulfilling her needs: the Year 12 aim of being able to get on a bus and use an Opal card just simply wasn't relevant to her.

She also needs a full-time communication partner to be able to communicate her needs and this is something they couldn't provide. But regardless, Jessica made it very clear from the way that she had progressed, that going to her local mainstream school with her brothers, was realistically only educational possibility for someone whose brain needed a mainstream education.

As I have continued on this journey - lived and breathed it for the last 6 years - and personally seen the benefits to all the other children in her classes, as well as the positives for her of not limiting her, I now fully believe that when a mainstream educational setting works well for a child with a disability, it should be the only option for any child of any ability, if they are to achieve their full potential.

### **When it does not work well, what that looks like...**

## Overt gatekeeping:

I have never been overtly told – “no, you can’t come here”. This is not socially or legally acceptable for a Principal of a school in this day and age, so not a smart move.

However, there are many ways in which Principals actively discourage your enrolment at their school. And can continue to keep encouraging you to leave, even after you have started at the school.

Examples I personally have experienced include:

At our current school:

The Deputy “welcome(d) [my daughter] with open arms” and she genuinely meant it and this was backed up by her actions.

The Principal, however, was not in the same camp and we had the following experiences:

- 3 separate phone calls on 3 different Sundays in the weeks leading up to my daughter starting at her local public school, from the School Counsellor to my mobile. Each lasted circa 1 hour – each encouraging me to look at this special school, then another special school, then another - and questioning every aspect of our decision to send my daughter to her local mainstream school
- Various attempts by staff members while at school to try and persuade me that we should go to special school. 1 lasting half an hour while I was waiting to help my daughter with a dance performance
- Storming out of the preliminary meeting with her therapists prior to starting school, and shouting “No!” when asked by the Deputy if she wanted to join the meeting
- Preliminary meetings taking place in a room at the top of steep stairs that I had to climb with my daughter. However, I love giving her opportunities to physically exert herself and had no problems doing it and showing that nothing was going to stop us, despite the physical exertion involved.

Since then, over the years, there have been a number of incidents and decisions made from above, which have made life uncomfortable for us at the school (see subliminal gatekeeping below). However, there have also

We had a very bad year last year, and whilst we were promised a better experience this year, and so far that has been true in the most part, I thought it prudent to do a review of local Catholic schools, all the same.

I visited 4 different schools. Only 1 seemed genuinely welcoming and at the others I experienced the following:

- Overtly told that a specialist unit would be much better for my daughter, before being taken on a tour of the school grounds and pointing out the unsuitability of the land / playground / access for someone with the level of needs of my daughter. Followed by rather fervently saying that she would be getting on the school to the Catholic Office straight after the meeting and start putting in motion our move to the school (something I hadn’t even expressed an opinion on either way). Naturally, I balked and sent an email straight after the meeting saying I wasn’t interested.
- Another school said that of course they would welcome my daughter and make all the necessary changes, but what followed was a detailed analysis of excessive building work

(including the Principal climbing up steep slopes behind a demountable) required to accommodate her there as a specialist unit that was coming in next year was the only accessible buildings there

- Conflicting / questionable “rules” or “procedures” of enrolment between the different Catholic schools I visited including
  - the Catholic office chooses which of their schools you get to go to – you don’t get to decide
  - You might not get 100% funding for support at one of our schools (even though she has always had 100% support funding at a NSW school due to my her high needs).
  - we would need to contact your current school first before we can see whether you’d be eligible for funding (after I’d specifically said I did not want this to happen until I was sure that I was joining the school).

In the same week another school in the same diocese confirmed that they had never even heard of this rule, except in cases where a child had been violent or harmed others or been a danger to themselves – something my daughter would never have the physical capability of doing!

So, hiding behind processes, procedures, and quoting government or governing / central bodies’ “rules” that are in place that quite simply don’t exist or their meaning is bent in order to put you off applying to a school – or staying at it - is a recurring tactic that I have experienced.

In most cases, any rule or process I have been told would apply to us, but which would make it difficult to join or continue at that particular school, I later find out there is no truth or substance behind it.

## Subliminal gatekeeping: Principal - level

We have been very lucky that both Deputies who we have been assigned have been passionate about inclusion and done their best to ensure Jessica has everything she needs.

However, unfortunately if the people at the top do not believe in it, the tireless and tiring efforts of these passionate advocates, fighting for her to have the same educational experience as her peers at her local mainstream school (her choice as well as her parents) WILL FAIL.

Below are some examples of what I will term subliminal gatekeeping. A number of decisions made from the top to make our lives uncomfortable and make things more difficult, harder than they need to be, so that in the end, we just give up and leave the school.

And there have been a number of parents of kids with disabilities at our local primary school, who have done exactly that – given up and moved in order to go to another school (one was the year above our’s at pre-school).

Examples include:

### Parking:

No allowance for parking near the school for 3.5 years despite the fact that my severely disabled daughter can only walk with assistance or independently for short distances in a walking frame, needs help with every transition and needs a wheelchair for long distances.

Following an expensive renovation of a large fully accessible school with parking inside it, we were told that there would no longer be provision for parking close to the school and the council were the only ones who could create a disabled parking space outside (which could be used by anyone and was not just for us).

Our Deputy who was trying to get us a proper spot as well as a proper chair for my daughter left the school suddenly and we had to take things on ourselves. The council were happy to make the spot but wanted the Department to pay for the levelling of the land as they had done in another local school in the district. The Principal told us that the Department had said no.

For 3.5 years we have used Kiss n pick and the SLSO has to meet us with my daughter's walker to get her into the school. On occasions when I have to take her into school, I have to park quite some distance away and push her up the hill in her walker (exhausting for her when she was younger).

Just this year our current Deputy advocate managed to get us access to the staff car park for pick-up times. We still use kiss n drop in the mornings. I haven't dared ask for the parking in the morning. I am so grateful to finally be in this position in the afternoons (even though I know this should always have been our fundamental right). That I don't want to rock the boat by asking for more.

This is a necessary adjustment a school legally needs to make. And one that I would have had every right to challenge legally (and have been encouraged to do so on a number of occasions, by many an outraged parent at the school).

However, this would have been a dangerous thing to do and would only have fuelled the flames.

The Principal of a school is all-powerful and ultimately controls what teacher you get, what support you get, how much access you have to the school and can make life very difficult if she wants to.

We were lucky enough to have 2 Deputy advocates (one who left, but then was replaced by another) and these have been responsible for all the good experiences we've had and a template for what works well and why.

### Teacher decisions:

Both Deputies ensured we had excellent teachers whilst we were in their jurisdiction. All 3 who wanted to give our daughter a fully inclusive educational experience and 1 of whom went to every type of effort to do so. The other 2, just really "got it" and Jessica had amazing years with them.

However, that is not to say they didn't have their problems. Both wanted to teach Jessica again the next year, they had enjoyed it so much. Both had this request refused by the Principal, and her Kindy teacher ended up leaving the school because of it – among other things that happened that made her life difficult as Jessica's class teacher (e.g. being the only teacher made to move classrooms 5 times during the renovation).

However, our's is a very high-performing school in Naplan, so in Year 3, the influence of the Principal was really felt. Jessica had been allocated 2 teachers that year, one of whom was the highly experienced learning support teacher. With no notice, the Principal swapped her out - without even telling us – for a brand-new graduate teacher straight out of uni.

The other, more experienced teacher (a category 3, unfortunately) actively excluded Jessica and gave her the worst year ever (as detailed below).

### Influence on 1:1 SLSO support:

Our first Deputy Advocate agreed to put in place a specialist education support company who consulted on educational adaptations so she could access the same educational activities as the other kids and supplied her 1:1 educational support for the first 2 years of her schooling life.

It gave her the best educational start she could hope for – every support person who worked with her was amazing and their focus on social and educational inclusion and ways to do this even for a severely disabled, non-verbal child was second to none.

After our 1<sup>st</sup> Deputy advocate left the school suddenly, we were told that the specialist company were no longer allowed to go in. The school have external sports and physical education teachers, dance teachers, music teachers, you name it - coming in to the school to teach subjects which require a much lesser specialist skill set, why couldn't my daughter continue with what was working?

We were told it was against “Department rules” – even though I know that other Principals at other schools in NSW still allow them to go into their schools.

Jessica's support situation and learning have been impacted greatly since the external school support specialists were ousted: and has had grave ramifications for the rest of the family – siblings and parents and relationships within the family, as a result of the additional stress involved as I try to keep her education up at home outside school hours and try desperately to get the support people that are in place.

When the Principal spoke with me directly on the subject, she went on to trying to persuade me to send Jessica to special school rather than continue in the local mainstream public school where her brothers go. The school she suggested was the local very high needs / high-dependency special schools - one I had visited and totally inappropriate for my child and the nature of her disability.

She also referred to autism - a disability my daughter doesn't have and in fact couldn't be more different.

Demonstrating an unwillingness to understand disability and an adversity to inclusion.

We have had a swinging door of between 2 and 4 SLSO's per year coming and going since at the school. At one point last year we had 4 different SLSO's across 5 days.

Despite my best efforts to find and refer good candidates to apply to the school for the positions when they come up, and our Deputy advocates' efforts to get good people employed, the good and most appropriate people, if they are referred by me, only get offered 1 day (if at all) and often for tenuous reasons.

And the “carer” profile (early childhood / childcare / carer / nursing) SLSO's are the ones who seem to get the job (including 1 who had “interviewed terribly in the last round – but actually we now think she'd be great for the job!”

My daughter is the most high-needs child at the school. Yet of the team of SLSO's the only 2 who were recently made permanent, are the 2 who will not work with my daughter – the carer types who don't understand her intellectual capabilities or that their job is the educational side. And a constant misunderstanding of her physical capabilities, despite multiple training sessions by physios – she can do most things with minimal handling – if you handle her properly

So there has been a constant stream of part-time people who don't have the right attitude in the first place.

And if there are good people, the culture from the top of “too hard – you might put your back out” and the attitude that parents should be kept out (meaning that I can’t train them properly in the adaptation method), means that it invariably ends up going sour and they either don’t want to do the job anymore. Or if they do, they don’t know what they are doing as I haven’t been allowed in to train them, and it becomes incredibly difficult for them to get anything out of Jessica.

Our Deputy advocate has spent years tirelessly trying to make things better for my daughter’s support at school since this happened and these influences and decisions made from above only make her job harder – and make things more difficult for Jessica and us as a family.

There are too many things that happen all the time at the school, where decisions from the top are designed to make our lives difficult, to even mention.

## Teacher / Classroom:

Year 3, last year, was unfortunately a year full of examples of how things are when it doesn’t work:

The main, more experienced teacher, who was mentoring the new grad, was openly excluding her from work in class, not giving the SLSO’s any work to do with her, excluding her from the classroom if she made noise (something she was doing due to frustration).

I discovered Jessica was not even getting any of the work the other kids were getting right at the beginning of the year, when they were handing out worksheets and didn’t give one to Jessica. I asked could Jessica have one and she said she would see if she had a “spare”.

When I complained about this afterwards, I was blocked from coming in the classroom for many months and told I was not allowed in. Even when I was going to help with toilets, I was not allowed to enter the classroom to get her and take her.

What ensued was not only the worst year of her personal and educational life, but also of mine (see below).

Her eye gaze – her voice – would often come home on mute. The teacher openly lied about things they said they were doing or going to do and I knew they weren’t.

No academic feedback - Despite a number of requests and me painstakingly preparing a folder of school work I had done at home with her and a key to go with it, she was completely unable to give me any academic feedback whatsoever for an entire school year. The only assessments that were ever completed were done by me at home.

Not engaging - I never saw any interaction with Jessica from the main teacher, and only had evidence to support the opposite from her OT and speech therapist who spent hours going in to try and make things better. The OT was completely ignored when she went in. The speech therapists only had one session with both teachers and for the 2<sup>nd</sup> the main teacher didn’t show up. And after that she told her they didn’t want any more meetings as they didn’t need her help. She only ever responded to me when she had to and in the end I gave up.

Jessica’s OT who has known her for years, said she was upset with her in a school visit and sounding like she was trying to verbally say something to her. She asked me to find out what it was, so I asked her to write a sentence for me. I expected it to maybe be about the fact that her OT had had to reduce her face-to-face sessions with her recently. Instead, she wrote the attached and as she was

spelling out the letters I felt sick to the stomach. That was when I realised how bad things really were and also how emotionally and mentally aware of everything she really is.

Attitude - In the IEP meeting the teacher had nothing to say and nothing to add, apart from raising that a child had tripped over the back of Jessica's desk chair leg and the parent had "understandably" complained and could we discuss how we could change Jessica's position in the classroom.

Social exclusion - the teacher's attitude to my daughter and this example of a way to treat a person with a disability was reflected in the stark contrast in the way her school friends treated her at her 9<sup>th</sup> birthday party that year, compared with the previous year. I asked her to write a sentence for the parents and children after her party, expecting "thank you for coming" or something similar that I could write on the birthday group chat to the parents instead of having to write a detailed message. Instead, she wrote the following sentence (see photo of her writing attached).

Restrictive practice - I found out via a physio who went in to do training at school, that the SLSO's (who'd been with Jessica in previous years and had always been kind and caring) were putting a mask on her when she was blowing raspberries (a short, involuntary outburst of breath common in her syndrome in times of excitement and stress – the latter of which was prevalent that school year with the teachers we had).

My understanding, although I may be wrong, was that this direction came from the teacher. I had never given my permission for them to do this, nor was I told this was happening, and more importantly my daughter had never given her permission for them to do this to her. Although I had an idea that something was wrong due to the things she was trying to tell me on her eye gaze device that "something is making me sad", "it's about someone else", she does not have the language on there to tell me something of that nature.

Once I found out from the physio that this had happened when she visited the school, I asked my daughter how often and how long it had been going on for. I was told several times a week. Over several months. I had this confirmed by my youngest son who is in the year below at the same school, who said it felt completely wrong when he used to see it, but he didn't think they would ever do something like that without my permission, so presumed that I had.

She is non-verbal and has hand apraxia and is physically very challenged so would completely unable to stop them doing this to her.

Quite apart from the human rights issue, the feeling of exclusion she was already feeling as a result of the way she was being treated by her teachers, was magnified even more by this treatment.

Social exclusion - Jessica was able to tell me on the eye gaze that she was being kept inside at lunchtimes eating away from the other kids (I want to go outside, playground, on repeat) after school on her eye gaze so I managed to work this out. But my normally happy child with an age-appropriate level of intellect and cognition whined and whinged for 4 hours every day after school for over a year while these things were happening to her.

Now we have a better teacher than before, and some better support than was in place before, this has stopped completely. So, no, it wasn't a product of her syndrome: it was frustration at the way she was being treated that she could not tell me anything about.

The presumption that my daughter was not going to be able to tell me what was happening because she is non verbal, was one of the most disturbing parts of this story.

And this is the most dangerous scenario: when schools tell parents they are or aren't doing one something, when they clearly are not. e.g. one of the class teachers is going to take the whole day to sit with your child and work with her 1:1; being shown work by 1 SLSO, and then 2 hours later, a different SLSO would show the same piece of work and say they'd just been doing it.

When a culture of lying to parents of kids with a disability in a school exists, it is a dangerous thing: your mind starts to wander and you think about all the other things you aren't finding out and all the other things your non-verbal child is trying to tell you is happening but is unable to.

But I know my situation is not as bad as other children's and at least Jessica's therapists were allowed in to the school.

And our only saving grace throughout has been our wonderful Deputy advocate who will always does her very best for Jessica whenever she can and whenever she knows about things going wrong for her (and unfortunately when things are bad, very often she doesn't).

\*Jessica did not want to sit the test, nor would we ever have made her: it isn't a relevant form of assessment with someone with a neurological apraxia, such as her's.

## 1:1 Support / SLSO's:

Jessica's education has directly suffered as a result of losing the external school support company and her support in school has been poor ever since: a revolving door of "carer" types who mostly didn't know how to adapt the curriculum for her, nor did they see that as their job to. Taken out of the classroom if she was whingeing (frustration due to not being able to do the same work as the other kids) and having baby books read to her outside the classroom.

There are quite a number of instances in recent times where SLSO's have gone "off-piste" and put in place their own (not agreed) processes around Jessica's physical, social and educational requirements.

These include:

- wheeling her around the playground and even to kiss n pick in her supportive desk chair which should never even leave the desk: Jessica does not use a wheelchair at school as she has a walker which she can walk in independently and walks with minimal assistance holding one hand
- taking a classroom table and chairs outside and sitting her in a corner facing a wall on her own to have her lunch, away from all the other children
- talking to her like a baby and singing "Twinkle, twinkle little star" to her
- not sitting opposite her to read her yes and no's or prompting her to give those multichoice answers properly, writing all over her whiteboard, instead of just using it to blow up e.g. just 1 number question – something she would not even be able to see or register due to her visual challenges – meaning that she can't answer questions in class.
- Choosing baby books from the library for her (instead of letting her choose her own, age-appropriate books)
- Reading things out to her in her learning instead of letting her read the number or words herself
- Not using her eye gaze device to model to her or ignoring the things she says on it

- Not crediting her with the same intellect as the other kids, so she becomes frustrated or bored and falls asleep.

As she confirmed to me on her eye gaze in a motivational discussion around her education just this week "(I am), smart, really, very, very, very, very..."

A number of these problems have arisen, quite simply because people have not been trained any better. And the root of all these problems and the main one I face at the moment is lack of communication with me and a resistance to letting me come in and train and show them how it should be done.

When the external school support company were ousted, our Deputy advocate managed (with my help) to employ 2 ex-employees of their's.

Unfortunately, the 1<sup>st</sup> left due to visa restrictions and the 2<sup>nd</sup>, whilst great with Jessica, was never trained properly and so I realised some time down the track that the system that we'd all worked hard to put in place wasn't being implemented. In addition, she was no longer being lead by the excellent educator who ran her old company and was instead being influenced by other SLSO's at the school, and also had no training in handling and experienced constant issues and time off of work.

This started a cycle of me regularly going in to school to help with toileting due to staffing issues, as Jessica needs 2 people to do this from a manual handling perspective due to having to get the back brace on and off.

Whilst it took it's toll and ultimately meant I had to change jobs to one with more flexibility in order to do keep doing this, I really didn't mind (and will always make myself available at school to help) as it meant I still had access to what was happening in the classroom, and could tailor her home school learning to make up for what was not happening at school.

What has since ensued from a learning perspective is a number of SLSO's who weren't using the learning system implemented by the world's leading literacy educator that Jessica is lucky enough to have sessions with online. This lady has worked with over 400 girls and women with and along with the initial company who were her support at school, set up her system of learning and ability to participate in all aspects of the mainstream curriculum despite her great challenges.

The problem was the resistance to letting me come in and train, and set things straight. Even when I was allowed, it was sporadic and only for 45 minutes at a time and only when the teachers could be there too.

It has severely impacted Jessica's literacy sessions at home. She stayed on the same level books for almost 2 years in the end. And then, even worse, due to what was happening in Year 3 and the way the teachers were treating her and the lack of learning she was getting, she refused to participate or in doing any work at all.

In the end, we took money out of our savings to go to a summer camp with other girls and families in the US followed by some face-to-face lessons with the Educator. It was amazing once she was away from school and in the right environment, where she was surrounded by people who believed in her and understood that inside her head she is a normal little girl with a normal 10-year old brain – just in a body that doesn't work very well.

Her motivation and learning came right back. She went up 2 reading levels in the end. I learnt so much and I picked up so much about how they could do adapt the harder work they were doing for her.

We had some great meetings at the end of last year with the new teacher, a different deputy and the new SLSO they had brought. Everyone was really keen and enthusiastic to learn and when I suggested it would be a good idea for me to come into the classroom for the first week or so to train the new SLSO, everyone thought it would be a great idea – why wouldn't you?

I almost skipped out of that meeting, and had the first summer in 3 years where I forgot about school and didn't spend every night waking up worrying about what I was going to get thrown at me at the beginning of the next school year to try and make us leave.

I needed the emotional break as it has taken its toll over the years and the whole experience for me has been the most stressful thing I have dealt with in 10 years – surpassing Jessica's diagnosis, her back brace, the onset of seizures – you name it.

However, now the year has started and the training was pulled right back. I was allowed in on the 2<sup>nd</sup> day and with the new teacher it was amazing. Jessica was beside herself with being included in that way and with the learning. The first week was great with communication with the teacher and SLSO.

And then all of a sudden, communications with the teacher went completely cold. All training was cancelled and the 2 meetings with her that replaced it were cancelled out of nowhere too.

The teacher is also a deputy principal who has been at the school a long time, so I have no doubt, this is, again at the hands of the Principal, and I am back to doing school work at home again and battling to get things done properly, as again her at-home literacy sessions have gone south. The teacher is complaining that Jessica sleeps all the time and doesn't do any work. This is because they are not doing the learning correctly and I have been blocked from going in to train, but every time a session gets booked, there is one reason or another it has to be cancelled

The impact of the stress and additional learning on Jessica's siblings, our marital relationship and the family harmony as a whole is incredibly negative. My youngest feels neglected and aged 8 is complaining that he is very sad and lonely. We are constantly being pushed and life is made difficult for us, but I will never, ever send Jessica to a special school. Despite everything, the benefits of the social skills she now has and the education she has received, and improvements to her in every area because she is there learning from her mainstream peers - however difficult it has been made for us - have to outweigh the costs.

And these benefits aside, Jessica has only got to where she is today by us treating her exactly the same as anyone else. And being hidden away from the community and segregated away into a special setting quite simply isn't something we believe in.

When Jessica goes to the shops, people come up to her and say hi all the time. At school, kids say hi when she arrives.

Not only does this make a massive difference to her life but it will influence every one of those people's outlook on diversity forever. And benefit the community as a whole.

## When it works well, what does it look like – what can it look like?

Jessica has had the experience of getting enough support to get a good education before.

And is entirely possible if the driving forces who lead the school, the district and the department itself believe that a child with a disability, however severe, has an equal right to the same educational opportunity at her local mainstream school as her siblings, and other children in the community.

It is entirely possible, with the same funding model – it just needs the right attitude of the people in charge:

I have seen it work really well when we have been given a good teacher, who embraces the opportunity to include a child with a disability in the same educational experiences as all the other kids. Also, with the right SLSO support.

My daughter started school with an amazing, external organisation who are specialists in adapting the curriculum for kids with disabilities in mainstream and other educational settings, and were allowed to provide that 1:1 support for my child at school. With advice I received internationally from a specialist educator in my daughter's rare genetic condition, both the teacher and the support organisation were happy to work together as a team to set up a great system to ensure that my daughter could join in all the same educational experiences as her peers.

So my physically-challenged, non-verbal daughter with severe hand apraxia and a disability so severe that even some parents I have met, dismiss their daughters as having "nothing there" has learnt to read, "write", give really smart comprehension answers and do amazing maths (top 1/3 in her class we were told in Year 1), create speeches and presentations, and give her opinion on topics, using this framework, and a yes and no board and her eye gaze device.

This is very starkly contrasted with our experience of her same-aged peers with the same disability who have not had this opportunity in a mainstream (or other) setting. By giving her the exposure to the same level of education and social interaction as her mainstream peers she has come on leaps and bounds and surpassed all expectations that were put upon her when she was diagnosed.

I have really pushed for inclusion at the school and this is one thing the SLSO team and teachers have really taken on board. Jessica is so much more motivated to learn when she sits in a reading group or has another child working with her.

The learning impact for her and the other child is amazing to see and there are benefits on so many levels.

And for someone who is really quite lonely and finds it hard to make friends because of her challenges, it literally lights up her life.

Jessica LIVES for being able to walk out in the playground and be with the other kids. A lot of kids don't get it, but some do and love to go up and chat to her and make her pictures and presents. Her happiness is insurmountable at these times, and for this alone, being at school in this setting means everything.

### Working together – Collaboration

I have learnt over 4.5 years of real highs and lows, that there needs to be a triangle of support:  
Teacher / SLSO / Parent.

- If one of those partners has inadequacies in terms of skill or attitude (willingness to make an equal learning opportunity work and a passion for true inclusion) - the child educationally and socially falls backwards.
- If communication fails or is blocked for any reason - the child educationally and socially falls backwards.

However, if communication is open and positive ideas are allowed flow between the parent, the SLSO's and the teacher, then the educational and adaptation process moves forward, the child continues to flourish, and as every year becomes harder, or the next medical or physical challenge arises, it is possible to overcome these obstacles because everyone is working together to move things forward.

And no-one is trying to block communication and progress can continue.

In Kindy and Year 1, I fed back what I was seeing in Jessica's home-learning and they fed back methods and techniques to me.

I would have regular calls with the teacher and they would tell me what was going well or not so well and I could work on areas of weakness at home.

Also, when disability is normalised and there isn't a constant reference to how hard things are or how she just can't do as much as the other kids, and your child is discussed in a normal way, the same as any other child, then you can focus on what is important – her and her education.

When the attitude is to value her as a person and her education as much as any other child at the school, then it works and you can see the positive changes in your child.

If the teacher and SLSO and parent can celebrate and enjoy together the progress she has made throughout the year, then it really works.

When you have this attitude from all 3 parties, it really works and you see real, tangible benefits as listed below.

### **Benefits of my daughter being in a mainstream school:**

She has developed socially and been able to learn to overcome some of the physical behaviours that are a trait of her disability – something therapists say is unheard of in most girls with the same disability. She has learnt to control her raspberries and also stop putting her hand in her mouth. She has been told these are socially unacceptable and also has the peer pressure from around her and has seen that the other children in her class don't do this so has stopped.

Again, virtually unheard of for someone with her disability.

Literacy – Jessica is reading, writing and spelling. She needs her head held really still so her eyes can track the words on the page and whilst her silent reading is below her peers, her reading comprehension and understanding of literature is age-appropriate.

She uses an a,b,c flipbook to write by looking at yes and no symbols to spell letter by letter, and whilst it can take 15 or 20 minutes, what she writes shows real, age-appropriate understanding and thought.

Her emotional maturity is astounding. Some of the emotional intelligence and wisdom she displays, even just using the limited vocabulary (with no real sentence structure) on her eye gaze is amazing.

She wrote a really thought-provoking talk on racism in Year 3, with some really interesting ideas in racism (relating it to her own situation) and also showed an ability to get her head round some difficult concepts.

Whilst it is challenging that so many kids and adults still don't understand her (and it is tough for her when they are mean), she takes so much joy from those that do.

In addition, Jessica is a child who is non-verbal and should never talk and in the last 6 months has started making a discernible babble to ask to go to the bathroom, say she wants to go to bed, say yes and also say no more.

I firmly believe that this is due to watching and learning from the mainstream kids around her, that she has made such positive advances.

Whilst it can be upsetting for all parties concerned, if people do stare at her or kids make comments, I truly believe that my daughter is an ambassador for future generations' attitudes towards disability.

On the odd, rare occasion I have met an adult who was at school with someone with a disability, I have been amazed by their warmth and with how normally they treat Jessica. Something she gets overjoyed about.

The benefits for the other children and society as a whole of my daughter being at the school far outweigh the extra efforts involved.

## Resources:

Our local public school underwent an expensive renovation which turned it into a fully accessible school space, with lifts and ramps throughout.

Before that, she had had a fall on her face in her walker over a bump in the concrete. However, this was an accident that could have happened anywhere, and ramps had already been put in the school to make things more accessible, even before the renovation.

My daughter has a fully accessible bathroom which has her customised toilet seat on it. She also has the classroom chair that she needs (see below). And is allowed to keep her walker outside the classroom for use at school.

The Deputy who is our main advocate there, works closely with my daughter's longstanding OT to get everything she needs, and applies through the department for these things ahead of time.

On the odd occasion when classes like music or science have to be in an inaccessible area up some stairs, I am lucky enough to be given that access and have been assured that I will be told and asked to come in and help her so she can be included.

However, this followed an instance in Year 3 where the teacher went home sick and the rest of the class went to a classroom upstairs and the lifts were broken and they left her in a room on her own with the SLSO when the rest of her class went upstairs. This made her pretty upset.

Following this and a number of concerning scenarios that happened last year in Year 3, this kind of issue has been addressed and I would like to think won't happen again and at worst I will be called in to help Jessica up some stairs.

The parking situation I have addressed above and we have made some headway in the last 6 months.

We have also had a proper, supportive chair for the most part. The funding for the first chair that the first Deputy had secured before she left the school - and the Department confirmed they had released to the school, but the school seemed to have no knowledge of for several months - meant Jessica had to stay in a badly positioned chair just as her scoliosis deteriorated rapidly.

Shortly after the Principal decided to pay for the chair anyway, even though the funding apparently still hadn't appeared, Jessica unfortunately was prescribed a plastic back brace which she needs to wear for 20 hours a day.

A rapidly deteriorating scoliosis is not uncommon around that age, and the lack of a suitable chair was not the only reason it happened – it would have happened anyway. But the timing wasn't great.

That said, since that time we have always had a great supportive chair in every classroom, and she has never grown out of one since. And her therapists are always allowed access to the classroom for these instances but also for training.

## Changes for success - to ensure success for everyone

I believe that a successful inclusive educational experience is 100% attainable in any setting for any kids – and only the smallest, most reasonable, cost and time-efficient changes need to be made.

There are low-cost, easy-to-implement ways for teachers to get better support at schools:

- 1) Everything comes from the top in NSW schools and the right attitude from the top is fundamental.

Principals and District heads need to:

- be educated as to how inclusion can work well, what the benefits are to the other pupils and their local communities,

- be incentivised to include children with additional needs and educate them to the best of their ability – e.g. a separate scoring matrix that all schools are graded on. The problem currently is that Naplan is the only way that schools are recognised as being good / not good.

Currently, even if your local public school happens to be a top-scoring Naplan school, the motivation for the Principal to accommodate your child and educate them to the best of *the child's* ability (rather than the status quo) is low.

- be given a set of minimum requirements for inclusion in education that they are bound to adhere to. Even there will mostly be category 2 people at the top (and therefore these need to be educated), there are also some category 3's and being subject to one of these in power is a highly unpleasant experience, when life is stressful enough with a child with a disability.

Minimum requirements include – parents cannot be blocked from the classroom or school, every effort made for the child to be included in the same educational and other activities as everyone else, exclusion from the classroom to be avoided at all costs, social inclusion is fundamental,

restrictive practice not allowed, deviance from the educational and care pro forma agreed at the IEP meeting – not allowed other than by agreement from the parents, therapists and the school.

- be held accountable if they fall short of these minimum requirements via an independent commission who conduct random (and anonymously instigated – via independent parent complaints commission) audits across all schools to see how they are upholding these. This should include interviewing the parents, the child if possible, any SLSO's who work with them and the teacher and executives in the school

- 2) A central educational support body who specialise in adapting the curriculum and classroom setting so that the child can participate too. And who can go in and train teachers who have pupils in their class with additional needs and show them how they could adapt their learning for the child, so that it works and fits in with the rest of the class. And also who they can draw on for support. Something like this already exists in Victoria and South Australia.
- 3) The ability to draw on expertise from external specialist school support consulting organisations – there is an excellent organisation who have achieved outstanding educational outcomes for disabled kids in mainstream schools that we are linked in with. Also, that they are allowed to go into all NSW schools and train senior staff, teachers and SLSO's in how to do it. And also provide SLSO's at a reasonable cost if the school and teacher want it. When we were in this position at our current school, our daughter's education flourished. Since this has been taken away and we were told it was not allowed, her learning has been impacted negatively.
- 4) Communication with child's existing allied health / therapy team, if this is the preference of the parents. The current set-up of e.g. speech therapists who work for the department falls short in that those people don't know the child and cannot understand them fully in the way that someone who has worked with them for years and knows their background can. I am lucky that my daughter's therapists have always been allowed into the school to train on basic competencies, make recommendations and provide guidance in the annual meetings. This should be allowed for all.
- 5) Involvement from parents is positively encouraged and not blocked. Parents are a free and invaluable resource who in a lot of cases are passionate about their child's learning and will often investigate methods of helping their child's learning in order to help school, the teachers and SLSO's. Communication should be open. Parents should be allowed to help train SLSO's and teachers. Parents should be allowed open communication with SLSO's. We have seen our daughter's learning outcomes go through the roof when this is allowed. And her learning and motivation go the other way when this is not the case.
- 6) SLSO's can have contact with parents outside of school. SLSO's can also work for the families of the child they support at school and be paid to support them in the home if they want to.
- 7) Teachers are encouraged to work with parents, rather than in some cases where they are encouraged to block involvement by the parents – and even worse – parents are blocked from entering the classroom (a dangerous situation if your child has a severe disability and is non-verbal). We have been party to both experiences, and in the former scenario, our daughter learnt to read, write, do amazing maths and understand and show knowledge of

concepts we were told she never would. In the latter, last year, we had grave concerns and some very worrying things were happening in the classroom as a result (see restrictive practices). As well as her missing out on fundamental learning areas that we had to spend extensive time at home teaching her ourselves to catch up.

- 8) Teachers are educated to understand that they are fully responsible for the education of the child with a disability – not the SLSO. They need to oversee the adaptation of the curriculum for the child, prescribe what the SLSO does in class to do this and be able to provide a full assessment of the child's educational development in the same way as the other children.
- 9) Recruitment of SLSO's – visa incentives given for therapists from overseas who cannot get qualified in Australia immediately to come and work in our schools. School should be allowed to sponsor people from overseas to come and work as SLSO's. These positions are not well-paid and need the right attitude and training, and this resource would be invaluable in what is becoming an increasing need.

### **Text email: 15 March 2024**

Please find attached my submission. I have taken COB in it's loosest term. Apologies - making time for this sort of thing when you have a daughter with high needs and other kids can be challenging.

Please also find attached some writing that Josie did to support some of the examples I have given and how she felt about those situations.

Josie uses an abc flipbook to write by looking at yes and no symbols to spell letter by letter, and whilst it can take 15 or 20 minutes, what she writes is her purest form of communication and is the truest depiction of what she is really thinking that we have.

The 1st sentence was written after her birthday party during a bad year at school where a teacher was excluding and ignoring her and this behaviour was influencing the kids in her class - something we have never seen at a social event with kids from school either before or since.

The 2nd sentence was written in response to something she seemed to be saying in an upset way to her OT when she was going into school that same year. I asked her why she seemed upset with her and what she was trying to say and that was what she wrote.

I hope you have time to read everything. I put my heart and soul into Josie's education and have lived and breathed the last 4 years of primary school with all it's ups and downs and have tried to put the same into this submission.

With Thanks,

She is job  
to fix school.



