

Susan Hoffmann's Story for the Disability Royal Commission on Behalf of my Daughter

This story is to be both a Submission to the Commission and a Response to the Promoting Inclusion Issues Paper.

I am the parent of a young woman, Molly, who is almost 16 years old. Molly has complex and multiple disabilities. The bulk of this response is to do with Molly's school experiences and our goal and vision for her to live an ordinary life, part of which is an inclusive education. So that probably leads into the first question of the Issues Paper...

Question 1: What does inclusion mean to you?

On behalf of Molly, as her primary advocate and champion in life as a young person living with significant disability - inclusion to us means an ordinary life. It means the person with a disability having the same opportunities and experiences as their non-disabled peers. In our family, Molly sits between two siblings. She has a sister who is 3 years younger and one who is 3 years older. The vision of an ordinary life is easy for us to envisage because she has typical siblings growing up in the same family who are the non-disabled peers who we can compare her experiences with.

Question 2: What makes an inclusive society?

An inclusive society is one that achieves those goals as noted above in Q1. It is a society where people with disability enjoy the same opportunities and experiences as, and can achieve the same goals and life outcomes as, people without disability.

Question 3: Do you think Australia is an inclusive society?

Far from it, but we have stepped onto the right pathway. We encounter barriers to Molly's inclusion in ordinary life every single day. I think that an inclusive society is something that evolves over a very long period of time and in a lot of different arenas - and I think that we have in Australia, as a society we have stepped onto the pathway, but we are a long way from the ultimate destination. That being: an ordinary life with the same opportunities and experiences for people with disability as those without get to enjoy. There is much more work to be done.

Question 4: How can an inclusive society support the independence and choice and control of people with disability?

I think that my main response to this Q would be "nothing about us without us" - including people with disabilities and their champions & advocates at all levels of the planning and organisation of whatever it happens to be. Whether it be employment, education, government, general community, facilities, Government structures etc.

Question 5: How can an inclusive society support a person with disability's right to live free from violence & abuse, neglect or exploitation?

My main point under this Q is that there is safety in community and the safest place for a child with a disability to be in education is to be with their same-aged peers - that is where they are best protected from violence, abuse, neglect and exploitation.

People with disability being visibly and actively involved, and participating in that ordinary community life, is what keeps them safe – with their typical peers looking out for them.

Question 6: What practical and sustainable steps can governments take to promote a more inclusive society for people with disability?

I looked at this from primarily the aspect of education and what needs to change in Australia and in NSW (my experience is in NSW). Stop the investment in segregated education settings and stop muddying the waters about what an inclusive education is and what it looks like. At the moment, the Department of Education (NSW) is only making it less clear and I believe that has to do with making it less obvious that they are failing in their fundamental responsibility under the UNCRPD General Comment on Inclusive Education. The overriding framework of inclusion in the UNCRPD General Comment 4 is incredibly clear about what young people and children should have a right to in terms of inclusion in education. It is very straightforward. Australia, and NSW (specifically), is absolutely failing in it's responsibility as a signatory to that UN convention. Every child has a right to inclusive education, and governments should be actively diverting funding for anything else away from the alternatives and investing in equipping the people and systems to provide authentic inclusive education.

The other aspect to do with this Q would be the NDIS and the changes that need to happen in that scheme, in particular with regard to people with a physical disability and assistive technology - because the attachment of dollar value to somebody's inclusion and independence is causing absolute chaos and heartbreak for people with disability and their families. We had a situation where there was a particular type of wheelchair that was absolutely without a doubt going to increase and improve Molly's independence and inclusion in ordinary society and life and school and interactions with peers, and in the future support Molly to be able to contribute to financial employment and economic participation.

We fought the NDIA for 2.5 years right to and through the AAT to get them to fund it, and families are having to do that constantly and repetitively to get what they need - in terms of assistive technology in particular because unfortunately they are somewhat expensive items. (Perhaps the government could launch an enquiry into the outrageous cost of this equipment, especially as much of it has to be imported and the local sole-suppliers are shamefully making a significant profit). You cannot put a \$-value on someone's independence and inclusion in ordinary life, and independence & inclusion is one of the fundamental underlying principles of the NDIS. It is absolutely abhorrent for NDIA to fight you on that.

To end up having to take them to the AAT puts families on a completely different power level to the Agency who have got absolutely no hesitation in throwing buckets of money at their legal representation to avoid having to spend that money. We ended up in a situation where we won because they had the gall to suggest that my daughter's independence and inclusion, the equipment that would provide that, was considered a "luxury item". I suggested that they view their legs as a luxury item they could happily do without.

I have to say that it was at that point in the documentation (obtained under FOI for all of their internal documents) – at around page 180 of about 220 – someone had written in biro on an internal NDIA form "wheelchair is a luxury item and we don't fund that". I knew then that I would happily stand up in court and argue against that, and likely win. And I did. But not every kid with a disability has a mother like me.

I, as Molly's mother and advocate and champion, am a tertiary-educated, English-speaking, pretty savvy person who is willing to be "that mother" and take on the system. There are plenty of young people with disability who do not have the luxury of a champion & advocate like myself.

Government agencies need to stop putting more barriers in the way. If the therapist has clearly demonstrated that this would improve the person with a disability's independence and inclusion in ordinary life, it should just be funded, there should be no question.

Question 7: What practical and sustainable steps can non-government institutions, the private sector and communities take to promote a more inclusive society?

The two words that come to mind are that they need to have the WILL and the SKILL. Fundamental willingness to do what it takes to include people with all kinds of disabilities and then the skills to implement that. Living with someone who is a power wheelchair user, physical access in our local community is not at all sorted - and there is a widespread belief that we have solved this as a nation. I can guarantee you that physical access is something that we battle with every single day, wherever we go. Often at non-government institutions – such as a shop with a single step at the front. Molly cannot enter and will not spend money in that establishment. Physical access continues to be an issue throughout this great country and city.

I think that when people are setting up businesses etc, they just fundamentally fail to consider all potential users of that service or facility. Governments do it (kind of) because they have to, because it has been mandated but there is a lot of getting away with not doing it in the private sector. They don't view people with disability as important valuable consumers who may wish to access the service.

Tiny example – perfect example (more going back to the Government question though). In our Local Government Area (LGA), Council decided to replace all the rubbish bins – including those around the local primary schools. Council has installed rubbish bins that are so tall that they cannot be used by a wheelchair user, small child or a person of small stature. So, a proportion of

people cannot access this public facility. If you suggest to the council that they are discriminating against wheelchair users and young children (and people of small stature) by installing such tall bins, they would probably be quite offended. Did they consider ALL of the potential users of this service/facility?

Another step that mainstream society could and should be taking is to consider all potential consumers of podcasts. Popularity of podcasts has exploded over recent years, but how many of them are transcribed for people without hearing? Almost none. That is a huge amount of information and entertainment that people without hearing do not have access to. Again, discriminating against people with disability. I did help to successfully campaign at the start of the pandemic to have the ABC's *Coronacast* podcast transcribed, even though I don't personally know anyone who is deaf. This kind of accessibility should not even need to be asked for – in a properly inclusive society it should just happen.

Question 8: What are the barriers and challenges to inclusion for people with disability?

(I don't know that I have specific comment about any of the particular groups listed in Q8.) Overall the main barriers are fear and ignorance and plain old "othering". Some examples of barriers and challenges... If you want to look at inclusive accessible housing – a huge can of worms barely begun to be opened in this country. Considering housing options available to us as a family which includes a power wheelchair user, in the area we live, the list of options is reduced monumentally (couldn't guess the percentage, but likely well under 5% of residential properties are accessible). Only a tiny proportion of homes are wheelchair accessible – which limits not only where we can live, but also means that Molly is unable to visit her friends' homes.

We live in an apartment building, which is almost completely accessible except for a giant step where the public footpath meets private property. I have begun to tackle the fight to get rid of this step but it will likely take years. First response from the council was an outright No. Right now, someone else has to get a temporary ramp so Molly can get into or out of our home. Multiple times a day, every time she goes out or returns home. This means she has no independence getting into and out of the property to access the community, school, etc.

We call this the "one-step barrier to inclusion and independence". The single step or stair at the entry that prevents any power wheelchair user from being able to access that property. And there is a plethora of them throughout our local area & suburb (and the wider city & country). If Council wanted to get serious about genuinely and authentically implementing a Disability Inclusion Action Plan (DIAP) they would immediately start work to eliminate every one of these steps. It can and should be done (and is being done by other nearby councils).

At the time our council's DIAP was being developed I involved myself in the process and participated in the community consultation, but the resulting document is the biggest pile of self-congratulatory claptrap I have ever had the misfortune to read. There is MUCH work to be done.

Question 9: Is there anything else we should know?

Yes – the Commission should know Molly’s inclusive education story. My bigger story & submission to the commission is about Molly’s school education and how inclusion relates to that. It is about her school education, theoretically an inclusive education, and Molly’s experience of the NSW public education system as it currently is and the battles we have fought and continue to fight along the way. Molly is a young person with significant disability – specifically physical disabilities, so she moves on wheels, has good functional use of only one hand and a vision impairment – notable for accessing education, school premises and the curriculum.

We developed a vision of that ordinary life very early in Molly’s life. Whatever her siblings and same-aged peers had a right to, and were enjoying in their lives, Molly should also have a right to and enjoy. It was a very clear pathway for us – the typical ordinary pathway as opposed to the divergent pathway of segregated settings, such as special classes, segregated schooling, separate special pathways, day programs & congregate housing – inevitably leading to not the ordinary life. This is not what we envisage for Molly’s future. We set off on the ordinary life pathway for Molly from when she was very young.

In our family, in terms of education, an ordinary life means local NSW public school education. Every child has the right to access their local public school. Knowing that right – and being willing & able to fight for it – is the only thing that meant we were successful in Molly attending our local primary school. It was a long drawn-out battle with the school, which commenced over two years before she started school. We did all the right things and we gave them a LOT of notice that we were intending to send Molly to that school. Sat back, watched and waited as the time for Molly to start school got closer and closer... and the school did nothing.

The Principal was eventually impressed upon to get her head out of the sand and realise that Molly would soon be starting - and despite some significant pushback, I was ready and willing to fight them on that point. After attending inclusive education workshops and reading about good examples of educational experiences, the overwhelming message is: if you find and have a good principal, all will be well.

Our story is about succeeding in spite of a destructive and negative Principal, who used every trick in the book to attempt to gate-keep Molly out of her local school. So we were determined to achieve an ordinary mainstream education for Molly, despite the powers that be. It was all of the important people at the school who were resistant – Principal, Assistant Principal/Kindergarten teacher, the School Counsellor, and the Learning & Support Teacher. No will and very little skill. They persisted in fighting Molly coming to the school to the very last. The Principal called me in just before Molly’s kindergarten year and said she can’t start school, you need to send her back to pre-school. I stood my ground, told them they had the summer holidays to get organised and pointed out that they’d had more than two years notice to be ready.

This led to some quite incredible meetings. In that situation you have to draw on others to stand with you – in our case that took the form of people from Molly’s medical health team, Molly’s therapy team and in particular the people above the school in the Department of Education who supported Molly’s right to access and attend her local school. It was an interesting moment where they called a big meeting after I was told without warning that she couldn’t start, and it was a very interesting dynamic to sit in that room and witness the Principal have this realisation that actually the people from the Department were not on her side. I was absolutely unwavering in my determination that Molly would attend her local public school. The big battle was getting her in the door, but the fight didn’t end there.

I was literally at loggerheads with the Principal for the duration of her remaining time at the school – I had to find other allies in the staff, and I had to keep reminding them of their fundamental obligations to have Molly at the school and to include her and to provide her with an education. Again, I am a tertiary-educated, English-speaking, well-read person who had to use all of that to battle the school and educate them about who Molly is and what their obligations are. Educating the educators. Molly’s education and advocacy became my full-time role, including the minutiae of ensuring she had access to everything that all the other children did, including community languages for example. Find a way or make a way. The will and the skill.

Consistently finding myself not wanting to have to find the solution for them, but having to find the solutions for them and force them to enact them. Educating the educators, while refusing to do their jobs for them. We chipped away and persisted and I really did become the teachers’ teacher. Educating the educators about their responsibilities and Molly’s right to an inclusive education. Her primary school education came together over an extended period of time. Constant advocacy, finding the allies, checking what was going on. Finding fellow champions who were willing to be part of Team Molly. Over a long period of time things changed, often it was the changes of people in key school roles. We outlasted all of the naysayers (almost). They got better at realising that Molly was in the school and going to stay – find a way or make a way to include her in all aspects, like excursions and camp. School didn’t even realise that they couldn’t make money the issue. There is funding that can support all of that. Continuously pushing & fighting.

Eventually the school got a new Deputy Principal who knew what Molly’s rights are and he became a great ally. Then, at the end of Molly’s Year 4, the discriminatory Principal left and was replaced by a fabulous, inclusive Principal. It comes down to the individual person who you are being forced to work with (or despite) and whether they are willing to get on board or continue to be an obstruction. It took a lot of work and chipping away. Over the course of her 7 years of primary school, Molly did eventually get close to an inclusive education.

Most of the naysayers had moved on. But in Molly’s very last months of primary school, the School Counsellor (who I had forgotten about) came out of the woodwork. She called me in, again without warning or explanation, and again tried to sell segregated special school education for High School to me! Had this woman learnt nothing about me at all over the past seven years??

So Molly finished Primary School on a high note – and the thing that was the saving grace from Molly’s perspective is that she was quite oblivious to much of the shitfight. Part of the challenge at primary school was to keep all the battles with school leadership in the background. Molly knew though in some ways – for example in the very early weeks when they had limited her to attending only two hours per day (again because the staff were unprepared and couldn’t cope), Molly was aware that she was the only one leaving, and did not want to come home.

A highlight of the end of her Primary School experience was Molly singing at the Opera House in the Festival of Choral Music. She successfully auditioned, in her own right, and then sang on the stage of the Concert Hall, with her typical classmates and 600 of her peers. Of course I needed to check out the practicalities and logistics of the Opera House before she even auditioned, to ensure she would be positioned with her peers. I started liaising with the Opera House a year before to ensure that Molly was able to access that equitably, which she did and it was fabulous.

Our vision of inclusion and ordinary life remained the same heading into High School, mainstream local high school with same-age peers. Transition this time was a lot less traumatic. It is not perfect, and the battles continue to this day. Molly is now in Year 10. I am still educating the educators while refusing to do their jobs for them. When it comes to inclusion for a kid like Molly, we are talking about three things: physical access, social inclusion and inclusion in curriculum. There is work to be done in all of those arenas, particularly in curricular inclusion.

Some High School teachers have no or few skills to adapt curriculum to meet Molly’s needs. We still have a way to go - but I continue to set that expectation of inclusion and expect them to rise to the occasion. Some do so willingly, and others fail her dismally. Inclusion means not only physically present but being included in a fair and equitable way. The school has a Learning & Support Teacher (LaST) who is available to help the classroom teachers but it comes down to their willingness to step up and do the job to adapt their lesson so she can access it in an equitable way. It is not perfect but better than her early primary school experience. There is ongoing conversations & challenges but fundamentally that attitude of “should she really be here, wouldn’t she be better off elsewhere”, “do we really have to accommodate all of those needs”, “wouldn’t it be easier if she was in that segregated separate setting” is no longer as prevalent.

An example that brought home how well Molly was being included in curriculum was home learning due to COVID. At school Molly has full-time SLSO support, as she requires that level of support in the classroom. None of this support transferred to home learning though. So there was me, mum, who became 10 High School teachers and 6 SLSO’s. I had to leave my paid job and do full-time education support for Molly. The suggestion that the education dept could transfer some of that support to the home environment was not received favourably or enacted. They would not even consider it. Suggestion that SLSO’s (who were still being paid and going to school) might drop resources home even was met with “no you can come and pick them up”. When I pushed back on what the school was expecting of students (and their families), the HS Principal said to me: “just don’t do the work” – clearly showing the importance of Molly’s ongoing learning

in her mind. Of course it would have been easier to just ignore schoolwork and just not do it, but that's not continuing her education under COVID times. I wasn't happy with that as a solution either, so we soldiered on and it was an interesting insight into what goes on in the classroom for Molly. I made it an opportunity to "audit" what was going on in the classroom and give them lots of feedback on what should be happening for Molly in terms of curricular inclusion. A lot of things we had been pushing for, like all the work be on computer – they now had to provide. Finding out what they should and could be doing in the classroom for her. Not that big an ask really - if mum can do it, surely so can they? COVID was an awful time for Molly - as a very sociable people-person she was like a miserable caged animal, stuck with mum as teacher!

So we soldier on and continue to fight the good fight for Molly's right to an inclusive education. Unfortunately NSW Department of Education is only muddying the waters on what that really is and looks like. They are bastardising the use of the term Inclusion and applying it to segregated education settings, and building more and more of these. Segregated education is a failing under the UNCRPD convention and also does not make financial sense. People think it's better, but it is an absolute myth that students are safer. It is an absolute falsity regarding safety and we need to be pulling down those fences. Every student has a right to an inclusive education. NSW Dept Ed needs to find a way and make a way for every student to have an authentic inclusive education experience – in their local school, with their typical peers and no separation or segregation.

I know that sometimes it is families who are pushing for segregated and alternate settings – often driven by fear and ignorance, and a lack of understanding about the rights of students with disability. The Government also pushes this message and agenda. Then we have people like 'Happy Families' parenting guru Dr Justin Coulson who publicly blames students with disability for poor teacher wellbeing – "Educator wellbeing is low. School leader wellbeing is lower... and it's little wonder. Behaviour challenges, students with special (additional) needs" (are the cause). Absolutely disgusting. It is this kind of dangerous messaging and attitude that promotes discrimination against and segregation of students with disability.

Final Word:

As the parent of a young person with a disability, I hope that the Commission realises that the stories that they actually get to hear are just the tip of an absolutely ENORMOUS iceberg. There are a great many families, and likely also people with disability themselves, who do not have the time, energy or 'headspace' to tell their stories (or do not feel safe to do so).

The volume of submissions by organisations rather than individuals, and the inherent power that organisations have in the lives of people with disability, concerns me greatly. The commission needs to have some kind of balance in the voices it is hearing from. I would be willing to speak to any of the points that I have raised at a public hearing.

I hope that Australia is ready to hear and implement the findings of this Royal Commission.