INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Name: Name suppressed

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Partially Confidential

Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

INTRODUCTION

I am the parent advocate of a young 15 year old autistic person. I am also a 49 year old person with a psychosocial disability. My partner has quite a significant caring role for both of us. We are completely financially dependent on welfare and therefore reliant on support services provided by government and which have little to no extra costs involved.

I welcome this opportunity to express our experience of the NDIS and more broadly of disability and support services, also to what could make that experience better. I welcome the NDIS and I hope at some point it will provide the support our family needs but at the moment it is not. This is presently the case for a number of reasons;

- Access issues in regards to the scheme and to needed support services outside the scheme.
- Mainstream services, which for us at the moment is primarily education and mental health, ensuring their own disability service provision and access at a state level.

When our family was reliant significantly on state based services there were gaps in regards to the meeting of our needs but there were services which we accessed which were significantly beneficial particularly because of their holistic approach. These services no longer exist (ie family intensive support, case management and respite provision) with the introduction of the NDIS as to with the change to an individual based approach. Our needs as individuals do not live in isolation to each other, they intersect and impact on as individuals together being a family unit.

At the moment it is only my young person who is accessing the NDIS as a participant. I am trying to become a participant but I may never be eligible. Without alternate support services and similar support frameworks existing particularly from a state perspective I am in the position where I may not ever get support I need. For all services I have ever tried to access either for myself, my young person or our family I have always been able to understand eligibility criteria, this has not been the case with the NDIS. I have also never been quite so put in the position whereby a system of support in accessing has caused such detrimental impacts on my and family's health and well being.

I feel strongly the NSW government could be doing a lot to ensure the success of the NDIS for NSW participants. They also need to address the gaps which currently exist and recognise their role in disability service provision as a state may not be as completely over as they thought with the introduction of the scheme. It really needs to be looked at what the NDIS is not supporting particularly what got lost in transition and ensuring mainstream services are accessible to and providing support to people with disability as they should be such as education.

A: THE IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND ITS SUCCESS OR OTHERWISE IN POROVIDING CHOICE AND CONTROL FOR PEOPLE WITH DISABILITY

For our family at the moment the NDIS is not what I would consider to be a "Success" in our lives and is contributing as well if at all in regards to choice and control.

We are from the Illawarra region where the NDIS rollout occurred June July 2017. My young Autistic person received their plan Mid September and we are almost a year through

As a person with a psychosocial disability I tried accessing the NDIS around December 2017 received notification in June 2018 that I had been unsuccessful. I have now put in a new application and whether I am successful or not it is likely going to take quite some time with the process being somewhat drawn out.

Our Status quo in relation to state and federal based support services prior to the NDIS

For my young autistic person;

My young person exhausted the limit of accessing state based health therapy services such as occupational therapy (ot) and speech quite early on ie around the age of 6. We were not in a financial position to continue these services privately. We were able to continue through the years to access speech language assessments and to some ot advice. Psychology we were able to continue off and on up until just before our young person left primary school. Due to our young person's late diagnosis of being autistic we were only eligible for one year of the Federal government's Fahcsia funding.

Access to these services were vital in providing support for my young person's development and being able to access the world around them. As then as is now this significant in regards to their access to education and the larger community.

My young person was not initially eligible for ADHC services as it was determined from cognitive assessments which were done if an intellectual disability existed it was only considered to be mild but more likely the outcomes were as a result of our young person being autistic and their associated severe language delay both receptive and expressive. My young person has had four cognitive assessments, the last apparently indicating a possible moderate intellectual delay, they became a client of ADHC when ADHC was in transition, winding down to no longer existing.

Despite not really being a client of ADHC over the years we did access ADHC support funding which included;

- Respite Initially this included our young person attending a social group every second
 weekend and us receiving a small monetary allocation once a month to contribute to a
 respite effect. When our young person no longer wanted to attend this allocation increased
 a little. In the last few years prior to transitioning across to the NDIS we became eligible and
 accessed what was called a flexible recreational respite package which was quite substantial.
- Family Intensive Support -At one point we accessed via a self referral family intensive support which was funded through ADHC. From what I understand about this support service/program while originating from FACs, was developed in the recognition that a family's experience of disability could put them in position of experiencing crisis thus needing a degree of intensive short term support to help them get through this.

- Case Management -Prior to the transition to the NDIS we again placed our names down for
 this type of assistance as well as longer term case management. We were not able to access
 this before transitioning to the NDIS.
- Transitional NDIS Funding for access to allied service professionals I discovered by
 accident that there was funding available to access such services whether we were ADHC
 'client' or not. We accessed both psychology and OT (Occupational Therapy), we had wanted
 speech as well but this did not eventuate. Our young person needed this for home, access to
 the community but particularly for access difficulties and issues with education.

At that time our young person was accessing a segregated specialist private educational setting. In this they had been further segregated from their class peers in a group of one, receiving their education predominately from an aide in a hallway. They were on an imposed partial attendance of four hours a day, had been suspended and on occasion being physically restrained. They were also about to transition to an Autistic specialised support class in a mainstream public high school.

In this transition they were suspended on their third day for 20 days from a result of their reactive behaviour to being restrained including an unsafe prone restraint face down on the ground. From this suspension an hour a day of school attendance for two years, for almost a year complete segregation from their class peers, a year of being in the class but sitting separately from peers and receiving learning predominately from an aide, as parents required to be at school while our young person was in attendance, was imposed. Our young person's continued enrolment was based on us accepting these unnegotiable conditions.

The access to these services were still limited and we had to keep reapplying, this was the basis why we got ADHC to reassess our young person's eligibility at the time in the hope it would help in this process.

For me as a person with a psychosocial disability;

- Family Intensive Support Even though my young person was the 'client'. There was a
 holistic and strength base approach to the service, so I was able to gain assistance in
 developing my own goals and advice as to what services may help me in association with my
 mental health and with the situation our family was in. These included;
 - Advocacy service Although the service which was sourced for us we were not eligible for
 - Home care We were not eligible for
 - Mental health rehabilitation service- I was eligible for
- NSW Mental health rehabilitation service For a short period of time I accessed this service
 under which I was provided with support to establish goals to try and get back to accessing
 the community. There was a period where I could not meet with the support worker due to
 a combination of my marriage breaking down, issues my young person was facing at school
 and my mental health. The service cancelled their service as a result of my inaction being
 determined as a lack of commitment on my part.
- **NSW Mental Health Line** –I accessed this on a number of occasions but due to capacity and or acute assessment, I only accessed meeting the team after my point of crisis. On a couple of occasions I was advised to go and present myself as emergency at local hospital which

had a psych unit. On one occasion I did this but after waiting well over an hour my anxiety and panic became too much so I had to leave.

- **Psychiatric and psychological care** Under continual mental health plans and Medicare funding I have been accessing regular psychology and on occasion psychiatric services
- Partners in Recovery Currently I am accessing this service which is a federally funded to
 assist me in trying to become a NDIS participant. So far have failed in my first attempt
 apparently I was rejected according to my PIR worker due to a lack of evidence/information
 about my capacity and functioning in relation to my disability.

Choice and Control for my young person as a NDIS participant

At the moment for my 15 year old the NDIS is happening to them and not with them. They are not at this stage an active willing (their choice) participant. I tried when entering the planning phase to find resources which would help them understand what the NDIS was all about and how they should be centered and positioned in the scheme. I also tried to find resources that what help design the NDIS planning process that would optimise their participation. For my young autistic person in particular this was particularly important in regards to their communication needs (eg severe language delay both receptive and expressive). I found nothing (a DVD or resource material developed with young people mind even would have helped but could not find anything), also we were not accessing a speech therapist at the time which could have helped. We were able to implement some superficial adjustments and strategies, my young person attended for part of the LAC planning meeting for their first plan but did so really without understanding why they were there and they really did not contribute to their own plan. Most of this was done through us their parents and LAC. While this might be reasonable somewhat in the context that our young person is still only 15 and we as parents are still in part responsible to be making decisions on their behalf, and more so ensuring they are getting the support they need, it is not conducive to any consideration of choice and control from an individual's perspective.

Under the consideration reasonable and otherwise we as parents on our young person's behalf have also not experienced what we have considered or would like to value choice and control in regards to the NDIS. This has been due to the following;

- What seems to be more demand than supply in our area. That is, having more participants in
 the scheme than services and support available. We have experienced waiting lists,
 organisational capacity issues, none of which are conducive to access and to choice and
 control.
- Our limited financial status. The NDIS funds support workers and only very limited activity (from what I understand this is specific disability orientated activity eg we have been informed our young person through the NIDS could attend disability specific social groups where we would not have to pay for). When we think of activities we have to consider the level of out of pocket expenses not only in regards to our young person's participation but also the support worker. We have given more thought about NDIS disability funded activities for our young person then what we would have if we were economically in a better position. For us we want as much inclusion for our young person as possible in regards to mainstream activities and services but this is difficult when faced with a lack of ability to afford such activities. We also don't want our young person to be left with no opportunity either.

I have understood and appreciated the "typical" argument in that the NDIS should not be responsible for funding for activities and items that people would be doing themselves regardless of a disability. However there should be some recognition and consideration of how socio economic status does impact on access, choice and control. Certainly, when this status has been contributed to and impacted by having a disability.

- Being so under prepared and overwhelmed by the business side of the scheme and therefore being positioned differently when it comes to choice and control. Regardless of my own psychosocial disability as a parent advocate I would have struggled in assisting my young person accessing the NDIS, with my mental health it feels quite impossible.
- A lack of support and needs being met for all members of our family which is in turn having an impact on our young person's ability to access the scheme.

B: THE EXPERIENCE OF PEOPLE WITH COMPLEX CARE AND SUPPORT NEEDS IN DEVELOPING, ENACTING AND REVIEWING NDIS PLANS

I can't say whether our family would be considered as having complex care and support needs in regards to the meaning intended by this term of reference. I certainly feel when I consider all the combination of our individual needs and as a family, a degree of complexity and how this experience has had an impact on so far of our young person's experiencing as the only NDIS participant and the scheme being a success in their life.

My young Autistic person's transition and experience so far on the NDIS

A little over a month away from their first plan being over they have not yet been able to access any funding in core support. The funding being utilised so far has been in regards to support coordination and in daily living in association with accessing allied service professionals.

Support Coordination

We felt as parents our young person would need support coordination on the following basis;

- While the start has not been as great as what we would have like in terms of our young
 person being an active participant in this scheme, we thought support coordination would
 be good to start on that road of our young person transitioning from us as parents to their
 own independent person.
- We as parents would struggle with the self management of our young person plan and access to the scheme.

In the first year of our young person's plan;

- We have had to access two different organisations
- We have had five different coordinators in our young person's first plan. For the first three it
 was not through our choice or control, it was due to staff leaving, the first organisation
 having issues with taking on more participants then what they had capacity for. By the time
 we were given a fourth option I decided these operational issues were not sustainable for
 our needs and therefore changed providers.
- Unfortunately the support coordinator when we transitioned was taking a month's leave.

 All of this has contributed significantly to my young person not accessing their plan in the way they need to

Review

In 2017 we submitted a review from our young person's first plan in particular expressing need for more funding to access allied service professionals. A little over a month to go until before the end of their first plan this review has not happened.

What this has meant has been a lack of access to allied services which our young person needs not only in accessing the scheme but also mainstream services such as education and the community which was incorporated in their NDIS goals.

E: THE PROVISION OF SUPPORT SERVICES INCLUDING ACCOMODATION SERVICES, FOR PEOPLE WITH DISABILITY REGARDLESS OF WHETHER THEY ARE ELIGIBLE OR INELIGIBLE TO PARTICIPATE IN THE NATIONAL DISABILITY INSURANCE SCHEME

My current need and support provision status quo as a person with a psychosocial disability and not being a participant of the NDIS

At the moment all I have access to in regards to support is seeing a psychologist about once a month and possible emergency options. I feel this has not been enough for me in regards to what my support needs are. Recently when accessing an assessment from an OT to contribute to an application to access the NDIS they informed me that most services which had existed prior to the NDIS which that would have matched my needs are transitioning to the NDIS. This is not a great position to be left in either for me or my family.

My partner's status quo as a carer

My partner at the moment is the only person in our family who has the capacity to work but due to their current caring role this is not possible. They look after not only physical and emotional needs of me and my young person but all household duties as well. For two years from an imposed condition of enrolment they also had to be at school for the hour our young person was allowed to be there.

With our young person being a participant the NDIS has not provided any support for them, largely because it is specifically not designed to do so but the intended respite effect is not occurring in relation to our young person not accessing formal care just at the moment within the scheme. Even if this was the case the NDIS could not address the situation that the education system has put our young person and family in.

F: THE ADEQUACY OF CURRENT REGULATIVE AND OVERSIGHT MECHANISMS IN RELATION TO DISABILITY SERVICE PROVIDERS

Restrictive practices and inconsistencies

My young person has been labelled with and been considered as a person with behaviour of concern. They have experienced restrictive practices in particular physical restraint. All this has occurred while in educational settings and not while in accessing any other disability services. I have seen the trauma experienced by my young person as a result. I really don't know what the status

quo was in NSW prior to the NDIS in regards to regulation and oversight mechanisms in regards to disability services except to say from an experience level that there seemed to be more than in regards to the education system.

As parents we don't believe in the use or have a reliance on the practice ourselves. The reason for this is we know where the function of the 'behaviour of concern' comes from, that is, our young person's reaction to something they are challenged by in their environment, which can be on occasion a flight and or fight response. This challenge typically for us indicates an unmet need. These needs can include communication and sensory.

In accessing disability services the focus has been on ensuring this and then if needed the development of a behaviour support plan. In our experience it has been rare to even have a discussion about the possibility of such a use. Unlike the education system I have felt a bit more reassured even though not knowing exactly how such a practice is being regulated by experiencing a culture and an ideology that such practices need to be eliminated and avoided within delivery of service.

In looking at NDIS QUALITY AND SAFEGUARDING FRAMEWORK 9 DECEMBER 2016 (https://www.dss.gov.au/sites/default/files/documents/04_2017/ndis quality and safeguarding framework final.pdf), it states NSW has agreed to the national framework to eliminate and reduce such practices but also highlights it is approaching it differently to other states and territories. It says NSW has set out high-level principles and objectives in legislation, which are relevant to but do not specifically address the use of restrictive practices and include specific requirements in policy (page 68)

In the NSW education system there seems to be little to no regulation or oversight mechanisms when it comes to their use of such practices in particular physical restraint. What regulation which does exist only seems establishes the obligation to use such practices (eg physical restraint) and staff rights in regards to such use. There is no regulation which exists to ensure any obligation to eliminate, reduce, and prevent such use. Also none which governs what should happen when it occurs.

My young person has experienced physical restraint from preschool all the way through to high school. Typical to this experience;

- At times use of untrained unsafe use of restraint.
- A lack of documentation regarding what happened and the use of restraint.
- A lack of notification for us as parents. In this circumstance our child has reported to us or we have found out well beyond the fact.
- A lack of follow up and review after restraint has been used to prevent its future use and of the injury suffered by our young person. This has included bruising and psychological trauma
- No recognition and addressing of the trauma experienced by my young person and the
 continuing impact this has on their well being and ability to walk back in into a school
 environment without fear and anxiety.
- This has occurred predominately while in segregated specialised support settings.
- Its intended use has been part of our young person's behaviour support plans.
- A lack of choice and access to information surrounding the practice.

• Difficulties as parents and advocates to ensure the use of restraint is eliminated as much as we can from our young person's experience

I can't say exactly how many times my young person has been restrained as we have not always been informed when it has occurred. I can say at least 10 times but suspect it has been more. It has occurred in each educational setting they have been in except perhaps while our young person was in a mainstream regular kindergarten class. For us as parents seeing the level of trauma experienced by our young person from the very first use, once was one time too many.

As parents and advocates for the times we have been aware we have had to question;

- Whether indeed there was an emergency situation that warranted the "last resort" use of
 physical restraint in particular was reasonable effort made to address any risk by non
 physical means? For us this in part includes whether or not our young person was being
 supported in the environment in regards to their disability in the first place and also when
 we have been reassured that staff have been trained in non physical strategies.
- How our young person has actually been restrained, whether this has been reasonably done safely and without risk to their health and safety?
- What has been done to ensure to eliminate any future use of restraint?
- How are our young person's best interests, and any associated rights, have informed these practices, and how their interests and welfare are being protected?

The following is what I understand to be the current status quo in regards to NSW education in regards to their use of physical restraint;

- NSW Education has no specific policy in regards to the use of physical restraint in their schools.
- They have no associated public procedural document except for a legal bulletin which is a
 brief guide for staff in regards to their actual obligation to use such restraint and what
 defence they can use if faced with allegations of assault
 https://education.nsw.gov.au/about-us/rights-and-accountability/media/documents/public-legal-issues-bulletins/LIB-9-Physical-restraint-of-students.pdf
- They have training available for staff, which significantly trains in non physical restraint strategies in dealing with risk associated behaviour and specific safe orientated restraints. This training is not mandatory. That they access this training from a private company in a train the trainer model.
- From our experience and what we have been informed schools are not in a position to develop their own policies and procedures. That their practice is informed by the legal bulletin, their training and their training manual as an ongoing reference and resource.
- Students and parents do not have access to this material and information potentially either due to copy right issues or internal operational consideration that the department does not want to make public.
- There is no mandatory reporting in regards to schools use of physical restraint. Schools are apparently encouraged though to report such incidents to NSW education's EPAC —The Employee performance and conduct directorate.

- According at least to our local well being support coordinator the education department has
 no review or monitoring system as to how well or effective their training has been in regards
 to preventing such use or is being done safely.
- Beyond this reporting there appears to be no mechanism or process whereby NSW
 education collects any specific data to the use of this practice in their schools, whether the
 restraint is occurring in line with training, being done by trained staff, whether appropriate
 and reasonable effort is being made not to use such restraint.
- That there is little protection in place and poor pathways for students or their representatives to address when restraint is used within questionable circumstances.

The last time our young person was physically restrained it was reported to EPAC and their finding was that the school's use of restraint was reasonable even including the use of an unsafe prone restraint. This determination occurred without investigation. On behalf of our young person we asked them and then the NSW Ombudsman to review this finding and again the level of restraint was found reasonable.

Our problems with these findings and these oversight mechanisms are the following;

- That the Department is oversighting itself. In this through legislation which positions the interests of child, young person against interests of staff and the organisation itself. This is different from what I can see exists when allegations are made to FACs which involve say parents or community members where the interests of the child are paramount.
- That the criteria relied upon was very general
- That the criteria and information relied upon in the determination did not include what staff training is in either non physical alternatives to the use of restraint or the safe practice of restraining.
- That the scope ultimately of the determination was about the liability of the actions and conduct of staff and therefore no value or oversight in regards to the Department's actual use of restraint.
- While I appreciated particularly at the Ombudsman level that the associated issues I had in association with the practice and what happened, for example the use of an unsafe, untrained prone restraint, I did not appreciate being informed any issues I had to go back to the school and try an address through a formal complaint process.

I certainly feel we are not well positioned when it comes to lodging a formal complaint;

- We currently don't have access to the statements made by the staff in regards to matter
 going to EPAC which was the only documentation which was made in relation to the use of
 the restraint. It was not even included in the risk assessment done by the school in relation
 to my young person's suspension at the time except for the intention of its continued use
- We don't have access to what staff are trained in to be able to specifically put forward what they may not have followed etc
- We have already requested a departmental review independent from the school to be done
 which was denied on the basis of EPAC's and the Ombudsman's findings as well as the risk
 assessment which was done which did not include the restraint itself even how it triggered
 my young person's behaviour which they got suspended for.

I: INCIDENTS WHERE INADEQUATE DISABILITY SUPPORTS RESULT IN GREATER STRAIN ON OTHER COMMUNITY SERVICES, SUCH AS JUSTICE AND HEALTH SERVICES

From the 2016 NDIS QUALITY AND SAFEGUARDING FRAMEWORK

"The Productivity Commission argued that the NDIS would generate longer-term savings through the benefits of early intervention, increased economic participation of people with disability and their carers, and the likelihood of increased productivity in the disability system." P5

https://www.dss.gov.au/sites/default/files/documents/04_2017/ndis_quality_and_safeguarding_fra_mework_final.pdf

Over the years of not been able to access support and services we have needed has had the following impact on our family;

- Impacted our ability to work. For my partner now the substantial caring role they play for
 me and my young person. For me how my mental health and associated physical health
 decline has impacted on my capacity and functioning in this regard. For my young person
 from a future perspective and in particular not receiving the support they needed to access
 an optimal level of learning, skill development and education
- Our physical and mental health. The stress and the strain of not having access to the support
 and services our family has needed over the years, has already taken a hefty toll on our
 health wellbeing.

For me significantly it has been the advocacy role I have had to play in regards to our experience with the education system, the services we have accessed, trying to access services and across all at times trying to navigate complex complaint mechanisms including legal. Also trying to fill the gaps for my young person, ie doing as much as I could for needs I was not well placed to do such as learning, psychology, speech and language and ot. I am not a qualified teacher, psychologist, ot etc but have felt I have needed to try and have such a skill base to ensure I was effectively providing the support to my young person that they need when we could not access such support services. I currently am morbidly obese, pre diabetic, very much house bound and socially isolated. I have had mental health issues since being a child and throughout adulthood but this over the last 10 years there has been on a steady decline as with my physical health.

For my partner who just recently was diagnosed as diabetic over recent years their role in our family has changed. Due to my health decline they do most of the physical care still required with my young person as well as assisting me with certain self care aspects. They do all the household duties such as cooking, washing and cleaning. For our young person they also have had to take them to and from school, be at school while our young person is there. Due to access issues currently with the NDIS for our young person they have not experienced a respite effect or an opportunity to consider employment even part time or casual. They are exhausted which is impacting on their well being.

For our young person their wellbeing has been compromised and at risk. They currently are very isolated and it is difficult and challenging for them to access the outside world. This ranges from social, medical, education now and very likely employment opportunity in the future.

 Our relationships with each other have been and at risk of being strained and not being as they should I suspect it will be very likely our needs being unmet as they have been, as they are now, and if they continue to be that as individuals and as a family unit our need and reliance on other services such as health will increase.

J: POLICIES, REGULATION OR OVERSIGHT MECHANISMS THAT COULD IMPROVE THE PROVISION AND ACCESIBLITY OF DISABILITY SERVICES ACROSS NSW

Respite and the support landscape for informal care

I would like the NSW government to consider what gaps have been left in regards to respite and support for carer's who are still in the position of significantly providing informal care and what role they could be playing that simply the NDIS does not and is not designed to do.

We knew with the introduction of the NDIS we would have to readjust our expectations and how we would receive respite. We certainly could not rely on the reassurance we would be no worse off in this regard with the change to the NDIS.

Respite for us as carer's has never been about spending time away from our young person. It has always been about that as carer's we are well placed to provide the informal care and support our young person needed in association with their disability. This therefore included our well being and providing the support itself.

If my young person was accessing the NDIS currently in the way they need to, and accessing mainstream services such as education as they need to we would be experiencing a respite effect. That is our young person spending time with a support worker (formal care), being able to access allied service professionals to assist with this, to assist us in continuing to provide a level of informal care and access to education, and mainstream services such as education ensuring they living up to their responsibilities to students with disabilities.

I would like to think this in itself would take care of all our respite and carer needs and since this is not currently the case it is hard for me to say. Having said this it always good to have monitoring systems in place to ensure any intended outcome is occurring.

I have mentioned already that my 15 year old at this point is not exactly a willing participant of the NDIS, that their transition to the NDIS in particular from informal to formal care has been difficult and as of yet impossible. I have also mentioned our status at the moment as carer's struggling in our role and ability to provide the informal care that they need. I have been asking myself what happens if this continues and at some point my young person does not choose formal care and that it is their preference is to continue to rely on informal care.

We no longer have access like we once did to state support services that through a holistic approach somewhat catered to this needs base. The NDIS does not really incorporate this scenario in its support framework. In this situation it seems that for my young person and for us as carer's we could end in a situation of no care and support. This too may well be the case equally for those people who the NDIS deems as ineligible.

I would like to think the government is thinking already about these possible scenarios and role it could be playing to ensure there are possible alternatives.

Mainstream Services

The government needs to fund and ensure that its mainstream services are adequately providing access and service provision to and for people with disability. In regards to our family at the moment that would be significantly education for my young person and the mental health system for me.

Education

Regretfully as parents we have continually chosen so called specialised segregated support settings for young person throughout their education. I say so called as in our experience the specialisation has not been there — not at any degree which has contributed to reasonable educational outcomes and experiences, not at any degree that justifies the segregation that is both in the circumstances of actually not receiving any more support and access to education if our young person remained in a regular class and even when this did occur the level at which it did I did not consider to be so 'special' that it could not be provided within a regular setting.

While I have indicated that we chose it has not been much of a choice particularly when put in the following position;

- When you are told you child will be able to go full time, when you are told they will be able to achieve more
- When you are put in the position where you feel they may not be safe, when you fear exclusion and the use of restrictive practices
- When you feel like you are being pressured, when you keep being bombarded with the
 messaging your child won't cope in a regular class and we can't give them the support they
 need
- When the choice, decision has been made in part because of a school's perspective on your child's behaviour is one they should not be in a regular class or even at the school itself.

Unfortunately for our young person all they have gotten from segregation and their experience of education is your difference is less, so much so you can't be included, that your education means less both in provision and what and how is supposed to contribute to your life and future.

No amount of funding from the NDIS will ensure my young person's access to education particularly while;

- Segregation remains as a model of education provision for students with disability
- A culture which sees such provision for students with disability as special continues. That is ultimately seeing students with disability and their differences as less
- The support needs of student are not incorporated in a universal design learning framework and resources not allocated
- Schools continuing to rely on restrictive practices (particularly without regulation) and harsh
 reactive disciplinary measures to address health and safety concerns of behaviour rather
 than the cause of such behaviour is unmet support needs

A change in mindset needs to happen in education. A lot can be learned from the rights based infused ideology of the NDIS and also what other countries are doing in fulfilling their UN obligations to provide authentic inclusive education. The following article looks how a small country like Portugal has taken such steps- Portugal's New School Inclusion Law: A small country taking big steps in the spirit of "All Means All"

http://allmeansall.org.au/portugals-new-school-inclusion-law-small-country-taking-big-steps-spirit-means/

Restrictive practices

My young person as person with a disability should be able to experience a consistent of safeguarding regardless of where ever they are and who ever is providing them with support whether they are a disability service or not. While education may be seen as a mainstream service the NSW government is still responsible regardless of the NDIS for the provision of support and services for students with disabilities.

From the:

2015 Inquiry Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability (https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_neglect/Report, Chapter 4)

4.109 It is not clear to the committee whether any of the state and territory education departments have any fully developed enforceable policy guidance on restrictive practices. While the Restrictive Practice Framework applies to most disability services and agencies, there is a notable absence of regulation of restrictive practice used on children and young adults with disability in schools or other educational facilities.89

4.142 As a matter of urgency, the Restrictive Practice Framework must be implemented as an enforceable, reviewable instrument for all schools, government and private, and there must be independent oversight of its implementation in schools.

From this Inquiry the government has left it seems for the state and territories to work out on their own with regards to the elimination and use of such practices.

I have seen work being done at the research level and disability peak organisations which seems to be focused in regards to disability services and the NDIS in developing safeguards in this area. I know the NSW education department from the 2017 NSW inquiry into the provision of education to students with disabilities is currently reviewing this provision but I don't know whether restrictive practices will be looked into and on what basis.

From this earlier 2017 state inquiry statistics provided by Education INQUIRY INTO THE EDUCATION OF STUDENTS WITH A DISABILITY OR SPECIAL NEEDS IN NEW SOUTH WALES SCHOOLS SUPPLEMENTARY

QUESTIONS

https://www.parliament.nsw.gov.au/lcdocs/other/10654/NSW%20Department%20of%20Education

<u>%20-%20Supplementary%20questions.pdf</u> p 5and 6 somewhat indicates that it is students with disability who maybe experiencing restrictive more than students without disabilities. Inquiries such as this one, the federal one earlier mentioned, and the 2017 NSW Ombudsman's report into behaviour management in NSW schools, certainly indicates this.

I would like to see a crossover where the same commitment occurs in state mainstreams services particularly those still responsible to provide disability support outside of the NDIS and that there is consistency and compatibility. The current status quo existing within NSW education to their use of restrictive practices is unacceptable.

Mental Health

In my current status quo, that is, being in a position whereby I may not be able to access the NDIS, I would like some thought given to ensuring similar services and support structures exist outside the NDIS. I can't inform this committee why I may not be eligible for the NDIS but when I look at my needs and the services and support I could receive as an NDIS participant I don't understand why I would not be eligible considering that from my evident need base such services and support don't exist away from the scheme. Governments really need to work through all of this. In expressing this I know it could be seen as putting forward a duplication of services but it certainly for me is not in the reality I have faced and will face if I am not able to access the scheme.

The status of state mental health services and support for me prior to the NDIS did not come close to what potential exists in the scheme for someone like me in particular in what it could mean for my daily living experience and wellbeing. With the introduction of the scheme it seems what services and support which did minimally exist in this regard are moving across to in provision within the scheme.

Whether I am eligible or not, and sadly at the moment that has likely more to do with how well I can put an application, evidence together rather that a true reliable eligibility criteria existing based on need, my needs do not change. I need the support and access from somewhere.

Advocacy

Over the years our family has accessed individual and systematic based disability advocacy services for difficulties and issues facing our young person in regards to accessing education. It was extremely distressing when I heard about the state government's plan to cut the funding they provide to such services. If the government did not change their minds these services our family would no longer be able to access.

Funding for advocacy I would like to see increased and committed to indefinitely regardless of the NDIS.

CONCLUSION

The NDIS has just not been rolled out overnight so to speak and in this I struggle to understand how the planning and the delivery have appeared to have gone so wrong, certainly at the very least for our family. This includes how our state has transitioned across to the scheme and the dismantling of its own provision of disability services. I do appreciate that in a large part the NDIS was supposed to

effectively replace this provision but in reality it is not. For me this has a lot to do with the scheme itself currently not operating as it should, but also the gaps to services and support which occurred in the transition. Certainly with our experience of the education and mental health system the state could be doing more in regards to disability provision within mainstream service delivery. I do appreciated while I label my own mental health as a disability, state provision of mental health services away from the NDIS may not encompass this consideration, but even so it should still envisage associated needs.