

**Submission  
No 163**

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

**Name:** Ms Lorraine Diaz  
**Date Received:** 8 August 2018

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Director and Members,

I recently attended a meeting with the Illawarra Disability Alliance to develop a joint submission to the Commission on the Parliamentary Enquiry into the Implementation of the NDIS.

As a parent and carer of a 29 year old young lady with Down Syndrome, I joined in to discuss the importance of successfully attaining services and support for my daughter Amy Diaz through the NDIS.

I hereby express the importance and urgency with two terms or reference relevant and submit my own daughter's case to the Parliament Enquiry.

# The implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability

# The adequacy and decision making rationale surrounding second year plans

I have witnessed the positive effect of Choice and Control previously with a Self-Managed Community Participation Program since 2012. The improvements to her confidence and the successful outcomes in her life proceeding into the NDIS in 2017 would see her live an independent lifestyle, volunteer for 3 hours at Vinnies alongside other community volunteers, hoping to one day attain paid employment, of which she is currently undertaking work experience for 2.5 hours per week at a child care centre with a Support Worker.

Amy attends art lessons with a Support Worker, her progress with completed art works are often displayed at annual art shows, community events, and local Art Gallery. Last September Amy held her 1<sup>st</sup> Solo Art Exhibition with great success and support from the community. The art lesson assist by calming her anxiety that previously manifested into clusters of 10 and more non-epileptic seizures resulting in many Hospital Emergency visits.

Amy's program activities with a Support Worker include; Swimming, Tennis, a Personal Fitness Gym routine along with making healthy food choices and diet to improve and maintain good health and well-being. Community Access to her local mall enables independence, grocery and clothing shopping teaches money skills, accompanied doctors and specialist appointments teaches her health awareness, Bus travel training teaches time management, food preparation and cooking, washing and cleaning in her home, teaches her to use appliances and develops skills towards independent living. Amy also talks to students at TAFE about her life and program activities, which helps them better understand the support work experience they can aspire to, with other people living with a disability. This builds her confidence, aiming to improve her conversation skills and interaction.

Goals and aspirations for Choice and Control were accepted and deemed necessary in her 1st Plan, starting July 2017. That said, I feel I need to point out the difficulties I endured in the process to attain necessary information through Uniting in the first year. NDIS had stated Uniting would provide Portal and Guidance Support with these goals. We did have the initial meeting with one LAC (Local Area Coordinator) who felt I could continue with what I was doing previously and sent us out with "call if you need anything". I was never guided through the Portal, never received any information nor received any return calls, even after many attempts of requesting assistance, with excuses that "he was not at his desk", "at a meeting", "with a client", "out to lunch", "away" and "he has left", then was told "he came back, but is doing other work".

Frustrated, I had to turn to the Service Provider Interchange Illawarra, the organisation we have known and trusted for 26 years, if it had not been for their understanding of the difficulties I have experienced with Uniting to continue the plan for Amy, I feel at that time my own despair would have me seeking other professional help.

In February 7 months on, I was at loss as to who and where some of the services I needed for Amy could be found; a Psychologist for her anxiety, an Occupational Therapist to assess our home and acquire equipment for personal safety. I attained the Psychologist, through my doctor and paid for it. The OT cancelled the assessment and suggested I obtain equipment with registered NDIS services. The bathroom renovations, we paid for were completed by a reputable plumber who had knowledge on the safety requirements.

In March, 8 months later I went into Uniting and told them Amy's Review plan was due in April and I wanted to prepare for it. There was talk that 2<sup>nd</sup> year funding had dropped significantly, so preparation and proving necessity was vital. Amy's Review was changed to June and I was told information would be sent out. I took the initiative and attended as many

workshops to prepare, still the all-important Portal was unknown to me. To add insult to my frustration, I attended a workshop and Amy's 1<sup>st</sup> LAC was guest speaker and proceeded to promote the support that Uniting would provide to all clients. There are other concerns and I feel I may have already given you an indication of what should not be happening to us. But the final straw came last month when I received her Review Plan with a \$20,166.71 deficit in the combined Improved Daily Living and Core Support Budget. Reducing her Support hours significantly but also reducing her interaction with peers vital to her maintaining friendships, to a ridiculous 1x5hour peer activity per month and 2x3 hour peer activities per month plus 1 weekend every 3 months. I will however be able to get self-management training with \$1,375.68 hopefully that will go towards learning to use the Portal. I called Uniting asking why this review was so unsuccessful and requested either the LAC who took Amy's Review information in note-form or the team leader to call me with a response and as yet no one has. I am still waiting!

Amy requires the same amount of support in fact I requested more in preparation for her to achieve the following;

First Goal: I want to live independently in my home and develop independent life skills.

Second Goal: I want to maintain my health and well-being and better control my anxiety and seizures.

Amy's longer term goals and aspirations are: Learning skills to attain paid employment in the community environment, wanting to better understand relationships and attend more social and community events, Amy wants 'choice and control' over her life and to access the community on her own (eventually) and I want Mum to gain access to self-management training for my NDIS plan...SO WHY DOES THE BUDGET NOT REFLECT THIS APPROVED PLAN? Was it due to the unspent budget in the first year not used due to the waiting periods for information or the times she was hospitalised for a knee operation, contracting Whooping Cough, the extraction of wisdom teeth and the recovery time it took for all three before resuming program?

The information in her plan I wrote explained that she will be living independently by January 2019. I can and will continue to support her (informal support) early mornings, afternoons, evenings and every weekend but the majority of the above goals will need formal support to establish independence and to maintain the continuity of the program she is accustomed to receiving. ONE YEAR is not suffice to attain the skills to achieve these goals successfully. I am appealing the decision as the expectation on receiving this reduced funding does not reflect Amy's detailed Review Plan, stating the deemed reasonable and necessary supports linked to the outcome, are clearly identified in her Plan.

I believe NDIS can be better by ensuring their selected organisation Uniting can fulfil their obligation of providing adequate information and instruction to all clients, empowering them with the right knowledge beneficial to proceed. Uniting must train staff specifically with fundamental and comparative insight towards those who are not proficient in NDIS terminology, codes and acronyms, not forgetting navigating the Portal and IT programs. We all do need training and if it's not provided, then the expectation of a system worthy of succeeding for obvious reasons will inevitably break apart.

The strain of it all does follow down the line and the service providers not being paid to be the narratives of Support Co-ordinators, Planners, Contractors of numerous Networks, are using their valuable time holding together the people who are over-whelmed by the uncertainty, what is expected of them and who foresee their failures in the change they waited so long to happen...NDIS need not be like this!

I have explicably divulged much of our experience to emphasise the importance of the National Disability Insurance Scheme becoming a success for people like us; those who have lived it, worked in it and the many that have succeeded by it!

Yours Sincerely Ms Lorraine Diaz

Parent and Carer