Submission
No 167

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

Name: Name suppressed

Date Received: 5 August 2018

Submission – NDIS inquiry:
Advocating for social justice on mismanagement of a welfare service.

have a son 28 years old with Down Syndrome. He has developmental delay and has no speech. He currently uses a communication system on his Iphone known as Proloquo2Go and is a voice output app which he is learning to use appropriately across all situations in his everyday life.

Augmentative systems of communicating through visual cues and sign language have limited use and understanding in the wider community. Reports from professional therapists throughout his years have indicated his need and potential, to further his capacity to learn and communicate more functionally. It is indicated that communication is provided through technology and supports that are currently available and accessible.

It is also felt necessary to continue this support long-term throughout his life as his life circumstances are constantly changing. It does mean continued therapy consultation with Speech therapist and a 'therapy assistant' that we would be seeking to include in future planning and funding.

Equally important is for to stay fit and healthy, having been born with low muscle tone and lax joints, we are very adamant that he should continue with exercise physiology and that he has continued Occupational Health therapists to assist him in his living skills.To ensure this future plans need to take notice of reports provided by the professionals and include the required funds.

lives at home with Mum and Dad, Dad being his main care person who 10 years ago was diagnosed with Parkinson's disease. Mum works to provide an income. is a young man of routine and habit. He is tall, physically strong and determined.

We have given time and energy into supporting throughout his life with transitions to school and post school. It has become obvious that there is a real need to prepare fully with his learning communication skills and his living skills before moving out of home and into another living environment. It is only then that he can potentially reach a level of certainty, by having more choice and control independent of us.

We struggle with the limits and the inuendoes that "communication and understanding" is not significant as he "gets by". That his physical weakness that he was born with, is now regarded as a 'lifestyle issue' against having submitted therapy, medical reports and summaries as was asked. To have funding devalued and disregarded on Therapists and Medical Professionals advice is appalling. To have reports devalued by those who are not experienced in these areas, making decisions on our son's funding is not equitable, reliable or appropriate.

Managing day to day routines around to provide 'Informal Supports' is shamefully taken for granted in all that we do, and it is so often seen by reduced hours in therapy supports each plan and a verbal consensus by Therapists that "it is not going to get better as more participants enter into the system".

Intervention is not limited to early childhood!! It is throughout a lifetime with those with a disability, every step of the way, every corner they turn.

The relevance of Professional Reports from Therapist and Doctors has been greatly diminished by the Planners when outcomes of reduced funding are highlighted in these very essential areas.

The fact that these reports illustrate eeds which incorporates basic requirements of eligibility but when it comes to funding the problem NDIS planning are quick to make their own assumptions, make it difficult at meetings and shown to be insensitive and lacking an understanding of disabilities.

We have always demonstrated and submitted factual documentation supporting what has been defined by the NDIS as ‘reasonable and necessary’ for
‘It is directly related to his disability’.
‘It is beneficial for him’.
‘There was no lower cost alternative available that would deliver the same outcomes’.
‘It is not funded under another system’.

GP Care plans are not the alternative for funding redirection. Funding should not be hidden in other areas of the plan with a differing definition. Boundaries are forever changing.

When a diagnosis is made of a child having ‘developmental delay the NDIS Act’ (section 25) judges a child under 6 yrs of ages, saying that impairments result in functional capacity in self-care, receptive and expressive language, cognitive development, motor development.

There is multiple diagnosis in ase and they are permanent, as reports have indicated.

Intervention does not stop just because they are older or have been given therapy support. Skills training / intervention must be sustained and consistent, consolidated and transferrable, and alleviate the impact of the impairment, and prevent deterioration of functional capacity.

It is supposed to strengthen the sustainability of informal supports through building capacity of the person who is carer. Not diminish the strength and hopes of those working closely with him.

We have only experienced a greater involvement than anticipated at all levels whether it be navigating the NDIS policy and procedures at all levels within the bureaucracy locally and Federally or with service providers who give the care. Our disappointment in keeping n a system of inequity, inconsistency, misinformation and misinterpretation have made us feel betrayed. We have been disgusted by the pressure exerted by teams of NDIS planners where justification for funding has been disputed by the inexperienced and insensitive nature of planners and their superiors.

herapies are provided through a reputable Cerebral Palsy Alliance Service. (They are not medicare providers). eeds continuity of care to ensure positive learning and reinforcing of same for “Best Practice”.

has experienced throughout the years, isolation and frustration through not being understood due to his lack of communication skills and education of those around him. It has led to behaviour difficulties which have and will continue to compromise his ability to become independent.

Signed up to the NDIS November 2016.
is plan managed by us with services of a financial intermediary.

It was a scheme that was envisaged as a vehicle to empower and improve the lives of the most vulnerable in our community but has invariably developed into a bungling system of inconsistencies and unreliable protocols and procedures that has disadvantaged and exploited the very people it was intended to assist. The current form of the NDIS no longer represents the ideals of the original concept.

"individual care plans x (3) in the first year, 2 plans we did not have a say in or informed about. 2 plans without our knowledge had been instigated, resulted for us a year of disappointment, disillusionment and disruption of home life with the stress and pressures put on the whole family.
We have endured flagrant inconsistencies in the application of the planning procedures and resource allocation, including rejection of medical reports, lack of consultation regarding client needs, unexplained allocation and re-allocation of funds and the use of innuendo to obtain compliance.

The impact of participating in the process on the morale has caused an increasing amount of anxiety, confusion, loss of hope and faith. Confidence and trust in the ability of representatives of the service to administer fair and equitable judgements has diminished.

The procedural dysfunction that is seen across areas created distress and a sense of hopelessness when we were warned that to follow recommended complaints procedures will take 6 months and "may" result in loss of funding.

Unless changes occur within the NDIS system and the implementation procedures and protocols across the states, inequity, disadvantage and loss of rightful opportunity will continue to be the "life plan" outcomes for the vulnerable including our son.

We would like to add how the NDIS have failed to dedicate funding to Services to manage their supports to participants.
We have had to fund time for carers to manage communication system. There is no training within the facilities anymore.

Disability workers lose out on wages, NDIS funding did not allow for "notetaking, report writing, travelling between jobs and behind the scenes client work and training and development.
(Sydney Morning Herald – Research – Anna Patty). Friday April 13 2018.

Our decision to voice our grievances in writing of our experiences and challenges in order for change within the system to ensure decisions regarding future be more positive.

The Advocacy Groups – Consulted We did not appeal for reasons of standing to lose funding, reallocation of funding and the time for the process to take place.
We need to see Advocacy funding continued to have independent representation on our behalf.

We refer to the use of **COS workers** – Co-ordinator of Supports. Who and what defines the eligibility of who gets this support when it was to be a right for the individual to have if preferred. Someone who is subjective and not associated with NDIS, without bias who can offer front line support and advocacy.

Someone not directly entrenched in a system that does not allow for Best Practices to obtain essential services required within the local community. In our case the LAC given to us was at a great disadvantage with her own Job Role being super inflated taking over the role of co-ordinator of supports when in fact they themselves were unfamiliar with procedures and guidelines from superiors.

Letter to the Minister for Social Services Hon Tehan.

Highlighting the redirecting of funding into Area Health Services. What NDIS committed to no longer takes total funding responsibility for.
The definition of funding is quoted "an impairment from a disability or that which is linked to a disability". Failure to attribute our son's physical needs to his disability and implying these are lifestyle conditions as they present in the general population.

There were notable shifts to GP Health Care Plans for Permanent Disabilities that was born with. It was both insulting and a total disregard of commitment to justify with further written confirmation over and above what had been submitted by GP's and professional Therapists, to have it debated and then have it half-heartedly acknowledged by someone who had no expertise or knowledge of the definition of someone having Down Syndrome. That it goes to someone higher in the Dept and still have the same outcome has been fundamentally objectionable in delivering funding according to 'reasonable and necessary'.
We can only assume then that it is a local area decision as other areas accommodate funding differences experienced in funding outcomes. Guideline interpretation from top management and individuals making rules where and when it suits apparent.

Letter to NDIS Re: concerns regarding systematic and procedural failures.

It seems from how we had gone about things to highlight our dissatisfaction and with 'a change of circumstance' that was not acknowledged after 6 weeks that the NDIS conducted a so called "review of a reviewable decision" in December 2017 regarding the approved supports in plan that were not approved by us or was the plan before, as we had been totally unaware of both plans that had been given.
We did receive an apology on behalf of the NDIS for our experience and the right to seek an external review and so it goes on.

There has been a lack of coordination, consistency and understanding between parties within the NDIS DEPTS. No centralized database in understanding disabilities, they lack training and experience and are making decisions sporadically, without fully understanding medical implications, documentation and facts relating to the individual.

There needs to be more transparency with guidelines and funding criteria to prevent misinterpretation and consequently misrepresentation.

Letter to the Ombudsmen and reply.

Investigations officer Commonwealth ombudsman.

There are changes happening to improve systems that we have identified. A new Participant Pathway.

That there is liaison between the Ombudsmen office and NDIA with reviews and recommendations of the Act.

That strategy teams gathering information undertake engaging with NDIA to bring about change.

We can only hope that the future of NDIS reflects a more positive connection by those placed in their care and which is seen in future directives and throughout their administrative organizations.

This submission has been authored by

This is a confidential submission.