Submission
No 283

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

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

Submission written by Martin McNally on behalf of my son
and all people in NSW with lifelong disability

This submission is written not to resolve any individual grievance with the National Disability Insurance Scheme. However, it is important to note that the NDIS in its infancy and is best assessed systemically by the implementation of best practice goals, strategies and benefits realised from individual cases such as our son's experience of the Scheme so far. From my perspective, and based on all that I know about my son's disability and symptoms, I can categorically say that without the NDIS implementing for him in August 2017, he would have continued the downward spiral of the past four years without this support. This submission seeks to provide an alternative view of how NDIS can be successfully delivered for people with disability, parents, carers and the varied types of supports available in the community.

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

a) "Choice and Control" are powerful words for a person with disability. These words provide the channel to allow a person with disability become an included member of our society. From our son's experience the lack of significant enforcement of Human Rights for people with disability in Australia has led to significant disempowerment for our son in most state and private support systems. In Education, our son has been disempowered from attending any High School even though he was very successfully accommodated for seven years in the Primary school setting. In Health and mental health, our son has been treated as a pariah because his symptoms stem from his disability. There is no legislative enforcement to protect our son so he can have a social and productive life in Australian society.

b) The NDIS is *a beacon of light* which if holistically implemented and driven by parents and carers can transform other governmental and non-governmental services so that standards can rise up to match the NDIS. All services that fail people with disability such as mental health services can in theory join with the NDIS in delivering a world class holistic service to its clients. The potential is that other countries will look to Australia to help them become more inclusive societies.

c) The first challenge with the NDIS is that "Choice and Control" is already been reduced by the National Disability Insurance Agency (NDIA). The sensitive topic of funding is coming to the fore. The Statutory function of this agency is *not to make planning decisions so that the NDIS is sustainable or cost efficient*.

d) Under Section 34 of the NDIS Act, the goals and funding are intrinsically linked. If the quantum of the goal is not reasonably calculated this can affect the level of funding. To understand the quantum of a goal, we decided to put in place a reporting process with our son's Intensive Support Worker's. Due to the agile and iterative nature of building and putting in place supports, all our Intensive support workers are required to complete a report after engaging with our son. With about 150+ reports from the last 12 months we can easily check the effectiveness of the support in achieving a goal, check if modification of the support is required and confirm when a goal/benefit has been realised. A great example is our son's first support worker. We reached out to the Faculty of Inclusive Education in a Sydney University. The Professor heading the faculty was more than willing for us to directly employ his best PHD student. This support worker's contribution to our son over the past 12 months is nothing short of astonishing. He has provided more benefit in a shorter period of time than if we had engaged a government service pre-NDIS. We can report that our son has returned to school and it was extremely cost effective as the support worker receives a daily rate that is more economical than a resource assigned from a government service pre-NDIS. More importantly, this support and students in the Universities receive hands on experience in their area of expertise and the passion that these people show our son is amazing. We are willing to state that without this support worker our son would not be making any sort of progress. That is the type of amazing people that can be found using this innovative, sustainable and cost effective approach.

e) In our son's first plan review a few weeks ago, a decision has been made to ***cut 50%*** off his funding and target certain funding categories such as Assistive Technology. This decision is besides the fact that all of his current goals in progress were carried over, additional goals were agreed with the NDIA planner and there were no goals fully achieved in the first 12 month period. Is this decision "reasonable and necessary"? Certainly from our perspective, NDIA planners agreeing and reporting goals that are not reasonably funded might be considered misleading in measuring the success of the Scheme. It is also evidence that the "flexibility" of NDIS is faltering with the NDIA targeting specific categories such as Assistive Technology. The NDIA Planner agrees to carry over a goal with Assistive Technology as a component but does not provide any funding to achieve the goal. Are Planners on KPI's? Are they been instructed to do this? Is this reasonable and necessary? These are the type of questions parents and carers ask which then leads to mistrust with the administration body which is never good.

f) Sustainability of the NDIS will occur through the parents and carers. Innovative strategies should be embraced and supported by the NDIA particularly if they result in cost savings and benefit the person with disability.

g) We want an NDIA that links goals and funding in cost effective and sustainable way that provides reasonable and necessary supports to achieve inclusion of our son and other people with disability. We would call into question the cost of administration of this agency to manage the NDIS and whether there is a “self-reservation” culture occurring. The staff of this agency must be capable, well trained and customer centric.

h) It must be emphasised that the NDIS has the potential of pulling the standards up for all government agencies. For our son, getting any form of High School education was quickly distinguished when he was discriminated by both the Catholic and State Educational authorities. Through the funding of NDIS, he has returned to school although there are still serious challenges, we are making progress daily so our son can be included again as he was in the seven years he spent in Primary school.

i) It must be borne in mind that there are examples of where schemes fail because at first they are setup to provide reasonable and necessary funding to support goals but ultimately due to budget deficits, the funding reduces and this impacts the outcome of the goals. The Victim Support Act 2013 is a good example where Victim Services ran into a budget deficit and appropriate reparations for crime no longer reflected the quantum of the crime. Similarly, appropriate funding for the quantum of a goal might be restricted over time if funding is not fully committed.

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The experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans

1. Our son has significant complex care and support needs. For us, developing an agile approach initially to target funding to his individual goals and needs was priority. Rome was not built in a day but as a family we wanted our son to have a more manageable and satisfying existence and to feel included in his community. Our son had been through so much over the years, a former victim of serious crime, a victim of the Catholic Education Office who decided he should not be allowed to attend his designated High School and the devastating impact his disability was having on his life. As a parent, I took a rational approach. With NDIS funding, I approached a Sydney University and utilised their students with PHD's and Masters in the area of disability. Why? These people are the future of the NDIS system and associated systems. The result has been extraordinary. The University students are more than willing to supply their time effort to get a real understanding of the world people with disability live in. It's a symbiotic relationship that realises tangible and measurable benefits for our son.
2. Enacting complex support has been a challenge. Firstly we use NDIS providers less and less and employ our own staff. This is cheaper and we get better results and a quality and flexible approach. That is not to say all NDIS providers are not reaching their potential but due to a sense of transformational change, some organisations are struggling, others are focusing on perceived profitable areas of support (e.g. early intervention) rather than unprofitable areas of support (e.g. support coordination) and some organisations are just not that good at supporting people with disability. Politically the Prime Minister, Malcolm Turnbull, introducing 100 federal agents to target organised crime seems great but perhaps the cost of these federal agents would be better spent on a Quality Commission at a Federal and State level that can push standards up. At the end of the day, the funding we receive is never enough and we need the NDIS Providers to be challenged to provide exceptional care across all areas. Another key point is that funding reviews should consider the amount of training required to ensure

support workers have the capability to support a person like our son in a safe and risk free environment.

3. Our son had his first plan review a few weeks ago. The meeting was really very progressive. The Planner listened to our feedback and was very caring overall. However, it all fell apart after the meeting. Firstly, we had provided an NDIS template progress report but the NDIS Portal is still not up-to-date with the information in this template. This seems bizarre as it is effectively a copy and paste. Also if our son's current and historical data is inaccurate, how can we provide Portal access to our son's providers? Second, the Planner communication post the meeting was non-existent. This was disappointing as we had some significant questions we wanted answered which are still not answered. Third, it seemed transparent that the Planner wanted "to move us on" and push us into either an internal review process or an unscheduled review process. Bear in mind we have limited time during a 12 month period so one Planner meeting a year is the preferred option. Fourth, the funding in our view has been manipulated across irrelevant funding categories to provide less transparency around the fact that the funding adequately reflects the goals agreed (e.g. Assistive Technology funding is not in the "Assistive Technology" category but in the "Consummables" category alledgely). Finally, the funding received is 50% of last year's funding which was fully expended three weeks before the end date of the last plan. The funding does not reflect the quantum of the goals (i.e. all our son's prior year's goals were carried over as agreed with the Planner and additional goals were added). What would be useful is that there is a clear and transparent statement linking each goal to the quantity and prices per the NDIS Price List.

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The effectiveness and impact of privatising government-run disability services

1. I believe we have referred to this question above. Refer to (b)2.
2. An additional point is that previously government-run disability services were bulk funded which guaranteed their funding. Now that people with disability under NDIS can source their preferred providers which don’t necessarily have to be NDIS providers, it is apparent that some organisations are resenting this. However, overall we don’t believe this is a significant issue and typically most organisations have embraced the competitive nature of the private disability market. Also, the other issue where people would not be allowed on waiting lists for disability services through third party organisations which was discriminating and causing people with disability problems accessing funding that they had a right to has been mitigated which is wonderful.

The provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the NDIS

1. Our son has complex intensive needs. He is aggressive and there is a risk of significant harm to his family, his supports, the public and himself. However, the funding for out of home care to help him and provide him with a level of independence has been reduced significantly. Accommodation Services provide the opportunity for our son to become more responsible, self-manage and still receive supports to re-integrate safely with the Community and his family. It is important to recognise that disability can trigger symptoms that require this type of intervention and that is whether you subscribe or not to the NDIS.

The adequacy of current regulations and oversight mechanisms in relation to disability service providers

1. We believe this will be addressed through the new Quality and Safeguard’s Commission. It is important to provide Disability Service Provider’s with breathing space as they transform and change to respond to a more agile and flexible disability environment.

Workforce issues impacting on the delivery of disability services

1. We noticed that when the NDIS was implemented in our area, disability provider waiting lists and availability became a serious challenge. However, the flexibility of self-managing meant we could look at employing non-NDIS provider support workers directly without too much of an administrative burden. The NDIS provides that flexibility that allows more benefit to be realised from the funding expended.
2. It is important to note that disability workers are low paid workers. Therefore commitment and consistency of service to a person with disability is a serious and constant issue. We have mitigated this as we said by screening and approaching people with passion in the industry through the universities. However, another recent example was that my son wanted a “friend” as he has no friends. So we hired a support worker though “Hireup”. This support worker is only a few years older than our son so our son saw him as a friend not a support worker. When we initially screened this support worker, we honestly though we were speaking to a 35 year old, not an 18 year old. This person had left school early and was doing a TAFE course in the disability area. However, his insight into the disability area and how to manage my son would blow you away. We need to all realise that passion in this industry is heaps better than academic prowess and we should consider that a benefit. I’ve also recommended for this young person to network with my other support worker so he can further his career and academic pathway which is clearly in the disability area. These actions benefit this wonderful country and support our governments.

Incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services

1. Our observation is that we need to consider this issue holistically. All services should work as one. When our son moves into a high arousal state and is aggressive, we find that the Police and Ambulance Service schedule him but he is de-scheduled at the hospital because he is considered to have had a behavioural episode related to his intellectual disability. That idea is disempowering as people with disability can exhibit mental illness symptoms which require appropriate psychological treatment. The lack of NDIS meant our son was having multiple hospital visits, the local Community Mental Health Service was inadequate and because he was diagnosed with an intellectual disability, they would allege he was not covered under the Mental Health Act. The introduction of NDIS has meant that we have more leverage to empower these other services to improve their standards, e.g. in response to our feedback, the NSW Police in our LAC have implemented training around Autism and how to appropriately respond to a person in a high arousal state.
2. Our son is at risk of been exposed to the Justice system as he can become aggressive towards family, support workers, members of the public and can also hurt himself. However, with the holistic support of the NSW Police working to advocate for improved services in Local Health, we have found that our son is less likely to be in trouble with the law. The NDIS support mitigates this risk more and more as time goes on. However, it is important that the goals and funding are matched to support these positive outcomes.
3. We find that thresholds for support in other systems are inconsistent and need revision. For example, the threshold to schedule someone differs with Police, Ambulance Staff, Hospital Doctors, FACS, etc. NDIS has a threshold around access to the scheme. It is important that people with lifelong mental illness should be considered disabled by their conditions and provided access to NDIS services. We have friends whose daughter tries to commit suicide regularly. Her ailment is evidently likely to be **lifelong. However, her Mum is struggling to access NDIS. We referred her to our Specialist but because her**

daughter does not have a recognised intellectual disability she is struggling to access the Scheme. This puts strain on other systems. NDIS should be considered holistically. It cannot live alone. It has to live and co-exist with the other systems.

Policies, regulation or oversight mechanisms that could improve the provision and accessabiltiy of disability services across New South Wales

1. Perhaps a Committee made up of Carers and Parents?

Any other related matter

1. One other related matter. The NDIS needs a repository of knowledge. Currently the knowledge and information for our son's support workers is collated in 150 reports. This permits us to get a true understanding of our son's disability and challenges. It focuses funding and makes achieving goals measurable. An innovative idea is for the NDIS to create an app where information is shared. We label our people with disability with this that and the other. However, we all know that treating the symptoms helps alleviate the challenges in their lives. Disability is permanent but symptoms are the variable. Symptomatically if we share our insights with each other, we can get more value and benefit from the funding allocated to the Scheme. We are expecting commission for this idea ☺.