

**Submission
No 111**

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

Name: Ms Sharon Grocott
Date Received: 30 July 2018

Dear Hon Greg Donnelly (MP),

I would like to make a submission to the parliamentary committee. My husband could not work for 6 months as my daughter was sitting at home waiting for post school -School Leaver Employment Service (SLES) funding to be approved.

I have attached the report that I shared with Hon Paul Fletcher (MP) which went to the Minister Christian Porter, at the time. My daughter Amber is a strong advocate in her own right and she would be happy to meet with the Parliamentary Committee to share her experience.

Amber's plan was reviewed and red flagged as urgent in February. I even wrote to the CEO of NDIA. I never heard back from Mr DeLuca.

Amber left school in the first week of September last year. Amber now has SLES funding and she attends Fighting Chance three days per week. She is very happy and doing so well. Amber's goal is to gain employment. She wants to be valued and participate in the work-force.

If we had not been strong advocates she would still be sitting at home in front of the television.

My number is I welcome the review.

kind regards,

Sharon Grocott

Feedback on the National Disability Insurance Scheme (NDIS)

Background - Amber's Story

Our daughter Amber is a 19-year-old young woman with a passion for animals and in particular horses. Through her own perseverance and with a great deal of support from her family she has achieved much in her life so far despite her dyspraxia. Amber would like to develop her independence from us and is looking for support to do that as well as seek meaningful employment.

Amber has a great work ethic and likes to be busy working in areas that support her passion for animals. Every Saturday Amber works at the Riding for the Disabled in Ryde. In fact, last year she was the Volunteer of the Year. Amber is dedicated to her volunteer work to the point where she has had one Saturday off in the last five years and this was due to being very ill with the flu. Amber is an amazing human being – she has dreams and aspirations like all of us.

The ethos of the NDIS seems to be about providing reasonable and necessary supports to help people with a disability live an ordinary life, including care and support to build skills and capability, so that they can engage in education, employment and community activities.

The establishment of the National Disability Insurance Scheme was a landmark achievement for Australia, a scheme to provide reasonable and necessary supports and services to people with disability enabling choice and control. Carers generally welcome the scheme and we embrace the ethos of NDIS.

The NDIA (the agency tasked with overseeing the NDIS), needs adequate investment so that the disability support system works as well as other public services such as Medicare. Although the issues we have experienced so far are relevant to Amber, many of the examples highlight systemic issues and the need for improvements in processes on the ground. I have highlighted Amber's story so far and the issues.

Lack of knowledge and expertise - Local Area Coordinators

How can the LAC can understand Amber's needs and aspirations when they only spent 30 minutes with her to develop her plan?

During our 30 minute planning meeting on 6 November 2016, the LAC was entering Amber's information onto an IPAD, which apparently links to a portal. The connection to the Internet did not work and as a result, the LAC did not record any information about Amber. I question the skills, experience, training and workloads of local area coordinators and planners.

The qualifications and level of training for local area coordinators (LACs) needs to be improved. It is critical that technology be working if relied upon for the development of an NDIS plan. The LAC needs to spend more time face to face to get to know the person.

LACs are responsible for coordinating and designing the NDIS plan. LACs are private organisations contracted to act as a conduit between people with disabilities, the agency and service providers. In our case, the LAC is provided by Uniting provides the LAC's. Uniting is an advocacy and service arm of the Uniting Church.

The role of the LAC's is to assist families to start their NDIS journey by provide support in the implementation of the plan and they connect families to the community. This cannot be achieved in a 30 minute meeting with someone they have never met.

Issues with the NDIS Planning Process

Amber's NDIS plan contains incorrect information. For instance, under the daily life section it notes Amber attending occupational therapy (OT) and lists OT as a service. Amber had attended OT in the past but we had prioritised weekly speech therapy at the planning meeting and she has been seeing a speech therapist since three years of age.

The information contained in the plan is incorrect. This has been highlighted in writing to the LAC with a request for the plan to be amended, and yet the plan has not been altered. In Part 1: Amber attends Brigidine College (Disability Support Unit) and not St Lucy's School as listed in the plan. Amber attended St Lucy's in the past as her primary school.

Amber found the plan offensive as she sounds like a young child. The plan is written in a way that makes Amber sound like a five year old and not a 19-year-old young woman. It is written from a deficit model and not a strength based approach.

The LAC seem to have very limited knowledge about dyspraxia and he did not seem to understand Amber's disability at all. When the LAC was approached as to whether all of Amber's assessments and reports had been taken into consideration when writing the plan, he responded with a 'no – the reports were not cited'.

We had submitted 17 years of reports containing all of Amber's pervious assessments over the years. There seems to be a failure with the NDIS systems and processes in that reports are not even considered when writing a plan. My biggest concern is that the plan is linked to funding and there is no correlation with the person's needs. The planning process is crucial as this determines how much funding and what supports people can access. The planning process in this instance was very poor and I have heard of similar stories from numerous parents.

Why would you not consider all of the assessments and reports when developing her plan?

The items included in the plan are not a priority for Amber. Her priority is leaving school and accessing a post school program. Amber's NDIS plan needs to focus on Amber achieving post school educational pathways and employment pathways. The NDIS' **School Leaver Employment Supports** (SLES) would assist Amber with the support she needs including

work experience, job site training, travel training and activities that contribute to achieving an employment outcome and linkages to ongoing employment support.

We question the methodology being used to finalise plans including the reference/typical support packages that are being used for this. The NDIA has highlighted the need to 'start young to set up expectations for employment' as the key strategy to address low expectations. According to Fighting Chance, the cost of a SLES program is around \$21,000 per year for the 3 days. Amber has received \$6, 839.28 worth of NDIS funding. The funding will cover one day per week of service in a SLES.

We have been engaging with Fighting Chance since Amber was 14 years of age. The organisation has the ethos and values that we believe in. Fighting Chance sets the highest standard in regards to supporting people with disabilities to achieve their goals and aspirations. We now find that Amber has finished school and we do not have any funding for post school or any plan in place.

Amber left school on 22 September 2017 and she has no funding for a SLES. Amber will be sitting at home in front of a television most days. How does this support young people with disabilities to have aspirations and dreams? **How does this support the pathway into education and employment?**

NDIS plan reviews

We have asked the LAC for a review. I am told by a number of other parents that it could be up to 6 months for a review meeting post the due date. Apparently, this has been the experience of many parents.

I have now only just discovered that I have to make a formal request for a review. There was a standard out of office message on the e-mail from the LAC that suggests that I go to the www.ndis.gov.au website and complete the 'Application for Review' of a reviewable decision. Once the form is completed, I then need to send the form and any supporting documents to feedback@ndis.gov.au

Our review meeting should be organised on 8 November 2017. I received a message this week from our LAC notifying us that he has changed roles. It seems we now do not have an LAC and I very much doubt a review meeting will be happening in the near future.

It has been very unclear as to how to access a review. Plans appear to be inflexible and a change seems to be exceptionally difficult to achieve, even when it does not prioritise the areas that Amber wants. Surely, we should have a right to have seen the draft of the plan before it was set. There have been many instances of people with intellectual disability not getting the opportunity to exercise choice and control which is highly concerning

I am aware that some parents have had changes to their funding and they have not been informed. We are worried that the funding is set and it will not take into consideration that Amber's needs have changed with her finishing school. The process for plan reviews or appeals needs to be much simpler and clearly communicated.

NDIS Co-ordination

I have received no information about the co-ordination of Amber's plan. There are massive gaps, such as who funds the co-ordination. I am a qualified Social Worker with over 25 years' experience largely in the disability sector, and even I am finding it hard to navigate the system.

I have received no information about how to access the funds and how to implement Amber's plan. Since the plan was received, there has been no follow up from the LAC. Families are being discouraged from pursuing self-management of plans, even when they have already been self-managing. I have been the case manager for Amber for many years. **Why are LAC's not providing families with the information required to effectively navigate the system?**

Funding for Carers

With the current plan in place and now having left school, Amber is spending large amounts of time at home. Without myself or my husband reviewing our careers, Amber will be by herself for a majority of the time, when she wants to be out working and contributing to the community.

We actively support our daughter and have always been flexible in our approach to our careers, but we are now at the point where one of us will have to look for part time or casual work in order to provide the necessary support for Amber. This will have a severe economic impact on our family, even if we can find flexible work. **What support and funding options are there for the Carers?**

Conclusion

We all want the NDIS and we want it to work but we need to urgently address these issues before it is too late. Building the capacity of people with disability to engage in employment should be a high priority area. The financial viability of the NDIS is intrinsically linked to increasing economic participation and achieving better employment outcomes for people with disability and their carers.

The NDIA has recently identified the existing 'culture of low expectations' of people with disability, their families, planners and the community as a significant barrier for achieving desirable employment outcomes.

Early NDIS plans are showing little emphasis on employment, with only 9% of plans including supports in this domain. Current plans do not reflect the employment aspirations of people with disability and there is minimal growth in demand for new employment support

services. (Source: <http://www.disabilityservicesconsulting.com.au/resources/ndis-employment-101>)

So how do we 'build the capacity' of people with disability and their support networks to imagine 'economic participation' as an achievable goal? How do we assist people to move from being 'dependent clients' to 'active citizens' when it comes to economic participation? This is a major concern and a question unanswered.