

Submission  
No 238

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

**Organisation:** NDIS Peer Support Group Lawson

**Date Received:** 9 August 2018

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9<sup>th</sup> August 2018

The Hon. Greg Donnelly MLC Committee Chair

Re: Private submission to Legislative Council regarding Inquiry into the National Disability Insurance Scheme in New South Wales

Dear Sir,

We are an NDIS Peer Support Group based in the Blue Mountains. Our group is made up of a mix of; (i) people who are recipients of the NDIS, (ii) parents and carers of people who are NDIS recipients and (iii) people who are awaiting NDIS acceptance. The group is supported by local community agencies that provide meeting space and support the facilitation and promotion of the group.

We are pleased to contribute to this inquiry.

### **1: Lack of NDIS registered services in our area**

Participants in our group report difficulty accessing NDIS registered services and as a result have difficulty finding adequate support and implementing their plans. The Blue Mountains is a regional area of Sydney with less access to service. Anecdotally local allied health and other professionals have suggested it is too difficult to obtain NDIS registration and opt out. Others have deregistered as a result of poor early experiences.

Members report (i) not being able to find a cleaner or support worker, (ii) not being able to get home modifications done, (iii) very long wait times to see an OT and other allied health (iv) not being able to implement plans or have certainty about the continuity adequate services.

*"I tried for ages to get a cleaner. When I finally found a place they came out and did an assessment and, because it was only 2 hours a week, said it wasn't worth it. I spent almost the whole life of the pan trying to find someone" - D*

**Recommendation:** Great supports for smaller and regional services to obtain NDIS registration.

### **2: Transport**

Transport in and around the Blue Mountains is difficult based both the area's geography and the large distances between villages. Train transport in the Blue Mountains is still inaccessible on the majority of stations.

One member reports the story of a young woman *"Before the NDIS she was going to TAFE at Richmond and taking part in an inclusive class. Since the NDIS she has not been able to continue this within her NDIS transport budget. She has since withdrawn from TAFE and has very reduced social participation as a result" - C*

For many the use of a private vehicle is the only option but NDIS rules in relation to vehicle modification can make this a challenge;

*“The challenge of vehicle modifications is almost insurmountable. If the vehicle is older than 3 years old then it’s not eligible for modifications. Who on a disability pension has that money?” - D*

*“For M to go out the support worker need to take our vehicle because it’s been modified. We did it years ago. Sadly it’s now deemed “Too old” and the worker isn’t allowed to drive it. We can’t afford to upgrade to a newer car and they can’t use the train because there’s no access at our station” – K*

Inaccessible public transport and inadequate NDIS transport budgets result in the following example;

*“Transport’s a real issue for me. My local station isn’t accessible so I have to travel to a neighbouring station to use the rail. There aren’t many accessible taxis in my area and even if there were it gets really expensive. I have to use my wheelchair to get home from the station, it’s about 4Km’s and I only just make it” - J*

The main issues reported by the group around transport are;

- (i) The NDIS transport allowance does not provide for the longer distances required for travel within the Blue Mountains, or, for the need to travel outside the area for essential services, education etc.
- (ii) Train transport is still inaccessible across the majority of the Blue Mountains line
- (iii) There are too few accessible taxi’s to service the area and the costs associated are unaffordable for most.
- (iv) NDIS rules around private vehicle modification are unrealistic for many on a Disability Support Pension

**Recommendations:** (i) Greater flexibility to account for regional and individual differences when allocating NDIS transport budget (ii) Improving accessibility of Blue Mountains train line (iii) Review of accessible taxi allocations and taxi subsidy for people with disability (iv) Review of rules around vehicle modification of NDIS

### **3: Interaction between NSW Health, Education and NDIS**

The Blue Mountains is one of the first roll out areas for the NDIS and has experienced some of the early separations of services. Members of the group report a disconnection between the NDIS and other NSW services such as Health and Education.

Some examples from the group are;

*“When B was with ADHC everything seemed to be taken care of. Now I just don’t know. We have to get special wraps for her oedema. We just used to get them from the hospital, now they say we have to use our NDIS plan, but when I asked the NDIS, they told me to go back to the hospital” - M*

*“I get scared now when we are in the hospital seeing all the signs saying “DO YOU HAVE AN NDIS PLAN” - J*

*“I have been able to get away with things but I am getting older. I need to maintain the health of my arms to ensure my mobility and independence is preserved. They will allocate funds to repair my chair, but nothing to ensure I keep my arms in good shape. I need deep tissue massage to keep it in good function but they don’t allow that. I have money left in my plan but I can’t use it for the things I need. You can’t separate disability and health” – D a wheelchair user*

**Recommendation:** Improved integration of NDIS with State based services and clearer guidelines for community to understand the distinction

#### **4: Transparency of language used by NDIS**

An ongoing conversation in the group is the difficulty in interpreting the language used by the NDIS and the difference this can make in the funding allocated to people with seemingly similar needs.

*“It really hard to decide what I need and then put it in NDIS speak. There is a lack of consistency and that makes it feel harder to get results. I don’t know how they want me to communicate my needs” – J*

*“I’ve seen very different NDIS funding allocations given to families with children with really similar needs. It seems to come down to how well you can advocate and how well you can speak the words they want to hear. It shouldn’t be like that” – C*

*“It’s like they (planners) know the right words but they just can’t be upfront and tell you how you should ask for things” – J*

In some instances language is simply confusing;

*“Things like Plan Manager and Coordinator of Supports sound like they are the same thing. They could make it simpler. If a plan manager is about handling the money then call them “Funds or Money Manager” if Coordinator of supports is about finding your services, call them “Coordinator of Services”. I was talking about this to an Auslan interpreter who said you can’t distinguish between these two terms using sign language, they are basically the same sign!” - C*

**Recommendation:** (i) Clearer guidelines around the use of NDIS language to obtain specific (ii) review and/or community consultation to improve simplicity of language.

#### **5: Withdrawal of State Based Services since introduction of NDIS**

The Blue Mountains is one of the first regions to experience withdrawal of state based services in the disability sector. This has had substantial impact on people who are newly disabled or newly diagnosed with disability. There are no services, with the exception of some limited volunteer based programs, currently able to offer in home supports to people who do not have an NDIS package.

The following example is current.

*A 56 year old man, P, lost the majority of his vision in January 2018. P lives alone, is not connected to family and has limited informal supports from a small network of friends. He is unable to leave his flat safely unsupported.*

*P receives Meals on Wheels but no other services. P is in urgent need of in home care and transport but cannot access these without an NDIS package. P has experienced a lengthy application process with the NDIS which took more than 6 months to obtain the necessary documents for NDIS to consider his application.*

*In the interim P's wellbeing has been compromised and what little supports are available to him are charitable or volunteer based with no certainty or continuity. Pre NDIS, P would have had an immediate right to access services.*

**Recommendation:** Preservation of some block funding to provide service to people who are awaiting NDIS approval.

## **6: Advocacy Services**

Our NDIS Peer Support Group acknowledges the commitment of the NSW State Government for continuing to fund Disability Advocacy Services. We believe the continued funding of these services is paramount to the wellbeing and inclusion of people with disability into the future. While the NDIS offers great promise it is recognised that only a portion of people with disability will take it up. Therefore it is important that funding, outside of the NDIS, continues to be allocated to Disability Advocacy Services. In addition many people with disability will seek advocacy related to area's which fall outside the NDIS.

**Recommendation:** Continued funding of Disability Advocacy Services independent of the NDIS budget.

Thank you for the opportunity to contribute. We are happy to be contacted via, Cherie Brandon,

Yours Sincerely,

Cherie Brandon on behalf of NDIS Peer Support Group Lawson