

Transport, the NDIS and YOU!

Report from the transport forum held on 4 November, 2015

I'll start with some quotes from a participant in the forum...

"Before the NDIS, I was able to do everything I wanted, when I wanted. I had a wonderful life accessing the community.

I've been with the NDIS for two years. Now I spend 98% of my time at home. I have gone backwards because of the cost of transport. It's astronomical. I can't understand how anyone can have a life of their own with the NDIS. It's a very, very degrading lifestyle."

"My son has Down Syndrome and transport is our main problem for him. NDIS just cannot sufficiently provide it for him. It's really stressful for my wife, having to get up early to take him to wherever he needs to be. They have three buses to catch, therefore he and my wife need to get up at 5:30 AM, to get him dressed, have breakfast and then on the bus by 7 AM. They tried travel training which didn't work. Coming home, he always slept on the bus and he cannot read the destinations on the bus. We still haven't been able to organise transport for him with the NDIS. It's very disappointing on behalf of the NDIS. He used to get support through his service provider 4 days a week, but now he only gets support on Tuesdays for gym. The other three days were computer skills, art and living skills. Because he hasn't been able to get there, he's lost his interest in those things. He's really lost motivation to do anything much now. I do hope we can somehow resolve this. It's just so stressful."

"I used to be able to spend my funding really flexibly to use taxis. Now I only get \$75 per fortnight. I spend that just getting to the shops on a Monday. Then I'm out of pocket for the rest of the fortnight. I just can't afford to go anywhere. The NDIS was supposed to cover any additional disability related expenses and we are just not seeing that happening."

"My service provider is now charging 78c per kilometre for me to get anywhere. I just can't afford to do all the things I need to do. Only my mobility allowance has been replaced but what happened to the funding that ADHC used to give service providers to subsidise travel for me? We didn't expect the NDIS to take this funding bucket for transport off people with disability."

The next quote comes from a man who is deaf-blind. "I have to catch the bus if I want to get anywhere. One, two, three buses drive past me without stopping to check with me if I want to get on. I can't see them coming so I can't signal to them to stop for me. And I have to walk a long way to even get to the bus stop (witnesses have seen trucks and buses swerving to avoid this man as he crosses a major road to access the closest bus stop)."

“My daughter was bullied on the school bus. The bus driver even said she had no place on the bus and encouraged the other kids to bully her to the point I had to transport her myself until she finally ended up getting assisted school transport (in a private taxi). We need to work on these issues otherwise our kids will continue to be separated from their peers AND it costs a helluva lot more.”

“There is only one wheelchair taxi in my area (Lake Macquarie). I can’t even count the number of times that I’ve missed out on things because I can’t get the taxi, even to medical appointments.”

The ability to move around the community underpins all aspects of life and is essential to achieving all the policy outcomes outlined in the National Disability Strategy—from learning and skills, to employment and to the enjoyment of rights. In order to move freely around the community, people with disability need access to private as well as public transport. The NDIS represents opportunities for people with disability to take their rightful place as actively contributing citizens to our community. It represents the opportunity for us to participate in and contribute to the social and economic life of our community. We need accessible and affordable transport to do this.

CDAH, the local user led disability support organisation heard of the pain that people with disability were experiencing around transport with the NDIS. We also know that transport is an issue that will make or break this Scheme. We found out that there was no working party at the local level dealing with the issue. So we contacted the National Office to find out that very little work was being done to address the mainstream interface with transport. Worst of all, there are no processes for people with disability and their families to be involved in co-design around transport and the NDIS.

So, we took the issue in to our own hands. In early November 2015, we ran a forum with people with disability and their families, government and other invited guests to shine a light on transport issues in the Hunter and to find solutions together. We ran the forum in partnership with ANSA (Adults Needing Supported Accommodation), another grassroots peer support organisation.

We invited a range of stakeholders that included the local NDIA office, ADHC, Executive of Disability Network Hunter (who represented service providers), NSW Ombudsman, NSW Trustee and Guardians, Community Transport Organisations, and staff from Newcastle and Lake Macquarie local government. MP’s - Jill Hall, Sharon Claydon, Pat Conroy and Yasmin Cattelly also came along and gave us a donation so we could run the event.

110 people participated on the day, 75 of those were people with disability and family members. Lack of safe, accessible, affordable, reliable transport is impacting on us, so who better to lead the way to finding solutions?

The day kicked off with a speech from Catherine Mahony, CDAH Coordinator, which I’ll submit to the committee.

David Bowen, CEO of the NDIA, addressed the forum and said that it was intended for plans to be used flexibly, that we can interchange our flexible supports to include transport. David also said that the intention was to give people plans that included a reasonable amount of funding for people to use as flexibly as they wished. Quote: “ It’s in your hands. How you make decisions about how you use your funding is up to you”.

We invited a range of other speakers including Maurice Sinclair, a local transport entrepreneur, who is developing a platform to deal with local inefficiencies around transport. We invited Maurice because we want bang for our buck. We want to stretch our disability dollar further. We want the NDIS to last for future generations. Maurice told us:

- there are more than enough transport providers to satisfy demand
- coordination is the issue
- more purchases of vehicles is a waste of funds, poor resource utilisation adds to the problem, and will not solve the coordination issue.

Maurice is proposing the development of a simplified booking, allocation and payment system that uses under-utilised vehicles in the region.

Over the rest of the day, we explored what’s working and what’s not working in relation to transport in the Hunter trial site.

We asked the forum, what I don’t want to see happen?

Major concerns included:

- that our recommendations from the forum are unheard or forgotten.
- that the current public transport system remains inadequate. Public transport in Newcastle was described as the transport of last resort. Long waits, long routes and is really only for people without cars.
- other major concerns including increasing isolation, community attitudes, exclusion and inaccessibility
- the biggest concern by far was the cost of transport for people with disability.

We went on to explore our dreams, hopes and aspirations for the future of transport.

We then developed recommendations for immediate action.

Recommendations for immediate action

1. A local working party

We know that the Scheme won’t work unless we work together. Let’s make this happen and let’s start a local working party. A local working party that works towards a public, private and community transport system that is accessible for the whole of the Hunter community.

2. Get rid of the levels.

It's a return to the bad old days of "one size fits all". Our transport requirements are as individual as we are.

3. Make NDIS Plans flexible NOW, so that participants can start using their NDIS budget flexibly to meet their own goals. We are the experts in our own lives and this was always the promise of the NDIS.

4. Planners need values based training and leadership. There are far too many examples in the Hunter trial where the expert voices of people with disability and their families have been dismissed or ignored by their Planner.

5. Be true and genuine in the co-design of the Scheme. Please don't pay lip service to co-design processes. Tokenism in any form whatsoever is not good for anyone.