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

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This submission is made for NDIS participant Emma Peachey by her nominee, David Peachey. Emma is a 35 year old woman with profound intellectual, physical and sensory disabilities, and complex care and support needs. Emma lives at home with her parents as her full-time carers.

Summary of our Experience of the implementation of the NDIS

The implementation of the NDIS began for Emma during September 2016 and proved to be a difficult, stressful and time-consuming process. It is our experience that the NDIS is a great idea very badly implemented with the NDIA comprehensively failing to treat people with disability, and their carers, with appropriate dignity and respect. The issues highlighted in the recently published Federal Ombudsman's report accurately represent our experience.

The poor implementation by the NDIA was made more difficult by the failure of NSW Department of Ageing Disability and Home Care [ADHC] to transfer Emma's records to the NDIA. Similarly, ADHC failed to forward records to the new agencies in their privatisation of former government services. We believe there was a total failure of ADHC's duty of care to facilitate an orderly transfer of critical information that would have resulted in a simpler less difficult transition to the NDIS.

The lack of an adequate level of funding for transport has become a significant problem to be resolved as it has the impact of causing social isolation for people with disabilities who need to use wheelchair modified vehicles [taxis] to access the community.

An increase in competition for services was a key objective of the NDIS however our experience is that the opposite is occurring with Emma's respite service, Estia Foundation, of over 16 years deciding to close due to the unsustainability of the NDIS model, and Northcott is closing its customised wheelchair service again due to the unsustainability of the NDIS model. Both of these services will cease on 31 August 2018.

Our experience in developing, enacting and reviewing NDIS plans

Emma's initial plan was developed in consultation with a NDIA Planner. This plan required review within 5 months as it failed to correctly address her support needs for her day programme with initial funding being 30% less than previously provided per the NSW Community Participation Programme.

Incorrect assumptions were made about Emma's support needs for 2 main reasons:

- 1. A standardised cookie cutter approach adopted by the NDIA that made wrong assumptions about the level of care required, specifically ignoring information provided during the planning meeting about specific high levels of care [2:1 and 1:1 for personal care and feeding].
- 2. NSW Department of Ageing Disability and Home Care [ADHC] failed to transfer Emma's personal records including her diagnostic records and funding history to the NDIA. We identified this major failure, in what we believe was ADHC's duty of care, during the review of Emma's NDIS Plan and was confirmed by a NDIS Deputy Director.

The review process that followed effectively required us to prove Emma's level of disability and the aligned support needs and was dragged out over a period of nearly 9 months.

- The NDIA was originally non-responsive with resolution being finalised only after escalation resulting from a public meeting with our local Member of Federal Parliament 5 months after our initial request for review.
- Emma was hospitalised, requiring surgery, during September 2017. The medical reports that resulted from this medical episode were used to prove the magnitude of Emma's multiple disabilities and the types and levels of support she requires. Had it not been for this unexpected hospitalisation the process of proving the extent of Emma's disabilities and support needs would have been much more difficult and time-consuming requiring us to provide new medical and neurological diagnosis documents.
 - NB: It is possible that the need for a review would have been avoided had ADHC properly exercised its duty of care by passing its records to the NDIA.
 - The Federal Ombudsman's Report has identified significant failings in the administration of the NDIS by the NDIA and has made recommendations which have, in principle been embraced by the NDIA, however the response from the CEO of the NDIA does not set any time frames for making the proposed improvements. We need clear deadlines and a real sense of urgency to have these changes implemented by 31 December 2018.
 - These failings have also been identified by the Deputy President of the Administrative Appeals Tribunal who described the NDIA's decision-making process as slow and difficult to interpret. He pressed Social Services Minister, Dan Tehan, to intervene as a matter of urgency in this "unsatisfactory state of affairs."

The effectiveness and impact of privatising government run disability services

Therapy Services

The privatisation of ADHC Therapy Services to The Benevolent Society was mismanaged. ADHC failed to transfer Emma's therapy records to The Benevolent Society resulting in delays in our ability to fully engage therapy services.

We succeeded in obtaining the required services only due to the outstanding service provided by therapists who transferred to The Benevolent Society [from ADHC] and had sufficient historical memory of Emma's therapy support needs

Short Term Accommodation [Respite] Services

We rely on short term accommodation [respite] services to maintain our health and wellbeing as fulltime carers for Emma.

The NDIS model has changed the funding dynamic within the marketplace that has resulted in our long-term respite service, The Estia Foundation, closing its Gladesville service due to it no longer being viable. We have been accessing this service for more than 16 years and now need to find a new service but our investigations have identified that respite services are decreasing rather than increasing under the NDIS model.

Customised Wheelchair Provider

We have been advised in the last week that Northcott will close its customised wheelchair service from 31 August confirming that the changes to the funding model under the NDIS has made the service unviable. There appears to have been no understanding of the way in which Enable NSW, which

previously managed customised wheelchair funding, managed administration to allow the marketplace to provide sustainable solutions

Emma has been using this service for more than 20 years and our initial enquiries indicate that there is now only one remaining service provider for this very specialised custom-made wheelchair service.

The provision of support services

Transport

We submit that a significant change in government policy is required to current transport support for people with profound intellectual and physical disabilities who must travel by wheelchair for their personal safety.

The NDIS does not adequately provide for the transport support needs of a person with profound intellectual and physical disabilities and complex support needs. Apart from a modest transport allowance the NDIS has stated that the provision of subsidised transport Is not a part of its programme. Current subsidised public transport [including taxis] for people with disabilities is provided by the NSW State Government.

The NDIS will however provide personal support to access public transport. This alternative provides a dramatic contrast in cost, transit time and safety to subsidised taxi services. The following example shows these differences for Emma's daily transport over 5 kilometres from our home in Denistone to her day programme at Marsfield.

Taxi compared to Public Transport with a personal attendant / carer

Taxi is the only safe and reliable method of transport for a person with profound intellectual and physical disabilities and who travels in a wheelchair.

- A door to door service is necessary
- Bus and / or train transport is not easily accessible at all transit points [alighting and exiting a bus or train] and requires extensive 'walking' in the open in all weather conditions for part of the journey. In this example uncovered 'walking' on public footpaths and across roadways represents 1.7km or 34% of the total distance.
- A person in a wheelchair and their attendant cannot be kept safe and dry in wet weather.

Taxi is the lowest cost option compared to a personal carer / attendant and public transport.

- A 10-15 minute taxi journey is equivalent to the replacement cost of 1 hour by public transport with 2.5 3 hours of attendant care return trip costs twice per day
 - The annualised cost comparison:
 - Taxi = \$11,830
 - Public Transport with attendant care = \$71,634 [+\$59,804 or +505%]
 - A taxi does not require an attendant / carer

The current transport allowance does not cover reasonable costs.

- Transport allowance is only \$50.19 per week.
- The taxi subsidy scheme provides a 50% subsidy of costs only.
- Out of pocket expenses exceed \$6,000 for a person travelling only 5km per journey 5 days per week, representing 25% of the Disability Support Pension.

We submit that a disability pensioner with profound disabilities who requires transport in a wheelchair should have access to a version of the Opal Card that can be used in taxis with personal costs capped per the Opal Card model [NSW Gold Opal Card maximum daily rate of \$2.50 per day].

Conclusion

It is our firm belief that the NSW Department of Ageing and Homecare failed in its duty of care to properly transfer the services it was providing under the old state funded disability services model and that this failure had a serious negative effect on Emma's transition to the NDIS and for many others.

We recommend that ADHC be required to provide evidence of the full transfer of all personal historical records of services provided by them to the new agencies providing these services under the privatised model and that they write to each person for whom they have records to allow them the opportunity to receive a copy for their own records.

Transport is now a critical issue for many people with disabilities who can only use a taxi as a safe form of transport. The solution for this problem is within the NSW Government's sphere of control however there is the risk of a State verses Commonwealth disagreement about how the funding should be provided. <u>Public transport is a State Government responsibility so we recommend that the NSW Government immediately develop a version of the Opal Card that allows a qualified person with a disability to access taxi transport under the same terms and conditions that currently apply to the <u>Gold Opal Card.</u></u>