Disability Care and Support Inquiry - Productivity Commission

Personal Response by Terri Carroll August 5, 2010

Experience – Professional

I have been working in the disability sector for just on 30 years, with the majority of my experience being in Day Services. My current role is Chief Executive Officer of Peninsula Access Support and Training (P.A.S.T), a Community Service Organisation providing support and services to people with a disability in the Southern Metropolitan Region, Victoria. I have held this position for the last 19 years.

The purpose of this submission is to give a personal perspective on the introduction of a NDIS. My professional response has been submitted via a collective response I and a number of my colleagues have put together and submitted to this inquiry

Experience – Personal

I am married to Barry (aged 61) and we have two children, Tom (20) and Molly (16). I am 46 years old. Barry has multiple disabilities. He was born with cerebral palsy (right side hemiplegic) and at the age of 40 was diagnosed with a muscle wasting disease (only affecting his 'good' left side). Shortly after this diagnosis, Barry was diagnosed with a mental heath condition, Bi Polar disorder.

Barry's life as a youngster was 'reasonably' normal. He went to mainstream primary and high school; he left school at 19 years old to take up a full time job at Nylex. Two years after that he took a job at Moorabbin airport and eighteen months later, left that job to take a proof reading position at the Herald Sun newspaper in Melbourne. Barry held this job until he was offered a redundancy in 1991.

Although Barry had what he would call a normal life it did include spending most Christmases and subsequent holidays as a young boy and teenager in the Children's Hospital undergoing various operations as a result of the cerebral palsy. When Barry was not in hospital recovering from one operation or another, he was seen as an outpatient for physio or occupational therapy. He would also attend various specialist visits and fittings for the calipers he had to wear. Barry remained a patient under the Children's Hospital until the age of 17.

Whilst the Children's Hospital was very supportive of Barry and his family, and his parents were eternally grateful for the support they received, there was a financial cost to this support. His parents were required to pay (fifty percent of the total cost) for his operations, (six in total) as well as the many contributions for the therapies, aids and equipment he required.

From aged 17 to 41, Barry led a very full and active life. He worked, drove, travelled overseas independently and with friends. He was very social and had a huge network of people both in his home town of Cheltenham and down on the Mornington Peninsula.

Life changed dramatically for Barry (and all those close to him) when he was diagnosed with the muscle wasting disease. The slow and progressive nature of the wasting disease saw him go from being able to walk, to using a walking stick, to using a manual wheelchair when he was out and about, to now being totally confined to an electric wheelchair. His ability to use the manual chair is becoming more and more difficult and really only used when we go to places where the electric wheelchair can't go.

Added to his changing physical situation, approximately 18 months after the muscle wasting diagnosis, Barry had a breakdown and was diagnosed with Bi Polar Disorder. His mental health spiraled out of control and remains so still today. Over the years we have found that although there is no clinical relationship between the muscle wasting and the bi polar, they do directly impact each other. When Barry's physical situation changes it usually affects his mental state triggering an episode and vice verse when he has an episode we notice that this affects him physically and he is unable to do some task that he may have previously been able to do before the episode.

Of all Barry's disabilities it is his mental health issues that are the most difficult for him/us to cope with. His episodes of depression usually last six weeks (and require hospitalisation) and these days we are lucky to get four weeks in between episodes. Medication is used but relatively ineffectual. Therapy sessions are attended weekly but do little to help prevent an episode reoccurring. We have come to accept that for the remainder of Barry's life this will be the rollercoaster ride we will be on.

Barry is under a myriad of doctors and specialists and with the exception of reports from each of these professionals going to his GP, there is no crossover. Barry is not seen as a person with a series of conditions in a holistic manner. He is seen by his neurologist for the muscle wasting disease. He is also seen by his Psychiatrist and Psychologist for his Bi Polar Disorder and he is seen by his GP for his skin conditions, swollen feet, medication repeats etc. Medical professionals are not geared to treat people with multiple disabilities and prefer that they go to the relevant specialist for whatever the particular issue is. There must be so much that goes unnoticed, therefore untreated or treated incorrectly because there is no adequate integration between professionals within the service system.

Life today for Barry is nothing like it was back when he was in his 20's and 30's. He is no longer able drive, his fine motor skills are little to non existent therefore he is unable to complete many basic daily tasks and he has lost nearly all his self confidence. He now has a very limited social network and relies on the support of his immediate family and our close 'family' friends for social stimulation. Over the years his friends have dropped off either because they did not know how to support or be around him when he was depressed or because much of the time he is in hospital. He has lost touch with people and therefore the art of communicating.

Barry is the 'domestic engineer' of our household. Our roles are reversed and given the type of work I do and the long hours that go with it, I rely heavily on him to keep the home running. In order for him to do this he needs to have the appropriate supports in place. This is not only important practically for us as a family unit but it is also important for him to maintain his independence, for his physical and mental well being and so that he can contribute to his family in a meaningful way, within his capacity and therefore feel valued.

Whilst the introduction of an NDS would not eliminate Barry's multiple conditions if it was in place, it would provide him with the opportunity to receive supports when and as he needed them. As a child growing up with cerebral palsy (mild as he would describe it), the supports required were minimal. However, when he was diagnosed with the muscle wasting disease and the bi polar disorder, a great deal of support was needed for him and the family. It took years and really only because I was working in the field that we managed to get some funding support. Now as Barry's needs change and his physical and mental health continues to deteriorate, we are in need of more funding support. An application is being submitted to the DSR and we find ourselves back in the position of having to justify Barry's deterioration and 'prove' why we need the additional funding for support. All of this goes to bureaucrats who know nothing about our life, the complexities of his multiple disabilities or our day to day situation and yet they get to decide whether we are worthy of this additional funding.

The introduction of a NDIS is imperative to people with disabilities. For those who are like Barry, born with a disability and /or acquire a disability following birth, they must have access to a scheme that provides appropriate timely funding and support based on their needs, when they need it. The introduction of a NDIS would mean the difference between someone 'having 'a life to someone just going day to day and 'surviving' life.

I realize that the introduction of an NDIS will not be available for Barry in his lifetime and even if it is, by the time it is introduced he would probably be ineligible due to his age. This does not mean that we should not fight for others who would benefit from such a scheme. People with disabilities have the right to lead a full and active life and as such have in place the appropriate supports to do so. I believe the only way this is truly going to happen is if a system like a NDIS is introduced.

I could go on and on as there is so much I could say about our life and the difficulties we have encountered over the years. I have not touched on the impacts that Barry's disabilities have had on our children, the strain it has placed on us financially or the problems I have encountered juggling a demanding full time job, raising a difficult teenager and being there for Barry when he needed me, often all at the same time. I know we will get through but I want nothing more than to see the introduction of a NDIS so that all people with disabilities are able to 'live' and not just survive like we are!

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Some further comments for the Commission's consideration–

- The scheme must look at providing holistic support to those with multiple disabilities
- The person and/or their advocates must have full input and control over their funding and supports however it should be recognised that not everyone will want control.
- Where a person does take control and self directs to the full extent, all HR and standard employment conditions of staff must be maintained.
- Families/Individuals must be supported to manage their funding
- The NDIS must consider greater funding subsidy for those who require vehicle modifications. The current rate for a modification to a mid range vehicle is in the order of $75k. Very few people can afford this sort of money for a vehicle.
- Eligibility should not be income based and there should be no means testing
- Any funding support must be separate from the DSP
- Eligibility should cease at the government mandated age of retirement
- Those who already receive funding and supports must continue to receive it regardless of when a NDIS is implemented and any conditions, eligibility and criteria.
- The scheme must address and include better, coordinated supports for people with multiple disabilities particularly where there is a mental health overlay
- Eligibility = Entitlement = Support. The level and type of support must be determined on the person's capacity, access to community and other services, goals and aspirations and other supports already in place.
- Supports must be flexible and responsive to changing need and not dictated by bureaucracy or be subject to others 'approval'
- The scheme must be easy to navigate through and as simple as possible in its administrative requirements
- The scheme should take into account other arrangements where funding/support is already in place i.e. Insurance payout, TAC etc.
- There must be a bigger investment in community and community infrastructure to support inclusion of people with disabilities
- The current disability service system must be maintained and supported to remain viable
- Accommodation support must be provided in the capacity of which the person and their family want it – not how the 'experts' think it should be provided
- Respite services must be more responsive and flexible to meet the need as and when it is required
- This scheme must be supported by the community, be transparent and accountable for the funds it is providing.
- In the long term (15 years from starting) the scheme must be ready to accept all eligible people and provide support as required