

PARLIAMENTARY JOINT STANDING COMMITTEE ON THE NDIS

Geelong Hearing April 14 2014

Who did you first speak to about becoming an NDIS participant? Existing Case Manager

Were you able to access easily all the information you needed about becoming a participant in the NDIS? Yes

Where did you access this information (e.g.: online, a Local Area Coordinator)? State Government Department of Human Services, Existing Service Provider, Existing Case Manager and On-line

Did you use *My Access Checker*? Yes with support from existing Case Manager

What was the process through which your **eligibility for the scheme** was assessed? My access checker and being a person with whom NDIA trialled a computer based assessment tool prior to launch and being an existing state funded client.

- Did the National Disability Insurance Agency seek specialist reports from clinicians about your condition? Were you satisfied with this process? Yes the NDIA demanded independent OT, Physio and Speech therapy assessments be conducted and they even suggested that they had a "preferred provider" that they wanted to utilise to do this work. I was not at all comfortable or satisfied with this process, I felt it was undermining the existing therapy team and I also felt that I had no choice and control in the matter
- If you were not eligible for an individual funding package, did you receive advice and information? Did you appeal the decision? N/A
- Is the **planning process for participants** working effectively? In our experience, the answer to this is a resounding NO. When the NDIS commenced in the Barwon region, my son Paul had an existing state funded Individual Support Package. This package only became fully recurrent in July 2012 after 11 years of battling with the system. For the first 8 years of that time we survived with totally inadequate, cobbled together, non-recurrent packages of funds. We only had 18 months to enjoy this relatively "stress-free" feeling that Paul's and our future was finally a whole lot more secure before the NDIS came along and decimated everything we had worked so hard for.

We had previously been advised by many people associated with NDIA that the transition for people from state-funded to NDIA funded supports, particularly in cases where things were working well would involve a "light-touch" review in the first instance and a fuller review 12 months down the track. In our case nothing could have been further from the truth our lives were completely turned upside down in January 2014 and the stress for us all has been enormous.

It is very evident to us that the disability/health interface is going to be critical for people with high and complex disability/medical needs like Paul. I am very concerned that NDIA staff keep telling me that certain things should be funded by health and, in theory, I agree with much of what they are saying. However, we are

living the reality that health do not fund much of what my son requires which is why I have always received funding for medical/health items related to my sons severe ABI via the ABI: Slow to Recover program and then via his DHS ISP. The NDIA are not funding many of these things now leaving my son at risk.

- Did your planner correctly identify your goals and the supports that you needed?

Paul's goals were clearly and correctly identified by us (family and case manager) and appropriately recorded in Paul's NDIA Plan. What was totally incorrectly identified and recorded were the supports that Paul needs to achieve those goals.

- How did you and your planner identify the supports that you needed?

Via two face to face meetings (a totally inadequate number of meetings given the complexity of Paul's support needs) and via a lot of emails the planner was provided with extensive details regarding Paul's existing supports that simply needed to be rolled over with some additional assistance with daily living hours added. Instead these supports were decimated.

- Has your level of support changed since you became a participant based on a medical assessment?

My level of support has not changed since becoming a NDIS participant but my funding and supports have been severely compromised putting me at risk.

- How did you **identify the service providers** that could best deliver the supports you needed?

- Did you 'shop around' for the best deal in choosing your supports?

Due to the complexity of Paul's needs I cannot "afford" to swap and change providers because this would put my son at risk. It has taken us many years to build a team that is, the best of the best, to support our son and "shopping around" will not add any value to Paul's quality of life.

I actually believe that the financial viability of the NDIS is being put at risk because of some of the prices that have been set by the system. E.g. Therapy being costed at \$164.00 per hour has significantly increased the cost to support Paul and we are also now paying for things via his plan that were always free to us or cost a very small gap fee in the past E.g. Continence Clinic via the Health System

## Other areas for the Committees Consideration

### 1. FAMILY MEMBERS AS PAID CARERS

Another area of NDIS implementation that concerns me greatly is this notion that family members should generally speaking not be paid carers.

The partnership in care approach between family carers, service providers and funding bodies is vital. Having legislation and rules like family carers cannot be paid carers is an attempt to standardise what should not be standardised. Each individual living with disability and family situation is unique and needs to be managed on a case by case basis within guidelines.

In a perfect world family carers should never have to be paid care workers unless they choose this path and it is in the best interests of the individual and family. However, we all know that there are many times when paid shifts cannot be filled and without family members stepping in to the gaps our loved ones would be left unsupported. I implore government agencies, funding bodies and service providers to implement a common sense approach to this very real dilemma.

### 2. SUPPORTS FOR SUSTAINING INFORMAL SUPPORTS – NDIS Operational Guideline

Another area of grave concern for me is the detail included on page 5 of the NDIS Operational Guideline for Supports for Sustaining Informal Supports regarding “Expectations as to Levels of Support Required”.

Why would we think it is OK for people who “work” in an unpaid family care role, often in a 24/7 capacity and for an entire lifetime to have anything less than 4 weeks off to recharge their batteries and enable them to continue in their family caring role for as long as they choose.

In the aged care arena Family Carers are entitled to up to 63 days (9 weeks) of government funded respite and we all know that generally speaking family carers, who care in the aged care space have to provide care for a much shorter period of time. Why are we telling family carers in the disability arena that they need less respite when they are supporting a loved one for an entire lifetime?

Every Australian worker who does not work anything close to 24/7 is entitled to 4 weeks annual leave why should unpaid carers who save the system unquantifiable amounts of money get anything less than that. In fact they should be funded to receive more if they need more.

Implementation of this operational guideline as it stands may save money in the short term but will cost the NDIA significantly in the longer term as we see “relinquishments” occur as families fracture due to a lack of adequate support for

their caring role. This was one of the things we were hoping we would ~~see~~ cease under an NDIS.

What has happened to the idea that the NDIS was going to be about the person with a disability and the families? No family should ever face the heart break of “relinquishment” simply because the service system that purports to support them has failed.

### **3. THE NDIS AS A SOCIAL INSURANCE MODEL**

In a mere 9 months we have seen the path to the Northern Light which sees people with a disability and their families embraced as equal and valued citizens in Australian society take a very disturbing detour.

We have lost the word social and have become solely focussed on the word insurance – this means we are shifting people with a disability and their families to being seen as “bags of money” and a “lifetime of liability”, this was never the intent of the NDIS as campaigned for by the sector, nor was it the intent in the PC report.

The notions of Choice and Control have already been completely overridden by “reasonable and necessary”, people are even being asked if they really need a shower everyday!!!

Previously people with a disability and their families were categorised as “charity and welfare cases” now we are relabelling them as “liabilities”.

Planners are now undertaking the role of “claims assessors” and that is most unfortunate as it flies in the face of everything we imagined this Lifetime Care and Support scheme would be.

How can any of this be seen to be fair when, as a Nation, we are willing to commit to paying a woman paid parental leave of 26 weeks at her actual wage or the national minimum wage (whichever is greater) plus superannuation. These women and babies are not being labelled as “liabilities” and neither they should be.

However if, as a country we cannot afford for people with a disability to have a shower everyday, how can we afford to fund people to have 6 months full paid leave following the birth of a baby, are some people in our society more worthy of “government support” than others or are we just not getting our priorities right in terms of how we expend the finite resources we have.

#### **4. THE DISMANTLING OF THE BLOCK FUNDED SUPPORT SYSTEM IS LEAVING “INELIGIBLE” PEOPLE WITH NO ACCESS TO SUPPORT**

Again a mere 9 months in to the NDIS and we are seeing some very concerning outcomes because of the dismantling of the “block-funded” systems without any discernment.

This is of particular concern in the acquired brain injury sector where we are seeing people deemed as ineligible for funded supports under the NDIS and at the same time, the other services that would have been able to assist them in the past have been or are being defunded and dismantled. This is leaving people with no services/supports and we are likely to see the impact of this in the higher cost service systems such as hospitals, jails, homelessness, nursing homes etc and this does not take in to account the human cost.

The types of services we have already seen cease are the Regional Neuropsychology Clinic and the ABI Case Management Service and associated flexible support packages, the Making a Difference Program etc.

A perfect example of this throwing the baby out with the bath water is the one respite bed funded under the 5 year COAG Young People in Residential Aged Care initiative known in Victoria as my future my choice.

This bed is at risk because State provided block funding for it will cease when all of the Shared Supported Accommodation services phase across to NDIS. This phasing commenced in April 2014.

The aim of this bed was to prevent younger people with high and complex needs having to utilise nursing homes as their only option for out of home respite. To lose this bed because of ill-thought through implementation of the NDIS will be an absolute travesty.

Hopefully other launch sites can learn from these mistakes but I am not sure how the Barwon region will ever recover from this launch and ultimately the continuum of options that people with a disability can access supports from is narrowing.

#### **5. THE NDIS IN ISOLATION OF THE NATIONAL DISABILITY STRATEGY**

As a matter of priority we need to put as much effort in to the NDS as we have put in to the NDIS. Without this much focussed work on the broader goals of the NDS we will never see the NDIS reach its potential and we will continue to see people with a disability and their families living as second class citizens in Australia.

Vanda Fear and Jacqui Pierce