SUBMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

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1 BACKGROUND

Disabled Son

My 12 year old son has severe quadraplegic cerebral palsy. He has global developmental delay and epilepsy. He is in a wheelchair, non-verbal, and tube fed. He requires continuous one-on-one care for all aspects of daily life, including dressing, bathing, toileting, feeding, and playing. Despite his condition, my son is happy, responsive and sociable.

Health Issues of Mother/Primary Carer

My wife and I are both aged 48. We jointly care for my son, and his twin brother who is not disabled. My wife is our son’s primary carer. In 1986 she was diagnosed with chronic myeloid leukaemia (CML). In that year, to treat the CML, she received a bone marrow transplant (BMT). This involved intensive chemotherapy and radiotherapy. She relapsed with CML in 1989, and had a second BMT in 1990. She has been in remission from CML since that time.

In 2002 my wife was diagnosed with a squamous cell carcinoma in the gum of her lower jaw. This was treated by mandiblectomy in 2002. This involved radiotherapy, and the removal of all of her teeth, bottom lip, and chin and part of her jaw. Her jaw bone was reconstructed using her fibula. She has had numerous subsequent reconstructive surgical procedures on her face and jaw. She now feeds by gastrostomy to maintain her nutrition.

Although in remission and well, my wife has been significantly physically affected through years of medical treatment and is quite frail.

Consequences

As a result of my son’s condition he requires intensive personal care and attention, frequent therapy and medical care and specialist educational support. Due to my wife’s medical condition we have had to seek support and respite assistance, occasionally on a crisis basis, to help us attend to our son’s needs. Over time, as my son grows, it will become increasingly difficult for my wife and me to provide for all his needs without increasing levels of support in all facets of his daily life. We are also very concerned about making provision for our son’s care in the event that we predecease him.

2 CURRENT CARE AND SUPPORT RECEIVED

We are currently in receipt of the following support:

- Intensive Family Support (IFS) funding amounting to approximately 20 hours per week of in-home respite. This is administered by ELBA Inc.
- From time to time, my son attends the Red Cross Lady Lawley Cottage respite facility on a day basis during school holidays
- The Centre for Cerebral Palsy (TCCP) provides speech, OT and physio therapy services amounting to about 6 hours per school term for each category. As required, the TCCP therapists apply for CAP funding for devices, materials and aids which my son requires for his daily needs. These include things such as wheelchairs, ankle/foot orthoses, splints, communication devices, standing frames and bath chairs
- TCCP also provides a contact person to coordinate therapy and other support services
- My son has a Local Area Coordinator available to him, however we rely on the TCCP for coordination of most services
- My son's school bus does not have wheelchair access, so we have to transport him to and from school ourselves in his wheelchair. We receive a token compensation for that
- My wife receives a Carers Allowance
- My son:
  - has a Health Care card
  - receives medical services through Princess Margaret Hospital, and occasional private surgery
  - is schooled privately, but in the past has been schooled in the State system at both Swanbourne Primary School and Sir David Brand School
  - is eligible for the State Government's Taxi Users' Subsidy Scheme

3 SUBMISSION

1. <u>General observations on the Proposal</u>

   The current system providing for care and support for disabled children such as my son is uncoordinated, poorly funded, uncertain, and is neither well known nor well communicated. There are not enough carers nor therapists, and they are poorly remunerated, and there are inadequate respite, accommodation and transport facilities available for disabled people.

   My family is now in a situation where we generally understand how the present system works, and our son can usually obtain what is required for his current requirements. What happens later in his life, for example when he leaves school, and when we, as his primary carers predecease him, is much less clear to us.

I am cautiously optimistic about the NDIS proposal. My optimism is mainly due to the suggestion that that there will be greater funds available. My concerns with the proposal generally are that;

- It may just create a new additional layer of administration to further add to the confusion
- A new department of bureaucrats based in Canberra may be created to administer the Fund who would place a new additional cost burden on the system, and further delay decision-making
- funding eligibility and other important decisions may be determined remotely by faceless administrators in Canberra, with little or no accountability, empathy, or sense of urgency, and no understanding of the complex, stressful personal issues faced by applicants and their families
- it may not solve the basic lack of resources, in particular carers, therapists and disabled facilities.

Mindful of these concerns, my specific comments on the Proposal are as set out below.

2. <u>Implement UN Convention</u>

- The NDIS enabling legislation should expressly acknowledge that Australia is a signatory to the UN Convention on the Rights of Persons with Disabilities (Convention), and that one of the purposes of the Act is for Australia to implement its obligations under the Convention.

- In particular these include Australia's obligations to take appropriate and effective measures to support people with disabilities, including in respect of:
    - living independently (A 19)
    - personal mobility (A 20)
    - education (A 24)
    - access to health services (A 25)
    - attaining habilitation (A 26)
    - employment opportunities (A 27)
    - participation in cultural, recreation, leisure and sport (A30).

3. <u>Administration of NDIS</u>

There should be a positive <u>personal</u> obligation on those administering the Fund, based expressly on the general principles set out in Article 3 of the Convention, to positively and proactively provide support and assistance to Australians with disabilities.

Once the threshold entitlement criteria are satisfied, the Agency personnel must have an express positive obligation to proactively assist recipients. There should not be an onerous, complex system requiring continual detailed applications, and assessments and evaluation and justifications for every single aspect of support and assistance for those with disabilities. The system should be flexible and cater for significant life changing transition events, such as starting school, leaving school, employment, and death of family carers, without having to go through a new application and assessment process at each stage.

4. More therapists and carers,
   As a user of services, my impression is there is currently an abundance of administrators working in the system, and a shortage of therapists and carers providing 'hands-on' services. The therapists appear to spend more time completing detailed funding applications, and less time actually treating and working with clients, being the work they were trained to do, and where their expertise could be more usefully directed.
   An objective of the NDIS should be to make available more qualified individual service providers; including therapists, carers and teachers assistants, and for them to be reasonably remunerated.

5. Direct funding
   Consideration should be given as to whether instead of only being based on individual funding packages, the Agency could directly fund service providers, such as TCCP, to build and operate capital intensive facilities; eg accommodation and respite facilities.

6. No interface issues
   Precisely what the Fund will apply to needs to be crystal clear to all concerned, and well communicated. For example there is a very close link between therapy, medical and educational services. In the current system, our son is entitled to some therapy services on a case by case basis. If he has surgery, his entitlement to follow up therapy can sometimes be dependent on whether the surgery was performed publicly or privately, although this is very unclear. This type of uncertainty is distressing and unnecessary. There are similar grey areas around the interface between education and therapy, and transportation. Adding a Commonwealth/State element to this may just aggravate this.
   We lived in the United Kingdom for 2 years and experienced the system there. As a 'user' it was much straightforward, with a virtual 'one stop shop' approach. For example the paediatrician from the local hospital would consult at the Local Authority special school which my son attended. There were therapists based at the school, and the Local Area provided transport to and from school. The provision of services was seamless to us. It would be a positive to strive for a system like that from a user's perspective.