

30 June 2011

Ms Patricia Scott
Commissioner
Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428
CANBERRA ACT 2601

Dear Ms Scott

INQUIRY INTO DISABILITY CARE AND SUPPORT

I am contributing to this document as a registered nurse with over 30 years in the care of children with disabilities. I am also a committee member of the Melbourne City Council Family and Children's Advisory Committee.

I fully support the National Disability Insurance Scheme NIDS and applaud the work that has been done and the information sought for this important document. The current system is not meeting the needs of all children and their families and is inequitable. We need a universal scheme available to meet the different needs of children with various disabilities and to be continued through their lifespan as required.

The role of carers also needs to be recognised. The majority of these but not exclusively, are female who have never been able to return to the workforce after the births of their babies. Many of these mothers are single parents who are caring for other family members as well as the child with disability. Adequate financial and other support would ease some burdens and contribute to healthier families and a more stable community.

A detailed review of the document has not been made however I wish to make the following specific comments as a contribution to the Inquiry.

The inequity of the current model

For example, ultimately there is no difference between the situations of infants and children who have been born healthy but have experienced severe illnesses such as meningitis and those of children who have had an episode of near drowning. The resulting disabilities are similar to those as a result of a motor vehicle accident and the care needs are the same. In the latter case funding is readily available through motor vehicle insurance, commensurate levels

of funding are not easily accessible in the other cases. Similarly, some families with a child born with severe disabilities resulting from birth trauma may be in a position to successfully pursue litigation.

More than one child in the family may have conditions such as mild autism including Asperger's syndrome. Due to the mild and or physically condition of the two (or more) children funding for support services is not forthcoming.

Funding needs to meet the care needs of every child and family. This needs to be flexible and be universal.

Respite

The financial impact on the family causes additional stress and often causes parents to lose their employment, home and results in marital breakdown. Many of these families are single parents (usually female) who are unable to access employment opportunities due to therapy, medical and other appointments for their children.

Support for carers in all areas is required and must be adaptable to meet their unique needs. This is important not just for individual families but for the health of a community.

Respite is difficult to obtain at a time to suit the family. If a respite booking is cancelled due to illness no other booking may be available for months.

More flexible and available respite is required.

Transport

Many families find it difficult to transport their families and wheelchairs. Funding for adequate and suitable transport is required. For example, transport to specialist schooling for children with very severe disabilities has been problematic. Often children are required to travel for extended periods far away from their homes to access an appropriate school. Some children have been refused access on the school bus as their medical problems increase. Children are social beings and enjoy travelling with their colleagues. This aspect of their development is fundamental to emotional growth and development.

Children have a right to education and transport to appropriate education to meet their needs is essential.

Equipment.

Equipment such as seating, feeding tubes, medications, toileting aids, home modifications, and other specialised items are expensive and not always readily forthcoming. Parents are often forced into fundraising themselves to access these in a timely manner.

Appropriate and readily available funding would make this less complicated and support families financially..

Transition stages in the life of a child with disability.

Support is required to minimise the added stress on families at these particular times of vulnerability including:

- **Diagnosis**

This may or not be at the time of birth. Counselling and other services such as therapy need to be available. Early intervention services also provide family support in addition to practical aspects of management.

Families find it very difficult to access and coordinate services when their child has been diagnosed with a disability. This is acknowledged as a traumatic time and parents are not always in a position to make decisions at this time.

An experienced case worker needs to be appointed as soon as possible. Support, counselling and guidance are required by an experienced worker. This needs to be community based and provide a family-centred service. All families are different and a flexible and adaptable service that meets their different needs is central to the health of the family.

- **Child care.** Funding and support to include the child who may need extra services such as enteral feeding, management of seizures and other medical problems.
- **Pre-school entry.** This may also coincide with the time a child with severe cerebral palsy may require a wheelchair for mobility. This is an added emotional stress on the family. Added to this the family car may not accommodate a wheelchair.
- **School entry.** The choice of school is problematic. Although children have a right to go to their local primary school many schools may not readily accept a child with extra needs. This is often due to funding and families experience rejection.
- **School leaving and transition to adult services.** Leaving the family home and long term accommodation. Where to go every day and where to live? This is an ongoing dilemma for families. Supported accommodation to meet the needs of young people requires adequate funding.

Yours faithfully

Bev Touzel