METRO NORTH
DISABILITY SUPPORT GROUP
Representing families of people with a disability

4 August 2006

The Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Sir/Madam,

**SENATE INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT**

The Metro North Disability Support Group represents families, carers and advocates in the “Metro North Region” of NSW (as described by the NSW Department for Ageing, Disability and Home Care) who have a family member with a disability.

The Group has collectively reviewed the terms of reference set for the Commonwealth review of the Commonwealth-State/Territory Disability Agreement and provide our comments as follows:

**Unmet Need**

1. Given the number of ageing parents, there is a huge immediate need for more respite places and for more long term supported accommodation places for people with a disability;

2. Furthermore, members of our group who already have children in a Group Home are generally very dissatisfied with the level of care offered to their child. The number of carers and the hours worked by carers has again recently been reduced in NSW. There is a constant change of staff with the majority being supplied through agencies, resulting in less consistency and higher costs. Furthermore, the monitoring of the staff has deteriorated markedly over the last few years resulting in a reduced quality of care.

3. It is impossible to obtain long term supported accommodation for a person with a disability in NSW without practically abandoning them to the State. There are no waiting lists – this is not because there is noone waiting; it is because the Government refuses to allow lists to be made. The NSW Government will not even consider taking a person into long term care until the family has reached or gone beyond crisis point. This leaves no hope for ageing parents, letalone younger parents who seek some sort of future for themselves and possibly even a return to the workforce. What every parent in our group seeks is certainty that there child will have a place in long term supported accommodation when the parent and child consider it appropriate for that step to be taken.

4. Respite places are also extremely limited in NSW leading to a further cause of crisis for families. At any point in time in NSW there are always between 20-30% of respite beds removed from general circulation by people who are waiting to find permanent places. This is well documented in last year's publication "End to the Silence" researched and written by Michael Carman. (copy attached with our Submission). The situation has recently been exacerbated in the Metro North DADHC region where the Region has been extended to include a wider population but the newly included region had no respite houses so the existing homes now need to be shared by a greater number of people.

   The Metro North Group support the theory that appropriate and flexible respite stems the flow of the requirement for early permanent accommodation, substantially pushing permanent accommodation further into the future. This results in substantial savings to Government.

## Appropriateness of Funding

5. Although the NSW Government has recently committed to increase funding for disability services, it is not nearly enough to cover the areas of concern identified above.

6. The Metro North Group has reviewed the Discussion Paper on Long Term Supported Accommodation submitted to the Committee by the Association for Children with a Disability NSW. One of the members of the Executive Committee of that Association is also a member of our Group. The Metro North Group fully supports the 10 Point Plan proposed in the Discussion Paper and the Submission made on behalf of that Association.

## Ageing/Disability Interface

7. Our group is not aware of how other States' disability systems are set up but, insofar as NSW is concerned, our members believe that disability services in NSW are suffering because they are grouped with Ageing. Given the ageing population, there is a real threat that services for the ageing will consume DADHC and be given greater priority.

Examples of how the disability/ageing interface is particularly detrimental to families of children with a disability are already plentiful amongst our group members. For example, when applying for Home Care help in the mornings to get her child ready for school, one of our members was recently advised that Home Care is primarily directed to providing help for the ageing so her application would be given lower priority. To add insult to injury, this parent's application had been lodged almost 12 months earlier. After the first assessment was conducted, the application had been lost by DADHC. Then the parent was advised that the application had been rejected due to Occupational Heath and Safety issues and, finally, a second assessment process had to be undertaken due to DADHC's inefficiencies. When the carer was finally engaged, the carer took the view that the job required 2 carers instead of one. This only served to prove to the parent how much is expected of parents given that she had hitherto been getting her child ready for school on her own as well as getting 2 other children out the door at the same time.

Another example of the disability/ageing interface is that certain respite providers give priority to ageing carers, eg Sunnyfield. This means that parents will go through the arduous task of completing the myriad of questions that the respite providers include in their applications only to be advised that they cannot receive respite because they are not sufficiently "ageing".

## Health/Disability Interface

8. Examples of the disability/health interface causing problems also abound amongst our members. Almost all our members experience problems when their child attends hospital for treatment. The hospitals are not set up with sufficient staff to attend to a disabled person to the extent necessary (which is practically during daytime on a full-time basis ) but respite providers are not allowed to work in a hospital setting. This means that the parent cannot access any help during a child's hospital stay and the rest of the family has to make do as best they can.

   This situation is no better for families who have their child in a Group Home. Cases were reported by our members whereby, although a carer from a Group Home may accompany a person with a disability to the hospital, the families have been charged for the replacement carer that needed to be provided at the Group Home during that time.

   These problems would be overcome if the hospitals could be staffed to cater for the needs of the disabled person.

   Also relevant to the disability/health interface is the lack of basic equipment available in a hospital for a person with a disability. One member of the Group reported that, during the last hospital visit for her daughter where she was admitted for 5 days, she was required to bring her child's commode (toilet equipment) into the hospital because there was no such equipment available. The mechanics of one parent arriving with her child (in a wheelchair), luggage for a week for the parent and the child as well as their child's commode has not been thought through by the hospital!

## Alternate funding arrangements

9. Our proposal is that the Commonwealth Government should accept the bulk of the financial responsibility for disability services and total funding for disability services needs to be substantially increased. A rough "back of the envelope" calculation based on the supporting documentation provided with this Submission suggests that total Government funding (State and Federal combined) needs to be increased threefold in order to meet the unmet needs of the people in NSW with a disability and their families. Given the current tax structure and budget deficits in NSW, the reality is that we will not see any further money flowing from the NSW Government and the Commonwealth Government needs to bear the burden of this increased funding.

   Funding should be made available to the States and to NGOs to deliver the services themselves. We feel it is critical to distinguish the funding role from the provider role in this way and we believe that the failure to distinguish those roles in NSW has led to the deterioration of services. In NSW, DADHC funds the same services that it monitors. It is little wonder that DADHC's monitoring of services has deteriorated so markedly over the last few years. Accountability is a key issue missing from current arrangements

   We recognise that one drawback of involving NGOs as providers is that they tend to take the least needy of the persons requiring services and the State tends to be left with the people with the highest support needs and greatest behavioural problems. This has certainly been the case in NSW. We believe that this problem could be overcome however if supplementary funding were made available to support those falling in the "most needy" category, just as is the case with the Commonwealth funding provided for people in nursing homes who have greater medical care needs.

## Recommendations:

To summarise, we outline below our Recommendations – Further data supporting our recommendations is provided in the attached schedule.

- ✓ Increase total funding for people with a disability to 3 times total current funding
- ✓ Commonwealth to bear the brunt of this additional funding whilst States and territories bear responsibility for implementation.
- ✓ More stringent accountability of funding to State and Territory, ensuring that CSTDA dollars are directed in the most efficient and effective economic manner in meeting the needs of the disabled.
- ✓ Funded bodies [Boards], be made more accountable for salary increases.

- ✓ Funded to funded organisation with management salaries in excess of $150,000 + benefits should be reviewed.
- ✓ Government to review the number of advocacy groups, systemic and individual, eliminating duplication and implementing consolidation and a higher degree of economic accountability.
- ✓ Urgent review of support to ageing carers who are finding it harder to meet the demands made upon them by their also ageing and growing siblings requiring additional time and energy in meeting their needs.
- ✓ Support should be targeting greater access to appropriate and flexible respite options.
- ✓ There must be a greater commitment to continuity of accommodation with a high degree of certainty of placement, choice of model, and appropriately trained and permanent staff within the CSTDA budget.
- ✓ Funding through the CSTDA must target major issues encountered by States and NGO run accommodation services specifically relating to:
  - ▪ Lack of accountable management.
  - ▪ Low staff moral and self esteem.
  - ▪ High turnover of staff and too much reliance on agency staff.
  - ▪ Staff training for permanent staff which is appropriate to meet client needs.
  - ▪ Recognise the past parent relationship.
  - ▪ Better communications between staff and Parent/Carers.
  - ▪ Accreditation for all Government operated accommodation with accreditors/ Auditors distinct from Government.
  - ▪ Accountability of spending at accommodation and client level.

**Conclusion:**

Families around Australia are relying heavily on this current Inquiry. Across Australia, services for people with disabilities have deteriorated markedly.

Before the next Federal Government hand-out in the way of tax cuts, baby bonuses and the like, it is imperative that we commit the funds for the future to lighten the enormous burden which currently falls on families with a child with a disability.

We urge the Committee to read the Discussion Paper prepared by the NSW Association for Children with a Disability (copy enclosed with our Submission also). Do not be put off by the figures you read elsewhere of the number of people falling into the broad definitions of “disabled” used by the statisticians. Consider those with a family member whose disability burdens their family day after day – those with moderate to profound needs. Once you sight the lesser numbers of people with these needs, we trust that you will find that an economic solution can be reached without unduly impacting upon the federal Budget.

For further information about the Metro North Disability Support Group or the attached Schedule of Recommendations, Discussion Paper or other attachments, please contact Katrina Clark on 02 9416 1725.

Yours sincerely,

Katrina Clark

# STATISTICS

i. Data obtained from the Australian Bureau of Statistics indicates that upwards of three-quarters of the care needs of people with a disability is provided by family, friends or advocates (Australian Bureau of Statistics *Survey of disability, ageing and Carers 1997/1998*). It is therefore critical in providing care to the disabled that this section of the overall community is recognised for what it is and what it provides. In particular, we refer to the impact on overall health (related illnesses, such as stress (physical and mental), depression and isolation etc), economic disadvantages and physical / emotional demands imposed on this sector of carers and their ability in providing continuous care.

ii. The overall provision of needs (mild, moderate and high support) is not static from the time of diagnosis. The holistic picture incorporates the level of needs and ageing of the person with a disability, linked to the ageing process of the Carer/s. These are what the Metro North Group terms "The Progressive Ageing Factors". As with the person with a disability, physical age has little to do with their chronological age, so too, with the impact of the Progressive Ageing Factors on carers, their physical age can, over the period of time, vary considerably to their chronological age. While the physical age of Carers is difficult to establish, the Carers Association of Australia Inc. survey (1997/1998), highlighted the chronological demographic of Carers as set out in Fig-1.

| **Carer Age** | **ABS Survey 1993 Principal Carers (%)** | **Carers Assoc. Survey (1997/1998) Carers (undefined) (%)** |
|---|---|---|
| Under 20 | 3.8 (age 15-24) | 0.3 |
| 20 – 39 | 34.7 (age 25 – 44) | 8.0 |
| 40 – 59 | 32.5 (age 45 – 59) | 36.4 |
| 60 – 74 | 29.0 (age 60+) | 37.7 |
| 75 or more | | 17.1 |
| Not Stated | | 0.5 |

Fig-1

ii. Fom the point of diagnosis, Government has implemented early intervention programs assisting carers come to grips with accepting the disability and providing services. However, this support gradually dissipates, with carers being set adrift relying upon other sources for support. The overall impact on carers in their ability to provide appropriate care diminishes with the advent of the Physical Ageing Factors putting a greater emphasis on support for carers and their need for accessible and flexible Government Respite Services if they are to continue in providing appropriate care.

iii. The Physical and emotional stress placed on carers is well documented. As one looks at the overall years a carer has provided appropriate level of care for their charge one becomes more aware of the value contributed by carers with extremely limited support. The Association of Australia Inc. survey (1997/1998), established that 30% of carers have been providing this care for in excess of 10 years, see Fig-2. Of this figure 12% have been providing care for over 20 years.

| **Years of Caring** | **ABS Survey 1993 Principal Carers (%)** | **Carers Assoc. Survey (1997/1998) Carers (undefined) (%)** |
|---|---|---|
| 0 – 2 | 28.5 | 21.7 |
| 3 – 9 | 42.6 | 46.9 |
| 10 – 19 | 28.9 | 18.0 |
| 20 or more | | 12.1 |
| Not stated | | 1.3 |

Fig - 2

iv. Taking into consideration that women, over the past two decades, have progressively delayed having children till their late thirties supports the 1997/1998 Survey in Fig-1 above stating that the vast majority of carers (some 93%) are likely to be in excess of 40 years of age

v. As carers age there is an ever stronger demand for permanent accommodation. Regrettably, over the past two decades, there has been an unprecedented push for community housing or “Group Homes”. While the Metro North Group is not against that form of housing, it is of the view that other options should also be available – refer for detail to the Group’s Submission to DADHC on this topic, a copy of which is included with this Submission.