

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

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

To: community.affairs.sen@aph.gov.au

4.8.06

Submission attached from

Mr Cale Dalton

I am the parent and carer of my 25yr old son who has cerebral palsy. I have been involved in many parent/carer support groups, advisory committees, advocacy organisations and disability service organisations at State and National levels over many years. There is a need for people with a disability, their families and carers to be empowered to make decisions about issues affecting them and there should be much better mechanisms for them to express their needs.

RECOMMENDATIONS for change that could be implemented through a new CSTDA are on pg 4.

NOTES

- The two terms of reference discussed below are expanded with sub-headings.
- My interpretation of **what is meant by 'unmet need'** is at the end of this paper.
- I have identified two key areas where extra support is needed although there are numerous others that will be the subject of other people's submissions – transport, equipment, accommodation etc.
- Some items discussed here such as **self-determination** relate to both these terms of reference.

ALTERNATIVE FUNDING, JURISDICTION AND ADMINISTRATIVE ARRANGEMENTS

1. **Self-determination. Need for self-managed funding.**
2. **Equity in service delivery.**
3. **Adequate identification and reporting of 'need'.**
4. **Service efficiency, accountability and consistency.**

THE UNMET NEED FOR SUPPORT

5. **Need for people with disabilities to have their say.**
 6. **Need for effective individual and systemic advocacy.**
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ALTERNATIVE FUNDING, JURISDICTION AND ADMINISTRATIVE ARRANGEMENTS

1. Self-determination and self-managed funding.

Present service delivery arrangements do not facilitate self-determination or empowerment of people with disabilities or their families/carers. These people often have more life experience of disability and consequently in many situations are able to make better decisions pertaining to their lives than the professionals who are funded by the sector and who make decisions on their behalf. This leads to unnecessary duplication and waste of available resources. People with disabilities and their families / carers are often required to 'beg' for services under the current funding, jurisdiction and administrative arrangements rather than expect any form of 'entitlement' to services.

Discussion and implementation of mechanisms that would empower people with disabilities and their families / carers such as Individualised funding and self-managed funding are not encouraged by service organisations despite such mechanisms for service delivery having been comprehensively tried and tested in overseas countries. There is great potential here for greater self-determination and efficiencies in service delivery but organisations perceive a loss of control and therefore stifle debate on the topics.

2. Equity in service delivery.

There is little equity in the assessment of consumers' needs despite legislation to the contrary contained in the SA Disability Services Act.¹ Unfortunately it is often a case of 'the squeaky wheel gathering the most oil'.

Disability organisations are unwilling to assess income/assets in relation to service provision. For example, a wealthy family (income/savings/assets) can receive the same services as a poor family as there is little assessment of financial status in relation to service provision. A young person with disability in a family with working parents may receive a package of \$20,000 p.a. for day options while a similar person who undertakes informal day activities under the full time care of parents who stay at home (and suffer loss of income) receives nothing to assist in the support provided (transport, activities etc.).

People with disabilities and their families / carers often have to personally seek solutions for needed services where they are not supplied by organisations. Disability service organisations do usually support personal applications by people with disabilities, their families and carers to community groups/philanthropic organisations for essential items. Unfortunately this often requires the person with disability (or their family/carer) completing detailed personal applications that include financial details etc. In such cases inequity is evident when some applicants have more efficient professionals advocating effectively for them while others are left largely to their own capabilities. Some have to go it alone to approach community clubs (Lions, etc.).

3. Adequate identification and reporting of 'need'.

The method used by organisations to identify and report on unmet need by various organisations including Government and non - Government [Disability Services SA (DSSA), ACROD, Novita etc.] is inadequate. Example: DSSA / Novita will not contribute to the cost of a van or modifications/hoist in a van that transports a person in a wheelchair, in many cases essential for their transportation and inclusion in the community. Such costs are therefore not included in the organisations' identification of unmet need.

The aim of disability services should be to support those who need assistance to participate in our community so at a broader legislative level the International Classification of Functioning (ICF) should be considered in a review of definitions of disability (and hence eligibility for services).

¹ **Section 4**

“ In receiving the services that supply such assistance and support, persons with disabilities—
(b)have the right to have those services provided in a manner that—

(ii)takes into account their individual needs, goals, age and other personal circumstances; and

(iii)takes into account any further disadvantage that may be suffered as a result of their gender, ethnic origin, aboriginality, **financial situation** or location”

4. Service efficiency, accountability and consistency.

There is much waste and duplication in service delivery and inconsistency between the different States (there is also limited portability). The restructure of administrative arrangements in SA into a one-stop resource has been talked about for approximately ten years but nothing has eventuated till recently in the form of a restructure to a partial 'one-stop shop' named 'Disability Services SA'. It is difficult to envisage meaningful changes in service efficiency, accountability and consistency in the short term because of the slow rate of reform.

The CSTDA would be a means to facilitate reform in service efficiency, accountability and consistency and other key areas as noted in this paper.

THE UNMET NEED FOR SUPPORT

5. Need for people with disabilities to have their say.

Despite people with disabilities and their families/ carers being the primary resource for their own informal supports² they have relatively little say in the development of disability policies and in service delivery structures or mechanisms that provide them with formal supports. The Government of the day and the funded organisations that deliver the services have most say and unfortunately the funded organisations often have a priority interest in their organisation rather than the individual needs of their 'consumers'. Directors of organisations comply with the Governance and legislative requirements of the Associations Incorporation Act, yet in doing this they do not necessarily promote the best interests of their consumers. Moreover there is not always a majority consumer representation on their Boards of governance. Mechanisms for obtaining and responding to feedback about services can be suspect.

Additionally funded organisations, by virtue of their funding arrangements, have difficulty in maintaining their independence in all matters.

6. Need for effective individual and systemic advocacy

Where people with disability are unable to act on their own behalf effective individual advocacy is necessary but advocacy organisations that perform this role are under-funded and their roles unnecessarily duplicated, as would be identified in the current review of advocacy programs.

Few resources are provided for systemic advocacy which potentially has the capacity to substantially reduce the unmet-need for individual advocacy.

Government / non-Government service organisations are restrained in their comments because of funding requirements, as are the funded advocacy organisations. Service organisations often do what is in the best interests of their organisation, not always what is in the best interest of the individual person with disability/family/carer. Additionally the voice of people with disabilities, their families and carers are fragmented with little cohesive/collective say in decision-making.

For example, disability services were recently restructured in South Australia. The consultation process with people with disabilities / families/ carers was initiated with individuals after decisions were made regarding the re-structure, an apparent breach of the SA Disability Services Act.³

² AIHW Reports: *Carers in Australia; The future supply of informal care 2003-2013: Alternative scenarios*

³ Section 6

(1) Before making any major decisions relating to the development, funding or discontinuance of disability services or research or development activities, the Minister must, to the extent that is practicable, consult with persons with disabilities or carers likely to be affected by the decision.

(i) to allow, to the extent that is practicable, the persons who use the services the opportunity for informed **participation in the design, development, management and evaluation of the services.**

RECOMMENDATIONS

that could be implemented through a new CSTDA

- a) **Develop independent State based advisory Councils that link/share information with each other and with people with disabilities, their families and carers through formal mechanisms. The Councils will provide advice to the individual State and Territory Governments. Their membership to be 'representative' of people with disabilities, their families and carers.**
- b) **Develop mechanisms to ensure that disability related organisations have adequate representation of people with disabilities and their families / carers / advocates in their Governance structures and that these organisations comply with all sections of the Disability Services Act (revised if appropriate).**
- c) **Introduce an independent complaints mechanism (or Ombudsman / Commissioner).**
- d) **Develop and implementation models of Individualised funding and self-managed funding for appropriate target groups.**
- e) **Ensure generic services are tailored to meet the individual needs and goals of people with disabilities and their families / carers.**
- f) **Pursue policies that will reduce the fragmentation and 'silo' effect of different organisations providing services.**
- g) **Pursue policies that will give (a) accurate information on 'need' (b) will assist in equitable service delivery (c) will improve service efficiency, accountability and consistency and (d) will improve the portability of services between the States and Territories.**
- h) **Ensure people with disabilities, their families and carers have access to more efficient individual advocacy. Support systemic advocacy at State and national levels so there is proper feedback to Governments on issues in order to reduce the pressure on individual advocacy.**
- i) **Ensure available resources are distributed on an equitable basis inline with the Disability Services Acts. Consider Centrelink income and assets tests in the provision of supports.**
- j) **Review definitions of disability (and hence eligibility criteria for services) taking into account the International Classification of Functioning (ICF).**
- k) **Ensure all disability policies, procedures and practices comply and are compatible with the principles and intent of the SA Carers' Recognition Act.**

Interpretation of 'unmet need'

I believe **'unmet need'** refers to the supports lacking that would be required to maintain a reasonable standard of living and a reasonable level of participation in most aspects of community life by a people with disabilities, their families and carers.

'Participation' refers to participation in education, using transport, employment, accessing health services, access to the built environment, therapy, equipment etc.

'Supports' are usually provided by people with disabilities / their families/carers, by disability services from Government and non-Government organisations and through philanthropy / other community sources.
