

# Productivity Commission Inquiry into Long Term Disability Care and Support

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## **NOT CONFIDENTIAL**

### **Introduction and Recognition**

Firstly we would like to give recognition of the value of this Productivity Commission Inquiry regarding a National Disability Insurance Scheme to enable the long term support of people with disabilities in Australia.

### **Disability Discourse**

We do not like to use the current disability discourse of “care”, firstly because it is difficult to define and secondly people with disabilities and their families require support services and equipment that might be delivered in a careful manner, by people who might care about their jobs and the people they are serving. But, the disability service/s sector is not a ‘care industry’ or, ‘care sector’, and this language is loaded with a range of assumptions about people with disability ‘needing care’, which not all of us do. People such as us care about each other, we care about our families, we take care of our lives, life, work and leisure styles and manage our money etc, but we do not want “care services”. We want support services.

We recognize that there are some people receiving services who rely on support workers who come into their homes as their social interaction and will often refer to these workers as ‘carers’ because they do want to be ‘cared’ about by their service provider.

### **What we want as service users**

We want:

- A good, well co-ordinated, flexible service, that is delivered with skill relevant to our life, work and leisure styles, with sensible OHS&W policy and procedure that is about ensuring safe workplaces (not those that reduce our rights in our own home);
- The right to hire, train and fire staff/support workers/personal attendants according to their ability to meet the need of those who require services, their life- work- and leisure-style, gender and age, family status and location.
- Equipment service and provision (shower chair, electric powered wheelchair, and orthotics etc) to be provided in a timely manner, with careful consideration given to what it is that service users can self-assess and is tailored to meet individual requirements.
- Equipment requirements also include (having been assessed as needing new equipment and) being able to get it *without* the current 2.5year waiting period.
- Responsive staff at disability service outlets who are aware of disability discourse, who can provide relevant, appropriate and timely information
- Accessibility at all service outlets to the physical and informational environments and;
- staff with a rights-based attitude to the way they deal with service users as customers

## **How do we and others with disability get what we want?**

**Through a new national disability scheme based on the UNCRPD framework of principals and articles.**

**Create an equitable tax-payer-paid tax** that will underpin the funding of lifelong (where necessary) on-going services that follow a person and their family through the journey of life; with built-in flexibility to enable portability, life changes through the age range and that enables 'accessibility' improvements across the nation to premises of all kinds. A **tax that everyone contributes to** and that recognises that those with more should contribute at least the same, if not more. The name of the scheme/funding does not have to be NDIS, but should preferably make reference to its universal coverage to Australian citizens.

People who currently have services must **not be made worse-off by any new system** developed. For example those who have in-home based services that meet their need should not lose those services

**Physical accessibility** to our work, social and community places. Mobility through accessibility to all premises, infrastructure and open-space must be encouraged and assisted. It should not remain the responsibility of people with disabilities to complain before access is provided. Work currently being done in relation to Disability Access to Premises Standards and AS1428 suite is appreciated and will assist the process. However, buildings are still being built today that have not been designed with equitable access and this must be addressed.

Informational access universally (i.e. government and private) to enable ourselves and our friends and colleagues who may be Deaf or hearing impaired, blind or with low vision to share in that information easily and in a timely manner.

**Our homes to be recognised and respected** as 'our homes first and foremost' and 'your workplace' second. Our home does provide a nice workplace that is safe. Where safety is a concern, such as lifting, or where a person requires a 2 person lift, equipment (i.e. such as lifting devices) should be provided before it is necessary for a person to have 2 workers in their home. Personal attendants to assist with personal care, grooming, meal preparation, housework, and other individually agreed tasks; assistance at work; and in the community etc, must be provided from a rights-based framework. It must be recognised that having people in your home is also an intrusion on the lives of other family members, who might be spouse, partners, children, grandchildren, stepchildren and friends. Staff must be able to work independently and autonomously when required i.e. at times when guests are present, stay over, children/grandchildren visit etc

**Workers in and across the sector must have values that recognise and promote the benefits of diversity** in the community and population as a whole; who are trained by service users to do things the way service users need them done and that are agree upon together to maintain ones individuality.

Through **increased community education and awareness**, the people who make up our communities and society, who work in their mainstream everyday jobs across the full breadth of services (i.e. restaurants, shops, surgeries, hospitals, schools, universities, childcare centres, local, state and federal government services including CentreLink, within and across tourism, accommodation and tourist destinations, etc etc) must be educated and, made disability aware, to treat all men, women and children with disabilities with dignity, respect and trustworthiness.

**To be rid of the old stereotypes of 'disability' that devalue and denigrate** people with disabilities as spongers, living off the pension, not wanting to work, or who cannot work, and are unable to be educated or unable to speak for themselves. People with disability are all different people and have facets of their lives they can be proud of and shall be valued as worthy of full citizenship and encouraged and enabled to participate in the full range of community, social, cultural, political and employment opportunities.

Further **development of the rights of all men women and children with disabilities to education at all levels** including childcare, pre-school, primary, middle and senior high, TAFE and Tertiary education centres. Education and childcare centres must be accessible. Teachers must be supported with technology, teaching aids and equipment, support staff to assist in the mainstreaming of children with disabilities being part of mainstream classes. Special schools are not 'special', they represent isolation and segregation. Children who require physio- and occupational therapy should not have to miss out on learning. Perhaps education needs to **focus on what kids learn** and not how much they churn out. Parents should be able to rely on education centres being able to work with their children with skill and expertise and not to have them sent home, expelled etc because teachers are unsupported. People with disabilities must be encouraged to be among those with higher education qualifications and what better way than to have people with disabilities being teachers and university teaching staff.

For **people with disabilities to be backed at all levels of government by policy** that makes it very clear that we are **to be consulted** on those issues that impact and affect our/their lives, incomes, and families.

For all families living with the full range of disability types and levels to be given choices that respect our rights to family, choice of living place and lifestyle, and that **enables us to live in the least restrictive environment**.

**The closure of places of institutional living.** Note: the words 'institutional care' have not been used as they are a semantic nonsense...a little like a 'disabled toilet'. Places in the community that enable people with severe and profound disability to live with support provided by service providers that enable family relationships to be freed from the 'burden of care' (.....again see what happens if you start using the word care.....? It is such a denigration of the person with the disability who is the recipient of the

care/support/service.....when the word care is used.) Community housing options should only be provided in a manner that *enables it as a choice and further enables personal life-work- and leisure-styles to be pursued*. All people with disabilities irrespective of type and severity should be enabled to live ordinary lives with ordinary relationships to their families and peers.

**Recognition of the intersectionality and gender disadvantaged across the disability sector.** *Women and girls* with disabilities are recognised in the UNCRPD as having additional disadvantage. People who are *refugees and those from NESB and CALD* communities who experience disability in their families have additional disadvantage. *Indigenous people* appear to be over-represented in relation to disability, but under-represented in the numbers who receive services. People with disabilities from the *gay, lesbian, trans-sexual and bi-sexual communities* vary rarely get a mention and experience disadvantage related to sexual preference discrimination, often difficulty in getting support workers; older lesbian women experience disadvantage in nursing homes and with support workers. *People with disabilities who are aging now*, in some areas of condition - for example Cerebral Palsy - may indeed be the first generation to grow old and be living in the community. History tells us that the majority of people with disabilities living in institutions did not grow old! We don't know the answers to these problems, but the recognition and *desegregated statistical data* would be a start to providing greater information on a range of groups. These groups could then be approached in targeted consultation processes to inform the sector of their particular disadvantage and service/supports required. The Greater London Authority (UK) has done some good consultative work with these groups: <http://www.london.gov.uk/consultation/disability-equality-scheme> that may be useful. They have looked at arts, sport, access, transport, differences of gender, race, faith etc It is one of the most contemporary and commendable action plans we have seen.

**ALL new Housing (public and private) to be designed and built to universal design principles** that enables: purchase without expensive modification to get in and use a bathroom; easy access visiting and easy access staying; and is able to be built for easy, economic modification as required over the life of the house. The cost of equitable housing must be met by Housing, not by individuals, and not by disability funding. Houses that are already built and need modification should be entitled to some sort of tax rebate/refund (to landlords, owners etc) At the state and federal levels there must be a cost shift for housing costs, from Disability to Housing.

**An increase of funding to the Australian Human Rights Commission** and the funding of a permanent Disability Discrimination Commissioner to further promote the human rights entitlements of people with disabilities and the support and protection from discrimination on the ground of disability. Funding must be on-going and assured. The Disability Discrimination Act 1992 must be amended to enable to enactment of the principles and articles of the UNCRPD. For example it is our understanding that under the CRPD an

individual can be 'taken to task' for disability discrimination, where the current DDA does not allow that to occur.

### **AHRC submission and Recommendations**

Further to the above views and suggestions for improvement **we support the submission by the Australian Human Rights Commission and their Recommendations.**

Thank you for the opportunity to contribute our thoughts about the way in which a NDIS could provide services for the long term in Australia. We would like to acknowledge this submission has been done without any further consultation with others, but has been done with many other people with disabilities in mind.

Mr Harrison and Ms Fowler