

Committee Secretary
Senate Community Affairs References Committee
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Parliament House
Canberra ACT 2600

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Dear Sir or Madam

Inquiry into Planning Options and Services for People Ageing with a Disability

To: *Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.*

Who am I?

I make this submission in the capacity of private citizen who has cerebral palsy (a lifelong impairment), which manifests as a profound physical disability (i.e. I need assistance with daily core activities such as eating, dressing, showering, toileting, etc) and I have a communication disability. My wife (almost 20 years), Jenni and my aunt also have serious physical disabilities. I am currently working on my Ph.D. in law and disability while being employed for four years by the ACT government as a senior policy officer in the field of disability.

Why am I making this submission?

Being 44 years of age, I am aware that I will soon be experiencing the further crippling effect of ageing with a serious disability as many of my friends are. My wife and I will soon be losing our parents as they, themselves, grow more dependent upon our siblings and others.

Our financial situation will continue to decline as my ability to work decreases and we require increasing number of expensive medications. We have not been able to purchase a home in order to build wealth and security for two reasons: (a) uncertainty around how long I could remain in the workforce, and (b) the lack of wheelchair accessible dwellings that were priced right to serve as an entry point into home-ownership. We are further disadvantaged by having had limited opportunities to contribute sufficiently to our superannuation. We have not accumulated enough capital to provide us with a living income or to supplement our government pensions. Wealth creation is extremely limited for us, despite my salary, because of our extremely high disability-related expenses. Our wheelchairs alone cost approximately \$20,000 and need to be replaced every five years as our physical needs change. We pay about \$500 per month for medications, personal care and equipment maintenance. In the 2008-09 financial year we paid in excess of \$11,000 in medical and disability related expenses. Yet unlike tax deductions related to running a business or maintaining employment, disability-related are not fully tax deductible for an employee. Less than 20 cents in the dollar is claimable on personal income tax assessment. Furthermore, unlike the Blind Disability Support Pension, the Disability Support Pension is income and assets assessable. This provides a significant disincentive to work to one's full capacity.

The costs associated with living with a severe disability are numerous and not always apparent to specialist disability Home and Community Care (HACC) funded service providers who insist on client contributions, with the justification that these funds contribute to further service provision. I suggest that expecting clients to pay for support, to meet the basic necessities of life, is unethical and is inconsistent with the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD). It also strongly discourages community inclusion by reducing the person's disposable income and limiting our ability to pay for transport to family gatherings and entertainment venues as well as to places of employment and education.

Government policies against retirement village style accommodation for people, such as ourselves, are also likely to result in premature entry into aged care facilities rather than better suited disability accommodation. The early to mid-1980s saw the adoption of a policy of deinstitutionalisation of people with severe disabilities (along with people who experienced mental illnesses). While my wife and I were among the many to be moved out of big institutions and have benefited immensely from being supported to live in own home, this policy is not without its faults. While growing up in a large Sydney institution for people with cerebral palsy, we had ready access to physicians, physiotherapists,

Please note – I make this submission in the capacity of private citizen and the views expressed herein are mine and are not necessarily those of my present or former employers.

occupational therapists, and speech therapists, teachers and psychologists who specialised in cerebral palsy. A centre of knowledge and excellence accumulated and benefited us all. Today we live in Canberra with no access to such expertise: the therapists that we do consult cost \$60 to \$120 per visit and do not have such specialist expertise in cerebral palsy.

The government policy of inclusion is mandated by Australia's ratification of the CRPD and the enactment of disability services legislation in all jurisdictions. The *Disability Discrimination Act 1992 (Cth)* and state anti-discrimination legislation removes direct and indirect discrimination from the public domain wherever it is not likely to cause financial hardship to do so. These anti-discrimination statutes do not protect people with significant disabilities from the overwhelming number of minute acts of discrimination, which if taken individually, are insignificant, but combined together result in people with severe disabilities being second class citizens. Whilst government rhetoric of inclusion and the anti-discrimination laws are welcomed, public funds are not sufficient to meet the unmet need for disability support. We are expected to participate in the workforce where possible and to sign legally binding employment contracts, yet we are not provided with nor guaranteed appropriate levels of financial support.

There is no National Disability Insurance Scheme for the building of public roads, railways, electricity or gas utilities. Disability should not be seen as a personal tragedy. Instead, people with serious disabilities should be conceptualised and empowered as important contributors to our community. Our support needs are the needs of the community in the same way that the needs of public school children are the needs of the community. Providing appropriate levels of support to people with a serious disability would stimulate the economy by creating more jobs for disability support workers. Increases in the pay rates of disability support workers would help turn these jobs into profession. And greater investment of public resources into increasing our support and incomes would better equip and integrate us into the community and the economy.

How are these matters related to the issues of access to planning options and services for people with a disability?

The history of people with disability in Australia, the legal and human rights framework in which support is provided, and the community's perception and expectations of people with serious disabilities, all contribute to building second-class lives and parallel worlds. The current system, including the CRPD, works to benefit those working at high levels in the industry. Guaranteed levels of support and direct funding of individuals, as happens in the United Kingdom, would place the person with the disability in a position of a true 'consumer' rather than an object of charity. Currently clients of services must compete with others by showing that they have the greater need for support. This fosters expertise in appearing needy, rather than fostering independence and innovation. Currently service providers are in the unenviable position of playing King Solomon: deciding which persons' needs are greater.

A planned new sports stadium for Canberra is rumoured to cost approximately \$104m. The Rudd Government's stimulus packages also saw hundreds of millions poured into the economy. Yet, my support workers can earn more money, cleaning toilets, packing supermarket shelves, or working in fast food eateries than assisting me with life sustaining daily core activities. How does this help to encourage good people into the industry? And, what does this say about the value placed on the lives of people with serious disabilities?

The *Convention on the Rights of Persons with Disabilities* (CRPD) and unmet need

The Joint Standing Committee on Treaties, when considering the CRPD stated 'the Australian Government, and the governments of the States and Territories, must be prepared to meet any implementation costs arising from the obligations of the Convention' (2008, Report 95, par.2.64). This statement was made in relation to the Liberal Government assertion in the National Impact Assessment that ratification of the CRPD would have no 'significant financial or regulatory implications'. Article 19 (Living independently and being included in the community), for instance, recognises the right of people with disabilities to be included in the community by, among other things:

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community

Evidence for the contrary can be found in the high numbers of the submissions to the Community Affairs' Inquiry into the *Funding and operation of the Commonwealth State/Territory Disability Agreement* from ageing parents and people with disabilities who spoke of enormous unmet disability support needs.

Whilst not lamenting the policy of deinstitutionalisation, politicians, and consequentially governments, have never seen this unmet as important. Until recently, many governments refused to collect statistics on the levels of this unmet for specialist disability support. Preferring instead the 'ignorance is bliss' policy.

What do I suggest?

Some twenty per cent of the Australian population experience some degree of impairment or disability. Approximately five per cent (\$1 million) have impairments so severe that we need assist with daily core activities. Yet we are not included in any sufficient way in major policy high decision-making. Nor are we included in politics.

Above I have suggested, explicitly or implicitly, a number of ways I think the provision of special disability services should be changed. To recap:

- The major political parties should be penalised for not including people with serious disabilities.
- The provision of disability support and income support should be characterised as a human right in the same way that access to the public education system is for Australian children.
- The funding of disability supports should be an entitlement and, consequentially, the level of public funds that are expended on disability support should be significantly increased to meet all unmet need.
- People with serious disabilities should have the option of having their allocation of funds paid directly to him or her, or to a nominated Special Disability Trust, guardian or service provider.
- Using the External Affairs power in the Constitution, the Commonwealth should assume responsibility of funding all disability support.
- Centres in disability excellence should be established for the research and information distribution to specialists in the medical and allied medical professions, as well as to other professionals who have contact with people with disability, such as teachers, disability support workers, and parents, and people with disability themselves.
- The costs associated with disability should be met by a Disability Living Allowance (similar to the current Mobility Allowance).

My availability to provide further advice

This submission merely outlines some of the many issues that confront ageing people with disabilities and their kin. An inquiry such as this one should not be permitted to conclude without hearing from the people who are affected by the issues being considered. While I do not profess to speak for everyone with a disability, I would be available to speak to any of the points raised above at the Committee's request. I also agree to the publication of this submission on the Senate's website.

Yours sincerely

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