

Submission to the Productivity Commission Hearing: Disability Care and Support

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"Disability is not something individuals have. What individuals have are impairments...Disability is the process that happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have."

Arts for All: opening doors to disabled people 2009

Preamble

Disabled Australians who experience severe impairment/limited body functioning know only too well the struggle they have in order to receive support to live every day. The current disability system across Australia is fragmented, inequitable, unfair, under-resourced, 'the disability services system is irretrievably broken and broke, chronically underfunded, under resourced, crisis driven struggling against a vast tide of unmet need' (NPWDACC, 2009, p. 19). A sense of hopelessness and fear has prevailed amongst the disabled community about their futures. For example, disability service providers are under-resourced which stymies contemporary service delivery – perpetrating a paternalistic, charitable/welfare model of support. Individuals living with disability fearing about their futures and where they and/or their loved one whom they care for, will end up.

Transformation change is required. Transformational social reform is paramount. All Australians deserve a natural entitlement to disability support and care, in contemporary design.

There is hope. Change is on the horizon. The Productivity Commission's Draft Report into Disability Care and Support ("Report") offers a solution to the broken and broke system, one whereby power relationships are equalised and a functional system which promotes freedom, choice and options for the disabled community.

**author's note: Disabled community includes people living with disability, service providers, parents/family carers, support workers, broader community.*

Introduction

This submission is presented to the Productivity Commission hearing in Hobart, Tasmania. As Chair, National Disability Insurance Scheme (NDIS) Taskforce, Tasmania I endeavour to best articulate reflections concerning the report on behalf of the Taskforce.

It is essential to note, the quick turn around time from the release of the report on February 28, 2011 to presenting a submission at the first hearing today April 4, 2011.

As contributors, we are also volunteers – giving our time and commitment towards undoubtedly, one of the most significant social reforms our nation has witnessed. Since the report's release, our group have had only one face-to-face meeting. However technology has provided avenues of communication and an online survey has been produced for all members. Some of the feedback shapes this submission.

The Productivity Commission (PC) is to be congratulated and highly commended for its report. They have captured the needs, wishes, wants and desires for a workable system that will meet the needs of all people now and in the future who experience disability.

The Commission has accepted all the evidence placed before it by disability advocates and agreed an NDIS should be based on the principles of equity, entitlement, self determination, efficiency, effectiveness and sustainability – and that is exactly what has been recommended in the report.

This is a historic moment – a body independent of the government and independent of the sector has recommended the introduction of a nationally consistent, equitable well planned and effective system which will finally meet the support needs of people with disability and their families.

This submission will highlight the following:

- That Tasmania is considered as the ideal 'trial' region for implementation in early 2014.
- Supports estimated costs of additional \$6.3 billion as critical. This is a critical minimal investment.
- Support for funds to be extrapolated from Federal Government's Consolidated Revenue, acknowledging consideration for the establishment of a 'future fund' in times of downward economic pressures to ensure certainty of funding.
- Governance of the National Disability Insurance Agency to ensure the voice of people living with disability is equally represented around the governance table along with funders and providers.
- Support for individualised funding models that includes the option of self-directing and self-managing funds.
- Support people living with disability to be market drivers, creating diverse, contemporary service delivery models.

A case for Tasmania

Since 2008, the Tasmanian State Government committed funding towards disability reform agenda. This agenda is now in its implementation stage. A key feature has been decentralisation of decision-making with the creation of the regional Gateway Services; a one stop shop for people living with disability whereby assessment and information/referral is provided. This model for disability services is the first implemented in Australia.

Secondly, Tasmania has the highest rate of disability in Australia, above the national average at 23.8% (ABS, 2003).

Tasmania has a population of approximately 500, 000 in urban, regional and remote locations making an excellent test study for the implementation of NDIS in 2014.

The NDIS Taskforce, Tasmania fully support that Tasmania becomes the trial state for NDIS. However, in our online survey feedback, many people living with disability expressed their desire for the scheme to be introduced nationally, rather than rolled out regionally and trialled, for the fear is, that for many living with disability, timelines are inappropriate.

"We live in a remote location of Tasmania and our one and only service provider in the district has refused to take on my son with an acquired brain injury. There are people in our community who want to work for us, they are qualified carers, but I am unable to gain confirmation from government that my family and I can self-manage our care package for my son. My wife and I are elderly, and we are providing all the care and support. We are simply at our wits end." Parent, Tasmania.

Appropriately funded scheme

The Report has correctly identified, that the 'current disability support system is underfunded, unfair, fragmented and inefficient and gives people with disability little choice and no certainty of access to appropriate supports' (PC 2011, p.2).

All Australians are under the misconception that if they experience disability through chronic illness/acquired or genetically, appropriately funded disability support and care is a natural entitlement. This is simply not the case.

The Report has estimated that an *additional* \$6.3 billion is to be committed to fix the broken system.

The NDIS Taskforce, Tasmania fully supports this estimation as a minimum amount. We encourage that such an estimate is not to be compromised due to political pressures, nor is it to be negotiated unless an increase in funding is paramount.

The disabled community need the assurance that funding is recurrent. Already, too many families, individuals living with disability and the responding providers are fearful of what may happen to them if funding is not forthcoming. The current underfunded situation perpetrates a culture of fragmentation, powerful relationships occur between current funders and providers, largely excluding people living with disability.

We support the Report's inference that a properly funded system will enhance productivity of the sector, creating diverse and contemporary service delivery which centres upon principles of self-determination, choice, flexibility, responsibility and options.

It is critical the NDIS is funded accordingly at an additional \$6.3 billion.

Government responsibility

United Convention on the Rights of People with Disability

- *Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons*
- *Non-discrimination*
- *Full and effective participation and inclusion in society*
- *Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity*
- *Equality of opportunity*
- *Accessibility*
- *Equality between men and women*
- *Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities*

<http://www.un.org/disabilities/default.asp?navid=15&pid=156>

As the disability community, we find it concerning that those whom may appose a NDIS, forget the spirit of government as developing systems which ensure all citizens have a right for equal and meaningful participation in a democratic society. In our understanding of Australian democratic government, a spirit of a fair go, assisting people who are vulnerable to live meaningful lives is part of our culture. Namely, a

model of citizenship. Since Australia ratified the UNCRPD, we now have a set of rights which must be adhered too. These rights are reflected in the Report's proposed solution for fixing the broken disability system which oppresses people living with disability.

In Tasmania, we are currently facing an economic crisis of high unemployment, a review of GST income, downward income from current GST earnings. We don't believe that Tasmania is in a position to fully fund the needs and supports required to fix the disability system and culture of care for Tasmanians. Presently, disability service providers and the state government are working in financially constrained environments. In the meantime, disability service providers are struggling to survive and people living with disability have limited choices in living a life that is equal to their non-disabled peers.

As stated in the report, 'given its capacity for raising efficient and sustainable taxes, the Australian Government should take responsibility for meeting the entire funding needs of the NDIS' (PC 2011, p.29).

The NDIS Taskforce Tasmania support the Report's recommendation that additional \$6.3billion funding should be provided for from consolidated revenue.

Good Governance

'The challenge then for social policy is ... to create a structure in which individuals can articulate their needs, wants and dreams directly and that allows the state to adjudicate and meet legitimate claims in a manner that does not in itself infringe the potential participation or autonomy of the person. In essence, what is required is a structure within which an ongoing dialogue can occur between the individual and the state, as the representative of the collective. Further, once claims are established, there must be a means to help people satisfy those claims consistent with the principles of self-determination and equity.' (Stainton, 2005)

Successful models of disability support systems in western societies has happened because all relevant stakeholders were meaningfully included around the negotiating and decision-making table (Adams, 2009; Arnstein, 1971; Bridgman & Davis, 2004; Stainton, 2005). It makes good policy sense to meaningfully include relevant communities of interest.

Generally, we support the implementation of an independent National Disability Insurance Agency. However, the National Disability Insurance Agency (NDIA) must

ensure that the voice of people living with disability and parent/family carers are represented authentically.

Further, the NDIS Taskforce Tasmania recommends that all board members and directors, particular those individuals who are not touched by disability directly, attend credible disability awareness training. Tasmanian heads of government agencies have been undergoing such training, and now extending to staff within agencies.

Self-determination and its applicability to people living with disability.

The authority of people living with disability to have ownership, control and choices over decisions that shape their own lives to ensure meaningful participation in society and authentic citizenship. To be self-determining requires capacity and means. (Wardlaw, 2009)

'... people with disabilities have the same rights as other citizens to freedom, equality, and equal protection under the law, and control over their own lives. These rights must be honoured if people who have disabilities are to be fully included as valued citizens in the relationships and opportunities of community life.'

The Seattle Declaration on Self-determination and Individualised Funding, 2000.

The PC is to be highly commended for its inclusion of self-directing models of care for people living with disability. For too long, individualised funding models have been too controlled by government because a minimal few believe that people living with disability cannot manage their own supports. The report has correctly identified that the research does not support such claims. Therefore, across Australia, disability support mechanisms are over regulated further oppressing people living with disability who are capable of, and want to, manage their own support needs. Disability is not homogeneous. Rather, disability is heterogeneous. Therefore, the option must be available without too much regulation for people living with disability who have the capacity to determine their needs and/or have family supports who know best, to self-manage supports.

Research conducted through the University of Tasmania's Department of Rural Health and Menzies Research Institute, revealed that a rights-based social model of care and support is paramount to enable self-determination and responsibility for people living with disability (Stainton & Boyce, 2004; Wardlaw, 2009).

There exist personal experiences of successful self-management models, (see for example self-determining shared management model, Tasmania) whereby fiscal intermediaries work closely with the self-manager and determine roles, responsibilities.

The Report is to be highly commended to ensuring that consumers living with disability have a system of support that promotes choice, flexibility, control and options.

Market Drivers, Not Market Takers

The NDIS proposed will create transformational social change for the disabled and broader community. By providing the tools and resources to fix the broken system and restructure the fragmented system, empowering people living with disability to have more choice, flexibility, control and exercise their self-determination, we anticipate that the creation of a new service economy will emerge.

Those disability service providers who do not meet current accreditation standards, yet continue to be funded because 'no other service exists' will have no choice but to lift their game to become competitive, as individuals with disability choose where best to purchase support. What will emerge are more innovative and creative care industry which will work harmoniously with their 'customers' including them in policy and programme development that is 'person-centred' as apposed to agency-directed and agency-dominated programmes.

The PC is to be congratulated for highlighting a spirit of competition and improved service models for people living with disability.

Conclusion

The Productivity Commission is to be highly commended for executing a draft report on disability support and care which reflects the dire circumstances of a volatile, unworkable, unfair, fragmented system which unconsciously oppresses the participation of all its citizens in Australian life. The larger disability community finally have hope for their futures. The fear and experience of oppression will be minimized as the independence of a properly funded system frees people living with disability to emerge as valued members of society.

It is vital that Government properly funds and provides the critical additional \$6.3 billion to ensure the development of a NDIS.

It is essential that the NDIS is implemented sooner, rather than later, for some families and individuals it may well be too late.

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