30 April 2011

Disability Care and Support Inquiry
Productivity Commission
PO Box 1428
Canberra City ACT 2601

Dear Commissioners

I commend you on the work and insight you have developed into the disability sector, and the lives of many with disability, as illustrated in your Draft Report of February 2011.

A number of my colleagues have presented at Public Hearings in the last two months, and I've prepared this submission on the Draft Report in the light of some of the points you have sought clarity on from them and through the Report itself. I welcome the holistic approach proposed to address disability issues in Australia. As my colleague Natasha Layton put to you, the challenges of lists and segmented service delivery often means suboptimal solutions are delivered – often at much higher cost both to the user and the community.

Classification and determining what is in and what is out

My expertise is in assistive technology and some of the ethical/philosophical thinking around disability. As such I approach your questions about defining those in the different tiers (and in particular Tier 3) from a pragmatic perspective. I commend to you the book 'Arguing about Disability: Philosophical Perspectives' and in particular the articles by Smith [1] and Vehmas and Mäkelä [2]. These works contrast both medical and social models of disability, as well as the moral and ethical nuances that emerge depending on your understanding of the causes and impact of both impairment and disability. In line with these authors, and recent work I have seen of the therapeutic impact of assistive technology, I suggest that you consider the following approach.

a) While the individual is managing (stabilising, recovering from or dealing with comorbidities of) their *impairment* (as defined through ICF), the activity and approach fall primarily under the medical model and hinge on pharmaceutical, surgical, medical and rehabilitation interventions. As such coverage by the health system seems most appropriate.
b) When a person, however constituted with their various body shapes, capabilities and desires, seeks to participate in society/their community (in all its forms) the barriers and opportunities are heavily influenced by social factors, enablers and barriers, and fall more within the social model of disability. Smith's 'social construction of disablement' seeks to take account of not only the barriers (political and social) as a result of a person's impairment, but also societal/political beliefs on what constitutes talent verses handicap. The second element of this is clearly in line with your Tier 1 approaches.

It is this participation area (b. above) that should be the prime focus for the NDIS. In essence it would exist to support people with the issues and challenges of *being* a person with a disability in Australian society.

A person who has a congenitally acquired disability that is stable (as in my case) would have only limited need of the health system specifically related to their impairment. More important is support to participate in education, recreation and gainful use of their skills/abilities (paid or not) where barriers (including costs and attitudes) exist that are not encountered by the 'undisabled' sections of society. As such there does need to be some medical/functional basis for those barriers. Vehmas & Mäkelä describe these as 'brute facts' – they exist with or without a name/diagnosis and are clear to all (eg absence of a leg) [2, p47]. I support the use of both functional and condition-based measures to assess eligibility since they focus more on outcomes and not on 'institutional facts' as Vehmas & Mäkelä calls the different names and diagnoses we use (e.g. 'Down's Syndrome', 'Cerebral Palsy')[2, p48]. I note that by specifying the requirement for impairment in mobility, self-care and/or communication, you have in part addressed issues surrounding 'social impairments' (as defined by Vehmas & Mäkelä [p49]) such as ADHD, where the 'brute facts' around the impairment are highly subjective.

The need for both health and the NDIS to operate in parallel, but with different foci, becomes clear when a relatively stable impairment begins to deteriorate (perhaps with age or an accident). In my case, a poorly formed hip is now approaching the end of functional use (after only 45 years). This requires medical intervention (a total hip replacement and associated rehabilitation), and the costs of the internal prosthesis, treatment, rehabilitation aids (probably on loan) and associated physiotherapy rightly belong within the health system. My significant leg length inequality will not change, and ongoing support for the regular maintenance and replacement of the extension prosthesis I wear will need to continue to come from a disability source.

I note your question on page 4.9 regarding prostheses. I would endorse your rationale, and suggest (like Layton and others) that any aid/technology that facilitates participation but is not part of a medical intervention associated with an impairment (e.g. hip replacement) should be covered by the NDIS. As such I think it wise for you to indicate that Box 4.1 reflects the breadth of specialist supports planned – and not just continuation of that covered by the NDA. I can assure you that your last sentence on p4.2 gives the National Disability Agreement credit for more than it actually delivers (e.g. therapy and equipment are often quite narrowly defined by most NDA signatories e.g. Home environment only). The holistic approach proposed by the NDIS needs to be truly recognised as *different* to the current, fragmented ways.

In a similar way, I would support the inclusion of the various support payments (p4.26) within the NDIS framework. Many capital intense or early interventions struggle for appropriate funding because the benefits usually have longer term economic and social benefits – through reduced need for care or home support. Currently as these are separate funding sources, there is regular cost shifting or disregard for sound whole of life management.

Assessment and Control

I believe you have tackled the assessment process well and sought a balance between person centred processes and control, and objective fairness and justice (through professional input and validated assessments). I would encourage you though to consider the order of Chapters 5 and 6. Current systems first engage people through assessments and evaluation, before the person has truly begun to plan or consider their future. As a result, many start on a pathway where meeting the assessment requirements and getting services (as many as possible – just in case) becomes the never-ending purpose of their life. I have been in specialist seating clinics where my opening question, 'So what do you want to be able to do with a new wheelchair?' is met by confusion – 'I just need one' can often be the response.

The Draft Report clearly emphasises the importance of empowering individuals, their families and community to enhance the lived experience of those with disabilities. We do not start assessing or offering different scholarships/bursaries/payments to teenagers for tertiary study/training until there is some indication from them as to their proposed path/goal. In the same way, the scope of Tier 1 services should empower all to consider their needs *and their plans/goals* and to help clarify them. With this information, appropriate assessments can be applied relevant only to the services needed to support the achievement of those plans and goals. As you note in your Early Intervention chapter (for example Box 11.2) establishing medium to long term goals and plan can provide a guide for the person seeking services as well as a critical element for evaluating effectiveness of supports. Giving people a target and plan helps them take greater control of their lives.

Governance

I support your proposals for a commercially robust and skilled Board and structure for the proposed NDIA. I agree that it would be dangerous (and against sound governance practice) to create a representative Board. The creation of an Independent Advisory Group is certainly appropriate. I would though encourage you to highlight the need for the NDIA to begin the culture change from the beginning by noting that disability *does not preclude* a person from any role in the NDIA. Many of us with disabilities have completed recognised Company Director training and can bring our skills to bear on such bodies. As several of your case studies highlight (as does the ShutOut Report) attitudinal barriers can stop the inclusion of those with disabilities into a selection pool. Just as there is currently a strong push to improve the gender balance of many large corporations' Boards, I would urge the NDIA to actively develop and include talented people with disabilities so they too can participate in all levels of NDIA (and other corporation and government body) governance and management.

Research

I note several examples within the Draft Report where you highlight the need for research (e.g. pp8.46,10.29,11.22), but have not specifically mentioned Australia's leading government research funding bodies (ARC & NHMRC). Currently these bodies have no way to target research work that focuses on people with disabilities as a specific group. The NHMRC for instance has no Peer Review Area listed (apart from Allied Health) that would actively target rehabilitation, disability and/or assistive technology. Projects that are thus important to those with disabilities (such as a randomised control trial of the effectiveness of a particular assistive technology) are not seen as 'population significant' when compared with say a project studying treatment of whiplash injury – for example. Neither of the two large programs (ARC and NHMRC) are the obvious 'home' for research relating to disability.

I would also draw the Commission's attention to my comments on research in my previous submission. In particular the following:

'Internationally some centres (and national funding schemes) are actively seeking to address this failing. The Toronto Rehabilitation Institute (with partner bodies – including industry) has several scholarships for higher degree research that are competitively awarded to highly skilled students with disabilities. Canada, the USA (NIDRR) and several European countries (as well as the EU itself) have specific, ring fenced, funding available to investigate issues relating to a range of applied (and sometimes theoretical) aspects of enablers and issues in disability. Several of these schemes include funding to not only undertake University or pilot project work, but also to translate the findings into useful and applied action for service providers or users. The Australian disability research sector is littered with highly successful pilot projects and research work that is then wasted because no agency or system exists to consider adoption of the findings more widely. Consumers and professionals regularly complain that they give and give to surveys, researchers and others, yet rarely get

feedback or a relevant report, let alone see changes in line with the recommendations or findings. The net result is researchers abandoning the sector (or doing it in their spare time through lack of ongoing funding), and consumers in particular, unwilling to participate in any further research activities.' (Submission 261)

As noted in the report by Connelly et al [3] there is much research in support of the benefits of assistive technology for older people (and equally for people with disabilities), but very little of it is done or has been contextualised for Australia. The NDIS needs to begin to redress this gap, potentially by challenging the major government funding bodies to find ways to enhance their support of research and development work relating to disability and associated specialised supports.

I wish you all well as you seek to draw all the threads of these complex issues together, but based on your work in the Interim Report and the discussions you have lead in Public Hearings, I look forward with confidence to the release of your Final Report.

Yours sincerely,

Dr Lloyd Walker.

References

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3. Connell J, Grealy C, Olver, K and Power J (2008) *Comprehensive scoping study on the use of assistive technology by frail older people living in the community,* Urbis for the Department of Health and Ageing. Available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-assistive-technology.htm