Submission on the Productivity Commission's Draft Report on Disability Care and Support

John Barnett, Victoria

I speak here as an individual; my views expressed are entirely independent of my employer and my disability service provider.

Qualifications to speak:

For over 50 years I have experienced juvenile rheumatoid arthritis of gross severity. I have massive deformity of and limitations to my skeletal structure.

My University of Melbourne Bachelor of Arts Degree with majors in Mathematics was achieved while working on the bed at home in the 1960s.

After an intensive three-year rehabilitation program, I learned about living a life more fully integrated into the community.

At the age of 36 I gained full-time employment which I have retained for the last 30 years. At 66 I am still full-time employed.

I live in my own Unit, supported every day by a team of attendant carers, without whom I could not survive. I utilise a range of specialised aids for independent living.

Issues of concern in the Draft Report:

Page 3: "A separate scheme is needed for people requiring lifetime care and support for catastrophic injuries." And "State and territory governments would be the major driver of this national reform." But what of people who experience catastrophic injury and regain independent living skills with work potential? They would need a seamless transition from one scheme to another; creation of a separate scheme would inevitably inhibit this. I argue for one all-encompassing scheme.

Page 12: "People with bad backs and other musculoskeletal conditions would also typically receive assistance from the health system." And Page 46: Support should be provided outside the NDIS for people whose ... support needs would be more appropriately met by the health and/or palliative care systems, comprising those who would benefit from largely medically oriented interventions (including less restrictive musculoskeletal and affective disorders, and many chronic conditions). The origin of my impairment is a musculoskeletal condition. I suggest the Commission is here confusing cause of disability with consequence of disability, namely the impairment resulting from the disabling condition. I argue for deletion of all references to musculoskeletal conditions. Rather, continue to focus on the definitions, as exampled on Page 45.

I come from the Victorian disability sector, with disability-related experience from inside and outside government departments and disability organisations, including self-help groups. I come from a culture of self-help, maximising personal independence, being mutually supportive, taking responsibility for my life and my future, teamwork, and contributing to and depending on the community. In 1981 at the age of 36, I won my first open-employment job. It enabled me to pay taxes and get off the Invalid Pension (as it was then called.) I am pleased to be a tax payer, paying thousands of dollars each year in income tax. My plan is to be independent of the Aged Pension, and very likely I will achieve that.

My life does not dramatically change at Pension age. My goals and aspirations continue as they have for the last 30 years.

Regarding the reaching of "pension age", Page 15 says "upon reaching the pension age (and at any time thereafter), the person with the disability could elect to stay with the NDIS or move to the aged care system." On the same page, the Report adds "Either way, after the pension age, the person with a disability would be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care." For this enquiry into Disability Care and Support, not being explicit

about how those co-contributions will be calculated is not good enough! If co-contributions are to be recommended, this Report should say explicitly what they are. Would such co-contributions be capped, or have an excess, or have any other limitations put on them?

On page 16, the Report adds "the aged care sector would fund the care and support needs of all people over the pension age. If a person elected to continue to use the NDIS care arrangements, the assessment tools from that system [Do you mean the Aged Care system?] would be used to determine their funding, and the person would continue to receive supports through the NDIS."

The draft Report needs clarification on these matters. I currently receive 34 hours a week support, spread over the seven days. What guarantees would I have that this allocation of support hours would be maintained if aged care assessments and funding sources were involved? For people with individualised funding packages who now buy their disability services, will those amounts remain as they go through the perceived pension age barrier? The Report should elaborate on its expectations of the transition of the individual from the NDIS to aged care, if that continues to be the Commission's preferred option.

Instead of pension age being the boundary, has the Commission considered, for those who have passed that age, including those who are still working being maintained within the NDIS? That may be a more consistent approach, especially in Australia's environment of an ageing community and encouragement for people to work longer and be more independent of government.

In my opinion, the functions of assessment and funding of eligible disability services must remain within the NDIS, irrespective of age. I argue for the second option referred to on Page 16 "A second option would be for the NDIS to continue to fund people with an earlier acquired disability *after* the pension age, but with the aged care sector funding the *incremental* support costs associated with natural ageing."

My preferred model for funding an NDIS is via taxation. We have the Australian culturally acceptable model of Medicare. Here services are free, but all taxpayers pay the Medicare levy. An NDIS funded by an additional levy on taxable income would be the fairest and most equitable scheme.

I am totally opposed to also paying a co-contribution. Just because I have exceeded the pension age, hitting me with a "double-whammy" would be most unfair. If you insist on a co-contribution, it should be at least tax deductible or qualify as a rebate on tax.

Page 28 of the Report dismisses the issues surrounding the GST as too difficult to change. Where would co-contributions sit regarding the GST? Would this be a triple whammy for people transitioning through the pension age barrier? Again, the Report fails people with disabilities and their families by passing over this issue as to difficult.

These key issues remain – a single system (like Medicare) or a split system (NDIS and aged care). Wherever you have a split system, clients will always have difficulties at the boundaries. And people with disabilities will especially experience difficulties there.

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Thank you for listening.