Submission to Productivity Commission inquiry into a National Long-term Disability Care and Support Scheme.

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Dear Commissioners,

Please accept these comments, suggestions and questions by way of my submission to the inquiry on a National Long-term Disability Care and Support Scheme, aka NDIS. I have personal experience of quadriplegia since 1978 and have experience in disability policy advice, advocacy and advocacy development, service provision and adult guardianship as a Tribunal member. My formal qualifications include a PhD (Philosophy); B Soc Sci (Hons); Assoc Dip (Human Service Administration).

The comprehensive Draft report offers a number of benefits, such as individual funding, flexibility in interface between disability and aged care systems, attention to Aboriginal people with disabilities, and greater stability of funding. These, unfortunately, appear to evaporate in the light of the report's values-free market-based approach to disability service. Besides there are many other problems with this report.

People with disability in Australia do indeed need fundamental change in the nature and extent of their care and support towards their full social inclusion. The recommendations in this report however will not give them that change. Social inclusion in the straight jacket of the market is not social inclusion. In the interests of people with disabilities, and those supporting them, this report should be significantly amended on the basis of:

- the incompatibility of its market-based approach with meeting real needs of people with disabilities for social inclusion, as required in the UNCRPD (especially articles 5, 19) and envisaged in the National Disability Strategy;
- not supporting its market-based approach as a viable route to social inclusion, with evidence of its effectiveness. As the proposer of change in the status quo the onus is on the Commission to do so;
- not basing itself on principles and rights, including the interactive definition of disability as in the CRPD;
- its inevitably inaccurate costing, in avoiding an examination of how resources are used to meet needs in the present 'dysfunctional' system;
- its non-participatory approach at any meaningful level and functioning of an NDIS;
- its non-consideration of imminent economic effects of climate change and an impending oil crisis in how disability support is funded;

- its failure in making suggestions on how current, small-scale initiatives that meet needs well, but might fail an NDIS cost-effectiveness benchmarking, would be safeguarded against defunding;
- its inability to provide a secure funding mechanism that would provide a stable basis for the social inclusion of people with disabilities in Australia over the next 40-50 years.

Instead the report should be rewritten from a starting point of needs, based on established principles and rights. I restate my suggestion for a needs-based scheme which pays attention to needs, takes responsibility for meeting them, does so competently and in responsiveness to their outcomes, involving participative relationships (Tronto, 1994, 1995). My submissions #109 and #471 to this inquiry refer.

Further, implementation of a disability allowance which recognises the substantial extra costs associated with living with a disability should be considered.

My beliefs and assumptions

My beliefs and assumptions underlying the below questions include:

A market-based approach based on cost-effectiveness and efficiency is not coherent with processes and aims of social inclusion and cannot therefore achieve them. Social inclusion is not built on contractual arrangements, cost-effectiveness, efficiency and competition. It involves co-operative relationships, trust, generosity, creativity and long-term commitment. The market chicken is unable to produce a social inclusion egg as they are different species.

The draft report’s apparent weakening of the importance and relevance of the UNCRPD to disability support, including its reframing of disability as including a medical dimension, is taking the disability cause of social inclusion back to prior to 1981, the International Year of the Disabled. This is a highly undesirable development.

The quest for ‘participation’ appears as mainly one of increased economic participation, in the main interest of the government’s financial bottom line. A meaningful commitment to increased social participation is absent in the report. Meaningful participation by end-users in every level and functioning of an NDIS/NDIA is not seriously considered. The proposed advisory council to a *commercial* board running the NDIS is an ineffective participatory mechanism and suggests tokenism. It also emphasises the dominant role of the market over that of n end-user-identified needs basis. The point of insisting on real participation at every organisational level, including in the services NDIS funds, is to engender a closeness to the lived experience of disability, which could better connect an NDIS bureaucracy an ability for meeting real needs. Presently, its contractual, cost-effectiveness starting point and ‘independent’ assessors do the opposite.

In any case, it seems not possible for this proposal to be needs-based in absence of its articulation of what fundamental human needs are, nor discussion of appropriate processes of person-centred needs assessment. A comprehensive review of best practice in individual needs planning, on the basis of their findings concluded that an optimal person-centred needs-based process starts with the “Intention – reason for planning”, next “Effectively identifying needs”, and “Developing appropriate strategies to respond to needs and aspirations”, before “Implementing identified strategies and from reviewing outcomes (Parsons, Cocks & Williamson, 2009).” In this NDIS proposal interests of Treasury, disability services industry and persons with disabilities have largely been promoted in the name of the latter but in fact the first two most powerful parties’ interests are paramount. The main ‘intent’ of the scheme has unfortunately been clouded. The same could be said about a conflation of needs of people with disabilities and that of carers where some needs overlap and some provide a conflict of interest, noticeable in particular in the report’s disturbing vagueness on any commitment to ‘good’ community-integrated lives, as opposed to segregated/congregated options (apartheid). It seems to have resulted in recommendations that are stated as in our best interests but appear to mostly serve financial sustainability purposes of government and services. Of course many support initiatives need money and the two are interlinked. The $13B question is what drives the process: needs of vulnerable people or financial needs of others? Starting with the money, as this NDIS campaign has done, is unlikely to lead to meeting real needs well. It is a recipe for more of the same, on steroids. The 56% of Shut Out respondents who identified ‘barriers’ will likely find the same attitudinal barriers to the achievement of their ‘good lives;’ under this NDIS.

This draft report steers a course towards a greater role for cost-effectiveness/efficiency/competition motives, where business partnerships are thought to deliver cost-savings to government and services, and likely, even profits. And cost-saving and profit taking are powerful motives in meeting those needs that are easier/cheaper to meet and make profits. Complex needs are less attractive to a market. Implementation of this NDIS proposal is in line with the National Compact, the Howard initiative of the Centre for Social Impacts agenda and its WA government-supported initiative, the Economic Audit approach to social services. These cause strong tensions between a market ideology and hard-fought inclusionary principles and disability rights. They involve service-as-business, large providers and token end-user participation under a rhetoric of increased choice, which is in fact constrained by criteria of cost-effectiveness and efficiency. Once these changes are implemented, service to people with disabilities will have undergone a fundamental *structural* change. It will however do little in shifting present disabling attitudes and practices that underlie a service system that does not meet needs well. In other words, not fundamental change at all.

The draft report’s starting claim that the “current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports” is part true and in part constructed to give its own answer: the situation seems, in the eyes of the Commission, no more than a market failure (as in its Aged Care inquiry report), requiring market-based remedies. Had it considered the nature of vulnerability of people with disabilities it would have drawn different conclusions about underlying principles to an NDIS, and how it ought to be run, monitored, evaluated, and individual needs assessed.

In talking about this fragmented, crisis-driven service system, at no point does the government or service industry accept responsibility for it, almost as if it has fallen out of the sky. There are always great dangers associated with wholesale change which does not understand the relevant underlying history, disregards available practice and research in favour of a state (market) ideology, and which has little basis in fact in the realm in which it is applied, in this case the support of a highly vulnerable group of people.

The absence of any mention of a need for strong, independent disability advocacy as a principal safeguard to vulnerable people with disabilities is noted. This would be of particular relevance to the large, central bureaucracy proposed in the draft report. Ignoring a role for advocacy seems a further indication that the Commission is more a believer in the invisible hand of the market in correcting 'market anomalies' in disability support, than it does in the power of such safeguarding mechanisms as protecting and advancing their social position. Its recommendations for awareness campaigns for example seem not based on evidence of the ability of such campaigns to dislodge and transform deeply held prejudices and fears about (people with) disability. I am not aware for example, of such campaigns helping people who experience racial prejudice or by reason of gender or sexual orientation achieve valued citizenship. In disability the causes of vulnerability are deeper still. Real transformations towards acceptance of someone with disability as of inherent equal human worth only come about through knowing a person in day-to-day relationships. Such relationships require a commitment to integration of people with disabilities and rejection of their segregation/congregation. Commitments such as the report appears to defer to the power of cost-effectiveness assessments (p 1.12), not principles of what is good for people. I accept this Wolfensberger definition of integration: "adaptive participation by a socially devalued person in a culturally normative quantity of contacts, interactions and relationships, with ordinary citizens, in typical activities, and in socially valued physical and social settings."

The two-prong proposal, ie two schemes based essentially on the physical cause and circumstances in acquiring an impairment, is another example of a scheme that is not focused on the needs associated with disability. The introduction of 'catastrophic injury' is inappropriate within a context where the vulnerability of people with disabilities is heightened by tragedy language and imagery. It is also imprecise.

It difficult to understand why this report would put a $6.4B extra cost on the NDIS, to be achieved by 2018, where it might immediately improve effectiveness of existing services by transforming it to a genuine end-user needs focus. We know needs are often ill-targeted and not well-met, and unnecessary layers of bureaucracy soak up funding dollars that could be spent now on individual needs. Attention to needs and quality of service do not necessarily require dollars but require transformation of attitudes towards service users. Big social 'dividends' might be achievable in this cost-effective way.

It seems a significant credibility gap in costing a future scheme, while ignoring impending economic, social and environmental impacts of climate change and an imminent global oil crisis, as foreshadowed by the normally conservative International Energy Agency – *at the latest by 2015*. If just the most recent natural disasters in Queensland, suggested as climate change-related by some experts, incurred such a magnitude of cost that the entire federal budget is significantly affected by it, then where will the financial axe fall under future effects? Disability and social welfare expenditure will likely be condemned as a burden, as we hear presently in increasingly harsh tones, voiced by government and opposition. The Commission ought to consider what should be done to safeguard against the effects on people with disabilities of these inevitable developments.

While the report acknowledges some problems in releasing a large amount of funding that would enable people with disabilities to employ carers privately, experience suggests that there are many more problems that need to be thought through. From my own experience and that of friends, I know that is very difficult to find quality, committed, trustworthy carers, who are compatible with the cared-for person. It is not primarily a matter of money, nor even of training. Caring is more of a calling, a grossly devalued one in our society, much of it arising from the same beliefs and attitudes that underlie the market-economic ideology. Many carers, in my experience want more hours, don’t turn up for interviews, leave after a short time for ‘better’ jobs or just don’t have the wherewithal to be a good carer. A number have pre-existing injuries or disabilities themselves and are looking for a private carer job after having been rejected by the job market. A working party of people with end-user experience and care providers could work on strategies to address these fundamental problems.

A new national disability research institute based on the overriding principles of cost-effectiveness and efficiency is a recipe for a market-based reframing of a relational view of disability. It will not be in the primary interests of people with disabilities to do so, but, again more in the interests of Treasuries (Treasury will oversee the commercial board that runs NDIS). Instead, good, creative disability research, conducted in a variety of disability research centres should continue to provide research that advances the social position of people with disabilities.

Questions

Among questions arising from the report, are these:

The draft NDIS report prizes accountability and transparency. How is it in the best interests of people with disabilities for the report not to give any evidence of effectiveness of its market-based approach to disability support, within a broad aim of social inclusion, as per the National Disability Strategy?

How is it in the best interests of people with disabilities for the report not to draw on available practice and body of research on what works best, and what does not work well, in supporting good lives of social inclusion, based on real needs, in high quality approaches?

How is it in the best interests of people with disabilities for the report not to roundly endorse the UNCRPD as its guiding principles, including its definition of disability, with its implications for recognising a heightened vulnerability of people with disability based on dominant social values?

How is it in the best interests of people with disabilities that when we know that NDIS will drive the National Disability Strategy, which in turn has as its central goal social inclusion, it very much looks like we will inevitably experience a pale reflection of real inclusion, shaped by the report's priorities of cost-effectiveness, efficiency and competition, which actually undermine the rich person/needs-based strategies known to support real inclusion?

How is it in the best interests of people with disabilities for the report to imply that whether segregated or integrated approaches to disability are preferred, ultimately depends on assessments of cost effectiveness?

How is it in the best interests of people with disabilities, or tax payers, for the report to recommend extra expenditure of $6.4Billion without providing its assessment of the real cost of disability support in the existing system, when it has not assessed what waste of resources occurs in the present system of which we're told it is 'dysfunctional?'

How is it in the best interests of people with disabilities for the report not to recommend an *immediate* reform process of the existing system, focused on real needs and quality, when doing so might free up resources from ill-targeted services, and unnecessary bureaucratic layers, able to show an effect well before the 2018 start-date for an NDIS?

How is it in the best interests of people with disabilities for the report not to recommend support for more, strong, effective, independent disability advocacy as a major safeguard to inevitable abuses and problems in this large bureaucracy and the services it funds?

How is it in the best interests of people with disabilities for the report to recommend recording personal, invasive data of NDIS recipients without ethical considerations that appear to prohibit such enforced participation, especially when the recorded data is to include one's 'natural supports', and we also know that national databanks have been hacked and will likely be in the future?"

How can we believe the report that it is fair dinkum about social, not only economic, participation of people with disabilities when there are no recommended opportunities for their meaningful participation at every level of structure and functioning in an NDIS/NDIA, enabling the bureaucracy to stay close to the lived experience of disability?

How is it in the best interests of people with disabilities to introduce a new 'disability-as-tragedy' label in creating "catastrophic disability?

How is it in our best interests for a ***commercial*** board to run NDIS with the obligatory advisory council hanging off it when we already know how disempowered our watered-down national advisory council is and commercialisation of disability services undermines efforts towards social inclusion?

How is it in the interests of good service to people with disabilities to create a new research monopoly around a narrow market view, emphasising cost effectiveness, efficiency, competition, with all its regulatory trappings? A large research institute such as that will suck oxygen out of existing, diverse, comprehensive, life-enhancing disability research and further cements a disabling market-view in delivering services.

How is this NDIS proposal a transformational shift when it is obviously more-of-the-same, based on the same market-based principles that drive the current dysfunctional system?

Why should we believe that an NDIS would be effective in aiding social participation of people with disabilities when its accompanying campaign and draft report show little sign of it?

Why do we need a market-based NDIS at all if we could turn our attention to real needs of people with disabilities right now, making the necessary resources available and build on best practice of individual funding and social inclusion?

What safeguards are there in the report against undermining and defunding the small, locally-based social inclusion programs that demonstrably work, but do not meet the NDIS cost-effectiveness benchmarks?

The NDIS draft report does not categorically support integration and social inclusion without exception. Instead it uses careful wording to say that it is cost-effectiveness that will determine whether service initiatives that promote community integration or segregation, will be funded. It does not subscribe to principles and rights such as in the CRPD that demand integration.

When we know that escalating effects of climate change will put government coffers under pressure (with disability support to cost $13B), and when we also know that an oil crisis is around the corner, with effects predicted by the IEA to hit, at the LATEST by 2015, why are these developments not factored into the draft report?

Conclusion

The draft report poses the wrong question in what is failing people with disabilities in disability service. It over-generalises, and risks throwing out good initiatives with the cost-effectiveness-scented bath water. It appears to have already thrown out the relevance of hard-fought disability principles and rights.

It does not acknowledge as primary attitudinal problems underlying the vulnerability of people with disability, both in wider society and in disability services. Its approach is to apply market responses to its perceived market failures of lack of services, choice, referral and information. This will not assist people with disabilities being socially included but may help the financial bottom lines of Treasury and services industry.

Given government instability, imminent global developments carrying significant economic, social and environmental risks, people with disabilities are in need of the strongest of buttresses to their good lives: social inclusion. The recommendations in the draft report however rely on a mainly economic buttress. Any kind of social valuation that rises and falls with economic fortunes is no social inclusion and represents no entitlement worth having. It mostly makes commodities and consumers out of people with disabilities in a new market.

Given the likely hard times ahead, we better get cracking on facilitating real social inclusion. This is not a role that should be left to government, although government can do much to assist it. It is a role for those who live with disability in their lives and their allies, wherever they are found, in their street, in government, or in services. Doing so also requires a disability movement to set its own social inclusion agenda.

References

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