Further submission

Making Care Count in a National Disability Care and Support Scheme

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

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Further to my earlier submission to this inquiry I am prompted to submit additional comment.

It expands in three areas:

1. Needs and segregation

2. Individual funding and needs

3. Diagram: *Components of a needs-based National Disability Care & Support Scheme*

Needs and segregation

Some suggest that whether to fund segregated/congregated facilities, and find an 'acceptable size' of these, may depend on cost-effectiveness, based on ideas of economies of scale. I believe that this economics approach to deciding how people with disabilities should live is inappropriate and counter to their established rights.

Given the National Disability Strategy's stated focus on inclusion, as is wider government policy including through the UN Convention on Rights of People with Disabilities (*full and effective* participation and inclusion in society), segregated models are incoherent with such a policy direction.

For purpose of this inquiry I recommend no new segregated/congregated services are to be funded by an NDCSS and existing such facilities are supported to transition to in-community support.

A recommendation of this sort will test the Productivity Commission's independence, given election promises involving extra 'places' in 'facilities', but it is evidence-based.

There is intrinsic value in living, learning and playing alongside other community members, *in* (the) community. Segregated models communicate the message that the people in them cannot and should not belong. The individual who is included gains vital knowledge and skills and exposes the community in positive ways to the gamut of the human condition which we should accept as normal. Indeed the rhetoric around an NDCSS states this to be so. Segregation is not a normal life, but pretty 'ordinary.'

It is clear that, whatever government is in office, people with disabilities will continue to be vulnerable to policies that segregate them. Perhaps in part because segregation is still the default-mode when most people think about disability, despite words to the contrary. This inquiry is an opportunity to make educated recommendations based on what we know about needs and segregation. It may make the difference for millions of Australians for the next decades between opportunities to flourish as human beings or be warehoused in the state of apartheid to which the Parliamentary Secretary for Disabilities has likened the experience of disability in Australia. Segregation is apartheid, i.e. ‘separateness.’

This is not an area where choice should be respected without having regard to the fundamental needs of those that this inquiry is all about: people with disabilities.

Giving families and carers the proper support that they need will undoubtedly help the cause of inclusion of people with disabilities. These needs are often intertwined and at times conflict. Both needs should be met, where needs of carers should not override that of the more vulnerable party, the person with the disability.

An NDCSS is to be a needs-based scheme. This makes sense. Why spend public money on support for people with disabilities on things they do not need? No-one *needs* segegration.

Consequently I would like to put before the commissioners a part of this literature so it may make informed decisions about its recommendations in this regard.

Jackson, R. (2008). Inclusion or Segregation for Children with an Intellectual Impairment: What does the Research Say? Conference paper Queensland Parents for People with a disability. http://www.include.com.au/papers/Inclusion_Seg.pdf

(Dr Jackson is an expert in this subject with some 30 years practical experience. This paper contains numerous references with regard to the effects of segregation. From this paper: *No review could be found comparing segregation and inclusion that came out in favour of segregation in over forty years of research.*)

Taylor, S., Harris, p. selected annotated bibliography Disability Studies and mental retardation. Reprinted from *Disability Studies Quarterly, 16*(3), 4-13.

http://thechp.syr.edu/dsbiblio.htm

(This annotated list contains 49 references with abstracts, including many with relevance to inclusion)

Lemay, R.A., (2009). Deinstitutionalization of People With Developmental Disabilities: A Review of the Literature. Canadian journal of community mental health,28, 1

(A review of 85 references. From the conclusion: “On the whole, the data are compelling: People, irrespective of their degree of disability, are apt to do better in the community on most measures and do no worse when it comes to challenging behaviours.(...) Very simply, the institution cannot replace the community in providing individuals—including those with developmental and serious psychiatric disabilities—with the opportunities for the good life. There are no compelling client-related arguments left for keeping people with cognitive limitations, and possibly people with psychiatric disabilities, away from their families and communities.”)

Individual funding and needs

Further to my comments in my first submission on individual funding I stress that it is a tool towards certain ends only. No-one needs individual funding. Everyone needs safety, belonging, health, social support, meaningful occupations, room to grow and express. Those are the things individual funding could facilitate, just as equipment and services might.

Portability and flexibility of individual funding are important. But content is more so. It is also important that organisations that are funded to facilitate individual funding do:

- not use inappropriately large slices of packages for their administration costs or profits;
- not supplant freely-given support with paid employees;
- pay attention to long-term stability of support and low turn-over of support workers;
- base themselves on positive values about people with disabilities, focus on their fundamental needs and do so competently, in full participation with the person or their family or allies.

Far from being 'academic' in their importance, a values-based orientation to this inquiry, based on what we know about fundamental human needs, has highly relevant practical effects in the lives of people with disabilities.

Components of a needs-based National Disability Care & Support Scheme

The below diagram represents the proposed structure of a National Disability Care & Support Scheme, as presented in my first submission to this inquiry. Although it is no doubt incomplete, perhaps it will clarify that proposal further.

This representation shows the interdependence and relationships between the components, while the elements of Tronto’s care framework are reflected throughout.

It is, in fundamental ways, a reflection of the daily reality of disability experience. That is, wellbeing and flourishing, in a good life, depend on taking care; participating in care; being cared for and about, in supportive relationships. Good life therefore is mostly recognised by the processes that attend it, rather than by counting hours, dollars, number of ‘interventions’, and assessments of impairments. Just counting the latter in assessing value of service is quite meaningless. Both qualitative and quantitative dimensions can be used in evaluating whether particular models of service work for the person with a disability.

What is a good life is only measurable in tangibles to some extent and that what makes it so can lose its importance when it cannot be counted in this way, and is consequently missed in services. Sophisticated evaluation models exist that do take account of both qualitative and quantitative dimensions. I recommend these be used in evaluating the NDCSS itself and in service funded by it.

It has been suggested that it is a matter of the ‘chicken and the egg’, meaning, it does not matter what means are employed, if you provide equipment, work, and services, the rest, like inclusion, will follow. Therefore it is sufficient to merely count such tangibles in devising and evaluating an NDCSS.

If outcomes are the egg and NDCSS the chicken I suggest that when we see the two as one, with its true nature being an ‘intangible’ ongoing process, it will profit us to pay attention to this process lest we lose sight of both chicken and egg, in this case representing the wellbeing of people who use an NDCSS.

The diagram follows

Thank you for accepting my second submission.

Components of a needs-based National Disability care and Support Scheme