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

Dear Sir or Madam

I submit my comments on the Productivity Commission draft report on Disability Support and Care.

First, I would like to say that I think the Productivity Commission report is an extraordinarily important step forward for disabled people in Australia. It is a cogent, balanced, considered proposal that would make a huge difference for people with disabilities, their families and for the quality of life in Australian society in the future. My comments should therefore be seen in the light of that general welcome and support.

The report has been heavily informed by the experience of people with physical and sensory disabilities using individualised funding arrangements to direct their own support. That is entirely appropriate, because these pioneers have led the way in changing our thinking about what is possible in disability services. However, many, perhaps most, of the people using specialist disability services are people with cognitive impairments like intellectual disability. For these people, decision-making needs to be assisted. The appropriate model is therefore not just one of attendant care but of skilled facilitation to help the person develop and grow and to enable the person to successfully take part in the activities of their own daily lives and in the life of the community. For example, a person with severe intellectual disabilities and serious challenging behaviour needs support from someone who not only has a good relationship with them, but who knows how to manage the level of demand in everyday situations so as not to trigger challenging behaviour[1].

The implication of this for the report is that it needs to be acknowledged that this is the case, and that the remuneration of such workers is therefore likely to be higher than that of attendant carers. This is not, in fact, a special characteristic of supporting people with intellectual disabilities since staff supporting people with complex medical needs or communication difficulties will also need to be more skilled. I emphasise that I agree with the observation in the report that a good relationship is the primary requirement of staff supporting the disabled person and that training builds on this but is not a substitute for it. It is also my impression that the kind of training provided to disability support workers in Victoria does not fit well with the kind of services we want in the future.

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[1] See for example the literature on ‘person-centred active support’ and ‘positive behaviour support’ for illustrations of how important the interactional style and content of staff support is for people with severe and profound intellectual disabilities: Ashman, B. and Beadle-Brown, J. (2006) A valued life: developing person-centred approaches so people can be more included. London: United Response; Beadle-Brown, J., Hutchinson, A. and Whelton, B. (2008) A better life: the implementation and effect of person-centred active support in the Avenues Trust. Tizard Learning Disability Review, 13(4), 15-24; Ashman, B., Ockendon, J., Beadle-Brown, J. and Mansell, J. (2010) Person-centred active support: a handbook. Brighton: Pavilion; Koegel, L. K., Koegel, R. L. and Dunlap, G. (1996) Positive behavioral support: including people with difficult behavior in the community. Baltimore: Brookes.

The second implication of assisted decision-making is that we must not underestimate the amount of ignorance, prejudice and low expectations towards people with severe and profound intellectual disabilities among the public and professionals. Many people still believe that much poorer standards for these people are all that can be achieved and are acceptable and appropriate. The Commission Report acknowledges the problem of bad judgement in selecting support in respect of interventions, where it says that they must be evidence-based, but it appears not to do this in respect of living arrangements. My concern is that families, beaten-down by their long experience of lack of services or poor-quality services and responding to the marketing brochures of service providers, might choose institutional care instead of supporting people in the community. This would not only achieve less than could be achieved for their disabled sons or daughters, but it would create an easy option for people looking for cheap services. When the shine wears off, these places present huge problems which take a lot of money, effort and time to undo. In England, the ‘campus’ developments built in some places in the early stages of deinstitutionalisation are now being closed in recognition that they could not offer an acceptable standard of care[2]. So I would want to extend the requirement in the Productivity Commission report that services purchased should be based on best practice, to all of the services concerned including the kind of supported accommodation and day care.

My third comment also relates to supported accommodation services. I was surprised that the Report did not explicitly embrace the separation of housing and support that has been a common theme in disability discourse for many years. In many countries, the development of group homes has given way to the provision of housing – social housing, rented housing in the private sector or part- or sole ownership – and the separate provision of support on a domiciliary care model. The advantages of this are seen to be that separate housing and support usually gives the individual more housing rights and also tends to avoid the re-creation of institutional practices when staff think of the group home as their place, rather than the residents’ home[3]. Everyone, no matter how severe or complex their needs, can be supported well in their own home in the community given adequate skilled support, led with vision and commitment[4]. Separating housing and support does not stop people choosing to live together but it does stop people being forced into situations that are administratively expedient but actually unworkable. I think it would be helpful if the report made explicit the principle of the separation of housing and support and removed references to group homes.

In terms of the structures and mechanisms to be used, the Report sensibly proposes a process of learning and adjustment. I was not completely clear about the separate contributions to be made by the proposed NDIS assessors, the case managers and the disability support organisations. In the UK, the assessment and construction of an individual service package is supposed to be the role of case managers. In fact this system has largely collapsed[5]; there are not enough case managers to do the job

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[2] Healthcare Commission and Commission for Social Care Inspection. (2006) Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust. London: Healthcare Commission; Department of Health. (2007) Opening the door to a new life for people with learning disabilities (press statement). London: Department of Health; for a review of the relevant evidence see Mansell, J. and Beadle-Brown, J. (2009) Dispersed or clustered housing for adults with intellectual disabilities: a systematic review. Journal of Intellectual & Developmental Disability, 34(4), 313-323.

[3] Kinsella, P. (1993) Supported living: a new paradigm. Manchester: National Development Team; Simons, K. (1998) Getting a Foot in the Door: the Strategic Significance of Supported Living. Tizard Learning Disability Review, 3(2), 7-16.

[4] Mansell, J. (2006) Deinstitutionalisation and community living: progress, problems and priorities. Journal of Intellectual and Developmental Disability, 31(2), 65-76; for examples of good community services for people with the most complex needs see Mansell, J. (1994) Specialized group homes for persons with severe or profound mental retardation and serious problem behaviour in England. Research in Developmental Disabilities, 15, 371-388, Mansell, J. (1995) Staffing and staff performance in services for people with severe or profound learning disability and serious challenging behaviour. Journal of Intellectual Disability Research, 39, 3-14 and Department of Health. (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities. A report by Professor Jim Mansell. London: Department of Health.

[5] Mansell, J. and Beadle-Brown, J. (2004) Person-centred planning or person-centred action? Policy and practice in intellectual disability services. Journal of Applied Research in Intellectual Disabilities, 17, 1-9.

and they face a conflict of interest because they work for the funding authority. In the NDIS, the assessment function is separate and that seems to me to be useful. The construction of a service package that suits the individual seems to me to be more likely to be done well when carried out by the person, their family and 'circle of support', supported by a disability support organisation than by a case manager. If disability support organisations were supported to undertake this role they would be doing most of the work of the case manager. In work in which I was involved as a Commissioner for Social Care Inspection in England, disabled people were clear that disability support organisations separate from government agencies were preferred in support of direct payments and case management was barely mentioned as a resource[6].

Finally, I would like to suggest a stronger reference in the report to changes in the rest of the public service which would facilitate the NDIS. In Australia, as in other countries, disabled people were typically directed to specialist services at their first contact with housing services, health services, education services, which defined their remit as serving only those without disabilities. NDIS will be a potent force to negotiate with other services about the appropriate boundaries and their respective responsibilities. However I think it would be much easier to do this if there was a clear principle, based in anti-discrimination law and expressed forcefully in public policy at the highest level, that public services are required to meet the needs of the whole community, including people with disabilities just as much as people from ethnic minorities, people with different sexuality or other groups. This would be something like the 'Public Sector Equality Duty' in the UK[7]. It would reduce or prevent the simple exclusion of disabled people from health services, mental health services, access to public housing and facilities like swimming pools and community centres, and encourage these services to make reasonable adjustments to meet the needs of disabled people.

Yours faithfully

Jim Mansell
Professor of Disability Studies

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[6] Commission for Social Care Inspection. (2004) Direct Payments. What are the barriers? London: Commission for Social Care Inspection.

[7] http://www.equalityhumanrights.com/advice-and-guidance/public-sector-equality-duty/