Response to Productivity Commission (PC) Draft Report: Disability Care and Support (April 2011)

Support for the Directions of the Draft PC Report

We applaud the overall directions in the draft PC report. It provides a systematic response to the difficulties that plague the disability support system in Australia by proposing a National Disability Insurance Scheme (NDIS). This scheme will form the basis of a support system that is sufficiently well resourced to meet the reasonable assessed needs of people with disabilities and provide certainty for individuals and their families, across their lifetimes. Processes and structures are proposed for decisions about eligibility and entitlement which will mean they are consistent across the country. The draft report implies tier 3, direct support, is available to people with disabilities with the highest support needs. Given a history in some jurisdictions of suggesting ‘some people are too expensive’ or the best practice service responses, such as the separation of housing and support are not available to people who require 24 hours support, a stronger statement of implied intent and priority to people with the highest support needs is needed. A statement of this nature may become critical if at some time in the future any form of limitation of funding or restriction of eligibility for tier 3 supports is developed. It is very difficult to imagine a future with no cost limitations.

The draft PC report incorporates current directions in the provision of disability support such as person centered or individualised responses and self directed funding as a means for people with disabilities to be included in society in a way that reflects their own life choices and preferences. Individual choice is a central organising principle for disability services. The report provides a basis for the types of support that can be purchased, suggesting they should be effective and evidence based, with the underlying assumption that such supports are best placed to assist people to live ‘adequately and reasonably.’ However, the NDIS should not create the conditions whereby poor standard services, which evidence suggest do not foster social inclusion, especially in models of housing and support, are available as if they were just another choice. Sub-standard services models, like therapies without evidence for effectiveness, should not be a feature of the NDIS options for direct funding.

Access to the Mainstream and Leverage Mechanisms.

Alongside individual choice is the principle that mainstream services and community facilities should be accessible and have the capacity to adapt to and accommodate people with disabilities. There remains a large task for the tier 1 activities of the NDIS to challenge many publicly held and conservative views today about how best people with an intellectual disability can live and contribute to the community. Some of these stereotypes can be found in the attitudes of families and service providers.

A concern too is the relative silence about the complexity of access and the various types of accommodations by mainstream services that are needed by people with different types of impairment.

A strong relationship between tiers 1, 2 and 3 is essential for the effectiveness and viability of tier 3 direct funding. The better the community at large and mainstream services respond to people with disabilities, the less the pressure will be on separate disability supports, and thus for funding guidelines to expand. Effectiveness at level 2 will reduce pressure on tier 3 by ensuring as many people as possible can be supported in the mainstream. This will ultimately determine the effectiveness of the NDIS system – particularly in relation to housing. If there is nowhere for people with disabilities to live – the quality of their support and their status as citizens becomes irrelevant.

Whilst the potential influence of the proposed National Disability Insurance Authority and high level memorandums of understanding should not be underestimated, we suggest a potent mechanism might be a strengthened focus on monitoring and compliance of mainstream services with anti discrimination legislation. Existing or strengthened legislative frameworks based on equal opportunity and anti discrimination could be very important in ensuring access and accommodation to the needs of people with disabilities in the crucial employment, health, education, housing and transport sectors. It is for example, unlikely the significant changes to workplace safety seen in Australia would have occurred without legislation and reliance solely on high level agreement between employer and employee organisations.

Taking Diversity into Account – People with Intellectual Disability

The remainder of this submission is focused on the issue diversity of people with disability and ways in which the proposed scheme should be further elaborated to ensure support provided through the NDIS for people with an intellectual disability is underpinned by best practice to improve their quality of life. The draft report recognises people with intellectual disability as a distinct needs group but then does not articulate the distinctive nature of support this group requires. Our concern is that the models of support described throughout the report are those most relevant to people without cognitive impairments and suggest a reliance on attendant care, that is, staff whose role it is to carry out specific physical functions for someone with a physical or sensory disability. People with an intellectual disability need support relevant to their cognitive impairment. Enabling and facilitative functions, delegated and supported decision making are essential components of the type of cognitive support required by people with intellectual disability who cannot direct their own lives unaided and who need assistance to make decisions.

We address a number of issues 1) that people with intellectual disability require very different types of support from that based on attendant care models, and the implications of this for organisation of support, services and training. 2) that measures such as reliance on evidence based practice should be applied to choices about housing and support as well as direct therapeutic services. 3) some very specific issues about people aging with a lifelong disability and proposals about the interface between aging and disability services and 4) a number of issues where we think further clarification of points in the report is required.

Distinct Support Needs of People with Intellectual Disabilities

The draft PC report establishes a framework based on the diversity of individuals and of impairment groups. Accordingly, greater recognition should be given to the different types of support or services required and outcomes sought, as well as the likelihood that measurement and monitoring strategies and indicators of quality will need to be different. There are examples throughout the report highlighting how physical impairment can be best supported through the provision of aids and equipment, therapies to maximise physical functioning and attendant carers to provide physical assistance as needed. It tends to leave the impression that the direct support staff are attendant carers – that is, staff who assist people with their physical needs and are directed by an individual with a disability. However, this is not the only requirement, and sometimes not a requirement at all, for the staff supporting people with an intellectual disability.

People with an intellectual disability, unlike any other impairment group, are recognised as a priority for individualised supports. The pervasive impact of intellectual disability for an individual has been recognised. The nature of intellectual disability means this group will continue to be the largest group of people requiring lifelong disability support and therefore whose carers/ family are a significant cohort within the informal care network. In fact many of the touchstone issues for people with disabilities have their origins with people with intellectual disability and their carers/ families, for example, ageing carers. This implies something distinctive about the support needs of this group, however the draft PC report does not elaborate on the details of that support.

For supports for people with an intellectual disability to be cost effective and maximise people's quality of life, the support needs to attend to communication, social relationships, learning, development and independence, problem solving and decision making. This is so much more than physical attendant care. If the different nature of support is not understood throughout the NDIS it is likely people with intellectual disability will be well cared for physically but not developmentally – thereby replicating circumstances from history before the potential of people with intellectual disability was recognised.

Staff who support people with an intellectual disability need to understand how each individual communicates, how much they understand, how to encourage involvement and participation, how they learn best, what circumstances bring out challenging behaviours, how to tell if someone is happy or not, comfortable with someone or something, how to note changes and development over time and in different settings, how to ensure information and experiences precede decision making, how to judge when someone can reliably and safely makes decisions for themselves, when they need assistance and what type. To do this staff typically need to have knowledge about the nature of intellectual impairment, skills in specific support strategies such as active support, positive behaviour support and positive language. They also need to know the person well, to recognise their own biases and separate their views from what they think the individual would prefer; as well as separate the preferences of an individual from those of close family and friends. Staff need to work in teams that coordinate with family and community members, which place the individual at the centre (person centred) of support. Staff have to ensure continuity of support, and maintain an approach or direction that may not be explicitly stated by the individual, who may not be able to provide direction about the type of support provided or comment on its quality. The provision of support by skilled staff, who work as teams with monitoring, direction and ongoing supervision in place is critical to ensuring that people's lives are not wasted by a series of isolated and unconnected events. Staff must also make complex judgements to determine what is a 'reasonable' risk is, what it is not and from whose perspective. Staff have to understand that someone simply saying 'no' ('I don't want to go out') is not a reason for someone to never go out.

There is an example in the PC draft report of someone in with an intellectual disability going to the pictures instead of the day centre. It is a good example but does not unpack the type of support that may underlie this choice being made and followed through. The example alone risks underestimating what staff need to do to ensure this individual enjoys the pictures. Unlike someone using a wheelchair who needs physical assistance to have a drink for example when they decide they want one, knows which film they want to see and can get there in modified taxi; someone supporting an individual with an intellectual disability needs to know how best to support the person to make choices, widen their experience of the choices available, as well as organizing the practical steps necessary to implement choice.

Intellectual disability affects all areas of development and staff require a breadth of understanding: how to communicate with this person; how do they learn and remember things; what assistance do they need with decision making; do they use behavior to communicate distress; how well do they understand social rules. This is not to underestimate the importance of effective and trained attendant carers but to highlight that staff supporting people with intellectual disabilities (and other cognitive impairments, ABI, psychiatric disability) must be more skilled and across a wider range of tasks and situations. Much greater judgment, initiation and planning is required from the support worker in these instances or people with intellectual disability will miss opportunities to learn and participate – and quite simply end up doing nothing.

For example, the task may be meal preparation, but the staff role is not a preparer of food but an enabler of a cooking experience, of a person’s engagement in their own life. The staff role is to provide varying amounts of direct physical and verbal prompting support to enable the person to be involved in the task not to do it for them. Being responsible for meal preparation may also include extending the range of foods someone tries and in different settings; attending to diet, health and exercise; building skills to be more independent or participate in shopping, preparing, cooking, eating and cleaning up. At the same time attending to cognitive and social skills, such as improving someone’s ability to wait and attend for longer time periods, to be happy to be with one or more people, to share or cooperate with other people, to tolerate being in the same room as others or in a noisy room; to follow directions in an accessible format (words, pictures, symbols or signs). Staff preparing the food while the person with an intellectual disability sits doing nothing is not effective support.

Individualised supports and funds can and should still lead to activities based on common interest and friendship groups. For people who can initiate and direct their own life circumstances, individual funds become a wonderful means to set up how people want to live. No additional assistance is required with what to do, who to do it with or how to do it. However people with an intellectual disability may not have friends, may not have developed a wide range of interests, and may not know what is possible. Skilled support staff can facilitate wider friendship groups and craft legitimate ways people may come to together so that people with intellectual disability can live less isolated lives.

Unskilled Staff Increase Support Costs

The reference to the most important attribute of direct support staff as nice people with good rapport is inadequate to describe the skills for staff working with people with an intellectual disability (and other cognitive impairments). Unskilled attendant care staff lead to greater problems for people with intellectual disability and risk institutionalising poor expectations of how people can live. Use of unskilled attendant support staff for people with an intellectual disability are also likely to *increase* care costs over time and *decrease* people's independence and capability. The failure to respond to a person's challenging behavior appropriately by using the principles of positive behavior support, is likely to increase the use of reportable restrictive practices such as chemical restraint, but may also mean that less obvious restrictions will permeate many aspects of someone's life such as limiting cups of coffee, when someone goes out, what time they go to bed, what movies they go to for example.

Extending the Requirement for Evidence-Based Practice

It is likely that many people with disabilities, their families and indeed case managers will have limited knowledge of the evidence base about support and services for people with intellectual disability. Traditionally many interventions and service models have been based on beliefs, commitment and ideology rather than research and evidence about models and outcomes. To inform people's choices, good evidence about best practice is needed. This is not the same as brochures from services.

Choices offered by the new scheme must also be the services or support that will best support the outcomes society seeks for people with disabilities. The scheme must reflect the principles of the National Disability Strategy, and the United Nations Convention on the Rights of Persons with Disabilities. Such principles place choice alongside maximum opportunities for independence and participation in the life of the community. There is a danger that if the new scheme does not prohibit some service models, some ‘choices’ will undermine opportunities for social inclusion and the myth will be perpetuated that some people are too disabled to live in the community. The PC draft report recognises this for early intervention and therapy effectiveness but not in respect of housing and support models.

The PC draft report is worryingly silent about the type of accommodation that could be chosen and would be funded. Reflecting the campaigns of recent years, when institutions such as Kew Cottages have closed, and more recently the flagged closure of Colanda, an institution for people with intellectual disability at Colac, this silence is of grave concern. Is it intended that an individual or their family may choose large cluster housing such as Norton Road in New South Wales where ten group homes were recently built side by side on one site or the Minda campus currently being refurbished, where over 400 people with intellectual disability live together?. The design of these services is contrary to the principles of current disability policy and legislation, UN conventions and best practice research.

Services, particularly accommodation and living arrangements, for people with intellectual disabilities have a long history of being restrictive, conservative and contributing to people having boring and isolated, sometimes abusive lives. Research over the last 10 or more years has demonstrated how this can be avoided. If supports which are known to minimise the impact of disability and promote community participation are the foundation of what is funded through the NDIS individual packages, then some forms of larger scale shared housing and support packages that entail clustered or congregated accommodation arrangements should be excluded. Community presence and thus living in the community individually or in small groups is a pre–requisite for social inclusion. See for example the position statement about housing and support options published in 2009 in the Journal of Intellectual and Developmental Disabilities

(Bigby & Fyffe, 2009) or the statement on community living published by the International Association for the Study of Intellectual Disability (Mansell & Beadle Brown, 2010), both attached to this submission

There is a significant body of research that demonstrates significant quality of life advantages for people with intellectual disability who live in small group or individualised housing and support options compared to those who live in larger settings or in cluster developments (see for example, Kozma, Mansell & Beadle Brown, 2009 ; Mansell & Beadle Brown, 2009; Emerson, 2004; Bigby, 2004). Bigby and Clement's research in Australia has shown that not all small group or individual living arrangements have good outcomes but international studies show the best small group homes far exceed that of large scale segregated options (see Making Life Good reports http://www.latrobe.edu.au/socialwork/schoolstaff/reports/making_life_good_project.html Bigby & Clement, 2010; Clement & Bigby, 2010; Bigby, Clement, Mansell & Beadle Brown, 2009; Mansell, 2006). Variable outcomes in group homes are due to poor implementation. Rationing and unmet need has led to things such as incompatible resident groupings based on urgency of need rather than choice and compatibility. Poor funding and organisational practices have led to staff who doubt the feasibility of inclusion for people with more severe intellectual disability, organisational cultures that undermine engagement and social inclusion, and front line workers without skilled or regular supervision.The proposed NDIS scheme will remove one part of the equation of poor implementation through better resourcing, responding to unmet need and less gate keeping.

The NDIS cannot afford to leave the supply of accommodation services, staff and organisational practices to consumer choice or the market alone – any more than it can for therapies, early interventions etc. The scheme must regulate the type of accommodation service that can be purchased to those with the potential to facilitate required outcomes. Better still it must separate housing from support, so type or place of housing is not restricted by the degree of support a person requires. Choice of accommodation, like other interventions such as therapies, must be within the parameters of research evidence about the effectiveness of different models. Choice of large scale or cluster type developments should be proscribed

Monitoring Outcomes and Quality

The NDIS requirement for evidence-based practice, longer term outcome data and data about service system effectiveness provides a basis for ensuring the support needs of people with an intellectual disability are met though support and enabling practices, not only physical care. People with severe intellectual disability will be a significant group in the new scheme. They have limited bargaining power, many cannot self report, and do not always have resourceful family members or advocates alongside them. For this group, the benchmark of quality is not care alone or staff doing things for people but 'active support' to be engaged in their own everyday lives and to facilitate convivial social encounters. The scheme should ensure ongoing rigorous independent monitoring of individual outcomes against benchmarks of engagement, social inclusion and quality of life. These must be finely tuned for different consumer groups, to avoid the attitude often found among staff that some people are 'too disabled to participate'. We suggest that additional indicators such as engagement, social relationships with people external to the household, or participation in community based organisations be added to Table 8.1 in addition to indicators such as health outcomes.

The rationale for requiring evidence–based responses must extend especially to what support workers do. It will be very important to include cost effectiveness as part of NDIS – consumer satisfaction alone is not enough. There is a need to measure quality of intellectual disability services in terms of distinct outcome measures, of engagement and social relationships – these are not the same types of measures or standards that would apply to services for people with other disabilities. While self report or parent/carer report can be useful, research has shown that observation of practice, audits and monitoring are also needed. For example, results from a recent study in Victoria suggest very low levels of resident engagement or staff support for people with severe intellectual disability living in shared supported accommodation, yet all six of the services involved in the study met the requirements set out in the relevant quality frameworks and standards documents (Bigby, Mansell, Beadle- Brown, in progress).

Decision Making

Experience, opportunity, and support are integral to making choices and decisions. The draft PC is relatively silent on how support with decision making is to occur for people with intellectual disability, or others who lack the capacity to make some types of decisions about their own lives. As the majority of people with intellectual disability are likely to be unable to make the entire range of decisions necessary to steer their lives it will be important to set out mechanism for supported or substitute decision making that will be required or accepted by the NDIA. Much reference is made to families, and in several places to guardians or proxies, but no clear process for who might be accepted in place of the person themselves, or what mechanisms might need to be put in place to reach a decision about alternative decision making processes are set out. Significant work on supported decision making is occurring across various Australian jurisdictions that are reviewing Guardianship legislation and substitute decision making. This work should be reflected in the final PC report, (see for example recent report of the Victorian Law Reform Commission, 2010, Guardianship Consultation Paper, and 2010 annual report of SA Public Advocate).

We would suggest that for adults with cognitive impairment, at least two people who know the person well but from different standpoints should be involved in supporting decision making, rather than relying on the sole views of a family member, service provider or advocate.

Aging with a Life Long Disability and the Interface of Aging and Disability Systems.

The PC draft report acknowledged the unique patterns and needs associated with aging as a person with a lifelong developmental or intellectual disability. The report has proposed a way of managing the interface between the disability and aged care system, which is welcomed and avoids complex cross sector funding or the meaningless task of trying to ascertain what needs are related to aging and which to disability.

Aging in Place

More detail could be provided to avert assumptions or misunderstandings about this issue. For example the availability of choice to remain in the disability system needs to be further explicated to make it clear that such a choice would enable the purchase of supports from either the aged care or disability system to take account of increased or different support needs that arise as a result of aging. It would be useful to provide a stronger statement about the right of people with a disability to choose to age in place if their home is some form of disability supported accommodation such as a group home; such a statement would make the right to increased costs and additional resources to enable aging in place unequivocal.

If support to age in place were embedded as a principal in the NDIS, there should also be some consideration of the grounds on which a decision might be made that it may no longer be reasonable to support a person to remain in their current accommodation and they should move to a residential aged care service. There is perhaps an inherent danger that cost may drive such a decision, (if as stated the costs of aged people with disabilities who remain in the disability system, would be met by the aged care system through a simple cost transfer). It is noted that the 2005 Senate Enquiry into Aged Care estimated the cost per capita of a place in residential aged care was $44,000 compared to the per capita cost in disability supported accommodation of $84,000. This cost differential may be a strong driver for decision making about aging in place in the disability system if costs increase significantly as a person ages.

It would be disadvantageous to people with lower support needs if decisions were made on the basis of increased costs incurred as a result of aging. People with lower support needs are likely to incur a greater degree of change as they age and higher associated costs than people with preexisting higher support needs, whose accommodation is already adapted to their needs. Attention therefore to the decision making criteria when it aging in place might no longer be supported is important, as too are the decision making processes given the heightened vulnerability of people with intellectual disability to lose the support of family and advocates as they age.

Access to Health and Geriatric Health Services at a Younger Age

Aging of people with lifelong disabilities will bring to the fore issues about access to mainstream services such as the health system and in particular geriatric health services such as falls clinics, comprehensive geriatric assessment dementia assessment and management services. As some groups of people with disability have the early onset of age related conditions, some form of special provision will have to be made for them by the health system and geriatric health services to enable their access to such services at an earlier age. The report is currently silent on how this might be done, as is the allied PC report on the aged care system. One simple mechanism is to make people with lifelong disabilities a special group in the aged care and health systems to enable access at an earlier chronological age.

Continued Need to Access Disability Related Support if Living in Aged Care

Many people with intellectual disability will need the capacity to continue to use disability related services if they move to residential age care. This will be particularly in respect of support with social activities and relationships, as they are more likely than other groups to lack of close family and have no spouse or children. In the current generation of aging people many will have lived in institutions or disability supported accommodation for much of their lives and support to maintain contacts with previous co residents and staff will be important. It is also clear from our research that although residential aged care facilities cater well for health care needs they struggle to support the social inclusion of people with intellectual disability (Bigby et al., 2010), which is a further indication of the continuing need for support from disability services.

Specialist Input into Aged Care – will the Market Provide

As suggested above, at the moment it known that residential aged care services provide good health care but not social inclusion for residents with intellectual disability. Older people with intellectual disability are a relatively small and scattered group, and it is likely that residential aged care facilities may require support to adapt and adjust to new residents with intellectual disability as they will encounter very few. Thus some form of external consultancy and support may be necessary to resource such adaptation. It may be argued that some specialization may develop driven by market demand. Given the small population there are dangers to such specialization, which to be viable may require a large catchment area and the consequent dislocation of older people from their known locales and proximity to those who know them well.

Queries about Points in the PC Draft Report - How the System Might Work

Roles of Case Managers and DSO's

The difference between the role of a case manager and DSO is not clear and there appears to be an overlap of functions. The type of case management to be offered by the NDIS is not at all clear and given the diversity of this role is not self evidence (see for example Bigby, 2008).

Widening the Focus from Individualised Funds

Without questioning individualised responses, i.e. tailored to each individual, it remains to be tested if all funding should be individualised and administered at the level of the individual. There are options for support which may be stymied without either block funding or project-based funding to bring individuals, families, community groups or DSOs together. Such innovations are typical in support for people with an intellectual disability. There are examples of mutual support for family carers and people with disabilities that require a coordinating role (such as Key Ring schemes or Personalised Lifestyle Assistance in Victoria see Rouget, 2010) or a block roster for staff to maximise flexibility of responses (such as overnight attendant care through Nightlife). All of these types of programs offer variations to how support is offered, including attention to individuals and family members supporting each other. All of these programs have struggled to be funded because they don't start from funding to an individual. At the least, there do need to be ways for DSOs to aggregate information so that services, family and individuals can locate others with common issues and interests and share. DSOs have to be the repository of information about possibilities, others in different circumstances.

Other forms of support that are based on groups rather than individuals are include support to form self advocacy groups, circles of support and micro boards, schemes to find housemates or rental housing for people wanting to share housing. It is not clear how such programs might be funded under the proposed schemed.

It is also not clear how wider community development activities which are currently funding in Victoria through the Department of Human Services or Office of Disability will be supported under the proposed scheme. Yet these are critical activities in creating accessibility and supporting individualized activities; and create the context of what is possible for an individual to do in their own local community. For example, who does the work with a local community group to ensure it is accessible and welcoming for a person with high support needs?

Research

The emphasis on the importance of systematic data collection about the scheme's operation is welcomed as well as the importance given to research about effectiveness of services and support. Varying research approaches complement each other, and we suggest it would be important to ensure where possible research is independent of the authority to allow a diversity of approach and ensure its independence and rigor. Use of competitive funding mechanisms is suggested, a requirement that all research proposals be subject to peer review and an expectation of publication in the peer reviewed academic literature as well as other forms of dissemination should characterise decisions about research projects.

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