Productivity Commission Inquiry into Disability Care and Support

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To:

The Productivity Commission
Level 2, 15 Moore Street
Canberra City ACT 2600, Australia
disability-support@pc.gov.au

From:

Professor Christine Bigby & Dr Chris Fyffe
Latrobe University
Bundoora
Victoria

NDIS and issues for people with an intellectual disability

Professor Christine Bigby and Dr Chris Fyffe have significant research, advocacy, practice and service development experience on behalf of, and with people with intellectual disability and their families.

The aim of this submission is to:

- Welcome the directions of a national insurance scheme promising lifelong certainty and support for people with disabilities
- Recognise that people with an intellectual disability will be significant users of a new NDIS scheme and therefore NDIS has to be responsive to their needs
- Describe the features of a new system which is sensitive to people many of whom neither easily represent themselves, articulate their needs nor make good life decisions, large or small.
- Draw attention to the absence of good representation of the views and experiences of people with intellectual in consultative and policy making processes about disability service systems.

We hope that the Commission will include academics and researchers in the body of people identified as stakeholders in the future directions for NDIS.

1. ABOUT INTELLECTUAL DISABILITY

1.1 Introduction

Many of the issues and achievements for people with disabilities have their origins in wanting to create a better life for people with intellectual disability, both in Australia and overseas. This is the large group of people at the core of moves to closing large congregate settings, and to developing services to support community living. Without assistance to live in the community many people with intellectual disability do not experience good lives, and neither do their families. While recognising that people with all disabilities have common needs for housing and good support to live well, the ways in which disability support needs are met are often quite distinct for people with intellectual disability compared with other impairment groups. This large group of people are also amongst the least able to directly provide their views and preferences, a paradox in a system increasingly governed by choice. Promoting personal empowerment is more complex than simply responding to the preferences of an individual with a disability. Recognition of people's rights alone will not automatically lead to better lives, and as Reinders (2002) suggests 'civic' friendship and relationships between people with and without intellectual disability are at the core of social inclusion and the realisation of rights. It is on this dimension that deinstitutionalisation has failed so dismally for people with intellectual disability.

Intellectual disability is also a disability which means possibilities for people's lives have been consistently underestimated. A gap between research and practice has persisted resulting in ongoing failures to implement evidenced based practice to support community living. 'Choice' again has been used as a means to underfund or not implement the support found through research to lead to the best outcomes for people. The result too often has been short falls in the implementation of deinstitutionalisation and community living programs which have led to these policies per se being challenged rather than pursuit of better implementation strategies, stemming from well researched staff and organisational practices.

It is likely the Commission is hearing very little from people with an intellectual disability directly, and a lot from family carers who are at their wits end. Family members have been expected to be quasi providers in roles well beyond typical family support. With the recognition of the shortage of alternative housing arrangements and the increasing life span of this group, currently much of the supporting role has been left to family carers with varying roles for service providers. People who do not have involved family members to act on their behalf are often solely reliant on well meaning staff who are not long term constants in people's lives.

Many of the higher profile drivers for the NDIS arise from the support issues which are characteristically important for people with an intellectual disability and their family carers. The lack of housing with appropriate support has been described as an issue for people with disabilities generally. However, it is the circumstances for people with an intellectual disability in particular which have become the touchstone issues for these shortfalls, such as ageing carers, ageing in place for people with disabilities and shortfalls in supported housing. If the new directions for the NDIS don't have leverage with housing providers, many of the possible support improvements will be jeopardised and the confusion between support needs of carers versus someone with a disability will continue to divide resources.

1.2 Assessment of a lifelong disability requiring lifelong support

The incidence/ prevalence figures in the Commission's papers suggest people with physical disability are the largest disability group. However, people with an intellectual disability are the largest group of lifelong service users in the current disability system. Intellectual disability is a developmental disability which affects all aspects of someone's development for life.

a. *Decision making and the nature of support*

Many people with an intellectual disability will require lifelong assistance, from early childhood to older age, in many life areas if they are to live lives as independent, purposeful and productive as possible.

> *People with intellectual disabilities represent one of the most disadvantaged social groups. ... The pervasive nature of intellectual disabilities creates very high level of need for assistance often throughout every aspect of an individual's existence and over the whole of a person's life (European Intellectual Disability Research Network 2003, p3).*

The distinction is sometimes drawn between 'support' which is progressive and promotes learning and development versus 'care' which is a response to people's physical support and safety needs. The principles of NDIS are consistent with the provision of support. People with an intellectual disability have difficulty with problem solving, decision making, planning, attention and memory. Support to people therefore needs to tackle cognitive accessibility and maximising people's ability to understand, communicate, learn and direct their own lives.

However, many people will not be able to make life's major decisions, and delegated or proxy decision making which guides alternative decision makers (that is family members or staff), without being dominated by formality and bureaucracy must be a feature of the NDIS. Not all people with intellectual disabilities have support to make decisions or a person to champion their needs and views who is outside the service system and solely focused on their well being. If people with intellectual disability are to flourish and gain the best possible support, mechanisms to ensure such independent representation of their needs at both an individual and collective level will need to be a fundamental part of the NDIS system.

b. Assessing people severed and profound impairments

The proposed NDIS target group of people with severe and profound impairment means that eligibility for people with an intellectual disability should be based on, cognitive testing and a determination of people's adaptive behaviour (how well they manage in their environment).

> *For people with severe and profound intellectual disabilities, especially for those with multiple disabilities or other complex needs such as challenging behaviour, any assessment is heavily dependent on assumptions about 'boundaries of the possible. Judgements about what kinds of services would be best for an individual depend on a knowledge of what can be achieved – both in terms of an awareness of the range of options ideally available in the community and what it would take to help individuals live this type of life if they wanted to do so – what is needed is not so much a clinical assessment but rather an ecological assessment (European Intellectual Disability Research Network 2003, p4).*

People with a mild intellectual disability can also have very poor adaptive behaviour (that is, complex care requirements) and so have a severe or profound impairment. There is a particularly vulnerable group of people with mild intellectual disability who are not in need of personal support but do require assistance with planning, decision making, problem solving and learning and memory to minimise their contact with the expensive tertiary service system, such as criminal justice, homelessness, and child protection systems.

Eligibility for the NDIS direct funding scheme should not be confounded however with decisions about the nature of support a person requires which is the result of a complex interplay of their degree of impairment, life course stage, available informal resources, the nature of the social and physical environment in which they live and their expressed, felt, normative, or comparative needs. These factors need review over time as people's support needs will vary as a function of this interplay of variables.

2. SYSTEMIC DISCRIMINATION AND PEOPLE WITH INTELLECTUAL DISABILITY

While people with an intellectual disability aspire to the same quality of life as all members of the Australian community, how this can be achieved needs specific attention. Disability policies which outline high order principles (such as empowerment, self direction, inclusion) without attention to what this means for people who cannot easily represent themselves or make life's major and minor decisions without assistance, risk systemic discrimination. There is no point being given 'a place at the table' if the person with an intellectual disability is given the same assistance to participate as someone without an intellectual disability. To this end, people with an intellectual disability share common issues with other people with cognitive impairments such as ABI and psychiatric disabilities. While there is much discussion, rightly, about physical accessibility, cognitive accessibility has never been pursued with the same vigour.

Issues for people with intellectual disability should drive development of the NDIS because of their numbers and well established and world-wide patterns of lifetime service usage. The risk is that if people are not well supported they are more dependant, require more resources, are at risk of exploitation in various forms, and the health of the individual and family carers deteriorates. This is a very different scenario from many people with physical and sensory disabilities who are articulate and able to specify what they want in terms of physical assistance. People with intellectual disability may require physical assistance but they will always require the more complex disability support roles arising from cognitive impairment. People with an intellectual disability need assistance with decision making. This does not mean many people can't make decisions, but how those decisions are discussed and decided requires cognitively appropriate supports. Some people will need assistance with all decisions, others with more complex decisions. Without such assistance people make poor decisions, don't live well and maybe at risk and unsafe.

We are keen to present the particular issues for people with an intellectual disability who maybe underrepresented in the NDIS submission process. This occurs partly because of the influence and vociferousness of people with physical and sensory disabilities, the confusion between the perspective of people with disabilities and their family carers and the lack of a strong voice from people with an intellectual disability in their own right. Even the intellectual disability support provider sector is characterised by small agencies with little infrastructure or linkages across the state and country.

In hindsight the intellectual disability sector has suffered from the reforms in the 70's/80's whereby moves to community living were confounded with reforms of the workforce in institutions. Unlike other groups (mental health, ABI, neurological disabilities), the intellectual disability sector argued 'anyone could work with someone with an intellectual disability'. This led to a loss of professionally trained staff and a reliance on minimally trained support staff. As the complexity of providing support in the community has progressively been researched, there has been a rear guard action to train direct support staff. It is likely a re-professionalisation of the workforce is needed in ways which support people to live in community settings and integrate workforce structures to provide better status, training, supervision and career structures for professionally trained and certificate trained direct support staff.

People with an intellectual disability have also been disadvantaged by the decimation of advocacy and self advocacy across Australia. Supporting people with an intellectual disability to have their say requires sustained and careful assistance over years.

> *Disability advocacy and self advocacy are distinctly different. Advocacy involves a second person representing, supporting, standing beside a person or persons with a disability. This occurs with minimal conflict of interest and in response to discrimination, the need for protection or difficulty in sustaining a case in which their choices, interests or rights may be prejudiced. Advocacy is most frequently provided by organisations. There are many activities associated with advocacy.*
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> *Conversely, self advocacy is primarily about a group process of mutual support, information sharing and action as determined by group members. This is not to deny that self advocacy needs to inform advocacy and may evolve to undertake advocacy activities. Conceptualising and planning to resource advocacy and self advocacy as parts of the one process, or continuum, risks self advocacy being overwhelmed, isolated and compromised.*
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> *Resourcing advocacy therefore means resourcing those varied organisations involved with advocacy for people with a disability to undertake wide-ranging advocacy activities, that is, all the contributors to the total advocacy effort. Resourcing self*

> *advocacy means supporting groups to undertake what is important to them, ranging from supporting each other to promoting rights, developing skills and making choices or acting to create social change (Fyffe et al 2004).*

The absence of a well funded independent self advocacy movement in Australia has meant the views of people with intellectual disabilities have been underrepresented in consultative and policy making forums. The experience of UK and US has demonstrated that if people with intellectual disability are to be involved at systems/policy levels robust participatory structures must be underpinned by strong self advocacy movements. Rigid adherence to ideas that only people with disabilities or their families should be involved in policy advisory roles has meant perspectives about people with intellectual disability have been largely absent on such bodies; as they are seldom included and when they are, have been poorly supported and proxy representatives such as researchers have been excluded (Frawely & Bigby, 2010). All advisory and decision making processes established as part of the NDIS that include stakeholder representation must be structured to ensure reliable rather than token strategies to include the perspectives of people with intellectual disability. Various models of such involvement are found in the international literature particularly in the formation and implementation of the Valuing People policy in the UK.

3. THERE IS RESEARCH

3.1 About practice and outcomes

It is in the fields of mental health and intellectual disability that initiatives promoting community living, and not institutions, were conceived and developed. There is a solid body of research over decades and from many countries, including Australia, about how best to support community based living for people with intellectual disabilities, the service models, the nature of staff training and supervision to lead to best outcomes for individuals (see for example Mansell reports UK Department of Health, 1993, 2003, 2010, and UK demonstration programs, Mansell et al, 1997; 2004). What is frequently found is that this practice is not routinely adopted by staff, or organisations (see for example, Clement & Bigby, 2010; Bigby et al., 2009). Why this has remained acceptable again begs the question about systemic disadvantage experienced by people with an intellectual disability. When simplistic notions of choice are added to the equation for people who find such concepts bewildering when not assisted, the reasons why people with intellectual disability don't experience good outcomes become apparent, that is, if they happen to have adequate services responses. It is little wonder families are often very sceptical about how government policies could possibly be implemented given the nature of support on offer. The challenge through NDIS is to enable the research knowledge to be implemented, to be a catalyst for further research programs and to support agencies training staff consistent with these practices (such as positive behavioural support, active support, total communication).

While it is true what the NDIS states about the disability sector and the paucity of research about funded program and organisational performance, it is not true to suggest that research needs to start at first principles about what the best practice should be. Staff who are supporting people with an intellectual disability are required to provide assistance to people across all areas of development through attention to cognitive accessibility. The role is well beyond physical attendant care, directed by the recipient of that assistance. Providers need incentives to train staff in the recognised best practices. To date this has not been insisted upon and organisations attempting to train their staff in these practices experience financial shortfalls in their funding arising from more costly training programs. Why would individuals and families be given the choice to select providers not adopting known best practices in staff training and support? But this is what occurs in the name of 'choice'.

3.2 About inter-system changes

As other submissions have articulated in more depth, alongside individualised funding or service provision, the NDIS has a role to promote the development of a high quality disability service system and heighten the capacity of 'generic' services to be accessible and responsive to people with intellectual disability. To date accessibility issues for people with intellectual disability have been largely ignored in broader disability anti discrimination measures which have focussed on equal opportunities rather than equal outcomes. Much attention has been paid to physical access but little to the unique cognitive access issues that effectively exclude people with intellectual disabilities from participation in their communities or use of services, facilities or institutions available to the general population.

For example, the establishment of a Medicare item for longer consultations for people with intellectual disabilities is a rare example of structural adjustment and adaption of a mainstream service. There is much further to go however and a lot could be learned from recent policy initiatives in UK, where the 'Death by Indifference' report brought the importance of access to secondary healthcare to the forefront, presenting six case studies of people with intellectual disabilities who had died as a result of institutional discrimination (Mencap 2007). This led to an independent inquiry into the healthcare of people with intellectual disabilities, and both national health policy reform and measures in the 'Valuing People Now' policy to re-affirm that general hospitals should review their capacity to provide quality services to people with intellectual disabilities (Department of Health 2007). That is, there are roles in all other sectors in their own right (such as heath, education, mental health, housing) to support people with intellectual disabilities and these roles should never be assigned to the disability support system.

3.3 About how to fund innovation

In relation to supporting people with intellectual disability, experience from the UK and USA shows that innovation is encouraged from well funded, well researched demonstration projects, where the learnings are disseminated through training and information strategies. Self advocacy for example has flourished in the UK through funding schemes that emphasise the employment of professional policy advocates, not lowly paid and under skilled support workers. This approach builds a clear connection between research, staff training and practice and outcomes for individuals. There is no expectation of a relationship between research, staff training and practice in Australia at present, leading to the belief that nothing is known. This is not the case.

4. ESSENTIAL FEATURES OF THE NDIS

The following features are important aspects of an NDIS if it is to respond well to people with an intellectual disability includes how the direct funding scheme is structured and how decision are made; strategies to improve the performance of the disability sector; and strategies to ensure other sectors have a role with people with disabilities.

4.1 Eligibility for direct funding

Eligibility for direct funding involves the following processes:

- Assessment for eligibility for the NDIS scheme should be an administrative decision that is uniformly administered across the country. People with mild to profound intellectual disability could be eligible depending on the impact of that disability on their lives and the complexity of the support they require.
- Administrative review processes of eligibility decisions would be similar to those for income support payments and the new parental leave scheme, and must be available and administered by an independent body skilled in this area such as the Social Security Appeals Tribunal
- Separation of assessment for eligibility for the NDIS and assessment of needs arising from impairment. Eligibility means entitlement for funding within the NDIS, not specification of supports
- Separation of the funding allocation from decisions about how funding is used. The latter role should be a professional case manager to work with individual and family (if relevant) to determine what they do want, particularly on entry to the system and then at specific times triggered by events, life stages etc; reviewing needs. Attention to how funding is used can consider:
  - Opportunities to learn – this has been lost sight of and is relevant in terms of maximising independence including employment and vocational opportunities. There is enormous potential for people with intellectual disability to live more productive lives, but not if the ability to be productive is the only measure of an employment initiative. There is anecdotal evidence that many people with intellectual disability have been 'pushed out of' supported employment settings because they could not work fast enough, accurately enough or persistently enough within the rigid program requirements.
  - Multiplicity of needs. People with an intellectual disability frequently have additional conditions, such as mental illness, ill health, being older.
  - Ways to build relationships between family, community and paid staff supporters where staff have a role in facilitating wider community links.
- Assessment of disability support needs should incorporate support to determine people's expressed wishes. Assessment must however be based on a wider range of perspectives than expressed wishes and draw on the expertise of professionals from a range of disciplines as well as those who

know the person well, and be mediated through a professionally based decision making process rather than simply the whimsical application of personal choice. While many people with an intellectual disability will be able to self direct aspects of their individual support, such competence should be determined by a process which favours self direction, provides assistance as people gain skills and experience in self direction and provides clear frameworks for alternative decision makers when they are needed.

- Specialisation of assessors for different impairments is recommended, including dual disabilities and ways to recognise the 'by exception' or complex circumstances requiring different responses. Panels maybe helpful approaches to exceptional situations.
- Incentives to reduce and contain costs are recommended which are driven by practices which increase people's independence and ability to steer their own lives.
- Adoption of support options which include strategies to increase someone's social and community participation, including but not limited to employment, and promote safeguarding such as circles of support.
- Timelines for decision making in the NDIS processes must be meaningful and create certainty for individual and families
- To minimise bureaucracy at all levels while maintaining a strong administrative system positioned to be enabling and benefiting, rather than gate keeping with arbitrary decision making.

4.2 Strategies to improve the performance of the disability sector

People with disabilities should be involved 'top to bottom' of NDIS, but if that is to include people with intellectual disabilities there must be very good processes to make that effective and beneficial for everyone. Consider:

- Support for self advocacy. There is not good advocacy support for this group and efforts are often confused with the voices of family carers. This is unlike many of the other disability groups which have state-wide and national bodies. The intellectual disability sector gets lost in the disability-wide system which can be dominated by people with sensory and physical disabilities, whose circumstances are fundamentally different. People with an intellectual disability will not have a strong voice simply by being 'given a voice at the table'.

- Recognition that the role of support staff varies and includes increasing cognitive accessibility so people can participate and a facilitative and community development role linking people in their local communities.
- Workforce development strategies which consider the overall workforce and the relationships between professionally trained and supervisory staff and direct support staff. Too much is being asked of an essentially undertrained workforce. Workforce development must be a subset of organisational and sector development, all of which have suffered within resources constrained environment. Good quality support depends on more than initiatives to train minimally trained direct support staff.

4.3 Strategies to ensure the role of other sectors

The NDIS needs to have influence and leverage with other sectors so that the interfaces are well managed at the individual and systemic level. For example, who funds the support for a person with an intellectual disability to be in hospital? Does the person with a disability have to pay for things other people don't have to, such as acute hospital care, through the requirement to have additional support staff? This is what the acute hospital system frequently requests, despite, for example, the health system using resources to ensure people who don't speak English can understand their hospital experience.

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