Comments on the Productivity Commission Draft Report:
Disability Care and Support

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About us

UnitingCare Queensland is the health and community service provider of the Uniting Church in Queensland and supports more than 14 000 people every day of the year.

With over 15 000 staff and 8 500 volunteers in more than 400 geographic locations across Queensland, it is one of Australia's largest non-profit health and community service providers, with annual revenue in excess of $1 bn.

Our Service Network

UnitingCare Queensland delivers quality and compassionate care through its network of agencies. Our agencies and services are:

Blue Care

- Blue Nursing
- Residential aged care services
- Allied health services
- Personal care, social support and domestic assistance to older people and people with disabilities in their own homes
- Respite care
- Palliative care
- Pastoral care and counselling

Lifeline Community Care

- Counselling
- Family services
- Youth and children's services
- Disability services
- Telephone counselling (24 hr crisis counselling line)
- Support to communities following a disaster
- Prison Ministry

UnitingCare Health

- The Wesley Hospital
- St Andrew's War Memorial Hospital
- St Stephen's Hospitals – Maryborough and Hervey Bay
- The Sunshine Coast Private Hospital

UnitingCare Centre for Social Justice

UnitingCare’s Centre for Social Justice uses research, education and advocacy to address social disadvantage

Wesley Mission Brisbane

- Residential aged care
- Disability employment services
- National service delivery to the deaf community
- Supported accommodation
- Youth services
- Childcare services
- Emergency relief
- Community centres
- Day respite services
- Community care
- Allied health services and hydrotherapy

Overview

UnitingCare Queensland welcomes the Productivity Commission's work to "enhance the quality of life and increase the economic and social participation of people with disabilities and their families" through a "practically implementable and efficient scheme" for disability care and support (1.11, 1.14).

We welcome the opportunity that this proposal presents for once-in-a-lifetime reform of the disability sector.

UnitingCare Queensland strongly endorses the Commission's focus on:

- Foundational principles of care and support and the related system reforms, particularly:
    - Move to an entitlement based system
    - A national system that embraces transportability
    - A focus on person-centred approaches
    - A shift in decision making to people with disabilities and their families and choices about how services are delivered
    - Flexibility in how services are delivered
    - An emphasis on inclusion in community life and local solutions
- A sustainable funding system (NDIS), scope and eligibility
- Recognition of the intersections of disability and ageing
- Acknowledgment of the impact of geography on pricing
- The proposed exemption from assets and income tests.

In finalising the report, UnitingCare Queensland would like to see more attention and emphasis on:

- Addressing complex needs and the needs of people who experience multiple disadvantages, including Aboriginal and Torres Strait Islander clients, those with difficult behaviours, those with dual diagnosis, those with recurrent and/or persistent mental health conditions and those who are non-verbal
- Addressing the needs of people with mild intellectual disabilities, given they are over-represented in mental health and homelessness services, and in the criminal justice system
- Pricing arrangements supportive of investment by service providers in innovation, workforce development, and high-quality personalised services.

In addition we would like to see more discussion about the role of the NDIA with respect to:

- Its systems advocacy role with respect to the adaption and improvement of mainstream 'services' and infrastructure, such as Universal Housing
- Its multiple functions as policy-maker, investor of NDIS funds, advocate, funder, and regulator, and the desirability of separating out the regulatory and complaints body roles (as has been recommended in the Carer for Older Australians report)[1].

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[1] Productivity Commission, 2011, Caring for Older Australians, http://www.pc.gov.au/__data/assets/pdf_file/0003/104889/09-chapter5.pdf

Key Questions

In relation to services for people experiencing multiple disadvantages and complex needs we have the following questions and comments:

- Assessment of need especially for those with complex needs is not straightforward
- Assessment needs to be embedded in knowing the person well and understanding their strengths and their challenges. How will this be possible within the approach proposed for the NDIA?
- What work will be done to ensure NDIA assessments are recognised by mainstream service providers such as Centrelink?
- What role will the NDIA take in relation to ensuring the quality and compatibility of mainstream services? For those in Tiers One and Tiers Two, this will be incredibly important, and in some cases, will help to ensure that their conditions don't deteriorate to the point that they enter Tier Three
- Will the NDIA be adequately funded, resourced and oversighted to manage its wide portfolio of responsibilities?
- Will sufficient investment be made to ensure that Aboriginal and Torres Strait Islander people can access NDIA services? We note that while responsibilities for addressing Indigenous disadvantage are shared, only by specifically earmarking funding to the challenge can real inroads be made
- Will sufficient investment be made to ensure that members of Australia's Deaf Community, including Aboriginal and Torres Strait Islander people and their primary support person(s) have appropriate and adequate access to a broad range of supports, including Auslan Interpreters and/or notetakers?
- What mechanisms will there be for the most disadvantaged clients, including those with challenging behaviour, those in forensic units, those in the criminal justice system, those who are non-verbal, and those with an intellectual disability?
- Will DSOs be sufficiently independent to carry out effective advocacy?
- Will assessment tools be able to overcome persistent bias against social impacts of disability, which particularly impact on the lives of those with intellectual disabilities?

In relation to pricing arrangements and service implementation we have the following questions:

- Will pricing arrangements capture the full costs of service provision, particularly in rural and regional areas and in emerging services? Will a ‘full costs’ definition be articulated so that services are equitably funded and not potentially competing against each other in relation to price?
- Will benchmarking of pricing be extended to those services currently run by the State Governments?
- Will pricing adequately capture the full costs of training and supporting an expanded workforce?
- Will legitimate resourcing costs be included, such as depreciation? (Currently these are not allowable in Queensland state government-funded services?)

Detailed commentary

Introduction

UnitingCare Queensland strongly supports the social insurance model proposed by the Productivity Commission as a sustainable, pragmatic plan to address the growing unmet demand for disability services and once and for all move the system out of perpetual crisis mode.

The model proposed by the Productivity Commission represents a massive step forward for the sector. It is marked by clear advantages over the current system, including:

- Foundational principles of care and support and the related system reforms, particularly:
  - Move to an entitlement based system
  - A national system that embraces transportability
  - A focus on person-centred approaches
  - A shift in decision making to people with disabilities and their families and choices about how services are delivered
  - Flexibility in how services are delivered
- An emphasis on inclusion in community life and local solutions
- A sustainable funding system (NDIS), scope and eligibility with the injection of massive new federal funding ($6B to add to the existing $6.5B), more efficient centralised administration by NDIA, and more competitive service provision, will support higher quality services, provided on the basis of need
- Strong focus on early intervention, whether the disability is identified in childhood, adolescence, or adulthood
- That eligibility is not restricted to those with a ‘severe or profound’ disability (ie. the report does not use the less than helpful ABS category definitions)
- Recognition of the critical intersections of disability and ageing and the choice of remaining in the disability system after aged 65
- Acknowledgment of the impact of pricing on geography
- That assessments undertaken by the NDIS may be recognised by Centrelink and other authorities
- The proposed exemption from Assets and Income tests.

Chapter 3 - Who is the NDIS for?

We agree that services should be provided according to need, whenever the need is identified.

We support the expanded, four-part eligibility criterion developed by the Productivity Commission, which moves beyond ‘severe and profound’ disability to encompass a wider understanding of support needs.

We also agree that eligibility should not be contingent on assets or income.

We note with approval that the draft report differs from the earlier DIG report of 2009 which only included people with an intellectual disability who had a severe or profound core activity limitation (p 14.17). We welcome the changes in this proposal which does not use ‘severe or profound’ as the criteria for eligibility and which acknowledges in submissions from AIHW and NSW Council for Intellectual Disabilities the need for support in non-core activity areas (p 3.10).

However we are concerned that not all persons with an intellectual disability are going to have access to the services they need under the NDIS and we urge the Productivity Commission to recommend support for all persons with an intellectual disability.

Although the draft report does not rule out people with functional definitions of so-called ‘mild’ intellectual disability, and the Commission has noted the relatively low costs of providing support to this group, not all persons having a ‘mild’ intellectual disability will benefit from support from the NDIS in its current format.

Strengthening the argument for early intervention for this group, Morrie O’Connor, Coordinator Community Living Association Inc, has emphasised to UnitingCare Queensland that people with IQ 55-70 face severe and profound difficulties, many of which can be dramatically de-escalated if they have appropriate support. This accords with our own experience.

Mr O’Connor also emphasises the vulnerability of this group to a steady deterioration in their living conditions without such support, particularly where they face other disadvantages and lack a strong social or family network.

The Commission seeks feedback on where the boundaries between the mental health sector and the NDIS might lie. In particular, the Commission would appreciate feedback on which system would be best placed to meet the daily support needs (not clinical needs) of individuals with a disability arising from long lasting mental health conditions (such as schizophrenia), including:

- *which services would be provided by the NDIS and not the mental health sector and how these could be clearly identified*
- *the magnitude of the budget that would be required*
- *how to guard against cost shifting*
- *how the NDIS would practically integrate any role in ongoing non-acute services with the wider mental health sector, including any shared responsibilities of case managers in the two systems.*

We support the Commission recommending that the NDIA accepts a duty of care for persons with a permanent mental health condition characterised by psychosis.

We recommend that the responsibility for services be split as simply and clearly as possible to prevent demarcation disputes between agencies.

We support the approach favoured by the Queensland Alliance of Mental Health that would see a system closely mirror the current division of responsibilities whereby the mental health sector (State-funded mental health services) would be "largely responsible for the delivery of clinical services to people with severe mental illness", and the community mental health sector (funded via the NDIA as approved disability service providers) would be "responsible for delivering the necessary non-clinical supports and services to people with severe mental illness"[2]. These non-clinical supports include:

- The development and implementation of a range of supported accommodation options for people living with recurrent and/or persistent psychotic disorders, giving priority to those living at home with ageing parents/caregivers

- Life Skill Development – A mix of outreach and in-home support to develop life skills to assist the individual to maintain personally meaningful and independent lifestyles. This could include direct support with hygiene and wellbeing, domestic skills, budgeting and paying bills, using public transport, cooking and nutrition and social and interpersonal skills

- Community Access Services – Emphasis is on promoting social inclusion, community access and integration. Outreach support is offered to support access to a range of social and recreational activities in the local area

- Vocational Support – Based on the understanding that obtaining and maintaining employment, and pursuing education and training goals are key ingredients to people with mental illness having a sense that they are giving back to and regaining citizenship in the broader community. Support is offered to explore and initiate steps towards achieving vocational goals by addressing barriers that make it difficult to obtain and maintain employment. This includes identifying career options and pathways; developing or updating a resume; targeting skills and industry types; accessing training, traineeships and apprenticeships; writing application letters and addressing employment criteria; improving interview skills; negotiating the recruitment process; maintaining employment through direct on the job support and training; and support to resolve conflicts or issues whilst at work.

Alongside this system, the primary mental health sector (GPs and privately practicing allied health professionals) would continue outside the NDIS to predominantly provide clinical services and non-clinical supports and services to people with mild to moderate mental illness.

With the Queensland Alliance for Mental Health we support the Commission's statement that "disability services should not replace mainstream or other specialist services available to the broader population". We also echo QAMH in cautioning that the NDIS should not respond to the current limited access to mainstream mental health services by providing its own substitute services. We agree with QAMH that this would unreasonably relieve "mainstream mental health services of their responsibility to provide adequate services to people with a disability, and may result in people with a mental illness being treated as lower priority and reduce the likelihood that mainstream services will make adequate effort to become truly accessible to people with a disability".

With the Queensland Alliance for Mental Health we support the Commission's recommendation to develop a Memorandum of Understanding between the NDIS and the mental health systems in each State and Territory, as well as the Commonwealth Department of Health and Ageing, to guard against individuals falling between the cracks of the respective schemes. We agree that this MOU should also "establish effective protocols for referrals and other transitions between systems, and should clearly articulate systems for escalating problems, issues and complaints when they arise".

Over time we would expect to see Queensland Health Mental Health Services and Medicare-funded local services become more responsive to the needs of any persons with a mental illness through the active lobbying, research and leadership of the NDIA.

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[2] Jeff Cheverton, Queensland Alliance for Mental Health, Draft Response, Disability Care and Support – Introducing the National Disability Insurance Scheme, by email 13 April 2011.

Chapter 4 - What individualised supports will the NDIS fund?

Links between NDIA and mainstream services

We have remaining questions around the ways in which the interface with mainstream services will be managed.

In many instances we believe the NDIA will need to be proactive in developing the relationship between mainstream services and disability services such as is proposed in the previous section on mental health.

The NDIA will need a strong and ongoing role in promoting the importance of mainstream services that are responsive to the needs of people with disabilities, and in supporting legislative and regulatory change where this is advisable.

Housing

UnitingCare Queensland supports the submission from Queensland Action for Universal Housing Design in response to the Commission's draft report[3]. We urge the Productivity Commission to support the regulation of minimum access requirements in all new and extensively modified housing through the Building Code of Australia.

NDIA and employment

We note that it is not always clear in the report the specific boundaries between 'job readiness' programs that will be funded by the NDIS, and mainstream employment service programs, which will not.

In reference to employment, we seek further clarification that the NDIA will have a sufficiently strong advocacy position to secure improvements to DEEWR employment programs for people with a disability, for example in relation to the current DES contracts with service providers which:

- Do not allow for flexible servicing arrangements
- Do not allow for flexible work options for clients to achieve employment outcomes
- Require service providers to see all clients fortnightly which in some cases is not reasonable due to the client's capacity to participate or family commitments
- Stipulate that if a client does not remain with the same employer for the duration of their outcome period then the DES service and client only have 20 working days to find alternative employment, even if the job loss resulted from an effect of the disability, and even if the client may need time to recover and plan for new strategies to achieve ongoing employment
- Establish an unrealistic baseline expectation for 'employment benchmark hours' that must be reached each week for the client to be considered to have reached a successful outcome.

We would welcome a number of specific changes in relation to mainstream employment services for people with a disability (which do not fit the NDIA criteria of 'job readiness schemes') including that:

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[3] Margaret Ward and Wendy Lovelace, QAHD Submission to the Productivity Commission Inquiry into Disability Care and Support, by email, 26 April 2011.

- The requirements around Break in Employment should have more flexibility when a client is tracking towards an outcome. The current system allows for 4 weeks break in the first 13 weeks and 4 weeks break in the second 13 weeks of a 26 week outcome. This does not allow for clients who experience an episodic condition or clients employed on a casual basis that require a longer period to gain alternative employment. There should be no limit to the number of times a client is permitted to have a break
- All levels of government should have a commitment to employ clients specifically from DES services, not only commitments to employ people with a disability.

NDIA and supported wages

We would also welcome more information around the role of the NDIA in relation to monitoring the effectiveness of supported wages to provide incentive to both employee and employer for participation in the workforce. Wage subsidies should be more appealing for employers as JSA providers have the ability to offer substantially higher subsidies than DES services.

NDIA and income support

In regards to income support, the draft report recognises that although the DSP (with coverage of 793,000 people as at June 2010) is outside the scope of the NDIS, “there are grounds for (further) reform of the DSP” to better support employment and independence outcomes for people with a disability, and to financially offset the NDIS (p 4.24).

While broadly in favour of reform for the purpose of maximising human potential, we would strongly resist any changes that might have the effect of re-allocating Disability Support Pensions away from people with so-called mild intellectual disabilities, particularly given the weak understanding and assessment of intellectual disabilities by mainstream agencies (p 4.25).

Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance and the Child Disability Assistance Payment

The Commission seeks feedback about whether Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment should fall within the scope of the NDIS.

We take the view that Carer Payment, Carer Supplement, Carer Allowance and the Child Disability Assistance Payment should not fall within the scope of the NDIS, however the Mobility Allowance should.

The broader eligibility criteria for these services, and their nature as ‘income support’, mean that Centrelink is better suited to their administration.

The Mobility Allowance on the other hand is more naturally associated with the care and support of persons with a disability.

We support the idea that where available the NDIS assessment should be utilised by Centrelink in assessing eligibility for disability related payments.

The Commission considers that needs assessments should take account of the extent of natural supports, and that the NDIS should waive the front-end deductible where the value of this support exceeds some government determined level. The Commission would welcome feedback on what that level should be.

We take the view that a modest fixed upfront contribution to the NDIS would be unlikely to be effective or necessary because:

1. The fee would usually be waived for people who are primarily cared for by their families because their contribution would always be significant
2. The fee would usually be waived for people who are not primarily cared for by their families because their capacity to pay would be limited
3. There are so few in a third group, not cared for by their families and with capacity to pay, as to be unlikely to warrant the cost of collecting the upfront contribution.

Chapter 5 - Assessing Care and Support Needs

Independence of assessments

While we are broadly in favour of independent assessment, separate and distinct from service ‘gatekeepers’, we urge the Commission to more clearly represent the need for approaches which build trust and open communication especially with people who have complex needs and/or multiple disadvantages. We have observed that the more disadvantaged the client, the less likely that some independent assessors will be able to get all the relevant information for an assessment. This issue can particularly affect work with some people with challenging behaviours, work with Aboriginal and Torres Strait Islander clients, and work with clients with dual diagnoses. Assessors are unlikely to get a full picture of the needs of these most marginalised clients without an existing relationship based on trust.

As a result the processes of assessment will be just as important as the tools that are utilised. When a person does not have strong advocates, this is especially important.

Timeliness of assessments

The availability of timely assessments at the local level will have a major impact on the client’s experience of the NDIS.

We have observed through our work in the aged care sector that waiting times for Aged Care Assessment Team assessments can be lengthy. As the Productivity Commission noted in the report, Caring for Older Australians, the long delays between referral and first face-to-face contact with the ACAT (on average 31 days in Queensland) can see clients referred to unsuitable services and long stays in hospitals (p 97)[4].

We acknowledge that the NDIS governance model differs to that of the ACAT, which is funded by the Commonwealth and delivered by State and Territory agencies.

We also note that the waiting list for assessments will potentially be managed at least in part through the process outlined on page 5.26 which provides for a short set of questions, and a self report questionnaire, completed by consumers prior to any full assessment of their needs.

However, Recommendations 5.1 to 5.9 which treat the topic of assessment do not specify how waiting times for assessments will be managed.

More information could be provided to indicate how services can be provided to people who have passed through this first, short assessment and are now waiting for a more in-depth assessment. This would also support the intent of the early intervention strategy.

We take the view that the Productivity Commission should strengthen the recommendations around the timeliness of assessments by including as a recommendation the text on page 5.27, so that “streamlined processes are employed to ensure that individuals do not have to wait excessive periods for their care and support package to be finalized” and that “The NDIA should report annually on this metric” (Disability Care and Support, p 5.27).

Quick approvals for client-proposed changes

We support the capacity for quick approvals as an effective way to ensure that an individual can have their needs met as these change from the time of the initial assessment, without needing to be subject to a full re-assessment.

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[4] Productivity Commission, 2011, Caring for Older Australians, http://www.pc.gov.au/__data/assets/pdf_file/0003/104889/09-chapter5.pdf

We urge stronger provisions to ensure that assessment can occur at a client's request, to meet the client's own objectives.

Sharing assessments with mainstream agencies

We are in favour of a universal standard of assessment of a person's care and support needs, so that assessments don't need to be repeated to access mainstream services, provided the person agrees with this sharing of information.

We take the view that with permission of the person with disability some mainstream services should have access to assessment data in order to prevent the unnecessary duplication of assessments of the client and to protect clients against having to tell their story over and over again.

We would support measures to ensure that NDIA assessments are recognised by mainstream service providers such as Centrelink. Using the e-health model, clients should have control over their information, and the ultimate authority over decisions to share it with other agencies.

Specific assessment tools

The Commission seeks feedback on whether these tools, or any other assessment tools, would be appropriate for assessing the care and support needs of individuals having regard for:

- *the role of the assessment process in the context of an NDIS*
- *the desirable traits as outlined in section 5.4.*

We take the view that not only the utility of the tools but also their useability and the processes of undertaking the assessment will be critical to ensure that approved plans comprehensively support individual choice and capacity. The client should be able to understand the assessment and give their consent to participate. Where that is genuinely not possible, the consent of the substitute decision-maker must be sought.

We would also welcome efforts toward the development of a tool which better measures the consumer's needs for protection and advocacy. Through the use of such a tool the case manager can ensure that the client is appropriately supported through the process. Without such a tool the case manager will have recourse only to their own subjective assessment to determine the consumer's needs for support, by a DSO or through their own circle of support, to navigate the system for example, press complaints, or negotiate the terms of their care and support package.

We also wish to draw the Commission's attention to particular, long-running problems with assessment which should be the focus of early and sustained development of best-practice tools:

- Intellectual disability
- Dual and multiple diagnosis (particularly where there is disability and mental illness)
- Sensory disability (deaf, blind and/or deaf/blind). Use of appropriate technology, format, visual/aural representation needs to be considered
- Work with Aboriginal and Torres Strait Islander communities
- Work with CALD communities.

Dual and multiple diagnoses

We note the difficulty of consistently and fairly assessing consumers with multiple diagnoses.

Through our work we see the particular problems faced by people with a ‘dual diagnosis’ of both a disability and a mental illness. We urge that this be a particular focus in the development of best-practice assessment models, which may not be tool-based.

In particular, we note that the difficulties of assessing around developmental needs require a multi-disciplinary approach.

Assessing intellectual disability

We are concerned that there is a current lack of accurate assessment tools for determining the impact of intellectual disability on a person’s life, and on their need for care and support.

We urge the Commission to recommend the development of more accurate assessment tools and processes for intellectual disability as a matter of priority for the NDIA.

We take the view that the NDIA will need to utilise assessment tools which properly and adequately chart the significant difficulties of people with intellectual disabilities and to recognise that these may be different tools from other people with a disability or this group may be unfairly disadvantaged.

Where other people with a disability are likely to accurately report functional impairments associated with their disability, a person with an intellectual disability is likely to want to stress their ‘sameness’ and thus to wrongly report themselves as able to carry out particular functions. In one case a person undertaking a functional assessment of someone with an intellectual disability and cerebral palsy asked a series of questions such as “Can you cook?”, “Can you paint a house?”, “Can you organize a dinner party?”, and the person with an intellectual disability replied in the affirmative to each of these questions even though they were things the person could not do or could do only with considerable support.

Assessors will need to be carefully trained and monitored to ensure that they understand the ways in which even so-called ‘mild’ degree of intellectual disability can severely impact a person’s life in the absence of appropriate support. The label ‘mild’ should not be used to immediately negate and downgrade the needs of a person, as is currently too often the case.

The severe difficulties that people with an intellectual disability face in relation to mobility, self-care and/or communication are in many ways quite different to the difficulties that other people with a disability face and may need to be assessed differently. For example a person with an IQ in the range of 55 to 70 may be able to speak clearly and be understandable to others. However, they are likely to have significant difficulties with communication which include:

- Finding it difficult to understand what others are saying particularly if they use complex concepts or words or speak quickly
- Finding it difficult to tell others that you don’t understand and therefore appearing to agree
- Agreeing out of anxiety to be accepted, even if it is not what you want
- Finding it difficult to read written language and comprehend, even if able to read individual words
- Finding it difficult to relate to numerical concepts e.g. time and money
- Finding it difficult to engage in more sophisticated communication, for example discussing feelings, or personal issues, or following humour.

These significant difficulties can lead people with intellectual disabilities in the range of IQ 55-70 to experience confusion and anxiety in everyday life, rejection and isolation in social situations and work places, and manipulation and exploitation in financial and other dealings.

People with an IQ in the range of 55-70 are likely to have 'significant difficulties' in self-care which include:

- Keeping self safe from sexual exploitation
- Keeping self safe from financial exploitation and other exploitation
- Keeping self physically healthy – rates of obesity, poor dental hygiene are high in this group. Substance abuse is becoming a growing issue for people with IQ 55-70 range (Dickson et al, 2005). Age of death is much lower than for the population average.

The severe and profound social disadvantages that people with an IQ 55-70 face are demonstrated by their gross over-representation as:

- Victims of sexual assault
- Victims of crime- (Jackson, et al, 2006; Lindsay et al, 2010)
- Offenders- (Jackson, et al, 2006; Lindsay et al, 2010)
- In the care of child safety (Fudge Scholmans and Rooke, 2008)
- Having their children taken into care of child safety (Hill, 2009)
- Homelessness
- Mental health diagnoses and disorders; and (Baludesian, 2005/2006)
- Unemployment and poverty. (Geener and Powers 2007).

These gross over-representations are the direct result of the inherent difficulties of attempting to negotiate our world with an intellectual disability.

The impact of disability is different for people with an IQ 55-70 than for many other people with a disability. While for other people with a disability difficulties around self care may lead to almost immediate physical harm, for a person with an IQ 55-70 it will be a slower grinding down into disadvantage, exploitation, poor health and early death.

The severe and profound difficulties that people with intellectual disabilities face can be dramatically de-escalated if people have appropriate support. Many people with IQ 55-70 live very safe if sometimes circumscribed lives in caring family environments. It is likely that the ultimate support needs of this group go largely unrecognised while such secure family support exists. If, however, this family support falters they are very vulnerable. However, many people with intellectual disabilities come from family backgrounds that expose them to severe disadvantage. If a young person with an intellectual disability is born into a family that experiences homelessness, drug use, poverty, mental illness, exploitation and child safety interventions, then their social outcomes are severely compromised.

In particular, following work by Nicholas Lennox and Gillian Eastgate, we urge the Commission to provide more detail about how GPs, as the health professionals most often consulted by people with intellectual disabilities, will be integrated into the NDIS system to ensure this group gets proper support[5].

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[5] Nicholas Lennox and Gillian Eastgate, 'Adults with intellectual disability and the GP', http://espace.library.uq.edu.au/eserv.php?pid=UQ:9277&dsID=n20040803lennox.pdf , viewed 20 April 2011.

Chapter 6 - Who has the decision-making power?

It is clear from a reading of the draft report and bibliography that the Commission has drawn much on the Western Australian experience of Local Area Coordination in the design of the service model. Local Area Coordination as it has been developed in Western Australia, applied in NSW through Local Support Co-ordination, and also further adapted in Queensland, first in rural areas, and now in one urban area (Goodna), offers huge advantages over bureaucratic models of service provision, including:

- The capacity to support people where they live, including away from the coastal metropolitan areas
- Supporting resilience, building the coping skills of families and individuals
- Supporting the development of natural networks and services based on relationships
- Providing some untied funds, so that individuals have flexibility to purchase the services they choose.

UnitingCare Queensland supports the comments of others such as John Homan, who have asked for the Commission to more clearly emphasise how the model will be implemented in a client-controlled manner which preserves flexibility and builds relationships at the local level, and will avoid becoming another rigid bureaucracy.

We believe that it will be very important to ensure that, while providing effective oversight and fiscal control, the senior management of the NDIA will continue to allow flexibility and control at the grassroots level: to the individual consumer, their DSO, and the local case manager.

It is at this local level that we wish to see relationships prioritised so that the needs of individuals can be met in a way which respects their dignity.

The effectiveness of local case managers could be undermined if they are bound too tightly in a hierarchic chain of command, controlled by targets and benchmarks, when their primary focus needs to be on their clients and their clients' needs.

Similarly, we urge the Commission to articulate the need for cultural change in the sector to fully support client-controlled systems, so that people are not bringing to their new roles the cultural baggage of their previous roles in a broken system (such as the habit of rationing services).

Adequate funding to individuals for DSO support

We believe the role of DSOs is sufficiently important to be provided 'free of charge' to consumers, in much the same way as job readiness services will be provided.

Disability Service Organisations will have an important role to play in assisting people to exercise choice in the NDIS, for example, helping them to understand and to navigate NDIS services, to have NDIS decisions reviewed, or to self-manage their own packages of support.

The draft report states that after initial subsidies for DSOs by the NDIA ended, funding for DSO services would be made according to consumer choice out of the individual budget.

We take the view that separate allocations in support packages will be required to finance DSO support for all those who would benefit from advocacy services to exercise their rights to choice and control under the NDIS.

For particular groups of consumers, such as those with an intellectual disability, support is crucial to help the consumer exercise choice.

We take the view that the NDIA should use the assessment process to identify consumers who would benefit from the support of a DSO and who would like the support of a DSO, where one is available.

We would urge that assessments consider the client’s need for independent advocacy and DSO support services at this stage, so that funding can be earmarked to enable the individual to be supported to exercise choice.

In this way, all those so identified who would benefit from DSO support to exercise choice should have ‘free of charge’ access to that support.

An allocation can be made to the individual’s funding to cover the costs of the DSO services at an agreed price, established by the NDIA and reimbursed to the DSO in the usual manner.

DSO services could be included in that class of goods and services which are not “included as items in a person’s individual budget, though they would be included in the overall budget allocated to the person through the assessment process” (6.26), which effectively makes them free to the consumer who needs them. This class of goods and services includes job readiness programs and specialist therapies.

Chapter 7 - Governance of the NDIS

Supporting capacity in service providers through clearer pricing mechanisms

We are concerned that the recommendations do not adequately support the development of capacity in service providers.

In particular we take the view that the pricing of services will be critical to ensuring the viability of service providers while supporting a vibrant and sustainable market for disability services and minimising up-front and additional costs to consumers.

The draft report makes clear that the National Disability Insurance Agency will be responsible for setting efficient prices and that these need to cover the full costs of agencies in service provision including for example:

- Travel time by specialists to remote areas (p 8.51)
- Ensuring adequate returns for capital investment (Overview, p 40)
- To provide sufficient incentive for providers to deliver services to clients with challenging behaviours, with complex needs, or in remote areas (Overview, p 42).

It is not clear to us how the infrastructure costs, organisational costs and overheads of service providers will be taken into account in the determination of pricing.

We would also like to see more discussion of the links between pricing and quality. Specifically, we would like more detail around the ways in which pricing mechanisms will protect against any tendency toward lower-cost, lower-quality services over time.

We are particularly concerned that without appropriate pricing arrangements the loss of funding certainty might diminish the capacity of smaller organisations, especially consumer-controlled organisations, to be sustainable and to invest in the costs of hiring specialist staff for service provision.

We would urge stronger provisions to provide for transparency and clarity around pricing, and mechanisms to be put into place to provide a means for prices to be reviewed at the request of service providers and to be adjusted in some situations.

Multiple roles of the NDIA

We would like to see more discussion in the final report regarding the governance model of the NDIA with respect to the potentially conflicting roles of the NDIA. In our view an appropriate safeguard for people with disabilities and their families would include a separation of the regulatory and complaints systems from the funding and policy making roles of the NDIA.

Chapter 8 - Delivering disability services

Foundational principles

We agree with other submitters, including the NSW Ombudsman, that the scheme should be closely aligned with the National Disability Strategy and the UN Convention on the Rights of Persons with a Disability.

We support the foundational principles as set out in the draft report.

Role of advocacy

We are concerned that the advocacy provisions of the NDIS are too weak to properly protect the rights of those most vulnerable, including for example those with an intellectual disability who have no one willing to act in their best interest.

We understand advocacy to mean the process of speaking, acting or writing with minimal conflict of interest on behalf of the interests of a person or group, in order to promote, protect and defend the welfare of and justice for either the person or group by:

- Being on their side and no one else's
- Being primarily concerned with their fundamental needs
- Remaining loyal and accountable to them in a way which is empathic and vigorous.[6]

The report acknowledges that:

> *people with an intellectual disability may have a diminished capacity to make informed rational decisions that serve their best interest and may have a limited ability or confidence to express any inadequacy in the services they are receiving (p 8.22).*

We believe that stronger advocacy provisions are necessary to meet the needs of this group, particularly those who are socially isolated and have no informal supports such as family to advocate on their behalf. Many of the most vulnerable people with disabilities in our society live in isolated, institutionalised settings such as boarding houses and hostels, and secure accommodation facilities. Without the assistance of independent advocacy organisations who are willing to uncover and question such practices, many of these people would remain in such settings, as service systems may be unable and unwilling to offer more life-affirming options.

While service providers, DSOs, and systems of quality regulation all have a role to play, we are concerned that these proposed avenues do not provide sufficient independence. When a person or group advocates on behalf of the interests of a vulnerable person or group, there is likely to be significant costs to the advocate. These costs (as outlined by advocacy groups such as the Combined Advocacy Groups Queensland) can include physical and emotional stress, time and resources, social opprobrium, rejection, and threats to livelihood. The capacity for service providers and/or DSOs to engage in advocacy is compromised by organisational and system realities and interests, and there is a very real risk that some of the most vulnerable people with disabilities in our society may not have their voices heard or interests met under such a system.

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[6] Department of Families, Housing, Community Services and Indigenous Affairs. (2011). *National disability advocacy program.* Retrieved April 13th, 2011, from http://www.fahcsia.gov.au/sa/disability/progserv/providers/NationalDisabilityAdvocacyProgram/Pages/NationalDisabilityAdvocacyProgram.aspx

A partisan approach is needed in disability advocacy as outlined in the National Disability Advocacy Program Framework (2011), by which the advocate or advocacy group is on the side only of the person with disability, and is distinct and autonomous from service brokerage and delivery[7]. We would urge the Productivity Commission to propose a place for other forms of advocacy distinct from DSOs and service providers within its proposed framework.

FAHCSIA (2011) categorises disability advocacy into six broad models being:

- Individual advocacy
- Citizen advocacy
- Family advocacy
- Self advocacy
- Legal advocacy and
- Systemic advocacy.

Of these, citizen advocacy, legal advocacy, and systemic advocacy are not well-integrated into the proposed model.

Recognition needs to be given to the important roles each advocacy model plays in ensuring that people with disabilities and their families are able to navigate the system. The Productivity Commission needs to consider how the NDIA will support the different forms of advocacy in the proposed model, and how disability advocacy can continue to be vigorous, independent and see important issues through to their conclusion under the current model. By not doing so, there is the likelihood that some disability consumers, particularly those with impaired capacity from disadvantaged backgrounds, will not be able to effectively access resources in the system.

Support for people with an intellectual disability

In making recommendations specific to advocacy we urge the Commission to provide more information about how the NDIS will relate to people with intellectual disabilities from disadvantaged background that may be unlikely to approach on their own behalf.

People with an intellectual disability from the most socially disadvantaged families are not likely to present seeking disability service support. All available research shows that they do not do well with mainstream service support.

In many ways people with IQ 55-70 who come from disadvantaged family backgrounds are exhibiting similar social outcomes to Aboriginal and Torres Strait Islander populations.

We take the view that more information is needed on the question of how these most marginalised consumers will navigate the system.

In the Local Area Coordination model, the ‘Supports Facilitator’ is one of the most critical roles, responsible for helping people navigate the available services.

This role can be effectively carried out by the local case manager in a similar way with adequate provision of time, resources, and flexibility to be responsive to individual needs.

It is also critical to have information available to clients in a variety of formats, and languages.

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[7] ibid

Chapter 9 - Disability within the Indigenous community

We would like to see specific funds earmarked for joint health-disability services on a matching funds basis with the states to address Indigenous disadvantage.

We note the goodwill expressed in Chapter Nine and the determination to make a difference for Aboriginal and Torres Strait Islander people with a disability.

The chapter covers key and indeed critical issues in relation to Aboriginal and Torres Strait Islander people’s access to formal services.

We take the view that the NDIA should build on the constructive suggestions in this chapter, and use specifically earmarked funding, to *take the lead* in key early intervention and prevention activities, jointly with State Health Departments, and to improve access by Aboriginal and Torres Strait Islander people to disability services.

Chapter 11 - Early intervention

We welcome the determination to focus on early intervention.

We welcome the Commission's recognition that early intervention can also include investments around specific transition points. We take the view that among these transition points it is important to include Tier 3 supports for young people with an intellectual disability exiting child safety services. Queensland Child Safety figures show one in four people exiting Child Safety have a disability with intellectual disability being one of the most common reported disabilities (Commission for Children and Young People and Child Guardian 2009).

With reference to our earlier comments, we also note that any long periods spent waiting for assessment will militate against the early intervention strategy.

Chapter 13 - Workforce issues

We are broadly in favour of approaches which seek to build a network of support, both paid and unpaid, around each person. We agree that the system needs to be able to adapt to people’s complex needs and changing circumstances in the least bureaucratic way possible.

It is important to recognise that training is one of the key ways that we support quality in our services.

Adequate pricing will be a critical to the attraction and retention of suitable and skilled staff.

We would also support initiatives to improve recruitment from Aboriginal and Torres Strait Islander communities.

Ultimately, our approach to meeting the challenge of an expanded, skilled workforce to meet unmet demand is to improve the professional satisfaction of the roles on offer. With more creative, responsive services in support of an interesting life for a person with a disability, will come more interesting and rewarding jobs in the sector.

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