Response to Productivity Commission Draft report of Inquiry into Disability Care and Support

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Centre for Developmental Disability Health staff would like to commend the Commissioners on their Report. The thorough and sensitive exploration and discussion of issues reflects both the quality of consideration the Commissioners have given to the submissions made, and the Commissioners' ability to draw together and synthesise the information into a coherent document and plan. There is now a tremendous sense of empowerment and positive energy in the sector that relates to being heard, as well as to the hope a NDIS will redesign the landscape of supports available to people with disabilities in Australia to one that better enables everyone to participate in and contribute to all sectors of the Australian community.

The Centre for Developmental Disability Health (CDDH) is an academic unit, established in 1998 through an initiative between the Victorian Dept of Human Services, Monash University and the University of Melbourne, with the aim of developing capacity in the generic health system to better meet the health needs of people with intellectual and associated developmental disabilities. The CDDH is administratively part of the Faculty of Medicine, Nursing and Health Sciences, Monash University, and associated with the Faculty of Medicine Dentistry and Health Sciences, University of Melbourne. We therefore have a unique position from which to influence the training, education and professional development of both students and practitioners of medicine and many other health professions. The CDDH is primarily funded by the Victorian Dept of Human Services, Disability Division, with supplementary funding from competitive research grants.

CDDH staff would like to comment on matters relating to the Productivity Commission's draft report:

A. Health and Disability

Quality of life is heavily dependent on health status. When physical or mental health issues result in pain, discomfort or further disablement, one's ability to access, participate in and contribute to relationships and communities is undermined. Pain and discomfort, whether of physical or mental origin, weaken resilience and impede the ability to immerse oneself in pleasurable experiences, engage with others, and take advantage of new opportunities.

The health of people with intellectual disabilities is poor in comparison to the general population. Life expectancy for those with severe disabilities is some 20 years less than the general population, and many people live with a burden of physical and mental illness that is unrecognised or inadequately treated. Conditions identified as being of particular concern by the Health Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disability (IASSID) in their international expert consensus statement *'Health Guidelines for Adults with an Intellectual Disability'* (IASSID 2002, Scheepers et al 2005) include dental disease; sensory impairment; poor nutrition; constipation; epilepsy; thyroid disease; mental illness; gastro-oesophageal reflux disease and Helicobacter Pylori; osteoporosis; medication issues(including inappropriate prescribing and polypharmacy); incomplete immunisation programs; limited physical activity and exercise; and gynaecological issues. These health concerns are compounded by social and financial disadvantage.

Significant barriers currently exist to people with intellectual disabilities receiving high quality healthcare. These include physical, economic, social, attitudinal and communication barriers - and the limited understanding and skills of health professionals.

Generic health service providers – in both physical and mental health services - frequently feel inadequately trained, supported or resourced to meet the health needs of people with intellectual and associated developmental disabilities.

Most doctors in current practice in Australia have had little or no teaching in Disability Health. Most medical schools still have no structured curriculum in this area. Teaching in disability for most medical students is largely confined to paediatrics and so, when they graduate, most doctors have a very limited understanding of the implications of disability for health and healthcare, and so how best to provide effective healthcare to adults with cognitive and communication difficulties. This gap in training contributed to people with disabilities not receiving the healthcare they need in either community or hospital settings (Iacono & Davis 2003).

The healthcare of children with disabilities is generally coordinated by a paediatrician, ideally in partnership with a GP. There is, however, **no specialist in adult medicine focusing on the specific health needs of people with intellectual disabilities. C**oordination and provision of care for adults therefore becomes the responsibility of the GP, with support of mainstream medical specialists. Many medical practitioners, both GPs and specialists, feel untrained, unprepared and under resourced for this crucial role.

Parents are usually the drivers of assessment and care for children with disabilities, but it is neither realistic nor appropriate for parents to bear this responsibility alone for their adult offspring. Currently, when adults leave the family home to live independently of parents in supported accommodation, responsibility for care becomes that of the Disability Support Workers (DSWs) and GPs.

Most DSWs have little or no training in health, and most GPs have had little or no training in disability. Together they provide healthcare to Victorians with the most complex health and social needs. This is a recipe for the poor health currently experienced by many people with intellectual disabilities.

The Centre for Developmental Disability Health Victoria (CDDH), and similar Centres in QLD, NSW and SA, work to improve the health and healthcare of people with intellectual and associated developmental disabilities by building the capacity of the generic health system through a range of education, research, clinical and advocacy activities.

The educational arm of the CDDH, for instance,

a. **Provides professional development, resources and support for the current workforce** (doctors through Divisions of General Practice and General Practice Victoria (GPV) and allied health professionals through Community Health Services).
www.cddh.monash.org/medical-practitioners.html
b. **Delivers educational programs for the future workforce** (medical students at Monash University and the University of Melbourne as well as dietetic, physiotherapy, paramedic, dentistry and oral health students).
www.cddh.monash.org/education.html
c. **Develops learning and teaching resources** in Developmental Disability Health.
www.cddh.monash.org/health-and-disability.html
www.cddh.monash.org/products-resources.html

Current research projects (www.cddh.monash.org/research) focus on the health and wellbeing of people with intellectual and associated developmental disabilities and include

- Alzheimer's Disease in People with Down Syndrome: Developing a Model of Care
- Assessment for Dementia of Alzheimer Type in Down Syndrome
- Collaboration in the Development of Behavioural Social Stories to Reduce Behaviours of Concern and Restrictive Practice
- Comparison of Inter-Professional Education Strategies Using a Video Case Scenario of Developmental Disability
- Depression, behaviours of concern and restrictive interventions
- Development and trial of a depression screening tool for people with complex communication needs
- Exposure to challenging behaviour and support worker/house supervisor well-being
- Factors that influence the management of challenging behaviour
- Protocol to guide a collaborative medication review for adults with behaviours of concern
- Evaluation of adaptive seating interventions on adults who have developmental disabilities
- Non pharmaceutical interventions for dementia in people with intellectual disabilities
- Targeted activity programs to reduce challenging behaviour in adults with intellectual disabilities
- Development of a resource pack and DVD for caregivers of people with intellectual disability and dementia
- The effect of a novel activity program on youth with anxiety, depression and intellectual disability.

CDDH clinical activities include

- Telephone advice and support for medical practitioners
- General Practitioner and Psychiatrist run assessment clinics to support mainstream medical practitioners in their care of their patients with developmental disabilities
- Human relations clinics

All CDDH clinics integrate research and educational with clinical activities.

- **Specialist health services in the landscape of a NDIS.**

The CDDH and the Centres in other states are largely funded through Disability Services and it is uncertain what will happen to these Centres under the NDIS. Advocacy and activities aimed at improving the health of people with intellectual and associated developmental disabilities is clearly of great importance. Professional development is required for the current health workforce, and education, training and experience for the future workforce is crucial to building capacity in all community health services in the future.

In an ideal world people with disabilities would have their physical and mental health needs met in their communities by mainstream health services, supported by specialists in Disability Health when required. This, however is not currently the case as

1. People with disabilities experience many barriers to accessing and receiving high quality health care

2. There is, as yet, no accredited medical speciality with a focus on the needs of people with intellectual and associated developmental disability.

Further education and training over many years will be required before mainstream primary health services effectively address the complex health issues experienced by people with disabilities, and supported by specialist health services when required. In the meantime it is important to acknowledge the role the current specialist Disability Health services in building the capacity of both the current and future workforce to address the health issues of people with disabilities and their families.

- **CDDHV concerns:**

  - Ideally, the physical and mental healthcare of people with intellectual and associated developmental disabilities would be provided seamlessly by mainstream health services. Unfortunately this is currently not the case, despite many years of policy based on generic services meeting the needs of all – and memoranda of understanding between Departments of Disability and Health/Mental Health.

  - Many healthcare managers, administrators and practitioners are still not aware of the **poor health currently experienced** by this disadvantaged population; the barriers they encounter to accessing mainstream services; and the strategies required to address their health and healthcare needs.

  - **People who have difficulty communicating express themselves through their behaviour**. A change in behaviour may be a communication (eg for food/drink, company/to be left alone, to be with or away from someone or something, the need for stimulation or the need for peace); the expression of emotion (happiness, fear, pleasure, confusion, joy or sadness); may reflect a change in the person's physical (pain, discomfort, nausea, lethargy) or mental health (depression, anxiety, mania, psychosis); a change in the environment (physical or social). Health professionals have had no training in understanding behaviour as a communication, and too often dismiss it as "just behavioural". Medical practitioners may prescribe inappropriate tranquilising or antipsychotic medication, and not identify the underlying cause of the person's distress.

  - The **demographic of people with intellectual disability has changed** over the last 3 decades from a young, largely paediatric, population living either with families or in institutional settings to a predominantly adult population living in a community setting. As community based health services are, for the most part, funded by the Commonwealth government the responsibility for the health status of this population has shifted. Unfortunately, apart from the afore mentioned state funded centres, there has been limited recognition or support to ensure the health of this vulnerable population.

  - As **healthcare knowledge develops**, it is imperative that people with disabilities are able to access **new services and interventions**. When delivered in a traditional hospital/acute based way, these are not always accessible to all. **Specialist disability services** can collect and channel new information to enhance access and support generic services to use this within their own intervention 'toolkits'. Examples include appropriate seating for people with severe physical disability, treatments for spasticity, communication tools for people who do not use speech and the understanding and management of behaviours of concern. Practice, innovation and research lead to new and understandings and interventions, but it takes many years before therapists working in community settings are aware of these changes in best practice. Those with specialist interest, expertise and experience are therefore crucial in providing assessment and advice to ensure people get the best that is available, as well as these specialist professionals having a crucial role in building the knowledge and capacity of mainstream providers through the education of the current and future healthcare workforce.

  - **Medical specialists in Disability Health** need to be recruited and trained to support generic providers meet the needs of this population, in the same way there is a need for Paediatricians, Geriatricians. This specialty area of medical practice is already well developed in other countries in the Western world, most notably the Netherlands and the United Kingdom.

  - If such specialist and capacity building services are to be provided, then **funding** must be sourced. Currently Centres focusing on health and disability in VIC, QLD, NSW and SA are funded through state **Disability** services. There is a strong argument that such funding should be through **Health** rather than through Disability (or the NDIS). Although ideologically sound, this approach does not reflect the experience of the last 20 years which has demonstrated a lack of interest, commitment and services from Departments other than Disability to address the barriers to mainstream health services, and advocacy for change is had only minor gains.

- **Joint funding by both Disability and Health** sectors may lead to ‘ownership’ of the problem and solution by both sides of this problematic service interface. Memoranda of Understanding have, thus far, been ineffective and insufficient to bridge the divide and prevent cost shifting and buck passing. Enforceable standards of access and care, and financial accountability, need therefore to be in place to ensure people receive the access and care to which they have a right.

- People with disabilities have a much **higher rate of disorders of mental health** than the general population. The reasons behind this reflect the bio-psycho-social risk factors for mental illness including differences in brain functioning related to structural injury or developmental difference; reduced coping mechanisms; and social disadvantage, stigma, devaluing, rejecting experiences and discrimination. Currently disorders of mental health in this population are often unrecognised and inadequately or inappropriately treated.

- **People with mental illness too often fall into the abyss between disability and mental health services** with their behaviour change being attributed either to mental illness or disability (whatever is NOT the responsibility of the service in question!) – when in reality there is often a contribution by both. Low levels of awareness, knowledge and skill in mainstream services – as well as inadequate resourcing putting enormous stress on systems and staff – mean that many people with disabilities and their families experience prolonged periods (often many years) of psychic pain and distress. This is, once again a situation in which the focus must be put on the individual and his or her need and not service boundaries. Perhaps teams comprising members from both disability and mental health could be jointly responsible for budgets tied to agreed access and health provision outcomes.

- To improve the health of this vulnerable population a great deal more work needs to be done – in **advocacy and raising awareness** of the problem; in working with those involved in health service **policy and implementation**; in **training the future workforce**; and in providing **professional development programs to the current workforce**. **Research** into the health issues, the effectiveness of interventions, and the health outcomes is fundamental to service improvement and improving quality of life through better health.

- **Secure funding** needs to be identified to establish and maintain a network of multidisciplinary, academic units in Disability Health able to offer the **professional support** to generic services providers in the health (and disability) sectors, **training and education** to the current and future workforce and **research in issues related to improving the health and healthcare** of people with disabilities. These Centres could form the ‘hub’ of a **‘hub and spoke’ model**, supporting professionals with special interest and expertise in this area of medical and health practice throughout the country who in turn built awareness, understanding, knowledge and capacity to achieve and maintain optimal health and function for all Australians with disabilities.

References

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B. Some further comments on the draft report

1. Financial support

The financial disadvantage experienced by many people with disabilities effects many areas of life and limits choices which, in turn, impacts indirectly on **health and wellbeing**. Financial disadvantage also directly affects the ability of an individual to access appropriate health services in a number of ways including:

- Most people with disabilities do not have **private health insurance** and yet this group, more than most, benefits from being able to choose their own doctor and having an ongoing relationship providing continuity of care through the private health system of Private insurance also facilitates access to private dental care and therapy, bypassing long waiting lists for public serves.

- **Allied health** services and **aids and equipment** are more readily available if one has the financial means to pay privately.

- People with physical disabilities often become less active at a younger age than their peers as their muscles tire and joints age prematurely. They require an **individualised exercise program** to achieve and maintain optimal flexibility and strength in order maximise and maintain their mobility and independence. Such programs can be designed by physiotherapists and implemented by personal trainers in conjunction with carers. Membership of local gymnasiums is also of benefit. Funding for such interventions is scarce, and sufficient income is therefore required to enable these activities to occur.

- Access to healthy dietary choices; attendant care support and transport for holidays and other recreational opportunities; and keeping a pet are examples of the many ways financial means, or lack thereof, can influence opportunities that impact on physical and mental health.

2. Research

We strongly support the Commissioners recommendation that the NDIA will have a role in commissioning research and disseminating research findings of commissioned and other relevant research.

People with disabilities and their families are vulnerable to those making claims that particular treatments or interventions will lead to miraculous improvement. Sometimes such practitioners are over enthusiastic or optimistic, sometimes they are 'snake oil salesmen' – exploiting people's vulnerability for their own gain.

Research is the foundation of good practice and future improvement. New interventions should be proven to be effective before being funded by the public purse.

3. Tier 2 and sustainability of the scheme:

A major risk to the proposed NDIS could be the pressure from people in Tier 2 seeking to ever increase the boundary of Tier 3 to include them. This would lead to cost blow outs and the scheme becoming unsustainable. In the current system, people frequently seek a diagnostic label (e.g. autism) to open the gate to the services they need (in this example the autism service system). This leads sometimes to multiple and repeated assessments in an attempt to ‘get’ the ‘right’ diagnosis. Individuals and families feel they need the key to this gateway because supports outside the gate are manifestly inadequate and they frequently experience confusion, frustration, fear and despair. They feel the only way to get the help they need is to keep on pushing to prove eligibility through obtaining the ‘right’ diagnosis for a particular service.

Some ways to minimise this pressure may include:

a. **Funding on the basis of support need, not diagnosis**. A diagnosis of say, autism spectrum disorder (ASD), or Attention Deficit Hyperactivity Disorder (ADHD) encompasses people with an enormous range of abilities and support needs, some of whom require supports under Tier 3 of the NDIS and others who would be better served through enhancing the capacity of community services to better meet the needs of all Australians, particularly those who are particularly vulnerable. A particular diagnosis should therefore not be an automatic key to the gateway to Tier 3 supports, but rather this key should be an assessment of core functional ability that would underpin an understanding of the supports required by a particular individual. Thus many would be eligible for the information, guidance and advocacy services of Tier 2, while only those with serious impairments in core functioning would be able to access the supports they need through the NDIS Tier 3 funding.

   Many people with ASD, including many adults who have not been formally diagnosed, have serious impairments in their ability to communicate with and relate to others, to understand and negotiate interpersonal relationships and interactions, and understand the expectations others have of them in relation to their behaviours. This applies to those both with and without associated intellectual disabilities. Those whose difficulties are compounded by other cognitive impairments, attention difficulties and sensory impairment will have a more apparent need. Those with ‘high functioning autism’ though, although not having an intellectual disability, often experience severe and major difficulties in their lives, and may come to the attention of the Criminal Justice System or Welfare System (housing, income support, counsellors etc) or Health system (injuries, self harm, disorders of mental health), The needs of this group of people are frequently inadequately addressed currently and one hopes that an NDIS would have the expertise, advocacy power and resources to provide people with the supports they need to live happy and fulfilling lives.

b. **Building the capacity of the community-based mainstream services** to meet the needs of those with milder degrees of impairment (not eligible for NDIS Tier 3 support) would reduce the pressure on the NDIS. We are concerned the Draft Report, in stating that the costs of Tier 2 services would be “small”, may be understating the need for work in this area of community capacity building. More spent on effectively building capacity in the generic services for people in Tier 2 will reduce the pressure on assessors to classify people as Tier 3. The quality of information, support and advocacy provided to those in Tier 2 may make the difference between the person accepting the decision and engaging with community support outside the NDIS and appealing the decision. We think that considerable energy and focus needs to be given to this role if constant battering on the Tier 3 ‘fence’ is to be avoided.

4. Advocacy and capacity building

Advocacy is a vital tool for empowerment - some people can speak for themselves, others need support to do so, and still others need those who care about them, usually their families, to help design the supports they need to live the best life possible.

An important role of the NDIS for those in Tier 2, as well as those in Tier 3, is going to be systemic advocacy and providing information to enable people to find out about and choose the services that will best meet their needs.

We would like to see more emphasis on advocacy, and systemic advocacy in particular, to reflect its importance in supporting and facilitating access to services and advocating for change or improvement as required.

5. Case management

Case management clearly plays a central role in facilitating access to necessary supports, identifying the impact of services on an individual and troubleshooting when required. Ideally the case manager will be a point of contact, a source of information, an advocate and a trusted advisor. Case manager will play a role in monitoring the scheme through their intimate knowledge of how it's working 'on the ground'. Their close relationship with the individuals requires them to be at arm's length from assessors as they are likely to see an individual's particular circumstances as taking priority over the scheme as a whole.

There will always be a tension between professional responsibility for the scheme's management and the personal desire and commitment of those involved to support the individual. This is a very difficulty balance to get, and will require a great deal of thought about professional relationships and responsibilities. Providing opportunities for professional support and collegiate contact and networking to enable people to share their experiences both informally as well as formally will also be important.

Stability in case management is very important, particularly for people who find the world a confusing and sometimes frightening place in which to live – and those with cognitive impairment and mental illness are in this group. Case management roles should be ongoing and career pathways and expectations should be structured in ways that minimise staff turnover.

6. Let's keep the good in the systems we have!

In redesigning the system of support for people with disabilities we need to identify and preserve the parts of our system that are working well. Disability Services in Victoria, for instance, have developed many excellent policies, resources and strategies for creating person-centred services that enable people to live rich and fulfilling lives. The challenge has been in the funding and implementation of these policies, and many barriers to effective implementation have been encountered including workforce issues, resources and difficulties at service interfaces.

In conclusion

The Centre for Developmental Disability Health staff congratulate the Commission on their work so far, and look forward to the final report. We fervently hope that the National Disability Insurance Scheme is adopted by Federal and State Governments, and a new landscape of supports is created that enable people with intellectual and associated developmental disabilities to take their place as active, engaged, valued and contributing members of their communities. We look forward to playing our part in working to ensure people can fully access, engage with and participate in their new opportunities through **better health laying the foundation for better lives**.