Inquiry into Disability Care and Support
by Australian Government Productivity Commission

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Background

The authors of this submission are both medical practitioners who have committed their careers to working with people with disabilities and their families. Our comments below reflect the experiences we have shared with thousands of families over the last 2-3 decades. The current system of support for people with disabilities and their families is inequitable. We have seen some families receive large compensation payouts that enable their sons or daughters to have a high standard of care, equipment, accommodation, respite, and recreation options – while others, with the same level of disability, struggle to arrange and pay for the most basic equipment, live in substandard accommodation without the required home modifications, and have few opportunities for choice, independence and community participation in their lives.

We support the concept of a universal scheme, such as the proposed National Disability Insurance Scheme. Such a scheme would deliver a more equitable and appropriate level of support to all those with disabilities in our community who need assistance to do the things most of us take for granted – to move independently, to communicate successfully, to make choices about where and how we live and who helps us with our intimate support needs, and to participate in and contribute to our communities.

NATIONAL DISABILITY INSURANCE SCHEME

A National Disability Insurance Scheme (NDIS) would revolutionize the care and quality of life of persons with disabilities and their families and abolish the inequalities that currently exist between those who receive insurance payouts and those who do not. Currently individuals who have sustained injury in motor vehicle accidents and families who successfully litigate receive payouts that reflect the person's level of care and support, whereas those in whom the cause of the disability is unknown or due to other causes do not have access to equivalent funds, and often struggle with inadequate financial resources that impact on the health and opportunities of both the person with the disability and his/her family. An equitable scheme, such as the proposed National Disability Insurance Scheme, would have a lifelong positive impact on individuals with disabilities, their families and the communities in which they live.

An NDIS would provide a whole of life approach, commencing at birth for some families and becoming available for those children and adults who sustain significant injuries or illnesses that result in disability. What is required is a suite of services and supports which vary dependent on the age of the individual. Such a scheme would enable a more respectful, valuing, flexible and timely approach than the current system where there is often great difficulty in catering for individual needs, long waiting lists and delays in obtaining essential services and equipment, and the indignity and limited opportunities that result from inadequate or inappropriate levels or manner of support.

Model of funding

Should be **universal**

- Disability can happen to anyone any time
- Disability is an integral part of the human experience - 3% of babies are born with a congenital abnormality severe enough to effect their functioning – many of these will include a difference in the development of or injury to the developing brain resulting in lifelong developmental disability.

SUPPORT FOR CHILDREN WITH DISABILITIES

When children have a disability their families need financial support for the following:

- **At birth or at the time of diagnosis**

A case manager/support coordinator should be appointed within 2 weeks (the right to help in this time frame should be enshrined in legislation) to help at this critical time. Families generally have no experience at this stage in navigating the service system and are in urgent need of support and linkage to appropriate services. Waiting lists are far too long in most areas of Victoria and a case manager/support coordinator could provide

- Emotional support
- Information about the disability and the services available
- Links to services
- Coordinating immediate practical support

- **In childhood:**

- Healthcare- doctors and allied health – community based as well as hospital based when required
- Aids and equipment (mobility, personal care, communication)
- Behavioural support***** – supporting the child to learn appropriate and functional ways to communicate wants and needs and how to behave in various social situations – this is essential for inclusion and participation
- Home modifications
- Family vehicle modifications
- Transport
- Continence products and associated supplies
- Enteral feeding equipment and associated supplies
- Respite
- Long term accommodation for some
- Counselling (individual, couple, sibling, extended family)
- Palliative care

Note: Loss of income: The couple may have planned financially for both to be working full time by a certain time (?1 year, ?5 years) after their child's birth. When a child has a disability, the child's need for additional support (including attending medical and therapy appointments, time in hospital etc) mean that the return to work for one of the parents may not be possible for an extended period. This loss of financial resources further impacts on the family's ability to cope and support their children (both those with and without disabilities). Financial stress can also be a factor in family breakdown.

- **Support for the child in childcare, kindergarten, preschool school**
    - An aide***** (for personal care, mobility, communication, behavioural education etc) may be required for the child to attend and access the curriculum.
    - Modifications to the environment of the childcare/kinder/preschool centre may be required – for each of the centres the child attends.
    - Aids and equipment (for seating, mobility, communication, toileting, feeding etc) may be required in each setting the child attends.

  - Consultancy by specialists may be required to provide advice in relation to the child's environment and support at school to optimise learning and social inclusion – for example physiotherapist, occupational therapist, speech pathologist, behavioural specialist, educational psychologist, special education teacher, specialist in hearing and/or vision impairment.

- **Support for the child in school**
  - An aide***** (for personal care, mobility, communication, behavioural education, to facilitate social inclusion etc) may be required for the child to attend and access the curriculum.
  - Modifications to the physical environment of the childcare/kinder/preschool centre may be required – for each of the centres the child attends.
  - Aids and equipment (for seating, mobility, communication, toileting, feeding etc) may be required in each setting the child attends.
  - Consultancy by specialists may be required to provide advice in relation to the child's environment and support at school to optimise learning and social inclusion – for example physiotherapist, occupational therapist, speech pathologist, behavioural specialist, educational psychologist, special education teacher, specialist in hearing and/or vision impairment.

***Note: Aides/skilled disability support workforce:** The support of children with disabilities takes commitment, knowledge and skill. Appropriate training and continuing professional development are integral to a satisfactory level of service and good outcome for the child. Appropriate remuneration is required to attract and retain a workforce in this field. The family and child should have input into who works with them in this intimate capacity.

<u>Current services</u>

Current resourcing for the needs of a child in preschool/educational settings, including funding for aids and equipment:

- Is cumbersome, time consuming for all involved, doctor dependent and inequitable
- Involves time and effort on the part of families in seeking funding sources
- Results in long waiting periods – people can wait many months for a much needed piece of equipment (e.g. wheelchair)
- Depends on high levels of knowledge, advocacy and literacy on the part of those applying for funding.

Current financial supports – including Carer Allowance, Carer Payment etc

- Is cumbersome, time consuming for all involved, doctor dependent and inequitable

  - Involves much duplication of information and effort
  - Depends on high levels of knowledge, advocacy and literacy on the part of those applying for funding.
  - Parents are often applying for support from:
    - Centrelink
    - State government (DHS)
    - Local Council
    - Various NGOs (e.g. Scope/Yooralla)
    - Charitable organisations e.g. Rotary, Variety club – applying for charity is demeaning for many families. Children should have their needs met by right, and not be dependent on the goodwill and whim of others.

- Each application requires reams of paper, often completion of **lengthy questionnaires** by doctors who need parental input to complete the paperwork appropriately, requiring lengthy periods of time both for parents and medical practitioners
- Each focuses on the child's areas of **deficit, impairment and disability** – a very negative and disheartening process for parents who want to see their child as an able competent valued person, albeit with some areas of difficulty.

Suggestion: **An expert review panel.** Perhaps a system of review by an expert panel every 5 years of a child and family's needs would be a more efficient, respectful and equitable system.

A dilemma: When funding is allocated to a particular family/child – who should decide how that money is spent? What treatments/interventions/management strategies are worthwhile – and which are a waste or resources? Which are snake oil – exploiting parents wish for cure at a vulnerable time? An evidence base is a helpful start (the Cerebral Palsy Institute has a system of traffic light colours – red, orange and green – indicating the level of evidence for particular treatments). But what of treatments/interventions that improve quality of life but have little/no evidence for improving function (e.g. massage, music therapy, aroma therapy)? Could there be core funding for evidence based treatment and then discretionary funding for interventions without an evidence base?

A solution: A **National Disability Research Institute** is strongly endorsed as this would enable the evidence base for treatments and interventions to be increased, so that families and service providers would have an improved knowledge of the efficacy of various approaches to achieve optimal outcomes for individuals with disabilities.

SUPPORT FOR ADULTS WITH DISABILITIES

People with disabilities may require

- Information about the disability and the services available
- Emotional support
- Links to services
- Coordinating immediate practical support
- Financial support

➢ **Support may be required in the following areas:**

- Assessment
- Health
- Therapy
- Personal care
- Education
- Financial support
- Employment
- Transport
- Social
- Accommodation
- Recreation
- Participation in and contribution to community
- Advocacy/access to legal advice

➢ **The following services may be required:**

- Multidisciplinary assessment and healthcare provision by doctors, nurses and allied health professionals – community based as well as hospital based when required
- Personal care*****
- Social support*****
- Aids and equipment (mobility, personal care, communication)
- Behavioural support***** – supporting the person to learn appropriate and functional ways to communicate wants and needs and how to behave in various social situations – this is essential for inclusion and participation.
- Home modifications
- Vehicle modifications
- Transport
- Continence products and associated supplies
- Enteral feeding equipment and associated supplies
- Counselling

- Palliative care
- Advocacy/access to legal advice
- Case Management**
- Respite
- Long term accommodation***

***Note: Disability support workforce.**

- A well trained, skilled and supported disability support workforce is required.
- People with disabilities have complex health and social needs. The support of people with disabilities takes commitment, knowledge and skill.
- Appropriate training, peer support and continuing professional development are integral to a satisfactory level of service and good outcome for the person.
- Appropriate remuneration is required to attract and retain a workforce in this field.
- The person and, where appropriate, their family/friends/advocates should be able to choose who works with them in this intimate capacity.

Disability support workers are currently an unskilled, low paid, transient workforce with a heavy reliance on the use of casual labour. This workforce cares for community members with the most complex health and social needs. A focus on **developing the skills, knowledge and professionalism of this workforce** is an important component to providing appropriate levels of advocacy and support to vulnerable Australians and ensure an optimal quality of life. (Reports on the Disability Support Workforce issues have recently been written at a state level (e.g. Queensland and Victoria).

People with cognitive and or communication difficulties are a vulnerable group and require ready access to advocacy and support throughout life.

****Note. Case management** is currently provided only when a particular need is identified and then the ‘case’ is closed when the need has been addressed. People with disabilities however often have **lifelong challenges and difficulties** and the lack of long term case management and advocacy leaves many without the services and supports they need – leading to ill health (physical and mental), loneliness and behavioural expression of distress (challenging or withdrawn behaviour).

*****Note: Long term accommodation:** Some people with disabilities need lifelong support in many areas of life – including personal care, life organisation, communication, mobility and community participation. Most people are cared for by parents throughout childhood. Currently the move out of home is often crisis driven and the person concerned has little or no choice about where and with whom they live.

We believe that people with disabilities should have a **right to move** out of the parental home and **into their own home** at a developmentally appropriate time – perhaps between 25 and 35 years. Such an expectation would make the move a normal transition, a rite of passage, something to look forward to and to be proud of. The young person would be moving out at a comparable time to their siblings and similar aged peers and their parents are likely to be well enough to support the transition. In this situation, the transition can be planned and parents involved in smoothing the process, informing staff about what their son/daughter does and doesn't like; how they express pleasure, pain or illness; who their friends are and what daily routines they currently enjoy. The young person can be proud of their new home – after all they have moved out just as their siblings have! Parents can stay involved but have the ability to move into their retirement years having time for themselves, time for their partners and other family members, and time to contribute to their communities. In a situation where this move from home is seen as a rite of passage, an expected and natural transition, friends could express a desire to live together.

Houses are staffed by Disability Support Workers and, for people with disabilities to experience a good quality of life, workforce issues of quality, training, professional development and professionalism will need to be addressed. Currently there are **excellent policies and legislation** (e.g. Victorian Disability Act 2006, Victorian Quality Standards Framework a commitment to Person Centred Active Support and Positive Behaviour Support) but the standard of **implementation** in relation to the care and support actually provided by Disability Support Workers to people with disabilities in accommodation settings is undermined by the level of skill, training and standards required of the workforce (which in turn is reflected in the lack of professional standards and appropriate remuneration).

HEALTH AND HEALTHCARE

Good health is fundamental to a good quality of life. If we are in pain or discomfort or feeling unwell barriers exist to independence, and community participation and contribution. People with disabilities of all ages tend to have complex health and social needs. We know that currently people with disabilities experience significant health inequalities when compared to the general population with higher levels of morbidity and premature death. Providing individuals with appropriate, timely health assessments and interventions is fundamental to achieving and maintaining optimum health. People with disabilities need:

- Access to **generic** health services

- Access to **specialist** health services as required, including specialists in disability health.
- **Proactive** health care, including regular health assessments and disease prevention and health promotion.
- Careful health **monitoring** and **documentation** (as people may find it difficult to provide their own health history) e.g. Personal Health Records
- Staff providing day to day care and support **trained** in basic health concepts and care so they can provide the health support and advocacy people in their care may need

Barriers

Currently people with disabilities experience multiple barriers to accessing the health services they need. These barriers include:

- Physical access
- Attitudinal barriers
- Communication difficulties
- Social and financial disadvantage
- Skills and knowledge of health professionals: most health professional have had little or no specific training in caring for people with developmental disabilities in their health practice. This certainly applies to medical practitioners.
- Service system barriers – complexity, time constraints, advocacy required, transitions between service interfaces (disability/mental health, paediatric/adult, adult/aged care etc)

Strategies to improve health care:

- Education and training of all health professionals, including doctors, dentists and nurses, in disability health
- Training of disability support workers in basic health concepts and health advocacy
- Acknowledging the health disadvantage of people with disabilities and providing priority access to community health services, including therapy, dietetic services and dentistry
- Providing secondary and tertiary specialist level care in disability health for those who need it

Positive initiatives

In recent years there have been some very positive initiatives in improving the health and healthcare of people with disabilities. These include:

Australian Government

- Developed MBS item numbers specifically for Health Assessments for people with intellectual disability, acknowledging the complexity of health, communication and social issues
- Funded the development of online GP professional development learning modules in disability health

The Victorian Department of Human Services

- Funds the **Centre for Developmental Disability Health** to improve the health and healthcare of people with disabilities through educational, clinical and research initiatives
- Has developed a demonstration model to improve the care of people with disabilities and chronic and complex health needs living in shared supported accommodation: the ***'Complex Health Needs Care Coordination demonstration project'*** in which the support and training of residential care support workers, and the professional development of community health services has been addressed
- Has developed **Transition Clinics for Young Adults** with Complex Disabilities at the Royal Melbourne Hospital, St Vincent's Health, the Monash Medical Centre and Bendigo Health. However, the resources allocated to these clinics are inadequate with currently a waiting time of 12-18 months for the Monash Clinic.

POSSIBLE COST SAVINGS OF NDIS

Providing good quality services to people with disabilities will not save money – but will lead to a more equitable, compassionate and caring society where the human rights of vulnerable citizens are upheld.

Currently money is being saved by

- Families caring for their sons and daughters for unreasonable amounts of time – until the parents themselves are elderly, become unwell or die.
- Disability support workers being a low paid, unskilled and undervalued workforce. This results in the quality for service provided being extremely variable, with many

people with disabilities receiving a suboptimal service and therefore leading lives where issues of health, social inclusion, friendship and opportunities for rich shared experiences are limited.
- People with complex health and social needs are cared for by an unskilled and casualised workforce.
- People with disabilities having little or no choice in where or with whom they live
- People with disabilities having poor physical and mental health, and a reduced life expectancy, compared to the general population.

The provision of good quality services provided by skilled and committed support staff will lead to some cost savings:

- **Streamlining of a currently cumbersome system** full of duplication and unnecessary re-assessments for lifelong disabilities.
- **Reduced secondary complications** – for instance good quality healthcare will prevent secondary complications of spasticity in people with cerebral palsy such as contractures and dislocations.
- **Reduced behaviours of concern** – if people have optimal communication are listened to and understood by skilled support workers, have their physical and mental health issues addressed effectively in a timely fashion and are provided with opportunities to make choices and live the kind of lives they want.
- **Reduced family crisis and breakdown**
- **Better carer health** – including reduced back injuries in carers
- **Reduced use of 'snake oil**' – unfounded therapies provided by people exploiting vulnerable people/parents seeking cures.
- **Equipment** – currently expensive equipment is imported for overseas and distributed through for profit organisations. If equipment could be produced/sourced locally and/or distributed through not-for- profit organisations then costs may be reduced. More efficient re-use and recycling of equipment could also be facilitated by central data bases and distribution networks.

COMMUNITY BENEFIT

A society in which people with disabilities are respected and valued as equal citizens with equal rights to the rich opportunities and experiences of other community members is one in which all will benefit. Embracing our diversity and acknowledging the strengths and weaknesses in us all, and the need we all have for support in our lives, provide the foundation of a compassionate and mature society which recognises the rich variety of ways community members contribute and the many benefits of interdependence, working together and caring for each other.