

Long term Disability Care and Support Scheme Productivity Commission Inquiry Submission on behalf of The Royal Children's Hospital, Melbourne

Introduction

The Royal Children's Hospital (RCH) welcomes the opportunity to provide this submission to the Productivity Commission's inquiry into a National long-term Disability care and Insurance Scheme (NDIS) in Australia.

The RCH is the major specialist paediatric hospital in Victoria. Our care extends to children in Tasmania, southern New South Wales, as well as other states and overseas. We are the designated state-wide major trauma centre for paediatrics in Victoria and a Nationally Funded Centre for cardiac and liver transplantation.

With our campus partners, Murdoch Childrens Research Institute and The University of Melbourne, Department of Paediatrics, we are united in our goal to improve the health outcomes for children.

In 2009-10, RCH treated close to 35,000 inpatients, more than 230,000 outpatients, 7,500 patients underwent surgery and 67,000 patients presented at our Emergency Department. A significant number of these children have some form of disability and have complex health needs.

This submission has been developed with the collective input of staff across RCH, including Allied Health, Social Work, Adolescent Health and Development Medicine.

In making this submission, we firstly acknowledge the efforts of government in this initiative, which has the potential to make a significant difference to the lives of many children and their families living with a disability. We support a well funded, co-ordinated and inclusive national disability care and support scheme which addresses the issues within the current system.

Our response follows the suggested framework provided by the Productivity Commission.

How a scheme could be designed and funded to better meet the long-term needs of people with disability, their families and carers.

The RCH supports a scheme design that includes:

1. **A central contact point** for all inquiries regarding the diagnosed disability and available services.
2. **A community based case manager to help locate, access and coordinate services.** Families generally have no experience in navigating the service system and are in urgent need of support and linkage to appropriate services.
3. **Family centred service provision:** Any new system should respect and recognise that families/carers know their child/adult with a disability better than anyone else. The RCH supports giving individuals/parents/carers the right to advocate on behalf of their child.
4. **A skilled disability support workforce:** Supporting children with disabilities takes commitment, knowledge and skill. The RCH believes appropriate training and continuing professional development would lead to a satisfactory level of service and a better outcome for children with disabilities. Appropriate remuneration would attract and retain a skilled workforce in this field.
5. **Accommodation:**
 - **Safe accommodation for the families of children with disabilities:** Without access to safe, long term accommodation, families with children with disabilities do not have access to basic services such as disability case management, mental health services and early childhood intervention services which are allocated on a person's address.
 - **Long-term supported accommodation:** There are currently inadequate placements where this option is required. Long-term supported accommodation can be of great benefit to both the family and child. The high care needs of children with disabilities can be intense both emotionally and physically for families. Many, exhausted by the ongoing stress may relinquish care, sometimes by leaving their children at hospital.
 - Having the option of **shared care model of accommodation** with trained carers can allow children with disabilities to live part time with their parents and part time in a shared care arrangement. This model of accommodation can reduce family 'burn out' and ensure continuity in the child/adult's attachment relationships.
6. **Communication:** The RCH believes effective communication is necessary between hospitals, service providers and various government departments including education, employment, disability services, and child protection so all parties can work with children with disabilities, and children with disabilities who are exposed to abuse, neglect and trauma.

7. **There is a strong case for improved access to easily understood information about available services.** Voluntary disability organisations such as the Association for Children with a Disability currently have a model which includes a good internet site and access to workers/advocates who can help people think through specific issues. Families and professionals find it difficult to source information on available services.
8. **Early childhood intervention:** The RCH believes there is a strong case for prompt access to community based allied health practitioners and social workers for infants and children with developmental disabilities. Current waiting lists prohibit early childhood intervention from occurring in a timely manner which can result in a child not being able to maximize their developmental potential. Parents become very distressed when they cannot access early childhood intervention for their child if advised to do so by a paediatrician.
9. **Care evaluation of the new arrangements:** A National Disability Insurance Scheme should have a monitoring and evaluation system in place at inception.

How an NDIS could provide a better funding model:

Observations on the current funding model

- Families where several children have moderate disabilities, but none severely enough to qualify for services, are often not eligible for funding or support. These families are very vulnerable.
- Parents whose material/financial resources have been significantly depleted, due for example to long periods of hospitalisation or substantial equipment purchases. Families have to reach financial crisis before they become eligible for additional financial support (current Centrelink asset testing approach). This causes situations to worsen for the family and impacts significantly on opportunities for other siblings.
- The current system relies too heavily on strict adherence to medical diagnoses. For example, children with very complex medical presentations and high care needs who are midway through the process of acquiring a specific diagnosis miss out on services and funding.

The RCH suggests consideration of the following:

1. **New Zealand model:** looking at the current funding model used in New Zealand.
2. **Centralised funding:** Currently families must access funding and services depending on where they live. Certain areas such as the western metropolitan region of Melbourne have longer waiting lists for case managers, early childhood intervention and respite services than

other areas. The RCH believes a central funding point would have the flexibility to respond to information from paediatricians/doctors and parents and provide funding as needed. Services should be equitable across geographical areas. A single point of funding may help to reduce inequity, compared with the current system where funding is allocated to various agencies to fund different programs in different regions.

3. **Funding should be flexible and responsive:** People living in regional areas may require more resources to find respite. For example, farming parents are disadvantaged because of distance from appropriate carers for respite and may not be able to , access school buses .A further example where flexibility of funding is required is when family circumstances change for example, when there is a death in the family.
4. **Funding should be needs based.** Each person requiring help should be assessed. Assessment should include determining the young person's cognitive ability, their physical abilities, their emotional and behavioural state including mental illness and behavioural problems, their ability to perform daily living activities independently, their equipment needs, their respite needs for themselves and their family/carers, their school or vocational support required, and their/families financial state. The RCH would support the development of a tool to measure these needs.
5. **The RCH supports increased funding for early childhood intervention services** so that children can receive services at the appropriate time. Evidence shows that provision of early childhood intervention is cost effective in the long term. Currently, there are waiting lists of 12 to 18 months for these services in western metropolitan Melbourne which is distressing to parents and health care professionals. An infant who is waiting for 12 or more months for early childhood intervention misses out on important opportunities to meet milestones. Long waiting lists make early intervention far less useful.

How to determine the people most in need of support, the services that should be available to them, and service delivery arrangements.

People most in need:

RCH supports a study into the impact of disability on individuals, carers and families to determine the people who are most in need of support.

For example, those who require additional care/parental time commitments beyond those of a normal/well child, and those whose condition is chronic or whose disability impacts on their ability to function at a normal or below normal level within mainstream community services.

RCH stakeholders believe a person/carer/family should be determined as being in need of support if it is established there is actually a need for help, not just a diagnosis. For example,

families with a child with development delays but no formal diagnosis should still be eligible for services.

Identification of eligibility can be carried out by health professionals. Family structures are diverse and complex and it would be ideal for any new scheme to weigh up protective and risk factors that take into account each family's unique situation/dynamic/abilities.

The RCH supports the provision of the following services:

- Community based healthcare and case managers to help with locating and accessing resources and services
- Early childhood intervention services – multidisciplinary
- Dedicated, consistent and understandable transition services for young people leaving paediatric services and entering adult services
- Safe accommodation
- Respite care:
 - Short term regular out-of-home respite to ensure that carers have time to care for themselves and dedicate time to their other children. Lack of regular respite leads to carer exhaustion and 'burn out'.
 - Many families from different cultures and those with infants and children with high support needs will not use out of home respite. Regular in-home respite with trained carers should be available for these families.
 - Long term care to allow families to recover when they have broken down from the stress of meeting the challenging care needs of the child/adult with a disability. Long term out-of-home or shared care should be made more available for families who can no longer undertake the care needs of their child or young adult.
- Counselling for loss/grief issues, and ongoing stress of meeting the high care needs of their child with a disability.
- Transport services to access medical appointments, school and recreational/social opportunities
- Funding to supply aids and equipment as identified by medical practitioners or allied health professionals
- Specific support for carers
- Education, career and workplace support
- More highly trained support workers who can provide regular respite and regular care for children with high medical needs.

Service delivery arrangements:

Coordination of services: Services currently provided by federal, state and local governments need to be coordinated and delivered as a co-ordinated, streamlined national system rather than the current decentralised model where services are subcontracted out to the stretched local community disability services. This would allow for a streamlined process, and increase consistency of assessments.

The RCH believes greater access to community based case managers would ensure families would receive better access to available services. Currently, many families drop out of service provision because they find it too hard to continue self-referring for services.

When a family first receives a diagnosis, they are generally required to search out relevant services for their child. This places a large burden on an already stressed family. Effective, responsive, well funded case management should be able to access the appropriate services for the child while still allowing families to determine their own needs and priorities.

Skilled disability support workforce: The support of people with disabilities takes commitment, knowledge and skill. The RCH agrees with the need to upskill this workforce to support children with disabilities and ensure they have a better quality of life. Appropriate remuneration is required to attract and retain a skilled support workforce.

Family friendly referral point is essential so families and carers can carry out the important role of advocating for their child.

Flexible service delivery: Service delivery arrangements need to change as the individual with the disability gets older, requiring different programs and support. What suits in the early years may not be appropriate for school age or adult years. Families should not be expected to fit into one model, the assessment process should be able to weigh up protective and risk factors that take into account each family's unique situation/dynamic/abilities.

Eligibility for the scheme should automatically lead to support in education and later in adult life.

Equipment: Currently expensive equipment is imported from overseas and distributed through for-profit organisations. If equipment could be produced/sourced locally and/or distributed through not-for-profit organisations, costs may be reduced. More efficient re-use and recycling of equipment could also be facilitated by central data bases and distribution networks.

Current services that work well:

In 2004/2005, in response to the recommendations of the *Review of Victorian Paediatric Services (2002)*, the DHS piloted and established four Young Adult Complex Disability Services (YACDS) through the *Transfer of Young Adults with Complex Needs Project*.

These services are situated at the Royal Melbourne Hospital (RMH), St Vincent's Hospital (SVH), Monash Medical Centre (MMC) and the Bendigo Base Hospital (BBH).

The clients the RCH refers to these disability services are predominantly from the spina bifida, cerebral palsy, complex neurology and genetic/metabolic condition cohorts. All young people referred have complex medical and disability needs and require ongoing care from a range of multidisciplinary and specialty services.

Each service has a distinct service model i.e. MMC is a short-term referral service that plans and coordinates future adult services, while SVH is a long-term multidisciplinary adult service. Despite the differences, the overarching model of care is an adult transition service that allows patients at the most complex end of the disability spectrum to be managed through the transfer from paediatric to adult services in a coordinated, multidisciplinary and comprehensive manner with clear pathways from paediatric to adult services.

The benefit to the patients, families/carers and referring clinicians is significant in having a holistic, comprehensive service that can coordinate and plan all ongoing medical service requirements resulting in better care and positive health outcomes for clients.

The major issue to date has been limited resources for these services. At this stage only four clinics have been established, each with distinct client groups. St Vincent's YACDS accept referrals predominantly for patients with cerebral palsy, whilst the RMH YACDS main client group is spina bifida. This means many young people who have significant accessibility and mobility issues because of their disabilities have to travel long distances to benefit from the services. With just one regional clinic in Bendigo, most of regional Victoria is without access to these services.

The second impact of this critical shortage of resources is the unacceptable waiting lists for these services, for example, MMC currently sits at 18 months. This places the young person at risk of developing complications due to inadequate review and management of their condition. It often results in young people having to stay under paediatric care well beyond what is considered an acceptable age for transfer.

This transition service model should be examined and evaluated as a model for all young people with a disability transferring from paediatric to adult care. This model, its benefits and future service recommendations have been well documented in the final report *Review of Transition of Young Adults Clinics (October 2008)* that was prepared for the Department of Human Services.

The number of young people surviving with complex disabilities into adulthood is increasing rapidly in line with medical advances and improved technology.

Research

More research is required to determine which programs are most effective for children and their families. The RCH, through its links with the Murdoch Childrens Research Institute and the University of Melbourne, is ideally placed to contribute to the extensive research program that is required so that intervention for children and families is evidence based and always consistent with best practice.

The costs, benefits, feasibility and funding options of alternative schemes

We are not in a position to comment on this area

How the scheme will interact with the health, aged care, informal care, income support and injury insurance systems

The RCH believes close integration with childcare, kindergarten, education and vocational support would decrease the burden on families.

Impact on the workforce

Many parents/carers and people with disabilities are keen to participate in employment, education and social activities in the broader community which would help give them a balanced life.

Greater provision of support services is needed – eg respite care, skilled support workers, transport, coordinated services, workshops and activities for adults with disabilities – to help parents/carers remain in employment or return to their careers.

More individuals with disabilities can be integrated into the workforce with greater vocational support.

Parents/carers should be recognised for their contribution to the workforce.

How any scheme should be introduced and governed

We are not in a position to comment on this area

What protections and safeguards should be part of the scheme?

The scheme should include a detailed needs analysis and regular assessment to govern the system, with an appeal mechanism for families/carers who are denied a service.