

Disability – anyone, anytime!
Creating a new world for people with disabilities and their families and carers in Australia

Submission to the Productivity Commission's Disability Care and Support Inquiry

Karingal Inc and St Laurence Community Services

Introduction – why do we need a life time care and support scheme?

Our vision is an Australian society that accepts and celebrates human difference and where each person is a valued citizen that has equal opportunities and can achieve his/her dreams and goals regardless of personal support needs.

This new society will expect and ensure full and equal social, economic, cultural and political participation of people with a disability, their family and carers. The overarching goal of any new scheme that is introduced to reform the disability care and support system must fundamentally support this vision.

In 21st century Australia, it is not longer acceptable that people with a disability and their families and carers often find themselves “Shut Out” from much that society has to offer. Australia has taken a first and significant step in changing this situation by ratifying the *United Nations Convention on the Rights of Persons with Disabilities* in 2008. This is the first step in what will be a long journey to ensure that the rights enshrined in the convention actually become a reality on a day to day basis for people with disabilities. It is also important to acknowledge that having your human rights recognised and realised is largely dependant on you having access to adequate resources.

A social insurance approach to disability funding is an important, individual part of what must be seen as a broader reform of the disability care and support system. Any new long term care and support scheme must be a fundamental plank in the *National Disability Strategy* currently being drafted by the Council of Australian Governments. The focus of this strategy is to address the systemic reform that is required to ensure that Australia has a National system in place that will ensure that people with disabilities, their families and carers have the same rights and opportunities as all other members of the community irrespective of the state jurisdiction in which they live.

It is of vital importance that any new disability care and support system is based on agreed principles that create the foundations and the framework from which a scheme can be created. These principles which include equity, self-determination, efficiency and sustainability will ensure that a new scheme delivers the kind of reform that people with a disability, their families, carers and support organisations have been seeking.

The current system of supporting people with disabilities is broke and broken and there are both economic and social imperatives for reform and the time is now.

1a Who should be the key focus of a new scheme and which groups are most in need of additional support and help?

1b How they may be practically and reliably identified?

1a

- People who have a permanent disability which has a significant impact on their daily life. People who have a need for ongoing, significant levels of support.
- The scheme must focus on the need for support and not the cause or the diagnosed level of disability. i.e. "severe or profound" cannot dictate eligibility.
- People born with a disability and people who acquire their disability through accident, progressive medical conditions or mental illness should all be eligible.
- Physical, sensory, intellectual, brain injury, progressive neurological conditions, autism spectrum disorders and psycho-social (mental health) disability should all be included.
- Disability related to the natural aging process should not be included. The aged care sector is well established to respond to this client group.
- The scheme will need to be retrospective and therefore inclusive of all people with a disability which has a significant impact on their daily life.

1b

- A National Disability Support Assessment Framework that is clearly defined, consistent, and transparent and has reliable and valid criteria needs to be developed.
- The current Commonwealth Rehabilitation Service or Aged Care Assessment Service (ACAS) are existing National service structures that could be modified and extended to fulfil this need.
- The National Disability Standards need to be incorporated into the assessment framework.
- The assessors need to be specifically trained and accredited to ensure consistency.
- Eligibility should not be reassessed (disability won't go away) but a review of the individual's support needs should occur every 3 – 5 years unless otherwise requested.

2 How do we reduce unfairness so that people with similar levels of need get similar support?

- The scheme must be a no-fault, national system.
- The scheme must operate from an entitlement rather than a rationed perspective.
- A national assessment framework will promote equity.
- The scheme must focus on the support required.
- The scheme must focus on the support needs of the individual.

3. What are the factors that affect how much support people need and who decides this?

- The support needs of the individual within his/her context. This context will be influenced by the individuals living situation, socioeconomic status, geographical

locality, family support, cultural demographics, physical support needs, and dual or multiple/complex disability issues.

- The determination of support needs must be a part of the national assessment framework.

4. What kind of services will need to be increased or created?

- Accommodation support – a continuum of options
- Respite support – a continuum of options
- Assistive and information technology equipment that enhance and increase independence
- Independent living skills development and pathways for people.
- Strong links to a social inclusion framework
- Supported employment with consideration given to wage subsidisation options
- A nationally recognised single point of access in to the service system like ACAS in the aged care system
- Cessation of “gaps in funding” e.g. part funding towards Aids and Equipment, Vehicle Modifications, Home Modifications
- Community infrastructure that is accessible and inclusive.

5. What is/are the best way/s of achieving early intervention?

- Right supports, right time, right place
- Automatic alert to the recognised point of access
- Early intervention that is from birth as well as immediate and ongoing access to rehabilitation following an acquired disability.

6. How do we improve service delivery?

- Technology
- Easy and early access to information for people with disabilities and their families and carers. E.g. recognised single point of entry to the service system which includes one stop info shops, “roadmaps” to guide people on their journey and is directly linked to the assessors and planners.
- Early intervention
- Well resourced and reimbursed workforce. This includes recognise, value and pay accordingly and ensure that skills development is enhanced by effective support and supervision.
- Reduced duplication – remove multiple planning for one individual

7. How do we ensure that any good aspects of current approaches are preserved?

- This will be consumer driven – “people will vote with their feet”
- There needs to be a community development focus which is driven from the individual level.
- Sector capacity building needs to be an essential component of the funding system. Individualised funding is entirely appropriate for personal support. Whereas, accommodation and respite support require foundation funding that is enhanced by individual funding. Service viability can become untenable if it is entirely reliant on individual funding.

8. What to we do in rural and remote areas where it is harder to get services?

- Increase use of assistive and information technology.

- Build in costs of travel, accommodation etc in to the persons entitlement so that he/she can still afford to purchase specialist support.
- Clearly define rural, remote, and regional and have transparent costing calculations associated with these definitions
- Encourage flexibility of support models

9. How do we give people with disabilities and their families and carers more power to make their own decisions?

- Self determination must be the guiding principle.
- People with a disability and their families and carers must have access to mechanisms that enable and enhance their ability to exercise choice and control
- The scheme must be person centred and individualised
- The continuum of services and supports available to be purchased must be broad and diverse.
- Self determination and being in control will have many positive impacts on the overall health and wellbeing of the individuals and their families.
- The scheme should promote and foster independence and interdependence rather than continuing with the current dependence culture.
- The scheme will need to recognise that some people will require greater levels of resourcing and support to exercise choice than others.
- Access to communication support, where required, is vital in ensuring self determination
- There will need to be investment in information, resources and advocacy to ensure that people are provided with the tools they require to make informed choices.

10. How can people appeal against decisions by others that they think are wrong?

- A National, clear and transparent complaints and disputes system will need to be established.

11. How do we get rid of wasteful paper burdens, overlapping assessments (the 'run around') and reducing duplication in the system?

- Ideally the scheme would not duplicate what should be provided by accessible and inclusive health, housing, employment, education, transport and income support systems.
- The scheme should not reduce the obligation on communities and governments of all levels to become more accessible and inclusive.
- Individuals should not have to use their entitlements to address systemic issues of inaccessibility or exclusion e.g. integration support for schooling should remain the responsibility of education departments.
- The scheme should be the safety net if the existing system fails an individual and/or if the individual requires substantially higher levels of support than that which can be accessed in the mainstream system.
- A new scheme needs to refocus from a short term, reactive crisis driven system to one that promotes long term outcomes.
- The scheme should not be part of a convoluted legislative structure that requires a massive bureaucracy to implement it.

12. How can a new scheme encourage the full participation by people with disabilities and their carers in the community and work?

- A new scheme needs to focus on longer term outcomes and the identification and development of services and support models which maximise independence, productivity and participation.
- This focus on long term outcomes align the interests of both individuals and the scheme as both will have the common goal of ensuring each individual has every opportunity to reach his/her full potential.
- The focus of a new scheme needs to be proactive, preventative and productive.
- Ensuring families and carers get the support they need to ensure that they are not forced to 'drop out' of society to become full time carers, unless they choose to do so.
- Another important feature of a new scheme should be adequate resourcing for efficient national data collection, research, benchmarking and best practice and support for innovation. This will allow us to guide future government and community planning and development in all areas with reliable and valid information.

13 How do we finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

- The fundamental principle of equity must also relate to the way the scheme is funded. The cost of supporting people with disabilities must be borne by the entire community. Disability – anyone anytime is the basis of this principle and therefore dictates that a social insurance model is the most appropriate approach.
- The focus needs to be on entitlement for support and care not compensation.
- The scheme needs to avoid becoming litigious.
- The scheme may need to be introduced incrementally to enable it to meet costs. Priority categories would need to be identified to be first in line e.g. newly acquired disability, people on waitlists currently not receiving any support.
- The system needs to be sustainable in a myriad of ways:
 - for the individual over his/her lifetime and responsive to his/her changing needs;
 - families need to be supported to sustain their caring role;
 - support organisations and governments must address service viability, capacity, workforce development, infrastructure, research and innovation.

Conclusion – the importance of a life time care and support scheme

The current disability service system is fundamentally flawed. It is unable to meet current, let alone growing demand, it is inequitable, it is under-resourced and overwhelmed, it is crisis driven, and it is highly rationed and therefore basically ineffectual in achieving any long term outcomes for people with disabilities.

Major reform of the entire system on a National level is what is required to make a real difference to the lives of people with disabilities and their families and carers.

At the heart of a long term care and support scheme must be a new funding model and a social insurance approach is the most appropriate model to take us forward.

We dream of an Australia where all people have access to the same opportunities, a National Disability Insurance Scheme would help turn this dream into reality.

It is time for us to implement transformational change for people with disabilities, their families and carers; it is time for a National Disability Insurance Scheme.