Life Without Barriers Submission

Productivity Commission Inquiry into Long Term Disability Care and Support

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Introduction

Life Without Barriers supports the Productivity Commission's inquiry into long term disability care and support as an important first step in the development of a sustainable and equitable service system that will meet the current and ongoing needs of Australians with disability.

Life Without Barriers supports the positive transformational change of disability services towards a system that fully enables and promotes the principles of the United Nations Convention on the Rights of Persons with Disabilities[1] i.e.

a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
b) Non-discrimination;
c) Full and effective participation and inclusion in society;
d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
e) Equality of opportunity;
f) Accessibility;
g) Equality between men and women;
h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Life Without Barriers proposes that to achieve this what is required is an equitable and transparent funded national service system that will support people with disability on the basis of **entitlement** to receive appropriate supports that are based on their individual needs. This system should be based on the development of a National

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[1] The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), together with its Optional Protocol, was adopted by consensus by the General Assembly on December 13, 2006 entering into force on the 3rd May 2008. The Convention and Optional Protocol were ratified by Australia on the 17th July 2008 and the 21st August 2009 respectively.

Disability Insurance Scheme that provides equitable support to all Australians with a disability.

Life Without Barriers advocates a National approach to disability support that:

- Facilitates the participation of people with disability;
- Improves community awareness of disability (and the understanding that disability is natural);
- Strengthens the individuals choice over how they are supported; and
- Improves the interface between sectors that support people with disability (e.g. education, corrective services, health and aged care etc.).

The information contained in this submission is a summary of the a) responses received by Life Without Barriers National Disability Practitioner in relation to the Productivity Commission’s Key Questions Paper and the 16 questions therein and b) discussion sessions that were conducted in review of the Key Questions Paper with the Life Without Barriers National Disability Consultation Group, a representative group made up of staff and clients of Life Without Barriers funded disability services.

The information presented in this submission is therefore not intended to represent the precise viewpoints of all people and levels within the organisation but rather is reflective of the actual feedback received after a call for input to the organisational submission.

For questions or comments in relation to this submission please direct your enquiries to Edward Birt, National Disability Practitioner
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A. Eligibility

1. Who should be in the new scheme and how could they be practically and reliably identified?

Australians with an assessed *significant core activity limitation* as a result of being born with or acquiring an impairment be it physical, cognitive, sensory, speech or psychiatric should be entitled to receive a level of support based on their assessed need.

Refer to the response given at Q.3 below, in relation to identifying those eligible.

2. Which groups are most in need of additional support and help?

Some of the key groups identified include the following (though it is recognised that support is not limited to these particular groups and there is a degree of crossover between groups):

- Families requiring access to early intervention support and case management services,
- Families and carers requiring access to respite services,
- People with an intellectual disability requiring support to develop life skills and access the community,
- Children and young people with disability in Out of Home Care,
- Integrated / inclusive school support services for students with learning disabilities,
- Support services for new parents of children with disabilities,
- People with swallowing and eating support needs as a result of their disability and who require health and allied specialist support.
- People with a disability within the criminal justice system.
- People with disability requiring access to dental health services.
- Parents with disabilities.
- Families with ageing parents of children with disabilities who require accommodation support.

3. **What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?**

The use of a single consistent assessment tool that focuses on a person's support needs (rather than diagnosis).

Support need assessment should be conducted by trained and registered assessors operating to an agreed set of assessment principles and guidelines.

Assessment could be conducted by a 3rd party assessor who is not connected to service provision or government and who will not gain financially or in kind from the arrangement (i.e. no conflict of interest). That is assessment is not conducted by government or by direct service providers themselves.

Quality control co-assessment system (e.g. for new assessors and ongoing e.g. 1 in every 100 assessments is co-assessed) to enable further quality control and to keep quality high and guard against breaches of principles and guidelines).

Assessors receive a standard rate for all assessments of clients with core activity limitation regardless of complexity.
Support level eligibility and funding levels is based on the assessment results.

B. Power

4. **How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?**

Control: Overall control of the allocation of their support funding should rest with the client and where required their supported decision making network.

Portability: Support allocations to service providers are allocated for an agreed period of time with a formal review at the end of this period. This would allow service providers some certainty about funding and most importantly would allow clients the ability to renegotiate or take their funding elsewhere if the service is not meeting their needs.

Transparency: Clients and families will require information about the relative costs of different services and this information should be readily available and the currency of the information assured. There could be website publishing ("Choice" style) of disability support agencies comparative costs and services provided etc. Quarterly statements should be provided to clients (and / or their families) of funded services regarding the support received so this may be compared to the original agreements held and discrepancies accounted for.

Appeals and Complaints: There must be a clear appeals process for clients with centralised complaints mechanism e.g. 1800 number, tribunal, etc.

Services could also provide online requests for support forms that clients, families, planners or case managers could complete to submit requests for service.

5. How should the amount of financial support and service entitlements of people be decided (and by whom)?

As a result of the standardised assessment process the level of support (i.e. service entitlement) would be determined. Financial support would be determined through looking at this information and reviewing associated costs of the person's support level through looking at domains of support, need for specialised services, hours of support etc and a support budget could thus be developed.

It will also be important to review comparative economic population based data for mean costs associated with an average person's support needs in the community and the difference covered under a National Disability support scheme. (E.g. if the average cost of raising a child in Sydney was $20,000 per annum and the costs associated with raising a child with a particular disability were $48,000 then the family of the child would be eligible to receive $28,000 worth of support services that may be utilised towards aids and equipment, education, family respite support etc).

A recommendation would be made by the independent support needs assessor and their findings submitted to a panel for approvals.

C. Services

6. What kinds of services particularly need to be increased or created?

Some of the services identified include the following:

- Assessment and Planning services.
- Intensive transition and case management support services (e.g. people moving out of home, leaving the prison system).
- Outreach community based accommodation support services providing supports to people to live in their own homes in the community.
- School inclusion services.
- Life skills development services.

- Respite support services for children with disabilities.
- Fill gaps between health and disability.
- Employment access and inclusion specialist services.
- Mental health support services.
- Early intervention support to families to focus on the development of social and communication skills in children and young people with Autism Spectrum Disorders.

7. How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

Refer to the answer provided at 4, above. Having control rest with the customer of the service (i.e. consumer directed disability support services) will improve services in a variety of ways relating to coordination, cost timeliness and innovation.

8. Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

Yes absolutely and all the literature is very clear on this as well as people's experiences strongly supports this fact. It is important to get supports to people in a timely fashion and not as a last resort as the present system encourages. Proactive planning, particularly around transitions periods e.g. finding out your child has a disability / acquiring a disability, school transition points, etc.

A focus on communication and providing early intervention services for children to assist with communication and learning.

Providing people with the equipment and aids they need when they need them and not making them wait. As people grow and change these aids need to be updated, modified and replaced as support needs do not go away.

A focus on skills development at all stages of the lifecycle encourages independence, resilience and gives people the best opportunities to realise their potential.

9. How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

A national approach to disability long term care and support must ensure that a Disability Support Pension safety net is in place and that there is no risk of losing entitlements if entering the workforce if a person with disability later is unable to work or find employment. If you are eligible for the DSP this should not be affected by periods in your life where you have paid employment.

Clients should be able to utilise their support flexibly to engage employment support professionals, personal assistants, mentors and others who specialise in opening up opportunities in the workforce and partnering with them to achieve successful employment outcomes.

10. How can a new system ensure that any good aspects of current approaches are preserved?

The move towards a system where power rests with people with a disability and their supported decision makers will ensure that the best aspects of the current system are preserved and rigid and inflexible support arrangements that do not meet people's needs are moved away from.

People eligible to access funded disability supports based on their assessed needs must be able to choose from a spectrum of support services which in many instances will have a good deal of similarity to the types of services available today though they will be more person centred and flexible in their scope.

The new system should not be a wholesale replacement of existing services but should instead augment and expand upon the spectrum of services available to support people with disabilities and their families.

11. What should be done in rural and remote areas where it is harder to get services?

Factored into support costs should be the costs associated with travel to and from regional and remote areas to access appropriate services and supports, relocation fees and expenses for families where this is appropriate and agreeable to the family or person with a disability.

There should be an expansion of existing community access and participation support services in rural and remote areas.

As stated at 4, above, people in rural and remote areas (as for people elsewhere around the country) would have control over their funding allocation which would also benefit those in rural and remote areas in that it will allow purchasing (contracting) in of local supports employing people from the local community as sole trader disability support professionals who would be able to deliver support to them directly rather than necessarily always needing to rely on specialist disability support providers which are often better represented in larger centres.

12. How could a new system get rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and duplication in the system?

A single needs based assessment system and point of entry will effectively minimise people having to tell their story again and again and will reduce paper burdens, multiple files and assessments and plans.

Consistent client tracking systems should create electronic records that can be accessed with the consent of the person with a disability to identify the total support being received which will also build up useful data over time creating efficiencies in the system.

D. Funding

13. How should a new scheme be financed?

Life Without Barriers supports the concept of a National Disability Insurance Scheme as outlined broadly on the NDIS campaign website - http://www.ndis.org.au/ - that is “...*an NDIS would be funded by all taxpayers through general revenue or an extension of the Medicare insurance levy*.”

14. How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

As per the above response a financing arrangement such as an NDIS tax or levy seems to offer the only real opportunity to realistically meet the current and ongoing needs of the Australian community (given the ageing population, shortage of and reduction in availability of unpaid carers and increasing number of people with disability in the population).

E. Policy

15. What are your views about the ‘nitty gritty’ aspects of a scheme that will make it work practically?

All of these aspects require further detail though a number have been mentioned here already and include:

- Eligibility criteria allow self assessment to determine if eligible for assessment.
- Support needs assessment determines level of funding support the person is entitled to.
- Person centred planning services identify aspirations and goals of the service recipient and identify funding allocations based on these plans.

- Funding is administered according to the wishes of the support recipient and may include direct cash payments, funding to specialist disability service providers directly, third party administration of funds or any combination of these.
- Outputs and outcomes are reviewed by customers and providers regularly and service is evaluated annually or at other agreed time intervals to determine the need for alterations and changes.

16. How long would be needed to start a new scheme, and what should happen in the interim?

A National Disability Insurance Scheme will require a number of years of planning to agree on the “nitty gritty” aspects of the scheme before wholesale implementation is conducted. Any agreed changes will mean changes to the taxation system which is likely to take considerable time and will require broad support from the Australian people. Additionally the States and Territories need to be working together and this may mean adopting a single national disability legislative instrument or at least aligning all State and Territory Disability Acts. In other words there is a good deal of foundational work that needs to be done before a new scheme can be implemented.