Yooralla's submission to the Productivity Commission's long-term disability care and support scheme

Yooralla

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This submission is by Yooralla, a not-for-profit organisation offering high quality support services for people with disability across Victoria.

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Executive Summary

Yooralla is a not-for-profit organisation offering high quality support services for people with disability across Victoria. Established in 1918, Yooralla offers a wide range of services to people of all ages who are either born with or acquire a disability. We have a long-standing commitment to working alongside people with disability to achieve high quality of life outcomes. 1,500 Yooralla employees work alongside more than 30,000 Victorians with a disability and their families each year.

Yooralla's vision is "a fair go for all people with disabilities". Our mission is "to actively support people with disability, their families and carers, in all their diversity, to live the life they choose". (For more information, please visit www.yooralla.com.au).

The implementation of a National Disability Insurance Scheme will go a long way toward maximizing opportunities for people with disability to participate actively within their own communities.

Yooralla's submission is made up of five components:

1. Section 1 is an introductory statement outlining the four key principles that Yooralla believes should apply within the scheme: **Equity, Self-determination, Efficiency and Sustainability.** A National Disability Insurance Scheme is the best way of achieving outcomes against these principles to bring about change that is needed to ensure a fair go for all people with disability.

2. Section 2 gives more detail to Yooralla's vision for a National Disability Insurance Scheme scheme, defining the scope and effectiveness of the scheme, describes the current issues in the management of comparable schemes and makes recommendations regarding best practice provision.

3. Section 3 addresses funded **Community Living Supports** that are anticipated to be the major focus of ongoing funded supports for people with disability. Self-determination, choice and equity underpin the recommendations made within this section.

4. Section 4 addresses funded **Assistive Technology** emphasising the need for environments and products to further the social inclusion agenda for people with disability allowing for changes in life situations, needs and aspirations.

5. Section 5 addresses funded supports for **Early Childhood Services** for children with disability, recognising the specialised nature of the support responses appropriate for children with disability and their families,

highlighting the particular implications their needs have on scheme design and administration.

Sections 2 to 5 are structured around the key elements of the core scheme design outlined in the Productivity Commission issues paper (May 2010, page 15, Figure 2):

- Power
- Supply
- Scope
- Financing

In keeping with the direction of the Productivity Commission, this paper is focussed on people with disability. However, Yooralla wishes to note that there are significant benefits to the entire Australian community flowing from a long-term disability care and support scheme. Needs based responses to the care and support needs of people with disability will:

- release family carers into the workforce, delivering productivity and taxation gains to the entire community.

- reduce the adverse effects of prolonged intense caring,[1] improving health and economic outcomes for family members and in turn reduce community health care costs.

- increase employment opportunities for people with disability, delivering health care cost and economic benefits.

The situation Australia faces at the moment is reminiscent of the problems associated with an ageing population and low superannuation coverage. Australia simply could not afford to continue it's reliance on annually funded pensions in the face of growing demand. Similarly, Australia cannot afford to continue to fund supports for people with disability within the current paradigm. An insurance model is required to support people with disability and the significant impact associated impairments have on their lives, just as Australia required a superannuation scheme to support our changing, ageing population.

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[1] Cummins, R. A. and J. Hughes (2007). The wellbeing of Australians: carer health and wellbeing. Report 17.1. Melbourne, Deakin University http://acqol.deakin.edu.au/index_wellbeing/index.htm.

Summary of the major recommendations from Yooralla's **submission**

(Refer to appendix 1 for a full list of recommendations contained within this report)

Section One: Introduction
- The four key principles that should underpin the structure of the scheme are Equity, Self-determination, Efficiency and Sustainability.
- That a National Disability Insurance Scheme would provide the best way of achieving the principles that underpin the structure of the scheme and achieve the transformational change required.

Section Two: Yooralla's Vision for the Scheme
- That in relation to ensuring best practice in the delivery of funded services and supports, the scheme requires that these funded services and supports be reasonable, improve the employment participation of all Australians with a disability and remove physical and attitudinal barriers to access and participation in all aspects of community life.
- That funding be available for disability research to enhance the use of evidence-based practice in policy and program development and in the delivery of support services to Australians with a disability.
- That the scheme fund services and supports under an individualised funding model to enable scheme participants to exercise choice over the way in which these services and supports are delivered.
- That the scheme empowers individuals to exercise personal choice regarding the delivery of funded supports
- That the scheme define eligibility both in terms of the impact of the disability on a person's function and support needs as measured by standardised assessment tools.
- That scheme eligibility be limited to people who acquire their disability when aged 65 (or are of pensionable age) or younger.
- That once a person is assessed as eligible for the scheme support and services continue for that person throughout the course of their life (i.e. post 65 years of age)
- That the scheme fund only those services and supports that are required as a result of the person's disability.

Section Three: Community Living Support

- That the scheme includes a policy that enables the person with a disability to nominate how their funds for attendant/personal care hours are spent
- That, in keeping with current and evolving practice, people with disability be able to directly employ their support workers.
- That person-centred planning processes be used to identify the disability related needs of scheme participants and to identify appropriate responses to these support needs.
- That supports (including accommodation support) are funded in a way that enables the person to choose - where they live and with whom and choose providers of supports and individual support workers.
- That the scheme partner with public housing, social housing agencies and with private developers to develop and implement a strategy to increase the stock of accessible housing, including:
- That the scheme fund supported accommodation in a way that enables the level of supports a person receives to be changed without requiring the person to move house.
- That this funding model breaks the connection between funding for housing and funding for support.
- That the scheme develops and implements an ongoing strategy to prevent young people being admitted to nursing homes and to enable young people in nursing homes to move to age appropriate supported accommodation, particularly as the current National Younger People in Nursing Homes Program has only twelve months to run.
- That the scheme fund incentives for employers to employ people with disability, including funding fixed term indemnity for workers compensation.
- That supported employment services targeted to deliver open employment outcomes and sustainability of employment be a funded service.
- That the scheme develop and implement a strategy to remove financial disincentives and penalties experienced by people with disability on commencing paid employment. These disincentives include low income thresholds for losing health care cards and other concessions or entitlements.
- That community living services and supports do not have specific time limits but adapt to changes in a person's level of function and life stage.
- That the range of community living services and supports funded is clearly defined and can be expanded as new service and support types are developed.
- That the scheme develops processes to manage the provision of supports to scheme participants with multiple and complex needs. This includes the intersection with other systems such as justice and health, and ensuring people are able to access services and supports not funded by the scheme.
- That the scheme provide for services and supports to be funded by: direct

payments to service and support providers, brokerage arrangements, individual funding agreements; and reimbursements to scheme participants.

Section Four: Assistive Technology

- That Assistive Technology policies reflect the aim of improving client outcomes across lifespan and whole of life activities.
- That access Assistive Technology (AT) should allow for changes in life situations, needs and aspirations of individuals (families and carers) which also reflect improvements in technology, such as portable hoist tracking systems.
- That people with disability have access to the type of service that will best meet their needs, regardless of location, (including rural and remote communities).
- That a national purchasing framework be established that acknowledges importance of local supplier service delivery and support in regional areas and for complex technology.
- That resources be available to the sector to investigate developments in interfacing between mainstream technologies and Assistive Technology.

Section Five: Early Childhood Services

- That the scheme support a model such as the 'Family Service Coordinator' or 'Key Worker model' to provide a sense of family empowerment so families are better supported and informed to make their own choices.
- That one entry point to the system be in place for families that is designed to make the scheme easy to navigate, in order to reduce the fragmentation caused by multiple entry points which resulting in an unnecessarily complicated system that is difficult to navigate.

Section 1: Introduction

The UN Convention on the Rights of Persons with Disabilities should be the over-arching framework to guide the Productivity Commission in setting the framework for a long-term disability care and support scheme.

In economic terms, **four key principles** should apply:

- Equity
- Self determination
- Efficiency; and,
- Sustainability

Recommendation

1.   That the Four key principles that underpin the development of the Scheme are:
- Equity
- Self Determination
- Efficiency
- Sustainability

1.1 Equity

In designing a new system for supporting people with disability there must be equity within the group of people with disability, between people with disability and without, and the costs of funding disability services must be shared equitably.

The scheme should therefore ensure that all people with a *permanent* disability are *eligible* for services and support, regardless of their specific disability or how or where they acquired their disability. Once a person is assessed as eligible for support within the scheme, supports should be available throughout that person's life (taking into account changing need over time). The scheme should be *no fault* and include people born with disability or who acquire disability through an accident or progressive medical condition and mental illness.

Equity does not mean that every person eligible for the scheme receives the same benefit or benefits as every other person. Funding allocated must be based on the assessed needs of the person to live an active life within their community. This will mean a different range of services and supports for people, even those who have similar impairments due to their disability, those in the same age group and from

similar backgrounds. One size does not fit all and funding must be flexible to meet individual need.

The scheme must be underpinned by defined assessment processes as well as strong claim management systems to ensure equity based on need rather than allocation of funds for types or groups of services that could potentially be seen as an entitlement for everyone.   Failure to provide safeguards such as strong claims management may result in the funding 'creep' seen in other insurance based schemes (e.g. the TAC in Victoria and the ACC in New Zealand).

Explicit boundaries are required to ensure that funding is made available to people that addresses needs related to their disability and not be available to fund ordinary life expenses. Review/appeal mechanisms must require that review bodies cannot make a decision that would result in the scheme funding ordinary life expenses or compromise the viability of the scheme via flow on effects.

People with disability under the age of 65 years or who are of pensionable age should be eligible for the scheme. The benefits to be covered by the scheme should include *essential services* for individual people with disability eligible for the scheme, and assistance for primary carers of those individuals, including:

- support and therapy
- case management, brokerage services and advocacy to facilitate independence, maximise potential and plan transitions over the life course
- family support, including respite and support for primary carers
- early intervention to maximise long term outcomes
- aids, equipment, technology and home modifications on a timely basis, and
- training, development and access to work to build self-esteem and reduce long term costs.

Eligible individuals should be *entitled* to the benefits based on an *assessment* of their needs. As needs change so should the benefits and this process should be facilitated by planning over the life course, taking into account both changes in individual and family circumstances.

In effect the scheme should seek to cover the costs of permanent disability, which vary from individual to individual; and over time.

Coverage under the scheme should be for life, to support people with disability to age in place, as for people without disability.   This does not preclude situations where support may be provided for relatively short periods of time, for example, speech therapy support for a young child who has not reached significant developmental milestones and needs early intervention to learn to speak or

communicate. Once that child has developed skills in this area it is possible they may go through life without the need for any further intervention. Similarly, a person who has been involved in an accident in the community that has resulted in physical and/or cognitive impairments, early intervention and support to re-establish themselves in the community may mean that ongoing costly supports may not be necessary.

The other dimension to equity is how disability services should be funded. Because disability can affect anyone at anytime, the most equitable way is based on a form of *social insurance*. This would be most readily achieved by adding a disability surcharge to the Medicare levy or from general revenue.

This point was addressed in the Issues Paper, which states:

There is a strong rationale for government to improve care and support arrangements for people with disabilities and their families. It is consistent with:
- community norms for upholding people's rights and for social justice, which are not fully recognised in current arrangements
- the desirability of sharing the costs that fall on people with disability and their families among a wider group of people—through a form of social insurance—and the low likelihood that private insurance markets would function equitably or efficiently in this area.'[2]

Equity also determines that the eligibility and benefit levels are set through uniform *national standards* and that there is *portability* of benefits between jurisdictions.

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[2] Productivity Commission Disability Care and Support Scheme, Issues Paper, May 2010

1.2 Self determination

It is essential that people with disability and their families are placed at the heart of the disability system.

Today, the extent of individual packages or self directed funding varies dramatically between States and Territories. There is therefore an opportunity to institutionalise *self determination* and *choice*, as features of a national scheme.

The scheme should be *person-centred*, individualized, built around the choices of the person with a disability and their family; flexible; responsive; and, recognise the changing needs of a person with disability over their lifetime.

Self determination is vital because there is widespread evidence that people who are in control have higher well-being and self esteem than people who are unnecessarily dependent on others.

Furthermore, once people with disability become consumers who are free to choose, the market will drive innovation and provide individuals with value for money, much more effectively than the exitisting systems in place. This change will also drive service providers to become more relevant to meeting individual need, moving away from rigid funding guidelines that constrain choice and flexibility.

Individual choice and the market are the best ways for people to maximise their well-being, recognising that in some cases people with disability will need support, through *advocacy* and *brokerage services*, in their decision making.

1.3 Efficiency

The efficiency and effectiveness of the disability system should be measured over time, not just at a point in time, based on the opportunities for people with disability to maximise their potential over their *life-course* and minimise *lifetime* costs of support.

Measures of effectiveness should explicitly take account of costs which are currently hidden such as the opportunity costs for families to participate in work, which they cannot do at the moment because of full-time caring roles.

Once viewed over the life-course, a key aspect of efficiency that comes to the fore is that services for people with disability are an *investment*, not just a cost.

Examples include
- early intervention for people with disability, leading to long-term opportunities and benefits and reduced long-term costs
- nurturing and sustaining carers in their roles rather than burning them out leading to long-term dependency on income support
- home modifications leading to greater independence and reduced support needs.

The lifetime approach also creates a natural alignment of interests between people with disability, their families, carers and government.

The scheme should also provide an entitlement to services over time rather than a lump sum payment from which an individual should pay for the services they need. In this way the scheme would automatically balance the risks that some people will live longer than expected and others shorter, while some will have more severe disabilities than expected, and for others their disabilities will be less than expected.

A system based on an entitlement to services can also be managed to minimise fraud or misspending.

Other important aspects of an efficient system are *data collection*, *research*, identification of *best practice*, support for *innovation* and *benchmarking*. All of these are not clearly in evidence today and should be features of the new system.

Other aspects of efficiency include institutional and supply-side arrangements to pool or link workforces that are organised around people rather than service providers, enabling individuals to receive personalised services at minimum cost.

1.4 Sustainability

In structuring a new disability scheme that will meet the needs of all Australians in the 21st century, it must be affordable over the economic cycle and take account of demographic and social trends.

Demand for government funded disability services is rising at 5 to 7% per annum in real terms and, based on current trends, government expenditure on disability services will need to double in the next 15 years. Any new system must lead to improved effectiveness as well as increase funding, so as to be *fiscally responsible*.

The demographic and social trends affecting disability expenditure include:
- increased life expectancy for people with disabilities
- increased incidence of disability at birth and through acquired injuries
- families having children later in life

- an increasing reduction in the capacity of families to provide informal care because family units are smaller, women want and often need to work and rates of marital breakdown are increasing (from Yooralla's experience it appears that this is the case especially amongst families with children with disability).

Currently, Australia does not set aside any funds to meet the future costs of care and support for people with disability, notwithstanding these powerful demographic and social forces. Any new disability care and support scheme should therefore include an element of future funding, like for superannuation, which sets aside billions of dollars each year so that future generations will not be solely responsible for the retirement incomes of people who are working today. This would assist with *intergenerational neutrality*.

The other aspects of sustainability relate to the supply side, including labour supply, service supply and community engagement.

A critical component for people with disability to have a quality life is having access to well-trained and regular support workers. Therefore, *workforce training, development and retention* must be an important feature of any new scheme*.*

For a competitive market there must be a range of organisations, preferably both non-profit and for-profit, providing services and which have different specialisations and service offerings.

1.5 A National Disability Insurance Scheme

In *The Way Forward*, the Disability Investment Group (DIG) suggested that an insurance approach would provide the best way of achieving the above principles and the transformational change that is needed:

'The key to this transformational shift would be the introduction of a **National Disability Insurance Scheme** which will provide eligible people with disability an individualised and lifetime approach to care and support.

The scheme would replace the current arrangements for funding disability services and would work in a similar way as the no-fault injury insurance schemes that currently operate in some States and Territories. Coordinated services would provide care and support including aids, equipment, transport, respite, accommodation support and a range of community access, vocational and day supports.

Such a scheme is not beyond Australia's capacity to deliver. In fact the DIG argued that ultimately the NDIS would be a net saving on government expenditure through a

more effective service system and better employment, health and social outcomes for people with disability.'[3]   In reaching this conclusion, the DIG commissioned PricewaterhouseCoopers (PwC) to estimate the costs of a National Disability Insurance Scheme (NDIS). PwC provide a range of estimates, but based on the DIG's preferred model, which included funding of 30 per cent of the costs of new incidence as well as meeting current needs, the additional *gross costs* of a NDIS over and above current government expenditures, would be equivalent to 0.8 per cent of taxable income.

The DIG also suggested that the *net costs* would be much lower, because people with disability are over-represented in emergency hospital admissions, amongst the homeless and in the judicial system, as in many cases today they do not receive the support they need. An NDIS could be expected to lead to very significant savings in these areas because of its additional tailored support to allow people with disability to live independently.

Similarly, over time, an NDIS could be expected to reduce dependence on the Disability Support Pension (DSP) and Care Payment. Each year fewer than 3 per cent of people come off the DSP without moving on to some other form of government income support.

This is a very poor outcome compared with no-fault compensation schemes. If the proportion of people coming off the DSP could be increased by one percentage point per annum for 10 years (a very conservative estimate), it would save close to $1 billion in the 10th year, thereby going a long way to offsetting the gross costs of an NDIS.

An insurance approach is therefore likely to be much more efficient than current approaches, while also contributing to inter-generational neutrality by setting aside funds now to meet future costs.

Other benefits of the insurance approach include a close long-term alignment through its inherent structure between the scheme management, people with disability, their families and carers and the potential for insurance companies to provide broader benefits.

For example, insurers have played key roles in promoting safer driving, the establishment of fire brigades in many communities and led to improvements in building regulations to reduce fire risks. This potential for insurance companies to deliver broad societal benefits and serve the interests of the insured population has been noted by Mr. Graeme Innes, the Disability Discrimination Commissioner:

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[3] Disability Investment Group, *The Way Forward*, September 2009, p4

'[A] person whose cause is represented by an organisation, or a statutory authority—or perhaps an insurer with an interest in favourable and efficient resolution of the matter—is not a man, or woman, alone anymore.

There is more to a social insurance scheme than payments to insured individuals. As well as paying benefits to individuals, insurers do all sorts of things to manage risk. And these things as it happens look very similar to many of the major mechanisms for social change provided in the obligations in DisCo [the UN Convention on Rights of Persons with Disabilities].'[4]

An insurance approach would also benefit people without disability, because it would provide a safety net for all people, not just those with disability today.

Service providers such as Yooralla will need to reorient the way supports are delivered and be flexible enough to compete in a demand driven market. Yooralla welcomes this challenge to move away from the rigidity of current funding constraints that focus on the program rather than the person.

Therefore, it is strongly recommended that the Productivity Commission should use the Disability Investment Group report and a *National Disability Insurance Scheme* as the centre-piece for its recommendations.

> **Recommendation**
>
> **2.** That a National Disability Insurance Scheme will provide the best way of achieving the underpinning principles of Equity, Self-determination, Efficiency and Sustainability.

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[4] Mr Graeme Innes, *DIG it at the DisCO: or, Money Changes Everything*, National Disability Summit, 28 April, 2010

Section 2: Yooralla's vision for a national disability insurance scheme

2.1. Evidence:

Best practice in a social insurance scheme will:

- ensure delivery of supports that are consistent with contemporary disability practice.
- enable delivery of both funded supports to scheme participants and broader initiatives that act at a systemic level to improve the work and community participation of all Australians with disability.

- establish protocols with related schemes, programs and benefits to facilitate transition into and out of the scheme.

Best practice in the delivery of funded supports

Australia's Human Rights Charters and its obligations under the UN Convention on the Rights of Persons with a Disability have a number of functions, including describing best practice in the delivery of funded supports for people with disability. As already emphasised in Section 1, the scheme proposed must ensure that funded supports are provided in a way that is consistent with this framework. The scheme's objectives should support and promote best practice in the provision of disability supports and specialist clinical services to ensure that people with disability are supported to achieve and maintain meaningful measurable outcomes in both function and participation.

The Transport Accident Commission (TAC) in Victoria and WorkSafe have developed a clinical framework for health services to support the achievement of the objectives of these schemes[5]. The clinical framework's focus on functional/activity and participation outcomes sets clear expectations for clients and providers about why supports are funded and provides a clear rational for why some supports may not be funded.

Both the TAC and WorkSafe schemes require that the funding of supports that are reasonable, particularly in regard to the achievement of functional/activity or participation outcomes. The TAC's governing legislation provides for the funding of 'the reasonable costs of medical and like services[6] and defines 'reasonable' as

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[5]   Transport Accident Commission & WorkSafe (2009) <u>Clinical Framework for the Delivery of Health Services</u> (retrieved 22 April 2010) http://www.tac.vic.gov.au/upload/clinical-framework-single.pdf

[6]   Parliament of Victoria (1986) <u>Transport Accident Act</u> Section 60 (2)(a) & Section (3)

having regard to the cost and amount of the service and the necessity of the service. The concept of the necessity of the service being linked to the achievement and maintenance of meaningful measurable outcomes has been upheld by both the Victorian Civil and Administrative Tribunal (VCAT) and the Supreme Court of Victoria. [7]

Both these schemes ensure that supports are provided in a way that is best practice for that particular service type. For national disability insurance scheme services, this means that the support should be the least restrictive response to meet that person's needs and consistent with achieving valued participation outcomes.

> **Recommendation**
>
> **3.** That in relation to ensuring best practice in the delivery of funded services and supports, the scheme requires that these funded services and supports be reasonable and that reasonableness have regard to:
> - the achievement or maintenance of measurable outcomes (functional/activity and participation).
> - whether the proposed funded support is the least restrictive response to the person's support need and consistent with achieving valued participation outcomes.
> - community norms, such as parental responsibilities of caring for young children or paying rent, in the case of an adult.

Best practice in the delivery of broad scheme initiatives

Regardless of the eligibility criteria of the scheme, all Australians with disabilities should benefit from systemic change that the scheme brings about.

Authorities that administer social insurance schemes often lead initiatives that benefit the wider community. The TAC, while funding a range of treatment and support services for people injured in transport accidents in Victoria, also has a key role in promoting road safety and improving Victoria's trauma care system. Broader scheme functions include:

- Improvements in road safety that not only enhance the viability of the TAC scheme but also benefit the entire community through fewer accidents and consequent improved productivity and positive impact on the economy.
- Improvements to Victoria's trauma care system, including infrastructure at major hospitals, which facilitates access to trauma care services for all people having had severe trauma.

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[7]   Supreme Court of Victoria (2004) John Russell v Transport Accident Commission (retrieved 20 April 2010) http://vsc.sirsidynix.net.au/Judgments/VSC/2004/T0442.pdf

- Jointly funded research programs such as the Victorian Neurotrauma Initiative Pty. Ltd. (VNI), co-funded with the Department of Innovation, Industry and Regional Development (DIIRD). The outcomes of VNI funded research translate into enhanced understanding of injury and disease processes[8] and improved clinical practice[9] and protocols[10] that benefit all victims of neuro-trauma regardless of their scheme participation status.

Like the TAC the role of the scheme could and should extend beyond that of funding long term care and support for Australians with severe and profound disabilities to include functions to enable sector reform in three areas:

- Improving the employment participation of all Australian with disability.
- Removing barriers to access and participation in all aspects of community life, including physical and attitudinal barriers.
- Funding of disability research to enhance the use of evidence-based practice in policy and program development and in the delivery of support services to Australians with a disability.

Recommendation

4. That in relation to ensuring best practice in the delivery of broad scheme initiatives, the scheme's objectives include:

- improving the employment participation of all Australians with disability.

- removing physical and attitudinal barriers to access and participation in all aspects of community life.

- funding disability research to enhance the use of evidence-based practice in policy and program development and in the delivery of support services to Australians with a disability.

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[8] O'Brien, T. et. Al (2009) Longitudinal In Vivo Study of Hippocampal Structure and Function, and Relationship to Neurocognitive, Neurobehavioral and Epileptic Outcomes, in a Model of Human Traumatic Brain Injury (retrieved 12 July 2010) http://www.vni.com.au/research/cid/381/parent/0/pid/68/t/research/title/publications

[9] WILLMOTT C, PONSFORD J (2008). Efficacy of methylphenidate in the rehabilitation of attention following traumatic brain injury: A randomized, crossover, double-blind, placebo controlled inpatient trial. Journal of Neurology Neurosurgery and Psychiatry; V90, p5522-557 http://www.vni.com.au/research/cid/72/parent/0/pid/68/t/research/title/rehabilitation-of-attention-following-tbi(retrieved 12 June 2010)

[10] Ponsford, J. (2009) Assessment and Intervention for Patients with Mild Traumatic Brain Injury http://www.vni.com.au/research/cid/211/parent/0/pid/68/t/research/title/assessment-intervention-for-mild-tbi (retrieved 12 July 2010)

Best practice in facilitating transition into and out of the scheme

Best practice in the administration of social insurance schemes manages the transition of people from one scheme to another, without impacting on the services and supports that the person receives. Changes in the funding source for supports and services happen 'behind the scenes', because these schemes recognise that the funded services and supports are not discretionary. Where there is uncertainty regarding the jurisdiction under which a service should be funded, or a change to another funding source is required, these changes in scheme participation or funding source should not adversely impact the delivery of that service or support.

Where a number of long-term disability care and support schemes operate concurrently (for example a transport accident scheme and a workers' compensation scheme in the same State) there are occasionally circumstances where it is initially unclear which scheme should accept the claim. Compensation schemes establish claim acceptance and scheme transfer protocols to enable:

- services and supports to be funded by the scheme that first receives a claim.
- the claim to be transferred to another scheme once a final agreement has been reached regarding which scheme should accept the claim
- funds to be recovered by the initially accepting scheme, where the claim is transferred to another scheme or program.

Where the participants of a scheme require funded supports and services that are not funded by the scheme, insurance schemes can implement agreements with these other funding agencies and departments to ensure service access and that funding is managed correctly and consistently (for example, TAC clients are entitled to the Pharmaceutical Benefits Scheme Subsidy for medications funded under the TAC scheme).

Recommendation
5. That the scheme develop and implement agreements with relevant agencies, departments and schemes to ensure that scheme participants continue to access non-scheme funded services and supports to which they are entitled, particularly health and mental health services.

2.2. The long-term disability care and support scheme in context and the current situation for Australians with disability.

Australia has national social insurance schemes to fund access to health care services and income support for those temporally or permanently unable to work. In addition, a number of States have compensation schemes that deliver medical, rehabilitation, vocational and disability services on a no fault basis. These social insurance schemes spread the insurance cost of providing benefits and supports across a sector of the Australian population.

Yet despite the prevalence of disability in our society (1 in 5 Australians report having some form of disability and 6.3% report having a severe or profound disability which restricts their participation in daily activities)[11] there is no equivalent national social insurance scheme that funds services for people with disability. Even for Australians whose disability was acquired through injury, service access is often determined by the cause of the person's disability (for example paraplegia caused by a fall from a ladder at work is covered by a workers' compensation scheme versus a fall from a ladder at home which is not) and the jurisdiction in which it occurred (an acquired brain injury from a single vehicle accident in Victoria entitles access to the TAC's lifetime care and support scheme, but the same accident in South Australia, which has an entirely fault based scheme, does not).

Recommendation

6. That the scheme be established in a way that enables consistent and equitable access to funded services and supports for all Australians with disability eligible for the scheme, including harmonization and transition arrangements with existing long term care and support schemes.

2.3. Current situation for the disability support sector

The disability support sector in Australia includes both the compensable and State funded systems.

The existence of these two systems has led to significant differences in the operating models of services that deliver supports within the two systems.

The compensable segment of the disability support sector has always operated under an individualised funding model where individuals have complete funding portability and are easily able to change the provider from whom they receive funded

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[11]   Australian Bureau of Statistics. (2004). Disability, Ageing and Carers, Australia: Summary of Findings, 2003. (retrieved 20 April 2010)
http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features12003?OpenDocument

supports. Within this segment both providers and clients are clear about the amount of funding that is available for each particular service. Providers in this sector operate under a business model that adapts to changes in the population of clients for whom they provide services.

The State funded segment of the disability support sector has traditionally operated under a block funding model, where funds are provided for supports to be delivered to a group of clients for a defined period of time. Within this model the amount of funding associated with a specific client may be unclear and as a result individuals are not as easily able to change the provider from whom they receive funded supports. Providers in this sector operate under a business model that relies on minimal changes in the population of clients for whom they provide services over a set period of time. This is changing and is expected to provide challenges to the service sector, regardless of whether or not a disability insurance scheme is established. However, a disability insurance scheme is likely to hasten such changes.

Recommendations

7. That the scheme fund services and supports under an individualised funding model to enable scheme participants to exercise choice over the way in which these services and supports are delivered.
8. That the scheme partner with the disability support sector to establish and implement transition arrangements to enable disability support providers who currently operate under a block funding model to move to operating under an individualised funding model.

2.4 Power

Who makes the decisions?

Scheme participant choice and upholding human rights are central to contemporary best practice in the provision of funded supports for people with disability and fundamental to the way in which such services should be funded under a long-term disability care and support scheme. Allowing scheme participants to have maximum control and choice in how supports are provided is consistent with best practice and the expectations of all Australians.

Best practice in the management of long-term disability care and support schemes recognizes the distinction between scheme administration functions (such as claim acceptance or profiling a person's support needs) and personal choices regarding the delivery of funded supports (such as the mix of supports within a given funding level, the choice of support provider or the choice of individual support workers).

Best practice in the administration of long-term disability care and support schemes, distinguishes between administrative decisions made by the scheme and personal choices made by scheme participants.

Administrative decisions made by a long-term disability care and support schemes include:

- determining eligibility for scheme participation
- determining the total amount of funding for ongoing care and support services for individual scheme participants
- determining provider eligibility criteria for service providers and supports for scheme participants.

Personal choices made by scheme participants include:

- the mix of supports for community living, within an assessed and approved funding amount
- the service provider and the individual workers who will deliver negotiated services and supports
- when, where and how supports are delivered
- changes to the mix of supports or when, where and how they are delivered.

Best practice in administering long-term disability care and support schemes focuses resources on scheme administration tasks. This approach empowers people with disability to make personal choices about the funded supports that they receive and does not 'over administer' claims where costs are running as expected. Person centred planning processes are an important strategy to empower clients to make personal choices regarding funded supports they may receive.

An individual funding agreement enables the person with disability to make choices about the services that they receive. Participants control an agreed amount of funds to be used to purchase defined services within a specified period of time, usually one year. Internationally, participants with this type of funding usually under spend rather than over spend and the increased control they gain over the services that they receive means that their efforts are focussed on ensuring those services are responsive to their needs[12].

Best practice in relation to individual funding agreements sets out:

- eligibility criteria for a funding agreement.
- the contents of individual funding agreements, the terms of the contract
- provisions for agreements where the participant has a cognitive disability
- other provisions, such as the type of services that can be purchased.

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[12]   Pamela Doty, Kevin J Mahoney, and Lori Simon-Rusinowitz, (2007) Designing the Cash and Counseling Demonstration and Evaluation Health Services Research, February; 42(1 Pt 2): 378–396

Recommendations
9. That, in relation to the delivery of funded supports, the scheme distinguishes between administration functions of claims management and matters of personal choice.
10. That the scheme empowers individuals to exercise personal choice regarding the delivery of funded supports.

Management of expectations of people with disability and families

The State and territory funded system currently operates in a very restricted funding environment that is characterised by limited access to funded supports (for example, narrow eligibility criteria for funding of disability supports and long waiting lists for services) and a restricted range of service options available (such as limits of the level of in-home attendant support that will be funded).

There is no expectation of enhanced services such as those provided under no fault schemes (for example, one to one 24 hour support, funding of highly modified vehicles, funding of adapted sporting equipment, funding of extensive home modifications). There is, under the current system, no need to manage expectations as expectations, and the reality, is of a rationed system.

Under a fully funded or partially funded non rationed scheme (funded according to DIG recommendations), the management of expectations can be a challenge both for the scheme and service providers. Private practitioners, such as case managers and therapists, working in the compensation sector often experience difficulties managing peoples' expectations of funded supports. These difficulties can be compounded by the medical and rehabilitation background of practitioners and their lack of experience in working within a social disability model of support. This can make it difficult for the practitioner to assist people to make the shift from a recovery focus to maximising opportunity and community participation as part of the process of adjusting to life with disability.

The risk in managing expectations of some clients and providers who become client advocates must not be under-estimated. Unusual expectations from a relatively few clients, supported by providers who 'fight for clients', upheld at review and appeal, can compromise scheme viability for everyone.

Yooralla understands that schemes such as the ACC and TAC have experience of some people coming to expect that the insurer will pay for ordinary life expenses and supports that go well beyond what is needed to respond to the disability, provide support and facilitate participation. In some instances, these views have been upheld by review authorities and in court. For example, the McRitchie decision in Victoria found the TAC liable for ordinary living expenses such as rental. A legislative

amendment was needed to mitigate the risk of the ruling extending to all people living in shared supported accommodation. A recent decision in New Zealand held ACC liable to fund the retrofit of a lift and other access features to a new home built by a man with long standing paraplegia who had not, in contravention of ACC policies, consulted with the ACC before building a home that would need modifications. Requests for in ground swimming pools, home gymnasiums, ordinary transport costs, computer systems not related to the disability, GPS systems and funding for ordinary child care are sadly common.

Explicit boundaries on what can be funded are required and review/appeal mechanisms must require that review bodies cannot make a decision that would result in the scheme funding ordinary life expenses or compromise the viability of the scheme via flow on effects.

The notion of an 'entitlement' scheme also becomes problematic when entitlement is taken to mean 'person A' had a computer/gym program/new bathroom funded so I am entitled to have that computer/gym program/new bathroom. Funding decisions must be grounded in needs-based responses and responses where there is a clear line of evidence that the response is consistent with best practice models and cost effectiveness.

Recommendations

11. That the review bodies cannot make a decision that would result in the scheme funding ordinary life expenses typical of peers.
12. That funding decisions be grounded in needs-based responses and responses where there is a clear line of evidence that the response is consistent with best practice models and cost effectiveness.
13. That review bodies cannot issue a decision that, via flow on, would adversely affect the viability of the scheme.

2.5 Supply

Specialist providers and mainstream providers

Changes to the range of certificate, undergraduate and post graduate courses available in health and disability, the curriculum of these courses and the employment opportunities for graduates of these courses have all affected the capacity of specialist providers to deliver services to people with disability.

The move to a postgraduate model of education for allied health and disability studies has affected the costs of undertaking these courses and the career choices of allied health graduates. Likewise, growth in the market for compensable allied

health services (in line with the growth in client numbers as no fault compensation schemes continue to mature) has influenced the career choices of some graduates. These changes have in turn influenced the curriculum of some courses, for example, a greater emphasis on private practices focussed on sports medicine or short term rehabilitation and a lesser emphasis on contemporary practice in the delivery of allied health services to people with disability.

Recommendations

14. That the scheme partner with tertiary institution and professional associations to maintain and enhance contemporary disability practice as a part of the curriculum.

15. That the scheme partner with professional associations to engage with specialist providers in strengthening the application of contemporary practice in the delivery of allied health services to people with disability (for example, strengthening the use of client centred planning to identify support needs as well as formal and informal responses to those support needs).

Mainstream Providers

People with disability often experience attitudinal barriers when accessing mainstream services because of the limited capacity of these providers to deliver their services for this customer group. A lack of knowledge about legal obligations, practical steps to make activities and services accessible and where to get support to improve the accessibility of activities perpetuates physical and attitudinal barriers to accessing mainstream services.

For example:

- Municipal swimming pools and gyms may be physically accessible for people with disability, but limitations in access may be driven out of lack of experience and training of staff in supporting people with behaviours of concern (challenging behaviours) or cognitive disabilities.

- Private providers of pre-school leisure activities (such as music, dance or come-and-try sport) may have no knowledge of how to adapt the activity to suit a young child with disability, be unsure of implications for public liability (a not uncommon concern) and not know how and where to get information and support about these issues.

Recommendation

16. That the scheme funds and administers a small grants program to support small private enterprises providing mainstream services to remove attitudinal and skill barriers.

2.6 Scope

Who should be eligible? What supports should be funded?

Scheme eligibility

The terms of reference for the Productivity Commission's feasibility study include a broad definition of eligible scheme participants as 'people with a severe or profound disability' and links scheme eligibility both with this level of disability and with an associated need for 'long-term essential care and support'.[13]   While this approach is best practice in the management of eligibility for long term care and support schemes and is currently used by State based disability services departments[14], lifetime personal injury insurance schemes in Australia[15][16] and internationally[17], it is critical to focus on the effect of the disability on the life of the person and their family rather than basing eligibility solely on whether the condition can be labeled 'severe or profound'.

In addition to considering a social model as the basis of eligibility, rather than a purely medical model, it is also important to consider equity between those who are just included in the scheme and those just outside the scheme. It would be unwise to set the scheme so narrowly as to create significant inequities. As a result the scheme eligibility criteria should be broad.

The Disability Act 2006 (Victoria) provides a useful starting point for defining disability.

"Disability" in relation to a person means—

(a)   a sensory, physical or neurological impairment or acquired brain injury or any combination thereof, which—

(i)   is, or is likely to be, permanent; and

(ii)   causes a substantially reduced capacity in at least one of the areas of self-care, self-management, mobility or communication; and

(iii)   requires significant ongoing or long term episodic support; and

(iv)   is not related to ageing;[18][19]

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[13]   http://www.pc.gov.au/projects/inquiry/disability-support/terms-of-reference (retrieved 16 April 2010)

[14]   Department of Human Services (Victoria) (2009) Disability Services Access Policy page 4 (retrieved 16 April 2010)http://www.dhs.vic.gov.au/disability/publications-library/access_policy

[15]   Transport Accident Commission (2008) Schedule 2 – Authorised Disability Services (retrieved 20 April 2010) http://www.tac.vic.gov.au/jsp/content/NavigationController.do?areaID=22&tierID=1&navID=DEFBB46F7F00000101A5D193EB2FDF2C&navLink=null&pageID=799

[16]   Lifetime Care & Support Authority (2008) Severe Injury Advice Form (Retrieved 22 April 2010) http://www.lifetimecare.nsw.gov.au/Severe_Injury_Advice_form.aspx

[17]   http://www.acc.co.nz/making-a-claim/how-do-i-make-a-claim/ECI0012#P2_170

[18]   (2006) Disability Act. Melbourne, Parliament of Victoria

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This definition of disability is noteworthy because it defines both the nature of a person's impairment and the impact that the impairment has on the person's level of activity. This definition is also used by the TAC (in a form slightly modified to be appropriate for a scheme managing people with transport accident injuries)[20] as their governing legislation does not define disability.

In New South Wales, the governing legislation of the Lifetime Care and Support Authority, the Motor Accidents (Lifetime Care and Support) Act 2006, does not define disability or eligibility for scheme participation but provides for this to occur through guidelines developed by the scheme[21]. Currently these guidelines specify eligibility for scheme participation as a combination of three factors:

1. defined injury types (brain injury, spinal cord injury, multiple amputations, certain full thickness burns and legal blindness).
2. injury severity (assessed with standardised clinical measures such as duration of post traumatic amnesia following acquired brain injury, level of spinal cord injury or amputations).
3. standardised measures of function (FIM/WeeFIM score)[22].

The use of standardised clinical assessment tools to determine the severity of a person's disability and the impact on that person's function provides a robust and equitable approach to managing scheme access. These assessment tools are objective and reliable measures that are accepted and used by the health and disability sectors and, in the case of standardised measures of function, can predict a person's need for support services.

Yooralla supports this approach to defining scheme eligibility as it is not the disability that a person has but their resultant need for care and support that necessarily defines scheme eligibility.

Many Australians with disability do not have a severe or profound disability and are therefore not limited in their ability to participate in core daily activities[23]. As these

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[19] The legislative references to intellectual disability and developmental delay have been left out as they are not regarded as helpful concepts, both are covered in (a) by virtue of reference to 'neurological impairment'. Similarly a reference to acquired brain injury is not needed.

[20] Transport Accident Commission (2008) Schedule 2 – Authorised Disability Services (retrieved 20 April 2010)
http://www.tac.vic.gov.au/jsp/content/NavigationController.do?areaID=22&tierID=1&navID=DEFBB46F7F00000101A5D193EB2FDF2C&navLink=null&pageID=799

[21] (2006) Motor Accidents (Lifetime Care and Support) Act. Sydney, Parliament of New South Wales

[22] Lifetime Care & Support Authority (2008) Severe Injury Advice Form (Retrieved 22 April 2010) http://www.lifetimecare.nsw.gov.au/Severe_Injury_Advice_form.aspx

[23] Australian Bureau of Statistics. (2004). Disability, Ageing and Carers, Australia: Summary of Findings, 2003. (retrieved 20 April 2010)
http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features12003?OpenDocument

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people with disability do not have a need for ongoing care and support it is clear that they should obtain this level of support as scheme participants. However, as people with disability with a mild or moderate level of impairment, it is important that the scheme has the capacity to meet their lesser support needs.

In all cases, and as with other insurance schemes, support benefits may only be claimable above an 'excess' or threshold amount.

The social model of disability supports the notion that disability is not a 'medical condition'. The scheme should focus on providing services and supports that enable the person with disability to live an ordinary life in the community, as most people aspire to. This is true also of families who have the responsibility for caring for their family member with disability. The family unit should receive supports to assist with the extraordinary tasks and costs of supporting the person with disability to enable them to function as other families do within the community.

Yooralla is of the view that only those people who acquire a disability before age 65, or are of pensionable age, should be covered by the scheme. Much of the reported prevalence of disability is associated with the ageing process and diseases of ageing. It is simply not possible to "insure against ageing".

Once deemed eligible for the scheme, however, the person should continue to receive the supports they require in relation to their disability throughout the course of their life. Yooralla currently supports many people with disability, for example people living and receiving supports in supported accommodation settings, who are older than 65 years. This is in keeping with the concept of 'aging in place', in one's own home and community.

Recommendations

17. That the scheme define eligibility both in terms of the nature of the disability and the impact on a person's function and support needs as measured by standardised assessment tools.
18. That the scheme eligibility be limited to people who acquire their disability when age 65 (or who are of pensionable age) or younger.
19. That once a person has been assessed as eligible for receiving supports through the scheme, services and supports continue throughout that person's life (i.e. post 65 years of age)

Scheme benefits

Most compulsory third party insurance schemes in Australia provide for funding of a range of benefits.

A clear mechanism for authorising services to be funded under the scheme communicates that the scheme is not intended to fund all costs associated with a person's life. For example, under lifetime care and support provisions schemes are not responsible for meeting the costs of ordinary life roles and activities.

In an ordinary family situation, for example, parents of a very young child are ordinarily expected to feed, bath their child. As the child grows to be an adolescent these roles drop away as the person becomes more independent. Where a child has a disability that impacts on their ability to develop independent skills in this area, there should be capacity within the scheme to fund support for the family where the time taken to provide those supports is in excess of one hour per day. Family members should not be expected to provide personal care tasks, as this is outside of community expectations around dignity and privacy.

A further example is an adult with disability going out to dinner with family or friends who requires their meal to be cut up so that they can eat it independently. It is fair to expect the family or friends to cut up the meal within the ordinary experience of sharing the meal as a group. However, should the adult with disability require full assistance to cut up and eat the meal, support should be funded to undertake that role so that everyone, family, friends and the person with disability, can enjoy the meal and the social experience.

Recommendations

20. That the scheme fund only those services and supports that are required as a result of the person's disability and where the support need cannot be met through the normal life roles of the person's family and extended support network.
21. That the scheme not fund ordinary life activities that are consistent with peer roles and expectations (and fund only those supports and services that are required as a result of the disability.
22. That the scheme should remain focussed on and be specialised in the management of long term care and support. Associated benefits and schemes such as income support should remain separate.

2.7 Financing

Using an insurance model to fund the scheme would enable it to proactively manage future demand for long-term disability care and support services and the community's capacity to provide and fund this support. An insurance model would provide funding for the future care needs of Australian's with disability according to their assessed individual needs, without passing this cost on to future generations[24]. In a society with an aging population, where both people with disability and their family carers are also aging, this funding approach is vital to ensure viability in the long-term.

The alternative and current funding model of annual departmental budgets does not allow for provision of high quality individualised services long term. Funds allocated do not take the cost of providing support services as their starting point and are usually only sufficient for services provided in the short-term. This annual budget funding model has left the State departments, who currently have primary responsibility for funding services for people with disability, to manage a situation where demand for services far exceeds supply. Accommodating growth in demand for services is extremely difficult resulting in the departments having little choice but to focus on a service delivery model that is crisis driven and overly reliant on family carers.[25] This situation is not sustainable because:

> 'For the next 70 years, the projected growth rate in the population with severe and profound disability is between two and three times the population growth rate as a whole. While the number of people with disability continues to grow, the availability of informal care is contracting. Fewer people take on informal caring roles because of a range of factors including increasing workforce participation by women and decreasing core family size. The impact of these trends on the disability services system will be significant. Because non-paid care provides for more support than paid care, a 10 % reduction in providing informal care translates into a 40 % increase in the need for funded services.'[26]

Yooralla supports the use of an insurance model to fund the scheme to ensure that it remains viable for future generations. Taking the cost of providing long-term disability care and support services and calculating a premium to cover these costs will enable

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[24] Productivity Commission webpage – Long Term Care and Support Scheme Terms of Reference http://www.pc.gov.au/projects/inquiry/disability-support/terms-of-reference

[25] Disability Investment Group (2009) The Way Forward – A New Disability Policy Framework for Australiahttp://www.fahcsia.gov.au/sa/disability/pubs/policy/way_forward/Pages/default.aspx page 2 (retrieved 20 April 2010)

[26] Disability Investment Group (2009) The Way Forward – A New Disability Policy Framework for Australiahttp://www.fahcsia.gov.au/sa/disability/pubs/policy/way_forward/Pages/default.aspxpage1 (retrieved 20 April 2010)

scheme participants' needs for long-term care and support services to be met and also enable broader reforms and initiatives to be undertaken.

Recommendation

23. That the scheme be funded under an insurance model to enable the scheme to be fully funded or at least partially funded (in line with the DIG recommendation), both in relation to providing supports for individual scheme participants and in relation to leading broader initiatives for all Australians with a disability.

Section 3: Best practice in Community Living Supports

3.1 Power

This section discusses the scope and effectiveness of scheme funded supports to enable community living for people with disability. It describes current issues from the consumer, practitioner, support service provider, funder and market perspectives, making recommendations for best practice in providing community living supports (CLS).

Firstly we describe the current situation in relation to community living and go on to discuss key design elements.

3.2 Benchmarking for Community Living Supports (CLS)

Best practice in providing community living supports recognises that the identification of and planning responses to, the support needs of people with disability should:

- be person-centred (or family-centred in the case of children) rather than service-based
- focus on peoples' abilities and the supports they may require to enhance their activity, engagement and participation (excluding ordinary life activities), rather than focus on impairment and deficit
- focus on the achievement of ordinary lives (participation), rather than ongoing rehabilitation and therapy (other than where outcome focused and episodic rehabilitation and therapy supports the achievement of ordinary lives)
- link people into generic services rather than disability specific services, unless a degree of technical expertise is required that cannot be delivered via a generic service or consultation to a generic service (for example, communication programs, behaviour support strategies)
- have a strong focus on enabling participation in the wider community.

3.3 Community Living Supports in context

None of us in life rely solely on services we can purchase to meet our needs for engagement, participation and self actualisation. So it is with people with disability. Services should be enablers with richness in life coming from informal networks such as friends and family, fellow employees etc. Relationships are a critical component of a satisfying life and a sense of well being. Formal services support lives and, as noted, are enablers rather than making up a good life. Informal support networks in a person's local community facilitates engagement with mainstream activities and provides the sense of community we all like to enjoy.

Providing the right supports at the right time maximises a person's capacity to lead the life they choose. Best practice delivery of funded community living supports, enables people with disability to achieve their goals. A number of indicators can be used to measure the achievement of these goals, including:

- quality of life measures
- wellbeing or mental health status measures
- formal planning setting goals for achievement with built in measures and reviews
- forming and maintaining friendships and relationships
- participating in productive activities (paid employment, study, recreation and volunteering).

3.4 Current situation for the CLS user

Best practice involves person-centred planning where the person with disability is at the centre of the support needs identification and planning process. Person-centred planning empowers the person to define their own life goals and identify appropriate responses to their disability related needs. The identification of appropriate responses may or may not require support. Appropriate responses are typically developed by reference to factors such as people's age, peer appropriate social roles, cultural relevance and the right to exercise choice and take risks.[27]

Currently CLS users face a range of issues in relation to the way these supports are funded. In general there is:

- limited portability of funding: in particular, the strong connection between funding for housing and funding for support restricts the portability of that funding and limits people's ability to re-locate and/or change living arrangements. Even where people have individual support packages the very fact that these packages are often used to purchase shared support means that one person's decision to move, for example, might compromise the arrangements for one or more other people. This is an acknowledged risk in small scale congregate care (shared supported accommodation or group homes) but is equally true of other arrangements such as neighbourhood networks (e.g., KeyRing)[28] or shared services on the same site
- limited flexibility regarding changes in service type or the way in which support is provided (when and where)

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[27] Smull, M. (1995). Revisiting choice - part 1 and part 2. Baltimore, Support Development Associates http://www.allenshea.com/choice.html.
[28] http://www.keyring.org/site/KEYR/Templates/Home.aspx?pageid=1&cc=GB

- transitional constraints, for example, funding for therapy and similar services typically falls dramatically when a child moves from disability funded early childhood services to education funded primary school. Adolescents experience barriers in transferring from the education system back to the disability support system and to adult supports and then as they age to aged care supports. The various funding 'silos' often work to prevent continuity of service provider and/or support workers

- limited interaction between systems, (health/mental health/ substance use, justice, disability, education, employment support etc.) that also restricts access to services by some people with disability.

Current service access and funding arrangements also include some disincentives to increasing independence and participation, such as:

- low income thresholds that trigger the removal of eligibility for health care cards that act as a disincentive for some people to seek and obtain paid employment. The threshold does not acknowledge the greater costs of living with disability nor the greater costs, typically transport, that can be associated with working for the person with disability

- funding structures for in-home support (such as attendant support)[29]. The difficulty of obtaining this type of support can mean people are reluctant to try other options for fear of no longer being able to access in-home support. Holding on to what one has is highly compelling in a resource constrained environment.

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[29]   Also referred to as attendant care in the ageing and disability sectors

System ⟍ ⟍ ⟍ Characteristic	State and territory funded services – disability, human services departments, HACC	Compensation schemes - both lump sum compensation payments and no-fault schemes
Access to supports	Demand far exceeds supply. Experience of waiting long waiting list or narrow eligibility criteria may make participants reluctant to consider other support options.	Supply meets demand (for eligible scheme participants); however the compensation environment can adversely influence participant willingness to consider other support options, such as informal supports.
Identification of needs and responses	Variable across and within jurisdictions – often service led (the person with a disability is assessed as eligible for a pre-defined package of supports).	Variable across schemes – may be practitioner led prescription of services or person centred planning.
Support options	Highly defined, capped packages of support.	Defined range of (usually) uncapped support services.
Portability	Variable (but usually very limited) portability of support.	Portability of support is greater but may be limited by scheme requirements for provider registration and barriers to accessing disability services when one is 'a compensable client'
Flexibility	Limited by both funding arrangements and by support provider capacity.	Limited by legislative and policy provisions as to what can be funded, schemes approach to claim management and support provider capacity.

3.5 Parents with disability

Yooralla has a strong commitment to supporting people with disability who are parents. Our close working relationship with has highlighted a lack of appropriate support and policy as key issues to be resolved.

Parents with disability have a number of additional needs over and above the needs of others with a disability and parents who do not have disability including:

- Little to no access to appropriate parenting and other independent living programs
- Little or no access to appropriately trained and resourced maternal and child health services
- Little to no access to appropriate housing especially for homeless parents or women escaping violence
- Discrimination and lack of support from workers within the child protection system.
- Little to no access to support in the legal system by appropriately trained legal practitioners.

A key complaint by a growing number of people with disability, who are parents, focuses on the lack of flexibility and understanding by agencies that provide their support. Current policy and practice does not allow for Individualised Support Packages (Department of Human Services funding) to assist them where their disability limits their capacity for support a family member in relation to normal child and family responsibilities. For example, funding may be available to assist a parent with a physical disability with their own personal care tasks such as bathing and toileting, but it may not be used to assist their young child to be bathed or toileted, even though their disability also limits their capacity to undertake these normal roles.

This inflexibility in policy and practice in the current support system means that parents with disability face serious daily challenges to proper parenting and puts inordinate strain on children and families.

Recommendation
24. That the scheme includes a policy that enables the person with a disability to nominate how their funds for attendant/personal care hours are spent and enables use for the purpose of more generalised family support.

3.6 Current Issues within the industry

Current practice varies across jurisdictions and between segments of the sector; however, with regard to community living support, some issues are common to both systems and across all jurisdictions. This is particularly the case for one to one in-home and community-based support (attendant support). Current issues in the provision of attendant support as a community living support option include:

- as already discussed, people with disability being reluctant to try other options for fear of losing access to funding for attendant support
- attendant support workers having variable capacity to support community participation of people with disability. This often leads to attendant support workers becoming the primary person with whom the person with disability interacts, rather than being a support to enable the person with disability to interact with others
- funding models that inadvertently provide incentives for attendant support agencies to foster dependence to guarantee stability of cash flow for the provider and a stable working roster for the worker
- changes to employment law have a profound affect, both positive and negative on funding requirements, scheme and service viability and workforce flexibility.
- an undersupply of allied health assistants. Often when no allied health assistant is available an attendant support worker is used to support a community based rehabilitation and/or therapy program. This results in an unclear distinction between community based rehabilitation and participating in community life (when out with a support worker)
- support delivery models that provide limited flexibility regarding where, when and how supports are provided. For example, fixed start and finish times for attendant support shifts and penalty loadings for work done outside of these times can limit access to paid employment as well as evening and weekend leisure activities.

3.7 Supply chain (labour market issues)

There is currently an imbalance between the demand for, and the supply of, State and territory funded support. This imbalance may mean that the existing work force does not have the capacity to meet an increase in demand for community living supports. In particular, the numbers of qualified experienced support workers, particularly in regional and remote areas, are limited.

Workforce issues are highly significant in the introduction of any scheme as the costs of employing workers is the main component in the provision of services to people with disability. In addition the workforce must be able to adapt to changing needs

and service models in response to the increasing complexity of needs and new individualized approaches to providing support.

A number of different service models could exist within a long-term disability care and support scheme and these will have an effect on the workforce requirements.

Workforce demand assumptions need to be made on the basis that the scheme:

- will involve a range of people with disability who have different needs at different stages of their life - it is a long term provision, from early childhood support to late in the individual's lives
- should include a range of service provision which includes the 16 life areas that are important to people (as outlined in the Quality Framework Disability Services, below).[30]

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[30] (2007). <u>Quality framework for disability services in Victoria</u>. Melbourne, Disability Services Division, Department of Human Services.

1. Always learning	9. Exercising rights and responsibilities
2. Being part of a community	10. Expressing culture
3. Being independent	11. Having fun
4. Being safe	12. How to live
5. Building relationships	13. Looking after self
6. Choosing supports	14. Moving around
7. Communicating	15. Paying for things
8. Doing valued work	16. Where to live

- should be offered in various ways, based on individual need and supporting goals related to reducing the impact of disability including vocational, recreational, spiritual and community access. Attendant support will often need to be included in a package to enable the goals in these areas to be met.

Accepting the preceding then leads to the following:

- There is a need to be highly flexible with workforce provision.
- The types of services will be increased in volume or range (i.e. new services offered).
- Disciplines across the workforce will need to be more coordinated.
- If informal care systems (family, friends and community supports) reduce, the need for paid employees (formal supports) will increase.
- There will be uncertainly and instability for disability service providers as individualized funding replaces block funding which has more financial certainty. However, service providers are having to move toward individualized funding models of support whether the scheme is implemented or not.

In turn, the implications for workforce will include:

- the need to increase responsiveness to individuals with flexibility of working hours being critical.
- the need to allow for changed conditions of employment as individuals with disability (or families) move to employ their own staff, rather than engaging agency staff
- the possibility that the current lack of career structure and status will be exacerbated
- workers needing to work with more autonomy and less formal supervision
- new funding arrangements may make it difficult to offer long-tem employment contracts or contracts with any certainty of hours
- further isolation of workers as the location of service is most likely to be community based

Implications that need to be taken into account if workers are employed directly by the person with disability include:

- fewer training and development opportunities being available
- Fewer safeguards in relation to Work cover and superannuation for workers
- insufficient part-time hours available to make a viable income for individual workers.
- poor back up/replacement options in the event that a worker is not available (planned or unplanned absence) for a shift
- fewer safeguards regarding Safe Work Practices and unfair dismissal
- the inadvertent establishment of a two tiered model – where employees employed by disability organisations have certain terms, conditions and provisions whilst those employed directly by the person with a disability do not.

Therefore a long-term disability care and support scheme will need to consider:

- support for staff working in isolation – from an organisation and geographically.
- need for infrastructure support, for example, Occupational Health and Safety (OHS) and employment laws as well as training and development for people with disability/families
- establishing strong claims management or methods to monitor and regulate service provision - transparency and same standards for all
- establishing mechanisms to address the uncertainty regarding cash flow for providers in transitioning from block funded services to individual tied dollars.

In some quarters it is argued that many of these problems could, and should be overcome by simply paying immediate family members living with the client to be the client's attendant support worker/s. The experience of the Accident Compensation Corporation, New Zealand, suggests that while this might be an appealing solution, it is not a solution in the best interests of the client, the family or the scheme. Yooralla recommends that advice as to such risks be sought from the Accident Compensation Corporation, New Zealand.

Where family members become paid workers the income rightly becomes the family income and is used, as any wage is used, to purchase life's necessities. Therefore any change to the quantum of attendant support funded can directly affect a family's ability to pay their mortgage, meet their bills and day-to-day living expenses. Under these circumstances a family may find themselves rejecting an option, (for example. a modified vehicle, an employment program, public transport training or assistance dog) that would serve to increase a person's independence because they simply cannot afford the loss of income.

For the person with disability decisions such as moving out of the family home to a home of their own might well be constrained by concerns about an adverse impact on the family income.

The nexus between family income and the person's support package leaves scheme administrators in a difficult situation when it is clear that a person no longer needs what they once required, in terms of attendant support, but changes are resisted by the client and the family for reasons of impact on income.

> **Recommendations:**
>
> **25.** That an ongoing role for attendant support agencies be recognised and supported as part of a diverse market and choice.
> **26.** That, in keeping with current and evolving practice, people be able to directly employ their support workers.
> **27.** That, to ensure minimum standards are met, models be developed whereby clients recruit workers/carers and disability agencies carry out necessary police screening, training and/or act as the employer.
> **28.** That the scheme not fund primary family members living in the family home with the client as the client's support workers (unless under extraordinary circumstances where there is no other option available).

3.8 The Proposal

Who makes the decisions?

As already discussed, best practice in the administration of long-term care and support schemes distinguishes between administrative decisions made by the scheme and personal choices made by scheme participants. Person centred planning processes are an essential strategy to empower clients to make personal choices regarding funded supports they may receive.

Existing schemes such as the TAC and the New Zealand Accident Compensation Corporation outsource service provision. Outsourcing of services needs to be a key feature of a scheme - a scheme should not be in the business of service provision. The exception to this approach could be case management (as distinct from claims management which is an administrative function). Various models of in-sourced case management, out-sourced case management and hybrid models are in place across different schemes. While case management may not be an option needed or wanted by every client, the critical point in delivery of community living support is that person-centred planning be the planning paradigm.

The use of person-centred planning processes:

- places the person with disability at the centre of the decision making process
- takes the person's life goals and choices as the starting point for planning community living supports

- empowers the person with disability to identify responses to community living supports they need
- maximizes the capacity of funded supports to enable the person's choices to be realized.

Establishing structures to enable scheme participants to have decision making power in relation to the funding of services and supports (for example, through a provision for the establishment of individual funding agreements) is an appropriate means of resting maximum power over service decisions with the person with disability. For people with stable and predictable needs and circumstances, an individual funding agreement affords the person with disability control over the services that they receive.

Including a provision for eligibility and funding decisions to be reviewed and establishing alternative dispute resolution processes, ensures decision making processes are accessible and transparent and that people with disability are active participants in these processes.

Recommendations:

29. That person-centred planning processes be used to identify the disability related needs of scheme participants and the appropriate responses to needs.

30. That supports (including accommodation support) are funded in a way that enables the person to choose - where they live and with whom and choose providers of supports and individual support workers.

31. That support provided for community living is funded within an individualised funding model that breaks the connection between the funding of accommodation and support.

32. That the scheme should provide for the establishment of individual funding agreements.

33. That the scheme includes provision for alternative dispute resolution and mediation processes and protocols.

3.9 Supply

Community Living Support options available to people with disability

Supported Accommodation

Both the compensation and State and Territory funded sectors operate a hybrid model with supported accommodation owned and operated by public housing authorities, the private and not-for-profit sectors and the funding agency itself. The TAC is currently piloting capital expenditure on supported accommodation facilities.

State disability departments, such as Victoria's Department of Human Services, and the private and not-for-profit sectors have a long history of funding the building and service provision within supported accommodation facilities.

Access to appropriate supported accommodation is restricted by:

- a limited stock of accessible housing – both public and private housing
- limits on funding available to undertake home modifications restricting the ability of people with high support needs to live in their own homes
- the limited availability of a range of supported accommodation models, both in metropolitan and regional/rural locations, meaning that people with disability are often unable to move to a different type of supported accommodation without moving from a familiar neighbourhood
- the limited availability of age appropriate supported accommodation for people with very high (nursing home level) support needs.
- limits on the funding available for in-home support restricting the ability of people with very high support needs to remain living in their own homes and with their families
- restricted tenancy rights of people with disability living in State department owned or funded supported accommodation. For example, a person living within shared support in a Department of Human Services owned group of units, may be required to move from that setting once their abilities/independence improve. The lack of other appropriate options in that town or metropolitan region may result in them being required to move to an unfamiliar neighbourhood and may lead to a deterioration in their abilities/independence.

Supported accommodation models should include:

- unit developments - individual units on one site or closely located apartments within the one building with shared support located on site- offered from one of the units. For example – the office of housing built development in Moe, Victoria providing support to people with disability and associated behaviours of concern include a separate unit for use by support staff (administration and sleep over capacity).
- dispersed unit settings - units or apartments dispersed throughout a housing development or neighbourhood where low level shared support is provided, sometimes on an on-call basis. For example the Parkville Commonwealth Games Village in Melbourne
- in home support – individual support (usually attendant support) provided in a house purchased for/by the person with disability or in a rental property
- community residential units (group homes) – where a number of people (usually up to 5) have private bedrooms and share bathrooms, living areas

and meals areas. Currently this is the predominant model in the State and Territory funded sector. Funding is used to provide shared staffing support In these houses

- lead tenant models – where people with disability share a house (either public or private housing) and access low level intermittent support from a lead tenant without a disability living in that house.

Recommendations

34. That the scheme partner with public housing, social housing agencies and with private developers to develop and implement a strategy to increase the stock of accessible housing, including:
- universal accessible design including physical access and provisions for the installation of personal care equipment such as ceiling hoists
- the inclusion of accessible housing in private developments
- designs that are appropriate for people with behaviours of concern.
- ensuring a range of supported accommodation options are available throughout metropolitan areas and regional centres.

35. That the scheme fund supported accommodation in a way that enables the level of supports a person receives to be changed without requiring the person to move house as needs change. This funding model breaks the connection between funding for housing and funding for support.

36. That the scheme develops and implements an ongoing strategy to prevent young people being admitted to nursing homes and to enable young people in nursing homes to move to age appropriate supported accommodation, particularly as the current National Younger People in Nursing Homes Program has only twelve months to run.

37. That the scheme includes tenancy rights for people living in supported accommodation.

3.10 Attendant support

Attendant support (sometimes called attendant care) is individualised support provided to a person with disability to enable that person to complete personal care tasks and/or to access the community. Best practice in person centred planning and identifying support responses for people with disability, identifies attendant support as a response when there are no other support options available to achieve the desired goal or where the client would pose a risk to themselves or others without this type of support.

In a fully or at least partially funded scheme (funded according to DIG recommendation) the funding of attendant support does not automatically assume that other family members in the household are an available support option. Best

practice in person centred planning has regard to the contribution that family members could reasonably be expected to make, including caring for others in a household. But it differentiates this from unpaid care. For example, all 12 month old babies require some assistance with feeding regardless of whether or not they have a disability, but a 10 year old child would only require assistance with feeding as a result of their disability. Feeding assistance provided to a 12 month old is a normal parental responsibility but full feeding assistance provided to a 10 year old is not.

Within the state and territory funded system, attendant support may currently be funded within a 'capped' package of in-home supports. Many people who access these packages of support are also heavily reliant on informal care to meet their support needs. Funding limits mean that new attendant support workers are often not trained in the use of a person's assistive technology. If the attendant support worker is not trained in the best way to use the person's assistive technology, for example a communication device, then this limits the person's function and ability to communicate. Within the compensable sector, attendant support funding is usually uncapped. Access to uncapped attendant support, approved against assessed need, enables people with very high support needs to remain living in their own homes.

The way, in which attendant support is funded and delivered, impacts on a person's capacity to try alternative support options. For example:

- extremely restricted access to attendant support may result in some people with disability being reluctant to access a leisure activity that provides shared support, for fear of no longer being able to access attendant support if they decide to stop accessing the supported leisure activity
- attendant support at a leisure facility that emphasizes interaction with the attendant support worker rather than the person with disability's friends, family and community; can foster reliance on attendant support workers at the expense of building and maintaining personal support networks.

The attendant support workforce has a similar profile to the supported accommodation workforce in that it is predominantly female and is an ageing workforce. Current pay rates for attendant support workers mean that employers and funders are competing with the retail and hospitality sector for workers. Within many State and Territory funded systems there is a disparity between pay rates for supported accommodation workers and (lower paid) attendant support workers. These workers perform the same tasks, the former in the person's home, the latter in a supported accommodation facility and both in the community. In many cases the role of an attendant support worker can be more challenging as they are working in isolation, often with little to no supervision and without team/peer support.

Recommendations

38. That the scheme fund attendant support within funding limits (sometimes called funding bands) that have regard to the person's disability, their support needs and their individual circumstances.

39. That the scheme provides for people with disability to:

- choose their provider of attendant support and their individual attendant support workers.
- choose when, where and how attendant support is provided
- change when, where and how attendant support is provided
- have portability of attendant support funding and use the same attendant support workers when they move to a new living situation, such as moving from supported accommodation to community living.

40. That the scheme funds:

- attendant support.
- attendant support worker training (attendant support worker time and specialist provider time) in relation to the delivery of individual attendant support programs.
- ongoing specialist support (such as therapist time) to enable attendant support workers to support the person with a disability to use assistive technology. This includes adapting to the person's changing support needs during the course of their life.

41. That the scheme funds alternative support services to attendant support, including:

- domestic services.
- assistance dogs.
- environmental controls and assistive technology.
- flexible respite options to enable informal (unfunded) support arrangements to continue.

42. That the scheme partner with the attendant support industry to:

- develop and implement a strategic, industry wide approach to attracting and retaining workers.
- develop and implement a strategic, industry wide approach to managing the aging attendant support workforce.
- manage the pay disparity between attendant support workers and supported accommodation workers.

3.11 Leisure and recreation services

Access to, and participation in, leisure and recreation activities by people with disability is affected by:

- the availability of formal and informal support to participate in activities
- physical and attitudinal barriers to access, both in terms of access to transport and to the activity
- the capacity of the leisure and recreation industry and the broader community to engage with people with disability.

While the physical accessibility of many public recreation facilities has improved, this is not generally the case for attitudinal barriers or for the capacity of workers in the recreational and leisure industries. Physical barriers of access also remain in many private recreation facilities, such as cafes and holiday destinations.

Recommendations

43. That person centred planning processes be used to:
- identify both formal and informal supports to facilitate a person with disability to access leisure and recreation activities
- develop and implement strategies to build or strengthen a person's informal support network
44. That the scheme fund formal support for participation in recreation and leisure activities (to be used in combination with the person's informal supports) and that the level of support funded have regard to the person's disability, their support needs and their individual circumstances.
45. That formal support for participation in recreation and leisure activities is flexible within funding limits (sometimes called funding bands) and portable.
46. That the scheme partner with the leisure and recreation industry to develop and implement initiatives to build the capacity of the sector to improve accessibility for people with disability.

3.12 Productive lives

Productive life roles include:

- Childhood play
- Learning (pre-school, primary, secondary and tertiary education)
- Working (paid employment)
- Volunteering

Childhood play, pre-school and primary is discussed in the ECS section and is not discussed further here.

Access to tertiary education for people with disability is currently supported by disability support services funded by, and located at, tertiary education institutions. Yooralla is a Registered Training Organisation and provides adult education opportunities at 244 Flinders Street and at a range of locations across Victoria. Support provided may include making reasonable adjustments to assignments and exams, note taking support or transposing course materials to an accessible format. Some tertiary students with disability who have compensable funds also receive support such as adapted computers and tutoring.

Access to paid employment can have significant positive impacts on a person's economic and social well-being. Recent experience in New Zealand Accident Compensation Corporation's work with people with serious injuries has shown that people with disability, who have been long-term unemployed and the recently injured, can return to work when provided with the opportunity and supports.[31]

A critical feature of successful models is skilled employment support from employment advisors to access and sustain employment. In particular, support to sustain employment is important to people with cognitive disabilities as they may find it more difficult to adapt to changes in the work environment than others. The employment advisers in turn have access to specialist clinical advice, if needed. Setting services in the context of employment, rather than a therapy intervention is an appropriate and effective means of achieving employment outcomes.

For people with disability, access to paid employment is supported by the Employment Assistance Fund (funded through the Commonwealth Department of Education, Employment & Workplace Relations) but is impacted on by:

- a lack of employer awareness of the benefits of employing people with disability (benefits can include: low staff turnover, low absenteeism and productivity and safety performance equal to able bodied co-workers)
- recruitment practices that create barriers to accessing employment for people with disability, such as pre-employment medical screening that is not related to job requirements
- employer concerns about liability for workers compensation claims. Employers may be uncertain of the person's work capacity and ability to adhere to safe systems of work due to their disability.

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[31]   Personal advice, Dr Maree Dyson, Strategic and Technical Advisor to the National Serious Injury Service of the ACC

People with disability who have compensable funding may be able to access employer incentive packages that include:

- work place modifications and adaptive workplace equipment similar to that funded by the Employment Assistance Fund
- time-limited wage subsidies
- fixed term workers compensation indemnity.

Many people with disability wish to volunteer, making a contribution in their community. For some people with disability, volunteering may be a step towards paid employment. Access to volunteering opportunities is impacted on by:

- the availability of attendant support to enable the person to participate
- the capacity of organisations to offer volunteering opportunities to people with disability.

Recommendations	
47.	That the scheme fund supports that complement, rather than duplicate, supports provided by tertiary education institutions.
48.	That employer incentives complement, rather than duplicate, the incentives and supports provided by the Employment Assistance Fund.
49.	That the scheme develop and implement a strategy to remove financial disincentives and penalties experienced by people with disability on commencing paid employment.
50.	That the scheme fund attendant support to enable people with disability to participate in volunteering opportunities.

3.13 Scope

Who should be eligible? What should be funded?

Eligibility for scheme participation has already been discussed in Section 2 of this submission and is not discussed again here.

In relation to eligibility for particular community living services or supports, best practice in long-term care and support schemes uses decision making principles rather than applying eligibility criteria to specific services or supports. In compensation schemes there are eligibility criteria regarding particular income and impairment benefits and limits to the funding of support for activities in which the person was not engaged pre-accident. Decisions regarding the funding of long-term care and support are based on principles. Yooralla supports the use of decision making principles to determine eligibility for long term care and support services.

Using person centred planning to identify support needs and responses to these needs, empowers people with disability to access a range of formal and informal supports that are the least restrictive responses. Yooralla supports this approach to identifying supports for a person with disability as it is responsive to the needs of each individual and can enable the scheme to remain viable without the application of arbitrary caps or time limits on particular services.

Decision making principles may include:

- the reasonableness of the service (including the cost, as well as whether the service will be of clear benefit to the person and enable them to achieve or maintain function and participation outcomes)
- community norms regarding the person and their family's life roles. For example, the need for all pre-school children to be supervised by an adult or the ability of the teenage children of a person with a disability to make their own school lunch
- community norms regarding participation in activities. For example, the community norm of attending the local gym rather than setting up a gym at home.

3.14 People with disability who have multiple and complex needs

The interaction with other schemes and service sectors and strategies to enable a smooth transition between schemes and funding sources has already been discussed.

The number of people with disability who have multiple and complex needs is growing. This is partly due to changes in medical care. A scheme design that clearly differentiates between the role of the scheme and related sectors, such as the health sector, is needed to prevent cost shifting to the scheme. For example, the scheme should specifically exclude hospital services, medical services, pharmaceutical benefits etc as there are systems in place for Australians to access such services

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Recommendations

51. That decisions regarding eligibility for particular funded community living services and supports have regard to the reasonableness of the service or support in terms of:

- The cost
- The clear benefit to the individual
- Consistency with community norms

52. That community living services and supports do not have specific caps or limits but that service utilization is managed through the use of person-centred planning processes with clearly defined boundaries with other related sectors

53. That community living services and supports do not have specific time limits but adapt to changes in a person's level of function and life stage.

54. That the range of community living services and supports funded is clearly defined and can be expanded as new service and support types are developed.

55. That the scheme develops processes to manage the provision of supports to scheme participants with multiple and complex needs. This includes the intersection with other systems such as justice and health, and ensuring people are able to access services and supports not funded by the scheme.

3.16 Attendant support pricing and supply

An approach to purchasing attendant support services (the most important service to clients and the one with the greatest liability impact for the Scheme) that is based on a set price, regardless of provider type, carries the risk of quickly driving non-government disability service providers out of the market.

Price for disability services paid to non-government providers is typically set by government with reference to the appropriate award and add-ons for overheads, training etc. Some private companies where salaries are tied to an enterprise bargaining agreement have the capacity to deliver attendant support services at a lower price, not because they are more efficient, but simply because they do not have to meet the award requirements that NGOs must meet.

The Scheme should aim for harmonization of industrial relations standards, in particular government run services often cost more than NGO services because of

penalty arrangements. Until such harmonization is achieved the price for attendant care must be based on the salary and penalties an organisation must pay. Without such an approach disability NGOs will not be able to compete against organisations with enterprise bargain agreements with different penalties. Experience will be lost and choice diminished.

Recommendation:

56. That the scheme aim for harmonization of industrial relations standards in relation to attendant support to maintain experience and expertise within the not for profit sector.

3.15 Financing

Financing methods

State and Territory funded services and supports are typically funded by direct payments made by the funder to the provider. For some services, such as packages of in-home support, funding may be via a broker. Where there is a long waiting list for services or supports, people with disability may also pay for the service if their financial circumstances allow. The most common self-funded supports are equipment and assistive technology, particularly wheelchairs, and home modifications. These systems do not usually allow for people to contribute to funding so that they receive a premium rather than a standard service, such as elite adaptive sporting equipment, or to claim reimbursement for services for which they did not want to wait. However, most people with disability do not have the financial resources to self–fund support.

Compensation schemes are usually designed to compensate (reimburse) scheme participants for the cost of services and supports. In reality, very few scheme participants pay for services and then seek reimbursement and those that do usually have less severe (recovering) injuries. Compensation schemes may provide for people to contribute to funding so that they receive a premium rather than a standard service, most commonly with equipment and home modifications. Compensable services and supports are provided by the private or not for profit sector.

Both State and Territory funded services and compensation schemes differentiate between the costs of services and supports and standard living costs; for example, food, rent, leisure activities and holidays. Neither of these funding systems funds the cost of standard living expenses.

Recommendations

57. That the scheme provide for services and supports to be funded by:

- direct payments to service and support providers,
- brokerage arrangements,
- individual funding agreements,
- reimbursements to scheme participants.

58. That scheme participants who have entered into individualised funding agreements be able to directly employ community living support workers.

59. That the scheme differentiate between funding community living supports and standard living expenses such as food, rent, leisure activities and holidays and that the scheme not fund standard living expenses.

60. That the scheme enables scheme participants to contribute to funding so that they may receive a premium rather than a standard service (for example, elite adaptive recreation equipment).

Section 4: Best practice in Assistive Technology

This section defines the scope and effectiveness of Assistive Technology (AT), describes current issues from the client, AT practitioner, funder and market standpoints and makes recommendations for better systems.

AT is a term for any device, system or design, whether acquired commercially or off the shelf, modified or customized, that allows an individual to perform a task that they would otherwise be unable to do, or increase the ease and safety with which the task is performed.

4.1 Power

Benchmarking Assistive Technology provision in Denmark

As a specialist centre in AT information and education, the Yooralla Independent Living Centre undertook benchmarking research in the United Kingdom, New Zealand (2004) and Denmark (2006) to evaluate current international practice (Waldron, D 2004). The pre-eminent AT service delivery system was in Denmark, where strong societal principles underpin AT policy:

Solidarity Principle
- Everyone in society has responsibility for individuals.
- The needs for people with disability are financed by the public sector, through taxation.

Compensation Principle
- To ensure people with disability are compensated for the consequence of their disability.
- People with disability should not have to cover any additional expenditure resulting from their disability.

Sector Responsibility
- The public sector offers activities, services or products and is responsible for ensuring the activities, services, or product in question are accessible to people with disability.
- The sector is responsible to a broad range of ministries and responsibility for AT grants is placed with the relevant authorities as the need arises.

4.2. AT in context

Strategies to manage and minimise the impact of disability upon life fall into several broad categories (Smith, R. O. 2002):

- interventions to reduce or compensate for the impairment
- redesign of the activity
- use of assistive devices
- redesign of the environment
- provision of personal care or support work.

The first two strategies are delivered primarily in health and rehabilitation settings. The majority of National Health & Medical Research Council (NH&MRC[32]) funding is delivered to this segment of care. The remaining strategies, introduction of assistive devices, environmental adaptations or modifications and personal care may be needed at any point within the course of the impairment and the life span of the individual and also during changes to life roles and tasks.

The impact and effectiveness of AT, in contrast to other techniques, is well illustrated by a physician living with a disability, as follows: 'There are limits on the extent to which we, in the rehabilitation professions, can help to improve on someone's impairments (e.g., strength, range of motion, pain) and the broader environment in which they live (at least in the short run). However, what a person with activity and participation limitations can instantaneously do when provided with the appropriate technology is far less constrained - witness the impact of a powered wheelchair or an interface that allows access to the Internet' (Stineman, M., and Lee Kirby, R. 2002).

AT, environmental adaptations and personal care, otherwise known as enablers, (Layton, N., & Wilson, E. 2010) are the primary means by which people with disability manage their lives. The right combination of enablers will maximise a person's capacity to lead the live they choose and aspire to. These enablers are most effective when delivered in conjunction with each other. When they are combined, enablers are referred to as an AT Solution***33***.

There is a large amount of evidence that delivery of AT solutions enables the achievement of life outcomes according to a number of indicators. These indicators

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32 Outcome of Funding Rounds '$*150 million to boost health and medical research*'http://www.nhmrc.gov.au/grants/rounds/index.htm

33 '*An assistive technology solution can be defined as an individually tailored combination of hard (actual devices) and soft (assessment, trial and other human factors) assistive technologies, environmental interventions and paid and/or unpaid care*'. www.at.org.au

include slowed functional decline, prevention of secondary complications, reduced hospital and residential care admissions, minimised carer burden, increased participation in employment and education, and improved quality of life.

4.3. Current situation for the AT user

Best practice involves person-centred planning where the AT user is at the centre of any intervention or process (Turner-Stokes, L. 2007 and Law, M 1996). It also reinforces the right for an AT user to define their own life goals (Andrich, R. and Besio, S. 2002 and WHO. 2001). However, medically-focussed and professionally-defined models of practice have dominated service delivery to people living with disability and remain in practice today (Gzil, F, 2007), (Shakespeare, T. 2006) and (Gabel, S., & Peters, S. 2004). These approaches and their limited view of outcomes are contrary to current thinking in disability (DHS 2007) and (United Nations 2008).

Currently AT users must engage with multiple service providers when constructing an AT solution for themselves. They are rarely involved with funding processes and until recently, have not had access to service supports which allow spending to be tailored to individual need, such as individualised payments (Laragy, C., & Naughtin, G. 2009).

Individuals endure excessively long waiting periods for assessment, prescription and availability of funding for AT solutions. In the case of children, when funding does eventually become available, their needs have often changed with growth and progression of the disability and therefore may require a repeat assessment. The entire process begins again, is time consuming and very frustrating for the person with disability and/or family.
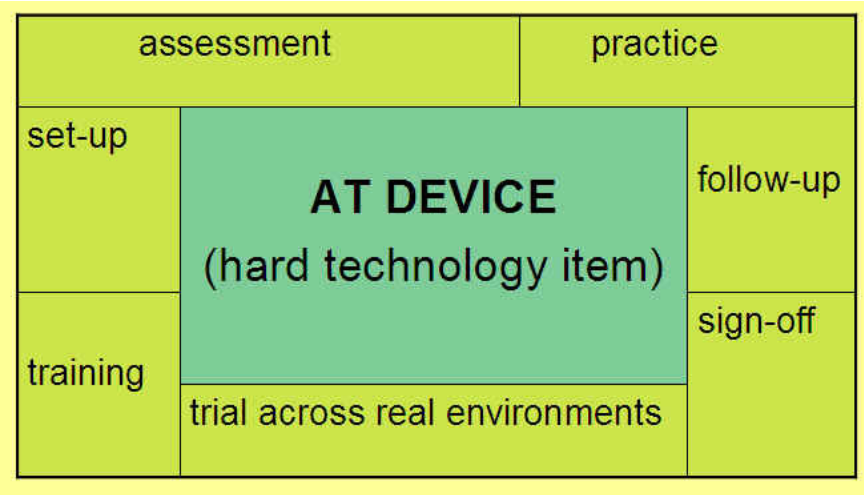
4.4. Current situation for the industry

Best practice in AT provision recognises that one solution will not fit all and tailors the AT solution to consumer diversity. However, AT solutions to support individuals in their unique participation patterns will only be as good as the supply sector supporting their availability. The AT sector in Australia is 'small and to date fragmented and dependent largely on imported products from overseas-based companies'[34]. Innovation is inconsistent with some areas such as mobility featuring broader choice of devices than others, e.g. recreation.

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[34]   'The knowledge and capacity that Australia used to have in wheeled mobility is slowly being eroded as large multinational companies acquire local companies to complement existing product lines, shifting research and development and manufacturing off-shore'
Hobbs, D., Close, J., Downing, A., Reynolds, K., & Walker, L. (2009:153). Developing a national research and development centre in assistive technologies for independent living. *Australian Health Review, 33*(1), 152-160.

Many AT devices, which could fill such gaps, are only available internationally and not imported to Australia. If individuals decide to locate and purchase the AT devices overseas, Australian funders will not cover the cost. The individual may also miss out on essential steps in AT provision, which include expert assessments, clinical advice, training and customizing. These elements are termed 'soft technologies', as they support the use of the 'hard technology' or the actual device and are essential to successful AT outcomes.

assessment	practice
set-up	follow-up
AT DEVICE (hard technology item)	
training	sign-off
trial across real environments	

(Adapted from Cook, A., & Hussey, S. (2002).)

Environmental controls and wheelchairs are examples of AT devices and systems that require a comprehensive understanding of the hard technology (device) itself, and systematic application of soft technology (needs assessment, set-up, trial, training and follow-up) for optimal outcomes.

Furthermore, rapid technological developments blur the line between mainstream technology and AT, bringing opportunities to move away from 'disability' products towards mainstream devices with sufficiently inclusive designs to encompass human diversity'[35].

Rapid changes in technology mean there are more mainstream devices that would assist people with disability achieve their life goals. However, the level of specialised technical support required to ensure successful adoption needs to be funded.

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[35] *When an assistive technology becomes so cheap that everybody can afford it, it will become 'universal' and mass-produced; and the mainstream aesthetics of Universal Design will make 'adaptation' as easy and desirable as 'personalisation'* Dong, H. Shifting Paradigms in Universal Design. In C. Stephanidis (Ed.), In Universal Access in Human Computer Interaction: Coping with Diversity (2007:69). Berlin: Springer-Verlag.

Accompanying this trend is an awareness that current AT provision systems bias prescription away from the mainstream with a 'tendency to rely on high technology when in fact for many people, low cost technology solutions are useful and appropriate but often unavailable under current funding systems (Commonwealth Government, 2009:27).

This increases costs, limits choice and continues to define AT users by their disability, rather than placing them in the role of a customer. Refer to Solutions Hierarchy Triangle below.
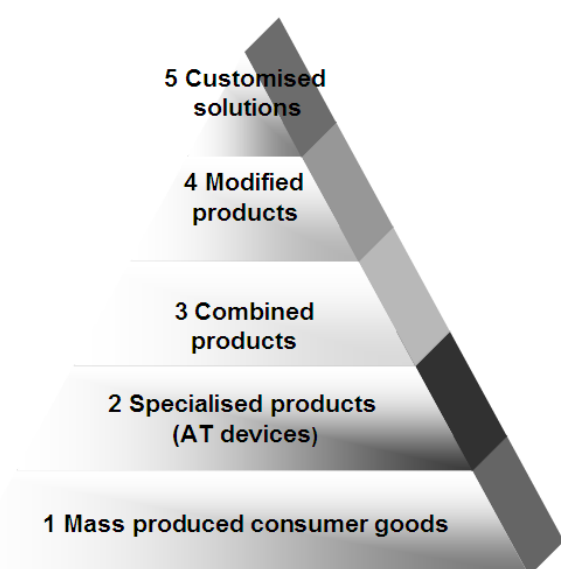
Solutions Hierarchy Triangle.
Symons, J., & Ross, D. (1991)
Examples:
1. Non-slip matting from Bunnings
2. Shower stool from AT supplier
3. Commercial dimmer system combined with rocker switch from AT supplier to operate lights
4. Customised postural supports within standard wheelchair
5. Custom manufacture of one-off device

4.5. Technology chain[36]

Assistive technologies exist in relation to the environments in which they are used. Enabling environments, such as a continuous levelled path in the house or local community for a person who uses a wheelchair, directly impacts the amount of AT required. For a person with impaired balance, levelled pathways may remove the need for handrails. For a person who uses an electronic wheelchair, the introduction of level access paths and kerb cuts, means a kerb climbing accessory will not be required.

Whilst the State government equipment funding schemes do contribute towards environmental adaptations of the home, according to recent research (Gzil, F, 2007),

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36   AAATE. (2003). AAATE Position paper: http://www.aaate.net/aaateInformation.asp

these adaptations are still roughly 75% underfunded. There is also still inadequate attention given to the external environment beyond the home.

Another example is enabling an individual to access internet, email and text messaging through funding of accessible features in electronic communication devices and specialised access options. State government equipment funding schemes contribute some costs towards specialised peripherals, but do not cover mainstream devices such as computers which are also required to make these solutions work. As outlined earlier in this submission, clear guidelines and a strong claims management system do need to be in place within the proposed scheme to ensure equity, but according to individual need rather than a standardised approach. For one person with disability a computer may be an essential tool to participating in the life of the community that might they might not otherwise be able to afford, leaving them isolated and segregated. For another person with disability who has a range of other ways of accessing the community, a computer (whether it can be afforded or not) is a 'nice to have' addition to their lives, but not an essential item to address issues such as isolation or segregation.

4.6. Current situation for the AT practitioner

AT service providers often have different and, at times, conflicting entry criteria. Generally they require a professional assessment and rarely address whole of life needs for the individual (Layton, N., & Wilson, E. 2010).

Frequently best practice processes cannot be followed as practitioners are faced with managing a constrained and rationed service system. Up to 4 hours per week of a practitioner's time are spent seeking top-up funds and therefore cannot be spent on clinical work with the person with disability (Pate, A., & Horn, M. October 2006).

The lack of funding typically results in partial funding for discrete AT devices[37]. Funders count the occasions of service or number of devices issued, however this does not necessarily represent an outcome for the individual who, despite receiving a partial subsidy, may still be a long way from obtaining a workable solution. Allocation of the subsidy amount represents an output for the funder, i.e. an individual was serviced, but there wasn't always an outcome for the individual, who must therefore source thousands of dollars of gap funding to actually obtain the required item (KPMG. 2006), (Wilson, E., Wong, J., and Goodridge, J. 2006) and (Pate, A., & Horn, M. October 2006).

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[37]   AT Reform: Snapshot survey of 50 practicing Occupational Therapists Personal communication from OT Australia to the Parliamentary Secretary for Disability 30 April 2010

Application to funding sources for AT involves an allied health practitioner e.g. Occupational Therapist, Physiotherapist, Nurse, Prosthetist, Orthotist, or a Speech Pathologist; who must frequently get a referral from a General Practitioner and then a review by the fund manager, who is generally an allied health practitioner in the role of gatekeeper (Barbara, A., & Curtain, M. 2008).

As schemes are rationed, entitlement, evidenced by eligibility and approval, does not guarantee supply, thus substantial clinical practice time is consumed in seeking band-aid solutions.

Clinical reasoning processes may be significantly compromised as procedural hurdles decrease the motivation and capacity of AT practitioners to collaboratively achieve optimal solutions with consumers.

Workforce shortages are compounded as clients cannot move through the application and provision process quickly, due to funding delays. Funders rarely pay the cost of the allied health assessment – for example, clients rely on public waiting lists for community health workers, or face paying for private practitioners. This is likely to be an unaffordable expense if they already require public funding for AT.

Prescribers need to include best practice elements in their AT prescriptions to maximise outcomes and minimise AT abandonment (Waldron, D., and Layton, N. 2008). Recognition in terms of clinical time or funding support for crucial soft technology steps such as trial, training, follow-up, and technical support is rare.

The complexity of the AT prescription has been documented and is currently under review (Hammel, J., & Angelo, J. 1996). Attempts to separate complex and straightforward AT requirements are flawed. This complexity may be due to the individual's personal factors, their life trajectory, and the effect of their impairment and/or the environment. This holistic view supports the notion that an expert triage system is required.

Opportunities exist to realign the scope of practice frameworks and incorporate roles for auxiliary staff and trans-disciplinary teams to contribute to delivering seamless hard and soft technologies as required.

4.7. The proposal

Who makes the decisions?

The answer to "who makes the decisions" will be driven by the principle(s) that are agreed as underpinning a long-term disability care and support scheme. As already

mentioned, in Denmark a national set of principles guide the structure, eligibility and the scope of AT provision.

In Australia there is no nationally agreed defined set of principles. Australia has ratified the Convention on the Rights of Persons with Disabilities and its Optional Protocol which would equate to a recognition that there is "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons[38]" This could provide the basis for the development of a national AT policy framework.

There is a compelling case for change given the recognition of the positive impact that Assistive Technology can make on a person's ability to individual autonomy.

Any emerging AT policy needs to be grounded in both agreed principles and agreed practice standards to enable schemes to meet a common ground minimum baseline. Harmonization requires acknowledgement of learning's from the current state based variations such as the significant needs of rural and remote communities.

The person-centred approach is a widely adopted practice within the sector and reinforces the importance of individual autonomy and self determination in all aspects of a person's own life goals.

Recommendations:

61.   That people with disability, carers and families have more control in relation to decision making around AT with:

• policies that reflect the aim of improving client outcomes across lifespan and whole of life activities.

• access to AT that allows for changes in life situations, needs and aspirations of individuals (families and carers) which also reflect improvements in technology

• access to AT funding that is responsive to individual need (also recognising the needs of families and carers), allowing for choice and the timely allocation of equipment that is appropriate for the individual.

• systems that include funding for therapy assessment, trial and training in the use of AT solutions for complex needs.

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[38] Article 3(a) Convention on the Rights of Persons with Disabilities (2007) downloaded from:
http://www.un.org/disabilities/convention/conventionfull.shtml

4.8 Supply

Nature of Supply

The model of AT supply within Australia varies nationally and within the States and Territories.

There have been significant reviews and remodeling of state AT programs and other programs such as the Continence Aids Payment Scheme. While the positive and negative aspects of State versus National AT schemes have been an ongoing debate in the sector, there are still issues of inequity and discrimination arising from the inflexibility in existing AT programs.

There are potential improvements to inequities of supply through the development of a national AT harmonization program and there is discussion within the sector of a National AT Reform Agenda which will further inform the Productivity Commission.

The New Zealand model as demonstrated through their Accident Compensation Scheme provides a working benchmark for effective provision of AT and within an insurance scheme model.

Recommendations:

62. Key elements that need to be included in considering the nature of supply of AT include:

- access through a single point of entry to services, in recognition that the most effective AT solutions require multiple enablers to be provided in relation to each other.
- gate keeping structures inherent in current schemes such as approved lists with a more responsive system based on agreed principles and practice standards.
- funds being made available in a timely manner to allow for efficient supply timelines.
- systems in place for the provision, maintenance and recycling of equipment should be designed to maximise the efficient use of government resources.
- developing a national purchasing framework that acknowledges importance of local supplier service delivery and support in regional areas and for complex technology.
- provision for direct payments to people with disability for low cost or replacement AT.

4.9 Scope

Who should be eligible?

Unmet need and service gaps for significant groups of people with disability have been one of the drivers in the disability sector for change. The Productivity Commission's inquiry has come about in part due to the recognition of systemic failure in ensuring that regardless of how a person may acquire a disability in their lifetime, they should have access to AT. It also recognises that those people who have access to AT still experience inequities and unmet need, depending on a raft of factors as outlined earlier.

Regardless of where the person resides they should have access to AT to meet their individual needs.

Recommendations

63.   Eligibility for AT solutions needs to build on underpinning principles and include:
- funding that is guaranteed against clear eligibility guidelines.
- a strengths-based assessment framework with flexibility to empower the expert AT user to participate in the AT attainment process.
- existing programs being reviewed, rationalised and harmonized.
- consistency, prescription and transparency in approval guidelines to ensure equity of access.
- resources being made available to investigate developments in interfacing between mainstream technologies and AT, to establish impacts on AT service delivery.
- increased access to people in rural and remote areas through application of telehealth, telecare and other e-solutions in the assessment process and support to individuals.
- resources for information and advice are recognized and promoted.
- resources for research developments in Universal Design and Smart House technologies and their impact on AT service delivery are recognized and funded.

4.10 Financing

Unmet need inherently goes unnoticed in the consideration of funding schemes and guidelines due to funding availability being treasury-driven rather than needs-based. Within the existing structure there is limited potential to address the funding gaps from a needs-based perspective. At best, the implementation of a review process that defines gaps in policies and systems and continually modifies them would create the potential for change over time. Therefore the implementation of a long-term disability care and support scheme would provide the opportunity to develop a financially sustainable program with review processes and accountability in place, to meet the AT requirements of Australians with disability.

Recommendation:

64.   The core elements of Assistive Technology delivery should include:
- major reform to ensure the efficient delivery of AT to people with disability, within a long-term disability care and support scheme.
- needs based eligibility criteria.
- needs based and eligibility and entitlement.
- single point of access.
- equipment lifecycle management.
- financially sustainable.

Section 5: Best practice in Early Childhood Services

Yooralla is one of Victoria's largest nonprofit organisations operating in Early Childhood Services (ECS) and currently offers a diverse range of centre-based, home-based and community-based ECS programs, including:

- specialist therapy and educational services for children with a disability and their families
- playgroups for children aged from birth to three years
- three and four year old play-based specialist groups
- home visiting and support to children who attend childcare and local kindergarten services in their community
- inclusion groups for three and four year olds and kindergarten inclusion support
- parent support groups
- support programs for brothers and sisters of children with special needs.

The complexity of the issues confronting families of children with a disability is often described by parents as overwhelming, as it is not just the child with disability that needs support. The following ten areas have been identified in the literature highlighting the issues that families confront when raising a child with disability: Obtaining treatment services for their child with disability is just one of many challenges families face in managing this complexity. "Indeed, it has been argued that a major goal of families is to create or maintain a sustainable and meaningful daily routine of family life" (Guralnick, M.J. 2004).

Family finances	Hours worked; flexibility of work schedule; adequacy of financial resources and the amount of coverage provided by medical insurance,
Services	Availability of services; eligibility for services; sources of transportation and the amount of parent involvement required.
Home/neighbourhood	Safety and accessibility of play area; alterations in home (installation of locks, fences related to safety concerns) and choice of neighbourhood.
Domestic workload	Amount of work that needs to be done; persons available to do it and the amount of time spent by different family members.
Childcare tasks	Complexity of childcare tasks; presence of extraordinary childcare demands (medical problems, behaviour problems) and availability of caregivers.

Child peer group	Child's play groups (children with disabilities vs. typically developing children); amount of parent supervision needed and role of siblings.
Marital roles	Amount of shared decision making regarding child with delays and degree to which childcare and household tasks are shared.
Instrumental/ emotional support	Availability and use of formal (church, parent groups) and informal (friends, relatives) sources of support and costs of using support.
Father/spouse role	Amount of involvement with child with delays and the amount of emotional support provided.
Parent information	Reliance on professional versus non-professional sources of information and the amount of time and effort spent accessing information (Guralnick, M.J. 2004).

5.1. Power

Who makes the decisions?

Families want more choices but not necessarily sole decision making power

Families want choices. There are some families who want segregated services, some that want a mix and others that want full access to mainstream services. Families want to be given the option to choose the type of service their child receives. Families feel they do not have choices and are often forced into a segregated system because the resources and supports for mainstream inclusion are inadequate.

It is important to understand the context that a family with a child who has disability, faces. Parents are still coming to terms with having become a parent of a child with disability and most often are looking for treatment for their child. Many are hoping that experts will provide the answers. For most, they are on the beginning of a lifelong journey that will affect their lives in a host of ways they are yet to fully comprehend. There is not enough information to make informed choices.

Parents often say that they don't know what to do after their child has been diagnosed. They find it very difficult to get the right information. A number of parents interviewed, said that it was not until they were pushed to the edge that they realised they were the only ones that would fight for their child. Often parents said the system made it difficult to get what they needed for their child, for example more funding. Parents said they had to be extremely active and vocal to get the services they

needed. Concerns were also raised for parents who do not have the language, culture or skills to be able to be effective advocates.

A Family Service Coordinator or Key Worker model is being increasingly employed in ECS throughout Victoria to assist parents with decision making. A key worker assists parents with the information, advocacy and support to make their own decisions about services. The worker enables the family to make informed choices.

Recommendation

65. That the new scheme support a similar model to the 'Family Service Coordinator' or 'Key Worker model' to provide a sense of family empowerment so families are better supported and informed to make their own choices.

Kim is struggling

Her child was in hospital for the first 6 months of his life and none of the doctors would explain his diagnosis because she was a young parent and they didn't want to tell her that her son had a disability and he was never going to be normal.

Her son has a rare diagnosis so she continues to be given little information either because the doctors don't know or they think she may not understand. She ended up going online and finding a support group in America but she says information nights or a local support group would make an enormous difference to the level of care she would be able to give her son.

Since becoming the parent of a child with a disability, Jodie says the thing that has helped her most has been Yooralla's Early Childhood Intervention Service.

5.2. Supply

Mainstream and specialist providers, people's choices

The following diagram, developed by the Centre for Community Child Health represents the proposed ideal relationship between specialist and mainstream children services (Moore, T 2009). Secondary Support Services are focussed on children (and families) with either mild or moderate disabilities. Tertiary Specialist Services are for children (and families) with chronic, complex and severe disabilities.

TERTIARY SPECIALIST SERVICES

SECONDARY SUPPORT SERVICES

MAINSTREAM SERVICES
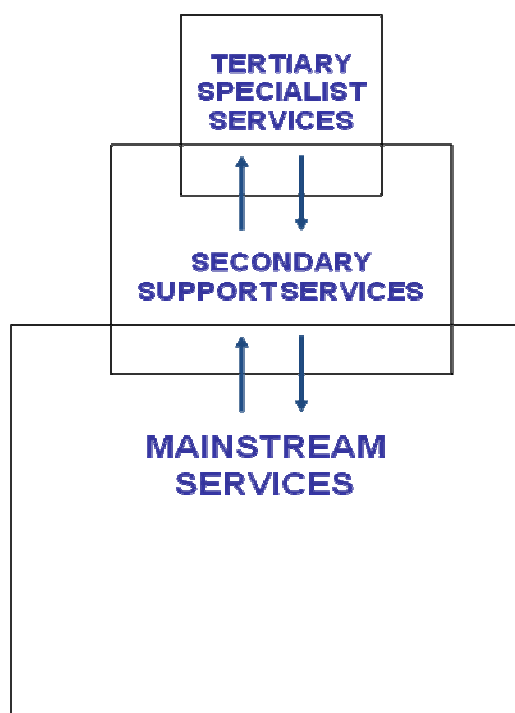
Location:

- Specialist services have outreach bases co-located with mainstream services.
- Specialist services provide at least some support in family and early childhood settings.

Referral arrangements:

- Specialist services work directly with some 'eligible' children, and provide consultant support for all others.
- Specialist services also provide consultant support to mainstream services on a broad range of child and family issues.

Information flow:

- Information flows both ways between mainstream and specialist services.
- Specialist and mainstream service providers collaborate as equal partners.

Recommendation:

66. That the scheme fund mainstream, secondary and tertiary support services to ensure families have access to

- **Resources** including coordination, case management, formal intervention programs (individual therapy, specialist education) respite, equipment etc., as well as supplemental supports (financial assistance, respite care etc.).
- **Social supports**, including parent-to-parent groups, family counselling, and mobilization of family and community networks.
- **Information:** educational programs and personal support and guidance (DEECD, 2009).

Both the Victorian Government and the research literature have identified the need to deliver a universally designed approach to services for all young children and their families in ECS. This is seen as "an effective way to ensure genuine participation, amelioration of disadvantage and improved developmental, learning and health

outcomes for all children... This approach supports a commitment to all children and families, equity in service provision, earlier identification and recognition of children and families with additional needs and better responses to families with increasingly complex needs." (DEECD, Reform of early childhood intervention 2009).

Universally designed services "have environments and activities that cater for a diverse population… settings in which all children and their families can participate and learn", (Moore, T 2008). The aim of services is to provide all parents and families with the knowledge, skills and support they require to meet the needs of their child and to optimise the child's development and ability to participate in family and community life.

"Inclusive practice rejects the notion that children with disabilities must be 'fixed' or meet certain criteria before they are ready to take there place in community environments. It recognizes parents as equal partners in the education of their child and that any choices they make are based upon informed choice," (Circle of Inclusion 2010).

Since 2007, generic children's centres funded by the Victorian Government are required to include the provision of early childhood intervention services as part of their service model. Childcare centres and kindergartens are legally required to accept children with a disability. This is intended to: "provide an opportunity for further strengthening inclusive practices across mainstream and specialist services", (DEECD 2010).

However, despite the positive intentions of the government's universal or inclusive approach, without adequate numbers of trained staff, resources and support, mainstream services are often not able to provide programs that are beneficial to the child or instill confidence in families. Current government funding to support the inclusion of children with disability is very limited and accessing the funds is often problematic, time consuming and has strict eligibility criteria (Mahwah, NJ and Erlbaum, L Yooralla 2010). Many families say they seek specialist services because they do not believe the universal system has the skills, commitment or resources to support their child appropriately.

It will be cost effective if the new scheme provides adequate funding for a universal and inclusive approach to service delivery for children with disability. A well resourced inclusive approach will facilitate outcomes that support long term family functioning and will enhance their ability to access mainstream support services. This will enable families to have a lesser reliance on expensive specialist services in later years.

Anthea's son will be attending a mainstream kindergarten next year but her son won't be receiving an aide because in the kindergarten's experience, it took over 100 hours of paperwork to get an aide into the class and even then an aide would only be available for 15 minutes in a 1.5 hour session.

5.3. Scope

Who should be in the scheme?

The focus of the new scheme in ECS should be the child and their family in the context of their natural learning environment

For the vast majority of families, ECS is their first contact with disability support services. The new scheme will need to acknowledge the importance of a family centred response to the needs of families of children with a disability. The following key elements have been identified in family centred practice:

- acknowledging the family as the constant in the child's life
- facilitating family/professional collaboration
- exchanging complete and unbiased information between families and professionals
- honouring cultural diversity
- respecting each family's individuality in their adaption to their child's needs and each family's expressed goals
- facilitating family-to-family support and networking
- ensuring all services are flexible, accessible and comprehensive
- appreciating families as families and children as children first, taking into account their wide range of strengths, concerns, emotions and aspirations beyond their need for specialized services and support (Llewellyn, G., Thompson, K., and Fante, M. 2002).

Children with disability need to be supported by the new scheme to participate in 'natural learning environments', an approach where the service response is to identify and utilise natural learning opportunities that occur in the course of children's everyday home and community routines, (DEECD, Early childhood intervention reform project, 2009). Natural environments are the places, resources and events which are part of children's everyday experiences. They include the family and home, informal environments such as playgrounds and supermarkets and formal settings such childcare and kindergarten.

The most important of the natural environment is the family. Recent research highlights that the method of family service provided also matters significantly. Practices that promote parent decision-making and action are seen to be the most effective, (Dunst, C.J. and Bruder, M.B. 2002). There is also an increasing emphasis

on the role of ECS in promoting family resilience through facilitating positive social support networks.

5.4 How could they be practically and reliably identified?

Many parents have to wait a long time to get a formal diagnosis, this means they are not eligible for funding even though it is obvious their child had a disability. A number of the families interviewed by Yooralla to prepare for this submission stated it is very hard to find a good specialist (and even harder to find a GP who understands) and as a result families are often have to wait a long time for a diagnosis.. While it is true that a period of observation by the specialist is required before a complete diagnosis can be made, it should not be the case that the child or family do not receive support services during this time. The new scheme should support the development of a fast track system for children to gain access to a pediatrician and appropriate supports services if a disability is suspected.

Many of the families interviewed also stated the negative impact the deficit based assessment systems have on the family. Parents constantly have to portray their child in a negative light to obtain funding. The deficit model means that parents are made to focus on everything their child can't do and what boxes they can't tick. This results in a strain on their marriage and family life. One parent stated "it is horrific to have to say as a parent that your child is a danger to themselves or others".

If children don't fit into a certain category they currently do not get funding. The new scheme needs to function less on the diagnosis and more on the child's functioning in the environments they encounter. Currently the child care system in Victoria is a good example for the new scheme of an improved assessment system. It has moved to a greater focus on funding being directed towards the adaptations the childcare service needs to make to support the child, rather than focusing on the child's deficits.

Assessments to determine each child's level of need is currently insufficient and the methods used do not always produce an accurate picture of a child's needs. A decision reached in a one off clinical based assessment cannot create a fair outcome for such a significant part of a child's life. Assessments in everyday environments including the play environment, the family and child care or classroom are essential to assess a child's behaviour.

> *Emma has Williams Syndrome and has problems with peer interaction. However, she loves adults. Emma was having a great day on the day of her two hour assessment for school entry and was responsive to the psychologist's test, scoring an IQ of 90. The support she has had until this point will now be stopped. Her mother joked that had she given Emma red*

cordial for breakfast, the result would have been different but because Emma had essentially failed to have a 'bad' day, her diagnosis was disregarded and her school life has been determined without consideration of her typical behaviour.

Recommendation [this should be an additional recommendation]

Children with a disability and families in need of support can be better identified through:
• decreased waiting times for multi-disciplinary teams for assessment and diagnosis
• assessment processes that focus on a child's strengths not deficits
• assessment that has a focus on adaptations in the environment to support the child's disability.

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

All groups in ECS are chronically under-funded. The majority of the parents interviewed said they need more funding and every major review of the system highlights that the current funding is totally inadequate. The outcome for the lack of resources is that families wait to see the pediatrician, they wait to get into central intake, they wait for ECS and they wait to see the government funded private therapists. The waiting times to receive services are far too long which means parents are often left with no funding or support during the crucial years that their child should be receiving early childhood intervention.

Recommendation:

67. That waiting times for early intervention services need to be reduced with more services and resources made available.

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

A recent review of the ECS system reported that the system is fragmented and poorly administered.

Recommendation:
68. Unfairness in the system would be reduced if:
• one entry point to the system is put in place for families that is designed to make the scheme easy to navigate, in order to reduce the fragmentation caused by current multiple entry points which result in unnecessary complications and difficulty with navigation.
• intake processes are standardised as they vary significantly across regions and programs.
• prioritisation criteria are consistently applied across regions.

The new scheme could address many of these issues with a nationally coordinated approach to assessment, intake, prioritisation and service coordination.

Another inequity in ECS is the Federal Government's funding response to children with autism. Currently the Federal Government provides support to over 4,300 children across Australia who has Autism Spectrum Disorders and early intervention funding of up to $12,000 per child (FaHCSIA 2009). Services for children with disability who do not have autism, receive far lower levels of State Government funded support.

These two different funding systems are creating serious inequities between families of children with autism and families whose child has another form of disability. It is very difficult to understand why the government would provide more support to a group based on their diagnosis and not on their needs. It is yet another strong argument in favour of the long term disability care and support scheme and its ability to deliver a national coordinated and more equitable approach, where all services will be funded on the same level.

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

All three program components that should feature in ECS are currently under-funded, these components (detailed earlier) are:
- resource support
- social support
- information

As well as the urgent need for additional funding for therapy and teaching support, a key element of the new scheme should be assistance for family support groups. The families interviewed stated the importance of meeting other families in similar situations. They often said that although their children may have different disabilities they feel they can relate to others families in similar situations. One parent said this gave her the opportunity to meet people who she could call after hours and say, 'I'm struggling'. A doctor may know their child's diagnosis but all parents said that knowing people who knew your child provided far more support. It allowed parents to feel like parents rather than feeling like carers. This gives them a chance to feel normal and be around people who truly understand.

Yooralla operates a number of family and sibling support groups across all Melbourne metropolitan regions including:

- Facilitated Playgroups (modeled on the Mother Goose programs) for parents and young children
- Pappa Bear programs for fathers
- Sibling groups
- Family networks programs

These are groups that are greatly valued by parents and families but are not funded – they are provided by Yooralla as we acknowledge the critical need for this type of support.

Three distinct outcomes of meeting with other families have been reported by parents participating in these groups:
1. Parents felt less alone, less isolated.
2. Parents were able to share valuable information and advice 'peer to peer'.
3. Parents gained a greater sense of control of their situations when meeting others in like situations.

International research has established that parent support is effective in increasing parents' sense of belonging and to deal with the day-to-day issues of raising a child with disabilities. Contact with other parents provides much needed emotional, social

and practical support and research has demonstrated that parents of children with special needs are uniquely qualified to help each other.

Recommendation	
69.	That the scheme fund parent and sibling support groups.

The new scheme should also put a high priority on the supporting children and families during the critical times of transition. Transitions are particularly important to families who have children with disability. The usual transitions faced by all families such as kindergarten to school and hospital to home are often made far more complex by disability. "Coordination across and between mainstream and specialist services and support to manage the range of services to meet an individual's needs both require improvement. While families' experience with individual services may be positive they report the need to continuously advocate in relation to service coordination and transition between services," (DEECD 2010).

Children often receive intensive support from therapists and early childhood teachers during their early pre-school years. As already mentioned Yooralla also offers a range of supports for families including peer support groups that meet regularly. When a child is transitioning to school families report a marked decrease in the level of support offered both to the child and to the family.

Recommendation	
70.	That transition points in a child's life are recognized as a critical time for both the child and family and that additional resources are available in a timely manner according to the need of each individual child and family.

Access to early intervention support and services is critical for every child who is not meeting critical developmental milestones. Yooralla believes that it is far better to err on the side of providing supporting to all children in this situation and risking the provision of support to a child who may not have a long term disability, than to wait until a formal diagnosis is made. Waiting may lead to longer term skills deficits that might have been addressed more successfully with an early intervention program.

It is often the case that a child needs to be observed over a period of time by family members and specialist practitioners for an accurate diagnosis to be made. It is essential that supports are available during this time and that neither the child nor the family are made to wait, sometimes for years, for a formal assessment of the child's disability.

Recommendation	
71.	Every child displaying a developmental delay should have timely access to therapy and supports to maximize long term skill development**.**

There is a need for more ECS so families can access early intervention as soon as significant delay is observed rather than go on a waiting list for months.

Recommendation

72.   That it is recognized that the key features of effective ECS include:

• an integrated system of all the services that children and families need to access for their education, care and health needs.

• accessible and affordable services for every child and family.

• the service and not the child or family, making adaptations as part of an inclusive philosophy, program and environment.

• every child and family to experience a strong sense of being drawn into and welcomed to a service.

• all children's education, care and wellbeing needs met in the mainstream services, with additional secondary or tertiary services when deemed necessary and provided within the mainstream service where possible.

• more comprehensive service delivery and more timely access to services.

• trans-disciplinary approach with different professionals learning from and with each other with ongoing opportunities for the transfer of knowledge, skills and practices.

• respect and acknowledgement of cultural and linguistic diversity (DEECD, Early childhood intervention reform project, 2009).

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

The ECS system has been allowed to develop in an ad hoc and fragmented way. The service/s a family and child with disability currently receive depends on where they live, the type of disability the child has and the service provider they connect with. Key challenges confronting the ECS system and the new scheme include:

• each State has its own ECS system from assessment through to treatment and support. When a parent moves interstate it is a nightmare, as it entails new assessments, new languages and new barriers to services

• integration between early childhood interventions services and universal services is inadequate

• recruiting and retaining suitable staff is difficult and there is a lack of investment in professional development

• there are opportunities for strengthening supports at key transition points

• there is a lack of quality data to support planning, performance monitoring and evaluation (KPMG 2009).

Australia needs a consistent national system of ECS and portability in a long term care and support scheme would be a huge step forward in providing consistent and

personalised services for families of children with disability. A long term care and support scheme should provide a framework for service integration and support the professional development of ECS staff. A key focus of the system should be on transitions children and families face.

Are there ways of intervening early to get improved outcomes over people's lifetimes?

The new scheme should include a heavy emphasis on ECS. These services are the first point of service delivery and contact for most families that will experience a lifetime living with disability. The foundations are laid at the time of ECS for long term family functioning and the relationship between the person with disability and the service system.

5.9. Financing

The Victorian Government recently identified that: "The level of investment in early childhood intervention is considered inadequate by service providers and sector representatives and demand for early childhood intervention outweighs the capacity of services to respond appropriately. As a result, children and families are experiencing significant delays in accessing early intervention services and are missing out on potentially beneficial intervention and support during a key development stage as well as receiving lower levels of service than could be considered 'optimal'," (KPMG 2009).

Funding is inadequate across the system and the opportunity to engage families in an approach that can be genuinely described as "early intervention" is often missed. A significant up-front investment in the new scheme on an appropriately funded national ECS system would support family functioning and reduce the long term cost burden on the system as children progress through adulthood.

A nationally coordinated term care and support scheme provides the opportunity to build best practice foundations for families and children. As with other insurance schemes, the insurer will seek ways to minimise future claims costs. A fully funded (or at least partially funded according to DIG recommendation), managed and delivered ECS system is a win-win outcome. It will provide a platform for enhanced individual and family functioning while creating a genuine early intervention system that reduces the scheme's costs in the long term.

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Appendix 1: Full List of Recommendations

1. That the Four key principles that underpin the development of the Scheme are:
- Equity
- Self Determination
- Efficiency
- Sustainability
2. That an insurance approach will provide the best way of achieving the underpinning principles of Equity, Self-determination, Efficiency and Sustainability.
3. That in relation to ensuring best practice in the delivery of funded services and supports, the scheme requires that these funded services and supports be reasonable and that reasonableness have regard to:

- the achievement or maintenance of measurable outcomes (functional/activity and participation).
- whether the proposed funded support is the least restrictive response to the person's support need and consistent with achieving valued participation outcomes.
- community norms, such as parental responsibilities of caring for young children or paying rent, in the case of an adult
4. That in relation to ensuring best practice in the delivery of broad scheme initiatives, the scheme's objectives include:
- improving the employment participation of all Australians with disability.
- removing physical and attitudinal barriers to access and participation in all aspects of community life.
- funding disability research to enhance the use of evidence-based practice in policy and program development and in the delivery of support services to Australians with a disability.
5. That the scheme develop and implement agreements with relevant agencies, departments and schemes to ensure that scheme participants continue to access non-scheme funded services and supports to which they are entitled, particularly health and mental health services.
6. That the scheme be established in a way that enables consistent and equitable access to funded services and supports for all Australians with disability eligible for the scheme, including harmonization and transition arrangements with existing long term care and support schemes.
7. That the scheme fund services and supports under an individualised funding model to enable scheme participants to exercise choice over the way in which these services and supports are delivered.

8.   That the scheme partner with the disability support sector to establish and implement transition arrangements to enable disability support providers who currently operate under a block funding model to move to operating under an individualised funding model.

9.   That, in relation to the delivery of funded supports, the scheme distinguishes between administration functions of claims management and matters of personal choice.

10.   That the scheme empowers individuals to exercise personal choice regarding the delivery of funded supports.

11.   That the review bodies cannot make a decision that would result in the scheme funding ordinary life expenses typical of peers.

12.   That funding decisions be grounded in needs-based responses and responses where there is a clear line of evidence that the response is consistent with best practice models and cost effectiveness.

13.   That review bodies cannot issue a decision that, via flow on, would adversely affect the viability of the scheme.

14.   That the scheme partner with tertiary institution and professional associations to maintain and enhance contemporary disability practice as a part of the curriculum.

15.   That the scheme partner with professional associations to engage with specialist providers in strengthening the application of contemporary practice in the delivery of allied health services to people with disability (for example, strengthening the use of client centred planning to identify support needs as well as formal and informal responses to those support needs).

16.   That the scheme funds and administers a small grants program to support small private enterprises providing mainstream services to remove attitudinal and skill barriers.

17.   That the scheme define eligibility both in terms of the nature of the disability and the impact on a person's function and support needs as measured by standardised assessment tools.

18.   That the scheme eligibility be limited to people who acquire their disability when aged 65 (or who are of pensionable age) or younger.

19.   That once a person has been assessed as eligible for receiving supports through the scheme, services and supports continue throughout that person's life (i.e. post 65 years of age)

20.   That the scheme fund only those services and supports that are required as a result of the person's disability and where the support need cannot be met through the normal life roles of the person's family and extended support network.

21. That the scheme not fund ordinary life activities that are consistent with peer roles and expectations (and fund only those supports and services that are required as a result of the disability.

22. That the scheme should remain focussed on and be specialised in the management of long term care and support. Associated benefits and schemes such as income support should remain separate.

23. That the scheme be funded under an insurance model to enable the scheme to be fully funded or at least partially funded (in line with the DIG recommendation), both in relation to providing supports for individual scheme participants and in relation to leading broader initiatives for all Australians with a disability.

24. That the scheme includes a policy that enables the person with a disability to nominate how their funds for attendant/personal care hours are spent and enables use for the purpose of more generalised family support.

25. That an ongoing role for attendant support agencies be recognised and supported as part of a diverse market and choice.

26. That, in keeping with current and evolving practice, people be able to directly employ their support workers.

27. That, to ensure minimum standards are met, models be developed whereby clients recruit workers/carers and disability agencies carry out necessary police screening, training and/or act as the employer.

28. That the scheme not fund primary family members living in the family home with the client as the client's support workers (unless under extraordinary circumstances where there is no other option available).

29. That person-centred planning processes be used to identify the disability related needs of scheme participants and the appropriate responses to needs.

30. That supports (including accommodation support) are funded in a way that enables the person to choose - where they live and with whom and choose providers of supports and individual support workers.

31. That support provided for community living is funded within an individualised funding model that breaks the connection between the funding of accommodation and support.

32. That the scheme should provide for the establishment of individual funding agreements

33. That the scheme includes provision for alternative dispute resolution and mediation processes and protocols.

34. That the scheme partner with public housing, social housing agencies and with private developers to develop and implement a strategy to increase the stock of accessible housing, including:

- universal accessible design including physical access and provisions for the installation of personal care equipment such as ceiling hoists
- the inclusion of accessible housing in private developments
- designs that are appropriate for people with behaviours of concern.
- ensuring a range of supported accommodation options are available throughout metropolitan areas and regional centres

35. That the scheme fund supported accommodation in a way that enables the level of supports a person receives to be changed without requiring the person to move house as needs change

36. That the scheme develops and implements an ongoing strategy to prevent young people being admitted to nursing homes and to enable young people in nursing homes to move to age appropriate supported accommodation, particularly as the current National Younger People in Nursing Homes Program has only twelve months to run.

37. That the scheme includes tenancy rights for people living in supported accommodation.

38. That the scheme fund attendant support within funding limits (sometimes called funding bands) that have regard to the person's disability, their support needs and their individual circumstances.

39. That the scheme provides for people with disability to:
- choose their provider of attendant support and their individual attendant support workers.
  choose when, where and how attendant support is provided
  change when, where and how attendant support is provided
  have portability of attendant support funding and use the same attendant support workers when they move to a new living situation, such as moving from supported accommodation to community living.

40. That the scheme funds:
- attendant support.
- attendant support worker training (attendant support worker time and specialist provider time) in relation to the delivery of individual attendant support programs.
- ongoing specialist support (such as therapist time) to enable attendant support workers to support the person with a disability to use assistive technology. This includes adapting to the person's changing support needs during the course of their life.

41. That the scheme funds alternative support services to attendant support, including:
- domestic services.
- assistance dogs.
- environmental controls and assistive technology.

- flexible respite options to enable informal (unfunded) support arrangements to continue.

42. That the scheme partner with the attendant support industry to:

- develop and implement a strategic, industry wide approach to attracting and retaining workers.

- develop and implement a strategic, industry wide approach to managing the aging attendant support workforce.

- manage the pay disparity between attendant support workers and supported accommodation workers.

43. That person centred planning processes be used to:

- identify both formal and informal supports to facilitate a person with disability to access leisure and recreation activities

- develop and implement strategies to build or strengthen a person's informal support network

44. That the scheme fund formal support for participation in recreation and leisure activities (to be used in combination with the person's informal supports) and that the level of support funded have regard to the person's disability, their support needs and their individual circumstances.

45. That formal support for participation in recreation and leisure activities is flexible within funding limits (sometimes called funding bands) and portable.

46. That the scheme partner with the leisure and recreation industry to develop and implement initiatives to build the capacity of the sector to improve accessibility for people with disability.

47. That the scheme fund supports that complement, rather than duplicate, supports provided by tertiary education institutions.

48. That employer incentives complement, rather than duplicate, the incentives and supports provided by the Employment Assistance Fund.

49. That the scheme develop and implement a strategy to remove financial disincentives and penalties experienced by people with disability on commencing paid employment.

50. That the scheme fund attendant support to enable people with disability to participate in volunteering opportunities.

51. That decisions regarding eligibility for particular funded community living services and supports have regard to the reasonableness of the service or support in terms of:

- The cost
- The clear benefit to the individual
- Consistency with community norms

52. That community living services and supports do not have specific caps or limits but that service utilization is managed through the use

of person-centred planning processes with clearly defined boundaries with other related sectors

53. That community living services and supports do not have specific time limits but adapt to changes in a person's level of function and life stage.

54. That the range of community living services and supports funded is clearly defined and can be expanded as new service and support types are developed.

55. That the scheme develops processes to manage the provision of supports to scheme participants with multiple and complex needs. This includes the intersection with other systems such as justice and health, and ensuring people are able to access services and supports not funded by the scheme.

56. That the scheme aim for harmonization of industrial relations standards in relation to attendant support to maintain experience and expertise within the not for profit sector.

57. That the scheme provide for services and supports to be funded by:
   • direct payments to service and support providers,
   • brokerage arrangements,
   • individual funding agreements,
   • reimbursements to scheme participants.

58. That scheme participants who have entered into individualised funding agreements be able to directly employ community living support workers.

59. That the scheme differentiate between funding community living supports and standard living expenses such as food, rent, leisure activities and holidays and that the scheme not fund standard living expenses.

60. That the scheme enables scheme participants to contribute to funding so that they may receive a premium rather than a standard service (for example, elite adaptive recreation equipment).

61. That people with disability, carers and families have more control in relation to decision making around AT with:
   • policies that reflect the aim of improving client outcomes across lifespan and whole of life activities.
   • access to AT that allows for changes in life situations, needs and aspirations of individuals (families and carers) which also reflect improvements in technology
   • access to AT funding that is responsive to individual need (also recognising the needs of families and carers), allowing for choice and the timely allocation of equipment that is appropriate for the individual.
   • systems that include funding for therapy assessment, trial and training in the use of AT solutions for complex needs.

62. Key elements that need to be included in considering the nature of supply of AT include:

- access through a single point of entry to services, in recognition that the most effective AT solutions require multiple enablers to be provided in relation to each other.
- gate keeping structures inherent in current schemes such as approved lists with a more responsive system based on agreed principles and practice standards.
- funds being made available in a timely manner to allow for efficient supply timelines.
- systems in place for the provision, maintenance and recycling of equipment should be designed to maximise the efficient use of government resources.
- developing a national purchasing framework that acknowledges importance of local supplier service delivery and support in regional areas and for complex technology.
- provision for direct payments to people with disability for low cost or replacement AT

63. Eligibility for AT solutions needs to build on underpinning principles and include:

- funding that is guaranteed against clear eligibility guidelines.
- a strengths-based assessment framework with flexibility to empower the expert AT user to participate in the AT attainment process.
- existing programs being reviewed, rationalised and harmonized.
- consistency, prescription and transparency approval guidelines to ensure equity of access.
- resources being made available to investigate developments in interfacing between mainstream technologies and AT, to establish impacts on AT service delivery.
- increased access to people in rural and remote areas through application of telehealth, telecare and other e-solutions in the assessment process and support to individuals.
- resources for information and advice are recognized and promoted.
- resources for research developments in Universal Design and Smart House technologies and their impact on AT service delivery are recognized and funded.

64. The core elements of Assistive Technology delivery should include:

- Major reform to ensure the efficient delivery of AT to people with disability, within a long-term disability care and support scheme.
- Needs based eligibility criteria.
- Needs based and eligibility and entitlement.
- Single point of access.
- Equipment lifecycle management.

- Financially sustainable.

65. That the new scheme support a similar model to the 'Family Service Coordinator' or 'Key Worker model' to provide a sense of family empowerment so families are better supported and informed to make their own choices.

66. That the scheme fund mainstream, secondary and tertiary support services to ensure famlies have access to

- **Resources** including coordination, case management, formal intervention programs (individual therapy, specialist education) respite, equipment etc., as well as supplemental supports (financial assistance, respite care etc.).

- **Social supports**, including parent-to-parent groups, family counselling, and mobilization of family and community networks.

- **Information:** educational programs and personal support and guidance (DEECD, 2009).

67. That waiting times for early intervention services need to be reduced with more services and resources made available.

68. Unfairness in the system could be reduced if:

- one entry point to the system be put in place for families that is designed to easily navigate to reduce the fragmentation caused by multiple entry points resulting in a complicated that is difficult to navigate.

- intake processes be improved as they vary significantly across regions and programs.

- Prioritisation criteria are consistently applied across regions.

69. That the scheme fund parent and sibling support groups.

70. Every child displaying a developmental delay should have timely access to therapy and supports to maximize long term skill development**.**

71. Access to early intervention support and services is critical for every child who is not meeting critical developmental milestones. Yooralla believes that it is far better to err on the side of providing supporting to all children in this situation and risking the provision of support to a child who may not have a long term disability, than to wait until a formal diagnosis is made. Waiting may lead to longer term skills deficits that might have been addressed more successfully with an early intervention program.

72. It is often the case that a child needs to be observed over a period of time by family members and specialist practitioners for an accurate diagnosis to be made. It is essential that supports are available during this time and that neither the child nor the family is made to wait, sometimes for years, for a formal assessment of the child's disability.

Every child displaying a developmental delay should have timely access to therapy and supports to maximize long term skill development**.** There is a need for more ECS so families can access early intervention as soon as the diagnosis is made rather than go on a waiting list for months.

73. That is recognized that the key features of effective ECS include:

- an integrated system of all the services that children and families need to access for their education, care and health needs.

- accessible and affordable services for every child and family.

- the service and not the child or family, making adaptations as part of an inclusive philosophy, program and environment.

- every child and family to experience a strong sense of being drawn into and welcomed to a service.

- all children's education, care and wellbeing needs met in the mainstream services, with additional secondary or tertiary services when deemed necessary and provided within the mainstream service where possible.

- more comprehensive service delivery and more timely access to services.

- trans-disciplinary approach with different professionals learning from and with each other with ongoing opportunities for the transfer of knowledge, skills and practices.

- respect and acknowledgement of cultural and linguistic diversity (DEECD, Early childhood intervention reform project, 2009).