DISABILITY CARE & SUPPORT SCHEME

A Submission from
Occupational Therapy Australia

The Peak Body Representing Occupational Therapists

Assistive Technology Committee
Occupational Therapy Australia

This submission was prepared for Occupational Therapy Australia by the Assistive Technology Committee.

Members of the Assistive Technology Committee are as follows:

Natasha Layton [Chairperson]	Aids and Equipment Action Alliance, Victoria
Gerri Clay	Independent Living Centre, Western Australia
Kerryn Moorhouse	Australian Capital Territory
Phillipa Tyson	Tasmania
Karen Arblaster	New South Wales
Robyne Cottee	New South Wales
Desleigh De Jonge	The University of Queensland
Sue van de Loo	South Australia Disability, South Australia
Libby Morris	Multiple Sclerosis Society of SA & NT
Felicity Pidgeon	Darwin Remote Aged & Disability Program, Northern Territory

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1. INTRODUCTION

This submission from Occupational Therapy Australia addresses some key questions identified by the Productivity Commission which are within the scope of expertise of Occupational Therapy Australia. It focuses on the application of assistive technologies within the context of disability. The Service Delivery Framework for Disability Care and Support needs an emphasis on fairness, choice and control for all Australians with a disability.

Occupational therapy is a profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying the environment to better support participation.

Occupational therapists have a broad education that equips them with skills and knowledge to work collaboratively with individuals or groups of people who have an impairment of body structure or function due to a health condition, and who experience barriers to participation. Occupational therapists believe that participation can be supported or restricted by physical, social, attitudinal and legislative environments. Therefore, occupational therapy practice may be directed to changing aspects of the environment to enhance participation.

Occupational therapy is practised in a wide range of settings, including hospitals, health centres, homes, workplaces, schools, reform institutions, housing and residential care facilities for older people. Clients are actively involved in the therapeutic process, and outcomes of occupational therapy are diverse, client-driven and measured in terms of participation or satisfaction derived from participation.[1]

People with Disabilities

The Assistive Technology Committee of Occupational Therapy Australia strongly supports the concept of the National Disability Long Term Care and Support Scheme for people with severe or profound disability. As clearly identified in the Productivity Commission report, the current systems and services are inequitable and inadequate across the disability groups and regions, and difficult to navigate even for a highly skilled professional.

The new Disability Care and Support Scheme needs to be:

- Based on needs, functional capacity, strengths and ability
- Equitable for all diagnoses and disability groups
- Flexible and require consent and control in decision making by people with disabilities and their families.
- Seamless across the States and Territories
- Have a single point of entry
- Independent but coordinated with existing insurance e.g. No Fault Motor Vehicle Insurance as in NSW & Victoria.
- Developed in consideration of, and coordinated with, the Caring for Older Australians Scheme.
- Smooth transition from children's disability services to adult disability services and then to aged care services.

The Effects of Impairment and Subsequent Disability

Individuals may find themselves struggling with activities of daily life at any stage of the life span, as a consequence of a myriad of impairments. In Australia currently, services are delivered according to criteria such as age, diagnostic group, compensable status, work status. Frequently individuals must engage with multiple service providers to obtain the supports they require so that they can continue to live at home and participate in their communities. This is particularly evident at transition points such as turning 18 (entry age for

[1] World Federation of Occupational Therapists (WFOT), 2004.

adult disability services). Occupational Therapists work to align the capacities of the individual with the demands of her/his occupations in the areas of self care, productivity and leisure, and with the demands of the environment. Occupational therapists have an approach which is both holistic and focused on function: strategies to mediate impairments may be needed at any point within the course of an individual's life span; and during changes to life roles and life tasks. In our perspective therefore, services must be delivered on the basis of need. Moreover, the current focus on harm reduction (prioritisation of those at risk from a safety perspective) within a limited funding environment, result in 'strengths-based' outcomes receiving little attention. Early interventions, such as community mobility training, or supported re-engagement in the voluntary sector, have great potential to positively impact quality of life, slow functional decline and decrease downstream costs. However these interventions remain a low priority within current restrictive funding scenarios.

Interventions to Mediate Impairment Effects

Ways to manage and minimise the impact of impairment and disability and enable participation fall into several broad categories.[2.] These are:

- Interventions to reduce or compensate for the impairment e.g. therapy;
- Provision of personal care or support work;
- Redesign of activity;
- Use of assistive technology devices (AT devices);
- Redesign of environment.

The first strategy listed above is delivered primarily in health and rehabilitation settings in emergency departments, in acute and rehabilitation units and community teams. Occupational therapists are one of a range of health professionals including Speech Pathologists, Rehabilitation Engineers, Orthotists and Physiotherapists trained in remediating and compensating for impairments. Occupational therapists have particular skills in assessing the need for AT devices and modifications or adaptations to the environment. Assessment for, and provision of, personal care hours is most effective when the mediating effect of AT devices or environmental change are considered, in other words providing the appropriate combination of AT and environmental modification e.g. a set of handrails and a stepless shower recess, is a more cost effective and independent solution than introducing a shower stool and personal carer twice per week for showering support. These strategies or enablers are the primary means by which people with disabilities manage their situations and maximise their capacity to lead full lives. Most effective when delivered in conjunction with each other, they are termed an AT Solution[3].

Assistive Technology Solutions are effective interventions for people with a disability.

Assistive technology (AT) includes a wide range of equipment from simple and cheap commercially available items such as a large handled potato peeler to disability specific products such as a long handled pick up stick to highly complex integrated controls for powered wheelchairs enabling the user to access not only the driving controls for the powered wheelchair but also using the same control to operate their home entertainment unit and a complex electronic speech generating device for communication (See appendix 1 for a listing of definitions).

There is good evidence that delivery of AT solutions enables the achievement of life outcomes according to a number of indicators. The international literature provides firm evidence for outcomes of AT provision in the areas of:

2 Smith, R. O. (2002). IMPACT 2 MODEL 2009, from http://www.r2d2.uwm.edu/archive/impact2model.html

[3] www.at.org.au

1. Preserved independence, decreased functional decline and reduced hospital admission rates;
2. Prevention of secondary medical complications;
3. Prevention of falls; maintenance of occupational roles via enabling environments;
4. Alleviating carer burden;
5. Reduced residential care placement;
6. Enabled activity and participation in specific life domains;
7. Overall health and community life outcomes;
8. Quality of life.
9. Prolonged participation in the workforce

2. CURRENT ASSISTIVE TECHNOLOGY (AT) SITUATION IN AUSTRALIA

Inequitable provision across Australia

Each state and territory manages its own AT services independently and there is considerable variation with issues of inequity and discrimination[4]. Funding inequity and waiting times for both assessment of AT needs to delivery and trial of equipment varies greatly across the nation. There is discrepancy between the states and territories in eligibility criteria for disability as well as what range of AT service is available to that consumer.

Chronic underfunding in recurrent budgets causes a shortfall in programs which operate a subsidy, or funding to run out before the end of the financial year, for example

- In the Western Sydney region of NSW, all funding for Level 2 Home Modifications for 2010 was allocated by mid 2009. Extensive waiting periods have resulted, leaving people isolated, at risk, and unable to complete daily activities or leave their house, in addition to those who have endured unnecessary periods of hospitalisation.
- Victoria's Aids and Equipment Program funds up to $4,400 for home modifications, once per lifetime. This represents 25% or less of the actual cost of an average home modification.

AT support and wait times are highly dependent upon the availability of funding. Services and innovative programs based on grant funding commonly run out of money or are closed down. This ends provision, sometimes quite abruptly, creates inequities and dissatisfaction. For example:

- The 2008-9 South Australian Government and Novita Children's Services Pilot Program the "Statewide Complex Communication Needs Project" provided assessment, provision and training of speech generating devices to disability groups not otherwise eligible for any speech generating equipment. This service has since closed and is no longer available to South Australians with complex communication needs.
- The "Mobile Rehab Unit" IRIS grant funded mid 2007 run by Multiple Sclerosis Society of SA and NT; since closed due to lack of follow up funds.

Lack of vision regarding emerging technologies

We note a general lack of attention to emerging AT devices or AT solutions at government level. For example, Independent Living Centre of Western Australia (ILCWA) put forward a submission to trial early provision of AT based on predictive prescription to prevent hospitalisation and reduce carer burden. This is based upon evidence that AT devices and environmental alterations such as the introduction of mobile hoists can impact significantly on the ongoing health of the carer and to prevent breakdown of the caring dyad[5] . The government response in WA at that time clearly indicated a failure to understand what AT was how it can potentially assist carers and provide respite in some circumstances from their caring role.

Funding and services for assistive devices and environmental modifications remains limited and extremely difficult to access. Those with AT funded by state schemes can be required to return the AT if moving interstate, even though it is essential for basic personal care and mobility. This can impact a consumer's ability to move interstate and be near family support which may have reduced the cost of paid care supports. Further, people cannot apply for equipment interstate prior to, which results in a significant period of time without essential items for daily living and mobility. This and other procedural complexities can result in people being without much needed AT for years. For a person with a disability deterioration or death can come before the required AT solution, despite forward planning and timely submission of applications.

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[4] NDS, Aids and Equipment Fact Sheet: Improving quality of life for people with a disability, June 2004.

5 ILC WA. (2006). *Family Carers and the Physical Impact of Caring - injury and prevention: research report.* Perth: Independent Living Centre of WA. http://www.ilc.com.au/pages/research-and-projects

Assistive technology such as basic items such as shower chairs, grab rails, hobless showers, as well as personal alarm systems connected to a monitoring service are generally readily available. It is imperative that people with disabilities have ready access to these as well as more complex assistive devices and modifications. An occupational therapy assessment and prescription is essential for appropriate provision of assistive technology for the promotion of safe activity and participation.

A National Disability scheme which encompasses AT and provides a uniform and equitable service for all Australians with a disability is recommended.

3. KEY QUESTIONS

KEY QUESTION 1

Who should be the focus of the Scheme and how will they be practically and reliably identified?

Occupational Therapists in disability services are professionals with a wide scope of practice. Occupational therapists are trained in cognitive and physical assessment. Like our speech pathology and physiotherapy colleagues, we maximise function through a variety of interventions in areas of rehabilitation and reconditioning. Our unique focus on the person, and their life occupations, tailors such interventions directly to the person with a disability and their family and their roles within in their environment. Occupational therapists are specifically trained to assess and measure functional impairment and can competently identify functional status and needs of the person with a disability.

- Occupational therapists are the profession able to prescribe optimal sets of AT devices, environmental interventions and recommend tailored personal care, to maximise independent living and quality of life.
- Occupational Therapists are uniquely placed to create and administer a national disability eligibility assessment tool similar to the existing national ACAT (Aged Care Assessment Team) to assist with national equity for people with disability.

Development of a national disability assessment criteria and accredited health professionals to administer the assessment to create equity for all Australians with a disability is a priority.

KEY QUESTION 2

Which Groups are most in Need of Additional Help?

From a consumer standpoint, the impact of impairment requires a seamless response regardless of a person's entry point into the system. For equitable and effective service delivery, a continuum of governance is essential to ensure a seamless transition between these major sectors (Health, Children's Services, Disability Services, Education and Employment Services). Currently this does not occur. Substantial differences exist across these sectors and services remain fragmented.

Particular groups of concern for the Disability Care system, who would particularly benefit from coordinated services, are:

- Consumers with pre-existing disability present prior to entry into adult disability care system many problems are currently noted when switching into adult disability services and removal of current service delivery
- People ageing into disability
- Vulnerable consumers in social housing and low income should be identified as in need of additional support and help
- Consumers with complex multiple conditions/disabilities especially those with mental health and physical or cognitive disability.
- Families providing care for their dependent disabled family member who are reliant on welfare payments
- Families where multiple family members have disability
- Young people in residential aged care facilities have been shown to have instances of mortality and increased morbidity due to lack of care appropriate to their needs (for

example, if a nursing home does not provide a wheelchair with postural supports, increased instances of choking occur when a person is fed in a 'tub' chair)[6]

- People with progressive conditions who require ongoing increasing levels of support
- Consumers in rural and remote regions who have no local disability service provision
- Indigenous consumers
- Young and aged carers

KEY QUESTION 3

The Kinds of Services that particularly need to be increased or created?

Occupational Therapists work in a variety of settings with people with disabilities including hospitals, rehabilitation, community, educational settings and private clinics and are key innovators in service delivery. There needs to be an increased focus on primary and preventative interventions based in the community; coupled with a strengthening of the services focussing on the transitions between Health and Community Services. A patchwork of services is currently provided by health, ageing and disability sectors, with substantial gaps being managed by consumers themselves, frequently with substantial strain, and persistent unmet needs. The range of services provided is appropriate at a basic level, however, reducing service silos and increasing consumer knowledge and control could improve the range and flexibility of services, and collaboration between these services. For example, consumers are often discharged from hospital with AT equipment provided by health, but on return to the community this equipment is removed prior to the provision of community disability services.

The Commission is referred to a development which occurred in the UK in 2006, when the UK National Health Service undertook a major review of its community equipment scheme and embarked upon the Transforming Community Equipment Program. The program aimed to enable individuals to achieve choice and control over their lives by providing increased availability of information, well designed and useful products and competent, knowledgeable individuals to provide assessment, product demonstration and advice, delivery, installation and fit of equipment . Their agenda to deliver a new service delivery model recognized three main categories of equipment: simple aids to daily living (low cost low technology); complex aids to daily living; and bespoke or special products. The new system has engineered a shift from a previous total loan equipment system to one of ownership by clients for low technology and low cost items which comprise a large percentage of the total products issued. The new system is prescription based: where there is an assessed need, government issues eligible users with a 'prescription' that can be exchanged for free equipment at an accredited retailer. Users are enabled to 'top-up' the prescription (building in both choice and empowerment) if they wish to have a similar item of different style or colour. This new system is creating an open retail market place intended to drive innovation and choice, and increase ease of access to equipment and services in more localities and during normal trading hours. The improved accessibility for all individuals to these low cost items normalises the experience of accessing and using equipment and provides a previously non-existent system for self funding. This model may serve as a key idea for innovation in the Australian Disability industry.

Occupational Therapists would support reform in the disability sector which delivers the following:

- Consistent and timely access to allied health services such as occupational therapy

[6] Winkler, D., Sloane, S., & Calloway, L. (2007). *My Future My Choice: Younger people in residential aged care: support needs, preferences and future directions.* Melbourne: Summer Foundation for Department of Human Services.

- Timely provision of AT support to prevent secondary complications for people with disability, as well as preventing depression, stress, illness and injury to primary carers.
- Wider provision of health promotion programs including fitness and exercise programs for people with disability and their carers inclusive of transport. Preventative programs such as this will assist with function, cardiovascular fitness, prevention of de-conditioning and contracture and increase endurance, well being and socialisation.
- Commitment to ongoing funding and wider rollout of innovative programs which deliver better outcomes for people with disability and their carers evidenced by research and best practise studies (see Appendix 2 for Australia wide examples of successful studies and programs).
- Establishment and maintenance of accredited training for professionals working in AT with emphasis on up-skilling professionals in rural and remote regions. For example, the new Single Equipment Service (SES) adopted by SA domiciliary Care service to streamline assistive technology service model. This was introduced in SA in 2009 requiring all Occupational Therapists in Disability South Australia (DSA) and relevant NGOs to register with an approved level of "prescriber status" to assess and prescribe equipment for people with disabilities, and the aged care sector. This model is due to include the paediatric disability population in SA later in August 2010.
- Co-ordinated response to emerging technologies: areas such as telehealth and telemonitoring have potential to support independent life in the community. Research and development of such technologies has predominantly occurred from engineering and economic perspectives. The delivery and supply of these technologies, (termed Ambient Assisted Living in Europe[7]) in an ethical and consumer-cantered way, will be essential to their success. Best practice guidelines and a model of service delivery must be developed for this area of AT. Allied health workers will require training in relation to these emerging technologies, as they will be the main professional groups to work with AT and disability. There will be education and training requirements in both the university and vocational education sectors.
- Sufficient supply of health professionals to provide assessments and interventions for disabled persons, including in rural and remote areas. This is a well documented area of short supply in workforce. Increasing intakes into university programs and incentive schemes for provision of services in rural and remote areas are required.
- An emphasis on recruitment of workforce from Aboriginal and culturally and linguistically diverse backgrounds, to roles at all levels and within all service types throughout the Disability Care System is essential. This workforce will not only provide culturally relevant and sensitive services, but can contribute to ongoing policy development and development of innovative service models to meet the special needs of these groups.

KEY QUESTION 4

Ways to achieve Early Intervention?

Systems currently focus on people at risk of hospitalisation or admission to residential care. This results in reactive rather than proactive approaches to triage and management of wait lists. Interventions which enable consumers to remain active and independent generate downstream cost benefits and are a worthwhile investment. Occupational therapists strongly advise that in addition to focussing on people with acute or high support needs, it is essential to respond to people's needs as they begin to develop activity restrictions and participation limitations. This would enable people with disabilities to maintain their independence and activity through early entry into a staged service delivery system. This requires a service sector with appropriate skills and capacity. Cornerstones of an improved approach include skilled assessors working within a strengths-based framework, and broad outcome areas such as enshrined in WHO ICF to be within the policy scope.

[7] http://www.aal-europe.eu/

Where early intervention has been implemented it has been very successful. There is a current funding focus on early family centred early intervention for children with disabilities such as the FaHCSIA (Department of Families, Housing, Community Services and Indigenous Affairs) package for children with Autism Spectrum Disorders (ASD). However, children with similar levels of need, without a diagnosis of ASD, are unable to access this level of service. This highlights just one of the many inequities across the paediatric services for children.

There is a large body of evidence supporting the positive outcomes for early intervention for children who are biologically or socially vulnerable. Early intervention for children needs to be community based and aimed at enhancing the developmental competence whilst preventing and minimising delay[8] and treating disorder.

Further ideas include:

- Flexibility within the AT system to complete predictive prescription with AT rather than in response to critical incidents. This both prevents carer stress and ensures consumers have appropriate AT continuously. AT provision in SA, Tasmania and Victoria are weighted towards crisis management rather than preventative early intervention
- Extension of the eligibility criteria for AT to allow consumers particularly with progressive conditions such as MS, to have early access to mobility options for "out and about". As fatigue is a major factor in progressive conditions consumers who are able to ambulate for short distances indoors become prematurely housebound, which subsequently affects their social isolation and wellbeing
- Local fitness groups targeting people with disabilities to encourage self determination in wellbeing and access to ongoing supportive groups and staff
- For progressive conditions, the ability to be able to register with disability services on diagnosis so there is a safety net if issues occur, instead of having to wait until there is a definite ongoing need for assistance and then have to wait for registration before they can access disability services
- Lifelong rather than episode of care model, as the latter restricts the amount of therapy and AT intervention in a timely manner and means families have lack of continuity in service provision
- Localised service provision enables quicker response and wider access to AT.
- A continued focus on early intervention for childhood services
- The creation of a research unit into best practice for AT for people with disabilities in Australia
- Continuous case management over the long term, to facilitate planning and choice, as well as smooth transitions as activity and participation restrictions increase

Emphases on early intervention need to be preventative and predictive rather than the current focus of crisis care.

KEY QUESTION 5

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

Provision of AT support enables people living with disabilities to pursue their interests and activities (including employment) in the community. Currently, with the long delays for service provision and AT support, people become socially isolated prior to re-engaging with the community. Further, accessing the community present a major barrier to engagement and reengagement. Many people with disabilities cannot get where they need to go. They rely

[8] Guralnick M J, (1997) The Effectiveness of Early Intervention, Paul H Brooks Publishing Co

on family, friends, churches, community groups, charitable organisations, community transport services or taxis, including accessible taxis. All of these options are appropriate in some situations but some people cannot use, or do not have access to, these options. Frequent medical visits may be expensive for someone on a pension, even with the disabled taxi subsidy. Safe, affordable and readily accessible transport should be considered in any disability planning. Several current facilitators of travel deserve a mention and could be extended in scope, particularly half price taxi travel, public transport concession fares, and the Companion Card.

The absence of sufficient safe and affordable transport, and a desire to maintain their independence, leads some drivers with disability particularly progressive conditions continue driving well beyond the point when they should stop. This places themselves and all other road users at serious risk.

Some Occupational Therapists have undergone specialised training to be accredited driving assessors for persons with disorders and disabilities that impact on their ability to drive. Medical officers should be encouraged to take responsibility for either referral to an occupational therapy driving assessor, or for informing the relevant state authority that a person is no longer safe to drive, if this is consistent with their assessment and diagnosis. For a multitude of reasons, including an awareness of the difficulty in accessing necessary transport, as well as a limited supply of driver trained occupational therapists and the cost of an occupational therapist driving assessment; medical officers fail to meet this responsibility. This places the person with a disability, their passengers and other road users at grave risk.

The responsibility to ensure disabled drivers are able to drive safely must be promoted and enforced with the medical profession. Access to affordable and timely Occupational Therapy Driver Assessment and Training services is critical to maintaining safe drivers, for appropriate prescription of AT for driving, and to evaluate unsafe drivers via on-road and off-road assessments. Creating access to funding for vehicle modification (such as modified driving controls) in those States/Territories without current vehicle modification schemes is essential.

Transport can be a limiting factor to any good programs and it is essential that there are accessible and affordable funded options. These could include:

- Affordable driver assessment units available for young adults learning and gaining their driver's license, as well as disabled adults being assessed for suitable AT controls
- Appropriate funding of vehicle modifications including wheelchair hoist installation and modified driving controls,
- more flexible and available community transport especially in rural areas.
- improved standards for taxi operators providing services for disabled children and adults,
- the development of a subset of taxi drivers trained to take frail and mentally impaired passengers,
- taxi subsidy dependant on need, including more access cab vouchers to enable participation in weekly outings such as fitness programs,
- Funding support for training of occupational therapy driving assessors to be made available on an ongoing basis.

Access to a timely, flexible and equitable AT support system will assist with community inclusion, decrease hospitalisations and maximise participation

in the community and workplace.

KEY QUESTION 7

How to Improve Service Delivery?

The presence of multiple entry points to disability services disempowers people with disabilities and their families. Multiple players, for example up to nine different funding sources for AT (many being different schemes administered by the same department) creates gaps and disjointed service particularly for people with co-morbidity. For example in SA, people with a mental health issue AND a biological impairment receive inadequate intervention due to lack of service coordination and funding.

- Eligibility for service delivery and AT provision needs to be consistent and equitable across all states and territories
- Single entry into the disability system to reduce confusion and poor case coordination
- Funding based on a standardised tiered funding system whereby an allocation of funding is made based on the outcome of a comprehensive intake assessment
- Flexibility for consumers and their families to make choices about how to spend these funds based on their own resource availability and preferences regarding activities and participation
- Local service providers need to be fully accredited and trained to provide the full range of funded services including AT, based on assessed need, without lengthy waiting periods and new systems for accreditation. This will require national standards for occupational therapists to provide quality approved services
- Establish national standards for funding to ensure sufficient funding in the Disability System to provide AT including home modifications and other solutions that enable independence and maintenance of activities and participation in chosen domains
- Services must be delivered on the basis of need and capacity to benefit.

A single process of entry with determination of level of funding/services required must be in place and needs to be extended to provide case coordination and smooth transition over the longer term. Experienced triage at point of entry is essential. Thorough knowledge of the Disability Sector and an ability to make referrals to appropriate health professionals and service providers in order to complete a comprehensive intake assessment is required.

A continuum of care, providing enablers in a person's home, including AT, emerging technologies, personal support services, home based respite care giving carers a break, rehabilitation after illness or injury, easily accessed increased care and support after hospitalisation, and timely access to residential placement in a facility close to one's home or family must be available. The existing continuum of care, while continually expanding, is not sufficient to meet current demand, and needs considerable growth in funding and scope to meet future growth in demand.

KEY QUESTION 8

The factors that affect how much support people get and who decides this?

Currently there are multiple systems, agencies and services involved in supporting children and adults with a disability. Every State and Territory has its own unique system and overall for the consumer and their family, it is inefficient, confusing and disempowering. This creates inequities in service provision, gaps in the system and barriers to service delivery.

Some of the issues involved include

- Poor co-ordination of funding and servicing between state government, federal government and NGO agencies
- Different pathways to funding have their own entry and exit criteria
- Different systems of service delivery between the 0-18year old and the 18-65 year old consumers with the point of transition being very difficult for the disabled person and their family
- Service delivery variances depending on the type of diagnosis, not on a needs basis.
- Accommodation options can vary depending on location, diagnosis, age and degree of disability
- Funding respite choices for the carer depending on the carer's age
- Funding for services are mainly aimed at hospital discharge and crisis intervention while many with progressive conditions slowly decline with little support until a crisis occurs
- Insufficient accommodation places, in combination with the current pressures on acute hospitals, forces younger disabled persons to accept the first available placement in a residential aged care facility. More places and greater flexibility in the system are required to ensure that younger disabled persons have sufficient accommodation choices suitable to their age

For continuous service delivery across the spectrum of disability and the life continuum there needs to be:

- A single entry point with a disability assessment performed by an accredited allied health assessor
- Consistency across the states and territories and uniformity between children's and adults services
- Funding per client to be based on need so that children with growth factors and people with a progressive disability condition are serviced in a timely manner. This is necessary to prevent secondary conditions and contractures that can occur with ill fitting and inappropriate AT support systems

Children and adults with a disability must be able to request occupational therapy assessment and support and this needs to be dealt with in a timely manner regardless of accommodation, age and diagnosis

KEY QUESTION 9

How to ensure that any good aspects of current approaches are preserved?

There are many good aspects in the current system and innovative successful programs are developed. Unfortunately most of these tend to be on short term funding and eventually fold.

Some of the issues involved with good programs that can be preserved are:-

- That emphasis be on preventative programs that concentrate on timely predictive AT prescription and wellness service delivery
- The use of AT to be prescribed and remain in place regardless of any changes in service delivery e.g. hospitals purchase AT necessary for discharge then hand over to the community for follow up and maintenance support
- More funding to rehab/fitness/exercise programs with transport attached to reduce the burden of caring (i.e. give the carer some respite while the disabled person attends the program), increase wellness, fitness and social stimulation
- Ensure roll over funding is in place to provide sustainability of the program
- To preserve the best aspects of service delivery the programme evaluation needs to count actual 'outcomes' rather than programme 'outputs'. For example, the most meaningful outcomes to be captured from provision of AT funding such as a wheelchair would be an increase in mobility. Frequently however, funders count the 'output' as being the cost of the wheelchair. Obtaining funds can cause substantial delays in actual outcome (improved mobility) and indeed may not occur should funding not be found

Service delivery performance should be focussed on person centred outcomes rather than programme outputs. It should utilise accepted benchmarks such as the WHO International Classification of Functioning, Disability and Health Classification System [9]. Australia has adopted the WHO ICF which, alongside the UN Convention on the Rights of Persons with Disability[10] enshrines the rights of Australians to participate in a wide variety of life areas, and to receive the necessary resources with which to do so.

KEY QUESTION 10

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

Currently service provision in rural and remote regions is often dependant on where the person with the disability lives and what funding criteria they fall under.

Some ideas to include in any service delivery to rural and remote communities are:

- Regular in-services and educational/accreditation programs for allied health working remotely
- More funded outreach for highly trained specialist staff to travel to remote regions and work alongside allied health doing joint AT prescription and offering advice/information/mentoring support and up-skilling the local therapy staff –from there a linked rural/city partnership
- Funding for specialist agencies to do "outreach" and visit/service people with disability in that region, liaise with local service providers and educate local community health.
- Continued funding for attractive salary packaging and incentives to work remotely with provisions for professional development
- Enabling the family access to funding on a client centred model e.g. consider expanding the Federal funding for Autism, ($2000 rural travel allowance for therapy attendance from FaCHSIA) to all disabilities.

[9] WHO. (2001). *International Classification of Functioning, Disability and Health*. Geneva: World Health Organisation.

[10] United Nations Convention on the rights of persons with disabilities and optional protocol, (2008).

Build capacity in central services to support rural and remote allied health and remote families and communities.

KEY QUESTION 11

Reducing unfairness, so that people with similar levels of need get similar support?

Currently substantial inequity exists across funding streams for provision of enabling solutions such as AT devices, environmental adaptations, personal care, or occupational therapy and other allied health interventions. Different disability groups receive different supports, consumers with the same clinical need receive substantially different services and therefore substantially different outcomes due to their eligibility for different funding types (children's services v adult services) or compensability status (e.g. compensable funded spinal cord injuries). The Department of Veterans Affairs has tiered service provision based on eligibility rather than need. Once again, rural, regional and State/ Territory differences also influence the playing field.

Detailed below are some examples of inequity noted by occupational therapists:

- A disabled palliative consumer assessed and provided with necessary AT device and care support, which was withdrawn when the consumer failed to die within three months
- In some jurisdictions, disabled younger clients lose all their equipment except their primary mobility aid when moved into aged care (often they are under 65)
- There is insufficient funding within Aged Care Facilities for consistent provision of AT; despite this, state based disability aids and appliances programs may exclude these clients. This is especially distressing for younger disabled people placed in aged care accommodation
- A large funding discrepancy exists between adult and children's services with waiting times being much longer in the adult services, as such many families attempt to get AT support for their children prior to turning 18

A real understanding of disabled people's needs is required so that funding and services can be developed appropriately. For example, assistive devices and environmental modifications have long been established as being effective in reducing morbidity, mortality and functional decline but the need for these interventions has not yet been mandated in service delivery.

There are system wide impacts of inadequate funding across the aged care, disability and health systems. For example, lack of appropriate residential accommodation such as cluster housing, may cause extended stay in hospital, subsequently blocking access to beds for those presenting to Emergency Departments. This clearly leads to significant risks to health and well being including de-conditioning and loss of function, falls and hospital acquired infections.

A Disability Assessment Scale needs to be developed that is based on need rather than diagnosis, age, and location.

KEY QUESTION 12

Getting rid of wasteful paper burdens, overlapping assessments (the 'run around") and reducing duplication in the system?

Because occupational therapists use a holistic and client-centred approach to practice, they are acutely aware of the duplication, inconsistencies and inequities that occur across and within systems. Occupational therapists generally work collaboratively with clients to navigate the patchwork of services and piece together a system of support that best meets the individual's needs.

Multiple agencies

Currently there appears to be too many pockets of funding all with differing aims, eligibility criteria and procedures. Consumers in crisis tend to call many agencies requesting assistance so duplication of servicing is common. A service delivery pathway that often involves many agencies is the provision of AT. For example, in South Australia, in the new single equipment service (SES) for a client with MS the pathway to get a piece of equipment (not including the seating clinic) involves 4 agencies and 9 steps.

Transition fracture points

A number of transition fracture points occur between child and adult services, or between hospital and community. These can involve removal of supports (such as AT devices) and reassessment and wait times from community AT device provision. For example, on hospital discharge a person with a disability may receive and complete one service/package (e.g. a Metro Home Link package in South Australia) and may then be waitlisted for any further service needs, leading to disjointed care and an intolerable burden on carers. More case coordination and planning would assist as well as more places/packages. Metro Home link (MHL) represent an attempt to introduce necessary therapy and support services at time of need, however at the end of the 6 week period, enablers such as AT devices are removed as they belong to the MHL provider. The person with the disability is then on a wait list with the disability service provider to provide the necessary AT and therapy support.

Wait times lead to downstream costs

As people with a disability wait for therapy services (community mobility training) and for equipment assessment and prescription (a power wheelchair and a hoist), the primary issue remains and frequently compounds. Subsequently, more referrals for allied health support are made (transfer assessment; primary carer back issues; home care support for shopping; isolation and depression) as issues multiply. If the initial problem that could easily have been solved with timely therapy intervention and provision of AT (power wheelchair and hoist) had been addressed in a timely way, the additional costs could have been avoided.

To assist with prevention and duplication of servicing:-

- A one point assessment entry system to co-ordinate all service provision must be in place which can be accessed by all key stakeholders
- Seamless transition across common fracture points (hospital to home; child to adult to aged care)
- When AT and other enablers are put in place, they remain in place regardless of any changes in agency service delivery
- Improve current practices of recycling AT equipment
- Ensure best practice in prescription and provision and training in the use of assistive technology to minimise AT abandonment, especially with the high cost high risk items
- Promote case management and coordination over the long term

A national disability recognition system

People living with disability describe periodic reassessment and the need to tell their story repeatedly to many different agencies. This is especially evident with those with deteriorating disabilities as each assessment indicates a further decline in their function. For those with static or permanent conditions they repeatedly have to certify that they have this disability or impairment to various government agencies and NGOs in order to receive a service.

Need for case co-ordination

Provision of skilled co-ordination services makes for a more seamless experience for the individual and family, as well as delivering multiple services in the most effective way. The case management model of care provides for this. Disability case managers can be funded to work with disabled consumers and their families over the long term, enabling care planning,

maintenance of activity and participation as well as a smooth transition between service types. This enables smooth transition from childhood services to adult services. A case manager can work with the disabled person and their family, taking into account their desires and personal circumstances, while also considering professional recommendations. Case managers should work with families to empower them to make choices, while also ensuring they receive appropriate professional assessment and advice. Processes to manage requests for change of case manager, and for dispute resolution are essential.

Skilled case co-ordination via a single entry point to services, enabling the consumer to 'build' their network of enablers and supports and eliminate current fracture points in service delivery. A national disability card based on the initial disability scale may minimise duplication of servicing.

KEY QUESTION 13

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

Occupational Therapy Australia support the notion of a national disability funding scheme, funded via an increase to the Medicare levy, to improve disability care and support in Australia. Several other proactive strategies will provide cost benefits into the future and should be considered as part of the reform agenda.

Universal design

Most current housing stock and built environments in Australia have been designed as though their users are upright adults despite the fact that one in five Australians lives with a disability, one in ten uses some form of assistive technology. As disability occurs, the home and community environments become increasing barriers to activities and participation. Environments which are not universally designed may also represent a barrier for people experiencing the impact of ageing, as can be seen from the extensive literature on falls and falls prevention[11]. Australians living with obesity, parents needing to propel prams in and out of dwellings and many others are impacted by non-social design.

Planning of communities, including housing developments, must promote accessible, safe environments that take an inclusive view of the population, and enable disabled persons to remain at home, maintaining their participation in family and community life. Retro-fitting environmental modifications is a costly exercise as compared with incorporating universal design and adaptable housing features at point of build[12]. Emerging technologies such as ambient assisted living technologies may be incorporated into new housing developments and communities. Calls for increased building regulation are increasing to 'future proof' housing and enable ageing and disabled consumers to age in place, within their communities, and have been successful overseas, for example Age In Place initiatives in Canada[13], and Lifetime Homes[14] in the UK. Updating building standards and urban planning guidelines in line with universal design principles will reduce the necessity for home modifications into the future.

Taking a societal perspective on costing allows the cost benefits of preventative measures such as support for carers and universal design within in new building standards and transport systems, to be

11 Clemson, L., Cumming, R., & Roland, M. (1996). Case–Control Study of Hazards in the Home and Risk of Falls and Hip Fractures. Age and Ageing, 25(2).

12 http://www.vcoss.org.au/documents/VCOSS%20docs/Housing/platform-email.pdf

13 http://www.visitablehousingcanada.com/holder1.html

14 Lifetime Homes, Lifetime Neighbourhoods: A National Strategy for Housing in an Ageing Society Retrieved. from http://www.communities.gov.uk/documents/housing/pdf/lifetimehomes.

recognised.

Occupational Therapy Australia support the notion of a national disability funding scheme, funded via an increase to the Medicare levy, to improve disability care and support in Australia.

4. CONCLUSION

Occupational Therapy Australia applauds the Federal Government for tasking the Productivity Commission to review Australia's capacity to care for people with disabilities through the Disability Care and Support Issues Paper. This submission to the Inquiry presents an alternate view of human need, focussing on the effects of impairment regardless of diagnosis. Also, a view of the potential of enabling environments and strengths-based assessment to maintain a high level of independent living and good quality of life at any point of entry into the Disability Services.

To implement such nuanced and tailored service delivery, a number of recommendations are made:

- Broad eligibility framework based on need, possibly via a disability assessment tool,
- Streamlined single point entry to the service system, crossing health, disability and ageing jurisdictions,
- Funding based on strengths based outcomes frameworks (eg WHO ICF),
- Service flexibility and consumer choice regarding service delivery and funding models eg direct payments,
- Adequate provision of assistive technology and environmental interventions as key enablers
- Focus on early intervention, understanding that preventative measures can slow functional decline,
- Availability of long term case coordination where needed,
- Sufficient community, respite and residential services ,
- National agenda for research and development of emerging technologies,
- Co-ordinated plan for transport and driving,
- Consolidation of existing government funded departments to create an across the lifespan approach,
- Benchmark to international standards such as UN Convention on the Rights of Persons with Disability.

Attending to the capacity for growth of the workforce is essential to implement a good service system into the future. This includes building on service models and roles that are currently working, and further developing roles of skilled assessors. And finally, aligned, accountable and connected governance across health, ageing and disability is required to genuinely build the whole service system around the consumer, as they move through their lifespan and as their capacities grow and change.

5. APPENDIX 1

DEFINITIONS:

Ambient Assisted Living (known as **AAL**) includes methods, concepts, (electronic) systems, devices as well as services that are providing unobtrusive support for daily life based on context and the situation of the assisted person. The technologies applied for AAL are user-centric, i.e. oriented towards the needs and capabilities of the actual user. They are also integrated into the immediate personal environment of the user.

An Assistive Technology Solution: 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'. [15]

Assistive Technology (AT): Any device, system or design, whether acquired commercially or off the shelf, modified or customised, that allows an individual to perform a task that they would otherwise be unable to do, or increase the ease and safety with which a task can be performed." [16]

Terms such as aids and equipment, invalid aids, gadgets or medical devices have been used interchangeably over the years to describe what is now internationally known as assistive technology devices.

AT Devices: Comprised of 'hard' technology, while related activities such as clinical advice, customising, and training represent 'soft' technology. 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.[17]

Environmental Control Unit (ECU) / Electronic aid to daily living (EADL)*:* Device that allows control of appliances (e.g. radio, television, CD player, telephone) through the use of one or more switches

The Technology Chain*:* Assistive technologies exist in relation to the environments in which they are used. Enabling environments (for example a level continuous path of travel in the home or community) directly impact the AT required (for a person with impaired balance, level pathways may remove the need for handrails; for the power wheelchair user, a stair climbing function will not be required) from:

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

Smart Homes*:* Denotes living environments in which automation is used to provide automatic functions including monitoring, communications, household functions (lights, air conditioning/heating, door locks) physiological measurements, medical alerts.

Tele-care: The term given to offering remote care of elderly and vulnerable people, providing the care and reassurance needed to allow them to remain living in their own homes. Use of sensors allows the management of risk and is part of a package which can support people with dementia, people at risk of falling or at risk of violence and prevents hospital admission. Tele-care refers to the idea of enabling people to remain independent in their own homes by providing person-centered reactive technologies to support the individual or their carers. In its simplest form, it can refer to a fixed or mobile telephone contact to monitor or to inform of any development. A technological more advanced solution is by using sensors, a range of potential risk situations including wandering (particularly useful for people with dementia), falls and intruders as well as environmental issues such as floods, fire and gas leaks. When a sensor is activated it sends a radio signal to a central home unit, which then automatically calls a 24-hour monitoring centre where operators can take the most appropriate action, whether it be contacting a local key holder, doctor or the emergency services. The system can equally link to members of a family support network.

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[15] www.at.org.au

[16] Independent Living Centres Australia http://www.ilcaustralia.org/home/assistive_technology.asp

17 Cook, A., & Hussey, S. (Eds.). (2008). Assistive Technologies: Principles and Practice (Vol. 3). St. Louis: Mosby Elsevier.

Technology and Health: There is a growing body of terminology explaining systems and functions of technology and its relationship to supporting, maintaining, and improving health outcomes. Definition for the more common terms Telehealth/ Telemedicine / Telemonitoring / e health are given.

Telehealth: The use of telecommunication technologies to provide health care services and access to medical and surgical information for training and educating health care professionals and consumers, to increase awareness and educate the public about health-related issues, and to facilitate medical research across distances.

Universal Design / Inclusive Design: Universal Design refers to broad-spectrum solutions that produce buildings, products and environments that are usable and effective for everyone, not just people with disabilities. Inclusive Design is a general approach to designing in which designers ensure that their products and services address the needs of the widest possible audience, irrespective of age or ability.

6. APPENDIX 2

EXISTING OR INNOVATIVE PILOT PROGRAMS

- WA, the Disability Services Commission funded a project titled “Mapping Best Practise in Voice Output Communication Devices, Prescription and Implementation” completed by the Independent Living Centre of WA.
- SA SCCN (Statewide Complex Communication Needs) program; funded by Novita and the SA government to provide complex communication intervention as well as AT to any south Australian with a disability.
- MSRU (Mobile Support Rehabilitation Unit) SA, funded by IRIS form SA government; giving local access to people with MS for annual rehabilitation checks.
- Federal initiative through FaHCSIA for the one off lump sum travel allowance payment of $2000 for families with a child with ASD living in remote or rural areas to access appropriate metropolitan services.