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Faculty of Arts and Social Sciences

The Role of Assistive Technology in Supporting People with Disabilities and Complex Care Needs: A Literature Review

Denise Thompson, Karen R. Fisher, Rosemary Kayess

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Table of contents

Abbreviations	vi
Executive summary	viii
Physical disabilities	viii
Sensory and communication disabilities	ix
Conclusion.....	x
1 Introduction.....	1
1.1 Use of assistive technology	1
1.2 Human rights.....	4
1.3 Policy context.....	5
Policy	5
Programs	7
1.4 Methodology.....	9
2 Physical Disabilities: AT Types	11
2.1 Introduction	11
2.2 Powered wheelchairs	13
2.3 AT for cognition.....	14
2.4 Home modifications	16
2.5 Smart homes	17
2.6 Microswitches	19
2.7 Telecare.....	19
3 Physical Disabilities: the Impact of AT on Care Needs	24
3.1 Improving independence and self-determination	24
3.2 User involvement	26
3.3 Abandonment	28
3.4 Assessment and evaluation tools.....	29
3.5 Usage among particular groups	30
3.6 AT and personal care.....	32
3.7 Examples of AT services and programs.....	35
3.8 Decreasing the cost of support services	39
3.9 Examples of arrangements designed to reduce costs	41
3.10 Decreasing the risk of injury among service users.....	45
3.11 Areas for further research.....	46
4 Sensory and Communication Disabilities: Introduction.....	48
4.1 Government and non-government AT providers	48
5 Deafness: AT Types and the Impact of AT on Care Needs	51
5.1 Hearing aids.....	51
5.2 Cochlear implants.....	52
5.3 Telecommunications	53
3.2.4 Other AT for deafness and hearing impairment.....	54

6	Blindness: AT Types and the Impact of AT on Care Needs.....	56
7	Deaf-blindness.....	58
8	Communication Disabilities and AAC.....	60
8.1	AAC devices.....	60
8.2	Services.....	62
8.3	Cost.....	63
	Cochlear implants/hearing aids.....	63
	Tele-interventions.....	64
8.4	Gaps in assistance.....	65
9	Conclusion.....	68
	References.....	70
	Appendix – Internet resources.....	82

Abbreviations

AAC	augmentative and alternative communication
ABI	acquired brain injury
ACROD	National Industry Association for Disability Services (now National Disability Services)
ADHC	Ageing, Disability and Home Care, Department of Family and Community Services NSW
ADL	Activities of daily living
AEAA	Aids and Equipment Action Alliance (Victoria)
AEP	Aids and Equipment Program (Victoria)
AIDAS	Aids for Individuals in the DADHC Accommodation Service
AIHW	Australian Institute of Health and Welfare
ALD	assistive listening device
ALS	amyotrophic lateral sclerosis (Lou Gehrig's disease)
ASD	autism spectrum disorder
AT	Assistive technology
CAAS	Continence Aids and Appliance Scheme
CCTV	closed circuit television
CD	compact disc
CES	Community Equipment Scheme (Tasmania)
COPD	chronic obstructive pulmonary disease
COPM	Canadian Occupational Performance Measure
CSTDA	Commonwealth State/Territory Disability Agreement
DADHC	Department of Ageing, Disability and Home Care, NSW (now ADHC)
DAISY	Digital Accessible Information System
DHH	deaf and hard of hearing
DHHS	Department of Health and Human Services (Tasmania)
DPRWG	Disability Policy & Research Working Group (Australia)
DVD	digital video disc
FCTD	Family Center on Technology and Disability (US)
GAS	Goal Attainment Scale
GPS	global positioning system
HACC	Home and Community Care
ICF	International Classification of Functioning
ICT	information and communication technology
ILC	Independent Living Centre
IP	Intellectual property
IPPA	Individually Prioritised Problem Assessment
MPT	Matching Person and Technology
MTAA	Medical Technology Association of Australia
NAERA	National Aids and Equipment Reform Alliance
NDIS	National Disability Insurance Scheme
NIIS	National Injury Insurance Scheme

NRS	National Relay Service
OHS	Office of Hearing Services (Australia)
PADP	Program of Appliances for Disabled People
PAPD	Program of Aids for People with a Disability
PDA	personal digital assistant
PIADS	Psycho-social Impact of Assistive Devices Scale
QALY	quality-adjusted life-year
QUEST	Quebec User Evaluation of Satisfaction with Assistive Technology
RFID	Radio Frequency Identification
SIAT	Swedish Institute of Assistive Technology
SDAC	Survey of Disability, Ageing and Carers
SHHH	Self Help for Hard of Hearing People
SPRC	Social Policy Research Centre
TDD	telecommunications device for the deaf
TRS	Telecommunications Relay Service (US)
TTS	text-to-speech
TTY	teletypewriter
UNSW	University of New South Wales
VOCA	Voice Output Communication Aid
WHO	World Health Organisation
WSD	Whole System Demonstrator (UK research program)

Executive summary

The Social Policy Research Centre (SPRC), University of New South Wales (UNSW) conducted a literature review about the role of assistive technology (AT) in supporting people with physical, sensory and communication disabilities and complex care needs. In this review, 'complex care needs' refers both to multiple care needs, that is needs that can only be met by the provision of multiple, integrated services; and serious care needs, that is needs that require intensive, high-level support. This document is the findings of the literature review.

It explores whether using AT in addition to personal services has the benefits of: improving the quality of care; deferring functional declines and institutionalisation; improving quality of life and social inclusion by easing difficulties with ADLs and reducing the level of unmet need; and alleviating pressures on the existing long-term care system.

Section 1, *Introduction*, gives some background to the current interest in the use of AT in community care, discusses the relevance to the issue of AT of the UN Convention on the Rights of Persons with Disabilities, gives a brief overview of the policy context in Australia and also in Sweden, and sets out the methodological framework for the review.

There is little data available about the extent of the use of AT or of the unmet need or about what life is like for these people, although large numbers of Australians rely on AT.

1.1.1 Physical disabilities

Section 2 describes six forms of AT relevant for people with physical disabilities: powered wheelchairs; computer-assisted technology; home modifications; 'smart homes'; microswitches; and telecare. This section also discusses ethical issues in the use of much of the new technology, especially considerations of privacy.

Section 3 describes the accessibility and acceptance of AT for people with physical disabilities, and the role that AT can play in improving their independence and self-determination. Despite the limited research, there are indications that AT increases people's autonomy by reducing task difficulty and the need for help from another person, especially in relation to mobility-related impairments, although it depends on how severe the disability is. Research shows that, even though using AT can be more painful, tiring and slower than personal assistance, people preferred if it gave them more control and privacy.

Section 3 also discusses the potential for AT to be a substitute for or a supplement to personal care. It notes that whether AT can reduce the need for support services is not entirely clear from the literature. Some studies find the use of personal care, whether formal or informal, is reduced with the use of AT, others do not. It also describes some examples of service arrangements in Australia and Sweden.

Section 3.8, *Decreasing the cost of support services*, points out that, decisions about cost depend on what is taken to count as 'cost', although there is a consensus in the literature that AT does have the potential for cost savings, however determined. Purchase cost is not the only consideration, and the costs (and benefits) are not always financial. Even simple inexpensive devices can promote independence, lessen the demands on carers, and possibly delay the introduction of formal care services, while quite expensive devices can supplement formal services and could substitute for institutionalisation. A number of ways of estimating costs are discussed, and this section also includes examples of service arrangements designed to reduce costs. It recommends that commissioning further research about the experience of people with physical disabilities using AT in NSW, including modelling the costs and benefits would assist policy decisions.

Section 3.11, *Areas for further research*, lists the following:

- Further investigation of the extent to which AT has substituted for aspects of personal care in the experience of people with disabilities in NSW
- Modelling the costs and benefits of their experiences
- Examining what the users themselves think of AT from their experience in NSW
- Carers' views about and experiences of AT
- Other stakeholders' views and experiences, for example allied health professionals, prescribers, and AT equipment providers.

1.1.2 Sensory and communication disabilities

The disabilities discussed in this section are deafness and hearing impairment, blindness and visual impairments, combined deafness and blindness, and communication disabilities.

As in the case of physical disabilities, the review did not find literature relating to the central question of interest: the extent to which AT could substitute for or supplement personal assistance in the case of people with sensory disabilities.

Section 4 discusses policy issues in relation to funding. It also lists a number of non-government organisations which provide aids and equipment for people on low incomes who are blind and/or deaf but who are not eligible for government provision

Section 5 discusses AT in relation to deafness, specifically hearing aids, cochlear implants and telecommunications. Key findings are: that around 24 per cent of Australians who would benefit from a hearing aid have one, a level which is comparable with other countries.

Section 6 discusses AT in relation to blindness, specifically the many types of devices available and the usefulness of the new communications technology.

Section 7 discusses deaf-blindness, noting that research in this area is even scarcer than for the other disabilities, and describing some devices developed to improve the independence of deaf-blind people, particularly relating to communication, together with a

case study involving an independent living project for deaf-blind young people with intellectual disabilities.

Section 8 discusses communication disabilities and some of the issues around augmentative and alternative communication (AAC) devices. It also discusses abandonment, and factors that might lead to the successful long-term usage of AAC.

1.1.3 Conclusion

The overall conclusion is that, whatever the difficulties, research on the whole tends towards a positive assessment of the benefits and potential of AT for all concerned. AT is unlikely ever to be a complete substitute for personal care, no matter how useful it might be as a supplement to it. But any technology that contributes to people's well-being and supports their independence contributes to their rights and represents a long term saving against other support alternatives.

2 Introduction

The Social Policy Research Centre (SPRC), University of New South Wales (UNSW) conducted a literature review about the role of assistive technology (AT) in supporting people with physical, sensory and communication disabilities and complex care needs. In this review, 'complex care needs' refers both to multiple care needs, that is needs that can only be met by the provision of multiple, integrated services; and serious care needs, that is needs that require intensive, high-level support. This document is the findings of the literature review.

The report is divided into two main sections, 'Physical disabilities' and 'Sensory and communication disabilities'. This was necessary because of the different needs and AT required by the two groups. There are similarities, the main one being the speed at which the technology changes. In both cases the literature quickly becomes out-of-date. As the Alt Beatty report (2011) has pointed out, the most up-to-date sources of information are likely to be the commercial enterprises which make the devices, e.g. Microsoft in the case of IT products. The peak agencies are also good sources of information, as are such specialist advisory services as the Independent Living Centre. Another source of information are the publications, both print and internet, which regularly review the latest technology (e.g. Pogue, 2011).

But it is the differences between the groups which require the two-part separation in what follows. The main difference is that generalising about AT needs for sensory difficulties is even more difficult than generalising about AT needs for physical disabilities. People with different physical disabilities may have similar support needs. Hoists or wheelchairs, for example, can be used by people with spinal cord injury or multiple sclerosis or Parkinson's, etc. However, the potential for AT to assist people with sensory disabilities is more specific. People who are deaf or hearing impaired can have their quality of care improved by kinds of AT which could not assist people with other sensory disabilities. Moreover, a device which suited a person with low vision might be completely useless for someone who is blind (Liu and Wilson-Hinds, 2007). Part 3 Sensory disabilities, is further divided into the four types of sensory disability.

2.1 Use of assistive technology

Interest in the potential of assistive technology to promote independence among people with disabilities arises out of concerns about quality of life, decreases in the availability of informal caregivers and a shrinking long-term care workforce. Using AT in addition to personal services could potentially improve the quality of care, and thus improve social inclusion and defer functional declines and institutionalisation (Agree et al, 2005). It is to be hoped that the use of AT can alleviate pressures on the existing long-term care system, while at the same time improving quality of life, easing difficulties with ADLs, and reducing the level of unmet need. Where the use of AT reduces the amount of personal care needed, public expenditures on home health care could be reduced and the responsibilities of informal care lightened.

In 2003, almost 1.9 million Australians relied on AT to live independently (AIHW, 2005). Analysis by the Australian Institute of Health and Welfare (AIHW) of the ABS 1998 Survey of Disability, Ageing and Carers (SDAC) (Bricknell, 2003) found that people aged 0-64 years were more likely to use aids or equipment if they frequently needed assistance with a core restriction (i.e. more than three times a day). As frequency drops, so does the reliance on aids. This was particularly true in the case of self-care—47 per cent of those who reported using a self-care aid required frequent assistance compared with 19 per cent of those who did not use one. But while the need for assistance with core activities is associated with the uptake of aids, many people who needed assistance with self-care, mobility or communication did not use any form of aid.

The 1981 SDAC asked people why they did not use aids even though they needed assistance. Reasons given included the cost, the difficulty with getting them, not knowing where to get them, and not needing them or not being able to use them yet (the question was not asked in the 1988, 1993 or 1998 SDAC surveys). Personal assistance only was by far the most common form of assistance received—44 per cent of those who needed help with self-care, 48 per cent with mobility, and 47 per cent with communication relied solely on a primary carer. In contrast, only 12 per cent of people needing assistance with self-care or mobility used aids alone, and only 5 per cent of those with a need for communication assistance. The proportions of people who used both aids and personal assistance were also low—11 per cent for self-care, 14 per cent for mobility and 5 per cent for communication. There were large proportions of people who did not receive assistance of either kind—43 per cent of people who needed assistance with communication, 33 per cent with self-care, and 27 with mobility.

Table 1 People aged 0–64 years with a severe or profound core activity restriction, by need for assistance with self-care, mobility or communication, by use of aids and primary care, 1998

Type of need	Type of assistance (per cent)			
	Aids only	Primary carer only	Aids and primary carer	Neither
Self-care	12.3	43.9	10.9	33.0
Mobility	11.7	47.9	13.5	27.0
Communication	5.2	47.0	5.4	42.5

People with primary carers had a higher use of aids than people without carers, across all severity groups and ages, although the association was least strong among people with a profound core activity restriction. Of people who had a primary carer, 60 per cent used aids, compared with 46 per cent of those who did not have a carer. The reason might be that having a primary carer means that the person has greater need for assistance and thus is more likely to rely on aids as well (Bricknell, 2003).

The *World Report on Disability* (WHO, 2011: 101) produced by the World Health Organisation and the World Bank, defined assistive technology (citing the US *Assistive Technology Act 2004*) as 'any item, piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the

functional capabilities of individuals with disabilities' (WHO, 2011). Assistive technology was defined in the 1988 US *Technology-Related Assistance of Individuals with Disabilities Act* as 'any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities' (Brodwin et al, 2003). The UK Foundation for Assistive Technology provides a more succinct definition, namely, 'any product or service designed to enable independence for disabled and older people'.¹ This would cover not only devices and services, but also environmental adaptations such as home modifications, and would range from simple objects like walking sticks and grab rails to complex devices like power wheelchairs (Hobbs et al, 2009).

It is widely accepted that assistive technologies are of vital importance for people with disabilities. The WHO report (2011), for example, said that they had been shown to be powerful tools to increase independence and improve participation, as long as they were appropriate for the users and for their environments. The report also noted that assistive devices had been known to be effective in reducing disability, and that they could at times substitute for support services, or at least complement them, and thus reduce the costs of care. (See also: MTAA, 2011)

A content analysis of the letters to the editor in two disability-related magazines in the US (Marini et al, 2009) found that adaptive aid equipment was clearly a major concern for the people with disabilities who wrote in to these magazines. It was the second most frequently cited issue (the issue most often cited was accessibility). A disability rights activist (Lance, 1999) put the case even more strongly. She said that she would have had great difficulty asserting her rights without technology, and that she knew many other people who were in the same position. 'Disability rights and modern technology', she said, 'almost seem destined to have converged into the field of assistive technology'.

Despite the recognition of its importance, research on AT is limited, at least in Australia. A scoping study for the Australian Government Department of Health and Ageing (Connell et al, 2008) on the use of AT by frail older people found that research in almost all the areas explored in the study was lacking in Australia (although home maintenance and modifications had been the subject of research by the Australian Housing and Urban Research Institute). While this scoping study was confined to older people, a study of assistive technology use by people with disabilities in Victoria (Layton et al, 2010) came to the same conclusion. Despite the fact that large numbers of Australians relied on AT, the researchers found that there was little data available about the extent of its use or the unmet need, or about what life was like for these people. What research there was suggested that provision was provided by a 'mosaic' of services across the government and non-government sectors, with no national data available (AIHW cited in Layton et al., 2010).

However, there is a body of published work that shows the effectiveness of AT in a range of areas:

¹. <http://www.fastuk.org/home.php>

- preservation of independence, decreased functional decline and reduced hospital admission rates;
- prevention of secondary medical complications;
- prevention of falls;
- maintenance of occupational roles via enabling environments;
- alleviation of carer-burden;
- reduction in residential care placements;
- enabling of activity and participation in specific life domains;
- overall health and community life outcomes; and
- improved quality of life.

As well, there is a strong social justice argument underpinning its provision (Layton et al, 2010).

2.2 Human rights

The United Nation Convention on the Rights of Persons with Disabilities 2008 (CRPD) addresses the issue of the provision and use of assistive technology, and requires states signatories to take measures to ensure that people with disabilities have access to it (Borg et al, 2011). The policy goals of the UN Convention are echoed in Australian policy documents at both the national (COAG, 2011) and the state levels. Compliance with the CRPD, for example, is listed first among the NSW Government's commitments in *Stronger Together 2011-16* (ADHC, 2010). A connection between the human rights of people with disabilities and the provision of assistive technology is made explicit in the Tasmanian government's review (Tasmanian DHHS, 2010). Given a rights-based framework for supporting people with disabilities, the review said, there are increasing expectations that the equipment necessary to facilitate participation and social inclusion will be available. As the PADP Community Alliance (2010) argued: 'assistive equipment for people with disability is a societal necessity, like shelter or sustenance, providing the basic elements of life to simply survive, to maximise independence, to participate and then to prevail'.

However, while the CRPD contains opportunities for the formulation of assistive technology policies and strategies, it also has limitations. Explicit mentions of assistive technology are scattered throughout, and that makes it difficult to use the measures for advocacy and policy just as they stand. Moreover, although the actions required by the CRPD are reasonably comprehensive, none of the articles covers all the basic AT areas, i.e. production, availability, affordability, information, training and use. Assessment and follow-up are another two areas which are not addressed at all, although it could certainly be argued that such activities are included in Article 26, in what is called 'comprehensive habilitation and rehabilitation services and programmes' (Borg et al, 2011).

Moreover, even though the CRPD explicitly identifies the responsibility of government to act to facilitate equal participation through legislation, programs and actual supports, this is rarely fully achieved because of resource constraints and other barriers. A Victorian study (Layton et al, 2010) found substantial limitations in AT provision among the study participants. There were even policy failures in relation to the Victorian State Disability Plan

and its Quality Framework. Recent research suggested that waiting times for accessing equipment through the state program were high, as was the cost to applicants, and there appeared to be a substantial level of unmet need. The authors commented that providing AT for people with disabilities was critically important, both for making a difference in people's lives, and for Australian governments to uphold the rights of persons with disabilities. (See also: Pate and Horn, 2009).

2.3 Policy context

2.3.1 Policy

Although AT is not included in the National Disability Agreement (NDA, was CSTDA), ACROD (2006), the National Industry Association for Disability Services (since re-named National Disability Services), argued that the need for a national AT strategy was pressing, and recommended the NDA as the appropriate framework for coordinating such a strategy.

Aids and equipment programs administered by the federal government are confined either to specific population groups or to particular types of disability. Examples include:

- Rehabilitation Appliance Program in the Department of Veterans' Affairs: veterans of Australia's defence force, war widows and widowers and their dependants, and veterans from allied countries (eligible for aids and appliances only in relation to accepted disabilities)
- Office of Hearing Services: people who are deaf or have hearing impairments;
- Contenance Aids and Assistance Program;
- Employment Assistance Fund, which contributes to the cost of workplace modifications (Tasmanian DHHS, 2010).

In 2007, the federal government announced a measure relating to AT in community care to improve the independence of frail older people and enable them to remain in their homes for as long as possible. The measure has two components: an industry body to promote the use of AT by community care providers; and a grants program to fund commercial innovation in assistive technology from 2008-09 (Connell et al, 2008).

To date there has been no similar federal initiative for people with disability across the lifespan. However, a National Disability Insurance Scheme will be implemented from 2012. The Productivity Commission report, *Disability Care and Support* (2011), recommended the creation of two national insurance schemes, a National Disability Insurance Scheme (NDIS) and a National Injury Insurance Scheme (NIIS)..

The Productivity Commission (2011) referred to AT in a number of contexts in relation to the proposed NDIS: as an area for research; as an aspect of early intervention to prevent hospitalisation and ease carer burden; and as a contribution to productivity improvement. The latter was likely to play an ever bigger role as time went on, the authors said, as aids and appliances decreased in price, as more people came to see the benefits of AT, as more people were supported by the same number of staff, and as lifetime costs (and

savings) were factored in to financial estimates. The Commission also recommended that equipment be funded by the NDIS unless it was to be used in relation to work or education.

The Medical Technology Association of Australia (MTAA, 2011), which represents the manufacturers, exporters, importers and distributors of medical technology products in Australia, commented on the Commission's report and recommended a number of areas where the NDIS should provide funding: for a national scheme for aids and appliances (including prosthetics such as artificial limbs); for an Essential Care List scheme to subsidise the purchase of consumable medical items; and for telehealth, i.e. technology for home and remote monitoring of people with disabilities and associated medical conditions. An Essential Care List, the authors said, would ensure that sub-acute-care medical products were readily available using a system that was equitable, transparent and affordable. As an example of such a scheme, they cited the proposal by the National Aids and Equipment Reform Alliance in their submission to the Productivity Commission (sub. 530), for a national scheme for aids and appliances complementary to schemes such as Medicare and the Pharmaceutical Benefits Scheme. This would replace the current scattered patchwork of over 100 separate equipment schemes across Australia, a system that has meant inconsistent funding and service delivery, duplication of services and administrative inefficiencies, and cost-shifting to expensive downstream services such as hospitals (NAERA, 2011).

In their submission to the Productivity Commission, the National Aids and Equipment Reform Alliance argued for the need for a major overhaul of the current national system of service delivery for aids and equipment, pointing out that the large number of separate equipment schemes operating in Australia with different patterns of funding and service delivery.

The NSW government's 10-year plan to transform the disability services sector in NSW, *Stronger Together*, has entered its second five-year stage (ADHC, 2010). This second phase will expand person-centred approaches across the sector, in order to ensure that people with a disability are at the forefront of the decision-making and choices that affect their lives. A greater focus on the provision of AT is one aspect of that expansion, a focus which will have an impact on four of the government's five reform directions:

- helping people to remain in their own homes;
- linking services to need;
- expanding options for people living in specialist support services; and
- creating a sustainable support system (ADHC, 2010).

The increased focus on AT is also an important aspect of the areas of effort belonging to the second phase, namely:

- the continuing emphasis on person-centred approaches;
- the emphasis on a lifespan approach, intended to certainty by building long-term pathways through the service system;
- the closure of the large residential centres and the move to care in the community; and

- a service system with the right capacity for meeting people's needs efficiently, at the right quality and the right time (ADHC, 2010).

In Sweden, both AT and home modifications are publicly funded (Lilja et al, 2003). The policy dates from the 1950s, when the Swedish policy of integration and 'normalisation' for people with disabilities was introduced. This policy was based on the belief that people with disabilities should not have to bear the costs of reducing environmental barriers to engaging in ADLs. AT is considered to be an integral part of healthcare, and it is prescribed, distributed, and financed through the national health system. Provision is based solely on need, and neither the person's economic status nor their place of residence is taken into consideration. AT is prescribed by occupational therapists, physical therapists and nurses in the course of their daily work, and most devices are provided in primary healthcare settings as part of rehabilitation services. Decisions are made jointly by the person and the therapist together. Housing modifications are paid for by the local authorities, who are required by law to provide grants for people with disabilities who need modifications of their dwellings and who live within the authority's catchment area. All costs are covered for adaptations deemed necessary for someone to be able to perform ADLs. (Initiatives in Sweden are discussed throughout this report).

2.3.2 Programs

ADHC funds the Aids for Individuals in the DADHC Accommodation Service program (AIDAS), which contributes funds for personal aids and appliances for clients living in accommodation services. People with disabilities living in ADHC accommodation services are also eligible for aids provided by agencies other than ADHC, e.g. the Commonwealth Continence Aids and Appliance Scheme (CAAS) and Hearing Australia. However, they are not eligible for the Program of Aids for People with a Disability (PADP), currently administered by EnableNSW within Health Support Services, NSW Health. EnableNSW provides AT devices (and specialised support services) to people living in the community, whereas AIDAS provides them for people in residential care. ADHC also funds non-government organisations for the provision of AT (mainly aids and equipment services), and clients and their families can purchase aids and appliances or use donations or special purpose funds to subsidise or pay for aids and appliances. ADHC also funds therapy services which have a role in the prescription and trialling of AT and the provision of training related to the use of AT (DADHC, 2005; NSW Health, 2011).

A review of the PADP scheme (PriceWaterhouseCoopers, 2006) found an unacceptable level of inconsistency, unpredictability and unreliability in the way the scheme operated. EnableNSW was established in response to the review, to integrate and manage PADP's administrative functions state-wide (along with four other disability support programs).

Programs in other states and territories which are equivalent to PADP are: the ACT Equipment Scheme (ACTES); the Northern Territory Independence and Mobility Equipment (TIME) Scheme; the Queensland Medical Aids Subsidy Scheme (MASS); the South Australian Independent Living Equipment Program (ILEP); the Tasmanian Community Equipment Scheme (CES); the Victorian Aids and Equipment Program (AEP);

and the Western Australian Community Aids and Equipment program (CAEP) (MTAA, 2011).

The Tasmanian Department of Health and Human Services (DHHS) undertook a review of the current provision of equipment and AT in the state (Tasmanian DHHS, 2010), with the aim of determining what was necessary to provide equipment effectively and efficiently to people with disabilities, the frail aged, and people who needed equipment on discharge from hospital. The review noted the presence of a large number of programs, each with its own purpose, target group, eligibility criteria, fees, and management and governance structures. As well as the CES (which was managed separately within each of the three DHHS regions), there were the Seating Clinics, the Spinal Account, the Equipment and Technology Library, the Independent Living Centre, Continence Aids Tasmania, and Palliative Care. The review also noted a number of problems with the current system, including the disparate nature of the programs, a significant level of unmet need, inconsistencies across regions, failure to coordinate purchasing and to take advantage of economies of scale, a lack of tracking systems for either clients or equipment, and a lack of governance and management structures. As a result of these findings, the review proposed a new approach to the provision of equipment in Tasmania, which would address all the problem areas and consequently improve equity of access.

Key points

- Assistive technology (AT) is defined as ‘any item, piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities’ (WHO, 2011).
- AT is important because it has the potential to improve quality of life, and reduce people’s needs for formal and informal caregivers (WHO, 2011; MTAA, 2011).
- In 2003, almost 1.9 million Australians relied on AT to live independently (AIHW, 2005)
- National data on AT use is limited, although it is known that people with primary carers have a higher use of AT than people without carers (AIHW, 2005; Bricknell, 2003).
- The principles of the UN Convention on the Rights of Persons with Disabilities are echoed in Australian policy documents (COAG, 2011; ADHC, 2010; Tasmanian DHHS, 2010).
- The Productivity Commission has recommended that the proposed National Disability Insurance Scheme fund AT (Productivity Commission, 2011).
- In NSW, Enable NSW provides AT devices (and specialised support services) to people living in the community, and there are similar schemes in the other States and Territories (DADHC, 2005; NSW Health, 2011).

2.4 Methodology

The aim of the review is to investigate AT in the following seven areas:

1. Improving independence and self-determination for the person with a disability.
2. Exploring service solutions that will reduce the need for support services.
3. The role of AT in decreasing the risk of injury for service users.
4. The role of AT in decreasing the cost of support services;
5. Identifying the need for AT across the lifespan in order to give families more certainty and the capacity to engage in life-long planning, together with its cost so as to guide new service investments.
6. Identifying the assistive technology needs of people with a severe physical disability who are palliative.
7. Improving service delivery, client outcomes and cost effectiveness.

The initial search strategy used the terms ‘assistive technology’, ‘aids and equipment’ and ‘disability’ in a number of sources, including Google Scholar, the Cochrane and Campbell

libraries, APAFT, ProQuest Social Science journals, ASSIA, Sociological Abstracts, and PAIS International. Articles were selected for inclusion if their abstracts indicated that they described research findings or other material relevant to these seven areas. We focused especially on articles and other sources that describe the capacity of AT to reduce the amount of care needed, and improve the quality of care. We also focused on AT for activities of daily living (ADLs) for people with disabilities and related complex support needs within the context of community care. Articles that described the use of AT in other contexts, such as for rehabilitation or for the training of rehabilitation professionals, or in educational or in employment settings, were not included.

We included articles that described the use of AT for frail aged people if they described assistance in areas that are relevant for younger people with disabilities. Some of the literature relating to older people is included, both because older people and people with disabilities more generally are sometimes discussed in the same article, and because many of the issues are the same. We excluded literature on the role of AT in managing dementia although it is possible for people younger than 65 to develop dementia (Tyson, 2007). There is an extensive literature on assistive technology for use in dementia care and with older adults more generally.²

The review does not include the literature relating to people with chronic diseases (diabetes, heart disease), or on the role of technology in improving developmental outcomes for infants and very young children with disability. It focuses on literature relating to both physical and sensory disabilities (i.e. deafness, blindness, deaf-blindness, and communication disorders), and AT used for the management of difficulties with ADLs. While much of the literature monitoring health symptoms 'at a distance' is not relevant to people with physical disabilities, some of it is and so it has been included in this present review (see the 'Smart homes' section below).

Both refereed and non-refereed (policy or 'grey' literature and information from manufacturers) is included in this review, as the scope of the review is broader than a systematic review. Non-refereed material is included to describe policy contexts and programs, the technical capabilities of AT, and findings from relevant studies that have not been published. We also included non-refereed material as the evidence from academic literature such as systematic reviews is fairly scant, and is likely to exclude promising material due to strict inclusion criteria. For example, a Cochrane systematic review, on smart homes, found no studies that met its criteria (Kelly et al., 2009) and a recent overview of systematic reviews of AT found high-quality evidence for only a small number of single AT (positive effects of providing AT in connection with home assessment and hearing aids, no effects of hip protectors) for limited populations (older people at home, people with hearing loss, and older people in institutional care, respectively) (Anttila et al., 2012).

². Hartke et al, 1998; Roelands et al, 2002; Tomita et al, 2004; Cornman et al, 2005; Freedman et al, 2005; Iwarsson, 2005; Mental Welfare Commission for Scotland, 2005; Wallace, 2005; Astell, 2006; Mulvenna et al, 2007; Alexander et al, 2008; Alzheimer's Society UK, 2008; de Bruin et al, 2008; Tunstall, 2008; Bharucha et al, 2009; Liu and Lapane, 2009; Wahl et al, 2009; Fleming and Sum, 2010; Pressler and Ferraro, 2010; Tak et al, 2010.

3 Physical Disabilities: AT Types

3.1 Introduction

Many of the types of AT listed in the Urbis Scoping Study for the Australian Government Department of Health and Ageing (Connell et al, 2008) are also relevant for younger people, even though the focus of the study was AT use by frail older people. The authors grouped the types of technology into four categories, all of which would be relevant for younger people with disabilities (although the particular details may not, e.g. ‘wander’ monitors).

Table 3.1 Types of assistive technology

Category of AT	Type of AT	Examples
Aids, appliances and equipment	‘Daily living’ aids	Reachers, bath seats, non-slip mats, handles, jar openers
	Mobility aids	Wheelchairs, vehicle conversions
	Communication and sensory aids	Hearing aids, speech output devices, large print screens, telephone amplifiers
	Cognitive and connectivity aids	Computer and internet access, specially designed user-interfaces, matching reasoning aids, ‘talking’ word processors
Environmental adaptations	Environmental switches and controls Home modifications	Remote control of doors, windows, locks Principles of inclusive design, modifying risky areas including bathroom, kitchen, installation of reinforced grab rails
Remote monitoring devices	Telecare Telehealth	First level telecare – alarm pendant connected to 24-hour monitoring centre Second level telecare – including bed sensors, medication reminder systems, fall monitors, gas monitors, flood monitors, ‘wander’ and motion monitors Third level telecare – ‘remote consultation’/virtual visiting, monitoring of vital signs, blood pressure check, temperature, respiration, pulse, weight
Integrated systems	Smart homes, age-[and disability]-friendly homes	Integrates telecare, electronic assistive technologies and environmental controls. Involves technology that learns behaviour and reacts to needs

Source: Connell et al, 2008: 23-4, Table 2.

Examples of assistive technology covered in the pilot study, Free Choice of Assistive Technology, carried out by the Swedish Institute of Assistive Technology for the Swedish government (Estreen, 2010a) included AT:

- for mobility—wheeled walking frames (rollators), manual and powered wheelchairs, beds, walking sticks, sanitary aids;
- for hearing—technical assistive hearing devices and hearing aids; for vision—Daisy players and braille clocks; and
- for medical treatment—mattresses and TENS (transcutaneous electrical nerve stimulation), devices for pain relief and muscle stimulation; and for cognition and communications—portable hand-held and palm computers, and alarms.

Estreen (2010a) also mentioned a Segway (an Anglicised version of the Italian word, 'segue'). This is a powered two-wheeled self-balancing form of personal transport which is usually ridden standing up, although the version described here had a seat. The advantage of this kind of Segway over a wheelchair is that the user can be seated at the same height as people who are standing. However, its use in public in NSW is illegal,³ and it appears that the seated version is not available in Australia.

The US Family Center on Technology and Disability (FCTD, 2010) listed several examples of AT that would allow greater independence for people with physical disabilities:

- Mobility and travel—mobility aids, such as wheelchairs, scooters and walkers, as well as adapted car seats and vehicle wheelchair restraints.
- Building modifications such as ramps, automatic door openers, grab bars and wider doorways.
- Computer software and hardware, such as voice recognition and screen enlargement, to enable people with mobility and sensory impairments to carry out educational or work-related tasks.
- Education and work aids such as automatic page turners, book holders, and adapted pencil grips;
- Adaptive switches which make it possible for a child with limited motor skills to play with toys and games.
- Devices to assist with ADLs, such as cooking, dressing and grooming, e.g. a one-handed cutting board, a wall-mounted can opener.

There is a growing literature on the role on information and communication technology (ICT), including social media, in improving the independence and social connectedness of people with disabilities. Online banking services, business websites and email have been available for around 15 years and are established as a routine part of the lives of many people. These services make an enormous difference to the independence of many people with disabilities. Smartphones and tablets are increasingly accessible for people with visual disabilities. Social media is problematic for people with disabilities for the same reasons that traditional media is, but also offers 'extraordinary opportunities for new ways to communicate, gain information, tell stories, offer cultural expressions and representation, conduct business, do politics, and, above all connect and participate' (Ellis and Googin, 2012: 12)

³. <http://www.zbox.com.au/legal.htm>

The literature on robots is also promising. Davenport (2005), for example, gives a number of examples of robots which have already been developed (many of them in Japan), e.g. a Personal Adaptive Mobility Aid (PAM-AID) which helps frail and visually impaired people to navigate their environment; a number of exoskeletons which help people with lower-extremity disabilities to walk greater distances, maintain a standing position or carry weights (Hybrid Assistive Leg (HAL-3); the Berkeley Lower-Extremity Exoskeleton (BLEEX); Wearable Walking Helper); a Power Suit which helps healthcare workers transfer patients; a series of powered wheelchairs with the capacity to raise someone to standing height, walk upstairs (potentially), and with extendable arms to pick things up; and a series of monitoring devices. The author believed that technological advances would reduce costs sooner or later and move the robots out of the laboratory and into society. At the moment, however, few were commercially available, and they tended to be too big, too clumsy and/or too expensive for general consumption.

The following types of AT are those which were discussed most extensively in the literature reviewed. There are many other types, some of which are listed above, but the types described below received the most attention in the literature.

3.2 Powered wheelchairs

Mobility aids, both manual and powered wheelchairs among them, constitute the AT most likely to be used by people with physical disabilities. They are the second most commonly used aid by people with all types of disability aged between 15 and 65 years in Australia (medical aids are the most common) (Bricknell, 2003).

Most of the assistive technology literature focuses on powered wheelchairs rather than manual ones. Research has found that developments in powered wheelchair technology have opened up a world of opportunities for people with disabilities. US research (Buning et al, 2001) found that the transition from a manual to a powered wheelchair tended to enhance the occupational performance, competence, adaptability and self-esteem for people with severe mobility impairments.

However, the study also found that it was not always clear whether the advantage of independent powered mobility offset the need for the sometimes quite radical changes people had to make. Some people were initially resistant to making the transition from a manual wheelchair to a powered one, feeling that they would lose function or be seen as less capable if they did. The transition could also feel like abandoning a familiar form of mobility that had long been part of a daily routine and even an aspect of one's self-image. Moreover, powered wheelchairs need complex adjustments, both on the part of the users and in the environment. Batteries need to be charged, the motors and controllers must be maintained and adjusted, and powered wheelchairs are larger and heavier than manual ones. The environment must have adequate turning space and transportation systems must include power lifts and tie-downs.

Other research (Arthanat et al, 2009) found that one of the key concerns with using powered wheelchairs indoors was the damage to property caused by problems of

drivability in restricted spaces. Most of the participants in this research lived in rental properties, and the damage posed a liability issue for them. But those people who moved from manual to powered wheelchairs reported marked improvements in many areas of their lives. The participants in this study were enthusiastic about their powered wheelchairs, as an adaptation that enabled them to perform tasks that they valued.

Given difficulties such as these, researchers have called for improvements in the tests for wheelchair usability. An Australian researcher (Hardy, 2004) argued that effective assessments for powered wheelchairs should examine all the elements, including the natural environments in which the wheelchair will be used (not just in a clinical setting). As well, she questioned the need for people to have performance skills before they can be considered for powered mobility. She suggested instead that assessments consider the possibility that people who might seem unable to use a powered wheelchair could eventually succeed if they were given ongoing support and the environment was appropriately adapted. Rather than simply indicating which skills are lacking, wheelchair performance tests should also offer direction for intervention. She said that there were no complete assessments and little published information for occupational therapists to use when evaluating a person's skills and limitations when moving in a powered wheelchair. However, she recommended the Occupational Performance Model (Australia) as a useful resource for evaluating usability issues. This provides a framework that takes into account the many factors that can influence the usability of a powered wheelchair, namely, the person's performance skills (biomechanical, sensory-motor, cognitive, intrapersonal and interpersonal), and their environment (physical, cultural and social).

Canadian researchers (Routhier et al, 2003) also found that assessment instruments failed to take into account all the factors involved in the usability of powered wheelchairs. They examined ten instruments used to assess the performance of wheelchair users, in order to find out which factors were considered in each tool. The factors which the authors identified as essential for wheelchair usability were: the user's profile; the wheelchair itself; the environments within which the wheelchair would be used; the user's daily activities and social roles; and the assessment and training received. They found that none of the measures used in the clinical assessment of wheelchair-user performance assessed all the factors influencing mobility.

3.3 AT for cognition

Although this review does not discuss modifications to computers which allow people with disabilities to use them, it does discuss the use of computers or computer-assisted devices for help with memory-related ADLs for people with acquired brain injury (ABI). Highly portable computers can potentially extend the range of tools for people with impairments of memory resulting from ABI, and there are a number of studies that have assessed these devices (Hart et al, 2003). For example, most of the 12 outpatients with ABI who were provided with palmtop computers in a US study (Kim et al, 2000) found them useful for helping with memory-dependent activities in their everyday lives, and all of them said they would recommend that computers be used with outpatients. The researchers noted that several factors needed to be taken into account. Computer design is important.

Commercially available computers are not designed for people with cognitive impairment, although there is ongoing research in several areas of computer science which focus on prosthetic software (Cole et al, 1994). Moreover, the characteristics of the patient need to (Gillespie et al., 20120). be considered. Some researchers (Giles and Shore, 1988) have suggested that people who are going to be using electronic memory aids need to have need to have a certain level of ability, e.g. to have retained their reasoning skills, and to have at least average intelligence, insight into their deficits, and adequate ability to initiate behaviour. Others (Gliskey et al, 1986) have found that even people with quite severe memory disorders can acquire the knowledge necessary for operating a computer.

A recent systematic review of the evidence on AT that support specific cognitive functions (Gillespie et al., 20120) found that AT has been used to effectively support cognitive functions relating to attention, calculation, emotion, experience of self, higher level cognitive functions (planning and time management) and memory. Examples include alarms which shift attention to tasks or pre-agreed goals, biofeedback devices that allow people with anxiety-related conditions to reduce autonomic arousal, and navigation aids which use GPS to locate the user.

One device has been subject to a randomised control trial. Called the NeuroPage, it is a portable pager specifically designed for people with ABI. It has a screen and an audible cue that sends messages to remind users of tasks or appointments, and it can be attached to a belt (Wilson et al, 1997. See also: Hersh and Treadgold, 1994). It uses an arrangement of microcomputers linked to a conventional computer and by telephone to a paging company. Once the scheduling for each person is entered into the computer, no other input is necessary. NeuroPage accesses the files and transmits the information on the appropriate date and time. The device has one large button which is easy to press even for those with motor difficulties. It was developed in California by a neuropsychologist and an engineer whose son had ABI and who had found that conventional memory aids were inadequate.

A UK study of 15 subjects with organic memory problems (Wilson et al, 1997) found that all 15 subjects benefited from using NeuroPage. The researchers commented that it had the potential to enhance independence and employability, to speed discharge from acute and rehabilitation services, and to reduce stress. One woman was able to return to college, while another found NeuroPage helpful in her workplace. The wife of another user was able to return to work because her husband was now capable of carrying out necessary tasks, including getting their children off to school. In a later randomised controlled trial study (Wilson et al, 2005), the researchers found that this paging system significantly reduced the everyday memory and planning problems of people with ABI.

A team in the Netherlands (de Joode et al, 2010) reviewed the published research into the efficacy and usability of a number of portable electronic aids such as Neuropage, as well as personal digital assistants (PDAs) and mobile phones, for adults with cognitive impairments due to ABI. The review found that the efficacy of AT had not yet been sufficiently researched—NeuroPage was the only device subject to a randomised controlled trial. However, several survey studies reported that results looked promising and that both potential users and clinicians were optimistic about the usability of AT. Three

other studies (as well as the 2005 Wilson et al study) also found that the NeuroPage was effective in supporting prospective memory in people with ABI. The Dutch researchers drew three clinical messages from the review: that AT such as pagers, PDAs and digital voice recorders can be used as cognitive aids, especially to support prospective memory; that both users and clinicians were optimistic about using AT as cognitive aids; and that it was possible to use multipurpose devices, such as PDAs or smartphones, for cognitive domains other than prospective memory, such as executive functioning or attention.

3.4 Home modifications

Home modifications are included in this review as an aspect of AT for physical disabilities. As Hoenig (2008) has pointed out, environmental adaptations need to be discussed in the context of AT because they are often used together. While assistive technologies compensate for disability by improving someone's ability to do things, environmental modifications reduce the environmental demands made on people. Consequently, this review includes discussions of environmental modifications as well as AT.

The WHO report on disability (WHO, 2011) cited a 2001 research study⁴ in the UK which examined the effectiveness of home modifications in England and Wales. By 'effectiveness' the researchers meant the degree to which the problems experienced by the person before adaptation were overcome without causing any new problems. The study found that:

- Minor adaptations (rails, ramps, over-bath showers, door entry systems), most of which cost less than £500, produced lasting benefits for the majority of recipients: 62 per cent said they felt safer, and 77 per cent said it had had a positive effect on their health.
- Major adaptations (bathroom conversions, extensions, lifts) in most cases had transformed people's lives.
- Where major adaptations failed and resulted in major waste, it was either because of weaknesses in the original specification (e.g. failure to provide for a child's growth) or because the job was done 'on the cheap' (e.g. extensions that were too small or too cold, substitutes for proper bathing facilities that were ineffective).
- Evidence from the recipients suggested that successful adaptations had kept people out of hospital, reduced the strain on carers and promoted social inclusion.
- The adaptations were most successful when users were carefully consulted, the needs of the whole family were considered and the integrity of the home respected.

The WHO authors said that, in the light of these findings, home modifications appeared to be a highly effective use of public resources, and investing resources in them was justified by the positive consequences for health and rehabilitation.

⁴. Heywood, F. *Money Well Spent: The Effectiveness and Value of Housing Adaptations* Bristol: The Policy Press, 2001.

A three-year study in the UK (Lansley et al, 2004) involved introducing AT into the homes of older people in public housing, and investigating the feasibility, acceptability, costs and outcomes of home modifications. Mobility needs constituted the main factor dictating the extent of the modifications needed, principally the use of mobility aids when getting into a property, moving around, moving to upper floors, and using bathrooms and shower rooms. Younger people with disabilities also have these mobility needs, so the findings of the study are relevant here. The researchers came to a number of conclusions for policy-makers. They suggested that there were many situations where home modifications and AT could be an attractive substitute for home-care although it would not eliminate the need for it altogether, and even sometimes for residential care. They also noted, however, that if adaptations and AT were to be more widely adopted, health and housing professionals would need to become more knowledgeable. As well, they pointed out that adaptations and AT should be viewed as integral to community care packages and not just as useful supplements. (This study is discussed further below, in the section 'Examples of arrangements designed to reduce costs')

3.5 Smart homes

'Smart homes' and electronic aids to daily living involve a further degree of technological sophistication than conventional home modifications. They are dwellings equipped with technology which monitors people's health and daily activities in the interests of their safety and independence. While most of the 'smart home' research focuses on older people and people with chronic ill-health conditions, many of the findings are generalisable to people with disability (MTAA, 2011). Electronic aids to daily living can facilitate the operation of electrical appliances for someone with a severe physical disability, and potentially provide great benefits, both psychological and functional, for the person with disability and their family and carers (Little, 2010). They also contribute to the experience of greater subjective quality of life (Rigby et al, 2011).

Mann and Milton (2005) summarise smart home functions by organising them into eight 'levels' of increasing complexity and decreasing length of time the function has been available (some are not yet available at all):

- Level 1: basic communications, e.g. phone, email
- Level 2: simple control commands, e.g. unlock/lock door
- Level 3: automatic household functions, e.g. air temperature, lights on/off at certain times
- Level 4: tracks location in the home, behaviours, health indicators
- Level 5: analyses data, makes decisions, takes actions, e.g. issues alerts, provides reports
- Level 6: provides information, reminders and prompts for ADLs
- Level 7: answers questions, e.g. 'Have I ... [done specific task]'
- Level 8: makes household arrangements, e.g. for maintenance and repairs, ordering food, preparing meals, house cleaning.

Tak et al (2010) classify the 'smart home' technology products into three types: those that can be worn ('on'); those that are embedded ('in'); and those that are placed in the person's environment ('around'). The authors were talking about older people, in this case those who were in long-term residential care, but many of the same issues arise for younger people in community care. At best, the authors said, the technology should be unobtrusive, preventive, personalised and remote, and the devices should be interconnected and work across the healthcare network. They should support ADLs and enhance people's quality of life by addressing safety, self-care activities (e.g. bathing, taking medication, eating, mobility, sleeping), communication (e.g. social interaction and connection), and entertainment (e.g. recreation, leisure). The technology should also support service providers and family members (e.g. through electronic medical records and recording devices, or through distance connectivity to enhance family caregiving). The authors believed that technology offered the possibility of performing more services with less manpower and lower administrative costs. They were not suggesting that technology could substitute for hands-on care, but many of the tasks performed by staff could be done by technology, leaving staff free for direct care.

In their review of a number of short-term, pilot smart homes projects in developed countries, Chan et al (2009) included three types of system within the concept of 'smart home': those which featured devices, either mobile (wearable, portable or implantable) or stationary (sensors, actuators or other ICT components embedded in the structural fabric of the building or in objects such as furniture); those which had 'intelligent' components in the sense of context awareness or decision-support properties; and those which transmitted or processed data automatically. The authors listed a number of people who could benefit from 'smart home' technology, including:

- People living alone who are unable to seek help in emergencies (unconsciousness, falls, strokes, myocardial infarction, etc.)
- People with physical disabilities
- People who need help with personal care activities (eating, toileting, getting dressed, bathing) and instrumental activities (cooking, dealing with medication, doing laundry)
- Carers for the elderly or for people with disabilities, both informal (family, friends, neighbours) and formal (care providers)
- People living in areas with inadequate health service provision, whether rural and remote or urban;
- People with chronic diseases who need continuous monitoring (diabetes, cancer, cardiovascular disease, asthma, COPD); and
- People involved in healthcare at a distance (telehealth) or with physicians practising 'virtual visits' (telemedicine).

The authors pointed to a number of disadvantages of 'smart home' technology: there has been little research on user needs; there is not yet any way of coordinating data collected electronically with other forms of data collection; set-up costs are high; there is a fear that technology might replace personal care; and above all, there is the issue of privacy, e.g.

when e-health devices reveal more information than the person desires (Chan et al, 2009: 94; Percival and Hanson, 2006).

The issue of privacy is of concern throughout the broader AT literature (e.g. Morgan, 2005). Researchers (e.g. Matthews, 2006) have found that that older adults, and presumably younger people as well, will accept limited intrusions into their privacy if it means enhanced independence and quality of life. At the same time, privacy protection is paramount, and it is important that those who recommend or provide healthcare monitoring devices, whether they be service providers, retailers or community agencies, obtain informed consent. Moreover, identifying data should not be inappropriately retained.

Whatever the problems and limitations, Chan et al (2009) strongly believed that user-centred, home-based systems would be the basis of healthcare in the future. And there are signs that Australian homes are becoming sites for high technology 'hospital' care, although this sits uneasily with the notion of home as a place of sanctuary, familiarity and belonging (Gardner, 2000). Mann and Milton (2005) said that the technology used in the Gator Tech smart home was already available, and although it was still experimental, when it had been sufficiently tested, it would be able to move from the laboratory into private homes.

However, there is very little evidence of either the advantages or the disadvantages of the 'smart home' technology. A systematic review (Martin et al, 2008) found no academic studies either supporting or refuting the use of smart home technologies within health and social care.

3.6 Microswitches

Another aspect of technology with the potential for increasing the independence of people with disabilities is the microswitch (Henwood, 2010), a device which requires minimal movement to turn things on and off. There have been a number of recent developments in microswitch technology with the aim of making them a more usable resource for people with multiple disabilities: the identification of new responses to benefit people with minimal motor ability; strategies to help people with multiple disabilities acquire multiple responses and exercise choice; and strategies to help people reach conventional goals, e.g. walking, reducing aberrant behaviour (Lancioni, et al, 2008). Mansell (2010) agreed that there was enormous scope for developing the use of microswitches for assistive technology in the home environment.

3.7 Telecare

Telecare is usually discussed in the context of aged care (e.g. Demiris et al, 2009; Capamagian, 2010), but it is also relevant for younger people with disabilities. It involves the use of technology such as sensors and alarms in conjunction with telecommunications as a form of remote monitoring of people's health status in their home environments. It is intended to minimise potential risks and to help people remain independent in their own homes (Capamagian, 2010). It involves the use of telecommunication technologies,

including video-conferencing, to enable communication between patients and healthcare providers separated by geographical distance (Demiris et al, 2009). According to the UK Department of Health (2005: 8), 'telecare is as much about the philosophy of dignity and independence as it is about equipment and services'. Examples are 'community alarm services that provide an emergency response and sensors that monitor and support daily living, through to more sophisticated solutions capable of monitoring vital signs'.

The Department makes a distinction between telecare and telehealth. Telecare refers to the supports needed by vulnerable people—those with physical disabilities, the frail aged, people with dementia or epilepsy—to enable them to keep living in the community. Telehealth is aimed at helping people manage their own long-term health problems in their own homes (e.g. diabetes, heart disease, cancer) (UK Department of Health, 2009). However, both forms of healthcare 'at a distance' are usually discussed together and the distinction is not relevant for what follows.

Citing recent research, the MTAA summarised the social and health benefits of telehealth as follows:

- it overcomes geographical barriers to people's access to healthcare and gives people in remote areas access to specialists;
- it reduces the pressure on the healthcare workforce;
- it enables early detection of abnormalities or symptom worsening and promotes proactive healthcare;
- it decreases the need for hospitalisation and admission to residential care;
- it provides a viable alternative to outpatient or doctor visits and reduces congestion in medical centres and emergency rooms;
- it increases quality of life and reduces the burden on carers;
- it helps both patients and carers to remain in the workforce;
- it reduces the likelihood of predictable factors that lead to care (e.g. falls, incontinence); and
- it decreases healthcare costs (MTAA, 2011: 8, Annex A).

Jennett et al (2003) identified many of the same benefits, namely: increased access to health services; cost-effectiveness; enhanced educational opportunities; improved health outcomes; better quality of care; better quality of life; and enhanced social support.

However, telecare also gives rise to many of the same ethical issues, around privacy, surveillance, and appropriateness for user needs, as smart homes. For example, research undertaken by the Welsh Centre for Learning Disabilities for the UK Social Care Institute for Excellence (SCIE) (Perry et al, 2010) explored the ethical issues surrounding telecare and the difficult decisions that professionals may have to face in providing it. These relate to issues to be considered prior to the installation of telecare, and the other relating to post-installation issues. Pre-installation factors related to assessment, consent, risks, sourcing equipment, and the actual installation itself. Post-installation factors involved privacy, social isolation and well-being, and fairness in the allocation of resources.

The intended audience for the report included social care commissioners (in the UK context), community care providers, telecare manufacturers and providers, and policy makers. It was also intended for users of telecare and their families, to give them some idea of what they might reasonably expect from professionals.

Researchers in the US (Demiris et al, 2009) noted that the American Telemedicine Association had produced ethical guidelines for the design and use of telehealth applications for home care. These guidelines provide criteria relating to the patient, the provider and the technology. The patient criteria involve a set of recommendations relating to the need for informed written consent, the selection of patients able to handle the equipment, and training to use it; the provider criteria involve training issues and after-hours support; and the technology criteria relating to the operation and maintenance of equipment, the establishment of clear procedures and safety codes, and the protection of patient privacy and record security. These guidelines are intended to serve as practical recommendations for the proper use of telehealth systems in both practice and research.

The literature overall stresses the point that telecare is not intended as a complete substitute for personal care, but as a complement to it. Demiris et al (2009) said that, despite the benefits of telecare, people who needed strong emotional or psychosocial support would find a video encounter inappropriate and inadequate, and there would be times when people needed a human touch. Whether technology had the positive effect of increasing access to care for under-served populations, or whether it deprived people of traditional care, would depend on the way it was used, as well as on the availability of other options. Telehealth is most effective when it allows for people to access specialised care when there are no other options available.

The MTAA (2011) noted that there had been little policy work done at the federal level to develop funding for telehealth or for other assistive technologies. The federal government was planning to introduce Medicare Benefit Schedule (MBS) item numbers for telehealth in July 2011, although the MTAA believed that the amount allocated would not be sufficient to cover all aspects of telehealth.⁵

⁵. For a number of examples of applications of AT, including 'smart homes' and telecare, see Cash, 2003. Because these are projects for people with dementia, they have little relevance, if any, for younger people with disabilities.

Key points

- Most of the literature on assistive technology focuses on its use in dementia care and with older adults more generally, as well as in the management of chronic diseases, although much of this literature is also relevant to younger people with physical disabilities (Connell et al., 2008)
- The main forms of AT discussed are powered wheelchairs, computer-assisted memory devices for people with ABI, home modifications, 'smart home' technology, microswitches and telecare/health (Bricknell, 2003; Wilson et al, 1997; Hoenig, 2008; Lansley et al., 2004)
- Mobility aids, wheelchairs among them, constitute the AT most likely to be used by people with physical disabilities (Bricknell, 2003)
- Powered wheelchairs have opened up a world of opportunities for people with disabilities (Buning et al, 2001; Arthanat et al, 2009)
- There can also be barriers to effective AT, e.g. the need to acquire the necessary skills, the greater size and weight of the chair (Arthanat et al, 2009; Hardy, 2004)
- More research is needed into the usability of powered wheelchairs (Hardy, 2003)
- Computer-assisted devices can help with memory-related ADLs for people with acquired brain injury (Wilson et al, 1997)
- Home modifications have been found to be a highly effective use of public resources in that they can keep people out of hospital, reduce the strain on carers and promote social inclusion. (Heywood, 2001; WHO, 2011)
- 'Smart homes' and electronic aids to daily living can provide great benefits, both psychological and functional, for people with severe disabilities and their families and carers (Chan et al., 2009; Tak et al, 2010)
- Again, there are also barriers, e.g. high set-up costs, data collection issues, privacy (Morgan, 2005; Matthews, 2006)
- Privacy is a concern throughout the broader AT literature (Matthews, 2006)
- Microswitches are also a promising technology for people with multiple disabilities because they require minimal movement to turn things on and off, although much of the technology is still in the product-development stage (Henwood, 2010; Lancioni et al., 2008; Mansel, 2010)
- Telecare is usually discussed in the context of aged care, but it is also relevant for younger people with disabilities to the extent that it provides a cost-effective way of increasing people's access to health services, a better quality of care and quality of

life, improved health outcomes, and enhanced social support (Demiris et al, 2009; MTAA, 2011)

4 Physical Disabilities: the Impact of AT on Care Needs

4.1 Improving independence and self-determination

The vast majority of adults with disabilities live in the community, and facilitating their ability to live independently is an increasingly important public concern (Agree and Freedman, 2003). There is an overall consensus in the literature that one of the main aims of AT is to improve the independence and self-determination of the person with disability. The use of AT is one of the most important avenues for research into ways of facilitating the independence of people with disabilities to enable them to live and work in the community (Agree and Freedman, 2004). Aids and equipment can promote feelings of autonomy and self-sufficiency because they deal with the specific functional problems experienced by the user, and they are always available whereas a personal carer might not be (Bricknell, 2003).

While outcomes research on AT is limited, there are studies that show that it can reduce task difficulty and the need for help from another person (Hoenig, 2008). Indeed, disability advocates have argued that autonomy and self-sufficiency are more likely to be maintained when equipment is used, and is sometimes lost with personal assistance. US research has found that equipment by itself can in fact more efficacious than personal assistance (alone or combined with equipment) (Verbrugge et al, 1997). A US study using the 1994 Survey of Asset and Health Dynamics of the Oldest Old (Agree, 1999) found that those who used equipment only (with no personal care) reported less residual⁶ difficulty with mobility than those who used personal assistance (either alone or with equipment).

The benefits include:

- AT is tailored and timely—it is designed for the specific task, it can be modified to suit the individual, and it is generally on hand when needed
- AT maintains a person's self-sufficiency and gives them pride in task improvements (Verbrugge and Sevak, 2002)

Personal assistance, in contrast, is less likely to be standardised and it may or may not fit with individual needs. It is also less likely to be readily available when needed.

⁶. 'Residual' disability is the degree of difficulty which remains after assistance, whether by personal care or by equipment. It is contrasted with 'underlying disability', which is the amount of disability that would be experienced without assistance (Agree, 1999). Assessing the amount of residual disability in the population is one way of identifying the extent of the need for new investment in innovations in long-term care. Agree (1999) has argued that it is likely that such innovations will consist of new technologies, which will meet currently unmet needs in ways that fulfil people's desires for independence and help to maintain them in the community.

These findings have policy implications because the design and dissemination of assistive devices can have a prompt and large impact on persons with disabilities. Hence, it is in the public interest to direct funding toward technology. Challenges include: improving the aesthetics of existing devices, redesigning equipment for easy use by all sorts of people, developing information programs and commercial outlets, and increasing public supports for purchase and maintenance (Verbrugge et al, 1997).

However, AT is not a substitute of personal care for everyone. Some people with disabilities do not find AT useful in ADL. Although relying solely on equipment does have advantages at all levels of severity, it is most effective for those with only mild to moderate levels of disability. Hence the severity of mobility impairment has to be taken into account in decisions about the use of AT (Agree, 1999). Moreover, whether or not equipment can be a substitute for personal care, or whether it can be a supplement to it, depends on the particular task and on the characteristics of the devices and of the personal care providers (Agree and Freedman, 2000).

People may value AT highly, and require less personal care, even if using AT is tiring or time-consuming. Another study by the same researchers (Agree and Freedman, 2003) examined a US national health survey (of adults aged 18+) for reported differences in residual difficulties with ADLs between technology users and users of personal care. The study examined three types of residual difficulty (pain, fatigue and slowness) and three activities (bathing, transferring into or out of beds or chairs, getting outside). The study found that technology was no better than personal care in alleviating pain or fatigue, or in shortening the time spent on a task. In fact, equipment users were more likely than personal-care users to report that a task was tiring or time-consuming even with the use of equipment and even though they tended to be less disabled than users of personal care. However despite the difficulties, the technology-alone group reported less unmet need for personal care than those who already used personal care (either alone or with technology as well). The reasons for this may be factors such as self-efficacy, motivation, autonomy and privacy (Agree and Freedman, 2004).

There may be links between use of AT and physical functioning and health, although studies have found contradictory evidence. One study found (Allen et al, 2001) that the physical effort required for people with disabilities to use some types of AT, e.g. canes, crutches, walkers, may help to slow functional decline by forcing them to exercise. However, their researchers (Putnam and Tang, 2007) have suggested that, at least in the case of people with multiple sclerosis, relying more heavily on AT than on personal assistance could be more tiring and decrease overall health.

Other researchers found that using equipment can leave people with symptoms such as tiredness, slowness and pain. However, the value of the pride, responsibility and independence that using AT brings, is greater than these costs (Verbrugge and Sevak, 2004).

Access to AT is therefore very important. Canadian research suggests that there could be a number of factors which influence whether or not young people transitioning into

adulthood are using it (Lindsay and Tsybina, 2011). Income was a crucial determinant, and the authors noted that cost was one of the main barriers to using AT. The cost of mobility devices was more significant in the case of 20-24-year-olds than 15-19-year-olds, probably because the latter were more likely to live at home. Those who were more likely to use AT, especially mobility devices, and to report unmet need, were: those who lived alone; young women; and those who spoke a language other than English.

The WHO report (2011) had a number of suggestions for improving access to AT:

- Introducing economies of scale in purchasing and production through centralised, large-scale collective purchasing, or consortium buying, nationally or regionally.
- Expanding markets beyond regional or national boundaries to generate the volume necessary to achieve economies of scale.
- Using universal design principles so that devices can be marketed more widely and hence mass produced.
- Manufacturing products locally using local materials or importing the components and assembling the final product locally.
- Offering tax exemptions and other subsidies or low-interest loans to enterprises producing aids for people with disabilities.
- Reducing duty and import taxes where countries need to import assistive devices.
- Awareness and information sharing among both professionals and people with disabilities about the availability of at.

4.2 User involvement

One of the most important aspects of independence is the opportunity for people to make their own decisions about what devices they will accept and whether they will accept any at all. As the AIHW report on aids and equipment (Bricknell, 2003) noted, people need to be involved in the selection process and to have control over the final decision.

The Swedish government has initiated a pilot project testing the feasibility of giving people the main responsibility for choosing and owning their AT devices (Estreen, 2010a). Called 'Free Choice of Assistive Technology 2007-2009', it is coordinated by the Swedish Institute of Assistive Technology (SIAT). It operates in three county councils, and is intended to change prescribers' ways of working, and to meet users' needs and strengthen their influence in the selection process. Users work with their prescribers to carry out the needs assessment, and the user subsequently receives a voucher for the allotted amount of the assistive device. The users buy, own and are responsible for the devices, and if they want a more expensive product than that covered by the voucher, they are responsible for the extra costs themselves. Two councils have introduced a servicing account for repair and maintenance. Almost half the devices prescribed through Free Choice in the first 20 months of operation were hearing aids, and a similar proportion were mobility aids, including wheelchairs. The changes needed to strengthen user-influence have come a long way towards being realised during the study period, although extending it would require further development.

Lessons learned so far include:

- Not viewing the device as a separate product but as a means in an ongoing process.
- More cooperation between users, at centres and units, and prescribers.
- Further development of the prescriber role and of the voucher system.
- Regular review of the level of reimbursement.
- Monitoring of servicing.
- Better opportunities for re-use of the device—private ownership means that service providers cannot re-use the device.
- Provision for ongoing assistance.

Other countries in Europe have introduced similar ‘free choice’ solutions for the provision of AT devices. In the majority of countries the devices are publicly financed and owned by the relevant public authority. In some countries they are financed by insurance funds or charitable organisations (the UK). In the majority of countries, the free-choice solutions are a complement to the standard provision process in the respective country (Estreen, 2011a: 48-9; Estreen, 2011b).

Swedish researchers (Lilja et al, 2003) have argued that the change in and improvement of services in Sweden has come about as a result of pressure by Swedish consumer groups, who have been very active and influential. The fact that most AT devices are free of charge, and that universal design has become an important consideration in building and construction, are cited by these authors as examples of consumers’ influence. They note that user influence is necessary, both in a general sense as a spur to policy-making and at the individual level, in order to implement a quality process for providing AT devices and home modifications, and also to ensure equitable distribution.

A review of the academic literature on the involvement of users in medical device technology development and evaluation (Shah and Robinson, 2007) found that user involvement was either limited in practice or it was being under-reported. However, they did find evidence that it was in fact essential, from the perspectives of both users and manufacturers, but that it required resources which were not always available. Too little time and not enough money were found to be the key impediments manufacturers faced, together with the absence of any tradition of involving users. The authors pointed out that, given that the importance of the consumer role in many aspects of manufacturing and production was increasingly being recognised, it needed to be properly integrated into the development of medical device technology. User involvement might need to be formally integrated into the health technology assessment process, and require approval from regulators as well as manufacturers.

However, there are other reasons than people’s independence for including them in decision-making. A review of studies reporting on users’ involvement in the development and evaluation of medical device technologies (Shah and Robinson, 2007) listed the main benefits of user involvement as:

- increased access by product developers to users’ needs, experiences and ideas;

- improvements in medical device designs and user interfaces; and
- an increase in the functionality, usability and quality of the devices.

4.3 Abandonment

Research has found a substantial level of users abandoning the use of AT devices. A national survey in the US found that 29 per cent of devices were discarded (Brodwin et al, 2003). Other studies have found rates between 30 and 59 per cent, at least among older people (Connell et al, 2008). Marcia Scherer (2002), who developed the Matching Person and Technology assessment instrument (see below), estimated that, on average, about one-third of the devices provided were not used or were abandoned or discontinued.

This high level of device abandonment is one very good reason for including users in the selection of the devices they are going to use. Researchers who reviewed the literature on AT use and abandonment (Pape et al, 2002) found that personal factors were often among the reasons people abandoned devices, and that rates of abandonment would fall if people were asked their views about the type of equipment they needed. The effectiveness (or otherwise) of AT in reducing environmental obstacles was not the sole determinant of whether devices are used (or alternatively abandoned). Personal factors such as the meanings people attribute to AT play a decisive role in whether AT will be successfully integrated into someone's life

Other researchers, too, have recommended asking people what they think about the AT devices they are provided with. US research with older people (55 and over) (Gitlin et al, 1996), who had been discharged from hospital with assistive devices after stroke, orthopaedic deficit, or lower limb amputation, found that only 50 per cent of the devices were used frequently or always. The researchers suggested that asking patients a simple, straightforward question such as 'Do you expect to use this device in your home and how?' could be enough to provide information about whether or not the patient would actually use the device, and about their ability to incorporate it into their daily routines. Involving the user in the selection of a device, and helping them to visualise how it might be used in activities in the home, could be a way to enhance utilisation.

There are many reasons why people abandon AT—lack of motivation, insufficient training, inadequacy of the device, accessibility problems. But the most significant reason is the failure to consider the user's opinions and preferences in the first place (Brodwin et al, 2003). Clearly, people need to be involved in selecting their aids and equipment, to be able to make choices and to have control over the final decision. As well, people need to be better informed, the providers as well as the users of the devices and their family members, abandonment is to be avoided (Bricknell, 2003). Scherer (2002) said that, in order to reduce device abandonment, increasing attention needs to be paid to the person with a disability as a unique user of a particular device. Each potential user brings to the AT evaluation and selection process a particular set of needs and expectations, as well as varying degrees of attraction to AT use and readiness for use. Ideally, these factors need to be assessed to achieve better outcomes, and ATs need to be customised to the user, training and trial use of devices arranged, and additional supports identified.

4.4 Assessment and evaluation tools

An Australian researcher (Karlsson, 2010) has recommended a number of measurement instruments that could contribute to reducing rates of abandonment. Designed to be compatible with the WHO International Classification of Functioning (ICF) (WHO, 2001), they can be used to assess a user's abilities and AT needs, as well as relevant contextual factors. Only one of these, the Matching Person and Technology (MPT) model developed by Marcia Scherer at the Institute for Matching Person & Technology, was specifically designed for AT assessment, but the others can also be used:

- The MPT was designed to match users of technologies with the most appropriate devices for them. It is one means for providing a more personal approach to matching person and technology. It contains a series of instruments (self-report checklists about consumer predispositions to and outcomes of technology use) which take into account: the environments in which the person uses the technology; the person's characteristics and preferences; and the technology's functions and features. There is also an assessment form for children aged 0-5, called Matching Assistive Technology and Child.⁷
- The Canadian Occupational Performance Measure (COPM) was developed to capture the client's individual occupational performance as an outcome measure, and it looks at three important sections of daily living—self-care, productivity and leisure. In an interview, the service provider helps the user to identify problem areas. It is not AT-specific, but it does look at AT needs from a client-centred perspective and can be combined with other instruments. It can be used with clients of any age, and with any disability and any form of AT.
- The Goal Attainment Scale (GAS), which was first introduced in 1968 to evaluate community mental health programs, can also be used in AT assessment. It is flexible enough to be used in different settings. Today it is widely used in pediatrics and rehabilitation as well as mental health. It measures changes in responses to individual goal-setting with five pre-determined levels of outcome. When clients or their families are involved in developing the goals, it has been known to result in a higher number of successfully implemented goals. Like the COPM, it can also be used with clients of any age and with all forms of disability and AT.
- The Individually Prioritised Problem Assessment (IPPA) is a generic instrument which can be used to measure the effectiveness of AT provision. The aim is to measure the degree of change and the IPPA has been found to be a sensitive measure of change. Like the COPM, this instrument is also administered by way of an interview with the service provider, who helps the user to identify problems. The user rates the importance and the level of difficulty.
- The Psycho-social Impact of Assistive Devices Scale (PIADS) measures the effects of an AT device on a user's functional independence, well-being and quality of life. It is a 26-item scale looking at competence, adaptability and self-esteem, and it can be administered through a self-administered questionnaire or through interviews. It

⁷. See also: Wielandt and Scherer, 2004; <http://matchingpersonandtechnology.com/>

was specifically designed to help uncover the reasons for both device use and abandonment.

- The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0) was designed to evaluate the user's satisfaction with the attributes of the AT, such as its weight, ease of use, comfort and effectiveness. The first version was adapted from the MPT model, and Version 2 (QUEST 2.0) is aligned with the ICF environmental domain. QUEST 2.0 can be used with adolescents, adults and the elderly, and a version for children (QUEST 2.1) has recently been developed. QUEST 2.0 has three scores, one for the device, one for services, and the third score is a total of the first two. It can be self-administered or administered through an interview. It is a generic outcome measure that can be applied to a variety of AT devices, and the user can add additional items, such as speed. The instrument has mainly been tested by the developers, but it shows promising results for reliability and validity.

With improved assessments, and guided by evidence-based practice and the ICF, both service providers and clients, can be supported in AT decision-making (Karlsson, 2010).

4.5 Usage among particular groups

US research analysing the responses to a 2005 survey of nearly 2,000 adult members of California Independent Living Centers (Kaye et al, 2008) found large differences in technology usage by age, race, ethnicity, education, income, and type and severity of disability.

- In the case of age, the use of low-tech devices was found to increase markedly with age, whereas there was a significant decline with age in the use of high-tech devices, especially over the age of 75.
- Disability related to mental as opposed to physical or sensory functioning. Physical and sensory disabilities were found to be highly associated with device usage, but cognitive or mental health disabilities did not contribute to the likelihood of a person's using AT.
- Lack of awareness of available technologies was an issue across all disability types. But people who were more educated were more likely to know about technologies, to feel confident about using them, and to be able to conduct their own research to learn about available devices.

Other factors that put certain people with disabilities at a disadvantage in accessing and using assistive devices were:

- Lower educational attainment
- Racial or ethnic minority status
- Lower household income
- Later onset of the disability. People who were born with their disability had higher usage rates and used more devices than those with later disability onset. (Kaye et al, 2008)

Other US research found two groups of people who face barriers to using AT: people living in rural and remote areas, and married women, whom the researchers found to be particularly reluctant to use equipment in place of hands-on help to facilitate mobility-related activities. The research was confined to older people and hence the finding in relation to married women may not have the same relevance for younger people with disability (Agree et al, 2004)

Low AT usage by people living in non-metropolitan areas in Australia was also reported by the Productivity Commission (2011). That report recommends that the proposed NDIS should actively fund telehealth technologies in rural areas, although the report also makes the recommendation dependent on increases in the accessibility of the high-speed internet in those areas. The MTAA (2011) notes, however, that often it is a lack of access to funding and service reimbursement, rather than lack of internet access, that prevents these types of services being delivered. The authors suggest that there are already a number of medical technologies that meet the challenges associated with providing healthcare to people with disabilities in remote areas. Videoconferencing can be used for medical screening, as well as rehabilitation and treatment; vital signs monitoring can be delivered via internet-based systems; and high-technology medical devices (e.g. implantable cardiac devices) can be monitored from a distance.

There is research (Allen et al, 2001) suggesting that younger people with disabilities have lower rates of use of mobility equipment than their older counterparts. This could reflect a greater desire for autonomy among younger people (as well as older people's greater frailty). It could also reflect perceptions by younger people and their family members that, while dependency is appropriate for older people, it is not appropriate at younger stages of the life course. If that is so, then interventions that de-stigmatise the use of assistive technology might be necessary to promote greater autonomy and quality of life for people with disabilities.

Key points

- Improving the independence and self-determination of the person with disability is one of the main aims of AT (Agree and Freedman, 2003; Agree and Freedman, 2004; Bricknell, 2003).
- There is evidence that AT can reduce task difficulty and the need for help from another person (Hoenig, 2008)
- Using AT instead of help from another person can maintain a person's self-sufficiency, because it does not rely on anyone else's cooperation (Verbrugge et al, 1997; Verbrugge and Sevak, 2002; Agree, 1999)
- Technology is no better than personal care in alleviating pain or fatigue, or in shortening the time spent, but people who used only technology (and no personal care) said they needed less personal care than people who used personal care (Agree and Freedman, 2004)
- People who use equipment prefer to put up with tiredness, slowness and pain because they value their independence (Verbrugge and Sevak, 2004)
- The effectiveness of equipment used alone decreases as the level of impairment increases (Agree, 1999; Agree and Freedman, 2000)

- People need to be able to make their own decisions about AT (Bricknell, 2003)
- There are a number of projects in Sweden and other European countries designed to strengthen users' influence in the AT selection process (Estreen, 2010a; Estreen, 2011b)
- Research has found a substantial level of device abandonment, between 30 and 60 per cent (Brodwin et al, 2003; Scherer, 2002)
- Including users in the selection of devices is important because failing to consider the user's opinions and preferences is one of the main reasons why people discard AT (Pape et al, 2002)
- There are a number of measurement instruments designed around the WHO International Classification of Functioning, which can be used to assess AT users' abilities and needs and relevant contextual factors, e.g. the Matching Person and Technology model (Karlsson, 2010)
- AT usage has been found to vary across different population groups. Factors associated with lower levels of usage are: lower educational attainment; racial or ethnic minority status; lower household income; later onset of the disability; and living in rural and remote areas (Kaye et al, 2008; Agree et al, 2004; Agree and Freedman, 2003)

4.6 AT and personal care

As the provision of care in the community has increased, the extent to which technology can substitute for personal care has become an important policy question (Agree et al, 2004). The *WHO World Report on Disability* (2011) suggested that relevant strategies for increasing access to technology that is appropriate, sustainable and affordable would include:

- establishing service provision for assistive devices;
- training users and following up;
- promoting local production;
- reducing duty and import tax; and
- improving economies of scale based on established need.

The report also recommended telerehabilitation—the use of ICT as a way of further enhancing capacity, accessibility and coordination of rehabilitation measures.

Researchers have found little information in the literature on the potential for AT to be a substitute for or a supplement to personal care (Agree and Freedman, 2000; Agree et al, 2004). There is US research which has focused explicitly on how AT was incorporated into community-based long-term care. At least one randomised control trial has shown that AT

and home modifications can forestall dependence on personal care among older adults (Mann et al, 1999), although the study was confined to older people aged 65 and over.⁸

Another US study (Allen et al, 2001) used the 1994-1995 US national health survey to investigate whether the use of mobility equipment could substitute for personal assistance, and whether it led to cost savings for formal home care services. The study found that the use of canes and crutches reduced both formal and informal hours of care received. However, the use of walkers and wheelchairs did not. The researchers noted that, although canes or crutches could substitute for personal help in particular ADL tasks, complete substitution of mobility equipment for human help was unlikely.

A later study (Allen et al, 2006) using the same health survey investigated whether home modifications influenced the amount of personal assistance provided to adults who used wheelchairs. It was known that people who used wheelchairs received substantially more hours of both formal and informal care than those who used any other type of mobility device. The study found that home accommodations did reduce the amount of unpaid help received, although not the amount of paid help. Particular types of modifications, namely ramps, railings, accessible parking and bathroom modifications, reduced the quantity of human help needed by people who lived alone.

Agree and Freedman (2000) also used the 1994-1995 US national health survey, and compared the use of personal care and equipment, again among older people. The analysis found that the use of devices was highest among people who used formal services. More than three-quarters of the respondents who used formal care also used equipment, whereas a smaller proportion of those with informal care supplemented it with AT, and only around half of those using no personal care used equipment. The authors commented that, if the higher AT use among users of formal care is because they have better access to AT through their contact with the formal healthcare system, then making it more directly available to people relying on informal helpers could increase their device use and relieve some of the burden on their carers.

The authors discussed four factors relevant to any consideration of whether AT could substitute for or supplement personal care. These factors also have relevance for younger people. They are:

- The ADL limitation because AT is task-specific. Tasks like toileting for which privacy is a concern may be most conducive to substitution, and mobility may require complex devices such as wheelchairs to supplement care-giving.
- The characteristics of the person with disabilities, especially the severity of the disability.
- The characteristics of the devices because there are differences in the method of acquisition, the cost and the amount of training needed (e.g. Low technology

⁸. This is described in more detail in section 5.1, among the examples of arrangements specifically designed to save costs.

devices are usually acquired by people themselves, they are not reimbursed by medical funds, and they require less training than complex devices).

- The characteristics of the care providers, especially the distinction between informal and formal care, not only for the obvious reason of cost, but also because informal and formal carers differ in their ability to access technologies.

The authors commented that it might be expected that simple devices (e.g. canes, walkers) would be more likely to substitute for informal care, whereas complex devices would be more likely to supplement formal care (although not to substitute for it). They suggested that it could be that informal carers are willing to make a greater effort to compensate for a loved one's disability before acquiring equipment, whereas formal caregivers may be motivated to minimise their own physical burden through the use of equipment.

Later research using the same survey (Agree et al, 2004) investigated the question of who among people (aged 50 and over) with mobility-related disabilities were most likely to use equipment in place of personal assistance. The study found that, whereas there were very few people who used personal care only, almost a third of respondents with mobility limitations used equipment only. One way of interpreting this finding, the authors said, is that nearly one-third of the people surveyed who had some difficulty with mobility were able to function independently through the use of assistive devices, rather than relying on personal care. Given that these were older people, the proportion is likely to be higher among younger people.

Another study using the same survey (Agree et al, 2005) (and again focusing on older people) found that AT was not replacing either formal or informal care, but rather supplementing personal care. The authors voiced a need for caution in any scheme to use AT to offset care costs, at least for the older population. While such devices could improve people's quality of life and promote their independence, whether or not they could substitute for more expensive formal care had not yet been established (Agree et al, 2005).

In contrast, another US study (Hoenig et al, 2003) (using a different national survey but again of older people aged 65 and over) did find that AT could substitute for at least some personal assistance with ADLs. The survey asked about specific types of AT, e.g. wheelchair, walker for mobility, shower seat for bathing. People who did not use AT reported about four hours more personal help a week than those who did use equipment. The authors noted that the findings had several important policy implications. In the first place, they indicated that fears that the provision of equipment might promote dependency were groundless. Moreover, given that fewer hours of personal help were used when there was technological assistance, providing AT could reduce carer-burden.

The Victorian Equipping Inclusion studies (Layton et al, 2010) cites studies that show that AT solutions need multiple elements—aids and equipment, environmental modifications, episodes of care, all used together—if they are to be maximally effective. Government funding of AT would be most effective if it provided AT 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' (quoting

the Assistive Technology Collaboration, n.d). Such a focus would allow solutions to be tailored to individual needs and aspirations and the person's own context, and enable planning the best way to fit the elements together.

As well as the tailoring of AT solutions, the authors also suggested other ways of improving service delivery, client outcomes and cost-effectiveness, namely:

- By expanding the range of aids and equipment, both disability-specific and generic, eligible for government funding—the study found that the AT required by survey respondents but currently ineligible for Victorian AEP subsidy fell within a relatively narrow range (a widening of eligible items according to ISO 9999 standards⁹ by only 4%), and would not therefore require very large budget increases.
- By recognising the dynamic and longitudinal nature of AT solutions—the study found a lack of responsiveness to changing circumstances on the part of the Victorian EAP, e.g. home modifications funded only once in a lifetime, equipment replaced only after seven years, lack of repairs or regular maintenance.

The report recommends the following principles for effective funding:

- Government funding of aids and equipment consistent with levels of demand and regularly adjusted to reflect demographic and technological changes;
- Transparent eligibility criteria and security of entitlement for people with disabilities;
- Responsiveness to individual need, both of people with disabilities and of their families and carers, and allowing for choice and timely allocation;
- Allowance for changes in technology, and in people's life situations, needs and aspirations; and
- Maximisation of the efficient use of government resources in the way equipment is provided and maintained, with provision for recycling and re-use. (Layton et al, 2010)

4.7 Examples of AT services and programs

In Australia and internationally, a range of programs for AT service provision have been introduced, and some of these have been subject to review and evaluation.

The Equipment Study (Victorian AEP)

The Victorian Aids and Equipment Action Alliance (AEAA) commissioned two studies into AT provision in Victoria, *The Equipment Study* and *The Economic Study* (Layton et al, 2010). *The Equipment Study* focused on the experiences of Victorian adults (n=100) with disabilities in their use of AT and its impact in their lives. (*The Economic Study* is discussed in section 5 below). It investigated the range of AT used, the life domains it enabled, and levels of difficulty, participation and satisfaction with current use. In addition, the study

⁹. From 13% to 17% of the assistive products classified by the International Organization for Standardization – http://www.iso.org/iso/iso_catalogue/catalogue_tc/catalogue_detail.htm?csnumber=50982

sought to identify what AT people needed and the impact it would have on their lives if they had it.

In relation to the question of who used AT only, this study found that only 2 per cent of respondents did so. This contrasts with the findings of the US research described above (Agree et al, 2004), which found that, among people with mobility limitations, the proportion who used AT only was nearly one-third. People in the Victorian study used a wide range of devices, over 100 different types. Currently, the Victorian AEP subsidises only 13 per cent of the AT device types available on the market. People used AT in all eight of the life domains in the WHO International Classification of Functioning, Disability and Health (WHO, 2001). Personal Life was the domain where respondents most often reported that their activity was supported by AT devices (94%), followed by Social Life (80%), and Recreation and Leisure Life (73%). However, aspects of AT were repeatedly seen to be effective in more than one life domain. A number of respondents said that they had had to limit their participation because of insufficient AT.

Overall, participants were dissatisfied with their participation levels in 39 per cent of their preferred life areas and activities, and in 5 per cent of these activities people were unable to participate at all. Nearly three-quarters of the survey respondents said they had unmet needs for AT solutions, despite the fact that the majority of respondents would have been eligible for AEP subsidies given their income and residential arrangements. Just over two-fifths (41%) identified the Victorian AEP as their main source of funding to purchase AT.

The study uncovered a number of problems with the Victorian AEP. While only 9 per cent of the respondents were ineligible for the AEP program, 30 per cent had self-funded their AT. Moreover, 73 per cent of the items participants identified as required but not provided, were on the AEP Aids and Equipment List. This suggests that people are not using the AEP, and they gave a range of reasons for this, including procedural hurdles, long waiting times, uncertain outcomes, lack of maintenance and repair of funded AT, and funding guidelines that prohibited updating when their needs changed. They reported using 386 devices that were not eligible for AEP subsidies, 32 per cent of which were ICT and 9 of which were mobility devices. As well, AEP subsidy rates on average cover 66 per cent or less of the current market costs of AT, and respondents reported significant financial stress from this level of co-contribution, given their low incomes.

The Home Independence Program (Western Australia)

In Western Australia, a home care agency ('Silver Chain') developed a service model of home care for older people intended to reduce the demand for home care. Rather than tightening eligibility or introducing waiting lists as a response to increasing demand, the model, called the Home Independence Program, involved working actively to reduce the demand for home care by promoting independence. AT was among the interventions, which also included task analysis and redesign and work simplification, strength, balance and endurance programs, self-management of disease, medication, continence and nutrition, and falls prevention. The program team was multi-disciplinary, consisting of professionals for each area of intervention. Of those who completed the pilot study, 39 per cent had reduced requirements for support and 32 per cent did not need ongoing services.

In a subsequent operational trial, 70 per cent of participants did not require ongoing services after completing the program (Lewin et al, 2008).

MND NSW

MND NSW (the Motor Neurone Disease Association of NSW)¹⁰ has an equipment loan scheme for association members. The scheme provides equipment that is not available from existing government programs, or that is not available soon enough, given the progression of the disease. People may also apply to borrow equipment while they are waiting for their EnableNSW application to be processed. There is no charge or time limit for these equipment loans

Lifetec Queensland

Lifetec Queensland is a not-for-profit organisation that delivers information, consultation and education about how to use assistive technologies correctly. It aims to address the problem that many people purchase 'off the shelf' solutions without seeking clinical advice. It is a state-wide service, and its staff regularly travel to all parts of Queensland, including rural and remote areas to assist Indigenous communities. It provides services to 16,000 people each year (Connell et al, 2008). It is a Home and Community Care HACC service provider, and the majority of its funding is from the state and federal governments. They also receive funding from Disability Services Queensland and Queensland Health.

Independent Living Centres in each state and territory offer similar services.

Sweden

A Swedish project explored the role of user-friendly information and communication technology (ICT) to enable family carers of older people to care more effectively and to work in partnership with professionals (Magnusson et al, 2005). Called 'ACTION', its aim was to enhance the independence and quality of life both of frail older people and of their carers by providing information, education and support through ICT. The study found that, with appropriate education and support, older people can fully engage with ICT, although a critical consideration is whether installing ICT in carers' homes might inadvertently coerce them to continue caring, and make it more difficult to decide to relinquish the role. The study reinforces the importance of providing a range of support services, especially respite. ICT-support services cannot replace existing formal services, but they do facilitate their optimal use and stimulate new forms of help.

According to one commentator (Williams, 2008), Sweden is leading the way when it comes to AT. There is not only a vast array of AT products in Sweden, the way they are prescribed differs from the situation in the UK (and Australia). For example, bicycles are provided for children with disabilities and wheelchairs for toddlers, and someone could be given four wheelchairs because they had different needs in different environments. There is also the government-funded Swedish Assistive Technology Centre.

¹⁰http://www.mndnsw.asn.au/index.php?option=com_content&view=category&layout=blog&id=42&Itemid=95

The Swedish Institute of Assistive Technology (SIAT)¹¹ is run by the Ministry of Health and Social Affairs and the Swedish Association of Local Authorities and Regions, and funded by the Swedish social insurance system. The local (municipalities) and regional (county councils) authorities have responsibility for the provision of AT. SIAT's work covers two policy areas, disability policy and policy for the elderly. People with disabilities receive assistive devices and technical support almost free of charge, regardless of income. It is the person's needs that are paramount. AT covers a wide field, including not only traditional items such as wheelchairs and hearing devices, but also computers, systems for speech recognition, and interpretation services for deaf people. An extensive system for the provision of AT has been established throughout the country.

Key points

Research on the use of AT to substitute for personal care is still emergent, but it has produced a number of relevant findings.

- The use of canes and crutches appears to reduce both formal and informal hours of care but walkers and wheelchairs do not, probably because using the latter indicates a level of impairment unlikely to be offset by mobility equipment alone. (Allen et al, 2001; Allen et al, 2006)
- Home accommodations reduce the amount of unpaid help received, although not the amount of paid help
- National surveys of AT use in the US among older people show that use is highest among people who use formal services. This may be because they have better access to at through contact with the formal healthcare system (Agree and Freedman, 2000)
- AT users are likely to use more care and more forms of care than non-users, and hence AT appears not to replace either formal or informal care, but rather to supplement both (Agree et al, 2005)
- AT can substitute for at least some personal assistance with ADLs, depending on the particular device(s) used (Hoenig et al, 2003)
- Using equipment can help to ameliorate disability, either by ensuring that people get physical exercise, or by enabling self-care tasks to be performed more efficiently (Hoenig et al, 2003)
- AT solutions may need multiple elements—aids and equipment, environmental modifications, episodes of care, all used together—if they are to be maximally effective (Layton et al, 2010)

¹¹. <http://www.hi.se/en/>

4.8 Decreasing the cost of support services

Deciding how much something costs and comparing two forms of service provision to determine which is the most cost-effective, depends on what is taken to count as 'cost'. Any specific costs that are included in what follows are not directly relevant to the NSW context, 1) because, to the extent that the research comes from other countries, the costs are not expressed in \$AUS, and 2) because specific dollar amounts date very quickly.

There is a consensus from research that AT and home modifications do have the potential for substantial cost savings. The MTAA (2011), for example, has calculated potential cost savings of approximately \$3.1 billion per annum that can be achieved by keeping people in their homes and AT and home modifications are crucial resources for doing so. Although the experimental studies investigating AT usage are small-scale, they do suggest that introducing AT can reduce the hours of personal care and health care expenditures (Agree et al, 2004). The report of the scoping study for the Australian Department of Health and Ageing (Connell et al, 2008) noted that the initial cost outlay was a barrier to healthcare investment in AT and that research about its cost-effectiveness was still in the early stages. However, the indications are that the potential cost savings are considerable, at least as measured by reduced hospitalisation for older people.

Most of this research is focused on frail older people and it does not always have relevance for younger people with disabilities. This is especially the case with projects specifically devised for people with dementia (e.g. Cash, 2003). Other studies, however, are more relevant. For example, the survey respondents in a US study (Hoenig et al, 2003) were over 65, but they had ADL limitations and not dementia. The study found that AT use was associated with fewer hours of personal assistance. The researchers estimated that the cost savings in hours of help averaged \$US30 a week, mostly from savings in the costs of informal care.

The demand for AT will increase in the future and increasingly sophisticated technology is increasingly likely to be used for a home care population with more severe disabilities (Agree et al, 2004). But even simple inexpensive devices can promote independence while at the same time lessening the demands on carers, and possibly delaying the introduction of formal care services. As well, more complex and even quite expensive devices supplementing formal services could substitute for institutionalisation (Agree and Freedman, 2000).

A study in Italy (Andrich and Caracciolo, 2007) investigated the cost aspects of AT using a questionnaire designed to help clinicians estimate the economic aspects of providing individual users with AT solutions. Called the Siva Cost Assessment Instrument (SCAI) and first released in 2001 (Andrich, 2002), it introduces the concept of 'social cost' (i.e. the sum of all the material and human resources mobilised by the intervention) as the main indicator of the economic impact of AT, and provides ways of comparing alternative AT solutions in terms of that level of cost. The study (Andrich and Caracciolo, 2007) involved a first attempt to derive social cost indicators for various categories of AT equipment, based on a survey of 31 AT programs over a number of years. The findings of the study were:

- Although most AT solutions are very expensive to buy, they lead to considerable savings in social costs due to the reduced burden of assistance.
- In some cases, the savings in social costs could be as much as €150,000 over five years.
- There are significant variations in the social costs for different cases with similar AT solutions. This suggests that it would be difficult to establish definitive social cost figures for any given device. A device's cost depends on the particular context and on its relationship with the other AT solutions in the program.

A review of the evidence for savings from housing adaptations and equipment for older and disabled people (Heywood and Turner, 2007) found that the evidence was not complete, and that more work needed to be done to understand fully the success of interventions that are known to be effective. However, the review did find that providing home modifications and equipment for people with disabilities could produce savings to health and community-care budgets in four major ways:

- By reducing or eliminating an existing outlay, e.g. for residential care or for intensive home-care.
- By preventing a cost that would otherwise have been incurred, e.g. as a result of accidents, or of the need for admission to hospital or residential care, or for other medical treatment.
- Through the prevention of waste, i.e. where money is spent with no useful outcome, typically through under-funding that causes delays and solutions that are ineffective or psychologically unacceptable.
- Through achieving better outcomes for the same expenditure, e.g. as an alternative to residential care or in order to speed up hospital discharge, to relieve the burden of carers or improve the mental health of a whole household.

The authors pointed out, however, that there were serious methodological problems in gathering definitive evidence about the cost-effectiveness of adaptations, equipment and AT. Nonetheless, there was sufficient evidence to show that adaptations and AT did save resources, particularly in the four ways described above. As the UK Audit Commission report (UK Audit Commission, 2000) said: 'If a drug was discovered with a similar cost-profile, it would be hailed as the wonder-drug of the age'. Similarly, a theoretical paper, developing a cost-benefit analysis methodology based on the social participation of AT users and the International Classification of Functioning, Disability and Health, argues for a more inclusive analysis of the costs and gains in effectiveness brought about by increased access to AT (Schraner et al., 2008).

The UK Audit Commission produced a report providing practical advice to National Health Service trusts¹² about how best to manage expenditure in the area of equipment for the elderly and people with disabilities (UK Audit Commission, 2000). The report addressed a number of problems with existing services. The authors pointed out that prevention is always better than cure, and that investment in equipment services delivers high quality at

¹². Public sector corporations which provide health services for the National Health Service.

low cost. Enabling people to remain independent in the community through the use of appropriate equipment is always preferable to having to treat them in other parts of the healthcare system.

The second study commissioned by the Victorian AEAA, *The Economic Study* (Layton et al, 2010), was an economic evaluation of AT interventions, which compared the outcomes of the current provision of AT with those generated by the provision of hypothetical 'optimal' AT solutions suggested by eight case-study participants. The study found that moving from the current provision to what the person really wanted could be achieved at a modest cost in most cases. The authors commented that, from a government affordability perspective, the change to an optimal package of AT for these participants did not entail an unrealistic amount of additional expenditure.

It would be useful for ADHC policy decision making to commission research about the experience of people with disabilities in NSW who use AT as a substitute for support services, including modelling the costs and benefits.

4.9 Examples of arrangements designed to reduce costs

Home modifications

The UK research study described in the WHO report on disability (WHO, 2011) (section 2.3), which examined the effectiveness of home modifications, found that lasting benefits could be obtained from even minor adaptations (i.e. costing less than £500), while major modifications had a profoundly beneficial effect on people's lives. When they were successful, adaptations had kept people out of hospital, reduced the burden on carers and promoted people's social inclusion. The study found that the adaptations failed and money was wasted, both when the work was not adequately planned in the first place, and when too little was spent on the major renovations. The adaptations were most successful when people were properly consulted, everyone's needs were taken into account, and the changes fitted into the original home environment. The authors of the WHO report commented that home modifications appeared to be a highly effective use of public resources.

The policy implication of the US research investigating whether home modifications influenced the amount of human help provided to adults who used wheelchairs (Allen et al, 2006) is that reimbursement for home accommodations could be an efficient response to the growing demand for home-care support. While modifying the home did not appear to lead to decreases in the amount of formal care, it did mean that people were less dependent on informal carers, and hence gave them more autonomy.

As already mentioned, in Sweden every local authority is obliged by law to provide housing modification grants to people with disabilities regardless of income or housing type (i.e. whether owned or rented, house or apartment). Rehabilitation and healthcare happen largely in people's homes these days, and the housing modification grant and AT have

important roles to play. The grant is also a cost-effective arrangement. In 2003, the cost to the local authority of a grant for one person in residential accommodation was around 1,800 kronor (\$US180) a day, whereas the average one-off modification grant was 15,000 kronor (\$US1,500). Hence there was a saving if the grant allowed someone to stay at home even for just an extra two weeks (Lilja et al, 2003).

Home modifications and AT

A randomised controlled trial in the US (Mann et al, 1999) evaluated a system of service provision involving both AT and home modification. The system was specifically designed to reduce healthcare costs for physically frail elderly people living in their own homes, as well as to promote their independence. Although focused on the elderly, the study showed such clear benefits that it does have some lessons for service provision for younger people with disabilities. At the end of the 18-month intervention period, both the intervention group (provided with the AT and the home modifications) and the control group (provided with 'usual care services') showed declines in functional independence. But the control group had declined significantly more than the intervention group had, and their pain scores had increased significantly more. In relation to healthcare costs, the intervention group cost more than the control group for AT and home modifications (not surprisingly), but the control group required significantly more expenditures for institutional care. There was no significant difference between the two groups in total home care personnel costs, although the control group had significantly greater expenditures for nurse visits and case manager visits. However, the small sample size (52 people in each group) means that no great weight can be placed on these results.

The functional decline the elderly people in this trial experienced is unlikely to happen to most younger people with disabilities over an 18-month period. However, the fact that the rate of decline was slowed by the intervention, indicates that it had a beneficial effect on functional limitations. In younger people, this could mean some improvement in functioning rather than simply a slowing of decline. In the case of healthcare costs, it is quite possible that providing younger people with AT and/or home modifications could also mean less hospitalisation. While the results in relation to home care visits are not definitive, the fact that there were differences between the two groups does suggest that this is an avenue worth exploring further.

The UK research investigating home modifications for older people in public housing (Lansley et al, 2004) found that a comprehensive package of home adaptations and AT was likely to result in significant economies by reducing the need for formal care services. The study also found that the costs of home modifications rose, and the likelihood that a property could be modified lessened, as user needs became more extensive and complex, especially where someone needed to use a wheelchair inside the home or where a hoist was needed for transfers. However, except for extreme cases, adaptations and AT, even when combined with formal care, were found to be much less costly than residential care, and for many other reasons they are distinctly preferable. Considerations of cost are, of course, influenced by length of use, and adaptations and AT are most appropriate when considering the long-term rather than the short-term.

The relevance for this present review of the long-term cost-savings uncovered by this research is limited by the fact that the modifications were done on public housing. Because the housing is publicly owned, any modifications remain with the housing authority and hence can be 're-cycled' when the original tenant no longer occupies the property. Privately owned dwellings give rise to different considerations, especially the re-sale value when the owner with disabilities moves on. Private rental properties give rise to even greater difficulties, e.g. permission from the landlord and rental agent (which may not be forthcoming). Nonetheless, the research did show that home modifications and AT could reduce the need for formal care, although the report doesn't give any details of cost savings. They say how much the adaptations + AT + formal care cost, but not how much the care would have cost without the adaptations and AT, and there's no comparison group. The authors suggested caution, however, in focusing too strongly on financial cost-benefit analyses. They pointed out that other issues were equally important, such as independence and quality of life.

Telecare

A number of researchers have found that telecare is cost-effective (e.g. Jennett et al, 2003; MTAA, 2011). A project in the North Yorkshire Council used part of a Department of Health preventive technology grant to put technology into older people's homes (Valios, 2010). Equipment costing less than £1,000 was free for the user and there was a weekly charge of £6 to cover the costs of monitoring. According to the corporate director for adult and community services, a financial analysis of people using telecare showed a 38 per cent reduction in costs in comparison with traditional models of care. The savings came from delaying residential care, not substituting for it, and from reducing the level of formal domiciliary care required. Savings were expected to increase as more people used telecare.

Mattresses

A study in Israel (Catz et al, 2005) compared the economic profitability of a new computerised mattress system used with hospitalised patients with spinal cord injuries, with two other alternatives, a foam 'egg carton' mattress positioned on a regular foam mattress, and a bed system incorporating differential air regulation. Pressure sores can be avoided with any of these options, but the two latter alternatives are known to require people to be repositioned. The foam mattress requires repositioning every 2.5 hours. It was, of course, the cheapest option considering only the purchase price. However, once the cost of the nursing manpower was taken into account, it was the computerised system that achieved the desired outcome for the least cost. The system was one of the newest technologies designed to improve the prevention and medical treatment of pressure sores. Called the 'Matrix 200' mattress it was manufactured in Israel by Medogar Technologies Ltd, and could be installed on a regular hospital bed. It works to prevent pressure through continuous monitoring over small units of the skin's contact surface. The mattress is divided into 216 independent air chambers, and the system monitors the pressure between each chamber and the skin. The pressure in each chamber can be viewed on a screen and its operation independently controlled with a keyboard. Air is pumped into or out of the chamber to adjust the pressure to the desired level. The study found that people could lie

on the mattress for at least four hours without developing pressure sores and without significant discomfort. Moreover, the authors commented that the need to change positions could theoretically be eliminated with the 'Matrix 200', although it had been tested only with time intervals of up to 4 hours between repositionings

Neuropage

The RCT investigating the efficacy of a portable pager (Wilson et al, 1997) concluded that it was likely to be cost-effective for health services. The average cost per patient per month was around £50 (comprising hire, air time, and the salary of the staff member running the program), which compared well with many drug regimes and salaries for healthcare assistants. The researchers gave the example of a patient who was able to leave hospital a week earlier than anticipated and who was also unlikely to be readmitted. A later report (Wilson et al, 2005) gave further examples: a saving of £6000 a year for the local health authority in the case of a woman who no longer required one week's respite every three months once she acquired a pager; and a saving of £60,000 a year in the case of a young man who learned to live independently in his own apartment with care reduced within three months from 24 hours a day hours to 12.

Neuroprostheses

Neuroprostheses are implanted devices which can restore some kinds of physical functioning. A US study (Creasey et al, 2000) investigated two types of neuroprostheses, one for bladder and bowel care and one for hand grasp, for the extent to which they were more cost-effective than conventional care. The cost of the bladder and bowel care prosthesis was estimated using the amount of supplies, medications and procedures in life care plan; and the cost of the hand grasp prosthesis was estimated in reductions in hours of attendant care. The former recovered its initial cost within five years, while the latter would recoup its cost over the user's lifetime if attendant care was reduced by two hours a day.

Key points

- Deciding how much something costs depends on what is taken to count as 'cost'. Cost analysis should not only take into account the purchase price, but also all the other resources used, including the unpaid labour of helpers and family members (Wells, 2003; Andrich and Caracciolo, 2007).
- Although there are no definitive answers from the research about the cost-effectiveness of AT and home modifications, there is a consensus among researchers that there is the potential for substantial savings (Heywood and Turner, 2007; UK Audit Commission, 2000)
- Home modifications can produce lasting benefits. When successful, adaptations can keep people out of hospital, reduce the burden on carers and promote social inclusion (WHO, 2011).

- Even simple devices and minor home modifications can lessen the demands on carers and delay the need for formal care services, while more expensive devices plus formal services can substitute for institutionalisation (Mann et al, 1999).
- In Sweden, rehabilitation and healthcare happen largely in people's homes, and the housing modification grant to people with disabilities regardless of income or housing type has been found to be a cost-effective arrangement (Lilja et al, 2003).
- Telecare has been found to be cost-effective in delaying the need for residential care and reducing the level of formal care (Jennett et al, 2003; MTAA, 2011).
- The development of other technologies also show promise, e.g. mattresses which reduce the need for staff to turn people to prevent pressure sores; portable paging devices (Catz et al, 2005).

4.10 Decreasing the risk of injury among service users

The 'assistive technology'/'independent living' literature is focused on the needs of service users and does not discuss matters relating to staff. Staff issues are covered in the literature addressing 'manual/patient handling', and ADHC has contracted SPRC to undertake a research project on these issues, specifically in relation to the need for two-person care in community services. Hoists will be discussed in that context.

Most of the literature discussing injury prevention among service users relates to older people (e.g. Witte, 2005). Devices for fall prevention such as hip protectors or walking aids are largely relevant only for the frail elderly, although they are also helpful for younger people who have degenerative nervous diseases. However, modifications to the physical environment can play a key role in injury prevention for anyone. Injuries from falls or from other causes can happen because of the poor design or poor maintenance of homes or public areas. Increased use of heating systems during the winter increases the chance of fire and carbon monoxide poisoning.

Home modifications and AT have been found to contribute to people's safety and security, at least in the case of older people (Lansley et al, 2004). The majority of respondents (62%) in the study cited by the WHO report (2011) said that they felt safer as a result of the adaptations to their homes.

Researchers in the US (Agree, 1999) said that it was difficult to find out the causes of injuries from health surveys. Although the quality of the home environment was an important factor to take into account when examining the effects of assistance on disability, it was rarely included in the surveys. Nonetheless, the effectiveness of many forms of AT depended on the architecture being appropriate, e.g. a cane is less effective for climbing stairs when they are narrow, badly lit or structurally unsound. The study found that, although barriers to the effective use of AT were usually to be found in homes of lower quality, expensive homes were also associated with greater amounts of residual difficulty. While poor quality homes are likely to contain barriers such as narrow hallways, expensive

homes are also likely to be demanding because they are larger, with more rooms and floors.

The UK Department of Health (2007) has prepared a best practice guide to dealing with risk in health and community care. It is based on the premise that people with disabilities need to retain the fullest possible control over their lives, and aims to avoid patronising or paternalistic approaches that focus too narrowly on risk reduction. Its goals are:

- to outline a common set of principles for managing risk in relation to decisions that people make about their own lives;
- to support the principle of empowerment through the transparent management of choice and risk;
- to provide a common approach to risk, and encourage the embedding of this approach into agencies' policies, cultures and working practices; and
- to show how to balance protection with choice and control, with the aim of helping people achieve their potential without compromising their safety.

The section on AT discusses devices that have been specifically designed to manage common risks, such as detectors (gas, flood, heat, falls), telecare alarm systems, telehealth monitoring, and 'Extra Care Housing' as an alternative to residential or nursing care. The guide contains a 'Supported Decision Tool' consisting of 21 questions designed to aid the discussion and record it when someone's choices could involve an element of risk.

Key points

- Most of the literature discussing injury prevention among service users relates to older people (e.g. Witte, 2005).
- Home modifications and AT have been found to contribute to people's safety and security, at least in the case of older people (WHO, 2011).
- The UK Department of Health has prepared a best practice guide to dealing with risk for people with disabilities in health and community care (UK Department of Health, 2007).

4.11 Areas for further research

As already noted, there is little information in the literature on the possibility that AT could substitute for aspects of personal care. The general consensus is that it can, at least in part, but commissioning research about the experience of people with disabilities in NSW who use AT would clarify some of the inconsistencies. What proportion of people use AT only and no personal assistance, either formal or informal? Who are they? Does AT replace both formal and informal care, or informal care only? What are the outcomes for

clients of using AT? What are the costs and benefits of AT use, modelled against the lifetime support needs of people with disabilities?

Self-care equipment and home modification have been shown to be effective in assisting people to stay in their home. New technologies including robotics are emerging as promising. There is a need for research on the integration of multiple forms of AT, and how different kinds of AT can work together for one person.

There is little research on what the users themselves think of AT. Most of the research findings are based on survey data which provide information on the factors associated with abandonment, but do not capture people's lived experience. How do the users manage the technology? What are the benefits?

Carers' views about and experiences of AT are under-researched. How do carers manage the technology? Are there particular types of technology that might help them in their caring role? If AT can replace aspects of informal care, and the research to date indicates that it can, what are those aspects?

There is also potential for the experiences and perspectives of other key stakeholders to be investigated: for example, allied health professionals with expertise in AT; agencies which lend, lease and sell AT equipment; and prescribers and government health agencies.

The extent to which access to AT contributes the rights of people with disabilities is another area of investigation. More research is needed into ways of reducing levels of unmet need and enabling people with disabilities to participate fully in their communities.

5 Sensory and Communication Disabilities: Introduction

The sensory disabilities discussed in this section are categorised as deafness and hearing impairment, blindness and visual impairments, combined deafness and blindness, and speech/communication impairment (Alt Beatty, 2011). These categories are often used to describe sensory disabilities, but there are a myriad of differences that exist within each of these disability types (Skellington et al, 2006).

There is limited literature on the service needs of people with sensory disabilities (as the Alt Beatty review (2011) also found). A systematic review of the research on dual sensory loss, i.e. deaf-blindness (Brennan and Bally, 2007), for example, found that there was limited information into its impact on people, a situation that was compounded by the lack of research and training infrastructure. A recent review of AT for low vision found no conclusive evidence of the effectiveness of AT for vision rehabilitation, although the evidence does indicate that optical devices, both electronic and non-electronic, are effective options for people with vision impairments (Jutai et al, 2009).

Again, as in the case of physical disabilities, we did not find research that determined the extent to which AT could substitute for or supplement personal assistance in the case of people with sensory disabilities.

Nonetheless, there is information on sensory disabilities more generally, and this is what is discussed in the sections below.

5.1 Government and non-government AT providers

The Commonwealth Government's Hearing Services Program provides free hearing assessments, hearing aids, and replacements for lost, damaged or obsolete aids, for people on government benefits, young people under 21, Indigenous people, old-age pensioners, defence-force personnel and war veterans. People over 21 and not in receipt of benefits can obtain help through the Commonwealth Rehabilitation Service if their hearing loss is limiting their job prospects.

For those who are not financially eligible for government services, major public hospitals provide hearing assessments free of charge, although usually not hearing aids. Most people have to pay for them themselves, although some health funds will partly reimburse the cost.¹³

The Australian Government's Hearing Services Program is administered by the Office of Hearing Services (OHS). Both the services and the aids are free to those who are eligible, except for a small annual fee for batteries and maintenance.¹⁴ In the case of the funding of hearing aids, the submission to the Australian Senate inquiry into hearing health in

¹³ http://www.shhhaust.org/information sheets/03_HowDoIGetAHearingAid.pdf

¹⁴ <http://www.hearing.com.au/office-of-hearing-services>

Australia by the Hearing Aid Manufacturers and Distributors Association of Australia said that around 75 per cent of hearing aids were paid for with public funding (The Senate, 2010: 75).

The list of hearing devices approved for public funding is reviewed every 18 months by the Australian Government Department of Health together with industry stakeholders, in order to incorporate technological advances. Recent advances have included enhanced user preferences, blue tooth connectivity and adaptable directional microphones (The Senate, 2010: 75-6).

There are also hearing-aid banks where people on low incomes who are not eligible for the government-funded aids (e.g. the unemployed, refugees) can obtain reconditioned behind-the-ear hearing aids at little or no cost. These are usually small-scale and run by volunteer or charity organisations, and sometimes by hospitals. They rely on donations of aids, which are then cleaned, reconditioned and fitted by volunteer hearing-aid practitioners (The Senate, 2010: 79).

The Deaf Society NSW has a loan scheme for baby cry alarms. The Deaf Society is also administering the NSW Government's Smoke Alarm Subsidy Scheme. People who are deaf, deafblind and hard of hearing will be provided with a smoke alarm with a strobe light, pillow shaker and beeper.

Vision Australia lists a range of non-government sources of AT provision or funding options for people who are blind or have low vision. Telstra, for example, is required by law to provide a Disability Equipment Program which supplies telecommunications equipment for Telstra customers with disabilities, including big button telephones, both print and Braille TTYs (teletypewriters) (Astbrink, 2010), and Telstra bills in large print or Braille.

In NSW, provision of equipment for assistance for physical disabilities is the responsibility of EnableNSW (and the equivalent organisations in the other states and territories). EnableNSW also funds or provides equipment in the area of sensory disability, for example, communication equipment for people with speech impairments,¹⁵ items such as Brailers and video magnifiers/CCTVs for people who are blind, and vibrating paging systems for people who are deaf-blind.¹⁶

Visual Independence is another resource. A Lions International Foundation, it provides help with AT for Australians living with blindness and low vision. There are two schemes – the ID Mate talking barcode-scanner grants, and the new Trekker Breeze GPS grants. Eligibility for both grants is means-tested – earnings should not exceed \$10,000 above Centrelink pension entitlements (and \$50,000 combined income if the applicant is partnered). In the case of the ID Mate, people in NSW can also apply through Vision Australia for assistance under PADP. In the case of the Trekker Breeze GPS devices, Visual Independence was offering nine units sponsored by NAVTEQ, between 26

¹⁵http://www.enable.health.nsw.gov.au/__data/assets/pdf_file/0003/154803/110728_About_EnableNSW_factsh eet_PRESS.pdf

¹⁶ <http://www.visionaustralia.org/info.aspx?page=2120>

September and 30 November 2011. People can also obtain Trekker Breeze units from mobility service providers such as the Guide Dog Associations.

Another resource for blind people is VisionCare NSW, which provides spectacles, magnifiers and low-vision aids to the value of \$230 once every two years, to people who receive benefits and who meet the criteria of the NSW government's means-test and other guidelines.¹⁷

¹⁷<http://www.visionaustralia.org/info.aspx?page=2120>;
http://www.visualindependence.org.au/main/page_grants.html

6 Deafness: AT Types and the Impact of AT on Care Needs

As noted by the Australian Senate Community Affairs References Committee inquiry into hearing health in Australia (The Senate, 2010), a comprehensive survey of the many types of technologies available for people with hearing impairments would be a huge task, and hence is beyond the scope of this report. This section describes only two of the most commonly used AR types.

The kind of AT a deaf person might use varies, not only depending on the degree of severity, but also on whether it is a lifelong condition (pre-lingual) or whether the person became deaf after they had learned spoken language (post-lingual). There are also cultural issues at stake, in particular the tension between viewing deafness as a defect to be rectified and viewing it as valid form of human identity (Byrd et al, 2011).

Hearing aids will not correct all forms of deafness, and cochlear and other forms of implant (see below) may not be appropriate for people who have developed signing as their primary means of communication and who are part of the Deaf community. Those most likely to need to participate in the hearing culture, and who would benefit most from assistive technologies which enabled them to do this, would be people whose hearing loss is post-lingual. People who are part of the Deaf community would have different AT needs.

6.1 Hearing aids

Hearing aids are the most common form of assistive technology for people with hearing impairment. According to the Hearing Care Industry Association submission to the Australian Senate inquiry into hearing health, around 24 per cent of Australians who would benefit from a hearing aid have one. This is in fact quite a good result by international standards, although it falls short of Denmark's international best practice level of 45 per cent (The Senate, 2010: 75).

There is research which suggests that access to hearing aids, at least in the US, is constrained by income. Brennan and Bally (2007), for example, reported on a US study of Hispanic adults with hearing loss, which found that those with incomes above the poverty line were nine times more likely to be using hearing aids than people with incomes below the poverty line. This is less likely to be the case in Australia, given the system of government provision for people on benefits, although people on low incomes would still have difficulty paying for high quality aids. Hearing aids cost between \$3,000 and \$10,000 a pair, as well as the cost of batteries and maintenance, and need replacing every three to five years (The Senate, 2011).

6.2 Cochlear implants

A cochlear implant is a surgically-implanted electronic device with an external sound (or speech) processor, which replaces the function of the damaged inner ear (the cochlea). It operates differently from a hearing aid. Instead of making sound louder, the implant operates by sending electrical impulses to the nerve endings in the inner ear.

Cochlear implants enable children to develop speech and language to levels comparable with those of their peers with hearing peers (Geers et al., 2003; Svirsky et al., 2000). In this context, it is also important to note that cochlear implants in very young children are contentious in the Deaf community, for a number of reasons, and that these ethical and political dimensions of implants are beyond the scope of this review (Blume, 2009).

A US study of 27 pre-lingually deaf young adults who received cochlear implants between the ages of two and 12 years (Spencer et al., 2004) found that the cohort compared favourably with their hearing peers on measures of academic achievement. Their educational level was similar to the level gained by their parents, and over 50 per cent of those who were college-age had enrolled in college. An earlier US study of 29 pre-lingually deaf children who had had cochlear implants three or more years before (Tomblin et al., 199) found that they had significantly better scores on language tests than pre-lingually deaf children without implants, even when the non-implant children used hearing aids. There were similar findings from more recent French study of 100 pre-lingually deaf children who received cochlear implants before six years of age (Venail et al., 2010). The children achieved satisfactory educational and employment outcomes, as long as they had no additional disabilities.

As in the case of hearing aids, access to cochlear implants depends on socio-economic factors, including income, certainly in the US but perhaps in Australia too. Another US study (cited in Alt Beatty, 2011), this time of 105 children aged five years and under, found that the children were more likely to be referred for cochlear implants if their parents were married and had health insurance, both of which are proxies for income status. In Australia, sound processors cost between \$8,000 and \$12,000, on top of batteries and maintenance, and last only about 10 years.

The clinical costs of the initial implant and ongoing medical treatment are covered by Medicare for all Australians. State and territory governments provide cochlear implantation at public hospitals (The Senate, 2011). Australian Hearing provides both pre- and post-implant communication training and audiological assessment. They also maintain, repair and upgrade implants and sound processors for eligible children.¹⁸ The Office of Hearing Services replaces damaged, lost or obsolete sound processors for eligible clients under 21 years of age, but not for adults 21 and over even though their level of income would qualify them for replacement hearing aids.

¹⁸ <http://www.hearing.com.au/cochlear-implants>

The Australian Senate Committee of inquiry into hearing health (The Senate, 2011) recommended that the Office of Hearing Services extend its policy on the replacement of implant processors to include eligible clients over 21 years of age, and not just those under 21.

6.3 Telecommunications

The standard telecommunications system for deaf people is the telephone typewriter (TTY) (or TDD – telecommunications devices for the deaf). This is a special device that enables people who are deaf, hard-of-hearing, or speech-impaired to use the telephone by typing messages back and forth to one another instead of talking and listening. A TTY is required at both ends of the conversation.¹⁹ This allows deaf people access to fixed line telephones, although only those equipped with TTY. This is the form of telecommunication recognised in the Australian legislation.

Deaf Australia, the national peak organisation for Deaf people,²⁰ has pointed out that TTY has a number of disadvantages:

- Only one person can 'talk' at a time (interrupting the other 'speaker' makes the letters jumble up).
- Typing speed is slow compared with spoken or signed communication (65 words a minute typing compared to 240-300 words a minute in speech or signing).
- It needs fluency in the English language to communicate with the hearing (English is a second language for many deaf people).
- It is not possible to convey the emotional content of the conversation fully and hence gauge the reactions of the other 'speaker'.
- It requires turn-taking signals such as ga (go ahead), which causes delays.
- It connects only with other TTYs or with the national relay service (NRS).

The NRS is an Australia-wide phone service available 24 hours a day seven days a week which allows people who are deaf or who have a hearing or speech impairment to communicate with someone who has a standard phone, and vice versa. It involves ringing a call centre where a staff member converts messages from TTY to the spoken word (and vice versa) and passes them on between the two callers.²¹ In the US, this system is called telecommunications relay services (TRS), and it is a requirement of the Americans with Disability Act that telephone companies establish continuous TRS both interstate and intrastate. In 2002, in response to the limitations of TTY and to the developments in new technology, the US Federal Communications Commission allowed for the provision of video-relayed calls as part of the TRS (Rosen, 2007).

According to Deaf Australia, TTY is now outmoded. Deaf people now use other methods of communication, e.g. SMS messaging, video communication using 3G network, the internet

¹⁹ <http://tcds.edb.utexas.edu/information-services/what-is-a-ttytd/>

²⁰ http://www.deafau.org.au/info/paper_voctel.php

²¹ <http://www.relayservice.com.au/about/>

using computer webcams, Instant Messaging and a slowly growing number of videophones using high-speed broadband. TTY did serve its purpose, given that there was no other telecommunication option available, but in the 20 years since it was introduced no alternative national telecommunications system for Deaf people has been developed.

Text-messaging is a rapidly growing practice among people who are deaf. Australian researchers (Power and Power, 2004) discussed what was known at the time about the use of mobile phones for texting by deaf people. They estimated that the rate of use was much higher than among hearing people because of the increase of mobile phone ownership among deaf people.

A Canadian study (Akamatsu et al, 2006) investigated the possibilities of using two-way pagers with text messaging as a way of increasing the independence of deaf adolescents and reducing their parents' concern about their safety. The study found that text messaging was indeed useful for the deaf adolescents, and that it helped alleviate at least some of the parental anxiety that kept them from developing their independence as readily as their hearing peers. So successful was the program that it spread to other schools by word-of-mouth, and the researchers recommended that the messaging devices be included in the students' Individual Education Plans, as well as funding them through Assistive Devices programs for people with disabilities.

Reeves (2010) also discussed the new technology and its usefulness for deaf people:

Quietly over the last decade, phones that make text messaging easy have changed life profoundly for millions of deaf people ... For the first time, a generation of deaf people can communicate with the world on its terms, using cell phones, BlackBerrys or iPhones.

This author also mentioned several US mobile phone companies which offered the plans specifically for deaf people, and US cities which have adopted texting as a way of accepting emergency calls.

6.3.1 3.2.4 Other AT for deafness and hearing impairment

Self Help for Hard of Hearing People (SHHH, no date) lists on their website a number of devices for people who are hard of hearing, called Assistive Listening Devices (ALD). These are intended to supplement a hearing aid, or even to substitute for it for those whose hearing loss is not severe or who cannot wear a hearing aid. All are available for trial use from SHHH (although not for sale). Listed are:

- Devices for listening to amplified sound (TV, radio), e.g. headphones, audio loop systems, telecoil, and for captioning TV programs;
- Devices for helping with interpersonal communication, e.g. mini amplifiers, hand-held microphones;
- Devices for using with the telephone, e.g. TTYs, telephone couplers and amplifiers; and
- Alarms and alerting devices.

The Australian Senate Committee inquiring into hearing health (The Senate, 2010) heard evidence about the limited extent to which closed captioning is available to help people with hearing impairments access television, DVDs and films. 'Closed' captioning means that it is not available to all viewers, only to those who activate it. Media Access Australia identified some of those limitations in relation to closed captioning in TV and DVDs: overnight free-to-air television, sports television, and digital multi-channel programming are rarely captioned; and less than half of subscription television and only 55 per cent of DVDs are captioned. Moreover, only 24 of the around 500 cinemas in Australia have closed captioned sessions.

Both commercial television broadcasting licensees and national broadcasters are required by the Broadcasting Services Act 1992 to provide captioning services for programs shown during prime TV viewing hours (6:00 p.m. to 10:30 p.m.) and for news or current affairs programs outside these hours. The Department of Broadband, Communications and the Digital Economy is reported to have said that, by December 2011, under agreements between the free-to-air TV broadcasters and the Australian Human Rights Commission, 85 per cent of content broadcast between 6:00 a.m. and midnight will also be captioned (The Senate, 2010).

Key points

- The AT needs of people who are deaf vary, depending on the degree of severity, on whether it is a pre-lingual condition (before the development of language) or post-lingual, and on the extent to which the person is a member of the Deaf community.
- Hearing aids and cochlear implants are the most common forms of AT (The Senate, 2010).
- Around 24 per cent of Australians who would benefit from a hearing aid have one, a level which is comparable with other countries (The Senate, 2010).
- Children who receive cochlear implants before the age of two develop better language ability than children who receive implants after that age, or who do not receive them (Byrd et al, 2011).
- The standard telecommunications system for deaf people is the telephone typewriter (TTY) although this has a number of disadvantages, e.g. it can only communicate with other TTY phones (Deaf Australia).
- There is a National Relay Service, a phone service available 24 hours a day seven days a week which allows people who are deaf or who have a hearing or speech impairment to communicate with someone who has a standard phone, and vice versa, via a call centre (Deaf Australia).
- Deaf people are now using other forms of telecommunications, e.g. text messaging (Deaf Australia).

7 Blindness: AT Types and the Impact of AT on Care Needs

Vision Australia defined assistive technology as 'all equipment and technology, both hardware and software, that assist people who are blind, deafblind or have low vision to access or participate in a particular activity or range of activities'.²²

Researchers in Germany (Becker et al, 2005) commented that there was a wealth of devices aimed at addressing the negative day-to-day consequences of vision impairment and blindness, perhaps more so than for any other chronic condition. Examples they gave of such devices included special eyeglasses, long canes, phones with enlarged buttons, magnifying glasses, large-print books, newspapers and journals read on cassettes, video magnifiers, and even spatial orientation and information aids based on the GPS.

A review of community care and mental health services for adults with sensory disabilities in Scotland (Skellington et al, 2006) also found that people with visual impairments could require a range of equipment to help them in their daily lives. Appropriate environmental aids and equipment are important additions to the quality of people's lives, and help in independent living. Examples include:

- Aids to mobility (including all types of cane).
- Oral/aural and written communication (digital voice-recorder, big-button telephone, writing frame, signature guide and braille equipment).
- Viewing and communications technology (computer equipment and software).
- Personal health and well-being equipment (medicine dispenser, talking body-thermometer, auto-drop eye-drop dispenser, talking blood-pressure monitor, talking clocks, watches, money holders).
- Domestic adaptations (talking appliances, tactile products and microwave, self-threading needles, tactile tape measure, liquid-level indicator, talking kitchen scales, safety can opener)
- Building and lighting adaptations (Skellington et al, 2006)

Computer-based technologies for people with visual impairments include:

- Braille embossers which convert computer-generated text into Braille.
- Braille translation programs which convert scanned-in or word-processed text into Braille.
- Reading tools and learning disabilities programs, both software and hardware, to make text-based materials more accessible for people who have difficulty with reading, e.g. Scanning, reformatting, navigating, speaking text aloud.
- Braille displays which lift small pins to form Braille characters and which can be refreshed as the reader moves from line to line.
- Screen enlargers or magnifiers.

²² <http://www.visionaustralia.org.au/info.aspx?page=1230>

- Screen readers which can speak everything on the screen – graphics, control buttons, and menus as well as text.
- Voice recognition programs which allow people to give commands and enter data using their voices rather than a mouse or keyboard.
- Text-to-Speech (TTS) synthesisers which speak out loud information on the screen such as letters, numbers and punctuation marks.
- Talking word processor software programs that use speech synthesisers to provide auditory feedback of what is typed. And
- Large-print word processors which allow the user to view everything in large text without added screen enlargement (Alt Beatty, 2011)

Most advocates for blind people say that users value highly their access to aids and technology and that it increases people's independence and quality of life (Alt Beatty, 2011). Assistive devices are an important means of self-efficacy in helping people to take control and in supporting them to attain important goals. At the same time, they could also be seen as a sign of loss of competence, and this could mean that people were reluctant to use them (Becker et al, 2005).

There is US research that indicates that the way people feel about using assistive technology can depend on the type of technology, at least in the case of people who are losing their sight later in life. Horowitz et al (2006) interviewed 438 older people with age-related vision impairment, in order to find out whether there was any relationship between their use of optical devices and adaptive aids on the one hand, and on the other, changes over a six-month period in levels of depression and in their ability to perform instrumental activities of daily living. The study found that those who used optical devices (e.g. magnifiers, telescopes, special lenses) experienced significant declines in disability and depressive symptoms, but those who used adaptive devices (e.g. large print materials, talking items, handwriting guides) did not. The researchers suggested that the differences were due to the fact that optical devices allow for continuity (people can still read visually), whereas adaptive aids compensate for lost function and hence emphasise its loss.

However, there is a drawback to most of this exciting new technology, and that is cost. The initial purchase and maintenance costs may be high, and devices often need to be updated regularly. Rosen (2007) pointed out that people with disabilities have been compensating for the less-than-inclusive standard telephone design, for example, by providing their own assistive technology, such as larger or more sensitive keypads, specially designed software for making phone calls.

Key points

- It has been estimated that there is a wider range of equipment available for people who are blind than for any of the other sensory disabilities (Becker et al, 2005).
- The drawback to most of the new technology is its cost, both the original purchase price and the cost of maintaining and replacing it (Rosen, 2007)

8 Deaf-blindness

Deaf-blindness is a low-incidence disability and there is very little research on this dual sensory loss (Glass, 2000). There is also a lack of rehabilitation services which integrate both vision and hearing impairments, at least in the US. A notable exception in the US is the rehabilitation program offered by the Helen Keller National Center for Deaf-Blind Youths and Adults (Brennan and Bally, 2007; Sauerberger, 1993; Sauerburger and Jones, 1997).

Dual sensory loss can happen at any age. It can be present at birth, the result of genetic factors, or it can be caused by accidents or illness. However, most cases of deaf-blindness are the result of age-related disease processes, and these rarely result in total deafness or blindness (Brennan and Bally, 2007). Many other deaf-blind people have been born deaf or hard-of-hearing and they lose their sight as adults (Azenkot et al, 2011).

Children who are born deaf-blind have unique communication, developmental, emotional, and educational needs that require special knowledge, expertise, technology, and assistance. However, new research into cochlear implants, cortical stimulators and augmentative communication is adding to knowledge of ways to improve the quality of life for the child who is deaf-blind (Holte et al, 2006). The Royal Institute for Deaf and Blind Children²³ in Australia has also pointed out that people who are both deaf and blind usually require ongoing, and sometimes quite extensive, support to participate in life, even at the most basic level of communication. How much support they need depends on the level of their impairment. For people with severe vision and hearing impairment, tactile communication is essential, e.g. finger-spelling, presenting objects as symbols (e.g. a sponge means having a bath).

When deaf-blind people go out in public, they commonly use cards with printed messages telling people they are deaf and blind, and giving information or asking for assistance (Azenkot et al, 2011), e.g. 'Please help me cross the street, Tap me if you can help. I am deaf and blind' (Bourquin and Sauerburger, 2005). A 2002 UK website for deaf-blind people lists a number of devices deaf-blind people can use for communication,²⁴ and a US website has information about orientation and mobility for deaf-blind people.²⁵

One example of the use of assistive technology to support the independence of people who are deaf-blind involved an Independent Living project in the US (Venn and Wadler, 1990). The project was designed to maximise the independence of teenage school students, who had severe to profound intellectual disabilities as well as being deaf and blind, in their transition from school to adulthood. The technology was a video monitoring system as a way of indirectly supervising the young people in an independent living apartment and of ensuring their safety. The students were unobtrusively supervised and

²³ http://www.ridbc.org.au/resources/db_info.asp

²⁴ <http://www.deafblind.com/index.html>

²⁵ <http://www.sauerburger.org/dona/db.htm>

monitored outside the apartment as well. They were non-verbal although they did understand a few basic signs and could use them to communicate. The parents' concerns about privacy and about the fact that boys and girls were living together were successfully addressed. In the four and a half years of the project, there was a marked increase in the young people's autonomy. They learned to manage many daily living and working skills they would not have acquired in traditional programs with one-on-one instruction and direct supervision.

Graduate students at the University of Washington (Azenkot and Fortuna, 2010) developed a tool which enables blind and deaf-blind people to use public transport. Based on MoBraille, it is a way of connecting an Android phone to any Wi-Fi-enabled Braille display and thus allow a Braille reader to benefit from the phone's features such as GPS and 3G network connectivity. It is intended to be an alternative to ATs for blind and deaf-blind people such as GPS systems or Humanware's DeafBlind Communicator. The latter enables communication between a hearing-sighted person and a deaf-blind person by displaying input from a mobile phone on a Braille display. But these devices are prohibitively expensive and have limited functionality. The MoBraille tool enables people to find the right bus stop, board the right bus, and get off at the right stop, and displays the information in Braille. The blind participants in the research said they preferred to use Braille rather than text-to-speech (TTS) when they were travelling because it was more private. TTS could be distracting and draw unwanted attention. It was also hard to hear on a busy street, and it sometimes mispronounced street names.

A further development by the same team (Azenkot et al, 2011) is GoBraille. This involves two related Braille-based applications that provide crowd-sourced information about bus stop landmarks as well as real-time bus arrival information, and use Braille input and output. The tool was mainly intended for blind people, but the researchers also involved a deaf-blind person as a co-designer. They found that the technology had potential for increasing the independence and safety of the blind people, and enabled them to explore unfamiliar places. They did encounter further difficulties with the deaf-blind person, who had limited proficiency either in English or in Braille. But a number of simplifying adaptations enabled this person to use the tool as well.

Key points

- Deaf-blindness is a low-incidence disability and there is very little research on dual sensory loss (Glass, 2000)
- People who are both deaf and blind usually require quite extensive support to participate in life, although most cases of deaf-blindness are the result of age-related disease processes and rarely result in total deafness or blindness (Brennan and Bally, 2007).
- There have been recent attempts in the US to develop cheap devices that enable deaf-blind people to navigate in public spaces and catch public transport (Azenkot and Fortuna, 2010).

9 Communication Disabilities and AAC

Communication disabilities may emerge from:

- Speech-language impairments, for example as the result of a stroke or degenerative condition.
- Hearing difficulties.
- Physical disabilities.
- Intellectual disabilities.
- Cognitive impairments, for example an acquired brain injury (Speech Pathology Australia n.d; Moore, 2008; Stern, 2008).

People with communication disabilities and complex communication needs may use Augmentative and Alternative Communication (AAC) technologies. AAC describes any system of non-speech communication, including body language and signing. AAC assistive technologies are types of AAC.

A study for the Independent Living Centre in Western Australia (Moore, 2008) found that it was difficult to get statistics on the extent of the need for communication devices, largely because of the different terminologies used to refer to communication disability. The report noted that the WA Disability Services Commission annual report said that 56 per cent of people who accessed the Commission's services in 2006-2007 required support with communication.

9.1 AAC devices

Communication aids give people with disabilities resources to communicate effectively, not only with people they know well, but also with those they meet casually. This allows people with a wide range of impairments – cerebral palsy, ASD, Alzheimer's, stroke survivors – to have new aspirations and expectations and to experience new chances in life. In contrast, the absence of any appropriate communication services can mean that people have low aspirations and often unnecessarily high levels of dependency on others. Communication is a vital aspect of enabling people with disabilities to be independent, have some control over their lives, and fulfil their potential as citizens (Bush and Scott, 2009),

Scope's Good Practice Guide in the UK (Scope, 2002) described low-tech aids as anything that didn't need batteries or an electricity supply. The authors commented that these aids were often more useful than high-tech aids because they could be used anywhere. They gave as examples alphabet boards and books with symbols and pictures as well as words. They pointed out that these low-tech aids also needed to be updated from time to time because new occasions and meeting new people meant that the communication aid needed new words, symbols or pictures.

People with communication disabilities may prefer low-tech (e.g. communication boards) or electronic AAC, or both. A survey of speech therapists in New Zealand (Sutherland et al,

2005) found that low-tech aids such as communication boards were the most likely AAC to be used by both adults and children. In order to ensure that people's needs are met, it is important that they have available an individualised assessment, services that support individual communication systems, and flexibility (Sampson, 2009).

Koul and Hester (2006) commented that the development of speech-generating devices has been one of the most significant advances in enhancing the communicative abilities of people with severe speech impairments. Such devices have been found to be particularly effective for people with severe intellectual disabilities, who seem to be better able to convey information using the devices than when they use gestures or vocalisations.

Synthetic speech is not useful for everyone. Some people dislike the unnaturalness of the voice, its lack of emotional range, and the inability to control the pitch and volume (Stern, 2008). However, other people prefer synthetic speech over their own voice, and research shows that people will work hard to accept it (Stern, 2008).

Some AAC devices are relatively expensive and acquiring them requires a lengthy and challenging process. It involves comprehensive multi-disciplinary assessment and implementation in consultation with a number of stakeholders, including the person and their family but also professionals such as speech pathologists and occupational therapists. Moreover, there are multiple challenges for the professionals working the area. The rapid advance of technology means that each new device requires clinicians to find additional money to buy it, to up-grade staff skills and to allow clients to trial it. AAC service provision requires the up-dating of clinical expertise, and it is difficult to find time for this when a therapist has a large caseload. Then after clients have been provided with the devices, there is an ongoing need for support from a therapist (Moore, 2008).

Rates of abandonment of AAC devices are thought to be high, although this is changing over time. Moore (2008) cited a 2007 study by Scope which found that 75 per cent of high-tech AAC devices were abandoned. However, AAC acceptance has increased in the last decade considerably, and both AAC users and carers have reported positive attitudes towards the technology in several studies (reviewed in Beukleman et al., 2007).

Commentators have noted that there are many benefits to using high-tech AAC systems, including a greater range of communication options and increased social acceptance (Sutherland et al, 2005). However, they are not perfect and they come with disadvantages as well. One of the people involved in producing Scope's Good Practice Guide said that he had tried a lot of electronic communication aids but that he and his personal assistants had found them slower and less personalised than spelling out the words he needed (Scope, 2002). Many of the participants in a US study also voiced their frustration with the slowness of communicating using AAC, and expressed the need for technology that was faster and easier to use. While they acknowledged its benefits, they also said that technology was not the most important factor contributing to the outcomes they wanted (Lund and Light, 2007).

A US study (Johnson et al, 2006) surveyed speech pathologists who were members of the American Speech-Language-Hearing Association, to find out what they believed were the

most important reasons why people *abandoned* their AAC devices. The authors reported five reasons, ranked in order of importance:

1. The user's communication partners believed they could understand the user without the device.
2. There was too little opportunity to use the device.
3. There was no need to use the device.
4. There was a lack of motivation on the part of communication partners.
5. The users preferred to communicate in other ways.

The authors also ranked the top five factors the speech pathologists believed related to the long-term *successful* usage of AAC:

1. The user succeeds in communicating.
2. The device is valued as a method of communication by both the user and the communication partners.
3. The system serves a variety of functions.
4. There is a match between the user's physical capabilities and the system characteristics. and
5. Both the user and their family support the use of the system (Johnson et al., 2006).

9.2 Services

The Disability Policy & Research Working Group, a standing committee of the Community and Disability Services Ministers' Advisory Council, has produced a list of core equipment for people with disabilities currently available in all Australian states and territories. The communication aids listed are: electro-larynx voice generators (devices which generate air oscillations in the throat, which are transformed into speech by the movement of the soft palate, tongue and mouth); and electronic dialogue units or communication devices (e.g. portable and non-portable digital electronic displays, recorded or synthetic speech output equipment) (DPRWG, 2011).

Access to AAC services for people with sensory disabilities can be problematic. The ILC WA project (Moore, 2008) found that that there were fewer services for adults than for children. Children with disabilities in WA are eligible for early intervention and school-aged therapy services, and for services provided through the WA Department of Health. But access to adult therapy services varies depending on factors such as the availability of therapists, the size of their caseloads and the adequacy of services to support the prescription and implementation of AAC.

There are limited opportunities for professionals to get training in the specialised skills required for the provision and use of AAC. Hunter (2010) cited an Australian study which surveyed a national sample of speech pathologists about their AAC practice (Balandin and Iacono, 1998). The study found that there were few avenues of access to higher qualifications in AAC, and limited opportunities to get support from therapists more experienced in the area. Many of the therapists surveyed said they were proficient in

unaided systems such as signing, but that they had less knowledge of high-tech AAC systems.

The same study also found that speech pathologists may not prescribe AAC because they are mistaken about its benefits. The authors concluded that there was some indication that professionals involved in AAC may be misinformed about its applicability for particular client groups (Hunter, 2010).

Key points

- AAC can be low-tech (e.g. communication charts, symbol boards), or mid- to high-tech (e.g. an electronic or synthesised voice), but both need to be updated periodically.
- Speech-generating devices have been found to be particularly effective for people with severe intellectual disabilities (Koul and Hester, 2006)
- Communication aids are provided through each Australian jurisdiction's aids and equipment program (DPRWG, 2011).
- While there are many benefits to high-tech AAC systems, there are also disadvantages, e.g. slowness, expense, the unnaturalness of the synthesised 'voice', a tendency to break down and difficulty getting them repaired, unreliability (Scope, 2002).
- Abandonment rates of AAC are thought to be very high, although decreasing over time (Moore, 2008; Beukelman et al., 2007)
- Reasons for abandonment include: a belief that it wasn't needed; too little opportunity to use it; and no desire to use it (Johnson et al., 2006).
- Factors leading to successful AAC usage include: successful communication; the device is valued; it serves a number of functions; and it matches the user's capabilities (Johnson et al., 2006).
- AAC services are limited, especially for adults (Moore, 2008)

9.3 Cost

9.3.1 Cochlear implants/hearing aids

The Alt Beatty report (2011), citing the Access Economics 2006 report, *Listen Hear! The Economic Impact and Cost of Hearing Loss in Australia*, noted that around 400 Australians received implants every year, and that one-third of those people were aged 18 or under. In October 2005, the cost of one particular cochlear implant system was \$25,070, adding up to a cost to Medicare of around \$10 million a year for implantable devices for

hearing loss. The Access Economics report cited Cochlear Ltd's estimate that fewer than 10 per cent of people likely to benefit had accessed the technology.

The Alt Beatty report (2011) also cited a social cost-benefit study of early intervention programs for children with hearing loss released by First Voice, a coalition of centres supporting children with hearing difficulties and their families. The study included both direct operational costs and the opportunity costs to families, and estimated \$203,300 in costs over five years. In contrast, the study estimated \$382,890 in benefits consisting of productivity gains, reduction in disability and enhanced quality of life, costs avoided, the likelihood of being in paid work and injuries avoided – a benefit-cost ratio of 1.9:1.

A US study (Francis et al, 1999) also found that cochlear implantation led to savings in educational services for deaf children. This was especially the case when it was combined with aural rehabilitation, which increased the children's access to acoustic information and spoken language, and consequently led to higher rates of placement in mainstream schools and lower dependence on special education support services. The costs associated with rehabilitation mainly relate to support (e.g. speech therapy, special-needs assistants, personal tutors) and education, mainstream schooling being less expensive than specialised schooling (Venail et al, 2010).

Other US studies (Palmer et al, 1999; Cheng et al, 2000; Mohr et al, 2000) have found that cochlear implants in profoundly deaf children have a positive effect on quality of life at reasonable direct costs. They also appear to result in net savings to society to the extent that the benefits lead to reduced educational costs and increased earnings. One study investigating cochlear implants in post-lingually deaf adults (Palmer et al, 1999) estimated a cost-utility of \$US14,670 per quality-adjusted life-year (QALY) using the Health Utility Index, and cost-utility ratios of between \$US9,029 and \$US5197 (depending on the estimation method used) for direct medical costs only.

The cultural and ethical dimensions of cochlear implants cited in Section 6.2 are also relevant to these studies.

9.3.2 Tele-interventions

Tele-interventions show promise as a way of reducing the cost of services for children who are DHH, deaf-blind, or visually impaired. Researchers in the US (McCarthy et al, 2010) reported on an Australian project which they referred to as the largest and most comprehensive tele-intervention effort yet undertaken to deliver early-intervention services to children. Run by the Royal Institute for Deaf and Blind Children since 2002, the project uses two-way video-conferencing to provide services to more than 100 children a year.²⁶ Videoconferencing equipment is set up in the family's home and instruction materials are sent to the families by post or over the Internet. Families are encouraged to visit the RIDBC central campus in Sydney, where they can access a wide range of services during this initial visit. They are provided with travel expenses and free accommodation. An evaluation

²⁶ <http://www.ridbc.org.au/services/teleschool.asp>

of the project²⁷ found that the cost of the tele-intervention services was slightly higher than the cost of face-to-face services. However, it was highly likely that that cost would decrease in the future, as the costs of the remote technology connections decreased and the motor vehicle costs rose with the escalation in fuel prices.

Nonetheless, there is still too little evidence about the cost-effectiveness of tele-interventions. The situation is similar to the case of telemedicine, where good-quality studies are scarce and there is insufficient evidence that the outcomes for children or the costs of delivery are comparable with those in face-to-face services. What is needed are randomised controlled trials comparing tele-intervention services with face-to-face services for large populations (McCarthy et al, 2010).

Key points

- Although there is little information on the cost to society of hearing impairment, there is evidence that interventions aimed at children could result in substantial savings, mostly in the reduced need for special education services (Palmer et al, 1999; Cheng et al, 2000; Mohr et al, 2000).
- Tele-interventions show promise as a way of reducing the cost of services for children who are DHH, deaf-blind, or visually impaired, although there is still too little evidence about their cost-effectiveness (McCarthy et al, 2010).

9.4 Gaps in assistance

Being unable to afford access to information technologies—aids and appliances including home safety systems, maintaining cochlear implants including replacing the external processors—is one of the main service gaps for people with sensory disabilities reported to government inquiries (Alt Beatty, 2011).

There is a need for more resources for training people in the use of the devices, for updating people's skills, or for updating the devices themselves (Hunter, 2010). Researchers in the UK (Murphy et al, 1996) estimated that the participants in their study of the use of AAC systems received just 40 hours of therapy per year. This contrasts with the 200 hours of teaching that someone learning English as a second language would need in order to be able to hold a basic conversation. Learning to use an alternative method of communication is like learning a language, and yet there is comparatively little time allowed for it. There are also few professionals who are adequately trained to prescribe them.

In the case of the hearing-aid banks, although they help many people who are ineligible for the Australian government scheme through the OHS, resources are limited and services are unable to cope with the demand. Moreover, there tends to be a limited range of devices, and there is limited knowledge of the existence of the banks. The Senate inquiry

²⁷ K. Dally and R. Conway (2008) *Invest to Grow: Local Evaluation Report for RIDBC Remote Early Learning Program* unpublished report, University of Newcastle.

into hearing health received submissions critical of a health system where such banks were necessary—‘a third world solution’—although most of the evidence was supportive of the banks themselves (The Senate, 2010: 79-81).

As well as hearing aids, the OHS supplies to children and young people under 21, and upgrades, the sound processors which are the externally worn part of the cochlear and other implants.²⁸ The processors must be replaced every five to 10 years and they cost between \$8,000 and \$10,000. Adults must pay to replace or upgrade processors out of their own pockets, even if their level of income means they are eligible for OHS services. Since these are people who by definition are on low incomes, most of them do not have access to such a large sum and hence must remain with no auditory function at all. In their submission to the Senate inquiry, Australian Hearing, the Australian government agency which supplies hearing devices, said that they did provide maintenance and replacement parts for existing processors, even though they couldn’t provide replacement processors or upgrade them.

Many people with sensory disabilities cannot use standard phones, and the current programs offered by Telstra (and to a lesser extent, Optus) do not meet all their needs, especially given the fact that the technology is constantly changing, as are the ways people use telecommunications. One of the chief barriers is expense. There are many off-the-shelf mobile phones with services and applications to suit specific disability needs (Apple’s iPhone being one example). But the cost is prohibitive for people on low incomes. There is a need for a Disability Equipment Program which is responsive to new technologies and reflects current trends towards mobile phones and internet-based communications, and which doesn’t focus only on products for fixed phones (Astbrink, 2010).

Because signing is the language of the Deaf community, they argue that video communication is the community’s equivalent of voice telephony for the hearing population. There are already technological possibilities for deaf people to communicate fluently in sign language through video devices using the internet, although these depend on high speed broadband and this has not yet been introduced. There is also a need for a telecommunications disability equipment program that is independent and not restricted to the two service providers as is currently the case.²⁹

The Australian Government Department of Broadband, Communications and the Digital Economy has completed a study into the feasibility of establishing a disability equipment program that is independent of telecommunication carriers (Astbrink 2010; Alt Beatty, 2011). At the time of writing, the report had not yet been released, although the submissions to the inquiry are available on the Department’s website.³⁰

Research in Scotland (Skellington et al, 2006) found that technology that could aid communication between deaf people and community-care services is not always used.

²⁸ <http://www.hearing.com.au/cochlear-implants>

²⁹ http://www.deafau.org.au/info/paper_voctel.php

³⁰ http://www.archive.dbcde.gov.au/2010/august/independent_disability_equipment_feasibility_study/independent_disability_equipment_program_feasibility_study_submissions

Almost one-third of social service departments did not have the telephone equipment or software that would enable deaf people to contact them. As well, people who become deaf in later life may not be using technological advances that could benefit them because they don't know about them. One of the indications of good practice in service provision for people with sensory disabilities highlighted by the review, is that people are provided with visual and hearing aids, aids to communication and appropriate communications technology as a matter of routine.

Key points

- Being unable to afford access to AT is one of the main service gaps for people with sensory disabilities which have been reported to government inquiries (Alt Beatty, 2011).
- There is a need for resources to train people to use devices, and to train professionals in prescribing them (Hunter, 2010).
- Provision of funding for hearing aids is limited and services are unable to cope with the demand (The Senate, 2010).
- Funding is also limited for the external processors for cochlear implants to children and young people under 21 (The Senate, 2010).
- Current arrangements in relation to fixed telephones for people with sensory disabilities are inadequate. The new mobile telecommunications technologies are more suitable but the cost is prohibitive for people on low incomes (Astbrink, 2010).
- The Deaf community argue that video communication should be made available for people who are deaf, given that signing is the language of the Deaf community (Deaf Australia).

10 Conclusion

Most of the literature on assistive technology deals with care of the aged, particularly in relation to dementia, or the care of people with chronic illnesses such as diabetes, cancer or congestive heart disease. Very little deals directly with younger people with disabilities. Nonetheless, a number of general conclusions can be drawn about the possibilities of AT.

The first conclusion is that there are no definitive answers to be found in the literature, partly because technological developments are so rapid in many areas, and because of the need for more research on integrating different types of AT, especially low-tech and electronic types. Included within the concept of 'assistive technology' there is a wide range of devices, from the non-technological (canes, walking frames, grab rails) to the highly sophisticated (powered wheelchairs, 'smart homes', microswitches, telecare, GPS systems).

There are ethical concerns, especially around privacy and surveillance, for some AT types, notably 'smart homes' and telecare. Guidelines specifically for the ethical use of telecare have been developed both in the UK and in the US. In the UK, research for the Social Care Institute for Excellence has devised a framework of four overarching principles which should inform the provision of telecare, namely autonomy, beneficence, non-maleficence (doing no harm) and justice.

There is consensus in the research that AT has potential for improving the independence and self-determination of people with disabilities. It has even been discovered that, in some instances, AT may allow more independence than personal care because it reduces the need to rely someone else, it is always available whereas a personal carer might not be, and people can operate it themselves. One of the most important aspects of self-determination is for the user to be centrally involved in the decision-making. As well as contributing to people's autonomy, this is a promising way to reduce rates of device abandonment.

Whether AT can reduce the need for support services, and if so, how and to what extent, is not entirely clear from the literature, not only because there is limited research, but also because the findings from different research studies vary. While some studies have found that AT and home modifications can substitute for personal assistance, the findings of other studies are more equivocal. For example, using canes and crutches reduced both formal and informal hours of care, but using walkers and wheelchairs did not. Home modifications were found to reduce the amount of unpaid help received, but not the amount of paid help. Another study found that those who used formal care were more likely to use equipment as well, while yet another study found that AT usage was associated with using both informal and formal care, with having more carers and more care hours, and with receiving assistance with more tasks.

Answering questions about the factor of costs depends on what counts as 'cost', even apart from the issue of reduced need for support services. It is clear that immediate

purchase price is not the only factor to be taken into consideration—expensive equipment or home modifications can delay or prevent even more expensive institutional care, for example. Moreover, the concept of social cost introduces the idea of taking into account the needs of all the relevant actors—the users, their families, the healthcare system, funding authorities, etc. One researcher identified three categories of costs of any health technology: those borne by the healthcare provider; those borne by patients and their families (measured by ‘quality adjusted life year’); and costs borne more widely such as health education. Clearly, not all of these costs can be taken into account in any particular instance. However, in the most general terms it can be said that anything that contributes to people’s well-being and supports their independence contributes to fulfilling their rights and is a long term saving in other support alternatives. Further research about the experience of people with disabilities using AT in NSW to model these lifetime cost benefits would assist ADHC policy decision making.

Nonetheless whatever the difficulties, researchers on the whole tend towards positive assessments of the benefits and the potential of AT for all concerned—for the users in increasing their autonomy and giving them greater control over their environments; for carers in diminishing the burden of care; and for funding authorities.

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Appendix – Internet resources

Disabled World: Assistive technology informational videos on assistive technology products and aids for persons with disabilities – <http://videos.disabled-world.com/category/assistive-technology>

Australia

ARATA assistive technology services directory 2007' Australian Rehabilitation & Assistive Technology Association – http://www.arata.org.au/resources_publications.php

Independent Living Centres – <http://www.ilcaustralia.org.au/home/default.asp>

Australia's assistive technology experts: Specialising in electronic devices for people with a disability – <http://www.tecsol.com.au/>

TADNSW – Technical Aid to the Disabled. 'Where no commercial products are available, TADNSW creates customised aids or modifies existing devices for people with a disability. A professional team is available in Sydney to help define the needs of clients. Devices are made by volunteers and clients pay only for the cost of the materials and a small administration fee' –

http://www.healthdirectory.com.au/Independence/Technology_assisted/search

SA government suggestions for assistive equipment –

<http://www.sa.gov.au/subject/Community+support/Disability/Corporate+and+business+information/Disability+information+and+publications/A-Z+of+Disability+SA+information+sheets+and+publications>

UK

Fast [Foundation for Assistive Technology] Research: The primary source of information about developments in assistive technology (AT) in the UK –

<http://www.fastuk.org/research/> - 460 research publications

Global Assistive Technology Encyclopedia (GATE) has been created by AbilityNet, the UK's largest provider of advice and information on all aspects of Access technology. Its purpose is to provide live and up to date information on everything to do with Assistive Technology. It's a showcase of both products and useful sources of information –

<http://abilitynet.wetpaint.com/>

<http://www.tiresias.org/research/links.htm> –This page provides links to external websites.

[Assist Ireland](#)

This online resource provides information on assistive technology and a directory of products available from Irish suppliers.

[Assist UK](#)

Assist UK lead a UK-wide network of centres which provide advice, assessment and the opportunity to try out the whole range of community service equipment.

[Disabled Living Foundation \(DLF\)](#)

DLF is a UK charity that provides free, impartial advice about all types of disability equipment and mobility products for older and disabled people, their carers and families.

US

Alliance for Technology Access (ATA) – <http://www.ataccess.org/>

The Alliance for Technology Access aims to make technology a regular part of the lives of people with disabilities. The Alliance is a national network of 41 technology resource centers which help children and adults with disabilities, parents, teachers, employers, and others to explore computer systems, adaptive devices and software.

Closing The Gap – <http://www.closingthegap.com/>

Closing The Gap, Inc. is an organization that focuses on computer technology for people with special needs through its bi-monthly newspaper, annual international conference and extensive web site.

Disability & Technology: A Resource Collection – <http://home.nas.net/~galambos/tech.htm>

This page contains links to web sites that focus on disability and technology. Most sites will refer to assistive/adaptive devices that are computer-based and/or related to computer access. However, since assistive technology can include any device that improves function, other technologies are mentioned on many pages.

Disability Resource Directory, Assistive and Adaptive Technology – <http://www.disability-resource.com/assistive-technology/index.php>

The Family Center on Technology and Disability –
<http://www.fctd.info/resources/tech101.php>

AbleData provides information about assistive technology products and rehabilitation equipment – <http://www.abledata.com/>

Medline Plus, a service of the U.S. National Library of Medicine, National Institutes of Health – <http://www.nlm.nih.gov/medlineplus/assistivedevices.html>

Trace Research and Development Center – <http://trace.wisc.edu/> (in English)

Trace is a research centre at the University of Wisconsin-Madison which focuses on making off-the-shelf technologies and systems like computers, the Internet, and information kiosks more accessible for everyone through universal design. The site contains copies of many of Trace's publications, including guidelines for the universal design of computers, telecommunications and information kiosks.

Europe

Association for the Advancement of Assistive Technology in Europe (AAATE) – <http://www.fernuni-hagen.de/FTB/AAATE.html> (in English) – ‘to stimulate the advancement of assistive technology for the benefit of persons with disabilities including the elderly people’ – includes email addresses for contacts in several European countries, as well as Brazil, Japan and Israel, and encourages membership from all interested parties. Membership benefits include access to discussion groups; special interest groups on robotics and education are also featured on the Web site.

Difnet – <http://www.difnet.org/> (in French and English) The site appears to be headquartered in Belgium, and contains links to articles on topics such as telecommuting for disabled persons.

Forschungsinstitut Technologie-Behindertenhilfe (FTB) – <http://www.fernuni-hagen.de/FTB/ftb/home-e.htm> (in English) The site contains brief descriptions of FTB's three centres: information, development, and testing.

Inclusion of Disabled and Elderly people in Telematics (INCLUDE) – <http://www.stakes.fi/include/> (in English with links to translations in several other languages) The focus of this site is on universal design. Features include a form for submitting questions and an international directory of consultants.

Servizio Informazioni e Valutazione Ausili (SIVA) – <http://www.siva.it/> (in Italian and English) Information on assistive technology as a support to independent living is SIVA's main concern. It runs an information, counselling, testing and research centre, and promotes the development of a network of Independent Living Information Centres covering most of Italy. The site includes information about other centres around the world and a variety of downloadable publications.

Swiss Foundation for Rehabilitation Technology – <http://www.fst.ch/> (in French and German; partially in Italian and English)
The goal of the FST is to put modern technology at the disposal of physically and/or mentally disabled people. It was created in 1982 by the Swiss Paraplegic Foundation and the Swiss Spastic Society. To date, more than 8000 people, in Switzerland as well as in Europe, are using an electronic aid provided by the FST. The site primarily discusses communication aids and monitoring devices for individuals with disabilities such as Alzheimer's.