The Australian Rehabilitation and Assistive Technology Association (ARATA) is a national association whose purpose is to serve as a forum for issues in rehabilitation and assistive technology. Membership is open to anyone who uses, supplies, designs, recommends, funds or undertakes research into the assistive technologies.

ARATA members see assistive technologies as critical to enabling people living with disabilities to participate equitably in society and applaud the Australian Government's ratification of the *United Nations Convention on the Rights of People with Disabilities* and its commitment to a whole-of-government, whole-of life approach to disability issues.

Strategies used by people living with a disability

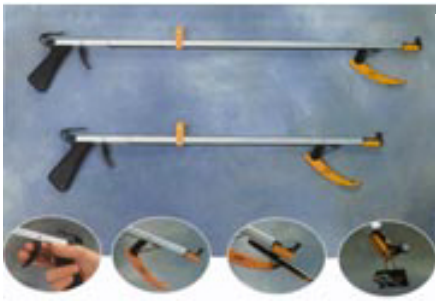
People living with a disability develop creative ways of doing things incorporating alternative methods, informal and formal supports, assistive technologies and environmental design. While some people rely on their own resources to develop this system of support, many require assistance to identify and fund these supports. The nature and availability of services and funding schemes have significant impacts on the supports people have access to and, by association, the outcomes they can achieve. Furthermore, these have an insidious impact on who and what can be supported, for what purpose and to what extent.

More specifically, people living with disabilities use a range of low and high tech devices, commonly referred to as assistive technologies (AT) to participate equitably in society.

> 'AT is an umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed' (WHO, 2004, p14).

Low-tech options are generally simple and inexpensive devices and include generic products such as mobile trolleys, jar openers etc

as well as specialised equipment such as over toilet frames, walking frames, communication boards.



High tech options include expensive, sophisticated, products such as adapted mobile phones, computer access equipment such as alternative keyboards and mice, voice recognition technology as well as dedicated technologies such as power wheelchairs, communication devices, specialised computer input and output devices and environmental control systems.

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participation through technology



Assistive technologies serve a much greater purpose than merely replacing lost function. They allow people to engage in everyday activities in many different environments and afford them autonomy and independence in activities in the home, getting out and about in the community, communicating with others, as well as participating in education and employment and community activities.

The effective use of assistive technologies is not only dependent on the hard technologies i.e. suitable devices, being available but also on the soft technologies such as human enablers such as “decision making, strategies, training, concept formation etc” (Cook & Hussey, 2002, p 6) that support the effective selection and use of these technologies.

Many people are not aware of the range of devices available, which are best suited to their situation and experience difficulty in raising or accessing suitable funding to purchase these devices. There are a limited number of services dedicated to assisting people in identifying the best technology to meet their needs and supporting people in the use of these technologies. However these services are significantly constrained by the limited resources available to meet people’s AT needs and build the capacity of the industry to respond to these needs.

As informed by the International Classification of Function (ICF) and consumer input to AT users’ priorities, this requirement can be defined as:

- The best **combination** of equipment, personal care and environmental design to meet their needs in every area of life
- Access to sufficient **funding** to pay for good quality and long lasting equipment
- Having needs looked at **holistically**, so that each piece of equipment works well and does not interfere with other equipment or supports
- Having equipment needs considered across the **lifespan**, as their needs change
- Accessing support across the **whole process** of getting equipment, including equipment trial, training and maintenance
- Access to resources **when** needed
- Being actively **involved** in deciding on the best option; and
- Having personal **preferences and identity** considered when identifying equipment to suit lifestyle and participation (de Jonge, Layton & Vicary, 2010)

Case studies are provided at the end of the document to highlight the importance of each of these priorities.

Attention to these user priorities requires that

- assistive technologies be recognised as an important enabler to participation and not just a device to compensate for lost function
- a clear understanding of the REAL need be established so that is sufficient funds are allocated to address people's existing and unmet AT needs
- an integrated and co-ordinated funding and service system be developed where there is good communication and collaboration within and across states, government departments, services and providers such that people's needs are not partitioned into silos.
- a comprehensive understanding of people's changing needs is developed so that needs are anticipated and prepared for rather than being responded to in an ad hoc way.
- a comprehensive service system is developed which people living with disability can access for information, trialing, training and assistance with identifying their AT needs, integrating AT into the application environment and ongoing technical, maintenance and repair issues.
- that AT related services are affordable, accessible, responsive and sensitive to the ongoing needs of AT users regardless of their geographic location or cultural background and have appropriate and adequate expertise to support people in making AT related decisions.
- people with disabilities are adequately informed and empowered to make decisions and direct the process.
- technologies are designed which afford people adequate choice and accommodate a variety of lifestyle preferences and that these choices are available to people when selecting a suitable device.

In addition, there needs to be a commitment to researching the current and ongoing needs of people with disabilities as well as the outcomes achieved through the use of assistive technology by:

- Determining the REAL and unmet need for assistive technologies, in particular people's communication, community mobility /driving and environmental control requirements
- Establishing the assistance people find important in making good AT decisions
- Understanding the ongoing needs of people as they develop and grow older
- To understand what is NOT currently working in terms of devices and service system and what is required for people to feel adequately supported
- To understand the system of supports that people currently use and how well these enable them to participate in society.
- To look at the costs incurred by people with disabilities in developing and maintaining the supports they use.

Suggestions for improving access to AT and AT outcomes for people with disabilities

ARATA recently surveyed assistive technology (AT) users, suppliers, prescribers, funders and other stakeholders involved in providing aids and equipment (assistive technology) services to people with disabilities across Australia. The aim of the survey was to examine issues experienced by AT users and those providing AT services and to identify how the industry could be improved to achieve good outcomes for AT users.

The respondents to the survey included:

AT Users	13
Suppliers	14
Funders	5
Prescribers	79
Others	24
	135

The AT used, supplied or prescribed included; wheelchairs, communication, computer access and environmental control devices as well as a range of other aids such as daily living aids, pressure care equipment, beds, hoists, commodes, electronic magnifying devices, home modifications, beds, mattresses, hygiene items, mobility devices, standing frames, orthotics and prosthetics, scooters, cognitive software, in vehicle hoist and motor vehicle hand controls.

The 79 prescribers included Occupational Therapists (54), Speech Pathologists (6), Medical Practitioners (5), AT / IT Consultants (5), Physiotherapists (4), Rehabilitation Engineers (2), Special Ed Teacher (1), Orthotist (1), and Rehabilitation Physician (1). Their years of experience ranged from less than 5 years (21.7%) and 5-10 years (16.5%) to more than 10 years (62.1%). Most prescribers worked in a capital city (52%), regional centre (22,8%) or rural town (21.5%). While prescribing assistive technology was 75-100% of their workload for some (22.8%), this type of work only constituted 25-74% of the time for 55.6%, and less than 25% of the workload for 21.5%.

Respondents who identified themselves as other included consultants, therapy educators, researchers, managers, advisors, and advocates.

There were six main themes in the respondents' suggestions for improving people with disabilities' access to and effective use of assistive technology. The suggested improvements included:

Increased resources

- Increased funding for provision of assistive technology to ensure people who have need for AT are identified early and have access to the right devices and the right support in a timely way
- Increased funding for the services that support the provision of AT - to ensure timely support for clients and more time spent with clients
- Development and better use of specialists services and experts
- A central and moderated database of available AT that is accessible to all that honestly lists the pros and cons of each item
- More access to a wider range AT for trial in the application environment

- Additional resources to support AT users in rural and remote areas to access specialists and equipment for trial

Consumer Control

- More power to clients and greater user control throughout the process
- Increased participation of consumers in the AT funding system (on boards/review panels).
- Evaluation of consumer outcomes as defined by the users i.e. increased participation across all life domains

Co-ordination and Collaboration

- Coordinated delivery of AT services
- Establishing mechanisms to provide ongoing and timely support to users and providers in rural and remote areas
- Collaboration between the health, disability, and aged care sector
- Nationally consistent and flexible funding systems
- Improved procedure for repairs, and maintenance

Dedicated training, support and mentoring

- Provision of quality dedicated education, professional development opportunities and post graduate training for prescribers ensuring access to people in rural and remote areas.
- Support, mentoring and peer review for prescribers
- Ongoing access to information/education/mentoring
- Focus on retaining experienced staff

Standards for service provision

- Requirement for dedicated training and experience for prescribers
- Appropriate competency based training and assessment of practitioners
- Guidelines/standards on acceptable AT prescription practice
- Supplier regulation to ensure the advice they provide is client specific and relevant

Follow up and Feedback

- Follow up – individually and with larger populations to measure changes/improvements made to lives of users
- Effective follow up and feedback structures so that presenting concerns are identified early and their health and participation is maintained
- Effective methods for measuring outcomes and gathering consumer feedback.
- Encourage evidence-based service delivery by funding the industry to build capacity, gather outcome data and undertake research

In summary, it is important that the Disability Care and Support Scheme facilitate people with disability to design and direct AT service/s, so that they receive the right amount of service with the right equipment, by the right people, in the right way, and at the right time. Further, it is important to invest in the AT industry to ensure that service providers have the right amount of resources and expertise to respond to people's current and ongoing needs.

CASE STUDIES

Determining the best combination of equipment, personal care and environmental design to meet their needs in every area of life

Many people develop a complex matrix of supports to enable them to carry out their everyday activities. Decisions about whether activities are best supported by changing when and how activities are undertaken, using informal or formal supports, acquiring suitable assistive technologies or redesigning the environment depend on the preferences of the person, the nature of the difficulty experienced and the resources available in the environment. This self-management is dynamic in nature. People adjust their system of supports in response to changes in life demands and throughout the course of life and the disability itself and vary considerably in terms of the range of personal and financial resources to which they have access. When the right resources are not available to support a given activity, the person is often forced to cease participation altogether.

Gary is a 40 year old man with a wife and young family. He has multiple sclerosis and is currently using a walking stick to mobilise safely within the home and his office and a scooter to mobilise in the community, taking his children to ride their bikes in the local park nearby. Gary has been quite inventive in developing alternative ways to perform activities at home and work as he aims to maintain his independence for as long as possible. He uses formal supports to assist him with maintaining his house and garden as he find these activities take him a long time and exhaust him, preventing him from participating in social activities on the weekend. He prefers to use informal supports to assist with personal care activities as this affords him greater privacy and control over how and when these occur and allows him to conserve his energy for his day at work. He also had his bathroom modified so that he can sit when showering and had wide pathways installed around the home and a ramp constructed at the rear of his low set house so that he can access the house using his scooter and power it up in the laundry area. Gary use to enjoy going to the football but finds it increasingly difficult to access the local and regional sporting facilities.

Accessing sufficient funding to pay for good quality and long lasting equipment

People living with disabilities often rely on a range of technologies to engage equitably in society. It is generally difficult for them to find the funds to purchase what they need. Consequently they are often forced make do with ineffective methods or to purchase devices that are ill equipped to serve their purposes. Cheaper equipment options often require ongoing maintenance and generally wear out more quickly. Conversely equipment that is well matched to the person's needs is well placed to respond to the demands placed on it and generally lasts longer. Abandonment remains a problem for devices which do not meet the users' requirements.

Kate is a young woman with an acquired brain injury who uses a manual wheelchair for mobility. She needs a new wheelchair and her family has been working with her therapist to find the most appropriate chair for her. After many months of looking at and trialling different chairs and 3 applications for funding, she still doesn't have a new chair. The funding body gave several reasons for refusing the funding applications, one of which was that it's policy is to fund what they perceive to be the most cost-effective solution, not the client's choice. The client's choice in this case was an ultra-light chair that could be lifted into the family car without making modifications to the car or using ramps that would also have to be lifted in and out of the car. The 'cost-effective' solution suggested by the funding body is a much heavier chair that places Kate's mother at risk of injury from repeated lifting or necessitates the addition of ramps or modifications to the family car, (neither of which are eligible for funding) so in this case 'cost-effective' to the funding body is not cost effective to the client.

Having needs looked at holistically - each piece of equipment functions effectively and does not interfere with other equipment or supports

AT users need their technologies to be considered holistically so that each piece of equipment works well, in combination with other equipment and supports to enable individuals in a range of situations and life areas. Technologies must be able to accommodate the unique way each individual functions and how they do things. In addition, technologies must be well integrated such that they do not interfere with other technologies and supports. AT users often have to navigate and manage a patchwork of services and personnel who do not understand their needs holistically and can destroy the delicate balance of supports and integration of equipment that are vital to their independence. Each time something is changed, or repaired with even a slight variation on the original setup, problems invariably arise that have to then be managed by the user and their support team.

Sally is an 8 year old girl with cerebral palsy. She has limited movement which means that she relies on a joystick to access all her equipment. Her motorised wheelchair is funded through a state equipment scheme, while her communication device, which she uses to communicate and access a computer is purchased through the education system. She would also like to be able to control devices at home such as the CD player and television in her bedroom however there is no funding for environmental control and the education department does not have responsibility for supporting her independence in the home. The family and her therapists have to work very hard to navigate the various funding schemes to secure a complete system for her the various application requirements, timeframes and restrictions on what any one system will cover makes it difficult to ensure that the equipment will be able to be integrated.

Having equipment needs considered across the lifespan, as their needs change

People's needs change over time as they move through various life stages or their capacities and skills develop or deteriorate. Changing interests, occupations and environmental demands also requires that the suitability of their existing assistive technologies be reconsidered. Technological developments also occur which means that equipment becomes outdated and incompatible with newer technologies. These newer technologies can also offer people

additional features and functions which many address one of their many existing unmet needs. One –off encounters with services and time restricted funding schemes makes it difficult for people living with disabilities to have their technologies needs met in an on-going way.

James is a 19 year old man with Arthrogroposis, causing immobile joints and limited upper and lower body movement. James is a talented student, and found that handwriting support was insufficient for him to keep up during his senior years at school. With the help of a laptop, a head controlled mouse, and onscreen cursor and a special switch James was able to complete his work independently and utilise computer based resources for research and learning. With help from the right computer assistive technology assessment, equipment provision, training and support provided along the way James was able to successfully complete his HSC and is currently studying a human services degree at University.

Access support through the whole process of getting equipment, including equipment trial, training and maintenance

It is not unusual that equipment is purchased sight unseen and people are often not able to determine it suitability for their specific requirements . One case where an expensive motorised wheelchair could not fit within the person's van several expensive modification were then required to the van and the ultimate outcome was not elegant or particularly functional.

Anthony is an 18 year old youth with Cerebral Palsy who lives at home with his parents and brother. He attends a community day program 3 days a week and is supported at home with a paid carer for 2 days. Anthony uses a powered chair for mobility both in the home and in the community. He required a new wheelchair when he had out grown his old wheelchair and seating. One of the essential considerations for the prescription of the new powered wheelchair was that it was able to fit into the wheelchair accessible vehicle that the family had purchased less than 2 years previously. Due the high cost of powered chairs most suppliers and service providers have limited stock of wheelchairs of various sizes available for trial. A recommendation was made, in good faith, for a wheelchair based on the written specifications available to the supplier. The wheelchair arrived 3 months after it was ordered (12 months after original prescription). Unfortunately the wheelchair did not meet the specifications to fit into the vehicle. Considerable time, cost and frustration could have been alleviated if the wheelchair had been available for **trial** prior to recommendation.

A co-ordinator for **repairs** is constantly battling tyre wear on motorised wheelchairs. The grey or white tyres have no or very little carbon added to the tyre, hence the poor performance, One reason for providing these tyres is because they do not mark floors. For a mobile PDW user this is a continually ongoing problem/ concern. However trying to source a tyre for people in a Powerdrive wheel chairs that can cope with the daily use city, rural or remote is just about impossible. It would seem that no tyre manufacture produce a tyre that will last more than 3-6

months. Motor bikes/ cars last twice that long and do a lot more work than a PDW. This puts pressure on the client (breakdowns) and funding bodies (cost of replacement) to numerous to mention .

Access to resources when needed – information and access to people with experience and expertise to assist with decision making

Nerida is a 15 year old girl with Cerebral Palsy and an undiagnosed movement disorder, was severely restricted in her communication, using a combination of facial expressions, gestures and occasional verbalisations to indicate her needs to her immediate family. Nerida was assessed and recommended a high tech communication device and then applied through the state equipment funding scheme for the device. Nerida's family were told that the state equipment funding scheme would only fund half of the device, so the family was forced to seek the rest of the funding from one of the charity organisations. For **two** years, Nerida and their family waited for the state equipment funding scheme to provide their part of the funding. In the end, they worked with the therapist to locate another charity to provide the remaining funding for the device. During this critical time in her life, Nerida remained very limited in her communication and was restricted in her participation at school, in the community and in hospital during an extended stay.

Being actively involved in deciding on the best option

Users of assistive technology need be involved in the identification of needs and the possible solutions to ensure that the equipment will be used. Being actively involved requires the user and their support team be given an opportunity to express their concerns, expectations and understanding of the possible solution. This may involve using the additional services and flexible service delivery models to enhance engage the client and carers.

Joshua is a 35 year old man with Cerebral Palsy who lives at home with elderly mother of Lebanese background, with limited English. His mother is responsible for attending to all of Joshua's personal care needs. He required a new wheelchair as his current chair was old and the considerable wear and tear had resulted in cracks in the frame which placed it at risk of breaking. A prescription was provided by the therapist following an assessment at the therapy clinic. Issues in regards to access to the home and routines for personal care were discussed (without an interpreter present). On delivery the mother was not happy with the wheelchair. After numerous meetings an interpreter was engaged and a visit attended at the client's home to address the issues. A compromise with modifications the chair and environment was reached that met the mother and Joshua's needs. Successful outcomes can be reached by ensuring that clients and carers (where necessary) are actively involved in decision making. This may involve engaging interpreters, awareness of culture needs, advocates and an assessment within home/community environment to ensure that optimal access to information is available.

Have personal preferences and identity considered when identifying equipment to suit lifestyle and participation.

Users of assistive technology live in our communities both within large cities and in rural areas. As Australians they come from many and varied cultural backgrounds want to participate in all the lifestyle options that our country offers. Flexible and collaborative service provision which is sensitive the unique needs of individuals can provide positive outcomes.

Jane is 43 year old woman with Cerebral Palsy. She moved to rural NSW from Sydney approximately 5 years ago to live in supported accommodation closer to her parents who live on the families' property. She required a new wheelchair and customised seating and a prescription was made by therapist from the local community health team. Jane's mother did not feel that the prescription made would adequately meet Janes needs. All previous chairs had been prescribed by a specialist seating service attached to a disability organisation in Sydney. A referral was subsequently made to this service for a second opinion. The seating service worked collaboratively with the local community health therapist to problem solve the concerns and a combined assessment appointment was arranged at a large rural centre close to the client. Although there was a wait time for this appointment to coincide with an outreach visit to the region the combination of local community resource with specialist services has provided a successful outcome for the client.

Jordan is a young woman with Rhett's Syndrome who uses a manual wheelchair for mobility. Her favourite colour is pink and most of her clothing and accessories are pink. Her mother requested that her new wheelchair be pink, to reflect Jordan's personality. The request was denied by the funding body who said they don't fund pink chairs because it limits the chair's suitability for potential subsequent users if and when Jordan no longer needs the chair. The colour choice was so important to Jordan's mother that she agreed to accept the new wheelchair in a neutral colour, pay to have it resprayed pink and then pay to have it restored to a neutral colour when Jordan no longer needs the chair.

References

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