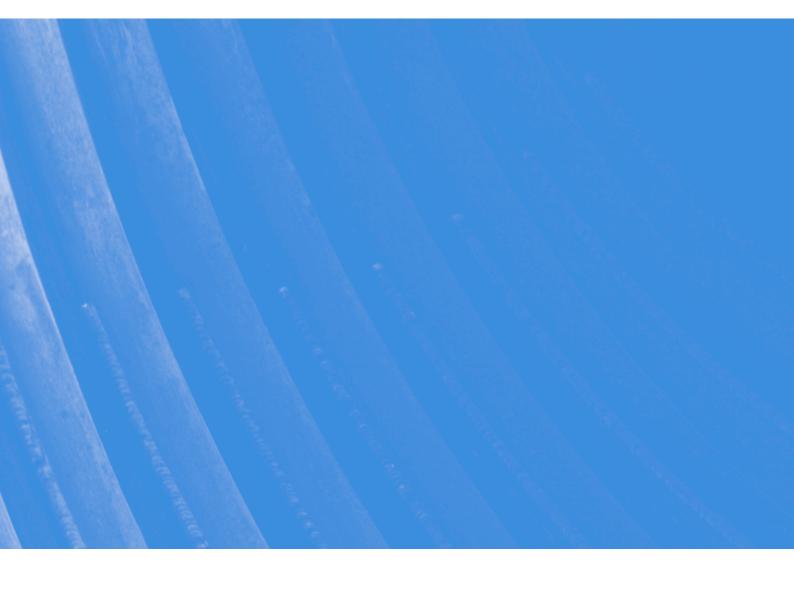
ASSISTIVE TECHNOLOGY COMMUNITY ALLIANCE OF NSW



A GUIDE TO MAXIMISING A PERSON'S
CHOICE AND CONTROL OVER
ASSISTIVE TECHNOLOGY

Introduction

This paper presents the views of the Assistive Technology Community Alliance of NSW (ATCAN) on how to increase person-centred (or 'user centred') approaches in the provision of assistive technology (AT).

Assistive technology is a crucial enabler of choice and control for people with disability. As disability services undergo a transformational shift towards person-centred approaches, it will be important for organisations to take on systems and processes that demonstrate that the person is the primary focus.

Traditionally, people with disability have found it challenging to explore AT preferences because their knowledge of what was available may not have beeen on par with Allied Health Professionals (AHPs) or AT suppliers. Additionally, ATCAN members understand that cost drivers have lead to pressure to preference 'stock items' over individualised solutions.

In assisting people to prepare for the NDIS, it is important the NDIS planners and Local Area Coordinators (LAC) are aware of AT issues, and understand the importance of putting the person at the centre of their AT solution.

This guide will unpack the key elements of person-centred approaches and apply them in the context of AT. It is ATCAN's hope that this document will serve as a guide to encourage best practice in the person-centred delivery of AT in NSW and provide some practical advice on what this looks like and how it can be done.

About ATCAN

This paper was developed by NCOSS in collaboration with members of ATCAN. This group is comprised of not-for-profit disability, community and welfare organisations, consumer and/or advocacy organisations with interest and expertise in AT issues. The purpose of ATCAN is to;

- provide a forum for the discussion of issues relating to supportive equipment and assistive technology AT for people with disability in NSW, and
- undertake coordinated activities to improve access to assistive technology as a basic right for people with disability.

The members of ATCAN include:

- Assistive Technology Suppliers Australia
- · Cerebral Palsy Alliance
- First Peoples' Disability Network
- · Greystanes Disability Services
- Independent Living Centre NSW
- Northcott Disability Services
- NSW Council of Social Service
- People with Disability Australia Inc
- Physical Disability Council NSW
- Spinal Cord Injuries Australia
- The Lymphoedema Action Alliance
- Vision Australia

What is AT?

Assistive technology (AT) is any device, system or design, that allows an individual to perform a task that they would otherwise be unable to do, or increase the ease and safety with which a task can be performed, or anything that assists individuals to carry-out daily activities.

Many types of AT can form part of a person's reasonable and necessary supports under the NDIS. AT can vary in complexity, from everyday items like a walking stick (unlikely to be covered by the NDIS) to simple items like shower chairs, to complex items like customised wheelchairs.

If a person uses complex AT, this will need to be maintained and repaired, and the person may need professional assessment before selecting a new device. These considerations should be discussed with the person, so that the full costs of their AT needs are factored into their NDIS plan.

ASSISTIVE TECHNOLOGY COMMUNITY ALLIANCE OF NSW

Person-centred approaches

An oft-cited definition of person-centred approaches states they are:

"Ways of commissioning, providing and organising services that people want to help them live in their communities as they choose. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person"²

This means placing the person's goals and aspirations, as they define them, above those identified as priorities by others. The Victorian Department of Health describes the elements of person-centredness as:

- Getting to know the client as a person
- Sharing of power and responsibility
- Accessibility and flexibility
- Coordination and integration of care by the service provider
- Having an environment that is conducive to person centred care both for the service providers and service users.³

Whereas traditional approaches to AT centre on the power and expertise of the AHP, in the person-centred approach, power is shared between the parties because the person's knowledge of their needs, goals and aspirations is just as important as the professional's expertise. Further references about personcentred approaches are at the end of the document.

A person-centred approach does not of itself entail more expensive products and services. Rather, it involves the focus being on the individual AT user's goals and aspirations. A long-term approach should be adopted. For example, although some titanium wheelchairs are more expensive than aluminium models,

they are also more durable, and may be more cost effective for users whose condition is likely to remain stable.

ATCAN notes that section 34 of the NDIS Act, mandates that a participant's supports need to assist them to achieve their goals, objectives and aspirations, while also representing value for money. This can pose a challenge to the person centred approach, which planners and LACs must be aware of.

The context

Under the National Disability Insurance Scheme (NDIS), people with disability are entitled to reasonable and necessary supports to enable them to have choice and control over their lives.

Under the NDIS, a person's reasonable and necessary supports must be itemised in their individual plan in order to be funded. This means the person should be guided to think about all aspects of their AT needs in advance.

ATCAN is pleased to see the National Disability Insurance Agency (NDIA) has recently released an Assistive Technology Strategy with a personcentred focus. ATCAN members applaud the inclusion of a participant capacity-building framework within the AT Strategy. This framework envisages that AHPs work with people with disability to assess their capacity in relation to decision-making around AT, and develop a plan to improve capacity over time.⁴

Although this guide relates mainly to the NDIS, similar considerations about to people over 65 who have a Consumer Directed Care package.

A person-centred approach requires an understanding of the context within which the equipment will be used.

Under a 'reasonable and necessary' approach, luggage carriers fitted to the front of a manual wheelchair (pictured below) would be funded, because they are performing the function of an able-bodied person's arms while the wheelchair user's arms are providing propulsion (ie doing the job of legs). Such an inclusion to a wheelchair increases the independence of the person with disability.

ATCAN members understand that such items are not currently funded, being viewed as 'bags' to be purchased by individuals. This restrictive approach does not consider

a person's needs in the context of their life and preferences.





Flip down armrests allow some wheelchairs to carry belongings, increasing independence



How to put the person at the centre of AT provision

1. Listen to what the person wants to achieve

A person's individual 'story' will affect their preferences around AT. This includes their daily routines, where they live, and how much independence they like.

AHPs, AT suppliers and NDIS planners should ask questions to determine an individual's goals, needs and preferences, giving them a sense of control over the process.

Service reflections on listening to the person

Have you asked?	Why?
What is your previous experience with this type of AT?	This question determines the level of explanation and support required to assist the user in decision-making, and what further questions to ask.
Tell me about your lifestyle? What outdoor and indoor environments do you require to use AT in?	Determines the user's needs, goals and preferences.
What expectations do you have about the AT?	It is important for users to have realistic expectations of the AT to avoid disappointment.
What about the AT is most important to you?	Much of AT involves a compromise; for example, does the user value the size or speed of the particular AT more? It is important that users are involved with decisions and their priorities are primary to the decision-making process. It is also critical that users are made aware of limitations or shortcomings of an AT solution.
What are your requirements for maintenance and backup?	It important that costs of maintenance and repairs be costed in a person's plan. As these services are currently block funded, by existing funding bodies, the user may not always consider this an item to budget for.

Choice and priority in action

A woman in her twenties purchased a child's electric wheelchair because the ability to fit under a table which adult wheelchairs were too big to do - was more important to her than enhanced speed.

2. The person using AT is the customer

Supplying AT involves a myriad of stakeholders, including the user, their allies, AHPs and often funding bodies. Suppliers walk a delicate line trying to satisfy all parties and in this process, the consideration given to the needs and preferences of the AT user can sometimes be reduced. If suppliers want to act in a person-centred approach, they need to put the wishes of the users first and foremost.

The internet has allowed suppliers and manufacturers to communicate directly with people who will use their products, including choice and control. It is important that online resources is supplemented with face-to-face information and 'expos'.

Service reflections that will enhance responsiveness to the person's needs

Have you asked the person what goals they want to achieve and what tasks they expect to use the AT for?

Have you worked with the person to consider a range of options that could work in these environments?

3. Knowledge is power; empower the user with knowledge

Growth and development of the AT market, in response to technological advances and population needs, increases the need for effective information dissemination to promote awareness among the population of potential AT users. Once aware of a user's goals and preferences, AHPs and suppliers should give the person options for comparison, emphasising the positive and negative aspects of each option.

Trials of AT in a person's home or workplace allow the person to gain first-hand knowledge of how the various AT will work for them. It may also be useful for professionals to link people with more experienced users of the identified AT, facilitating the sharing of knowledge and experience.

Service reflections that will enhance a person's knowledge of AT options and uses

Have you demonstrated the full capacity of the device to the person who will use it?

Have you recommended AT options which the AT user might not be aware of which might help them achieve their stated goal and preferences?

Does the AT user have the capacity to trial and evaluate AT without the assistance of an AHP?

4. Communicate with the AT user about timeframes

Clear communication is a crucial part of delivering person-centred service. Communication about a person's AT needs to be understandable to them, and avoid jargon which can create confusion.

There are often delays in the process of ordering and customising AT, and the possibility of these delays should be explained upfront to give the person realistic expectations about timeframes.

For example, instead of telling the person their wheelchair should be ready one month from when they receive funding, it is better to explain that the process of customising a wheelchair may require the AHP to liaise with the manufacturer or supplier, potentially taking longer than anticipated.

When delays occur they should be explained to the person, together with the new anticipated timeframe before the AT is ready to use.

Information is empowering. The simple step of including the person into all communications from AHPs, suppliers and funders concerning their AT purchase would improve information flow and demonstrate inclusive practice.

Service reflections that will enhance a person's inclusion in ongoing communication

Is your communication in plain language, without jargon? Will the reader understand what you are trying to say?

Does the information include what the AT user needs to know?

- Are the anticipated timeframes clear?
- Does the communication indicate who to contact with queries?

Have you included the AT user in emails about delays, price/specification changes etc.?

Is information about pricing (including any co-payment required) properly itemised and explained?

Have you asked the AT user what form of communication is preferred:

- telephone
- · text message
- email
- letter

Has the AT user been told how to appeal a decision they disagree with?

One size does not fit all

Person-centred AT models suggest that the person's individual goals, needs and preferences should be considered before selecting the AT. However, ATCAN members that they sometimes face pressure to prescribe their clients 'stock' or re-issue devices, which may not optimally meet their needs. It is reported that a client may be dissatisfied with elements of a device (for example size) if the first time they have seen it is at delivery, necessitating a complex adjustment process.⁶

ATCAN recognises that stock items can sometimes meet a user's needs. Adopting a person- centred approach, the user and their allies should be given information to make informed choices about using stock items compared to devices tailored to them.

Planners and LACs should ensure a person itemises customized AT in their plan if they require it.

Service reflections that will enhance a person's knowledge of AT options and uses

Have you demonstrated the full capacity of the AT to the person who will use it?

Have you recommended AT options or devices which the person might not to be aware of which might help them achieve their stated goal and preferences?

Does the person have the capacity to trial AT without the assistance of an AHP?

Methods of improving and facilitating person centred practice in AT

There are some basic steps that can be taken to ensure person-centred approaches are being delivered. These include:

- Asking the person about their preferences and providing them with information about possible options, including the benefits and drawbacks of all options;
- Collaborate with the person when identifying objectives, planning and implementing solutions; Include the person in all communications about them;
- Include the person in all communications about them;
- Encourage the person to bring a support person or advocate to appointments to assist them to articulate their requirements and preferences.

The costs and benefits of a person-centred approach

The following case study of a man from rural NSW illustrates that in addition to empowering the consumer, a person-centred approach to AT saves considerable time and resources. It is important that NDIS planners play their part in delivering person-centred approach.

A person-centred approach would have involved including the user in all communication from the outset, informing them ahead of time of the items not to be funded, and basing these decisions on his needs and preferences, rather than a defined set of rules.

As the table on the following page shows, a person-centred approach could have shortened the process by more than 6 months, saving time and resources for all involved.

Actual Event	In person-centred practice
February	
Wheelchair user is assessed by an AHP undergoes a wheelchair trial with assistance from a Sydney based supplier. Equipment funding request is submitted to funding body. Wheelchair user is assessed by an AHP undergoes a wheelchair trial with assistance from a Sydney based supplier. Equipment funding request is submitted to funding body.	The user would have received a copy of the itemised quotation.
June	
User receives notification from EnableNSW that he is eligible for funding, but is told he has to pay 1/3rd of the total cost.	An internal review would have assessed whether the decision to request a 33% contribution from the consumer aligns with a person-centred approach. If all options to meet their order without a large contribution had been exhausted, the user would have been provided with a clear explanation of:
	what will not be funded and whydetails of the appeal process; andan expected timeframe for delivery of solution
User writes to EnableNSW requesting additional information before committing to funding the shortfall.	The above response would have likely answered any questions raised by the consumer in June.
July	
EnableNSW writes to user explaining funding shortfall.	
User (with help of AHP) challenges most of the reasons that items were not funded.	This step could have commenced in June if direct communication had occurred.
Additional equipment trials were conducted and further correspondence ensued between consumer, EnableNSW and AHP.	Correspondence not required if direct communication had occurred at the outset.
November	
User receives written advice from EnableNSW that following additional information provided by the AHP his wheelchair will be fully funded, except for one item of low value.	Detailed communication about a user's needs and preferences would have established funding at outset (in February).
December	
Due to the extensive delay from the initial assessment to placement of order, a further reassessment is conducted by the AHP and supplier prior to the order being confirmed.	This step would not have occurred. A person-centred approach provides a greater level of detail at earlier stages and avoids repetition of processes.
January	
New wheelchair received.	Allowing for 3 months to process order, this could have occurred in June.

Further references on person centred practice

- Australian Rehabilitation & Assistive Technology Association (ARATA) www.arata.org.au, resources on person-centred AT, including in relation to the NDIS
- De Jonge, D. M., Layton, N., & Vicary, F. (2009). Keynote Address A fresh analysis of the AT system in Australia: listening to and understanding the perspectives of stakeholders in order to meet AT users expectations. Paper presented at the NSW ILC Conference, Parramatta. cited in Jonge, Layton, Vicary & Steel (2015) Motivations and incentives: exploring assistive technology service delivery from the perspectives of multiple stakeholders. Paper presented at the RESNA 2015: New Frontiers in Assistive Technology Arlington, VA;
- Steel, E. J., Layton, N. A., Foster, M. M., & Bennett, S. (2014). Challenges of user-centred assistive technology provision in Australia: shopping without a prescription. Disability and Rehabilitation: Assistive Technology, 11(3), 235-240,
- Steel, E and Layton N (2016) "Assistive Technology in Australia: Integrating theory and evidence into action", Australian Occupational Therapy Journal vol. 63, issue 6, pp. 381-390.

Endnotes

- 1. Independent Living Centres Australia
- 2. UK Department of Health (2001) "Valuing People A New Strategy for Learning Disability in the 21st Strategy: Guidance for Implementation Groups"

 Available at http://valuingpeople.gov.uk
- Victorian Department of Health (2008) "Person Centred Practice: Guide to implementing personcentred practice in your health", p 2,
 Available at http://www.health.vic.gov.au/older/toolkit/02PersonCentredPractice/docs/
 Guide%20to%20implentating%20Person%20centred%20practice.pdf
- 4. National Disability Insurance Agency (2016) Assistive Technology Strategy available at https://www.ndis.gov.au/html/sites/default/files/AT-Paper_0.pdf.

