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participation through technology

ARATA's response to the NDIA's Assistive Technology Discussion Paper

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ARATA's response to the NDIA's Assistive Technology Discussion Paper

The Australian Rehabilitation and Assistive Technology Association (ARATA) is the national peak body representing rehabilitation & assistive technology stakeholders, working to advance access to rehabilitation and assistive technologies, and to promote practices that ensure positive outcomes from their use. ARATA provides a national forum for information sharing and liaison between people who are involved with the use, selection, customisation, supply, research and ongoing support of rehabilitation and assistive technologies. We promote, develop, and support the national rehabilitation and assistive technology community of practice.

Through its membership, ARATA represents the interests and opinions of the full range of assistive technology (AT) stakeholders in Australia: AT users, AT researchers, AT suppliers, and AT Practitioners including most allied health professions and rehabilitation engineers. ARATA's response to the NDIA's AT Discussion Paper therefore encompasses many viewpoints, and advocates that roles for all stakeholders must be considered.

Overall comments on the Discussion Paper

ARATA commends the NDIA for their focus on assistive technology solutions as key supports which have potential to deliver on the aspirations of the Scheme as a whole, for many participants. Having been in the field for over 20 years, ARATA offers the comments below in the spirit of co-constructing an excellent system, and remains willing to share knowledge and participate further as policy is formed and as rollout occurs.

There seems to be a tension between participant choice on the one hand, and cost saving suggestions regarding procurement on the other. It should be noted that there is little research into the adoption of 'choice' as a policy principle to guide AT provision, and thus a lot of uncertainty about how this can be operationalised [1,2].

Research into the use of choice as a policy principle in health and social services has demonstrated wide variations in the interpretation of choice by consumers, providers and policy-makers, and constraints on choice that limit the equity of access and quality of outcomes for consumers of health and social services [3-5]. ARATA encourages the NDIA to consider the international literature in this domain as well as research into AT provision models internationally and carefully evaluate and consider offering a range of options for the procurement and provision of AT to participants.

There is also a tension between innovation and these procurement proposals (such as a panel system). Processes to propose, trial, select and list AT products on a panel system will take time. Innovation however can arise very quickly, particularly in areas such as computers, tablets, phones and environmental controls. Further detail regarding the application of the proposed procurement system for products sourced overseas is requested, as this has been identified as a key issue for the Australian AT market [6].

Summary of ARATA's key recommendations arising from the Discussion Paper:

1. Evaluate outcomes from AT provision in trial sites and other systems to inform in the development of procurement and service delivery policy, consumer supports, and continuing professional development.
2. Support practitioners and researchers to validate existing AT service models for use in Australia.
3. Assist ARATA and other key stakeholders to develop a national accreditation system for AT practitioners and suppliers.
4. Investigate and document the roles, activities, and scope of practice of suppliers and peer mentors in AT service delivery, and associated outcomes for AT users.
5. Ensure the coupling of AT devices with appropriate soft technology support for device selection, implementation and review.
6. Investigate the efficacy and potential expansion of existing peer and consumer networking channels.
7. Support research into consumer use of information and decision-making in AT provision.
8. Fund independent AT information services and explore options for facilitating consumer ratings of products and services.
9. Identify AT products not yet available on the Australian market.
10. Fund research into AT development and commercialisation in Australia.

A comment on terminology

ARATA acknowledges that AT terminology is not used consistently in literature and practice, but recognises the importance of conceptual clarity and defined scope in the development of policy and practice guidance. Thus, ARATA's general comments and responses to the questions posed by the NDIA are informed by internationally recognised definitions of key terms used in AT provision, which may not be consistent with the usage of those terms by the NDIA.

Such key terms include:

- Assistive technology (AT): A broad range of devices, services, strategies, and practices that are conceived and applied to ameliorate the problems faced by individuals who have disabilities [7]. This definition includes the concepts of both products and services, yet the term AT is often used to describe only products.
- Assistive products: The International Standards Organisation (ISO) defines these as any product (including devices, equipment, instruments and software), especially produced or generally available, used by or for persons with disability for participation; to protect, support, train, measure or substitute for body functions/structures and activities; or to prevent impairments, activity limitations or participation restrictions [8]. This definition excludes medicines, implants and products used only by healthcare professionals. It also excludes the personal assistance, installation, financial support and combinations of products that are often critical to the successful use of assistive products. The scope of inclusion varies in practice, as seen in the differences between the funding models of aids and equipment schemes operated by the States and Territories. In Australia, "aids and equipment" is a term often used [9-12], though "assistive technology" tends to be used synonymously [13].

- AT devices: International legislative, policy and research literature predominantly uses the term "assistive technology" [14], but because this term may include devices and services, some authors use the term "assistive technology devices (ATDs)" [15].
- AT services: The service aspect of AT can also be defined separately, where the term 'AT service' describes "any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device" [7].
- Assistive technology Practitioner (ATP): This term is not commonly used in Australia, but when used in North America refers to "a specialist in assistive technology application; typically has a professional background in engineering, occupational therapy, physical therapy, recreation therapy, special education, speech-language pathology, or vocational rehabilitation counselling."[7] ARATA recognises the diversity of expertise, formal qualifications, workplace roles and responsibilities of ATPs in Australia, and has begun work on formal accreditation of ATPs and credentialing of AT suppliers in order to improve the quality and consistency of service delivery and professional development in Australia.

Do you think the participant capacity building framework (Attachment 2) will help participants reach their own decisions and give them better control over choices about assistive technology solutions?

ARATA has long worked to champion and embed the AT user at the centre of AT service delivery systems, and to recognise the 'user expert'. ARATA therefore believes the 'Participant capacity building framework' is a positive step to building efficacy for participants who wish to increase their skillset, and to recognise expertise in many longstanding AT users.

ARATA note however that the Framework is untested and does not appear to draw on the available literature base. Indeed, a careful reading of the evidence which IS cited in the paper, would suggest the critical role of AT professionals within the participants choice-making processes. This role entails far more than the provision of information.

Page 4 of the AT Discussion Paper states: 'Participants have access to all the information they require to identify assistive technology options and explore the 'fit-for-purpose', relevance and utility of potential solutions to their situation'. This appears to indicate that 'information' is all that is needed [16,17]. In practice, long-term AT users tell us there are many instances where a managed introduction and supported approach to identifying AT is required. These include the situation of newly acquired spinal cord injury where participants do not have sufficient insight and psychological readiness to make decisions which will benefit their participation in the long term; rapid onset Motor Neuron Disease, where participants will not be ready to anticipate future stages; and Deafblind individuals who cannot chose without significant support and demonstration being selected 'for them', based on outcome evidence. These instances are related to USER and PERSONAL FACTORS, as well as ENVIRONMENT, and will therefore not necessarily be picked up in via the Participant Empowerment Framework with its primary focus on the AT device.

International research has found that while more public AT information is available than ever before, many AT Practitioners and AT users (consumers) report not having sufficient information or training to *confidently* choose between AT options [12,18]. Identifying and articulating AT-related needs is not simple, and what information is adequate is not known, and may be different for each individual. Information

may be provided on the AT devices' cost, safety, comfort, availability, adaptability, usability and ease of use. Different users (consumers) will prioritise different attributes [19,20]. AT Practitioners are one of the main sources of information for potential AT users [21,22]. AT users regard Practitioners as people with whom they can discuss the pros and cons of AT options they are considering, and help them relate the use of AT devices to their own personal and environmental factors [23,24]. Public use of AT databases (such as the Independent Living Centre databases in Australia) has not been formally studied in comparison with use of other online AT information sources. It is unclear whether potential AT users access AT databases, or distinguish between commercial online marketing and not-for-profit AT information sources. Overall, there is insufficient research into the attributes of information that potential AT users seek, and how they use information in AT choices [25].

It is important to realise that anyone's capacity to make decisions about AT solutions is limited by the complexity and uncertainty of AT provision [26]. It may be useful for the NDIA to refer back to literature on the nature of the human-activity-assistive technology interaction, and note that transactional models are used to describe 'fit' [7,27]. The inherent complexity of AT provision is a significant reason for high rates of non-use that are reported [28-30]. Models of AT use stress that device, user, task and other contextual factors interact, making the selection of a device (or AT solution) difficult [31]. Therefore AT service delivery models incorporate involvement of AT Practitioners who consider these many factors in their clinical reasoning and interactions with users. In practice, AT Practitioners may rely on expertise and experience to drive this process, rather than relying on formal assessment instruments or checklists [32]. There are valid and reliable measures to evaluate the 'fit' or 'match' of device and user, but not predict it [33].

How useful would it be to have access to peer support people, such as Assistive Technology Mentors?

Anecdotal evidence suggests peer mentors have always been involved in AT provision providing mentoring and training services to novice AT users [7,34,35]. However this has not been well documented in AT literature and models of practice are only now emerging. AT users in developed countries report informally networking with peers to seek information and share strategies regarding devices and AT service delivery systems [24,28]. Contact with peer mentors has been linked to increased, choice, control and long-term self-management [24]. ARATA suggests that if the NDIA is considering these, it should review both published and developing models and then consider the potential application within the NDIS.

ARATA proposes the following regarding peer support:

- Clarity is required around the role and scope of practice of peer AT mentors. This should include requirements for full disclosure of any conflicts of interest that peers may have, and the intersection of AT mentors with other AT service delivery personnel.
- Consumer and peer networking is already facilitated in Australia through consumer- and organisation- driven networks, the ARATA listserv, and other online forums and discussion arenas where consumers can ask questions about experiences with AT. This networking is under-researched. A potential sector development role for the NDIA is in funding research into the efficacy of these networking modes. This could focus on aspects of user or participant empowerment, and its effectiveness in building participant capacity.

- The NDIA is in a position to improve information flow regarding AT products and services, using new or existing resources. The concept of an online database collating consumer ratings (e.g. Trip Advisor) and other ratings based on common measures (e.g. My School) have been proposed in other jurisdictions reforming disability services with greater consumer choice [36]. This can act as an incentive for suppliers to continually work toward improving the quality of their services [37]. NDIS participants should have access to the same type of information (experiences both with AT products and AT services), so that they can benefit from each other's experiences. A person might be happy with the product received but not the way there were spoken to or the administrative hurdles they had to go through. Careful design and ongoing support is required for such systems to be effective given the small and heterogeneous population and the challenge of rating complex goods and services [36].

How important do you think "expert advisers" will be in assisting with assistive technology solutions and decision-making? What are the main skills and attributes you think they should have?

Expert advisors (which ARATA refers to as AT Practitioners) undertake many different activities when working with users to trial, assess and select AT. These include:

- Schedule and manage appointments with various suppliers for AT trials. ATP becomes single point of contact for user for organising trials with multiple suppliers.
- Ensure required AT is available and set up ready for trial at the time/date to minimise waiting time for the AT user
- Provide independent review and advice on specifications and quotes provided by AT suppliers during AT provision.
- Provide expert knowledge on health and medical conditions as they impact on functioning, activities and participation. Also includes knowledge of how these can change over time and with ageing.
- A broad knowledge of AT products, devices, technologies used across different environments.
- Gather, consolidate and explain material / literature on AT for the user
- Facilitate negotiation of AT specifications with user and AT supplier. This can include price negotiations.
- Facilitate expert reflection with the user on activities & participation both at home and in the community.
- Facilitate expert reflection with the user on potential features and performance of AT (especially where compromise is needed due to incompatible features).
- Liaise with other health and medical practitioners around the impact of AT on the user's health status. Provide professional support to AT users at health and medical appointments.
- Train AT users, carers and family members on the correct and safe use of AT.
- Provide advice and guidance on adapting / customising / modifying AT if the user's needs change.
- Provide information and advice on AT use for newly identified activities or participation, e.g. holidays, specific events.
- Conduct access assessments for different environments, e.g. educational institution, workplace.
- Provide training to peers, colleagues, teachers, principals, managers, etc. on AT use and accessibility adaptations e.g. educational institution, workplace.

ARATA recognises that Allied Health Professionals have skills and expertise in foundation AT provision within the scope of practice of each profession. ARATA also note the requirement for postgraduate skill development and expertise in some areas of AT provision (often only available via mentorship) and, at times, the necessity of a multidisciplinary team [38,39]. ARATA believes a distinction must be made between:

- Technical expertise (such as knowledge of specific devices types) that can be attained via experience and vocational training models, and;
- Professional expertise (in dealing with people in the context of uncertainty and complexity) that requires experience as well as critical thinking, reflection and problem solving skills.

ARATA supports exploring means of developing, sustaining and recognising expertise in various aspects of AT provision. Credentialing and/or accreditation systems that allow AT Practitioners to demonstrate and maintain competence may be developed in consultation with the sector [40]. Opportunities for ongoing professional development should also be explored. Substantial research towards this has occurred through, among other things, the NDIS Practical Design Fund [40].

Literature shows that consumers who have previously received advice assumed to be 'free', where the provider is assumed to cover the costs, are reluctant to pay for advice [41-43]. In AT provision, this 'free' advice may come from not-for-profit or independent information services (such as Australia's Independent Living Centres or the ARATA members' listserv), or commission-based sales. Consumers may not perceive what is an evidenced 'value add'; that AT solutions are more likely to be successful when there is a balance between soft technology/professional support and a well-matched AT device [44] On the basis of this evidence, ARATA therefore recommends the NDIA be directive regarding the 'coupling' of AT devices with appropriate 'soft technology' support for device selection, implementation and review [45]. Given free choice, participants may perceive that funding could be better allocated to devices or other more tangible and consumable commodities as opposed to purchasing advice and support [46].

ARATA believes further detail is needed around how and when various stakeholders (including expert advisors, peer mentors, and suppliers) should declare and manage any competing conflicts of interest.

Provide suggestions for processes and/or activities to ensure that assistive technology solutions are identified correctly, with minimal error, and are effective in supporting participants to achieve their goals.

The discussion paper has no reference list, or indication that a comprehensive review of the current literature has been undertaken.

ARATA strongly believes that a review of evidence around AT assessment, selection, and decision-making could provide answers to these questions. Australian researchers are well placed to lead this work. Areas requiring research include:

- Validate the existing (mainly USA-developed) service delivery models to see if they accurately reflect the Australian setting;
- Investigate / document roles and activities of suppliers in AT service delivery (modelled on work by Sprigle et al. in the USA 47);

- Research on consumer decision making in AT - using theories & methods from consumer behaviour / marketing / product development domains rather than healthcare / medical domains;
- Conduct "root cause analysis" type investigations of AT selection "errors" to establish what actually went wrong. Too often the funders label it as "prescriber error" when in fact it may not have been possible to anticipate the problems.

What do you think of the acquisition and procurement approach (including having a third party entity manage the pricing sourcing and procurement arrangements and contracted supply agreements)?

The AT Discussion Paper has little information on the Panel Supply approach being proposed for complex, high-risk AT. The brief description on Page 19 (bottom right corner) suggests two parts:

- Potential suppliers tender for inclusion on the panels; and
- A participant's AT specification is put to the panel so that suppliers can quote on it.

The paper states that this approach has never been used before in AT within Australia. This appears a high-risk strategy for procurement, particularly for complex, high-risk AT that requires custom-manufacturing and/or significant customisations. Research strongly suggests that complex AT requires greater involvement of multiple stakeholders through the assessment and trial processes, including appropriately skilled AT suppliers [47,48], and AT Practitioners (such as OTs, physiotherapists, Rehabilitation Engineers, Speech Pathologists, etc.)[49-51].

There are no details on how trials of complex equipment will occur in practice. Details around who owns the trial equipment, who funds the delivery and set up and training of participants and carers, who is responsible for breakdown repairs during trials, and so on, are not included. It is not clear how (or who) is responsible for producing the AT specification which would then go to the panel. Further, the panel supply approach implies that any supplier - potentially one who has not been involved in any assessments, trials and specifications - can pick up the specification, implement the solution and provide ongoing support and maintenance. There is no published evidence that supports this approach. Further, it suggests that NDIS participants may not have a choice in supplier.

There are also issues of intellectual property when AT specifications are developed, particularly for custom-made AT and AT that is highly customised for an individual user. If a panel requires substantial detail of the AT specification, how will suppliers be compensated for the time and cost involved in producing the specification? How will intellectual property be managed?

One ARATA member provided the following comment:

> *'When the Productivity Commission proposed the NDIS, and the legislation was drawn up, I don't think anyone would have anticipated that this would be the proposed model for AT provision. Having a third-party managed system is an important element, but should only be one option for participants. This may work well for some participants, but may also be what some participants are hoping to avoid in order to exercise the choice and control they've been promised. Third party management can be efficient in some ways, limits the whole purpose of the scheme to use market levers for greater choice and competition. Perhaps the next version of this paper can*

include a discussion of various options that may be chosen by participants, and evaluate the strengths and limitations and implications for service equity and quality for each'.

ARATA suggests it is imperative to evaluate the impacts of this type of acquisition and procurement approach before any commitment is made to implement it. Evaluation must include a bird's eye view of impacts well beyond initial costs and benefits for the Agency, in order to capture downstream impacts upon, for example, the viability of smaller AT suppliers.

What do you think about the use of refurbished items (assuming that all appropriate health and safety procedures and necessary safeguards will be in place)?

Refurbished AT devices represent an environmentally sound and potentially economically effective option for some devices, for use by some participants. It is, however, difficult to advise on this point when there is no context regarding the choice and control aspects of selecting refurbished devices.

From an AT user perspective, it is necessary to underpin any re-issue scheme with policies based on a nuanced understanding of identity, AT embodiment and the cultural and experiential aspects of device history. AT users may not wish to purchase or acquire "used" AT, even if refurbishment is undertaken to the highest possible standards. From a pragmatic perspective, ARATA would point out that there is considerable variability between current funding schemes in terms of infection control, ownership of AT, liability, ongoing maintenance, record keeping and many other aspects. Therefore the indicator regarding 'all appropriate' health and safety and necessary safeguards' does not infer consensus or good practice criteria are yet in place.

All of these questions point to the need for the NDIA clarify what is meant by choice and control in AT service delivery, and how this will be limited or managed.

In what ways could further innovation be introduced and explored so that NDIA participants can have access to the best and brightest technical solutions?

ARATA, as an information sharing forum between AT users, AT Practitioners and AT suppliers, has decades of experience regarding grassroots innovations. These frequently arise in dialogue between AT users, their AT Practitioners, and are frequently enacted by skilled AT suppliers. Such solutions are invariably not funded by state equipment funders, and frequently remain known only in the 'grey literature' of blogs and listservs.

In the immediate term, ARATA propose that NDIA conduct a gap analysis using the ISO 9999 Assistive Products for Persons with Disability taxonomy, to identify the products as yet unavailable on the Australian market. A subsequent strategy to support innovation would provide incentives for AT stakeholders to come up with designs and adaptations on a single case basis: that is, stimulate ground-up solutions for individual participants. Such innovations have been demonstrated to lead to more adaptable and applicable solutions for the population more broadly (see Technical Aid to the Disabled design and developments).

More broadly, NDIA could significantly develop the innovation sector by funding research into AT development and commercialisation. Any such initiative requires an embedding of user experts (such as

employing a pool of AT users to test new designs and identify novel solutions) and a focus on collaborations across sectors and countries.

ARATA notes with concern that the relationship between AT suppliers as potential innovators and a source of product tailoring, is likely to be lost in many instances with the procurement models proposed.

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Australian Rehabilitation and Assistive Technology Association (ARATA)
c/- Technical Solutions
109 Ferndale Road
Silvan, Victoria 3795
Australia