

Abstract

Purpose: People with disability have a right to assistive technology devices and services, to support their inclusion and participation in society. User-centred approaches aim to address consumer dissatisfaction and sub-optimal outcomes from assistive technology provision, but make assumptions of consumer literacy and empowerment. Policy discourses about consumer choice prompt careful reflection, and this paper aims to provide a critical perspective on user involvement in assistive technology provision.

Method: User-centred approaches are considered, using literature to critically reflect on what user involvement means in assistive technology provision. Challenges at the level of interactions between practitioners and consumers, and also the level of markets and policies are discussed, using examples from Australia.

Results: There is no unanimous conceptual framework for user-centred practice. Power imbalances and differing perspectives between practitioners and consumers make it difficult for consumers to feel empowered. Online access to information and international suppliers has not surmounted information asymmetries for consumers or lifted the regulation of publicly funded assistive technology devices.

Conclusions: Ensuring access and equity in the public provision of assistive technology is challenging in an expanding market with diverse stakeholders. Consumers require personalised information and support to facilitate their involvement and choice in assistive technology provision.

Introduction

Assistive technology (AT) can improve quality of life and increase participation for people with disability [1,2]. It is one of several interventions used to optimise the functioning of individuals and reduce negative impacts of disability, where disability is regarded as

occurring at the interface of the individual and their environment, rather than resulting from impairments or environmental factors alone [3]. As well as benefitting individuals, AT often has a positive impact on caregivers of people with disability and their communities [4].

In Australia, an ageing and growing population has contributed to an increase in the number of people with disability [5]. More than 141,000 consumers access primary AT programmes run by state and territory governments to support children and adults with permanent disability and chronic conditions [6]. In 2010-2011 these programmes had combined annual budgets of approximately \$600 million (2010-2011), with mobility and personal care devices accounting for 50-60% of expenditure. However, the Australian Institute of Health and Welfare (AIHW) has estimated that governments' expenditure on AT represents only 17% of the total annual AT expenditure in Australia, which was approximated at between \$3.5 and \$4.5 billion in 2009-2010 [6].

Access to AT devices and services is recognised as critical for the inclusion of people with disability in societies, along with access to healthcare services and income support [1,7,8]. However, AT policy in Australia fails to deliver equitable access to, and optimal outcomes from AT [9]. Rapid advances in the international AT device market, and policy discourses about consumer choice and control prompt careful reflection on AT provision practices and consideration of future approaches.

This paper aims to illustrate the complexity of AT provision and challenges of user-centred approaches in policy and practice. It begins with an overview of AT and the policy and market context in which it is provided in Australia, before examining user-centred AT provision. This is followed by a discussion of the challenges for practitioners and policymakers in realising consumer access and equity and meeting individual consumer needs. Specifically, it focuses on the differences in power and perspectives between

consumers and practitioners, and the challenges of informing so that they are actively involved in AT provision.

Background and context of AT provision

Assistive technology (AT) describes devices or systems used by individuals with impairments, and also refers to a range of services or practices that support device use [10]. AT may be used in the context of a short-term need, such as rehabilitation from orthopaedic surgery, but this paper focuses on its use to support people with longer-term changes in functioning or impairments that contribute to disability. This paper uses the term ‘AT users’ to describe individuals with impairment who use AT, and considers individuals with potential to benefit from AT as ‘potential AT users’. ‘Consumers’ of AT services include AT users, potential AT users, and their caregivers.

An ‘assistive solution’ combines AT devices with personal assistance and environmental design, tailored to an individual’s situation via processes of assessment, trial, and adaptation [11,12]. Human support for a potential AT user’s decision-making and skill development is termed ‘soft technology’ [10], and this combination of clinical and functional knowledge with therapeutic engagement is deemed necessary for successful use of AT devices [10,13]. The introduction of an assistive solution can bridge a gap between the environmental demands and an individual’s capacity, where such a gap results in participation restrictions [10,14]. AT provision activities, and the decisions made by practitioners, are important because they influence whether or not consumers acquire assistive solutions, how and when AT devices are used, and therefore what outcomes are possible [1,15].

In Australia, consumers generally access the elements of an assistive solution from multiple services, through complex negotiation and coordination with practitioners [6,16]. For example, a consumer might access a subsidised white cane through a charity (e.g. Queensland

Blind Association), receive minor home modifications via a Commonwealth-funded community service (e.g. Commonwealth Home and Community Care (HACC) Program), and work with orientation and mobility trainers or peers from a not-for-profit organisation (e.g. Guide Dogs Queensland). AT users strive to acquire assistive solutions that enable them to participate in all major life areas [17], but are limited by the scope of public funding for AT device types and a policy focus on safety and independence rather than whole of life outcomes [18]. Public funding for AT generally does not extend to ‘mainstream’ devices that, while consistent with AT models and forming part of an assistive solution, are also used by the general public [16]. This includes computers and phones that can be customised with applications or modifications to facilitate communication. The high use of and need for mainstream and AT devices that are ineligible for public subsidies leads to the provision of incomplete assistive solutions, and puts pressure on consumers to independently source funding for devices and services considered necessary for participation [16]. While some consumers are persistent in making these arrangements, others choose to purchase and coordinate all components of their assistive solutions independently, often to avoid waiting on public AT services [16]. Some consumers relinquish valued occupations when their need for an assistive solution is not identified or adequately addressed [19].

Australian AT users have advocated for systemic changes to the funding and structure of public AT provision [20,21]. Most Australians wait between three and six months for initial assessments for complex AT, for example a wheelchair with customised seating, and many wait for one or two years before acquiring AT devices [6], frustrating consumers and impacting negatively on AT outcomes [7]. Funding that plans for, and provides soft technologies across the lifespan of AT users and the lifecycle of their assistive solutions is crucial for users to gain and sustain optimal outcomes from AT provision [17].

The internet has increased the availability of AT information in public domains, and started to shift AT devices into mainstream consumer markets [10]. AT device manufacturers and suppliers traditionally targeted their educational and marketing activities to practitioners [10], but increasingly, often through new media and procurement opportunities, they communicate directly with consumers. In Australia this has meant that the AT market has become internationalised, so that consumers can view and purchase devices not previously available from local suppliers. The online and international AT market has highlighted price disparities between Australia's AT market, which is heavily reliant on imported devices with price inflation at each step of the supply chain [22]. It has also generated concerns about regulation of devices that might not be TGA-approved or meet Australian Standards [6,22]. For consumers, however, the new AT market should facilitate comparison of alternatives, addressing one problem of traditional public provision where consumers tend to be given only one option [22].

User-centred AT provision

User-centred AT provision has evolved along with society's understanding of disability, and now informs practice in both developing and well-resourced countries [1,23,24]. This paper, as with most AT literature, uses the term, 'user-centred' as a synonym for 'person-centred' and 'client-centred'. According to the WHO, in person-centred practice 'individuals are involved in decisions about the support they receive and have maximum control over their lives' [25]. The concepts of autonomy and self-determination inform user-centred practice and are enshrined in the UN CRPD [8].

User-centred approaches recognise the subjective and objective factors that influence a user's reaction to AT [26]. Traditional approaches, described as clinical, medical or mechanistic, link a device to a disability or diagnosis, aiming to correct or reduce impairment through AT

device use [14]. The term ‘prescription’, commonly used to describe an assistive solution recommended to a consumer by a professional, is a symbol of entrenched and legitimised professional power in these approaches [27,28]. Clinical approaches are associated with practitioner expertise, objective measurement, and expectations of patient compliance with prescribed AT devices [29,30]. A key limitation of clinical approaches is that assistive solutions that work in a clinical environment are often difficult to integrate into the environments of their intended use [31]. User-centred approaches to AT provision require evaluation and engagement with consumers’ preferences, and support for their psychological and emotional adjustment to disability and adoption of technologies into their lifestyles [32,33].

Functional approaches to AT provision focus more broadly on consumers’ abilities and environmental demands than clinical approaches. Features of AT devices are evaluated against task requirements, where possible during trials in consumers’ homes or workplaces [31]. However, AT researchers contend that functional approaches do not sufficiently recognise the unique situation of each individual, and the extent to which their values and emotions influence their use of and satisfaction with AT [31,32].

AT users are a heterogeneous population, in terms of their personal characteristics and context, and the socio-economic resources at their disposal. The personal context of potential AT users contributes to differing experiences of AT acquisition. Injury, illness or a decline in function can indicate potential for AT use, but may be associated with grief or stigma, affecting the type of AT those consumers will accept [34]. People rehabilitating from injury, for example, can feel overwhelmed, and find it difficult to make AT choices, with little knowledge of what to choose, but an awareness of the expense [35]. As a comparison, the starting point of AT provision for elderly people who experience difficulties in everyday activities is less clearly defined, but they seem to experience similar difficulties [19].

AT models suggest that consumers' individual goals, needs and preferences should be considered before selecting devices [23], but it has been observed that is sometimes reversed in practice, where consumers acquire a device and then find their goals compromised or constrained [34]. A frequently-cited study from the USA found a lack of consideration for consumers' opinions in AT device selection to be a factor significantly related to AT device abandonment [36]. A more recent study on the provision of wheelchairs and hearing-aids to 285 adults in Bangladesh showed that user involvement increased the likelihood of positive outcomes from AT use [1]. Significant associations were found between approaches and processes used in AT provision, and the outcomes reported by users, supporting the argument that the involvement of users, or practices promoting a sense of control in users, can improve clinical and economic outcomes [1,37]. Consumer opinions, involvement and choice in AT provision have been described as elements of 'shopping' experiences [38]. The dissonance between the concepts of 'shopping' and 'prescription' illustrate the distance between clinical and user-centred approaches to AT provision.

Challenges in user-centred practice

The heterogeneity of users and practitioners in an expanding and internationalised AT market makes the prospect of designing an equitable and efficient AT provision system complex and challenging. Differences in power and perspectives, and limited awareness and understanding of AT options among practitioners and consumers limit the effectiveness of user-centred approaches. It is critical to address the challenges, as research findings indicate general dissatisfaction with AT provision, and a mismatch between desired or espoused, and actual practices [31,39].

Power-sharing and the roles of practitioners and peers in user-centred approaches

Literature on AT provision largely focuses on the actions and objectives of practitioners in relation to AT user outcomes. Selection of assistive solutions requires the identification of current and future abilities and needs, and the ability to forecast changes resulting from development, ageing and experience [31]. This is particularly challenging given the multiple disciplines, perspectives and professions involved in AT provision [40]. Health professionals regularly involved in AT provision include: medical doctors, occupational therapists, physiotherapists, nurses, and speech and language pathologists [41]. Other stakeholders who may be directly involved in AT provision include administrators in AT services or funding organisations, practitioners and vendors from AT suppliers, personal assistants, family members and peers [42]. There is often great variability between stakeholders' levels of formal education, specialisation, and proportion of time spent working with AT [14], and concerns about this variation have been expressed by consumers [7].

Guidelines and evidence support a user-centred approach to AT service delivery [1,43], but consumers of health and social services are often in vulnerable positions with less power than other stakeholders, and may require guidance and representation when making AT choices [44]. Some researchers have suggested that user-centred practice is generally not user-led, but interactive, with power shared between the user and practitioner [34,45]. Power tends to be shared unequally if AT providers have competing objectives, particularly in public service provision where practitioners are also responsible for resources allocation from a finite budget [44]. In Australia, funding guidelines and budgets influence practitioners, who are often intrinsically motivated to collaborate with users on individualised solutions, to focus on AT devices above services, and recommend least-costly alternatives to optimal solutions [17]. The challenge of balancing consumer choice and control against the distribution of collective resources is insufficiently recognised in user-centred approaches that focus on individual consumers [46]. A failure to resolve this challenge in policy and practice could

result in either unsustainable consumption of public resources or meaningless policy rhetoric.

Transparent policies regarding funding and eligibility for AT devices and services are required to ensure that resource allocation decisions are not left to practitioners to manage alone.

While not widely discussed in AT literature, user-centred approaches regard the involvement of professionals as optional, rather than obligatory pathways to AT acquisition [47].

Experienced AT users (sometimes called ‘expert users’ or ‘peer mentors’) are increasingly involved in AT provision, providing mentoring and training services to novice AT users [10,24,47]. Peer mentors have first-hand experience in AT use, meaning they can empathise with new AT users and work with them to realise their potential [24]. Peer mentoring is provided and advocated for in a range of developed and less-developed countries [24,48-50], but AT users in developed countries report informally networking with peers to seek information and share strategies regarding devices and AT service delivery systems [34,35]. Contact with peers mentors has been linked to increased, choice, control and long-term self-management [35]. The principles of self-management, adopted by people with chronic illnesses and symptoms, are also applicable for AT users living with long-term disabilities [35]. Incorporating elements of peer mentoring and self-management into AT provision is an important consideration in the development of user-centred approaches and recognised as part of the future of evidence-based practice [51]. To be sustainable and equitable, this requires formal recognition and remuneration of the expertise of AT users; which may present cultural or governance challenges for service providers.

The perspectives and involvement of users in AT provision and outcomes

The centrality of the consumer and expectations of their involvement in AT provision appear to vary. While there is agreement on the importance of user-centred approaches, consumer

involvement is often not documented or clearly described. Some studies have described the actions taken by practitioners to facilitate user-centred practice, such as: asking the consumer about their preferences and providing them with training [1]; allowing consumers the opportunity to voice opinions regarding AT device choices [37]; collaborating with consumers when identifying objectives, planning and implementing interventions [34]; or individualising interventions by connecting with consumers and understanding their perspective [32]. Alternatively, studies describe the actions of consumers themselves, for example: stating their priorities, signing application forms, writing a letter identifying needs and anticipated uses of AT [31], or taking primary responsibility for decision-making [47]. The different interpretations of consumer involvement reflect both diversity and limitations of practices claiming to adopt user-centred approaches. This suggests that practitioners need to be alert to the diversity of consumer needs and expectations in order to provide appropriate support.

AT users and providers tend to prioritise different outcomes from AT acquisition and use [35]. AT practitioners' discipline-specific perspectives and standards, values and preferences are reflected in their practices, such as assessments and device recommendations, and in their interactions with consumers [34,52]. Most AT provision models have been developed by service providers, informed by their perceptions of important activities and attributes, such as evaluation and training, and coordination [31]. The dominance of practitioners in AT service design may contribute to a bias toward changes in impairment or activity measures, rather than changes in participation in social and societal contexts. Use of the ICF framework and terminology has been proposed to support conceptual clarity and communication with a consistent focus on users to coordinate AT provision across the range of disciplines and service sectors [2,33].

To address differing perspectives on AT outcomes, user-centred approaches can be applied in AT service evaluations. One way this is achieved is by incorporating subjective measures, such as consumer satisfaction and feelings of being informed, in control or active in decision-making, in addition to objective outcome measures [35,43]. User satisfaction is a desirable outcome from AT provision, but is not on its own indicative of user-centred practice or optimal AT use. Inconsistent correlation between user satisfaction and health outcomes has encouraged other AT researchers to measure it alongside a range of other medical, functional and societal outcomes [53]. The incongruence of user satisfaction with other outcomes from AT acquisition was noted in a Scandinavian study comparing waiting times, access to follow-up and other structural factors in the provision of scooters [42]. This led the authors to suggest that, while regarded as an important outcome for user-centred service delivery, user satisfaction is influenced by individual expectations and societal attitudes and values, and might be better considered a quality indicator that has an impact on user outcomes from AT use, rather than an outcome itself [42].

Awareness and access to AT information

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. Insufficient information and awareness of both potential AT users and practitioners are identified factors contributing to unmet AT needs of elderly populations [54,55]. A lack of information about AT and other accommodations for employees and employers is an important factor contributing to low workforce participation of some people with disability [56]. Access to information on AT services and devices is essential both for consumers to acquire and use assistive solutions and for service providers to support consumers' decision-making [10].

Consumer awareness of AT options for consumers is widely acknowledged as important for user access and successful outcomes from AT service delivery [19,43]. Consumers need information about AT and other intervention options available to them, and informed of factors affecting their use in order to be involved in, and confident when making AT decisions [2]. Identifying and articulating AT-related needs however, is not simple, and what information is adequate is not known, and may be different for each individual. Information may be provided on devices' cost, safety, comfort, availability, adaptability and ease of use, but different consumers will prioritise different attributes [45]. Assessments are an important means of eliciting individual information needs and priorities, and should be available in AT provision systems that aim to be user-centred. Alternatives to practitioner-led assessment may be provided in peer mentoring and self-management models of AT provision.

Practitioners are one of the main sources of information for potential AT users [43,55]. 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 situation [19,35]. Researchers have highlighted the importance of access to information for practitioners, in order to develop and maintain a breadth of knowledge, due to the impact of their AT choices on the lives of individuals [13,37]. The information sources and strategies of AT practitioners have not been specifically studied, but a survey of 29 rehabilitation practitioners in Europe found online catalogues and databases to be the least frequently used source of AT information [41]. Practitioners reported accessing AT information most frequently from colleagues, the internet, and paper catalogues. What is perhaps more important for consumer access is the awareness of referring practitioners, who often have the power to authorise access to AT devices and services. A lack of awareness of AT services by referring healthcare providers, such as general practitioners and community nurses, has been highlighted as a barrier to individuals accessing AT [6,57]. Providing multiple entry-points

into AT provision systems may open the gate for potential AT users and increase equity of access.

More public AT information is available than ever before, yet many practitioners and consumers report not having sufficient information or training to confidently choose between AT options [6,23]. Pro-active wheelchair users report going online to find other users and further information about AT devices from sources such as blogs or websites [34]. AT users access these resources mostly through informal browsing, due to the limited availability of consumer reviews on AT [35], and the significant investment of time required to locate and compare alternative suppliers or AT devices [22]. This is consistent with the concept of 'bounded reality', where shoppers must limit their options to a reasonable selection from which one may be chosen [58].

When it comes to purchasing, many online suppliers do not provide prices until consumers submit personal information [22]. Consumers are increasingly purchasing AT devices directly from overseas suppliers, with both positive and negative outcomes [6]. Australia's public AT provision systems do not endorse purchase of overseas AT devices, as pre-purchase trial, technical support and parts may not be available locally [6,59]. So while there are significant price disparities between international AT markets, online marketing has not lifted the restrictions on public funding of AT devices, or addressed the information asymmetry that puts AT consumers at a disadvantage in the market [22]. The small market and expense of customised and complex assistive solutions, along with the risk of harm to consumers if using inappropriate AT devices, means that market solutions for AT provision may fail.

One strategy to address potential failures of AT device markets is the provision of information from unbiased government or not-for-profit organisations. Many countries have established AT databases to provide validated and updated information about devices and

services. Based in the USA, ABLEDATA (abledata.com) is the most well-known database, providing information on almost 40,000 devices via internet, phone, fax or mail services [10,60]. Similar services, providing information and a product database, are available in Australia (<http://ilcaustralia.org.au>) and in Europe (www.eastin.eu). AT databases group devices into categories based on features of the device or the physical condition or diagnosis of the user. They each use different classification systems, terminology, and search functions, though often the category boundaries are not distinct [61,62]. Public use of AT databases has not been formally studied in comparison with use of other online AT information sources, so it is unclear whether potential AT users access AT databases, or distinguish between commercial online marketing and not-for-profit AT information sources.

AT databases tend to contain technical specification, such as size or speed, or contact details for manufacturers or suppliers, but limited information on functional effects or other outcomes that a potential AT user might want to know about when choosing between AT devices. Databases may also reverse the order of AT provision, by starting with a search for a desired or prescribed AT device rather than an assessment of individual needs and preferences. Attempts to address this problem and synthesise technical data with considerations for use is found in the AskSARA self-assessment tool hosted by the Disabled Living Foundation in the UK [63]. It combines an AT database with a problem-based search function, so that consumers choose a topic or activity, such as gardening or shopping, and answer a series of questions. Based on the responses, the tool generates an individual report that provides information on commonly used AT devices and contact details for local services. Being able to search based on identified needs or desired outcomes, when not yet aware of AT options, may increase the usefulness of online information sources.

Professional services to help consumers choose assistive solutions whether online or in person, are critical strategies to influence AT use [31]. The heterogeneity of needs and

abilities of people with disabilities add many variables, and thus complexity to AT choices. In Australia, occupational therapists are important stakeholders in AT provision, employed by Independent Living Centres (ILCs), but also increasingly by AT suppliers who recognise the value of professional assessments and information provision as consumer services. The provision of information as a service, and active efforts to promote awareness, may be critical to ensure that consumers benefit from the potential of AT. Independent peer and practitioner services should be promoted to assist consumers navigating AT local and international AT markets.

Conclusion

The context of AT service delivery and the approaches that inform practice have a profound influence on equity of access and outcomes for consumers. User-centred approaches aim to address sub-optimal and inconsistent outcomes and consumer dissatisfaction with AT provision, but the many stakeholders and their interpretations of user involvement contribute to inconsistencies in practice. Power imbalances between practitioners and consumers present barriers to the realisation of user-centred practice. Policy-makers are challenged to recognise the heterogeneity of AT users, and need for flexibility of funding when constructing assistive solutions. An internationalised and online market for AT devices is increasing the need for effective information provision strategies and services. Practitioners must recognise the need for personalised assessment and information provision to facilitate consumer involvement in AT provision, and champion the adoption of strategies in policy and practice that promote equitable access and outcomes for consumers. The promotion of consumer choice in disability services is relatively new in Australia, and extends user-centred approaches. Several strategies can be adopted in policy and practice to support users to have a shopping experience when acquiring AT. Access to and awareness of AT provision services could be

facilitated by ensuring multiple entry points, and provision of independent information services that are staffed to support personal consultations. Formal service delivery structures are important to offer peer mentoring and self management approaches to a wider range of consumers. Use of a common language amongst practitioners and other stakeholders in AT provision is critical to avoid ambiguity and promote integration of purpose and process for consumers accessing AT devices and services. Consistent evaluation of AT provision with user-centred approaches is necessary to ensure continued funding of effective approaches and adoption of innovative approaches for quality improvement.

The complexity of AT provision and the limited understanding of AT and assistive solutions in policy and practice provide the rationale for further research exploring the relationship between conceptualisations of AT and the enactment of choice. Research into this has social significance, as it will help address the important and contemporary challenge of how society can support and include a growing population of people with disability. AT literature recognises the influence of funding and policy structures on service delivery processes and actions of practitioners, and outcomes for AT users. The majority of literature on choice in AT provision has focused on the decision-making of practitioners providing AT, or the range of AT devices available in local markets. Future research should explore the relationship between conceptualisations of AT, the context and interpretation of choice in AT provision, the interactions between AT providers and consumers, and experiences of choice for consumers acquiring AT.

Declaration of interest

The authors report no declarations of interest.

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