Understanding assistive technology as a pre-requisite for choice and participation

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Assistive technology (AT) is an often-used intervention to enhance participation and occupational performance, but disparities in access to and outcomes from its use are common. The occupational science of being and becoming an AT user is missing from the discourse on the right to, and choice of, assistive technology, and policies guiding its provision. This paper investigates the experiences of people operating outside of public AT programs in Australia, and their experiences of access to, choice of, and outcomes from AT.

Interpretive Phenomenological Analysis (IPA) of interviews with two participants with extensive and diverse experiences of AT provision demonstrates how a person becomes an AT user over time. The emergent themes discussed are: becoming an AT user; self-management by AT users; and the risks and responsibilities of choice without awareness or support. The findings illustrate that being an AT user is an occupation that involves ongoing learning and problem-solving as part of self-management, and support the notion that AT is a pre-requisite for participation and choice.

AT users can only make and realise choices if facilitating conditions are present. These include the existence and awareness of options, support to explore and experience new products and skills, respect for preferences, and ongoing servicing responsibilities. Policies emphasising individual consumer choice discount the iterative processes, risks and responsibilities involved in AT provision and the importance of relationships. Policymakers require an understanding of what is involved in being and becoming an AT user, and how this precedes participation and choice for people with disability.

Keywords: assistive technology, participation, choice, disability, self-management, policy, IPA, qualitative research

Subject classification codes: include these here if the journal requires them

Introduction

Assistive technology (AT) comprises products and services used to mediate individuals' environments and enable occupational performance and participation. Access to AT is recognised as critical for the inclusion of people with disability in societies (United Nations, 2006) and enablers of occupational opportunities and choices (World Federation of Occupational Therapists, 2012). Since the 1970s, disability rights activists around the world have called on governments and societies to respect the autonomy and dignity of people with disability. This movement culminated in the United Nations' (UN) Convention on the Rights of Persons with Disabilities (CRPD), which establishes a vision of equality for people with disability, asserting their right to participation, including making choices pertaining to their own lives. Australia ratified the CRPD in 2008 and, following extensive consultation, proposed major national reforms to the disability sector, including the creation of a National Disability Insurance Scheme (NDIS). The failure of policies in Australia to deliver equitable access to, and optimal outcomes from AT was highlighted during consultation (National People with Disabilities and Carers Council, 2009), but to date no study has analysed the implications and implementation of the CRPD for AT provision policies in Australia.

This paper is centred on the concepts of AT and choice, described briefly below. These terms are understood in different ways by people who develop and implement policy, and citizens including service providers and consumers. Assumptions about these concepts are implicit in policy and practice, and generally remain unchallenged, shaping the ways in which human rights are implemented. This paper is part of a larger study responding to a recommendation from an audit of disability research in Australia, which found "a lack of research…utilizing the experiences of people with disability and/or their family and carers to influence policy development" (Llewellyn, 2014, p. 49).

Although not defined in Australian law, AT is generally understood to include both assistive products (International Organization for Standardization, 2016) and AT services. Assistive products include mainstream and specially-designed products that make activities easier or possible, while AT services identify and match these products to the needs, preferences and context of individuals (Cook & Polgar, 2015). In Australia, assistive products are often called ‘aids and equipment’ (National Aids and Equipment Reform Alliance, 2010), and may be expensive and complex, such as customised seating or communication systems, or inexpensive and basic, such as jar openers or talking clocks. Most individuals use a combination of assistive products, environmental modifications and human supports, called an ‘assistive solution’ (Association for the Advancement of Assistive Technology in Europe, 2012). AT services include assessment, trialling and customising assistive products, and maintaining assistive solutions to ensure ongoing and effective use.

The introduction of an assistive solution usually requires occupational adaptation, including re-organisation of the task, physical environment, and personal assistance (Andrich and Besio, 2002; Hocking, 1999). High rates of non-use and abandonment of assistive products, reported to range from 29-90%, have been reported in several studies investigating AT outcomes (Martin, Martin, Stumbo, & Morrill, 2011; Peterson and Murray, 2006). Non-use of assistive products can be attributed to environmental factors and AT services, including opportunities to trial and be trained to use assistive products, ongoing maintenance, and social support (Wessels, Dijcks, Soede, Gelderblom, & De Witte, 2003). A greater understanding of the complexities of AT acquisition may facilitate positive outcomes for individuals, and reduce rates of abandonment and other negative consequences (Mortenson and Miller, 2008).

‘Choice’ has been adopted as a principle in international human rights and in public policy by liberal democratic governments. It is defined both as the act of choosing between two or more possibilities, and as the possibilities from which one or more may be chosen (Oxford English Dictionary, 2013). Choice is also defined as the power, right or faculty of choosing, and a feature of human autonomy and self-determination, deemed necessary for full participation and inclusion in society (Curryer, Stancliffe, & Dew, 2015). Depending on its interpretation, choice may be translated into policy and practice in different ways, affecting the mechanisms by which it is offered or delivered, and outcomes for individuals and society. Despite AT research highlighting the importance of ‘informed choice’ (Verdonck, Steggles, Nolan, & Chard, 2014) and ‘feeling informed’ (Martin, Martin, Stumbo, & Morrill, 2011), the concept of choice is has not been deconstructed, and little is known about consumers’ involvement in decision-making, and feelings of autonomy and self-determination when acquiring AT.

This paper investigates experiences of access to, choice of, and outcomes from AT at a time where two different discourses are intersecting in the reforms to Australia’s disability sector. The first is the human rights movement that emphasises respect for the autonomy and dignity of people with disability, and their right to participation, including making choices pertaining to their own occupations (World Federation of Occupational Therapists, 2006). The second discourse is the growing emphasis on choice in public policy, and its association with individualised funding and market mechanisms that attempt to produce economic efficiencies. This has been written about extensively by disability scholars (Foster, Henman, Fleming, Tilse, & Harrington, 2012; Mladenov, 2015; Soldatic & Chapman, 2010), but with greater attention to welfare systems and human supports for people with disability in Australia (McDonald & Chenoweth, 2009; Purcal, Fisher, & Laragy, 2014). Little consideration has been given to the perhaps irreconcilable incongruities of these two discourses in relation to AT provision; it is possible that privileging one may undermine the other. The occupational science of AT use can contribute to understanding the implications of these competing discourses on AT provision policy and practice and the realisation of human rights as established by the CRPD.

Much of Australia’s AT provision occurs through private or non-government channels, with estimates that the AUD$600 million in combined annual budgets of government programs accounted for only 17% of total annual expenditure on AT (for 2009-2010), with 70% coming from individuals' out-of-pocket expenses (Pearson, O'Brien, Hill, & Moore, 2013). Therefore, this paper investigated the experiences of people operating outside of public AT programs in Australia, and their experiences of access to, choice of, and outcomes from AT. It is part of a larger research study that used interpretive policy analysis methods to explore the relationship between the macro context of Australia's policies and experiences at the micro level of AT provision (Steel, 2017). This paper seeks to understand AT and the occupation of being and becoming an AT user by investigating the lived experiences of access to and choice in AT provision.

Methods

An interpretive analysis was conducted, based on a relativist ontological stance and using qualitative methods to give voice to the experiences of people with disability (Imrie & Edwards, 2007). Interpretive research acknowledges that the perspectives of individuals directly involved in the studied phenomena are crucial to understanding their actions and interactions (Lopez & Willis, 2004). Qualitative research methods support a depth of understanding rather than a breadth, attempting to explain social phenomena by extracting meaning from data (Patton, 2002). Interpretive Phenomenological Analysis (IPA) is a qualitative method that aims to understand lived experience through individual cases. Beyond description, the added layer of interpretation can illuminate connections or divergences between perspectives of participants, the context in which they arise, and what is already known about a phenomenon (Smith & Osborn, 2008).

This paper draws on in-depth interviews with two participants conducted as part of the larger research study (Steel, 2017): an AT user (CJ) who has low vision and has tried many different assistive solutions; and a service provider (Amy) who supports people with dual sensory loss (hearing and vision) to understand and use AT. The study adheres to the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, 2007), as assessed by the Behavioural and Social Sciences Ethical Review Committee of The University of Queensland (approval number 2014001471).

Because of the idiographic focus of IPA, a small sample was purposively selected to enable detailed case-by-case analysis (Finlay, 2011). “Operational construct sampling” (Patton, 2002, p. 238) was used to establish eligibility criteria for participants who could share accounts that opened possibilities to explore the concepts of AT and choice. These included service providers and AT users recruited via the researcher’s networks and via formal communications. AT user participants were considered eligible for participation if aged between 18 and 65 years and living with impairment affecting participation in more than one life domain (World Health Organization, 2001), because people with impairment affecting their participation in ‘core’ daily activities such as self-care, mobility and communication (Australian Institute of Health and Welfare, 2009) are more likely to require assistive solutions. AT users were excluded from participation if unable to consent to participate in the study or requiring, or anticipating the need for, assistive solutions for a period of less than one year, as these situations present significantly different contexts for AT provision and choice. Service providers were considered eligible for participation if able to articulate specific or substantial knowledge or experience of access to AT or advocacy for an under-represented consumer population or sphere of practice.

Semi-structured interviews of between 1-2 hours each were used with participants to enable detailed examination of their experiences and perspectives using IPA. Participants were asked about their views and reflections related to choice in accessing and using AT, and involved in making sense of their experiences rather than simply recalling events or reporting attitudes (Finlay, 2011). Questions and prompts during interviews related to participants’ understanding and perceptions of AT and choice, experiences of AT provision, and contextual information. All interviews were conducted by the author, and transcribed from audio-recordings.

The interview transcripts were translated into summaries for each participant, serving two purposes. First, the summary was sent back to each participant for their confirmation or clarification of the accuracy of the researcher's interpretation and opportunity to provide further comments or identify additional artefacts (Hammersley, 2008). Second, the summaries were revised based on participants' feedback and then used in the findings of this paper, to bring to life the context of AT provision and policy implications for the reader, by articulating lived experiences.

The analysis was conducted by the author in several steps based on Smith et al. (2009) (see Table 1). Each interview was analysed individually, completing the first four steps before moving on to the next transcript. After all the transcripts were analysed, the themes were revised and compared with the literature to highlight associations and promote deeper insight into both the emergent findings and extant knowledge (Eisenhardt, 1989). Computer-assisted qualitative data analysis software (CAQDAS) NVivo was used for coding, visualising models of the data and connecting the emergent themes to the transcripts.

Table 1. Steps of Interpretive Phenomenological Analysis based on Smith et al. (2009)

1. Reading and re-reading
2. Initial noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Continuing the analysis with other transcripts

The strengths of IPA as a research method are the insights offered from layers of interpretation, and its systematic approach that increases rigour and the robustness of findings (Finlay, 2011). A second researcher was not present in the interviews, as this is not considered conducive to building rapport, however the interview transcriptions enabled review and feedback. Coding of the transcripts was reviewed by a research supervisor to check the application of the IPA approach. Sections of interview transcripts are quoted throughout the findings and discussion sections below to illustrate the authenticity of the voice of participants; a recommended writing and presentation strategy for IPA (Smith & Osborn, 2008).

Findings

Phenomenological research methods often begin with descriptive accounts before adding the interpretive layer, to distinguish between the participants' accounts and the researchers' interpretations (Finlay, 2011; Smith & Osborn, 2008). The summaries of the two interviews are presented in this section, followed in the next section by a discussion of the emergent themes that links the analysis and implications to literature. Both the findings and discussion sections of this paper are interspersed with verbatim extracts from the transcripts to illuminate the themes.

Amy's story

Amy coordinates a philanthropically-funded centre for people with profound dual sensory loss (hearing and vision) in a large city. The primary goal of the centre is to help people access and use some form of communication, to avoid isolation and to continue living in the community. It focuses on telecommunications and has a range of phones and other products that people can learn how to use and try out various in combinations and settings as they develop skills.

Many of the people who access the centre are Deaf and fluent in sign language, but have lost their vision. Other people accessing the centre were born without vision or have experienced loss of vision followed by loss of hearing. Sensory loss occurs gradually, so many of the people accessing the centre are aged in their 40’s and older. Dual sensory loss necessitates very different communication skills and resources to single sensory loss, usually through a continuous process of responding to changes over time. Amy described how people with dual sensory loss who live alone generally have limited means of communication (e.g. tactile signing with an interpreter, fax machine) and require assistance with activities including banking and shopping.

> They’re not getting interpreting services. They’re getting nothing, and that’s why learning the technology is so powerful for them.
> If someone knocks at the front door, they don’t know if someone’s there unless they’re expecting them. You know, they don’t all have lights and vibrators and things because they’re quite expensive.

Many of the clients are teaching themselves and getting help from peers once they have a system that is suitably configured. Therefore, as Amy explained, the initial priority is to get people connected, regardless which products they are using.

> The connectivity is absolutely crucial. Absolutely crucial. They don’t really learn anything until they’re connected, and got their own personal accounts. It’s entry into the world, it really is.

Many of the products and software are designed for people with single sensory loss. For example, screen readers and Braille displays are designed for people with vision loss, and convert text or Braille into audio. This can be managed with combinations of hardware and software from mainstream and specialist products, but there are no manuals for many of these solutions (e.g. configuring a Braille display with an iPhone), and the configurations often must be adjusted each time software upgrades are installed.

> All that they learn, they are having to learn the different operating systems, so it's very sophisticated, and we basically have to write the manual for that combination of devices.

The solutions are different for each person, depending on the activities they want to use them for, the nature and extent of their sensory loss, pre-existing sign language and Braille skills, ICT literacy, and preferences.

> I've had guys come who can't read or write, so they have to do literacy first. If they're totally blind and deaf they've got to learn Braille first. So they've got to pen and paper learn to read and write. Then they've got to know, learn what a computer is.

Other than some funding for landline phone services and a Disability Support Pension (which is not means or assets tested for people who are permanently blind), there is no public funding for these solutions, and the investment is significant, with Braille devices costing between AUD$2,500 and $10,000 on top of the costs of a smartphone, software and usage.

The centre's stock of products allows clients to try out different phones and other products before buying. Depending on the user's experience, trialling new products or combinations can take a few hours or several months. Amy described how people are very good at learning and problem-solving once they get connected, but it can take a long time to learn and become comfortable doing new activities with telecommunications. This is due to the complexity of the system configuration and the nature of working in two languages (Braille and English), but also because of the limited opportunities many people with dual sensory loss have had to participate in activities.

> With each technology there's all this, 'aha' around "of course they wouldn't know that!" you know they haven't had any of this exposure so they haven't got any of these

> foundation skills, either literacy or conceptual understanding, or just sort of background knowledge.

This is exemplified in the centre’s project to support people to learn how to do their banking online. Amy commented that many of the clients have family members managing their banking, and don’t access their own accounts or have any opportunity to learn the concepts and practices associated with banking. Others who do their own banking are often only doing this by visiting branches and using passbook accounts; unaware of the existence of phone and internet banking, let alone having the necessary personal identification numbers (PINs) or cards. This lack of awareness of and opportunities to try these alternative banking methods is complicated by the risks inherent in training, where others have access to personal banking details.

> So, it’s breaking down all those barriers first, just to even get them to the first step. And unfortunately, like everything, with banking, they’ve got to actually start with their own money to learn it. There’s no simulated program they can get into and just practise, which means that they’re doing scary stuff with their live money.

Amy commented however, that clients may be just as reticent to try activities commonly perceived to be less risky, such as Facebook. It’s not possible for them to watch what another person does, and it can be difficult for a user without dual sensory loss to describe what is happening, how and why, in an effective manner.

> They’re constantly asking questions, “why is this?” and “I never knew that” and “no-one told me that” you know. Everything they’ve been taught has been through an interpreter, who may or may not be telling them what’s going on. You know, the interpreter might not realise that they should be telling them funny things that are happening, or sharing conversations. They don’t know, they just get 10% or 5%.

A leap of faith is often required, as actually doing the activity tends to be the most effective way to grasp the concepts and purpose of a new activity, and the tasks involved.

This tends to require an up-front investment, such as purchasing a smartphone, and many of Amy's clients purchase a phone outright, to avoid entering contracts that they do not understand or are unable to utilise until set up with an accessible solution. Amy encourages people to go to shops with support workers and gather as much information as possible before purchasing, as she can then translate it into sign language so that they understand what they are buying. Contracts, whether for mobile phones or home internet bundles, are generally not available in print or accessible formats, so present a higher purchase risk and often result in 'bill shock'. Yet, Amy says, clients take these risks because of the critical importance of connectivity; the benefits of being connected to the world outweigh the costs.

> You'll meet a client and you know, for about the first maybe even 6 months, even a year, they'll have one contact in their device, either their daughter, or sometimes it's even a worker. And then after, once they finally get the hang of it, you know, they'll go from one to 10, and then they might go to 20 contacts, so it's a very easy measure. Or they'll start off on Facebook and they'll have 5 friends and then they'll end up with 100 friends. And I mean it sounds twee to us, but in a lot of cases it connects them with school friends they've lost contact with, old family members, but also next generational members, nieces and nephews, grand-nieces or grand-nephews who can all share their lives with them, which they didn't have that option before. So it is really transformational.

CJ's story

CJ has low vision and wears spectacles, but notes that it was only in adulthood that she was diagnosed as legally blind and "had lived more than half my life without even specs, and my vision hasn't changed". She uses a computer for work, and recalls the many different pieces of equipment and software she's purchased or been provided over the past ten years.

Although CJ is legally blind and has specific accessibility needs, she's had difficulty accessing the specialist accessibility technical support she was referred onto when asking for advice from an Independent Living Centre (ILC). Her attempts to source advice and support from both mainstream and specialist technology suppliers have proved difficult, and she has at times fallen in a gap between the two systems. As an example, approximately nine years ago CJ was introduced to ZoomText and told it would “enhance your work” but the only way she could access it was by being part of the ‘Jobs in Jeopardy’ program.

> And not that my job was in jeopardy, but that was what they had to say it was to access the equipment.

She followed the advice and was provided with ZoomText and a scanning projector, but felt this was “crazy” and questioned the implications: “well can this then be used against me down the track?”

CJ reflected on this as a disappointing and wasteful experience, and one of several experiences of being provided with expensive, and potentially useful, pieces of equipment that were not appropriate or effective. She didn’t use the projector because she wasn’t ever trained or given time to learn how to use it. The inability to repair damaged equipment or adequately assess and review the physical layout of workstations, even when moving offices, meant that this and other assistive products were not used, despite CJ’s attempts to communicate the issues. This negatively affected her participation in work and her attitude toward using AT.

CJ has tried many assistive products, but has found them all “too fiddly”, and instead relies on her spectacles. She’s learned strategies for things like filing and activities she would like help with to save time, because she feels that she already loses a lot of time with other accommodations she makes for her vision. She wonders whether the AT providers she’s encountered have ready solutions for people who are blind, but are not adaptable to people like her who have low vision and many existing compensatory strategies. What frustrates her is that the techniques and preferences she’s developed after many years are not taken into consideration in assessment.

> How you can just get someone to come in and do an assessment straight off without really getting to know you and getting to understand what you're doing, what your lifestyle is; I don't get it. I don't get it; it's about really the assessor needs to actually understand you and what my lifestyle is and what are the things that really work for me, rather than coming and saying you need this, this, and it's like, read your diagnosis and say this is what you need.

CJ also suggested that more on-the-job support for her to learn to use new equipment would have been effective in avoiding the non-use of equipment that has been provided to her, rather than the basic initial instructions she was given before being left on her own.

For more than two years now, CJ has spent a lot of time grappling with compatibility issues between her home computer hardware and the ZoomText software. Her primary point of contact has been two technicians from the local store where she purchased her computer. She describes the problem as her monitor suddenly “blacking out” or displaying error messages from Microsoft or ZoomText when she is working. CJ was initially advised to buy a new monitor but when still experiencing the same problems on three different monitors she pressed the staff to revise their diagnosis and contacted the store manager. She has been a customer of the store for years, from a relationship built on knowing the manager in an earlier job she had with a local organisation. But in recent years the store has grown and she feels she might have had fewer problems if she’d been dealing directly with the manager rather than the technicians. At the time of interview, the problems had still not been resolved, and the unreliability of her computer set-up meant that CJ had missed a deadline for a job application and lost several draft emails and documents.

When asked, CJ could identify someone who had been helpful; one of the staff at Vision Australia who she met almost eight years ago and had recently run into on several occasions. She’d previously recommended computer navigation with ‘short keys’ (keyboard shortcuts) instead of a mouse, and while CJ had continued to use a mouse, she now acknowledged the advantages of short keys. CJ described her as “someone who tends to listen", and who had previously taken an interest in CJ's issues with ZoomText and sought to help. She contrasted this with the technicians from the computer store; "I think the guys just think 'oh it's you' in some ways. You know." CJ feels that having someone available to spend time with her working through using hardware and software for different activities and adjusting to system updates would be incredibly valuable. But while some people with disability can access regular support workers, she's not been able to access this type of intermittent support. She expressed frustration with the funding that goes into expensive products not being backed up with training and monitoring.

> It's a waste of resources. Like, it would be better off doing the proper assessment, getting one piece of equipment and then putting somewhere, having some money put aside to actually do proper training.

When asked what more choice would mean for CJ, she didn't focus on the products, saying "it would be fantastic to be able to choose the person". Having experience directing services for her sister who has high support needs, she knows the difference it makes to be able to choose who is involved. For CJ, this would be "someone who is really experienced. Not just a salesperson; someone who's genuinely interested." This would require funding for independent advisors with specialist knowledge of the product range but no commercial interest in a particular brand, whose role includes spending time to work out an individual solution and provide training without an arbitrary time limit.

Discussion

Participants described protracted interactions and negotiations as part of becoming an AT user, and challenges in acquiring and sustaining assistive solutions to enable occupational participation. Amy illustrated the necessity of AT to enable basic communication as a pre-requisite for social participation and self-care occupations such as banking. CJ first had access to AT support when employed, but requires AT to engage in the occupation of applying for work. Both participants illustrated the incongruities of informed consumers trying to exercise choice in markets offering limited opportunities for autonomy or self-determination. Interpretive analysis of the emergent themes emphasises the importance of relationships and access to ongoing support for AT users whose occupations involve risk-taking and financial commitments as part of self-management.

Becoming an AT user

AT policies and practices are often so focused on assistive products that the process of becoming an AT user can be overshadowed. The participants reflected on early experiences of using AT and the development of strategies and preferences over time. This is consistent with research that has identified several junctures in the process of becoming an AT user, and the individual variation in the time this takes (Lindqvist, Nygard, & Borell, 2013). Amy described how the peer-support model at the Centre actively supports people to become AT users with its explicit emphasis on continued learning.

> I reckon I probably only do about 10% of formal stuff, because once you set them up with training materials and formal training they are really keen to just fly on their own. So 10% of it is formal. Most of it's just trying to link them with each other and try and trouble-shoot as the problems emerge.

Amy emphasised that the learning curve is much steeper for some people with dual sensory loss, because of occupational deprivation. A history of institutionalisation and other exclusionary practices means that some people with disability missed opportunities to develop general life skills such as literacy and banking earlier in life.

> When I first started here, and they all started on email, they couldn't write. They'd never written. And so…often that's a barrier. "I can't do email because I'm poor at English". But they started then to write something and then they'd send it to a trusted person and

> “please fix my English and send it back to me” and you’d fix their English, send it back, then they’d send it out. So there’s been a really big strong transition into written text, it’s been really hard.

Once connected, users can spend years operating only basic functions while they learn, as Amy described

> For example, these guys…they’re really good power users. They haven’t really moved beyond the SMS and email. They don’t know about using their apps, they don’t feel comfortable. I don’t know what it is, they just take a long time to step into new environments. Yeah, they’re very slow with their learning. They’re slow, but they’re clever, like it’s a really big mix between them being able to manage this very sophisticated equipment and in a different language which is braille, and manage their communications through written form and stuff, which is English. You know they’ve got a lot of skills, but at the same time they don’t have a lot of conceptual knowledge around what’s available and how to uptake it.

Self-management by AT users

The principles of self-management, adopted by people with chronic illnesses and symptoms, are also applicable to being and becoming an AT user (Hammel et al., 2013). While training is assumed to facilitate new users’ acceptance of AT, there is also an argument for a broader focus on facilitating readiness in all aspects of becoming an AT user (Hocking, 1999).

AT users often develop solutions for poor fit with the physical or social environment, or barriers to accessing formal supports; processes that correspond with core self-management activities such as problem-solving, decision-making, action planning and self-tailoring (Hammel et al., 2013). The participants’ accounts support previous research that suggests skills and confidence in self-management influence outcomes including choice and control in life across participation domains (Hammel et al., 2013), but also illustrate how difficult it is to access these supports and the importance of relationships.

CJ described how she had learned effective compensatory strategies in the absence of well-matched AT. However, often CJ was not actively supported in her self-management, with her preferences dismissed in AT provision systems, and little to no support when shopping for AT.

> I've grown up over the years and not known that I was legally blind. I really learnt very good…compensation skills. Extremely. I mean the doctor said to me years ago that a lot of people who have got vision loss like mine would basically be home, they wouldn't bother even attempting to do this stuff that I do. And there's just all this stuff that I've developed over the years.

The risks and responsibilities of choice without awareness or support

The findings demonstrated the risks and responsibilities that AT users are confronted with when learning and self-managing. Insufficient information and awareness of both potential AT users and practitioners have been identified as factors contributing to unmet AT needs of elderly populations (Löfqvist, Nygren, Széman, & Iwarsson, 2005) and to low workforce participation of some people with disability (Gamble, Dowler, & Hirsh, 2004). In CJ's case, a lack of awareness of the extent of her vision impairment and the AT options available to her meant she adopted AT later in life.

> So, I had lived more than half my life without even specs, and my vision hasn't changed, I mean it was just one of those things that we discovered that, it worked.

A review of government-funded development projects supporting choice in social services in the UK found little or no evidence for specific information access needs in relation to AT (Baxter, Glendinning, & Clarke, 2008). This finding may reflect a lack of awareness or narrow understanding of AT, or difficulty communicating needs. Identifying and articulating AT-related needs is not simple, as CJ has experienced.

> I’ve been using [this store] for years …because I’ve got that relationship with them I’ve tended to just stay with them. But my daughter will say ‘mum, they’re useless, like just go into Harvey Norman [a large, multi-national chain of retail stores] and just buy yourself’ and I’m thinking ‘no, I’m not going to do that’ because that’s just not me. I mean, well it’s not me because I don’t, well I think they would get frustrated with me because I don’t know the questions to actually be asking.

Even with awareness and information, AT users have limited support prior to and after making decisions about assistive products. Despite making efforts to contain costs and understand pricing structures, Amy said that it was not uncommon for her clients to spend more than they anticipated.

> …getting them to really understand what they’ve contracted, you know how much data they’ve got and how to manage it and how to check and how not to have massive big bills, and how to turn features off on their phone. And then they get an update on their phone and all the features go back on spontaneously and then, you know, bill shock is a really big issue.

When CJ first had trouble with ZoomText she was advised that the problem was with the monitor, so she went and bought a new one

> Then I said to the computer guys, surely it can't be the computer. I can't have gone through two computer monitors like that; there has to be something wrong. So anyway, they kind of…did an upgrade whatever. I had to then buy another monitor (laughs), which is just ridiculous. Like, it's just crazy. And then the problems have just continued, so I said it's not my monitor.

When asked about who was responsible for post-sales service or problems, CJ said this wasn’t discussed.

> …just said if something breaks you’re responsible for it, unless it’s under warranty of course.

> And then he kind of, when the issue I was having about ZoomText, he said oh well, he said well I think you can follow that up yourself. And I’m thinking, well I’m happy for you to do it. You know the language; I don’t know the computer language.

Choice is often conceptualised as a discrete act or one-off transaction, but in AT provision it may be more accurately described as an ongoing and interactive process of decision-making, negotiating and risk-taking. Because of the individuality of assistive solutions, many mainstream and assistive products are not sold with the specific user’s needs and context in mind, and the responsibility and cost of identifying and implementing the solution falls on the user.

Understanding assistive technology as a pre-requisite for choice and Participation

Participants described the necessity of AT as a pre-requisite for occupational opportunities including self-care activities, socialising and maintaining family relationships, and participating in paid employment. Both CJ and Amy discussed the ongoing nature of AT provision and importance of relationships in learning and responding to problems and changes over time. AT users can only make and realise choices if facilitating conditions are present. These include the existence and awareness of options, support to explore and experience new products and skills, respect for preferences, and ongoing servicing responsibilities. Developing skills and confidence in self-management activities may facilitate achievement of desired functional and social outcomes for AT users.

Conclusion

This interpretive phenomenological analysis investigated the AT experiences and perspectives of two individuals and illustrated some of the practical considerations factored into choices about AT and the investment in the process of becoming an AT user. The occupational science of being and becoming an AT user is missing from the discourse on the right to, and choice of AT, and policies guiding its provision. Conditions for realising choice could be enabled in policy by re-framing choice as both a means and an end, consistent with a capabilities approach that aims to boost people's opportunities in life through individual and collective resources (Sen, 2005). Sen's 'capabilities' approach is consistent with the objectives of equal opportunities for inclusion and participation espoused by the CRPD (Hammell, 2015; Sen, 2005). Such policies would emphasise access to ongoing services for AT users, recognising that AT itself enhances individuals' autonomy and opportunities to function in society, making choices on an equal basis to others in society. Understanding that AT is often a pre-requisite for participation and choice may reorient AT policies toward readiness for self-management and relationships of ongoing support.

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