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Assistive technology and people: a position paper from the first global research, innovation and education on assistive technology (GREAT) summit

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ABSTRACT

Assistive technology (AT) is a powerful enabler of participation. The World Health Organization's Global Collaboration on Assistive Technology (GATE) programme is actively working towards access to assistive technology for all. Developed through collaborative work as a part of the Global Research, Innovation and Education on Assistive Technology (GREAT) Summit, this position paper provides a "state of the science" view of AT users, conceptualized as "People" within the set of GATE strategic "P"s. People are at the core of policy, products, personnel and provision. AT is an interface between the person and the life they would like to lead. People's preferences, perspectives and goals are fundamental to defining and determining the success of AT. Maximizing the impact of AT in enabling participation requires an individualized and holistic understanding of the value and meaning of AT for the individual, taking a universal model perspective, focusing on the person, in context, and then considering the condition and/or the technology. This paper aims to situate and emphasize people at the centre of AT systems: we highlight personal meanings and perspectives on AT use and consider the role of advocacy, empowerment and co-design in developing and driving AT processes.

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Introduction

The aim of this position paper is to situate and emphasize "people" within assistive technology (AT) systems. People requiring AT are historically disadvantaged: a complexity of human needs, power relations, interactions and contextual constraints make it challenging to enact choices and to pursue valued and meaningful opportunities based on equality, dignity and respect [1–3]. Appropriate provision of AT can enable people to exercise human rights and fundamental freedoms, and needs to be taken seriously given the potential cost to life and living should provision be inadequate or absent [4–6]. Adopting principles of a human rights framework, this paper takes a universal perspective where everyone has the right to access appropriate AT to meet their individual health and well-being needs, enabling participation in civil society across the life course [7]. The paper will discuss person-centred perspectives on AT use, and consider personally meaningful gains and outcomes. We discuss the role of advocacy and consider empowerment and maker perspectives in supporting the active and central involvement of people in all stages of the AT process to optimize access, choice and use. This paper concludes by considering future directions for shaping AT systems to empower and support people in their endeavours. Table 1 outlines working definitions of assistive products, AT systems and people.

People, society and assistive technology

Our experiences of identity are mediated by the body and are often enacted through a relationship with technology [9,10]. Technology products, in the broadest definition, enable people to participate in and control their environments. AT enhances possibilities for participation for all people and can serve to help in the promotion and protection of full and equal enjoyment of all human rights and fundamental freedoms [6,11]. Human identity can be partially embodied in our choices of technologies. Possessing certain technology products such as smart devices may be recognized as a marker of status and prestige, as can be seen in popular media. In the same way, human identity is susceptible to stigma, defined as disqualification from "full social acceptance" [12,p.9]. The concept of stigma is relevant to technology use in the context of technologies designed and marketed to address disability. Enabling technologies designed for people with physical impairments, non-communicable diseases and/or the effects of ageing became a specialized "subset" of mainstream products in the nineteenth and

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Table 1. Definitions of assistive products, assistive technology systems and people requiring assistive technology.

An *assistive product* is "any product (including devices, equipment, instruments, and software), either specially designed and produced or generally available, whose primary purpose is to maintain or improve an individual's functioning and independence and thereby promote their wellbeing" [8,p.2229]. The term "assistive technology" (AT) is often used as a generic term.

Assistive technology systems refer to "the development and application of organized knowledge, skills, procedures, and policies relevant to the provision, use, and assessment of assistive products" [8,p.2229]. This therefore includes training in the use of AT and other infrastructure and technologies, such as ICT, that promote the effectiveness of AT.

People refers to individuals (often referred to in the literature as "end users") using, or who would benefit from, AT and their circle of support (including family, carers, personal assistants, educators, practitioners and possibly others).

twentieth centuries in the developed world. AT was usually identified with medicalised terms such as "medical equipment" or "invalid aid" or "rehabilitation appliance", was available through prescription and was frequently institutionalized in intent and appearance [13,14]. These "assistive technologies", usually designed for the "disabled other" and described in terms of the diagnoses or deficits they addressed, came to be seen as markers of illness and loss [15]. The medical model of provision reinforced the conceptualization and experience of AT as a compensation for impairment rather than an enabler of participation.

Contemporary AT classification takes a universalizing approach to the diverse nature of all humans, and locates technologies more neutrally, suggesting products are used "for participation, and/or to protect, support, train, measure or substitute for body functions, structures and activities, or prevent impairments, activity limitations or participation restrictions" [16,p.1]. An assistive product is then an interface between the person and the life that they would like to lead [9]. If we accept the premise that human behaviour is organized around the pursuit of personally meaningful and valued goals, that direct activities give structure and meaning to people's lives [17,18], incorporating AT use can be conceptualized as a process through which strategies for new ways of being-in- the world or participating in the world are created [9,19].

Contemporary AT definitions include mainstream, every day, or "generally available" products (Table 1) and include technologies for different domains such as sensory functioning, mobility, communication, cognition, environment and self-care. A paradigm shift towards universal and inclusive design ("design for all") [20–22] is mainstreaming products with enabling features into the marketplace: wheels on suitcases, propping seats at workbenches, easy grips on tools, long-handled and non-slip products are a good idea for everyone. Mainstream apps and systems are increasingly customized to the needs of a learner and personalized around an individual's interests and circumstances. Technologies such as home automation have, almost accidentally, provided enabling technology solutions for people with functional impairments, although the challenge remains to embed features suitable across human diversity [23–25]. The increasingly rapid rate of technology development and deployment has catalyzed the growing overlap between the objective of AT which focuses on enabling an individual to overcome challenges in a person's environment and a Universal Design approach which focuses on universal access through mainstream accessible products, services and technologies. Universal Design is a valuable framework to ensure people's involvement in all aspects of the production and design of products and services, including AT. We stand therefore at this early moment in the twenty-first century, ready to re-realize the scope and outcomes of AT, and the best way to co-construct the systems and services necessary to deliver them.

Individual construction of self and AT

Use of AT can present challenges and compromises in self-identity and can impose cognitive, behavioural and pragmatic adaptations [26]. There is an ongoing and dynamic interplay among the persons, their environment and the potential of AT [9]. When the environment is unsupportive, negative perceptions and experiences can be such that the potential usefulness of assistive technologies is uncoupled from their perceived value [27]. AT is frequently abandoned or not used, the reasons are often multifactorial, and can include difficulties in incorporating assistive technologies in identity and self-image [13,28,29].

In optimizing the use of AT, it is important to understand the *meaning* the user ascribes to its use; for some an assistive product can embody ability and possibility, for others it may represent decline, restriction or disability; these beliefs can change across time and context, and are critically important determinants of the individuals relationship with the technology and interaction with their environment [9,27,30,31]. Within existing literature and practice, there has been a tendency to concentrate on physical functioning and the frequency of AT use as metrics of "success" while under-estimating the importance of the psychological, spiritual, emotional and social components that contribute to the person's quality of life and participation [32]. Improving understanding of user preferences, the personal salience of technologies for the user, and personally meaningful outcomes of AT use can contribute to technological solutions that are person-centred rather than technology-led.

Individual adaptation and AT use

Adapting to AT use is often entangled in the broader experience of adapting to illness or impairment, changes in functional ability across the life course, and confrontation with a range of physical and psychosocial threats and challenges including declines in physical and/or cognitive functioning, alterations in self-concept, changes in body image, emotional distress, disruptions to valued goals, roles and activities and changes in lifestyle and/or occupation [33]. According to Livneh and Antonak [34], adaptation is a dynamic and evolving process through which the individual strives to approach an optimal state of congruence with their environment. Adjustment is the final phase in an evolving process of adaptation distinguished by: (1) maintaining psychosocial equilibrium; (2) achieving a state of reintegration; (3) positively engaging in the pursuit of life goals; (4) evidencing positive self-esteem, self-concept and self-regard; and (5) experiencing positive attitudes towards oneself and others. Models describing influential factors in adjustment suggest a complex interplay between *risk factors*, including disease/impairment parameters, functional limitations, and psychosocial stressors; *resource factors*, including stress-processing and coping strategies; *intrapersonal,* including personality characteristics; and *social-ecological* factors, including social support and family environment [35,36]. These factors can serve as barriers or facilitators of AT use. Many of these factors are also subject to changes across time and so attention must be directed to the evolving and developing factors that impact on AT use/non-use across developmental stages and as

people age. Indeed, even in relatively short frames changes in these factors can significantly impact AT use.

People guide the selection of the solution as well as the choice to use or not use an assistive solution, under what circumstances, and in what settings and environments [30]. For many, there is a considerable physical, cognitive, psychological and social workload in beginning to use AT and adapting to its use; training is on-the-job, the commitment is unlimited and in many instances the wider environment is unsupportive [37]. A central focus on understanding the lived-experience of AT use that considers individual circumstances, capabilities, preferences, values, priorities and aspirations offers the best possibility to ensure the AT is enhancing the persons possibilities and facilitating their preferences for participation [38].

A person's mood state (notably presence of depression and/or anxiety) can affect their engagement in rehabilitation and expectations about the benefits of rehabilitation and AT use. Mood can also alter perceptions of self, energy and receptivity to new and alternative ways of doing things [30]. Bodily changes and changes in body image can have significant and long-lasting impacts on an individuals' sense of identity and agency [39] as well as on personal relationships and interactions with others [40]. Incorporating AT use can have a transformative impact on body image and self-concept [19,41] influencing how people view themselves and experience (dis)ability.

Stress-processing factors and coping strategies play a critical mediating role in managing experiences associated with AT use. The basic premise of the stress-coping model is that people confronted with a potential stressor, evaluate the stressor, and this evaluation determines their emotional and behavioral responses [42]. No one coping strategy is considered inherently better than another; coping is a dynamic and ongoing process of negotiating life demands, what is effective in one situation for one person may not be effective for another person, or for the same person at a different point in time. In very general terms, more passive, self-blame and avoidance-escape coping modalities tend to result in poorer psychosocial adaptation and increased psychological distress. Where appropriate, psychological intervention to improve mood and self-esteem, increase adaptive behaviours and facilitate engagement in rehabilitation can be beneficial [43].

AT use necessitates physical competencies to use a product, but also cognitive capacities to learn new skills and adapt to different situations and environments [44,45]. Individuals with impairments in domains such as memory, attention and organizational skills are likely to face significant challenges in learning how to use AT as they may struggle to retain new information and/or initiate new behaviours [46,47]. People are highly differentiated and training in the use of AT should be tailored to the strengths of individuals so that optimal outcomes can be achieved. People with cognitive impairments may need simplified information and instructions on how to use AT, and may require daily assistance and support from others to be able to use the technology. Therefore, including the person's circle of support and care in the assessment, provision and training processes is critically important [48]. People with cognitive impairments might also need more frequent and proactive follow-up, including technology maintenance and review of support needs and availability across all important locations of their life.

Individual adaptation, acceptance and success of AT use are not constructed solely by personal factors. People requiring AT face significant and evolving challenges to access appropriate technologies within service systems with scarce resources. Poor infrastructures, education and lack of understanding about the meaning of AT and the importance of getting AT "right" have major consequences for health, well-being and ultimate survival, effecting non-participation and technology abandonment.

Assistive technology models involving people

Arguably all technology is assistive in some way, and therefore use of AT is universal. With technology all around us and used to do multiple tasks in our everyday lives, there is a high expectation that AT will support people to perform daily activities. While having technology is important, having the *right* technology to do the activities that we want or need to do is critical. It is a person's use, experience and level satisfaction with enabling technologies that matters; whether it allows engagement, interaction and access within the context of a person's whole environment, and increases desired participation, potential and equality of opportunity. In considering who we are as AT users it is important to critically reflect on our assumptions about the nature and role of AT use and the connectivity with other AT stakeholders, such as professionals, to strengthen the success of sustainable outcomes.

Different stakeholders may hold very different perspectives or standpoints regarding differences in ability and health across the life course. It can therefore be challenging to adopt a universal model perspective, applicable to everyone, which strikes a balance between medical, social and environmental components within context [11,49]. Three perspectives are presented briefly here to illustrate the variability of standpoints. Firstly, the "disability academy", that is, authors and activists with lived experience of disability, present a discourse which differs from that presented in much medical and rehabilitation literature [50,51]. Assumptions as to the quality of life with disability [50], and whether people with disability seek removal of that disability [52], are challenged and refuted. The experience of impairment may be a "central and structuring" part of their experience [53,p.238], in which case interventions such as AT do not attempt to "fix" the body, but to address the elements which are "disabling" in a person's situation or environment [54]. Congruent with this idea is the capability approach, where developmental economists [55,56] suggest that disability, like poverty, social exclusion and other forms of disadvantage, be viewed through a "capability lens" and resources allocated to close the capability gap between a person's capacities and their aspirations [56]. Secondly, "disability" is a contested term [57,58] and does not fully represent all AT users: many with long-term illness and people experiencing the impact of age-related conditions may not identify as disabled, yet benefit from assistive technologies. Thirdly, the peer reviewed literature, and we through the act of writing, assume shared understandings of concepts such as disability, technology and the environment as either barriers or facilitators. In the majority world, specifically low- and middle-income countries and diverse cultural settings, concepts such as disability may not exist, and the use of natural supports including family members may present alternate strategies to assistive technologies, and AT may in fact disrupt socio-cultural systems [59–61].

Culturally sensitive and culturally competent AT provision is essential. This means AT design and development must be sensitive to:

1. a person's personal goals and desired outcomes;
2. the way the AT portrays and depicts the human variation which a person is experiencing; and
3. whether the locus of intervention with AT products is the person themselves, or the environment, to close a capability gap.

Assistive product design and development is continual; current growth in technology sectors less informed by disability, specifically the ageing sector and engineering-led advances in the use of smart home and information technologies for monitoring, has not

typically incorporated explicit person-centred design approaches but are now beginning to consider the value of user-directed design [62–64]. Technology transfer, from design to the marketplace, requires a relationship between product focused- and process-led solutions to ensure appropriate AT provision. Theoretical models of AT provision have been developed over the last 30 years. In these models, the person is central to AT service provision processes [65,66], for example, the Human Activity-Assistive Technology (HAAT) Model [67,68], the Matching Person and Technology (MPT) Model [69,70] and the Assistive Technology Service Method [70]. Successful application of models such as these is dependent on in-country drivers and commitment to enact and implement sustainable AT service provision systems with investment in community (Natural, Human and Social and Built) capital. Empowering all AT stakeholders to work together as a community of practice is the way forward; people focused initiatives are required to cultivate connectivity and common purpose.

Advocacy and co-design

Systemic advocacy by people with disability is long-standing. Landmark events include the recognition of disabled persons organizations (DPOs) in the 1970s, the Declaration on the Rights of Disabled Persons [71], and the International Year of Disabled Persons in 1981 [72,73]. DPOs are those controlled by a majority of people with disability (51%) at the board and membership levels. With the call out by disabled people for "nothing about us without us", group advocacy of this nature has profoundly altered the power relations between disability service providers and "professionals", and transformed the consumer from passive service recipient to customer and self-advocate [51], albeit with continuous struggles. Decades of activism have led to recognition through the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, rule four which places State responsibility for the provision of AT [74] and more recently the UN Convention on the Rights of Persons with Disabilities [11]. Raising the profile of people with disability as rights bearers and of society as duty-bearers has increased scrutiny on our progress towards the realization of rights, including the right to AT [6,75]. Reflection on the reasons for limited progression and the lens in which we, the world, view "rights" for all people are required. Advocacy initiatives require a paradigm shift, moving beyond "duty" to societal responsibility to champion access to AT for all. Such a shift in civic society moves us towards inclusive communities where there is less and less need for modification, and where people are central to determine their own diverse needs within their environment. An international push is evident to more fully locate the person in the centre of any social service delivery context. This has been described variously as consumer-directed care (CDC), person-centred planning (PCP) and public and patient involvement (PPI). Within this, health policy internationally is being democratized; consumers are increasingly invited to engage with policy processes [76], with research development and production [77–79], and to assume active roles and competencies in regard to information.

The disruptive evolution of technology coincides with this democratization and with the empowered voices of people with disabilities and has begun to disturb traditional professional – consumer relationships. Miesenberger [80] outlined a number of supporting trends towards more inclusive technologies which could be identified and strengthened in order to increase the impact of technological development on the way people participate in the information society. These include accessible Human Computer Interaction Interfaces that can be adaptive and personal, more user-centred and individual products, improvements in independent living and participation through basic technology, accessibility and universal design. It is worth noting that in each one of these trends people hold a central role (even in terminology – see "human", "individual" and "personal"), highlighting the critical role of people in directing current (assistive) technology research and development.

Enacting the principles of co-design is the most appropriate means to realize empowerment and equality in service delivery, in research production and indeed in the consumer/provider partnership. Through a co-design lens, "educating" consumers actually infers a low level of participation as it is a process of "doing to" the person. Informing, consulting and engaging activities involve more active participation, but still represent actions which are "doing for" the person. Co-designing and co-producing are genuine "doing with" activities [81].

Empowering the need knower, the maker and the process shaper

Although largely absent from the peer reviewed literature, it is clear that people are continually innovating in order to tailor and adapt existing technologies or create new ways to do and to be. The long-standing maker movement [82] is undergoing a resurgence as commercially accessible technologies such as 3D printing locate the power to "make" with the consumer in an affordable way [83]. The "value added" by an AT professional may not be visible, and creating assistive products whilst avoiding the "lengthy and expensive process of professional-led needs assessment and procurement" is alluring; a range of benefits and limitations are becoming evident [84,p.597]. The marketing of maker culture may obscure the socio-cultural and political aspects of making, with a focus on engineered solutions and an objectification and fragmentation of the consumer as "need knower" where a need is viewed solely as a challenge for technology makers [85]. Efficacy and usability trials of AT during design, production and technology transfer require consumer involvement, taking into consideration objective and subjective measures of assistive product performance, as well as meaningful outcomes [86,87].

In addition, unresolved is the relationship to regulation and standards. Most AT procurement programmes require some adherence to manufacturing and design standards: essential for safety and longevity of devices, however, potentially limiting and irrelevant to the individual user in their individual situation. "Technology-led design" has been critiqued as missing this critical contextual step whereby person is holistically viewed in the context of environment as well as task. A "deep engagement with human diversity" [88] is needed by technologists and designers. Approaching the field person-led design ready to listen to the consumer expert, will, it is hoped, lead to genuine collaborations between "need-knowers" (people requiring AT) and AT developers, and greater awareness, education and empowerment.

Focusing on product production rather than process-led provision has occupational justice implications, inhibiting participation and depriving people of reaching their desired potential [89]. Engaging key stakeholders as process shapers to support the development, delivery and evaluation of AT is required to optimize person focussed outcomes.

Evidence and research methods which empower people

Several bodies of research evidence are catalysts for user empowerment. Evaluation against human rights benchmarks such as the Convention on the Rights of Persons with Disabilities [11] creates powerful tools for people empowerment including

Table 2. What AT users in Australia want from AT services [101].

1. Determination of the best combination of devices, personal care and environmental design.
2. Access to sufficient funding for good quality and long-lasting devices.
3. Funding to meet AT needs in every area of life.
4. Holistic assessment of needs, so that each device works well and does not interfere with other supports.
5. Consideration of AT needs across the lifespan and as needs change.
6. Support throughout the process of getting AT, including device trial, training and maintenance.
7. Access to resources when needed.
8. Active involvement in decision making.
9. Consideration of personal preferences and identity so that AT is chosen to suit lifestyle and participation.

rights-based checklists [75,90,91]. Critical analysis of the nature of empirical evidence [92,93] creates a space for person-led methodologies which cope with heterogeneous people, environments and technologies, measured against individualized outcomes [66]. Cultural safety in research can only be guaranteed through research which has as its starting point the lived experience of people within their context setting. Successful examples include studies into the experience of AT provision by people in the Navajo nation [94], and explorations of the meaning of disability and technology within indigenous communities in Australia [59] – both leading to more tailored approaches to introducing technology.

Measuring outcomes

Technology itself cannot achieve anything; rather it is the way in which it is used that is crucial [9]. An assistive product cannot be assessed independently of the person using it or of the context in which it is used. Indeed, at an individual level the very concept of a *successful outcome* can only be understood with the users' perspective to the fore [29,32]. We need greater emphasis on identifying the outcomes of importance from the perspective of the user and on developing multimodal ways to appropriately and meaningfully assess and monitor these outcomes over time. Measuring the personal impact and outcomes of AT in the lives of users is essential in identifying and analyzing need, meaningful planning, matching (unmet) need to appropriate AT solutions, optimizing usage and participation. It is also critical in demonstrating fundamental and added value that technologies offer, quantifying this impact and informing funding decisions.

Yet, the lens of much AT research has been directed at the performance of technology rather than the persons experience and participation. This can be seen in discussions of AT outcomes [95]. Similarly, what consumers might want from their AT service delivery has often been inferred from studies focussed upon products or services, for example, the need for information, education, product range, context-appropriate products and service/maintenance [4,96]. However, emphasis on identifying and valuing user priorities and preferences around AT services and provision is growing [28,97–100]. For example, De Jonge et al. [101] recently described nine priorities developed by and validated with Australian AT users (Table 2). Modelling such approaches could be helpful in developing and strengthening emerging AT services and in reform of existing service provision.

Conclusion

This position paper suggests a number of ways forward to fully embed people at the centre of AT systems. People's needs and preferences are unique and often complex. Assistive products are interfaces between the person and the life that they would like to lead [9]. People must be central to decision-making. This means selecting models of practice and research methods on the basis of people's centrality. In practice, personally salient, goal-orientated AT selection processes need to be a priority regardless of the type of AT. The meeting of specialized and mainstream design exemplifies the importance of this priority; new ways must be sought to embed people within AT design. A deep respect for the intrapersonal and socio-cultural meaning of AT use, as well as for human diversity, demands a lifelong learning approach in AT practitioners. A position of mutual exchange with people, as experts in their own needs and experiences, represents the most authentic way to elicit individual goals and to respect individual meaning and potential. This holds for the AT service sector (service providers, AT practitioners) as well as mainstream designers, technologists and innovators. A co-production approach to the inclusion of people to work on infrastructure, sustainability, research, policy and development can ensure we hear this most important voice of all – people.

Disclosure statement

No potential conflict of interest was reported by the authors.

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