Re-conceptualizing disability and assistive technology: Australian consumers driving policy change

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Abstract. For people living with a disability, enablers such as assistive technologies, environmental modifications and personal care can make the difference between living fully and merely existing. This article is written from the standpoints of people with disabilities and professionals in one Australian State who found their government and service system to be a constraining rather than an enabling force. It presents two key components of policy and practice change in the area of assistive technology: challenging understandings of disability, assistive technology, and the desired life outcomes that assistive technology contributes to; and building a public evidence base through consumer-focussed research. In short, government funding of assistive technology needs to move beyond a limited focus on functional needs and take responsibility for fully equipping people to live the lives they aspire to.

Keywords: Assistive technology, outcomes, life domains, policy, funding, impairment

1. Introduction

1.1. The Australian context

As is the case in many countries, the Australian health, disability and aged care sectors provide varying levels of support for Australians requiring assistive technologies (AT) and other enablers to live. Health services for Australia's 20 million people (one in five of whom have a disability) [1] are publically funded through a universal Medicare levy, although a significant number of Australians also elect to have private health insurance to cover for non-government funded services such as dental care. While cover for 'common' assistive technologies such as optical is optional, no private insurer in Australia covers devices such as wheelchairs or bathing equipment. Thus, Australians must self-fund or rely on other type of compensation (State and Territory-based traffic accident compensation schemes and work-related injury schemes, or the federal Department of Veteran Affairs for eligible veterans). Delivery of many health and welfare resources is split across the three tiers of government in Australia, for example aged care services are the responsibility of the federal government; equipment funding was devolved to eight individual State or Territory governments in the 1970's, while home and community care services funding goes directly from federal government to local government authorities. The AT supply sector in Australia is 'small and fragmented, and dependent largely on imported product from overseas-based companies' [10, p. 153].

1.2. The Victorian context

In Victoria, a State of 5.3 million people on the south eastern seaboard, the Victorian Aids and Equip-

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Table 1
Summary list of eligible and ineligible aids and equipment – VAEP

Categories	Examples of AT provided by VAEP	Examples of AT not provided by VAEP
Mobility Aids and Equipment	Walking frames Manual wheelchairs Powered wheelchairs Scooters	*Sticks* *Crutches* *Sports wheelchairs*
Orthoses	Calipers Shoes (specialised) Custom moulded orthosis / build-ups	*Jobst garments* *Over the counter splints*
Personal Aids and Equipment	Continence Aids Washable waterproof covers	*Disposable continence products* *Urinals and bedpans*
Environmental Control Units	ECU's	*Commercially available intercom style systems*
Personal Use Items	Adjustable beds Pressure mattresses Wheeled commodes Shower chairs Hoists Specialised seating	*Air conditioners* *Computers* *Visual aids* *Bed ladders* *Footstools*
Communication Aids and Equipment	Electronic Voice Aids Voice prosthesis Electronic communication device	*Communication boards*
Home Modifications	Bathroom, toilet, kitchen, laundry modifications related to disability Hand basins for wheel chair access hand rails or grips Painting repairs related to modifications Ramps/step modifications	*Many aspects of modification are excluded eg. making good the bathroom flooring when a stepless shower base is installed*
Vehicle Modifications	Modified driving controls to enable a person with a disability to drive a vehicle Conversion of vehicle for wheelchair access Specialised trailers, lifters and carriers for wheelchairs Specialised seats Air conditioning for people with thermo regulatory conditions	*Items generally available for purchase, including mirrors, cruise control, window tinting* *The purchase of new or second hand vehicles*

ment Scheme (VAEP) is the primary government funding source for assistive technology devices [9]. VAEP, which provided 26,619 Victorians with equipment with a budget of $21 million in 2005–06 [11], operates as a 'subsidy' scheme whereby eligible applicants can seek funding amounts towards purchase of eligible items. Items are collated on a list of approved items and subsidies capped against each item. (see Table 1).

There is a substantial lag between devices coming onto the market and getting onto the VAEP list of eligible items: vehicle modifications for example as a category of allowable devices and alterations was only added in 2007. Also, the scheme is becoming progressively less enabling as costs escalate and the subsidy rates do not keep pace. For example, equipment subsidy rates are not regularly indexed and so over the

last thirty years they progressively cover less and less of the real cost of AT devices (see Table 2). Recent research into user experience of the VAEP documented problems with both cost burden and wait times for applicants. This study identified that needed AT takes an average of seven to eight months to be provided, and the subsidy only covers an average of 60% of the cost [23].

As well as the limited equipment list, eligibility boundaries exclude certain groups requiring AT. Children or adults with a long-term or permanent disability, or frailty, are eligible, individuals with progressive disorders or requiring palliative care are not. A post-hospital discharge cooling off period of 30 days excludes public hospital patients who need assistive technologies and home modifications for safe dis-

Table 2
Examples of subsidy gaps in VAEP aids and equipment list

Equipment	Maximum subsidy (A$)	Approximate average cost* (A$)	Approximate subsidy gap
Walking frames	$300	$412	27%
Manual wheelchairs – basic	$1000	$1371	27%
Manual wheelchairs – lightweight	$1250	$2147	41%
Powered bed	$2000	$2882	30%
Bedstick	$200	$220	9%
Portable Ramps	$400	$618	35%
Pressure care equipment	(max subsidy $1070 per 2 years)	Static pressure cushions: $551 Static pressure mattress: $1,493 Dynamic pressure mattress $2,133	47% (calculated on one static cushion and one static mattress within 2 year period)
Mobile Hoist	$2,600	$3,145	17%
Home Modifications**	$4,400 per lifetime subsidy	Ramp to eliminate a 500–600 mm rise (3–4 steps) costs $8,000–$10,000 Average bathroom modification costs $10,000–$15,000	75% (calculated on $8,000 ramp and $10,000 bathroom with no other entrances or rooms modified)

*Mean price per equipment category downloaded from Independent Living Centre (ILC) Victoria product database (http://www.ilcaustralia.org/home/default.asp).
**Approx costs via personal communication: OT Australia Victoria 2010.

charge. This policy, intended to ensure hospitals provide discharge-related AT, causes a situation where patients are typically loaned basic items through hospital occupational therapy departments, until sufficient time elapses and application can be made via a community-based occupational therapist, to the VAEP. Such limitations to the scheme are effectively operating as rationing strategies for a scheme that, by one estimate, is 50% underfunded [5].

2. Victorian Aids and Equipment Action Alliance

The Victorian Aids and Equipment Action Alliance (AEAA) is a coalition of more than fifty members representing disability and aged care service providers, academics, practitioners and consumers of assistive technology (AT) [2]. The AEAA is largely voluntary, although currently supported by a philanthropically funded, part time project worker, and is focussed on driving change via lobbying, advocacy, information sharing and evidence-collection. Formed in 2006, this alliance aims to:

1. Achieve increased investment in the Victorian Aids and Equipment Program
2. Ensure greater choice and equity for people with a disability and their carers in the way aids and equipment policies, programs, and supports are delivered.

Whilst calls for increased government funding for assistive technology are not new, the approach of the AEAA offers two significant new contributions to social change in this area. These are discussed below.

3. Challenging understandings of disability, assistive technology, and the desired life outcomes that assistive technology contributes to

3.1. Impairment and disability

Impairment or alteration to a body's structure and/or function, and subsequent disability, is part of the lives of 10 per cent of any given population according to the UN [14]. According to the current WHO International Classification of Functioning, Disability and Health (ICF), disability is understood as the product of the interaction between an individual's impairment, their personal characteristics and the environment in which they live [15]. One disability studies academic, Tom Shakespeare, positions impairment as a 'predicament' to be managed as the ongoing work of living occurs [16].

These points offer important base assumptions to social and policy change work around AT. Firstly, the focus of AT needs to be on the 'work of living'; in other words the life tasks and life aspirations of individuals. This shifts the policy focus away from 'im-

pairment', and the narrow application of AT to address impairment-related functional capacity. The shift entails a recognition of the prime function of AT as enabling individuals to fulfill their life requirements across the diverse life areas partly identified in the ICF. Secondly recognizing that 'the experience of disability is crucially influenced by environmental factors' [3, p.1]. Understanding disability as a product, at least partly, of environment emphasizes the importance of a policy and funding focus on environmental changes (including attitudinal, physical and structural elements of environment) [12,15].

3.2. 'Assistive technology' or 'aids and equipment'

These understandings have provided impetus for the AEAA to re-define what elements should be considered part of an appropriate assistive technology response. In reality, a range of elements or enablers contribute to solutions for each individual, including interventions to reduce or compensate for the impairment, redesign of activity and environment, and the use of assistive devices and personal care [17]. The following illustration of the potential significance of AT as an enabler is taken from the American Journal of Physical Medicine and Rehabilitation, 'There are limits on the extent to which we in the rehabilitation professions can help to improve on someone's impairments (e.g., strength, range of motion, pain) and the broader environment in which they live (at least in the short run). However, what a person with activity and participation limitations can instantaneously do when provided with the appropriate technology is far less constrained - witness the impact of a powered wheelchair or an interface that allows access to the Internet' [18, p. 136].

Relating this back to the VAEP [9] as mentioned, the scheme provides a silo of funding for certain categories of assistive devices but has no capacity to provide enablers other than AT 'on the list' and no intersection with other funding silos. For example, re-designing the environment receives only a token portion of funding within the scheme (limited to home modifications), and personal care is provided entirely separately, fragmented into separate funding areas under different State or Commonwealth government schemes. This means applicants may receive one parcel of funding but not the requisite partner funding or cross-funder referral to enact a total assistive technology solution.

By contrast, the AEAA advocates for a wider view of elements essential to an appropriate assistive technology response. It recognizes that overcoming disabling factors requires a mix of assistive devices, environmental modifications and personal care [4,6]. The definition which best represents this view is from the AT Collaboration as follows, 'an assistive technology solution can be defined as an individually tailored combination of hard (actual devices) and soft (assessment, trial and other human factors) assistive technologies, environmental interventions and paid and/or unpaid care' [4]. This definition recognizes the fundamental inter-play between these three elements, and offers a new way to frame government policy in this area.

3.3. Redefining outcomes of the funding of assistive technology

Historically grounded in the medical paradigm, the rehabilitation model on which the VAEP is based, dictates the way outcomes related to assistive technology are defined [8]. The rehabilitation model takes a functional approach to defining outcomes of assistive technology provision, focusing on improved physical and cognitive performance. The overriding picture is one where self-care, mobility and domestic tasks are hierarchically valued over community, economic and other life areas. This limited view results in, 'failure to acknowledge in our outcome measures and conceptual frameworks the extent of the freedom that good AT provides' [18, p. 636].

This is reflected in government policy that allocates AT funding based on a narrow list of devices aligned with an extremely limited set of valued outcomes, largely functional in nature. For example, while a wheelchair may be eligible for funding to meet mobility (ie. functional) needs, tailoring the wheelchair features to enable participation in an individual's sporting and social life will not be. This meets an immediate functional need to mobilize around the house and local shops for example, but not the larger life needs to lead to a healthy and active life such as navigating irregular terrain during events at the local Dog Club or having sufficient battery power to accompany friends on regular Historic Society community walks. By contrast, literature emerging from the disability studies field both questions and refutes the ordering of these outcomes, '... disabled people are starting to question why social, leisure, relationships and sexual expression have not been addressed' [19, p.128].

Research is commencing to articulate what people living with disabilities actually value in terms of AT [7]. The ICF, too, represents a major step forward from its predecessors in that it describes lives in a neutral man-

ner, articulating a range of life experiences or domains. For the AEAA, the articulation of 'activities and participation' according to life domains of the ICF, such as chapter nine 'community, social & civic life', is a welcome affirmation of the aspirations of its members in that it reflects the goals and aspirations of society at large [21]. One challenge however has been that areas such as 'mobility' and 'self-care' are placed alongside such 'meta' domains as 'major life areas', perhaps elevating the importance of these underpinning but largely functional tasks to an end in themselves along the lines of rehabilitation model as previously discussed. Certainly no one would argue that communication and mobility are not crucial elements of performance in life: but people generally do not define them as an end goal. A set of life domains that better reflects this concept is the Scope Outcomes Framework [22]. Here, all domains focus on areas of human participation, and component activities sit within these. Hence, communication, mobility and other 'sub-domains' are found nested within each of the following life areas.

3.4. SCOPE Outcomes Framework (2006)

- Personal Well-being;
- Social life;
- Political life;
- Cultural life;
- Recreational and Leisure life;
- Economic life;
- Educational life; and
- Spiritual life

Assistive technology is then understood as enabling performance in any life domain of importance to the individual. As one physician living with a disability states, 'Powered mobility liberated me to achieve my dreams to complete internship, become a doctor, and practice medicine' [18, p. 636]. For this individual, life has been transformed in the personal, social, economic and educational domains and most likely impacts upon other domains too. Costs can be measured against whole of life benefits when they are allocated against outcomes in multiple life areas. Thus the powerful potential of AT such as stand-up and stair-climbing wheelchairs, currently not available within the VAEP, can be demonstrated, and an argument made for more 'optimal' prescription that transcends functional utility [12].

In terms of government policy, this requires that assistive technology programs should support the provi-

sion of AT across all life domains. Each life domain necessarily includes addressing the functional and instrumental requirements of self care, mobility and communication as pre-requisites for participation in life activities.

4. Building a public evidence base

As mentioned earlier, calls for increased funding for assistive technology are not new in most countries. As in many other jurisdictions, the government program that funds aids and equipment in Victoria (VAEP) has undergone review multiple times, though only limited data has been made publically available from these reviews. Prompted by shared concerns about the high level of unmet need for aids and equipment in Victoria, an initial group of organisations from the disability and health sector supported research activities as part of establishing a public evidence base. Two research reports (one by Melbourne City Mission and one by Scope) were published [13,23]. Whilst small in scope (both with sample sizes of less than 100), both were driven by concerned professionals practising in the area of AT provision. One analysed survey data from practitioners, the other audited client file data across Victoria. Used together, the reports evidenced a high level of consistency of findings and provided the first publically available evidence of problems within this jurisdiction. Further agency collaboration, led to a public forum (Equipping Inclusion Forum) to explore policy options for an improved aids and equipment system and involved a wide range of stakeholders from the disability sector, including people with a disability. The Forum coincided with another Victorian Government Review of the Victorian Aids and Equipment Program. The Aids and Equipment Action Alliance was formed in response to the high level of interest expressed at the Forum and in the three years following its formation, has accessed more than $100,000 of research funds to further research the benefits of changes in government AT policy and provision. Consumers play a critical role in the AEAA, and research undertaken by the AEAA has sought to place their views and experiences at its centre, recognising that these are frequently absent from published literature and practice settings.

5. Conclusion

Re-framing government, practitioner, and public understandings of assistive technology and what con-

sumers wish to achieve via its use, have been central to the social change process in Victoria, Australia. Coupled with this has been the work to establish a public evidence base that speaks to the nature and extent of problems with the current system of AT funding and provision, along with the outcomes people experience from its use (including a focus on an economic analysis of these). This approach has translated into a clear policy platform for AT policy reform. The AEAA advocates that any government program for allocating assistive technology should meet the following principles [2]:

– Budget equals demand: Government investment in assistive technology should be consistent with levels of demand, and should be regularly adjusted to reflect demographic and technological changes.
– Meets individual needs: Access to assistive technology funding should be responsive to individual need (also recognizing the needs of families and carers), allowing for choice and the timely allocation of AT that is appropriate to the individual.
– Funding guaranteed against clear eligibility guidelines: People with a disability who need aids and equipment should have security of entitlement, and eligibility criteria should be transparent.
– Allows for life changes: Assistive technology should be provided which allow for changes in the life situations, needs and aspirations of individuals (families and carers) and which reflect improvements in technology.
– Efficient systems: Systems for the provision, maintenance and recycling of equipment should be designed to maximize the efficient use of government resources.

This combination of approaches including the formation of an advocacy coalition (involving practitioners, academics and consumers), the reframing of key understandings, and the building of a public evidence base, has been highly influential in achieving change. A comprehensive survey of 100 Victorians and economic analysis of the AT needs of a subset of these, is due for publication in June 2010 and will be available via the AEAA website. To date, successive government budgets have shown increases in financial allocations to the VAEP, and the government has embarked on a program and policy overhaul in which the AEAA has had key advisory roles. The most recent review of the VAEP (2007) has been made public and pleasingly includes statement of principles which address lifestyle choices and needs across the lifespan [20]. Specific recommendations include steps to improve outcomes through as-

sessment and prioritization frameworks, improve equity to facilitate affordability via periodic review of subsidy levels, restructuring 29 local issuing centres into one statewide centre, and repositioning the program according to current policy contexts [20]. Social change is a lengthy and incremental process; however, the experience of the AEAA in Australia reinforces the need to constantly revise the understandings and theoretical positions that underpin, mostly implicitly, social policy.

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