



Disability Justice Advocacy inc.



**Aids and Equipment Action Alliance**  
Making participation and inclusion a reality

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*'We want it painted black'*



- Able Australia •Action for Community Living
- Association for Children with a Disability •Australian Orthotic Prosthetic Association •Bayview Disability Services •Care Connect •Carers Victoria •CAUS Communication Rights Australia •DEAL Communication Centre •Disability Advocacy Resource Unit •Disability Justice Advocacy •Housing Resource and Support Service •ISIS Primary Care •Mackillop Family Services •Melbourne Citymission •MS Australia •National Disability Services •Nillumbik Community Health Service •Office of the Public Advocate •OT Australia •ParaQuad Victoria •Royal Talbot Victorian Spinal Service •Scope •VCOSS •Vision Australia •Yooralla •Youth Disability Advocacy Service •B Gabe •D Humphris •Dr E Wilson •Dr R McDonald •M DeSanto •N Layton •R Domagalski •S Wallace •S Whiting

Why do we exist?  
... because people don't get what they need!

*it should not require such an extraordinary effort to live an ordinary life*

*Rhonda Galbally 'Shut Out' report: The Age 10 August 2009*

'Young Grant is trapped inside the (aged care) facility as he does not have a modified wheelchair to access the outside. He spends most of his time in a tub chair, which is inappropriate for his needs.'

(Summer Foundation: Winkler et al 2007)



Downstream costs: contraindications  
eg aspiration pneumonia  
Silo funding

Cam requires a replacement powered wheelchair, but has a funding shortfall of \$8k. Sells chocolates for 6 months and raises \$400 meanwhile Cam experiences worsening scoliosis and decreased function in his old wheelchair.

(Too Little Too Late: Wilson 2006)

Inadequate subsidy gap prevents positive outcomes

How does the extent of AT provision relate to outcomes?

optimal vs. sub-optimal critical paths


well-matched AT is essential to outcomes

... assistive technology (AT) can empower people with disabilities in ways that go far beyond medicine and surgery.

Witness my own life! Powered mobility liberated me to achieve my dreams to complete internship, become a doctor, and practice medicine. ...

ongoing discoveries of new AT solutions to my lifelong challenges suggest that the power of AT is under-recognised (even by physicians with disabilities) and that the potential of AT as an aid to patients is not fully tapped...

*Ref: M Stineman, MD Letter to the Editor: AT outcomes: commodity or therapy? American Journal of Physical Medicine and Rehabilitation, 2002;81(8):636-7*



*Picture of Caylin Weir courtesy of ARATA News Winter 2009*

## In the real world, we need a broad definition of AT

**Assistive technology solution**

an assistive technology solution can be defined as an individually tailored combination of **hard** (actual devices) and **soft** (assessment, trial, support and other human factors) **assistive technologies, environmental interventions and paid or unpaid care.**



AT Collaboration  
[www.at.org.au](http://www.at.org.au)


## What needs to change?

1. **Take the consumer viewpoint**
2. **Consumer-defined outcomes**
3. **Same rights and choices as other consumers in the marketplace**



### 1. Consumer standpoint: user expert

The prescription of AT without knowing what life with disabilities means is as ludicrous as having a stranger (rather than yourself) select the options on the car you just purchased. Yet, the wrong wheelchair or environmental interface can have consequences as devastating as the wrong antibiotic ...although the clinician needs a special knowledge base to prescribe... (appropriate seating, optimal biomechanics etc) the patient (or consumer) must be involved in **all aspects** of AT selection.



*Stineman M, Letter to the Editor: AT outcomes: commodity or therapy? American Journal of Physical Medicine and Rehabilitation, 2002;81(6):636-7*

### 1. Consumer standpoint: respect consumer knowledge

...special home accommodations like ramps or removing thresholds are not required to gain full benefit from a cane or crutches, but they are essential for wheeled mobility.

Allen and colleagues gained insight into the need for personal assistance among AT users when they explicitly included the environment...

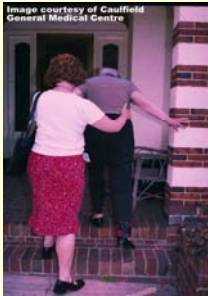
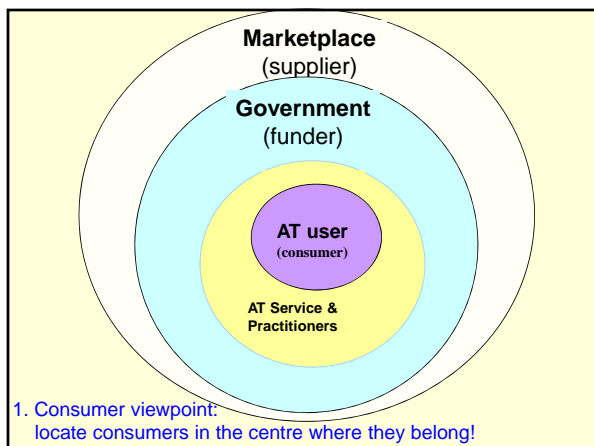


Image courtesy of Caulfield General Medical Centre

*Allen, S., Foster, A., & Berg, K. (2001). Receiving help at home: the interplay of human and technological assistance. Journal of Gerontology 56(6), 374-382.*




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2. Consumer-defined outcomes:

## hierarchy of concerns in rehabilitation



c) OT Australia

Self-defined  
leisure  
work  
community  
domestic  
personal care  
survival

2. Consumer-defined outcomes:

## is independence essential?


*'Professionals working in services for disabled people... often use the promotion of independence as a central reference point ... many disabled people experience this professionalized approach to the issue of independence as irrelevant and oppressive'*



Colin Goble  
Disabling Barriers – Enabling Environments p 42-43

2. Consumer-defined outcomes:

## the right to define for ourselves



Justin Stevenson with bowling arm  
Herald Sun

**empowerment ... should not be related to physical outcomes.**

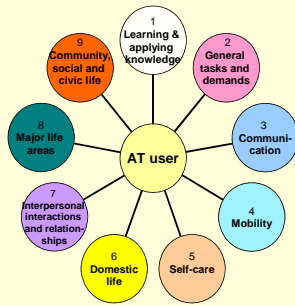
This result goes against the traditional medical model that views positive outcomes in light of physical abilities...

**individual's should be defined beyond their disabilities.**

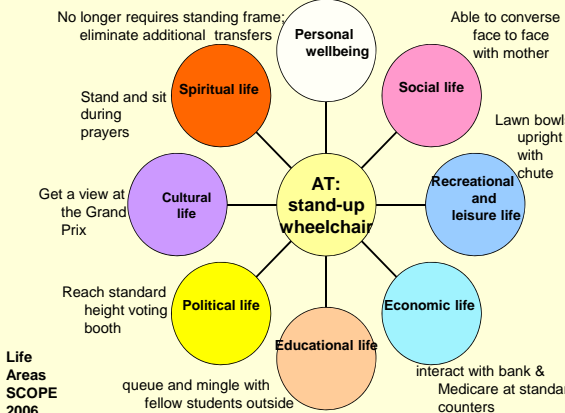
*Frain, M., Molly, T., & Bishop, M. (2009). Empowerment Variables as Predictors of Outcomes in Rehabilitation. Journal of Rehabilitation, 75(1), 27-35.*

2. Consumer-defined outcomes:

## ICF life domains



Life Domains WHO ICF 2001



**AT: stand-up wheelchair**

- Personal wellbeing:** No longer requires standing frame; eliminate additional transfers
- Social life:** Able to converse face to face with mother
- Recreational and leisure life:** Lawn bowls upright with chute
- Economic life:** interact with bank & Medicare at standard counters
- Educational life:** queue and mingle with fellow students outside lectures
- Political life:** Reach standard height voting booth
- Cultural life:** Get a view at the Grand Prix
- Spiritual life:** Stand and sit during prayers

Life Areas SCOPE 2006

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3. Same rights and choices as other consumers in the marketplace:

### design

If and when **human diversity** becomes a **natural starting point** ... all special terms will vanish, and so they should. In the end, one could say that there are only two types of design: **bad design** and **good design** (p28)



Wijk, M. (2001). "The Dutch Struggle for Accessibility Awareness." In Universal Design Handbook, edited by W.F.E Preiser. New York: McGraw-Hill

3. Same rights and choices as other consumers in the marketplace:

### great to use

Market Research:


- Shopping Mall Behaviour: people select products and possessions which function as statements about their **social status** and **identity**
- People deliberately communicate aspects of their **identity** through their possessions, such as cars and appliances



**Sexy Porsche Pegasus Wheelchair**  
Tuesday, June 12, 2007  
[http://medgadget.com/archives/2007/06/pegasus\\_wheelchair\\_1.html](http://medgadget.com/archives/2007/06/pegasus_wheelchair_1.html)

3. Same rights and choices as other consumers in the marketplace:

### identity meanings



The **meaning of wheelchairs** shifted after World War II, from a means of transporting patients to an independent means of transport. This shift in meaning paralleled and reflected a **change of identity** for spinal cord injured veterans, from invalids to "wheel chair types", people returning to the community...

Wheelchairs, however, retain **negative connotations**, revealing an **identity as wheelchair-bound**, of being confined to a chair

Hocking C. Objects of Meaning: assistive devices as symbols of professionalism, identity and disability (2008)

3. Same rights and choices as other consumers in the marketplace:

### try it on




Participation means doing things in the social world... **consumers need not just opportunities to trial equipment, but trials out in the real world...a period of "trying it on"**, to experience participation enabled by technology and experience the identity the technology brings.

Hocking 2008

3. Same rights and choices as other consumers in the marketplace:

### products that do the job



Overall, **wheelchairs are perceived as the leading source of activity limitation among disabled persons**, most notably those with SCI.

Despite steady technologic advances and progress with levels of access, the **independence of wheelchair users continues to be challenged by stairs, curbs, uneven terrain, and loose ground coverings**

Evaluation of a stair-climbing power wheelchair in 25 people with tetraplegia. Laffont, I., Guillon, B., Fermanian, C., Pouillot, S., Even-Schneider, A., Boyer, F., et al. (2008). Archives of Physical Medicine and Rehabilitation, 89, (p1958)

3. Same rights and choices as other consumers in the marketplace:

### market innovation today



The speed of innovation keeps increasing for devices on the consumer market

**For Assistive Technology, supporting persons with impairment however the speed of innovation is much less spectacular.**

This results in a state of the art regarding AT technology adoption lagging almost a decade in comparison to the mainstream market.

Although there are some types of assistive technology that are suitable for a (growing) large number of users, most assistive technology is suitable for a relative small target audience, forming a small market.

November 2009 Innovating Assistive Technology Symposium Maastricht in the Netherlands

<http://www.vilans.nl/lookingbacktothefuture>

3. Same rights and choices as other consumers in the marketplace:

**user expert**

**'A sexy new stylish wheelchair from Nomad Wheelchairs'**



'...Mark emphasises how wheelchair manufacturers often overlook what's important to the user" (consumer and manufacturer)

<http://www.accessatlast.com/accessibility-news/article/133/>

**Does it matter if its not black? Yes it does, if we want optimal outcomes**



**Utility**  
 "...it only allows me to survive rather than live"  
**Utility transcended** "...rather than a thousand remote controls on my lap... (with it) I can do everything... without it I kind of feel disabled"  
**Transcendence of utility denied** 'its rather limited... I can switch it on or off but can't change the station... Can't use the one in the kitchen'

Palmer and Seale (2007)

**How to get the right colour solution for all? through collaborative design**

- Social status/position
- Human-object relationships
- Cultural significance



- User studies
- User-centered design
- Interface
- Usability
- Aesthetics
- Sustainability
- Brand development

- Financial planning
- Marketing plans
- Sales strategy
- Pricing strategy
- Market research
- Advertising
- Public relations

- Functionality
- Manufacturing process
- Materials
- Technology application
- Prototyping

Collaborative Design: Shaping Assistive Technology Devices  
 Douun Shin Assistant Professor of Industrial Design Arizona State University

An adolescent using a wheelchair, needs to access the first floor of his home.

4 options were costed:

- Two attendants
- Mobile stair climber (attendant operated)
- Side-mounted stair climber
- Lift

The lift (most costly at outset) proved cost neutral after less than 4 years

Andrich, R. (2002). The SCAI instrument: measuring costs of individual assistive technology programmes.

**How can we fund a black one? Take a societal perspective**

**How can you argue for black?**

- Clinical reasoning in constrained contexts
- Use clinical reasoning theory to make practice constraints explicit; use decision-making theory; engage in person-centered collaborative practice
- Lack of best practice guidelines
- Clean good practice from the evidence
- Health and disability is limited lens for societal viewpoint
- Partner with others to name and frame issues; learn from other viewpoints
- Nature of existing evidence narrows our viewpoint
- Set the research agenda by asking the questions you know are important

**So, paint it black! Thank you**

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Aids and Equipment Action Alliance



### More Research...

*Sample: Victorian adults whose impairments necessitate use of assistive technology solutions*

- 'Whole of life' Equipment survey n <100
- Subset of subsequent interviews (purposeful sample) n 6-24
- Expert panel to code standard versus optimal AT solutions
- Economic evaluation of standard versus optimal

AEEA, Buckland Foundation & Deakin University

### The Equipment Survey

#### 1. Equipment Survey

Things I use  
 Other help I get  
 Overall, how much difficulty? (1-5)  
 Costs aside, what aids and equipment improvement or solution would best meet your needs? (devices, environments, support)  
 What could you do as a result of these changes that you can't do now?  
 What impact on your time would these changes have?

#### Repeat survey questions for each domain:

- Personal wellbeing
- Social life
- Political life
- Cultural life
- Recreational and leisure life
- Economic life
- Educational life
- Spiritual life

#### 2. AQOL

#### 3. Demographic Questions



The wheelchair is still widely viewed as a symbol of illness and loss. The linking of the wheelchair to injury, illness, passivity and dependency not only misinterprets the technology as simply a medical device; it also had, and continues to have, wider consequences. It disables the users in that they are themselves medicalised. ... in addition it has produced a lack of understanding on the part of both the agencies that supply wheelchairs and the companies that manufacture and design them.

**Watson, N., & Woods, B. (2005). No Wheelchairs Beyond this Point: A Historical Examination of Wheelchair Access in the Twentieth Century in Britain and America. *Social Policy and Society*, 4(1), 97.**