



Aids and Equipment Action Alliance ^{Inc}

Making participation and inclusion a reality

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Aids and Equipment Alliance Inclusive Research Partnership Document 2012

Proposal

The Aids and Equipment Action Alliance (AEAA) is a non-profit, multi-stakeholder group of Victorians working to ensure equipment is readily and equitably available to all people who require it to enable full participation in society¹. A key objective of the AEAA is to gather evidence in relation to the provision and use of aids and equipment. Therefore, the Inclusive Research Partnerships approach positions AEAA as a research partner well-positioned to foster consumer-focussed and meaningful research on topics that matter.

The Aids and Equipment Action Alliance

AEAA has been in operation since 2006, and has made a substantial contribution to the evidence base and policy context of assistive technology in Victoria since this time. Key achievements have been the formation of a legal entity along with a constitution, commissioning of The Equipping Inclusion Studies (2010), the Wait Times Project (2012), the AEAA website with its evidence database and funding navigator, as well as member networking, systemic advocacy, conference presentations, and regular and ongoing consultation with the Victorian government on key aspects of AT policy.

¹ AEAA (2011) AEAA Constitution. Melbourne, AEAA.

Additionally, major national changes to the AT landscape in the form of the proposed National Disability Insurance Scheme have created a dynamic environment in which stakeholder input is even more important²³, yet responses are required in a way that is different to previous cycles of research applications and single research studies.

What the AEAA can offer as a research partner

AEAA offers a single point of entry to research-aware stakeholders, which is highly valued by researchers. Universities and other organisations are directed through the National Disability Research Agenda⁴ to partner with consumers and other stakeholders to ensure research is relevant, responsive, and meaningful.

The AEAA membership represents a unique groups of stakeholders within the AT scene in Victoria. The diversity of consumers, professionals and other workers represent a broad range of organisations and individuals from across the disability sector as well as health, carers and aging. Additionally, a high degree of cohesion is present across the membership, focussed upon key principles for the funding of AT for Victorians and Australians, and illustrated by our Policy Statement⁴.

AEAA can offer co-ordinated access to people living and working with AT in the real world, and a clear vision of the research questions which matter. AEAA has a research and advocacy track record over 6 years, with a particular focus on the effectiveness and practical impacts of research. The AEAA research approach is one of co-production, recognising that all stakeholders hold expertise in aspects of living with AT. As such, this is highly congruent with emerging standards for inclusive and participatory research⁵⁶⁷⁸ (see Appendix 2).

² Productivity Commission (2011) Disability Care and Support Final Report. Canberra.

³ National People with Disabilities and Carers Council (2009) Shut Out: the experience of people with disabilities and their families in Australia - National Disability Strategy Consultation Report. Canberra, Commonwealth Government.

⁴ AEAA Policy Issues Statement 2011-2013. Melbourne, AEAA.

⁵ National Disability Research and Development Working Group (2011) National Disability Research and Development Agenda. National Disability Research and Development Working Group.

⁶ French, S. (1992) Researching disability: the way forward. *Disability & Rehabilitation*, 14, 183.

⁷ Barnes, C. (2001) 'Emancipatory' Disability Research: project or process? Public Lecture at City Chambers. Glasgow.

⁸ Barnes, C. & Mercer, G. (Eds.) (2004) *Implementing the Social Model of Disability: Theory and Research* Leeds, The Disability Press.

Appendix 1

VISION

That Aids and Equipment is readily and equitably available to all people who require it to enable full participation in society.

MISSION

To alleviate the barriers commonly faced by people accessing aids and equipment in order to promote the health, wellbeing and inclusion of all Victorians.

OBJECTIVES

1. To achieve increased investment in Aids and Equipment programs in Victoria.
2. To advocate for greater choice in the provision of aids and equipment, targeted to suit individuals.
3. To gather evidence in relation to the provision and use of aids and equipment.
4. To increase public awareness of issues relating to the availability and provision of aids and equipment.

PRINCIPLES

In line with relevant Human Rights legislation any system involved in the provision and funding of aids and equipment should meet the following principles:

- A fair balance of government and private expenditure: Government investment in aids and equipment should be consistent with levels of need, and should be regularly adjusted to reflect demographic and technological changes.
- Meets individual needs: Access to government funding for aids and equipment should be responsive to individual need and recognising the needs of families and carers, allow for choice and the timely allocation of equipment that is appropriate to the individual.
- Government funding guaranteed against clear eligibility guidelines: Any individual who needs aids and equipment should have security of entitlement if they are eligible, and eligibility criteria should be transparent.
- Allows for life changes: Provision of aids and equipment must be timely and responsive to changes in the life situations, needs and aspirations of individuals, families and carers and reflect improvements in technology.
- Efficient systems: Systems for the provision, maintenance and recycling of equipment should be designed to maximise the efficient use of government resources.

Appendix 2: Quality Statement of the Disability Inclusive Research Collaboration⁹ (2012)

1. **Research that is informed by and/or led by people with disability** – The need for research, and its design must be identified and led by people with disability.
 2. **Ownership** – The research process, its design, management, implementation and findings must be owned by people with disability and their representative organisations.
 3. **Inclusive and participatory** – The research process, and its methodologies, must ensure that people with disability, about whom and for whom the research is designed, play a central role as researchers and as research participants; and the voice of people with disability is validated as data.
 4. **Co-presenting** – People with disability must be provided with opportunities to present research findings.
 5. **Materials that are accessible** – Information about the research process, research tools, and research reports, must be provided in ways and in formats that are accessible.
 6. **A range of types of activities** – Adjustment must be made to the design of research to render research appropriate to the participants and accommodate a variety of approaches (research design reflects the diversity of potential research participants). Good research design must emphasise the need for a variety of approaches to ensure that a diversity of views are researched.
 7. **Research that transfers through to real life** – Research by and with people with disability must provide tangible benefits to individuals and the constituency of people with disability, and work toward greater inclusion of people with disability in the community.
 8. **Re-defining what research is** – Inclusive disability research is part of the universal research endeavour, and as such must contribute to ongoing discussions about the role and form of research in general.
 9. **“The right people asking the right questions and getting the right answers”** – Inclusive disability research must be careful to ensure that research questions are relevant and important to people with disability (determined/informed by them), and that answers are sought from the correct sources using the best inclusive methods (identify “right people”).
 10. **Consent** – Researchers must apply processes of ethics approval that ensure that people with disability are included in the research as willing and supportive participants.
- (REF: DIRCC 2012)

⁹ Disability Inclusive Research Collaboration (2012) Quality Statement. Sydney.