Aids and Equipment Action Alliance Inc

Making participation and inclusion a reality

ABN : 32 630 351 403

13 February 2014

Family and Community Development Committee
Parliament House
Spring Street
EAST MELBOURNE VIC 3002
Sent via email: FCDC@parliament.vic.gov.au.

Re: INQUIRY INTO SOCIAL INCLUSION AND VICTORIANS WITH A DISABILITY

The Victorian Aids and Equipment Action Alliance (AEAA) is a non-profit, multi-member group consisting of people with disabilities, advocates, health professionals and service providers working to improve the availability of aids and equipment to aged and disabled Victorians.

The AEAA applaud the invitation to make this submission, and offer comments and underpinning data regarding three key aspects of social inclusion:

- Aids and equipment or assistive technology (AT) as a facilitator of social inclusion
- The performance of State AT funding bodies in delivering social inclusion
- Community attitude and understanding

The information provided below includes evidence from recent research, as well as the experiences and knowledge of AEAA members providing evidence of lived experience. This submission includes a range of ideas to make social inclusion a reality.

Further enquiries regarding this submission should be directed to the Victorian Aids & Equipment Action Alliance's executive committee.

Thank you for the opportunity to make this submission.

Yours sincerely,

Peter Willcocks
Deputy chair person

Recent AEAA Studies on Assistive Technology and Social inclusion

The Victorian Aids & Equipment Action Alliance (AEAA) research into assistive technology is centred on social inclusion. It is of little value to have a piece of equipment unless it is suited for the environment of the individual and meets their needs, for if their needs and aspirations are not met, the equipment will lie idle or under utilised.

AEAA research into assistive technology (AT) provision in Victoria, funded by the William Buckland Foundation and conducted by two teams from Deakin University[1], provides the following evidence:

Under provision of necessary supports

Many Victorians don't fully participate in the community due to a lack of basic supports. For example, limited personal care support may mean only having one shower per week. The underfunded Statewide Equipment Program partially subsides one wheelchair, although many Victorians require both an indoor and outdoor device; and provision of only a minimal budget for home modifications support limits the ability of people to independently access their homes.

Information and communication technologies are a key facilitator of social inclusion yet only a small fraction of available communication technologies are covered by the State funding scheme[2].

Identification of AT that would meet individuals' needs

> *Overall, 74% of the 100 survey respondents identified unmet need for AT solutions to achieve their life aspirations. These desired solutions included aids and equipment (identified by 70% of respondents and including up to nine additional/alternative devices), home modifications (46% of respondents), environmental modifications in the community (52% of respondents) and personal care (24% of respondents). The majority of respondents appear to be technically eligible for VAEP subsidy given their income and residential arrangements. (Layton et al, 2010)*

Constraints on participation

> *Most respondents identified difficulty levels of 'moderate' to 'moderate to severe' across life areas. The area of Personal Life evidenced the highest level of difficulty followed by Recreation and Leisure Life, and Cultural Life.*
>
> *The 100 survey respondents provided a detailed set of qualitative data that uniformly spoke to levels of dissatisfaction and frustration with current participation levels. The eight case participants were also asked to rate their level of satisfaction with their participation in the life domains of their choice. Overall, participants were dissatisfied with their participation levels in*

[1] The 'Equipping Inclusion Studies' can be downloaded from http://aeaa.org.au/wp-content/uploads/2013/12/Equipping-Inclusion-Full-Reports-Final-01-Oct-2010.pdf .)

[2] page 30 of The 'Equipping Inclusion Studies' (Layton et al, 2010) compares the international listing of assistive devices for persons with disability ISO 9999 and the Victorian Aids & Equipment Program's (VAEP) Aids and Equipment List. VAEP has been rebranded as SWEP since this study was completed, but the list remains limited.

more than a third (39%) of their preferred life areas and activities, with some activities (5%) evidencing complete restriction of participation. (Layton et al, 2010)

The impact of waiting for needed supports

In 2011, the State Trustees funded the AEAA to conduct the 'Wait-Times Project'. The purpose of the project was to investigate wait times for AT in Victoria and to present policy options. The project was based on concerns with the wait times faced by Victorians eligible for equipment funding through the VAEP, which operates as the Statewide Equipment Program (SWEP)[3].

Evidence of current unmet need:

Since 2010, Victoria's AT scheme (SWEP) has undergone an extensive technical restructure. This includes a decrease in the number of issuing centres, increased transparency of allocation systems and a state-wide co-ordination of reissue, repair and maintenance. However the ongoing presence of wait lists (up to 9 months) indicates that SWEP funding is insufficient to meet current demand (It is noted that there is no wait list for oxygen or for SAEAS clients). In the absence of sufficient budget to meet demand, demand will outstrip supply. When this occurs, schemes such as SWEP are forced to prioritise eligible consumers and therefore to ration services. It is in this context that State Trustees funded AEAA to conduct the 'Wait Times' Project. (Layton, 2012)

Furthermore, a striking example of the extremes that people requiring assistive technology endure, before social inclusion is possible, is the struggle to provide stop gap funding to pay for their basic equipment needs.

Examples include consumers relinquishing the personal support hours needed for showers or community access, to pay the gap costs for needed AT. Second, using alternate funds in this way serves to mask unmet need. That is, the 'participation poverty' and opportunity costs experienced by consumers and services in allocating money to address funding shortfalls, may not be taken into account. (Layton, 2012)

What Do We Mean By Social Inclusion?

Social inclusion is a given for all, for all activities of human endeavour. Too often that social inclusion is defined by an individual's ability to partake in a community activity. It is well recognised that social inclusion and participation have benefits to an individual's health; hence reduced care costs, but most importantly, social inclusion for people managing disability is productive and adds a positive dimension to community values. There are many challenges for participation so I will only cite two examples of the many that have a direct impact on social inclusion: 1) unrestricted access, and 2) the need for public education.

1) The need for unrestricted access from place of residence to place of event

It is essential that unrestricted access is addressed in a more inclusive way than current practice. Those without mobility challenges are more often than not provided with easy access via wide open steps in

[3] The Executive Summary of the 'Wait times' report can be access at: http://aeaa.org.au/wp-content/uploads/2013/12/2012-AEAA-Wait-Times-Project.pdf.)

publicly visible, well lit areas, whereas lifts and ramps are too often positioned in less open and less publicly safe areas. The current railway station upgrades are often more inclusive for those without mobility challenges than for those requiring lift or ramp access:

- Most of our homes and public places are accessed via stepped entry. There is absolutely no need for this to be the case and a fine example of this is that banks, supermarket chains and major shopping centres are more likely to welcome their customers with stepless entry than do many of our medical practices.
- Many of Victoria's current railway station upgrades are dominated by solutions that involve the use of excessively long ramps. For example:
    - Williams Landing Station upgrade has restricted lift access that can barely manage one large power chair and carer. Long access high ramps are not suitable for people with walkers, prams, nor those managing fatigue or anxiety.
    - The Balaclava Railway Station's $13.3 million upgrade has provision for a lift, but it is not anticipated to be installed in the current upgrade. One of the ramps is in excess of 100 metres in length.
    - There are similar concerns with upgrades at Footscray, Ringwood and Sunshine railway stations.

2) The need for improved understanding and education regarding the differing effects of health conditions

- Too often we assume that people acting in an erratic manner are alcohol or drug affected, when in many cases, their presentation could equally be due to a range of health conditions that give that impression. One example of this is a member of the Bayside Polio Group who has been stopped three times by police because he struggles to walk straight. He is constantly battling fatigue and chooses not to wear callipers. While this is a relatively minor confrontation where the individual once the police determine he is to not in distress is left to his own devices to continue walking home but not before being humiliated for ten minutes.
- There is perhaps an even greater challenge for people who have no visible signs of disability; often people do not necessarily identify their needs. One case in point is a person who has a brain injury from a car accident, yet this person has developed a very successful online business. In spite of not being able to manage the financial and administration areas of her business, she is a whiz at independently managing production and public relations. Her customers include major department stores in Australia and overseas. However, because she does not have any visible signs of disability, people often don't recognise her needs. This person can get confused and frightened in busy or complex environments. She is unable to manage taxis on her own as she gets confused about time and directions. There have been so many instances that she now requires an attendant carer so she can participate in her outdoor business and social commitments.

Any person managing a disability, or who just looks or acts 'different' will have their own stories to tell. Too often, it just becomes too hard and it is easier to stay at home in a controlled environment. Media has played a big part in changing public attitudes and we have recently benefited from the NDIS awareness programs, but this education needs to continue. In 2013, there were 823,000 recipients of the Australian

Disability Support Pension and the total number of people managing disability is increasing as we live longer. Accordingly, the need for social inclusion in order to lead productive lives is something that we as a community need to address urgently.

> *In many western countries both the proportion of the population who have a disability and who are aging are increasing (AIHW, 2007; ABS a, 2010; ABS b, 2010). For example, in Australia it is estimated that in 2010 4,026,413 people or 18.5% of the total population had a disability. Although the Australian population has aged more slowly than other industrialised countries, because of the influx of younger people under immigration programs (McCallum & Kobayashi, 2001), life expectancy continues to rise (ABS, 2012) and the percentage of Australians aged 65 and over is expected to increase to 24% of the total population by 2036*
> *(AIHW, 2007) (Cooper & Bigby, 2013)*

As a consequence of funding, non-profit disability service providers have all needed to modify their programs and the area that has suffered most is public awareness. There have been well documented cuts backs at Scope, MS Australia, Vision Australia and Yooralla, to name some of the major providers affected. Peak bodies like Polio Australia receives no government funding at all. State governments support state organisations and Polio Australia does not fit any of the criteria for federal funding. It would seem to me that these organisations should receive increased funding to raise community awareness of the conditions and be encouraged to provide support to people who fall into their areas of health expertise, no matter where they live in Australia.

Five Ideas to Help Social Inclusion Become a Reality

- Ensure social inclusion is a priority for all people, regardless of ability and should be seen as such.
- Remove financial barriers and time delay with the supply of assistive technology.
- Encourage future proofed adaptable housing — a manageable incentive for future proofing housing may be via home owner grants, just as we have with solar power.
- Manage public transport access needs by employing access consultants who work with the community and who have a direct impact upon design.
- Provide financial support for public awareness programs that are managed by organisations that work with and employ people in an inclusive manner and that understand the impediments and consequences of isolation.

Reference List

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