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Doing Disability Policy Better: Learning from Research and Policy Change Activities for The Equipping Inclusion Studies.

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Introduction
Between 2008 and 2010, Deakin University was commissioned to undertake two studies, The Equipping Inclusion Studies (Layton, Wilson, Colgan, Moodie, Carter, 2010) by the Victorian Aids and Equipment Action Alliance (AEAA). The studies sought to provide an evidence base to effect improvements in policy and program provision in relation to assistive technology (AT) funding in Victoria. This was part of ongoing influencing activities undertaken by the AEAA, an alliance of service providers, people with disabilities, academics and advocacy groups, that focused on achieving a more effective system of funding for assistive technology. This paper offers some insights from this research in relation to elements of effective policy for people with disabilities. While the research included only a small sample of people with intellectual disability (10% of the cohort of 100), it is felt that the learnings from the research offer useful insights into policy in relation to people with disability in Victoria, including those with an intellectual disability.

Background to the Research
Disability policy
Increasingly, the disability policies of governments in Australia are focusing on the goals of citizenship and inclusion of people with disabilities, fostering equal rights, opportunities and responsibilities with all citizens. The Commonwealth Government's 2008 Discussion Paper on the National Disability Strategy envisions that 'People with disability and their carers have an enhanced quality of life and participate as valued members of society'. To this end, core outcome areas are named as follows:

i) People with disability achieve economic participation and social inclusion;

ii) People with disability enjoy choice, wellbeing and the opportunity to live as independently as possible; and

iii) Families and carers are well supported (Commonwealth of Australia, 2008: 10).

The Commonwealth government explicitly states that the key aims of the National Disability Strategy will be aligned with the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Commonwealth of Australia, 2008).

In Victoria, the state government's Victorian State Disability Plan 2002-2012 (State Government of Victoria, 2002) identifies the key goals as: 'Pursuing individual lifestyles'; 'Building inclusive communities'; and 'Leading the way' (State Government of Victoria, 2002: 11).

The State Disability Plan is attended by a Quality Framework for Disability Services that identifies outcomes expected of funding and supports provided to people with disabilities (Department of Human Services, 2007). In Victoria, outcomes focus on sixteen life areas such as 'being part of community', 'doing valued work', and 'having fun' (Department of Human Services, n.d:12-13).

The place of Assistive Technology in disability policy
While these larger policy frameworks identify the intent of governments in relation to people with disabilities, it is the lower level policies of program guidelines that bear the burden of enacting these and ultimately are responsible for the success or failure of the larger policies they sit within. A useful case study is that of the funding and provision of assistive technology in Victoria.

The Victorian state government subsidizes the purchase of eligible items of aids and equipment under the Victorian Aids and Equipment Program (VAEP). This program fits within the policy parameters of the State Disability Plan and the Quality Framework, summarized above. Given Australia's obligations under the UNCRPD, the program necessarily now also has a relationship to this larger policy framework.

Despite the strong emphasis on citizenship, equality and inclusion discussed in State, Commonwealth and international policy, the VAEP names its aim far more narrowly to:

'Provide people with a permanent or long-term disability with subsidised aids, equipment, vehicle and home modifications to enhance independence in their home, facilitate community participation and support families and carers in their role' (Department of Human Services, 2010).

While the emphasis is on 'aids and equipment', a small proportion of funds within this program supports environmental and vehicle modifications. Provision of personal care is not included in current program guidelines and must be sought through other programs.
It is argued later in this paper that this restricted framing of program goals, combined with a drastically inadequate budget (see commentary in Coalition for Disability Rights, 2006), and a range of narrow eligibility criteria, bring about policy failure at a range of levels.

While assistive technology overall is an under-researched field (Lovarini, McCluskey & Curtin, 2006), several studies within Victoria have already begun to document issues with provision of AT, particularly related to government funding through the VAEP. In a Victorian study in 2006, Wilson, Wong & Goodridge demonstrated substantial cost burdens to people with disability (average subsidy shortfalls of 40% of actual purchase price of equipment), and wait times (up to 18 month delay in provision of needed equipment). In a concurrent study, Pate and Horn (2006) described the systemic impacts of inadequate funding within VAEP for both families and the practitioners supporting them. Pate and Horn (2006) calculated that occupational therapists and case managers spent approximately 4 hours per week seeking gap funding. A third and more recent study of occupational therapists working in community health (Quick, Harman, Morgan & Stagnitti, 2010), also documented these issues, noting access to funding through the VAEP to be an enormous barrier for community health practice in Victoria (2010:99). In short, the picture emerging from these studies is that people with a disability have extremely limited access to needed aids, equipment and environmental modifications, which negatively impacts individuals, their carers and families.

The link between the affordable and timely provision of assistive technology and the achievement of policy goals such as citizenship, participation and inclusion, does not appear to have been understood by governments, given their failure to ensure provision of AT to those who need it. This is despite good available evidence (both internationally and in Australia) to show that the provision of assistive technology and environmental modifications are key contributors to the achievement of a range of economic and life outcomes. This literature evidences outcomes of AT related to:

- Enabled activity and participation in specific life domains;
- Overall health and community life outcomes;
- Quality of life;
- Preserved independence, decreased functional decline and reduced hospital admission rates;
- Prevention of secondary medical complications;
- Prevention of falls;
- Maintenance of occupational roles via enabling environments;
- Alleviating carer burden;
- Reduced residential care placement (Layton et al, 2010).

These outcomes are consistent with government policies outlined above, so that it could be argued that in order to meet these policy goals, governments can justify expenditure on AT, as without the provision of AT resources, the achievement of these policy goals is likely to be limited. It is in this context that The Equipping Inclusion Studies were undertaken.

Overview of the Equipping Inclusion Studies

Method

Two studies were commissioned by the AEAA in 2008 with the broad intent of exploring the link between assistive technology and the life outcomes of people with disabilities, and the cost effectiveness of the provision of AT.

The AEAA required the study design to include: the participation of people with a diverse range of disabilities (rather than one diagnostic group) in the research; a focus on a broad range of AT; attention to a wide range of life outcomes; and an underpinning methodology that privileged the views and experiences of people with disabilities using AT. Methods included literature reviews, an online and paper based survey of 100 adults with disabilities in Victoria1, indepth interviewing and outcomes assessment of a sub set of 8 individuals, and an economic analysis.

Study participants: the demographics of AT users with disabilities in Victoria

The study population of 100 respondents represented a wide cross section of people with a disability in Victoria. The survey respondents were 59% female and 41% male. The majority lived independently (62%), most with a spouse or partner, and 14% lived in the family home (with parents or relatives). Most respondents were aged 45-64 years (39%) and 25-44 years (20%), with 13% over the age of 65.

Participants identified nearly 60 separate diagnoses, with the majority of these classified as relating to physical disability (60%), followed by multiple (14%) and sensory (13%) disabilities. Of these, 10 respondents (10% of sample) have been identified as individuals living with intellectual disability2.

Study participants evidenced a higher than average level of unemployment (74%) compared with the
Australian population of persons with a disability. Along with the low rate of paid employment, most respondents (75%) were dependent on government pensions or allowances as their main source of income. Sixty seven percent (67%) reported their income as being under $21,600 per annum and a further 25% identified their income as under $58,000 per annum. This is consistent with the income poverty of people with disability in Australia generally. Despite low levels of paid employment, a significant number of respondents (21%) engaged in volunteer work and a further 4% wished to do so but lacked the enablers to make this happen.

Participants also evidenced significant social disadvantage, reporting hardship in multiple indices of deprivation and social exclusion (from Saunders and Wong, 2009), including economic hardship and lack of community participation. In addition, The Equipping Inclusion Studies compared health related quality of life of Victorian participants with disabilities, with the broader population. The health related quality of life of the study population was less than half that of the norm for the Australian population (0.32 compared to 0.80) as measured by the Assessment of Quality of Life (AQoL-6D) tool (Hawthorne, Richardson & Osborne, 1999). The study population experienced particularly low scores in relation to some quality of life domains, including those of Independent Living, (where they experienced less than a quarter of the life quality of the Australian population), and of Relationships (where the study population experienced around half the life quality of the Australian population). This data confirms a range of other literature that speaks to the ongoing levels of significant disadvantage on a wide range of indices of people with disabilities.

Data analysis re policy outcomes

A range of analyses were undertaken and analytical frameworks applied. Given the research aimed to determine the needs and outcomes of people with disabilities in relation to assistive technology, and the implications for current government policy and practice, the research also included an explicit policy analysis of the data in a number of ways.

This analysis mapped data to two policy frameworks: 1) the Department of Human Services (DHS) Quality Framework, and in particular, the sixteen life areas / outcomes in this framework; and 2) the United Nations Convention on the Rights of Persons with Disabilities. In each, the researchers identified instances where respondents reported they had achieved life attainments consistent with elements of these frameworks (i.e. any of the 16 life areas of DHS, or the Articles of the Convention) as a direct result of the provision of assistive technology solutions, as well as instances where respondents identified failures to achieve in relation to these areas due to inadequate provision of AT solutions.

This enabled researchers to clearly explore the link between the provision of a specific element of assistive technology and the achievement of life outcomes and rights. In effect, this clarified the relationship between the provision of AT support and the success of government policy or compliance with international requirements. This was an important element of the research as it clearly linked individual life experiences with government policy, and provided an evaluation of the latter.

Secondly, researchers undertook a more detailed analysis of one element of government policy, the guidelines of the Victorian Aids and Equipment Program. In particular, researchers analysed the number and type of items listed as eligible for funding within this policy and matched this both to a wider international listing of available items (ISO 9999, 2007) and to items both currently used and identified as required by respondents. This highlighted key gaps in current Victorian government policy (i.e. only one third of items needed by respondents were included as 'eligible' for government funding). Further, researchers matched the level of funding provided by government with actual purchase costs for all eligible items funded by government (finding that government provides less than 66% of purchase cost on average).

These combined analyses enabled researchers to discuss the assumptions of government policy and its overall fit to the needs of people with disabilities, as well as its likely success in achieving its own stated policy aims.

Overall, this set of methods generated significant data about how to best structure effective policy in relation to assistive technology funding. Most important for this paper, the research also generated some key conclusions in relation to general policy design for people with disabilities. These are discussed below.

Implications for Effective Policy for People with Disabilities

Policy design must match the demographics of its target group

As discussed above, the study population evidenced significant levels of disadvantage. People with disabilities in Victoria requiring AT are usually unemployed, have an income less than $21,600 per annum, are dependent on government for this income, and experience many
other dimensions of disadvantage including participation poverty and poor health related quality of life. However, *The Equipping Inclusion Studies* also found that this group had multiple aspirations for their lives as productive and active citizens. Seventy four percent (74%) of respondents identified unmet need for AT solutions to achieve their life aspirations, most commonly in the areas of Personal Life (identified by 68% of respondents), Social Life (48% of respondents), and Recreation and Leisure Life (38%). It is this context of unmet aspiration and financial limitation that the VAEP needs to match.

The VAEP currently operates as a ‘subsidy’ scheme whereby eligible applicants can seek funding towards purchase of eligible items. Items are identified on a list of approved items and subsidies capped against each. Subsidy schemes are premised on the assumption that the target group has the financial resources to afford co-payments. In most subsidy programs, for example Medicare, the level of subsidy is set relative to the affordability and feasibility of the level of co-payment in relation to the characteristics of the recipient group (level of need, ability to pay etc). In many instances, subsidy programs include a ‘safety net’ provision for those who cannot meet the level of co-payment, or for whom frequency of need and use of the program makes the cumulative co-payment level too onerous. There is no safety net provision within the VAEP at present. *The Equipping Inclusion Studies* evidence that the capacity of people with disabilities in Victoria to make co-payments for AT is severely limited. The studies found that the need for AT is substantial, with most respondents requiring up to 13 devices and other modifications as part of their AT solution, and this suggests co-payments would be repeated. Therefore, the VAEP is operating in a way incompatible with its target recipient group to the extent that the group cannot afford to participate in the program.

To be effective, policy needs to match the demographics and context of its recipients. In this case, the introduction of safety nets are part of required policy change, as is full or increased levels of government funding to ensure equity.

The equity argument is particularly relevant to this context and its absence from much disability policy notable. The economic analysis of *The Equipping Inclusion Studies* pointed to the need to adopt an equity argument to the funding of AT (Colgan, Moodie & Carter, 2010). As part of the economic analysis, researchers sought to identify the costs and outcomes of providing an optimal package of assistive technology to a sub set of respondents (n=8). Outcomes improved across all cases as a result of optimal provision, and the cost of this provision of AT was small (under $7000) in half of the cases. However, in 50% of cases, though the actual cost of AT was moderate to high (between $11,000 and $30,000), these costs were identified as being cost in-effective as they represented an expenditure of more than $50,000 per quality adjusted life year. However, *The Equipping Inclusion Studies* propose that an equity argument is needed to more fairly determine budget allocations for special needs groups. The standard measure of Quality Adjusted Life Year works against groups like the case study participants because, regardless of the health intervention provided, their disability will continue to prevent them from scoring highly in generic health related quality of life instruments. Such lower quality of life outcomes result in poorer cost-effectiveness results when compared to other client groups who are able to achieve higher quality of life outcomes. This is likely to bias government resource allocation decisions against them, as outcomes appear a comparatively poor return on investment (Layton et al, 2010).

Adopting an equity approach recognises the importance of adequately valuing the outcomes desired by the disadvantaged target group, and the need to attach higher weight to these outcomes (thus decreasing the comparative cost of achieving this). This analysis, in conjunction with the evidence of significant disadvantage of people with a disability, suggests that equity arguments need to be employed within policy arenas to do with disability. An equity approach affirms that heightened expenditure on people with disabilities, in order to narrow the gap between their life outcomes and those of the general population, is a justifiable, even necessary, one on which to build disability policy.

**The outcomes identified by policy should be those valued and prioritised by the target group**

The AEAA directed the researchers to consider ‘whole of life’ outcomes, not simply atomised outcomes such as ‘mobility’ or ‘safety’ which have been a feature of much of the published literature around outcomes of AT to date (Layton & Wilson, 2010). Therefore, the study was structured around a series of life domains (Wilson, 2006): personal, social, political, cultural, economic, recreation and leisure, and spiritual. Respondents were asked to identify the equipment, environmental modifications, personal care and any other enablers they used to attain outcomes in life domains of relevance to them. Additionally, the study elicited data regarding current and potential degree of difficulty engaging in these life domains.
Over 900 instances of activity and participation for 100 survey participants were captured in *The Equipping Inclusion Studies* via this analysis. The 100 participants used AT to participate in multiple life domains. All eight life domains were populated with examples of AT use that enabled involvement in life activities. Most respondents (94%) reported activity supported by AT use in Personal Life, followed by Social Life (80%), and Recreation and Leisure Life (73%). Elements of AT were repeatedly seen to be effective in more than one life domain. Asking about whole of life outcomes around AT demonstrated that a single intervention (AT) achieves outcomes across a wide range of life areas.

While the provision of assistive technology results in a wide range of impacts on people’s lives and enables them to participate in varied life areas, the data also shows that inadequate access to AT acts as a significant barrier to participation. The 100 survey respondents provided a detailed set of qualitative data that uniformly spoke to levels of dissatisfaction and frustration with current participation levels. Overall, case study participants were dissatisfied with their participation levels in more than a third (33%) of their preferred life areas and activities, with some activities (5%) evidencing complete restriction of participation. As discussed above, 74% of the 100 survey respondents identified unmet need for AT solutions to achieve their life aspirations, with the majority of respondents seeking outcomes in the areas of personal, social, and recreation and leisure life.

The lack of provision of AT resulted in respondents reporting 114 incidents of failure to achieve results in the sixteen ‘life areas’ of the Quality Framework (Department of Human Services, 2007). Of these, most were related to the area of ‘moving around’, followed by ‘having fun’, ‘paying for things’, ‘exercising rights and responsibilities’ and ‘expressing culture’. In addition, respondents reported other areas of failed aspirations that could not be aligned to the life areas of the Quality Framework. Examples include spiritual life and development; planning for the future; and volunteering.

By contrast, the aims of the VAEP (identified above) are listed as enhancing independence at home, facilitating community participation, and supporting carers and families (Department of Human Services, 2010). These do not appear to adequately capture either the aspirations of people with disabilities, or the use of AT by this group, across all their life areas. Provision of equipment and environmental modifications are evidenced as being required to achieve a diverse array of outcomes across a much wider range of life domains than is currently envisaged, or allowed, within VAEP policy. Similarly, the Quality Framework has not adequately captured the breadth of aspirations of, and outcomes experienced by, people with disability, suggesting that some life aspirations will remain unvalued, unsupported and unfunded by government.

This analysis suggests that both broader policy (such as the Quality Framework) and program policy (such as the aims of the VAEP), do not match the aspirations of people with disabilities and potentially serve to limit the life activities and chances of this group where funding is limited to this narrower vision.

**Policy needs to support the known elements that lead to valued outcomes**

*The Equipping Inclusion Studies* provide evidence in regard to the ingredients or elements of AT provision that result in outcomes for people with disabilities. Respondents used multiple items of equipment (an average of 8), multiple environmental modifications (in both home and the community), as well as personal care, in suites of interdependent elements. Such ‘suits’ included an average of 13 elements overall – invariably sourced from multiple funders and services. The majority of respondents (66%) used elements in a combination of equipment, environmental modifications and personal care, and only 2% used equipment alone.

In relation to solutions to unmet need, respondents also identified this range of elements. Most respondents (70%) identified a need for aids and equipment in order to meet their (unattained) life aspirations. This included up to nine additional or alternative items of equipment per individual. Around half (56%) identified a need for home modifications and environmental modifications in the community (52%). Almost a quarter (24%) identified personal care as a solution to achieve desired life outcomes. People with intellectual disability provided examples of need across all of these elements, with a strong emphasis on increased personal care to support social participation.

Current developments in the assistive technology field acknowledge these three elements (equipment, environmental modifications, and personal care) as key and co-dependent ingredients of effective solutions to meeting people’s needs. As a result, language is shifting to an emerging emphasis on ‘Assistive Technology solutions’, defined as entailing:

‘a combination of devices ( aids and equipment),
environmental modifications (both in the home and outside of it), and personal care (paid and unpaid)’

(Prosthetic Technology Collaboration, n.d.).
In contrast to this broad definition of 'assistive technology solutions', however, Commonwealth and State government policy and program discourse widely uses the term 'aids and equipment', demonstrating a considerably narrower focus on the device rather than the broader environments and supports that interface with it. Current government policy and funding is atomised, focusing on single elements of this 'suite' of solutions in isolation. This leads to the nonsense that one item of a required set might be funded, despite being less or not functional without the other elements in place.

It is therefore important that policy focuses on 'fit for purpose' rather than narrow definitions of eligible items without regard to context or outcome. Finally, because the 'suite' of solutions encompasses personal care, equipment and environmental modifications, policy attention needs to be broad enough to co-ordinate and support the provision of this range of responses. Despite being clearly resonant with the three broad goals of the current State Disability Plan (listed earlier), no policy or program attention has been given to the co-ordination (across programs and departments) required to ensure all ingredients of success are supported.

Policy makers need to ask 'what are the ingredients to achieving valued outcomes in these areas?' and then ensure government provides mechanisms to support, co-ordinate or directly fund them all. The current situation, as evidenced through The Equipping Inclusion Studies, of partially subsidising one of these ingredients and hoping the others will take care of themselves, is not effective policy.

Significant attention needs to be paid to the ways to manage insufficient budget allocations

The Equipping Inclusion Studies demonstrate that the VAEP is currently not meeting the level of demand for assistive technology solutions from Victorians with a disability. Individuals remain without needed items and life outcomes are restricted or denied as a result. In short, demand exceeds the program's capacity.

A major mechanism for managing inadequate budget allocations, i.e. insufficient funds to meet demand, is to set up various gate-keeping strategies such as eligibility criteria, priority criteria and wait lists. In the case of VAEP, two of these strategies to manage inadequate funds are the list of eligible items and the subsidy caps on these.

Currently, only those items deemed eligible are subsidized by the VAEP. In contrast, respondents identified a high demand for a wide range of equipment, around a third of which is not currently eligible for VAEP funding. Mapping the VAEP list to that of ISO 9999 (2007), an internationally accepted classification system for assistive products for persons with disability, demonstrated coverage of only 13% of device types listed in the ISO 9999. The VAEP list excludes many device types (listed in the ISO 9999) that support mobility, communication, and other categories within the VAEP funding scope, with no apparent rationale for their exclusion. Further, there was a high demand for equipment that was not currently eligible for VAEP funding. Respondents identified a high demand for 'generic' items such as mobile phones and computer applications. In all instances, the generic item was an essential part of a highly customised AT solution that produced desired life outcomes (for example, a type of mobile phone that can download communication applications for customized use). These generic or 'mainstream' items are not included on the VAEP list, despite their critical place in a suite of solutions or their cost effectiveness. The inability to purchase all the required elements of a suite of solutions, renders individual funded items less or not effective. This approach also leads to use of those elements which are eligible for funding, rather than those which are most effective or affordable. Overall, such an approach is unlikely to achieve effective outcomes from such ad hoc and piecemeal investment.

Mechanisms such as priority criteria, narrow approved item lists, and waiting lists function as deterrents to the use of the VAEP by eligible potential applicants. It may be that this is an intentional function of the gate-keeping mechanisms. Of the 100 survey respondents, 91% are theoretically eligible for the VAEP program, yet 30% self funded their AT. Further, 73% of the items identified as required by participants, (but remaining unprovided), are eligible for VAEP funding. This suggests that people with disabilities are not using the VAEP to the full extent of their eligibility. Qualitative data provides a range of reasons for this. Some participants described opting out of the VAEP system on the grounds that procedural hurdles, waiting times and uncertain outcomes render it an ineffective option, despite then experiencing substantial hardship and compromised participation. In some cases, respondents reported utilising other sources of Department of Human Services funding (such as individualised packages) to overcome or avoid the hurdles and limitations of the VAEP system.

This analysis identified that policy needs to 'build-in' increased and explicit accountability around such funding management mechanisms in relation to how they impact on a) the target group and b) policy attainment (including international policy
obligations). More work is needed to ensure that such policy mechanisms to manage inadequate funding do not prevent outcomes for those who are eligible for funding. This should be a key litmus test for program guidelines in regard to the broader policies they aim to enact.

Policies must be tracked through into program guidelines

This research shows that there is a clear disjuncture between international, commonwealth, state government disability policy and the focus of the VAEP. Evidence from this research shows that the lack of AT provision (the arena of VAEP) has significant implications for policy achievement and failure at all of these levels. Insufficient attention has been paid to the way policies at ground level (i.e. program guidelines) restrictively re-interpret, or function to undermine, the overarching policies in which they sit.

The Equipping Inclusion Studies found substantial limitations in AT provision, which act as a barrier to the achievement of participation as detailed in disability policies. As well as the previously mentioned 114 incidents that were identified as policy failures in relation to the Victorian State Disability Plan and its Quality Framework, some 138 instances of failure to achieve rights as explicated in the articles of UNCRPD were identified. Overall, the UNCRPD contains 19 references to assistive technologies and enabling environments, and strongly reinforces the rights of people with disabilities to access and obtain AT solutions to meet their life needs in the broadest sense (UN, 2007). In this study, Articles against which respondents identified the highest level of failed attainment relating to lack of AT provision were: ‘Accessibility’ (Article 9) with 32 instances of failure to achieve the article standard; ‘Living independently and being included in the community’ (Article 19) with 23 instances of failure reported; ‘Adequate standard of living and social protection’ (Article 28) with 18 instances of failure; and the combined elements of Article 4 ‘General Obligations’ (together totaling 25 instances).

Each of these instances of policy failure (and lack of attainment of specified human rights) was identified as related to lack of provision of assistive technology solutions. Thus, without provision of needed supports at the level of VAEP, policies at all levels risk significant levels of preventable failure. This analysis highlights how important ground level program policy is to the attainment of higher level policy and legislative obligation. This is a key area of neglect in disability policy in Australia and Victoria – that program policies and guidelines have not been matched to overarching policy intents and obligations, and have been allowed to function in a largely de-contextualised and atomised fashion.

Policies must be streamlined and co-ordination across them actively managed by government

As with many other areas of disability funding, the funding arena for assistive technology solutions is complex and confusing, with funding pockets found at all levels of government and in the philanthropic sector. In this study, respondents reported accessing up to 12 separate funding sources to fund their suites of AT solutions. Respondents discussed the enormous detriments of such an environment that wasted time and resources on searches for funds, each limited by different eligibility criteria. For example, in one case, a participant who ran her website business from a hospital bed at home was ineligible for workplace funding for essential computer and communications technologies as she was self-employed. In another, a participant with deaf blindness required a mobile phone with refreshable Braille interface to be able to communicate with others when away from an interpreter or adapted computer. She found she was ineligible to apply as a jobseeker as she needed to be in work.

Respondents also reported severe limitations placed on them by program funding that sought to restrict use of funded items (and outcomes from items) into a single area of life (e.g. an individual could only use funded wheelchair at school and not in the community or at home). The silos of government policy and funding were found to limit the life outcomes of individuals. In one instance, a participant had creatively solved her need for personal care, and thus freed up use of her individualised funds for use on other AT and life needs, by organising a boarder to stay with her in her Ministry of Housing flat in return for personal care. As the boarder did not meet the criteria for Ministry of Housing tenancy, this solution was not allowed.32

The Equipping Inclusion Studies propose an important role for government to co-ordinate ‘back of house’ transfer of funds between funding silos and departmental areas, and to broker agreements for multiple use of funded items in a range of life contexts, with a range of outcomes spanning different government policy and departmental parameters. This brokerage and co-ordination role is currently unfunded and falls, de facto, to therapists, case managers, carers, and individuals with disabilities and their families. Having created this environment, government policy needs to recognise its own responsibility in dismantling such ‘disabling’ structures, or at the least, taking other steps to overcome these effects.
Co-ordination and streamlining need to be an explicit part of government policy in relation to, at least, its own provision of service, support and funding for people with disabilities.

Conclusion
The State Disability Plan 2002-2012 has provided a ten year framework articulating broad policies around social inclusion and citizenship for people with disabilities. It has been reinforced with more specific guidelines, particularly the Quality Framework and its sixteen life outcome areas. The Equipping Inclusion Studies have offered some useful learnings about analysing the effectiveness of this policy arena and the programs, such as the VAEP, that deliver it. The Studies have reinforced previous data on the economic poverty of people with disability in Victoria, as well as their social disadvantage. These harsh realities must be at the forefront of future policy development to ensure policy and programs will match the needs and capacities of this group. Further, The Equipping Inclusion Studies show that people with a disability, including people with intellectual disabilities, live whole lives with diverse interests and experiences in social, cultural, political, employment, education, economic and spiritual areas. However, lack of provision of fundamental services means they miss out on achieving the outcomes they aspire to as Victorian citizens and have rights to under the UNCRPD. Disability policy has failed where people are forced to make trade offs around fundamental life needs. Rational life outcomes and citizenship in our society cannot continue to underpin disability policy and programs for the next ten years.

References


### Appendix One:

#### Table 1 Cross-walking ICF Activity and Participation Chapters (WHO 2001) to Life Domains (Wilson, 2006)

<table>
<thead>
<tr>
<th>Life domains (Wilson, 2006)</th>
<th>Personal and family wellbeing</th>
<th>Social and interpersonal activities</th>
<th>Recreation and leisure life</th>
<th>Economic life</th>
<th>Educational life</th>
<th>Political life</th>
<th>Cultural Life</th>
<th>Spiritual life</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICF (WHO 2001)</td>
<td>Learning &amp; applying knowledge*</td>
<td>Communication*</td>
<td>Major life areas</td>
<td>Domestic life</td>
<td>General tasks &amp; demands*</td>
<td>Community, social &amp; civic life</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-care*</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
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</tbody>
</table>

*these domains are embedded within each of the Life Domains (Wilson, 2006) and are considered to be essential preconditions to performance of each life domain.

### Appendix Two:

#### Table 2 Analysis for participants with intellectual disability by DHS Quality Framework

<table>
<thead>
<tr>
<th>Life Area</th>
<th>Examples of outcomes not achieved from ID specific data (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Always learning</td>
<td>[Re personal wellbeing; I would like] a program in Healesville where I live. Currently I am bussed for 2 hours each day to access my ATSS – leaves a bit to be desired. [Re educational life; I use] ATSS – an adult training program – not sure what they’re training me for exactly – spend many hours in bus…I know how to put my seat belt on! Actually think my education finished on leaving school.</td>
</tr>
<tr>
<td>2 Being part of a community</td>
<td>[Re recreation &amp; leisure; I would like] accessing places that are wheelchair friendly. Having others accept my differences (e.g. noise that I may make)... [this would] enable me to be an accepted member of the community.</td>
</tr>
<tr>
<td>3 Being independent</td>
<td>[I would like] Service dog, handle by the front door [This would enable me to] leave the house without having family come and get me... improved independence.</td>
</tr>
<tr>
<td>4 Being safe</td>
<td>My son needs to walk for an hour a day to maintain his muscle tone and strength so he can continue to independently toilet himself. The local Council has only just agreed to pave the footpath -next year to connect with the local shops from my son's flat so he may be safe – currently he has to walk (slowly) on the road in his walker that has been dangerous with the local hoons... [We would like] increased access to the local shops and walk with safety.</td>
</tr>
<tr>
<td>5 Building relationships</td>
<td>[Re social life; I would like] funding for carers to take me out and support for my parents who are getting older but still want me at home part time. [Re social life] I need to be supervised, my mum is my biggest aid.</td>
</tr>
<tr>
<td>6 Choosing supports</td>
<td>[Re social life; I would like to] pay my mum more so I can access more activities...[then] I could go more places... I could do more exercise.</td>
</tr>
</tbody>
</table>
7 Communicating
[Re educational life: I would like to] try to have some sort of communication aid. [This would enable me] to let people know how I am feeling and what I would like to eat or do.

8 Doing valued work
Employment in rural Victoria for people with disabilities is extremely limited — need more opportunities. Kitchen modifications are required for him to learn more cooking skills — currently negotiating with Uniting Care landlord to redirect funds back to finishing the promise of a new kitchen. [I would like] more volunteer friends to assist in including him into the local sporting and recreational activities including the local Community Radio Station. [These would enable] Increased self esteem as he gains new skills in the kitchen...gets a paid job.

9 Exercising rights and responsibilities
[Re political life] I have been to these sessions [ie advocacy and information meetings] but my anxieties get the better of me and I spend time in the foyer/car/outside waiting for Mum to have her input and then we leave early usually...too hard to answer these big questions — mum fixes everything.

10 Expressing culture
I would like to have a couple of carers who could take me out during the week and weekends ie music concerts, the city, festivals, pools, bowling. I have the time but not the carers and funding for them.

11 Having fun
[Re social life: I would like] help with respite, also a wheelchair accessible car...[in order to have] better access to a lot of things. I cannot do anything by myself. I need someone to help me access all of my activities...go swimming more, access the football more often, and go out with other people...

[Re social life: I would like] more accessible activities and options in the community. Carers who can take me to them. Sometimes I wish I could take risks eg go in a helicopter or on a fast ride, but everyone always worries about OH&S and litigation...[If I had these things I would be able to do] lots! I wouldn’t be stuck in a day program each day and my parents wouldn’t struggle so much with lifting me...[I would be] spending time on things I want to do.

12 How to live
[I want to] move into a home closer to family, with others I choose to live with. Be around others without disabilities for a change.

13 Looking after self
[Re personal life: I would like to be involved in choosing my own paid carers and wish I could get out into the community — once a week isn’t enough. Everyone tells me I need 2 carers and there isn’t enough funding for this.]

14 Moving around
[Re social life: I use a] walker; grew out of a modified trike — would love to have another trike but it needs modifying to allow one leg to pass through to the other pedal...[I would like] an Adult Trike — modified for me to get my difficult leg over to the other pedal...I would need a trailer for my adult trike. [I would like a] hoist at the Healesville Swimming Pool. [If I had these things I could] go on bike trails...A bit more physical activity would benefit my obesity.

15 Paying for things
[I need] tracks/hoist in the family home so mum and dad don’t have to keep lifting me when I’m home 3 days per week; wheelchair access into my family home; a ‘power pack’ for my wheelchair which is very heavy for carers to push.

[Re economic life: I would like to] get a housing commission house, get a car to transport me and my things appropriately...[This would enable me to] have house that is not damp, get a car that would take me anywhere...I could use my bedroom in winter to sleep, I could go anywhere with my bike, my mum would not be so stressed.

16 Where to live
[Re personal life: I would like] to be able to live closer to my family. The shared supported accomm is too far away from them and my day program. To spend more time with family and my brothers which could happen if they had adaptations/equipment which they cannot afford to pay for. [I would like] more funding — I only have funding for day program at present.

Endnotes
1 Inclusion criteria included being a person with a disability, a user of AT, a Victorian, an adult, and having sufficient English and cognitive capacity to complete the questions without the need for proxy reporting (use of scribbling or other physical assistance was not an exclusion criteria). The survey was available in paper format, or as an accessible on-line version with custom built on-line survey software developed for the project to enable the widest possible accessibility for people with disabilities and those using assistive technology to complete the survey on-line (Gottlieben, Layton & Wilson, 2010).

2 This includes 5 individuals who reported an intellectual disability; 2 individuals noting multiple impairment and 3 individuals noting ‘physical’ disability, whose survey responses point to a degree of intellectual disability.

3 This level of volunteerism is higher than that among the broader population (Zappala, 2000, and significantly higher than the 14.5% cited by Lyons & Hocking (2000) of volunteerism among unemployed people in Australia.

4 The incidents reported in The Equipping Inclusion Studies provide qualitative confirmation of the statistics reported by Saunders and Wong (2009), such as 32% of people with a disability in Australia, and 39% of people with a disability in Victoria, did not participate in community activities and 3% of Australians with a disability and 60% of Victorians with disabilities did not have $500 in emergency savings.

5 An instance of unmet need or failure to meet policy elements was identified as follows: where activity or participation is moderately to severely limited, not engaged upon, or relinquished, due to lack of AT and other cranials/ish and where the instance maps to valued participation as per UNCRPD or DIS Quality Framework (Layton et al, 2010).

6 This method involves estimating the costs of the service and support and comparing this to outcomes assessed by asking respondents to identify the changes in their quality of life in a range of domains via the use of the Quality of Life data collection instrument (Hawthorne et al, 1999). This data is translated into a cost per Quality Adjusted Life Year.
7 The method by which quality of life is measured is norm referenced, meaning that ‘perfect’ scores represent total unimpaired capacity in a range of domains. Even with the best interventions, many people with disabilities will retain core impairments (i.e. will never be able to communicate unaided). This means their scores will always remain lower than the ‘norm’ and outcomes of any intervention will be limited when judged against such narrow criteria.

8 In relation to The Equipping Inclusion Studies, some respondents would need their quality of life outcome to be weighted by a 2-3 fold equity factor in order to make the provision of optimal AT a ‘cost effective’ intervention.

9 These can be matched to the WHO ICF Activity and Participation Chapters (WHO, 2001), an internationally accepted classification system (see Appendix I).

10 See Leyton et al (2010) for a discussion of the problematics of using level of difficulty as an outcome indicator. Many respondents in this study identified problems with rating life in terms of ‘difficulty’ and argued that this did not capture their aspiration or experience. For some, the provision of suitable AT would enable them to achieve an increased range of life outcomes, sometimes with more independence, though difficulty in doing so would increase, and this was seen as a desirable outcome.

11 Appendix 2 provides a subset of comments from respondents with intellectual disability and their proxies in relation to their needs in these life areas.

12 This situation has since been negotiated with the relevant government department and a discretionary though temporary agreement made to enable the boarder.