

Aids and equipment for Victorians with disabilities - entitlement or hand-out?

A Position Paper
Recommendations for an effective
Victorian Aids & Equipment Program
for the 21st Century

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Melbourne Citymission
Building Inclusive Communities

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Principles for an effective Aids & Equipment Program

Melbourne Citymission believes that:

a) People with disabilities have a right to aids and equipment including modifications to their home, to ensure a standard of living that:

- minimises the impact of their disability on their daily living
- maximises their participation in their local community
- maintains their health, well-being and functioning
- reduces the further deterioration in their condition due to inactivity or isolation

b) Allocation of aids and equipment should be equitably based, taking into account individual circumstances and capacities to contribute resources.

c) Prompt allocation of aids and equipment should be undertaken to ensure that the health and well-being of both the recipient and their carer are not adversely affected by unreasonable delays.

d) The needs of children with disabilities should be treated with urgency so as to avoid delay in the provision of aids and equipment that would adversely affect their development and longer term functioning and well-being.

e) Prompt allocation of aids and equipment is also important because it reduces costs to the community of more expensive solutions such as institutional care.

f) Waiting lists, where necessary, should be designed to ensure priority allocation on the basis of urgency and fairness. For particular items, a maximum waiting period should be set, after which time, authority for providers to expend funds to meet client needs should be given using a designated resource pool.

g) Cost-effective processes for distribution, collection after use and reissue are essential to maximise reuse of aids and equipment owned by VA&EP.

h) Design of aids and equipment should facilitate low cost modification and upgrade to enable increased levels of reissue.

1. Introduction

1.1 Context

Melbourne Citymission welcomes the current Review of the Victorian Aids and Equipment Program (VA&EP) and hopes that the State Government will take this opportunity to enhance investment and to increase the program's efficiency. If the vision of an inclusive community contained in the State Disability Plan is to be realised, the timely provision of appropriate aids and equipment to people with disabilities is essential. (DHS 2002a) Investment in the VA&EP should be seen as a preventative strategy, which enhances people's independence and reduces the need for more costly interventions. (ACROD 2004)

A recent Melbourne Citymission report summarises under-investment in the Victorian Aids and Equipment Program during recent years:

'Growth allocations by the State Government have been patchy, with non-recurrent allocations made in the last two years to deal with backlogs only. Expenditure caps on items have not been revised for some time, despite escalating prices, meaning that top-ups will frequently exceed 50% of the item cost. It is suggested that a significant advocacy effort is required to address a range of issues with the program.' (Longmuir 2006: 69)

Melbourne Citymission believes that increased investment in the VA&EP is vital, along with strategies to improve the program's efficiency. This position is based on our substantial experience of providing support to children and adults with disabilities, and on some new research detailed here, which sought the experience and views of case managers and therapists in the northern suburbs who assist people with disabilities to access subsidised aids and equipment through the program.

1.2 Demand for Aids and Equipment

A range of socio-demographic, health policy and technology related changes have led to increased demand for aids and equipment in the community. These include:

- Increasing numbers of children and adults with physical disabilities due to the ageing of the population and to health care improvements that increase the survival rates for children and overall life expectancy.
- De-institutionalisation policies and normalisation practices have resulted in greater responsibility for caring of people with disabilities in the home and community. As a consequence, expectations for aids and equipment that assist in the caring role, and improve the quality of life for both client and carer, have significantly increased.

- Improvements in engineering design, electronics and materials technology have increased the availability of increasingly specialised aids and equipment to meet individual client needs, often however for more limited stages or periods in their lives. Individualised design and manufacture of specialist items does not deliver economy of scale and lower unit costs. There has been extraordinary growth in the costs of many items that makes them unaffordable for low-income families or households at the time when they are most needed. This places increased demand and strain on government resources.

1.3 The Victorian Aids and Equipment Program

The Victorian Aids and Equipment program, formerly known as the Program of Aids for Disabled People (PADP), has been operating since 1987 when responsibility for funding and program management was transferred to the States and Territories.

The aim of the VA&EP is to *'provide people with permanent or long term disabilities with subsidised aids, equipment and home modifications to enhance their safety and independence, reduce their reliance on carers and prevent premature admission to institutional care or high cost services.'* (DHS 2002a:5)

These aims are in accordance with the State Disability Plan, which affirms the rights of all people with disabilities to live and participate in the community on an equal footing to all citizens. For people with disabilities, aids and equipment provide an essential means to enabling their participation and independence. In this context, it could be argued that VA&EP should be an uncapped program, at least with respect to some aids and equipment.

A range of over thirty service providers, including hospitals, community health centres and community agencies are approved to administer the program for DHS. Service providers are responsible for purchase, supply and monitoring of aids, equipment and home modifications in accordance with the Guidelines, including the processing of applications and management of waiting lists.

Applications for aids and equipment are assessed on initial eligibility criteria followed by prioritisation according to three categories:

- 'no waiting' for immediate needs, such as oxygen equipment, wheelchair repairs, continence aids.
- 'high urgency' where aids and equipment are issued as soon as funds are available to purchase items or re-issued items are identified; and their provision is critical to safety, serves to prevent deterioration in health or function or jeopardises care/living arrangements
- 'low urgent' where items are made available subject to budget, waiting period and clinical factors (DHS 2002a).

The current guidelines make it clear that there is no guarantee that a particular aid or equipment item will be provided. Availability of stock is clearly subject to budget constraints with a rationing procedure developed to allocate on a priority basis.

In addition, the VA&EP is limited to those items listed in the Guidelines. The DHS Aids and Equipment Committee is responsible for reviewing the list of items, and the level of subsidy for each item. Maximum subsidies apply to all items (DHS 2002a). The capping of subsidies to levels well below the actual cost of items necessitates substantial effort by community service providers, such as Melbourne Citymission, to raise the top-up funds for the unfunded amount to ensure the needs of disadvantaged families are met.

According to Longmuir, this is particularly felt for home renovations and high technology or high cost equipment, such as custom-made wheelchairs:

'Families and workers in early childhood services become very familiar with the letter or submission to charitable trusts and discretionary funding pools. Frequently, multiple sources of additional funds will be approached, each with its own processes of capping allocations and making funding decisions. The system is very inefficient, and very disrespectful of the family and child's right to privacy and timely response.' (Longmuir 2006:54)

Ownership of all items remains with DHS except in the cases of home modifications, specified personal use items or when the client contribution to the cost is over 50%. In the latter instance, clients can opt to transfer ownership to the VA&EP (with the VA&EP being responsible for repairs).

No incentives or accountabilities are in the Guidelines to maximise reuse or reclaiming of equipment from clients. Relinquishment and disposal of items is left to the discretion of users and/or service providers. The target for reissue of items in the VA&EP is low - 10% (it is understood that N&W Region achieves an aggregate 12% of all items) - and depends on the level of return by clients, and refurbishment to an acceptable standard to meet needs safely and dependably. Different categories of items evidently have variable reuse rates.

The Guidelines specify that reclaimed items that are not reissued within one month to local service provider waiting list applicants should be placed on the statewide re-issue list. The aim of this list is to meet client needs in a more equitable way across Victoria. However, it is understood that the statewide list is no longer in use.

As a result of under-investment, increasing demand, and inefficiencies in the program, access to aids and equipment is characterised by long waiting times for many people with disabilities: most families who participated in recent Melbourne Citymission research had experienced delays (Longmuir 2006). The impact on individual health and well-being of unreasonable delays in meeting needs can be substantial for all those with disabilities, but especially for children:

'The developmental, maturation, sudden and rapid growth patterns of children, however, combine with changing, often critical, medical conditions to create a particular urgency about children's need for equipment.' (Dowling cited in Owen et al, 2002:70)

2. Findings of an Agency Survey in the Northern Region

In early 2006 the Case Management Action Group (a network of case management providers which Melbourne Citymission auspices) conducted a Survey of staff working in fourteen health and community service organisations in Melbourne's northern suburbs, regarding their experience of supporting clients to obtain equipment through the Victorian Aids and Equipment Program (VA&EP).

The aim was to collect data on the impacts on clients and carers of unmet needs and delays in obtaining aids and equipment; to gather evidence on the extent to which equipment is recycled; and to canvass some ideas for reform of the VA&EP. The data collected provides an evidence base for ongoing advocacy for investment and improvement in the program.

Melbourne Citymission would like to thank all the respondents for participating, particularly as many of them have been frustrated by the level of unmet need and delays in the VA&EP for a number of years. Several commented on the complexity of collecting data on unmet needs, and one said, *"We have done data collection and statistics to give to DHS in the past without much result"*. We hope that this time the voices of our respondents will not go unheard.

2.1 Profile of respondents

A total of 26 responses were received from individual staff working in 12 different agencies (2 respondents did not name their organisation). Twelve respondents (46%) worked in community health centres; 8 in community sector agencies; 1 in a peak body; 1 in a carer support agency; and 2 in a disability support service.

Respondents worked with a range of client groups including older people, children and adults. Half of the 26 respondents worked with children.

Fifteen respondents (58%) were employed as case managers; 8 (31%) were occupational therapists; and 3 (11%) were team leaders or managers.

Respondents used a range of issuing centres, in the following order of frequency: Northern, the Royal Children's Hospital, St. Vincent's, MECRA, Austin & Repatriation, Yooralla and Mercy.

Nearly all respondents (92%) routinely supported people to access the VA&EP.

2.2 The impacts on clients and carers of delays and unmet need

Twenty-one (81%) respondents said they had been unable to purchase equipment when it was needed

Respondents indicated that a total of 74 clients with whom they had worked during 2005 had been affected by a delay in obtaining aids and equipment. Several commented that nearly all clients who were assisted to obtain equipment experienced delays. In some cases these delays were very lengthy. Respondents commented that high cost items are hard to get except by reissue, and that high cost items, eg. bathrooms and wheelchairs, are waitlisted and can take more than one year. Delays were also worse towards the end of the financial year according to several respondents.

Delays had a number of significant impacts on clients

Eighteen respondents indicated that clients experienced stress or depression; 16 indicated there were consequences for clients' physical health; 12 indicated that clients suffered exclusion; 12 indicated that delays caused isolation for clients; and 4 mentioned lost opportunity in the developmental years. All of these impacts reduce quality of life and increase dependency. One respondent mentioned a client whose move into independent housing was substantially delayed due to the long wait to obtain modifications on the property.

- Delays sometimes led to a worsening of physical conditions.

'Waiting on funding for wheelchairs has resulted in worsening of scoliosis in that time [12 months]. Most often, families will not request equipment or modifications until they feel it is absolutely necessary, meaning that it becomes an urgent issue when requested.' reported one respondent.

- Delays were particularly problematic for children and adolescents due to their rapid growth, and multiple needs.

One respondent commented:

'There is up to two-year wait for wheelchairs in some cases, so that by the time the equipment is received it is no longer usable. Carers Link North provides top-up funding to support carers' needs for respite, but the inadequate subsidy rates of the VA&EP means that they are unable to provide enough top up funding for adolescents who require several pieces of equipment at one time due to changing needs.'

- **Delays could cause financial hardship** as people waiting for equipment rented items instead. In some cases, clients also resorted to using inappropriate substitutes while waiting for equipment.

'We will often try to loan equipment from the school or the Equipment Library in Brooklyn while waiting on funding from VA&EP. This loaned, and often less than appropriate, equipment, is used for 6 months to 2 years.'

- Delays mean that some **agencies use their own funds to meet costs for clients**, reducing their funds for other vital services. For example, CarerLinks North reported that they pay start up and initial monthly payments for clients needing personal alarms, because of the waiting list for these items. This diminishes the funding available for other vital supports.

Many respondents were also concerned about the effects of delays on carers.

Carers experienced stress and financial hardship due to delays in receiving aids and equipment. Carers who were forced to go without or use loan equipment, especially if they were waiting for bath seats and hoists, were at risk of injury. Clients were often waiting for bathroom modifications, ramps and hoists, and without these council help is not provided, which means that carers do excess lifting. Two respondents mentioned the risks to mothers when they continue to try to lift their children without proper equipment.

One respondent commented:

'Long waiting lists and high costs add to the carers' deterioration in physical health. This is of significant concern especially as many of these mothers are the sole carer of their children. Families experience significant stress when they are unable to meet the needs of their children due to financial constraints. The process of seeking funding can cause a lot of anxiety for parents as it can take a very long time to obtain all the funding required.'

Unmet needs

- **Respondents emphasised the importance of access into the community and the need for appropriate equipment to facilitate this.** Under the current guidelines, people with disabilities can apply for either a manual or an electric wheelchair, and are eligible for a replacement every seven years. For example, one respondent mentioned that a client was refused funding for a wheelchair because they had had a new one two years previously. In another case, a reissued wheelchair was allocated due to lack of funding for a new one, but did not meet the client's needs.
- **Some types of needs are not met by the VA&EP at present.** For example, the DeafBlind Association drew attention to the fact that their clients do not currently have access to funding through the VA&EP, because items specifically to assist people with sensory impairments are not included in the list of aids and equipment. Clients seek funding through other sources and experience long waiting times, which means that in some cases by the time they get the equipment (eg. a microscope for low vision) it is no longer appropriate or useful.

2.3 Sources of top-up funds

The VA&EP sets maximum subsidy levels for all items, meaning that recipients must provide additional top up funds. Case managers and therapists reported spending between 1 and 20 hours each week supporting people to apply to the VA&EP and to source top-up funding.

The total number of hours spent providing this support each week by the 26 participants was 109 - **4 hours per week on average**. We have estimated the annual costs of this effort across the State based on the following assumptions:

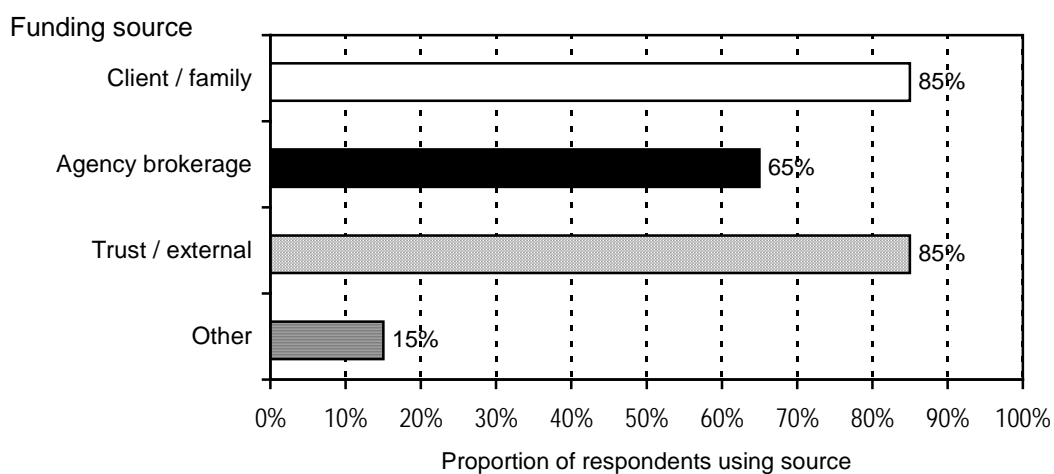
Average hourly salary (with on-costs) per worker: \$35.75
 Average hours in seeking top-up funds and support: 4 hrs/week

 Annual cost for every 100 workers = $100 \times 4 \times \$35.75 \times 52 = \mathbf{\$743,000}$

This is an indicative estimate of expenditure in support of applications, due to the lack of data relating to number of applicants or staff resources spent for this purpose. Whilst a proportion of this time is clearly part of good practice in support of applicants, our calculation serves to show the inefficiency in terms of use of skilled resources under current program arrangements. Whilst the total number of workers statewide is not known, a figure between \$2m and \$3m is realistic.

Case managers and therapists sought top-up funds from other organisations or philanthropic trusts, client or family resources, agency brokerage, and other sources. 25 of the 26 respondents sought top-up funds from more than one kind of source, and the majority used all three of these methods plus other sources of funds. Figure 1 shows the extent to which responding service workers were using the range of possible funding sources.

Figure 1: Service worker utilisation of top-up funds



2.4 Ownership, maintenance and recycling of equipment

When VA&EP has contributed more than 50% towards the cost of an item, it is owned by VA&EP. In these cases, the program is responsible for maintenance, and once the aids and equipment are no longer needed they should be returned to VA&EP.

- 25 out of 26 (96%) respondents said that equipment is usually owned by VA&EP

Reflecting the fact that most equipment is owned by VA&EP, 23 (88%) of the respondents reported that maintenance was also mainly the responsibility of the VA&EP. Eight indicated that sometimes the client was also responsible; 3 that the respondent's agency was responsible; and 1 'other'. Respondents commented that clients are responsible for scooter and wheelchair tyres. One noted that their agency carries out maintenance because of the urgency of need and delays in the system, even though they do not have responsibility for this.

Recycling of VA&EP equipment

Nineteen respondents (73%) said that equipment owned by VA&EP is generally reclaimed by VA&EP, although additional comments indicated that this depends on the family or client contacting the VA&EP. Equipment is also disposed of or sold by the client (2 respondents); or recycled in some way (5 respondents). Several respondents indicated that VA&EP equipment remains unused or that they do not know what happens to it when it is no longer needed.

Recycling of equipment not owned by VA&EP

Respondents were often unsure what happens to equipment not owned by VA&EP after it is no longer needed: 20 (77%) indicated that equipment is 'recycled in some other way'. Ten (38%) indicated that it is disposed of or sold by the client; 4 said it remains unused; and 5 commented that equipment owned by their agency is sometimes recycled internally.

Agency stores of equipment

Respondents were asked whether their agency maintained a store for aids and equipment.

- 6 out of the 12 agencies represented in the survey had a store for equipment.

Therapists were more likely than case managers to report having a store at their agency. Agencies with a store mainly held a small number (4-25) of items of equipment, and often this was for loan, trial or emergency purposes rather than for purchase. In order of frequency, the types of equipment held were walking aids, bathroom equipment, wheelchairs, specialised beds / mattresses, and small aids eg. tap-turners or reachers not funded by VA&EP. Respondents noted that the equipment in their stores was not VA&EP equipment.

Reissuing programs

Respondents were asked whether their agency had a reissuing program.

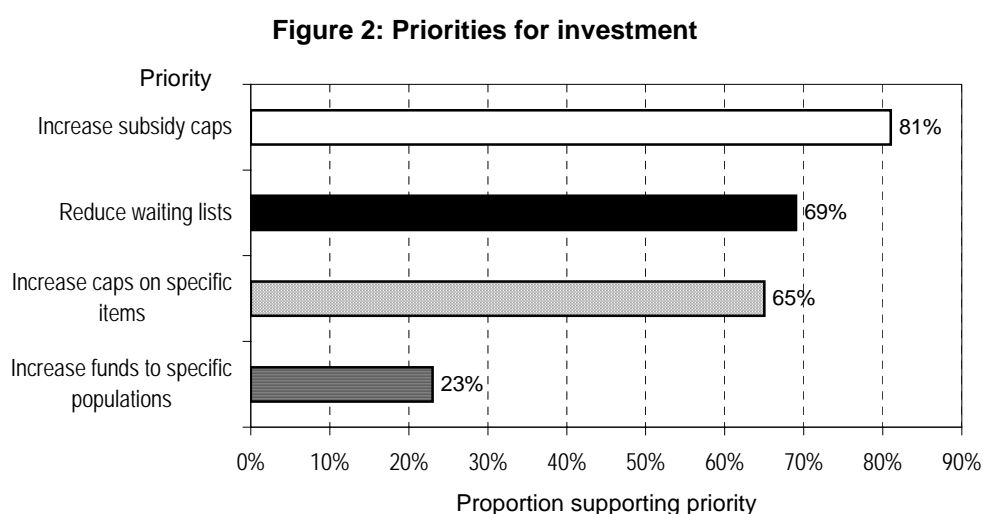
- 5 of the 12 agencies represented in the survey had a reissuing program.

Respondents described these programs as 'unofficial', internal schemes, which included equipment for loan purposes.

Respondents were also asked whether they thought equipment could be recycled if their agency was supported to do this. Twelve respondents (46%) said it could; 4 (15%) said it could not; and 10 (38%) gave no response. Several respondents commented that lack of space prevents their agency having a store or running a recycling scheme. One respondent commented that case managers are not qualified to reissue equipment.

2.5 Improving the VA&EP: investment priorities and reforms

Respondents were also asked for their views on a number of suggested priorities for investment if increased funding is made available to VA&EP. All the options were supported, especially increasing subsidy caps on all items. Two-thirds of all respondents believed that more than one solution was needed. On average each respondent supported

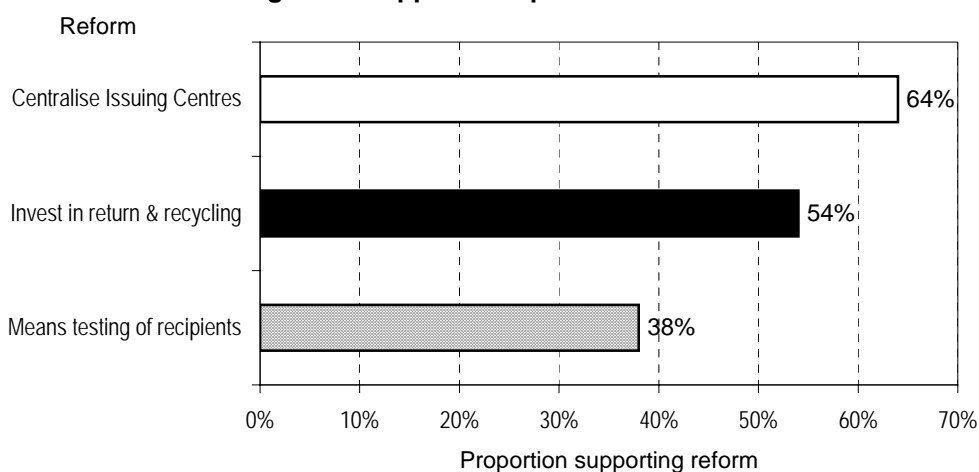


two strategies. Figure 2 below indicates respondent views on priorities for investment.

- Bathrooms and home modifications were the most frequently named items requiring increased subsidy caps. Also mentioned were wheelchairs, and specialist seating.
- Respondents who supported increases for particular populations mentioned children, deafblind people, and people in nursing homes.
- Several respondents felt that vehicle modifications should be included in the VA&EP.

Centralising Issuing Centres, investing in return and recycling, and means testing of recipients were canvassed as options to increase efficiency and reduce costs. Respondents supported all of these options, although means testing was less well supported than the other two options. Figure 3 below indicates the proportion of respondents supporting each of these options. Nearly two-thirds of respondents supported the principle of centralising the current array of Issuing Centres.

Figure 3: Support for specific reforms



Respondents also provided their own suggestions for improving the VA&EP: the following were proposed:

- factoring children’s developmental needs into the cost of the program;
- increasing budget resourcing to the program;
- providing additional help targeted to households on lowest incomes; and
- adding low vision equipment to the VA&EP.

In general, respondents sought a more proactive and effective response from the VA&EP to meet client needs.

3. Discussion

3.1 Costs and Subsidy Levels

Respondents to the Survey identified the following issues in relation to aids and equipment costs and the subsidy levels under the VA&EP. Melbourne Citymission's experience confirms these perceptions.

- a) The current subsidy of \$4,400 per person per lifetime for home modifications was felt to be inadequate, due to rising costs of home modifications and equipment:

'The amounts allocated to particular pieces of equipment should be increased as costs have risen. Separate funding should be available for bathroom modifications and ramps. Many bathrooms cost over \$10,000. VA&EP funding for home modifications does not cover this, let alone ramps. We often have to look for funding to cover the full cost of ramps. This is becoming harder, as funds get harder to source.'

'Home modification subsidies should reflect market prices and increases. Surely it is less expensive to keep people in their own homes with support than in supported accommodation or nursing homes.'

The once in a lifetime funding opportunity for home modifications is viewed by Survey respondents as severely inadequate. It creates risks for clients and carers and limits their ability to relocate. Moving house is a normal feature of most people's lives: ABS data released in 1999, for example, showed that 29% of the population over the age of 18 had moved house at least once in the preceding three years (ABS 1999). Economic and socio-demographic trends in respect of job mobility, housing tenure and household formation all contribute to the need for greater flexibility in provision of resources to enable modifications to be undertaken in a new home.

Melbourne Citymission's own experience indicates that some families faced with the once in a lifetime funding opportunity currently make the difficult decision to wait for their child to grow to adulthood *before* they apply for funding. This can have a number of consequences: for example, as a result of unsuitable bathroom design, parents may be lifting their child in ways that risk injury to themselves and to the child.

- b) Additionally, the VA&EP list of equipment is slow to be updated to include cheaper alternatives due to advances in technology, for example, new kinds of bathroom modifications. Opportunities to increase cost efficiency are being lost.
- c) The inadequate level of subsidy means that quite substantial amounts of top-up funds must sometimes be found before the equipment can be provided to clients, even if the equipment is available. The need to source large amounts of money, and the pressure on these sources of top-up funding, can contribute to the delays in receiving aids and equipment.

Case Study: Tom – aged 5 years

Tom needs a wheelchair for getting around at home, to access public transport and enable social participation. Both his parents are unemployed, and they have 4 other children aged between 3 and 10 years. It is very uncomfortable for the parents to lift and carry Tom, and the mother reported that the constant lifting had caused her to miscarry.

It has been almost a year since Tom's wheelchair was ordered and because of the need to obtain top-up funding there have been continual delays. Multiple referrals and assessments have had to be conducted and paperwork processed, while the family anxiously waited for their child's first wheelchair. The case manager finally managed to obtain further top-up funding from an external source.

- d) The inadequate level of subsidy caps may also lead to people attempting to take short cuts. One respondent noted that a family caring for an older person had submitted a bathroom modification quote that was well below the estimate. It was suggested the family may be intending to have the modifications completed cheaply and unsafely by a family friend. The VA&EP will assess the quote but this example indicates the pressures that are felt by families and clients seeking support through the program, and the potential risks for the recipient in the longer term.
- e) There was also a perception amongst respondents to the survey that funding allocations to issuing centres do not always reflect local needs and lead to inequity in meeting needs, as the following comment exemplifies:

"It would seem there is not equity across VA&EP centres with funding...electric scooters are issued elsewhere with only three to four months' wait time. In our area there is a two-year wait for reissue scooters. It is becoming increasingly difficult to get high cost items due to low funds for this area."

3.2 Impacts of Delays

The Survey showed that delays in receiving aids and equipment are common, and can lead to substantial risk of harm and of degeneration in health, due to either not having any aids or equipment, or the use of inappropriate substitutes. This case study illustrates how a client's health and independence are being compromised because she cannot obtain a powered wheelchair within a reasonable time period. It also shows how the system is not flexible enough to meet her assessed medical needs for two forms of mobility equipment.

Case Study: Jane – aged 30 years

Jane has spina bifida and has recently experienced a decline in her mobility. She is using a wheelchair obtained when she was sixteen. She needs a manual wheelchair for indoor use and short distances, but cannot push herself to the local shops or train station and thus needs an electric wheelchair for this.

Under the VA&EP, Jane can only apply for either a manual or a power wheelchair. She therefore chose to apply for the powered option (scooter), and was advised that there is a two-year wait. Additional funding is also needed for a manual wheelchair. An application to RDSI was made, however, this was rejected.

The therapist has been in discussion with a specialist who supported this approach to improving her mobility and quality of life, but was unable to help in obtaining the equipment. There is no resolution to this issue and no new equipment is likely to be provided in the near future.

The following client, Donna, is dealing with a number of family stresses and the expected lengthy delay in obtaining a scooter is likely to lead to a worsening of her situation and her ability to care for her children, with consequent adverse impacts on their development and wellbeing.

Case Study: Donna – aged 45 years

Donna has back problems, obesity and depression and is a single parent with four children – 2 are at home, and 1 is at school. She also cares for her frail mother and there is significant family stress with her siblings relating to her mother's care. Donna is socially isolated and is dependent on her son, who drives a car, works full-time and is in a relationship, for help with transport. She can access taxis, although with some difficulty due to her size, but being on a pension she can only afford this for important trips

An electric scooter would greatly improve her independence, self-esteem, and capacity to look after her family, and decrease her depression and family stress. Donna's application is on a waiting list but the therapist has been told that Donna is highly unlikely to get a scooter due to the need for a special size seat capacity (no reissue is available), and that this is not seen as a priority case.

3.3 Impact of Unmet Needs

Particular items of aids and equipment are currently excluded from the VA&EP. In addition, some needs are not given high priority for funding.

a) Exclusion of some items from the VA&EP

Items to address needs for sensory impairment are not currently included in the list of aids and equipment, as expressed by one respondent to the survey:

'Our deafblind clients fall in a gap: they are mostly on a pension, however, they are still independent enough to be ineligible for other programs or funding applications. They cannot afford to purchase badly needed equipment that maintains their independence and contact with society and the community, but get rejected when applying for funding on the basis that they are not in great enough need. Therefore they are left with no options at all, other than to become more isolated than they already are. If some low vision equipment was available on the VA&EP it would offer one option to them.'

The following case study illustrates the impact of the exclusion from the VA&EP of particular items such as vehicle modifications. It also shows the juggling act that families perform to obtain different items of equipment, and the particular difficulties experienced by families who have more than one child with a disability.

Case Study: Family A

Family A experienced significant difficulty in sourcing funds for a \$12,000 split-level lift system for a van to allow their three children aged 5, 11 and 17 to travel together. All three children have osteo-genesis imperfecta and are wheelchair dependent. The family needs a lot of aids and equipment, including many big-ticket items, which are increasingly difficult to obtain, especially as some items such as vehicle modifications are not covered in the VA&EP.

The parents are proactive and have used their own resources to modify their house and buy a van, so that all the children can travel together as a family to school and other activities in their wheelchairs. The family could not afford the split-level lift system for the van as they had spent their money on a manual wheelchair for their youngest child, needed for use in the classroom. The manual wheelchair was not funded by the VA&EP because they had previously applied for an electric wheelchair for the child.

The parents had tried unsuccessfully to apply for funds for a lift for the van from VA&EP, and had explored other funding options. The case manager had to make three individual applications to RDSI for funding: RDSI approved \$5,000. The case manager was unable to source CarerLinks North funding, because these funds were used for respite care. The case manager then approached a philanthropic trust, but the trust would only provide limited funds after the rest had been found. Eventually, the case manager was able to access \$4,500 of agency brokerage money. The remaining costs were met by the Trust. The significant time (four months) spent on applying for funds and waiting for approvals has been very difficult for the family, who needed the lift before the school term started. Whilst the funding has finally been obtained, the parents are now waiting again, for the lift to be fitted to the van. The delay has meant the family have had to arrange short-term use of friends' transport, arrangements which are stressful for them.

b) *Low priority given to some needs, especially in relation to community access*

Survey respondents felt that mobility and access to the community were not seen as priority needs, but that they are important for quality of life and to reduce dependence on other funded programs:

'It is often stated that equipment is not provided to enhance quality of life, eg, provision of electric scooters. I believe that providing a client with a means of independent living is very important – 'what is life without quality?' In our area it is very difficult to have a scooter funded and the costs are really not excessive to purchase one.'

'Scooters are often seen as 'quality of life' that is different from other safety and quality of life assessments. Sometimes the impact of quality of life could reduce the use of other government funding eg. money for subsidised taxis.'

The State Disability Plan affirms that people with a disability have the right to 'equal opportunities to participate in the social, economic, cultural, political and spiritual life of society' (DHS 2002b: 9). Without *timely* access to appropriate aids and equipment these opportunities will not be realised for many people with a disability.

Case Study: Agnes – aged 75 years

Agnes lives alone in a Ministry of Housing unit and has poor mobility and a range of health problems. Until recently she drove her own car, but it has now been sent to the scrapyards, so she has no money available for an alternative. Agnes has a supportive family network but they cannot be of regular assistance, and in any case she enjoys her independence and does not wish to be a burden on her family. Her unit is ideally located within her community near services and shops.

An application is being made to the VA&EP for an electric scooter. A scooter would allow Agnes to do her shopping, visit the doctor, etc, and would reduce her isolation and depression. This could reduce the burden on the health care system in the longer term. However, she has no hope of getting a scooter through the VA&EP in the foreseeable future.

3.4 Inefficiencies in the VA&EP

Increased funding is only one part of the solution to the ongoing problems with the VA&EP. Respondents felt that a number of cost and efficiency gains could be made if Issuing Centres were centralised or rationalised and if a stronger focus was directed to increasing the return and reissue of equipment.

Centralising or rationalising Issuing Centres was felt by respondents to be an option which would help to improve efficiency. Although some respondents supported keeping local centres, their responses suggested that this was related to the overall problem of supply. They valued good relationships with local centre staff to help them achieve better outcomes for their clients, that is to overcome or minimise delays in obtaining items.

Respondents also supported greater investment in maintenance to prolong the life of equipment. Currently, wheelchair maintenance is only carried out when the client asks for it.

The limited reissue of equipment is wasteful and increases costs. Increased investment in recycling was supported by respondents, as long as this is done in ways which meet health and safety requirements.

Respondents were also concerned about the amount of time they spend chasing top-up funds from a variety of sources. This was a recurrent theme in the survey responses, as this quote typifies:

'In some instances I have had to rely on other external agencies and spend many hours completing and documenting referral forms and follow up calls of other specialists involved. However, it is the individuals and families who suffer and experience stress and anxiety when I explain there will be a nine month or twelve month or two year wait for help.'

The average time spent by respondents in applying to the VA&EP and seeking top-up funds is four hours each week, representing a significant amount of staff effort within agencies funded by government to provide case management and therapy services.

If subsidy levels of aids and equipment in the VA&EP were increased, this would reduce the need for top-up funds and the time spent in sourcing them, thus saving money in other parts of the system.

Case Study: Mr and Mrs G

Mr and Mrs G. both have complex needs and are in their early 50's. Their home bathroom needed to be modified as both were at risk of injury due to the small shower with a step at the entrance. It is not possible to submit funding applications to VA&EP for each client individually. Funding was finally sourced from multiple other sources (Carer Links North, RDSI, chronic illness fund, and case management agency).

After a long wait, the modifications were eventually completed. The process of obtaining funding constituted a huge demand on the therapist's time, and was highly inefficient. The therapist commented that 'if it is all government money, then it should be streamlined for efficiency'.

The difficulty in sourcing top-up funds means that case managers and therapists increasingly use brokerage funds for this purpose, which obviously reduces the money available from these funds for other needs. Data from Melbourne Citymission indicates that the amounts being set aside in these programs for aids and equipment are increasing. For example, in care plans for the final six months of 2005/6, \$25,563 out of a budget of \$175,000 (15%) has been allocated to provide top-up funding for 21 pieces of equipment for 19 children in the *Making a Difference* and *Early Choices* Programs. In the previous six months, the top-up funding totalled \$11,122.

Equipment being funded included wheelchairs (total top-up of \$6,100), ramps, and ceiling hoists. In addition, Melbourne Citymission reserves some of the *Making a Difference* program budget for contingencies, which are often linked to meeting needs for aids and equipment.

3.5 Reducing the Cost Burden on People with Disabilities

A number of possibilities could be explored with both levels of government to reduce the cost burden on people with disabilities. These could include Commonwealth tax reforms to reduce the burden on households with a person with a disability. Opportunities to reduce or eliminate GST on housing modifications and other aids and equipment could also be sought.

If vehicle modifications were added to the list aids and equipment in the VA&EP, the State Government could consider exempting modified vehicles from car registration taxes.

4. Recommendations

Melbourne Citymission is encouraged that the State Government has established a Review of the Aids and Equipment Program, but notes that this is the third review in seven years and that previous reviews have not led to substantial change.

The impact of unmet needs and delays, documented in this report, creates a moral imperative for increased funding and for reform of the VA&EP. One-off funding allocations such as the additional \$2.7million announced in May 2006, do not go far enough to resolve the under-investment in the VA&EP and the failure of the program to meet its own aims of enhancing safety and independence and for preventing use of high cost services. It is imperative to reduce and eliminate waiting periods for all items of aids and equipment for which unreasonable delay in supply will adversely affect the health and wellbeing of the recipient or carer.

The Government's welcome Action Plan to address social disadvantage, *A Fairer Victoria*, states that

'people with a disability are entitled to live, learn, work and engage with their families, neighbourhoods and communities with the same rights and opportunities as all citizens'. (DPC 2005: 42).

Melbourne Citymission believes that the delays and unmet needs in relation to aids and equipment severely limit the attainment of these entitlements by Victorians living with disabilities. In addition, the ineffectiveness of the current program has significant adverse impact on the development and wellbeing of children with disabilities.

The following recommendations are based on the consultations undertaken with a wide range of support organisations in the northern metropolitan suburbs and on Melbourne Citymission's experience in provision of support to people with disabilities.

Whilst we have not costed these recommendations, we consider that they are both affordable and achievable for a Government committed to improving the quality of life for some of the most disadvantaged Victorians.

We also anticipate that substantial efficiencies can be derived through implementation of a number of the recommendations, for example by substantially reducing the wasted time spent by therapists and case managers in chasing top-up funds and supporting applicants on the waiting lists. Investment in the short term to meet community needs for aids and equipment will produce longer-term net benefits through improved health and well-being.

Resources:

1. Increase the recurrent budget for aids and equipment to ensure identified needs are met. Resource allocations should be based on revised targets regarding demand and reissue rates, given efficiency gains achieved through some of the following proposals.

2. Commonwealth and State governments to review and increase rebates through the tax system for prescribed medical expenses that include aids and equipment, in order to reduce demand on the VA&EP.
3. Review and increase the maximum funding available (subsidy) through the VA&EP for all items to take into account advances in technology and actual purchase costs. For example, a Consultation Draft by the Association for Children with a Disability recommends increasing the maximum subsidy for an electric wheelchair from \$6000 to \$12000 to reflect prices and available models. (ACD 2006)

Supply:

4. Collaborate with manufacturers and suppliers of selected items to modify designs to enable cost effective modification, adaptation and upgrade to increase levels of reuse.

Program:

5. Introduce incentives on provider agencies to significantly increase collection and reissue rates of high need items.
6. Encourage greater awareness amongst equipment users of the importance of returning items to the issuing centre through a targeted campaign accompanied by strategies to facilitate return rates.
7. Develop a centralised allocation, storage and distribution process to simplify procedures and introduce greater efficiencies into the VA&EP. Consideration should be given to a single statewide Issuing Centre, or possibly one Centre for children and one for adults.
8. Introduce *maximum* waiting times for priority items after which a designated resource pool can be utilised by provider agencies to ensure supply of items to recipients. Priority items should be selected and waiting times determined on the basis of impact on health and well-being or risk of harm to the recipient or carer.
9. Abolish the policy of 'once in a lifetime' allocations for home modifications to reflect developmental needs and the legitimate aspirations of people with disabilities to live normal lives, which may involve relocating for work or other reasons. The Association for Children with a Disability suggests that a realistic allocation would allow for home modification assistance at least twice during childhood (0-18 years) and twice during adulthood. (ACD 2006)
10. Increase wheelchair subsidies as suggested above (Recommendation 3) and review the minimum times for eligibility for replacements.
11. Include vehicle modifications in the list of aids and equipment available through the VA&EP.
12. Consider other items not currently included in the list for inclusion in the program. Specifically, the needs of people with visual and hearing impairments require a far more comprehensive response from Government than is currently the case.

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