Review of Assistive Technology funding and equipment for disability and its application in the West Australian community

Nola Kenny
Research Officer, ILC

Mary Carey, Research Associate
&
Associate Professor Barbara Horner
Centre for Research into Aged Care Services, Curtin University of Technology

December  2005
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0 Executive Summary and Recommendations</td>
<td>7</td>
</tr>
<tr>
<td>2.0 Introduction</td>
<td>24</td>
</tr>
<tr>
<td>3.0 Aims and Objectives</td>
<td>26</td>
</tr>
<tr>
<td>4.0 Methods</td>
<td>27</td>
</tr>
<tr>
<td>4.1 Literature review</td>
<td>27</td>
</tr>
<tr>
<td>4.2 LWDEG program administrative data</td>
<td>28</td>
</tr>
<tr>
<td>4.3 Questionnaire surveys</td>
<td>28</td>
</tr>
<tr>
<td>4.4 Focus group discussion</td>
<td>29</td>
</tr>
<tr>
<td>4.5 Expert consultation</td>
<td>29</td>
</tr>
<tr>
<td>4.6 Posting on ARATA list serve</td>
<td>29</td>
</tr>
<tr>
<td>4.7 Sampling and analysis</td>
<td>29</td>
</tr>
<tr>
<td>5.0 Literature review</td>
<td>31</td>
</tr>
<tr>
<td>6.0 Results</td>
<td>39</td>
</tr>
<tr>
<td>6.1 LWDEG program administrative data</td>
<td>39</td>
</tr>
<tr>
<td>Client demographics</td>
<td></td>
</tr>
<tr>
<td>6.2 Questionnaire surveys</td>
<td>43</td>
</tr>
<tr>
<td>6.2.1 Grant recipient questionnaire</td>
<td>43</td>
</tr>
<tr>
<td>6.2.2 Agency questionnaire</td>
<td>51</td>
</tr>
<tr>
<td>6.2.3 Stakeholder questionnaire</td>
<td>57</td>
</tr>
<tr>
<td>6.2.4 Family/carer questionnaire</td>
<td>59</td>
</tr>
<tr>
<td>6.2.5 Limitations</td>
<td>60</td>
</tr>
</tbody>
</table>
6.3 Focus group discussion 61
6.4 Expert consultation 62
6.5 ARATA posting on list serve 62

7.0 Discussion and Recommendations 63
7.1 Strengths and weaknesses of LWDEG program 63
7.1.1 Funding of equipment grants pre and post ILC managing LWDEG program 63
7.1.2 Access and equity 63
7.1.3 Funding application process 65
7.1.4 Grant processing 67
7.1.5 Satisfaction 68
7.1.6 Equipment assessment, advice, trial, training and support 69
7.1.7 Equipment use and maintenance 70
7.1.8 Quality of life outcomes for grantees as a result of equipment provision 71
7.2 Unmet equipment needs 72
7.3 WA stakeholder feedback of currently unfunded AT equipment that could be considered for funding 73
7.4 Other unmet need – funding gaps and issues within the WA disability community 79
7.5 Need for further research - Alternative approaches for meeting unmet need 83
7.6 Disability policy 85

8.0 References 86
9.0 Appendices
  9.1 Equipment currently funded by LWDEG program
  9.2 Equipment currently funded by CAEP
  9.3 Assistive Technology categories
  9.4 Bank of subject headings and keywords used in literature search
  9.5 Comments on quality of life – Grant recipient perspective
  9.6 Comments on quality of life – Agency perspective
  9.7 Comments on quality of life – Family/Carer perspective
  9.8 Focus group commentary

10.0 Glossary
Tables

Table 1. Disability diagnosis of individual funding applications 39

Table 2. AT funded by LWDEG program Oct 2003 - Aug 2005 40

Table 3. Number of grants, agencies and LWDEG funds for financial years 2001-2005 inclusive 40

Table 4. Age categories of LDWEG grantees compared to the WA population 41

Table 5. Location of LDWEG grantees by ARIA+ Remoteness Index 42

Table 6. Number of grant applications per LWDEG income category 42

Table 7. Unmet equipment needs identified by supporting Agencies 55
Figures

Figure 1. Grant recipient disability groups 43

Figure 2. Grant recipients’ need for equipment 44

Figure 3. LWDEG funded equipment (Grant recipient Questionnaire) 44

Figure 4. LWDEG funded equipment (Agency Questionnaire) 51

Figure 5. How clients found out about grants 51

Figure 6. Mode of assessing equipment needs 52

Figure 7. Assistance with LWDEG application 52

Figure 8. Respondent’s relationship to grant recipient 59
Executive Summary

BACKGROUND
In 2003 following a review of the Lotterywest Equipment Grants for Individuals with a Disability Program, the Independent Living Centre (ILC) of Western Australia was engaged to manage a Pilot Project to develop and implement a community based equipment grants program for people with a disability. This grant management project, the Lotterywest Disability Equipment Grant (LWDEG) provides grants for specific items of Assistive Technology equipment to people with permanent disabilities who would not otherwise be able to afford the equipment. Where another government agency has a policy and funding responsibility for the item (for example Community Aids and Equipment Program [CAEP]) the LWDEG program will not fund that item but may provide supplementary funding where the total cost of the item exceeds that funded by the government agency.

AIM
The aim of this review was to inform Lotterywest and government regarding the targeting of current assistive Assistive Technology funding schemes in terms of Assistive Technology funded by them, and to make appropriate recommendations for any changes based on a review of local feedback, national and international research.

OBJECTIVES
The objectives were to:
1. To identify the strengths and weaknesses of LWDEG program
2. To identify prioritized unmet Assistive AT needs
3. To identify Assistive equipment and technologies not currently funded but which merit funding, as identified through
   o Western Australian stakeholder feedback
   o Best practice funding schemes and evidence based research in Australia and Internationally
4. To identify the funding gaps within the Western Australian community and how the funding gaps could be addressed
5. To identify the need for further research and advise Lotterywest which areas should be a priority for further research
6. To make policy and planning recommendations based on the evaluation findings
METHODS
A range of different data collection methods was involved and a mix of both qualitative and quantitative research methodologies was adopted. The review was based on the following data gathering processes:
- Literature review
- LWDEG administrative data extraction
- Questionnaire surveys
- Focus group discussion
- Expert consultation
- Posting on list serve

RESULTS

Objective 1: Identify the strengths and weaknesses of the Lotterywest Disability Equipment Grant Management Program

STRENGTHS - the review found that

a) Since the ILC assumed management of the program it has successfully expanded from 40 agencies supporting 127 equipment grants in 2002/2003 to 47 agencies supporting 234 grants in 2004/2005. To date 73 agencies have supported a total of 471 grants. This has been accompanied by an increase in resources from $650k to $800k.

b) One of the strengths of the program has been the management role of the ILC LWDEG project officer. The project officer’s role and the assistance available was seen as a valued component of the grant management scheme by individual grant applicants, sponsoring agencies and other stakeholders involved in equipment assessment and grant application process.

c) The LWDEG management database provided valuable demographic information to answer questions regarding access and equity of funding for eligible clients. It offers a means of validating survey findings and contains useful baseline data against which to monitor future program activities.

d) Individuals from a wide variety of disability groups are making grant applications.

e) A wide range of agencies are supporting individuals to make grant applications including disability support agencies, community associations, and shire councils.

f) The ILC to date has acted as the support agency for more than a quarter of all grant applications for individual clients; a benefit to individuals who are not, or prefer not to be aligned with a disability group.
g) The greater portions of grants (79.1%) are made to individuals in the lowest of the eligible income categories. Individual grants range from $300 to $10,000.

h) The LWDEG program funded seven grants (1.6%) under its ‘exceptional circumstance clause’.

i) The LWDEG administrative database revealed that most applicants are major WA city and inner regional residents; there are more male than female applicants; and that children below the age of four are underrepresented amongst applicants.

j) Most agencies and consumers expressed moderate to high satisfaction with the LWDEG program as it is currently being managed.

k) The funding application process was not seen as overly burdensome by the majority of agency respondents.

l) Gaining support for the grant application was not a difficulty for the vast majority of individual respondents.

m) The ILC has an established practice for processing urgent applications, in particular air conditioning.

n) Specialist OT driver assessment is advised for people seeking to drive a modified vehicle. The LWDEGMP has funding available to assist clients with this assessment.

o) Respondents reported high ongoing use of granted equipment.

**Weaknesses - the review found that**

a) Lotterywest may need to defend criticism that a clear funding priority is not evident and that access to AT is more difficult for some individuals. This concern is based on vision impaired clients and those with Multiple Sclerosis being the two major beneficiaries of group funding from LWDEG ($400,000 to Association for the Blind in 2004/2005; $175,000 to the Multiple Sclerosis Society between 2003 and 2005).

b) The LWDEG program database is currently maintained solely for the purpose of managing the grant scheme. There is an opportunity to develop a more useful database for monitoring and research activities. Knowledge about the program’s reach and the ability to monitor trends in
funding applications from diverse geographic locations and populations within WA should be an integral part of the LWDEG program.

c) At present it is not certain whether WA outer regional and remote clients have similar access to the LWDEG program as their city and inner regional counterparts. More complete post code data collection and an increasing sample size will contribute to improved future monitoring and evaluation of this aspect of the LWDEG program.

d) The LWDEG management database does not presently collect data on Indigenous of Culturally and Linguistically Diverse background. Consequently it is not possible to determine whether these two groups have adequate representation within the granting program.

e) The research and monitoring potential of the database is also limited by the absence of other useful variables which are readily obtainable. Information should be collected on: applicant’s living arrangements, accommodation setting, country of birth, English speaker or not, if they have a carer and whether paid or unpaid.

f) Feedback from a small minority of Individual and agency respondents suggests the ongoing need to communicate and clarify procedures, policies and guidelines associated with the grant application.

g) Some individuals still experience long delays despite a reduction in the average wait for grant approval. It is acknowledged that some hold ups may be beyond the control of the LWDEG Project Officer.

h) Individuals are not fully utilizing expertise available within the ILC for obtaining valuable advice and information about their AT needs.

i) Grant applicants are seeking a less than expected amount of driver assessment for their vehicle modifications.

j) There was a lack of awareness by agencies as to whether or not granted equipment had been trialed.

k) Agencies may be experiencing difficulty providing the vital services of orientation, training and ongoing support for use of granted AT.
Objective 2: What is the prioritised unmet need within the WA disability community?

A wide range of AT need was identified amongst WA individuals with a disability. Focus group participants acknowledged that whilst there are priority demands, other identified unmet equipment need was equally valid depending upon the specific needs of the individual with a disability. Whilst some equipment might not be considered basic and essential (and therefore not eligible for CAEP funding) it nonetheless enhanced their independence and improved their quality of life.

By stakeholder consensus, the current priority unmet AT need in WA includes:
  - Environmental controls and basic communication systems/devices
  - Car seats and restraints
  - Second mobility aid for community use
  - Electric beds

Individuals also prioritized:
  - Specialized seating
  - Pool hoist at home
  - Adaptive technology to scan material with screen reader

The focus group and survey respondents were in agreement regarding unmet need for many other unprioritised AT items.

Achieving full independence is a challenge for individuals reliant on funding bodies for their AT needs. The unmet AT needs of low income non CAEP eligible individuals continues to be an unaddressed problem.
Objective 3: Identify assistive equipment and technologies currently not funded that could be funded

Respondents’ collective opinion is that current funding criteria for individuals with a disability (CAEP, DoH, Commonwealth, and other service providers) prevent their AT needs being met in a holistic manner with the inevitable consequence that their independence is not being fully supported.

Unfunded items considered to merit funding by focus group discussion include in priority order:

**Priority one**
- Environmental controls and basic communication systems/devices
- Car seats and restraints
- Second mobility aid

**Priority two**
- Electric beds

**Merits funding**
- Specialized seating
- Agency requiring hoist in the home

The rationale and options provided (in the body of this report) for their proposed funding is based on demonstrated need evidenced by stakeholder feedback; equipment type requested in recent EFL grant distributions; and consideration/interpretation of current funding policy and its intended coverage. Also of relevance is the need to keep abreast of new developments in technology and to match the widespread use of and greater reliance on new technologies occurring in the wider community.

Specific recommendations are made for funding bodies to review funding criteria in addition to the overarching recommendation for a task force of key stakeholders to discuss, advocate for and implement a more coordinated and integrated approach to AT service delivery in this state.
Objective 4: Identify funding gaps and issues within the Western Australian community

The focus group was concerned about a range of other unmet AT needs and issues affecting service provision within the WA community.

The funding gaps and issues discussed by the focus group included:

**Equipment that is needed short term or for consumers who have a short/medium life expectancy**
People who are learning new skills, are improving medically or have a degenerative disease may need different equipment for short periods due to improvement or worsening of their function. There is also a need for short term use if equipment breaks down. Existing hire and loan AT services have service gaps including an absence of funding for short term hire of equipment for CAEP ineligible individuals.

**Old and unused equipment – other than CAEP equipment**
Electronically tagging and bar-coding equipment can improve equipment recycling rates, (in particular, equipment gifted via the LWDEG), thus keeping equipment 'in the system' for more effective use in potential AT hire and loan schemes.

**Medical equipment - suction, medical consumables and continence items**

**Suction equipment**
Whilst some hospitals have loan equipment, it is generally old, large and noisy and there is no consistency to the funding of these items.

**Medical consumables**
There is limited provision of medical consumables post discharge. A bulk buying service entity like the ILC could assist in defraying ongoing cost of these items to family and individuals.

**Continence**
For people with continence issues, funding is provided from different sources for the following ages
- 3 -16 years - Lotterywest funding (previously State government)
- 16 - 65 years - Commonwealth funding
- Over 65 years - no funding

Whilst the continence equipment problem is most acute for the over 65’s both children and adults remain under funded in this area.

**Commonwealth funded consumers**
The absence of equipment funding for Commonwealth-funded consumers (in a nursing home or hostel environment) to meet individual needs such as mobility,
seating, standing and quality of life needs also limits their ability to access the community.

**Low income non CAEP eligible people**

Individuals on low incomes ineligible for CAEP funding to purchase or hire equipment are identified as a category with high unmet equipment needs. Many are not aware there is some relief available via the Commonwealth rebate, though to be of real benefit the rebate rate needs to be raised to 100% and the rebate threshold lowered. They could benefit from the establishment of low or no interest loan schemes to assist with their AT needs or from an extension of the WANILS program (for essential household goods) to also cover AT items.

**Assessing and specifying equipment for CAEP funding**

Currently when CAEP funding is sought, CAEP affiliated health professionals assess and specify for clients from the Disability Services Commission and for CAEP eligible non government organizations. However there can be delays in assessment and the specification stage for

- Health Department clients where there is sometimes a waiting list, thus increasing the overall waiting time for equipment.

- People who aren’t linked with an agency as they must access a service provider for assessment because funds do not go directly to an individual.

These issues are further evidence of the lack of integration in AT services in WA. An overarching recommendation is made that the attention of all key disability stakeholders is required to address the considerable gaps that have resulted from uncoordinated funding arrangements which are not adequately covering AT needs.
Objective 5: Need for further research - Alternative approaches for meeting unmet need

Finite AT funding and narrowing eligibility criteria demand alternative approaches to help provide AT to underserved individuals. A variety of AT service provision models is the most practical way to address and maintain service delivery in an environment of constant technological change and many contextual variables such as fluctuating symptoms and rapidly changing needs.

This current project made preliminary investigations into the establishment of a community no interest/low cost loan service and a short term hire scheme to address specific gaps in AT provision identified by respondent feedback and focus group discussion.

Recommendations are made for the collaborative progressing of this research by key disability stakeholders with the possibility of Lotterywest funding the necessary resources to undertake the research.

Objective 6: Policy recommendations

A key recommendation of this report is the establishment of a task force comprising key WA disability stakeholders. Such a group has the capacity to make written submissions and undertake effective representational and lobbying activities to influence AT policy and planning.

Three areas are identified where the proposed task force can take a role in increasing the awareness and responsiveness of government and other influential bodies to the AT needs of people with disability.

Commonwealth/State Disability Agreement
As equipment should be considered an essential component of the range of disability services provided by both Commonwealth and State Governments, the provision of services and funding for equipment should be written into any future Commonwealth/State Disability Agreement.

National Strategy for an Ageing Australia
As the National Strategy for an Ageing Australia is primarily concerned with developing a proactive response to the emerging issues related to population ageing, consideration needs to be given to the role and funding of Assistive Technology.

Commonwealth Medicare rebate
The Commonwealth Medicare rebate on disability goods and services is one of few forms of financial subsidy available to assist low income
individuals access necessary aids and equipment. A review of the current level of subsidy is required to achieve greater equity for low income individuals who are ineligible for alternate funding.
RECOMMENDATIONS
The following recommendations are made to provide a more focused and coordinated response towards addressing the AT needs and issues of people with a disability in WA.

OVERARCHING RECOMMENDATIONS

Recommendation 1
That a task force of key WA disability stakeholders (the AT Task Force) is established to use the findings of this report to inform the development of a targeted and strategic response toward AT provision which espouses a holistic assessment of individual’s existing and future AT needs.

Recommendation 2
That the present ILC LWDEG management database system is expanded and appropriately developed to provide improved monitoring and research opportunities required to enhance current and future AT service provision.

Recommendation 3
That ongoing systematic monitoring and evaluation processes are incorporated into the LWDEG program and all its related activities to expand the evidence base for AT services.

Further recommendations:

Recommendation 4
That the ILC, as a crucial provider of AT services in WA, take a lead role in planning and coordinating the strategic response recommended in this report.

Strategies
- The ILC establish the AT Task Force or similar body comprising key disability stakeholders with the capacity to influence decision makers. The ILC to act as the driver in determining a plan of action to address the funding gaps, unmet need and their potential solutions as discussed in this report.
- The proposed AT Task Force defines and reaffirms a contemporary concept of disability which supports full independence via holistic provision of AT needs. The AT Task Force promotes this concept to the disability sector and the community.

Recommendation 5
That given the ongoing successful expansion of the LWDEG program, the expressed high level of satisfaction with its management and the significant positive QOL outcomes, it is recommended to continue the program under ILC management with consideration to recommendations made for enhancing and strengthening its operation.
DATABASE DEVELOPMENT

Recommendation 6
That LW/ILC devotes sufficient resources and staff support toward developing the most useful database and other outputs for ongoing monitoring and research purposes. These additional activities can be accomplished by the current database manager.

Strategies
- LWDEG database manager investigates the database operations of an existing single health service provider such as Meals on Wheels or The Volunteer Task Force including e.g.
  - templates for data collection
  - agency work process
  - database type (Excel, Access) and the required functions and outputs

Recommendation 7
That a key objective of the database development is its potential for future linkage with other health service and research databases (e.g. Silver Chain, hospital morbidity data) to provide a more comprehensive view of AT outcomes.

Strategies
- Expand the LWDEG program database to include collection of additional variables permitting assessment of the program’s reach, including CALD and Indigenous status, country of birth, English speaking or not.
- Expand the LWDEG program database to include collection of additional factors to enrich program evaluation including applicant’s living arrangements, accommodation setting, if applicant has a carer, whether paid or unpaid and level of assistance required.
- Enhance existing data collection including e.g. more complete recording of post codes.
- Collect data in appropriate formats conforming to data dictionary standards of other health service data collections to facilitate future linkage e.g.
  - Adopt an existing health services data dictionary such as the HACC data dictionary

FUNDING ALLOCATION

Recommendation 8
That the ILC and Lotterywest re-examine and evaluate the equitable distribution of their historical funding allocation to the Association for the Blind and the Multiple Sclerosis Association.
GRANT APPLICATION PROCESS

Recommendation 9
That an ongoing information and communication strategy is implemented to increase individual and agency knowledge about application procedures and granting policy and guidelines.

Strategies
- Future information and communication activities can in part be informed and guided by this report’s survey responses.

Recommendation 10
That the ILC ensures there is sufficient information available to agencies and individuals about the knowledge and expertise available from the ILC (advice, assessment, trialing, and training) and that there is more encouragement to use this valuable resource.

Strategies
- To be discussed – this is distinct from the information dissemination activities at Recommendation 14 below.

MONITORING AND EVALUATION

Recommendation 11
That the ILC adequately monitor its LWDEG program systems and procedures to ensure they are adequate for the purpose.

Strategies
- Establish ongoing monitoring of operations and outcomes including eg;
  - monitoring of waiting times
  - monitoring of agency capacity to provide training
  - monitoring agency capacity to provide ongoing AT support
- Develop guidelines for program operations including eg;
  - consistency in requirement for trialing and training of AT
- In time, identify and develop best practice principles for LWDEG processes.

Recommendation 12
That the ILC develop a systematic monitoring, communication and review process for grant application waiting times.

Strategies
- Automatically flag delays/hold ups, identify their source and update clients. This is an important aspect of quality improvement and
appropriate measures should be implemented by the LWDEG program ASAP. E.g.
➢ provide grant applicants with an anticipated ‘progress time line’ for their grant application

**Recommendation 13**
That ILC incorporate formative evaluation studies into its entire LWDEG program related activities and services.

**Recommendation 14**
That ILC undertake a summative/comprehensive evaluation study of its entire LWDEG program related activities and services on a regular basis eg biannually.

**Strategies**
- Develop a suitable range of assessment instruments for the formative and summative appraisal of all aspects of the granting process.
- Incorporate a qualitative component (individual and carer interviews) to assess AT issues from the client’s perspective.

**INFORMATION DISSEMINATION**

**Recommendation 15**
That the role and activities of the ILC are known and understood amongst all of the disability sector and by individuals with a disability.

**Strategies**
- Undertake a survey to gain understanding of stakeholder’s perceptions and knowledge regarding ILC’s role and activities within the disability community. Respondent information gathered in this review will also inform the strategy.
- Investigate marketing strategies to improve industry and consumer perceptions and understanding of the role of the ILC and the ILC project officer.
- Ensure there is effective marketing of the ILC and the LWDEG program via a Marketing Plan to reach all potential grant recipients.

**FUNDING UNMET NEED**

**Recommendation 16**
That CAEP, DoH and Lotterywest (and where relevant liaising with other agencies including Homeswest and the Department of Planning and Infrastructure) discuss and consider broadening the range of equipment funded to cover the following prioritized unfunded items:
• Environmental controls
• Basic communication systems/devices
• Car seats and restraints
• Mobility aid
• Electric Beds
• Specialised seating

Recommendation 17
That providers of care packages in the home review their funding provision and where appropriate consider inclusion of portable hoist and training in hoist use.

Strategies
  o The proposed Task Force advocates and makes submission to providers of care packages in the home.

Recommendation 18
That the proposed AT Task Force investigates the establishment of a hire/loan service which could operate to fulfill the short term needs of disability consumers in WA.

Strategies
  o Initiate a project to research existing hire/loan schemes. Lotterywest could potentially fund this research.

Recommendation 19
That the proposed AT Task Force investigates how more funded equipment can be retained in the system through improved recycling rates.
  ➢ Service providers each electronically tag and barcode equipment
  ➢ LWDEG program and other government funding programs link into the CAEP equipment tracking system

Recommendation 20
That the proposed AT Task Force discuss and address the issue of old and outdated hospitals hire suction equipment and bring to the attention of hospitals concerned.

Strategies
  o Initiate a project to investigate alternative funding or hire/loan arrangements for this equipment. Lotterywest could potentially fund this research.
Recommendation 21
That the proposed AT Task Force discuss and address the issues of inadequate medical consumables funding.

Strategies
- Investigate establishing a service to facilitate discount purchase of medical consumables. This research could potentially be funded by Lotterywest.
- Advocate for more consistent and greater funding of medical consumables to Federal and state health ministers.

Recommendation 22
That the proposed AT Task Force addresses the issue of inadequate continence funding.

Strategies
- Advocate for more consistent and greater funding of continence products to Federal and state health ministers.

Recommendation 23
That the proposed AT Task Force investigate how funding deficits which limit community access for nursing home and hostel clients can be addressed.

Strategies
- Increase awareness amongst all stakeholders (consumers, families, disability service providers, organisations and communities) of the need for AT in this population.
  - Disseminate appropriate information in a variety of formats
- Ensure client assessments address the specialized equipment needs (e.g. special seating and mobility aids) of nursing home and hostel clients.
- Provide relevant information to all stakeholders regarding funding schemes/subsidies (e.g. CAEP, LWDEG, Commonwealth Medicare rebate) to assist with their identified AT needs.
  - Disseminate appropriate information in a variety of formats

Recommendation 24
That the proposed AT Task Force discusses how the unmet AT needs of low income non CAEP eligible people can be more adequately met.
Recommendation 25
That the proposed AT Task Force discusses how to provide a more responsive service when CAEP affiliated health professionals assess and specify equipment for CAEP funding.

Recommendation 26
That the proposed AT Task Force investigates the establishment of a low or no cost credit scheme to fund purchase of AT needs for low income individuals.

Strategies
- Research the WANILS scheme run by the WA Department of Family and Community Service.
- Identify and engage potential supporters of low cost loans amongst equipment suppliers and within the finance sector. This research could potentially be funded by Lotterywest.

POLICY RECOMMENDATIONS

Recommendation 27
That the proposed AT Task Force makes appropriate representation to State and Commonwealth Health Ministers for the provision of services and funding for AT equipment to be written into any future Commonwealth/State Disability Agreement.

Strategies
- Prepare a written submission based on the findings of this report.

Recommendation 28
That the proposed AT Task Force makes appropriate representation to the Commonwealth Department of Health and Ageing/Federal Minister for Health to review its National Strategy for an Ageing Australia giving greater prominence to the role and funding of Assistive Technology.

Strategies
- Prepare a written submission based on the findings of this report.

Recommendation 29
That the proposed AT Task Force makes appropriate representation to the Commonwealth Department of Health and Ageing/Federal Minister for Health to review and increase the level of subsidy currently available from the Commonwealth Medicare rebate for disability goods and services.

Strategies
- Prepare a written submission based on the findings of this report.
2.0 Introduction

**Background**
Lotterywest has recently reviewed its Equipment Grants for Individuals with a Disability Program. Subsequently in 2003, the Independent Living Centre (ILC) of Western Australia was engaged by Lotterywest to manage a Pilot Project to develop and implement a community based grants program for, for people with a disability – the Lotterywest Disability Equipment Grant program (LWDEG).

The project provides grants for specific items of Assistive Technology to people with permanent disabilities who would not otherwise be able to afford the cost of such items. Where another government agency has a policy and funding responsibility for an Assistive Technology item(s) (for example through Community Aids and Equipment Program [CAEP] funding) individuals are ineligible for a LWDEG. However supplementary funding through the LWDEG may be available where the total cost of the item exceeds that funded by the government agency.

The schedule of equipment items that are currently considered for LWDEG funding are regularly reviewed to ensure that the program keeps pace with changing needs and priorities of people with a disability and new developments in technology. The review process is undertaken by the Sector Advisory Group (SAG) who evaluate the relevant submissions and information (including the findings of this review) with the final decision resting with Lotterywest. The original contractual agreement between Lotterywest and the ILC stated there was to be no significant changes to the range of equipment funded in the first two years of the project. The current range of LWDEG funded Assistive Technology is shown at Appendix 9.1. The volume of funds available to the LWDEG program is also at the discretion of Lotterywest.

In Western Australia CAEP funds the purchase of basic and essential aids and equipment to assist people with disabilities to manage at home. People who are eligible for services from the Disabilities Services Commission (DSC), with a long term disability and who are living in the community may apply for CAEP funding. A list of Assistive Technology which is currently funded by CAEP is shown at Appendix 9.2.

**Equipment funding options other than Lotterywest**
In the West Australian community funding for Assistive Technology items other than those considered basic and essential may be provided by Service groups (e.g. Lions) and Charitable Trusts (e.g. Variety Club).

**Assistive Technology**
The ILC in July 2005 adopted the following definition for AT:
‘Assistive Technology is a term for any device, system or design, whether acquired commercially or off the shelf, modified or customized, that allows an individual to perform a task that they would otherwise be unable to do, or increase the ease and safety with which a task can be performed’

The purpose of such technology is to allow individuals to maintain their maximum independence and autonomy.

Assistive Technology devices can help improve physical or mental functioning, overcome a disorder or impairment, help prevent the worsening of a condition, strengthen a physical or mental weakness, enhance learning capacity, or even replace a missing limb. Assistive Technology products thus enable people with disabilities to accomplish daily living tasks, assist them in communication, education, work or recreation activities; in essence, help them achieve greater independence and enhance their quality of life. Appendix 9.3 shows generally available the categories of Assistive Technology products.
3.0 Aims and Objectives

**Aims**
The aim of this review was to inform Lotterywest and government regarding the targeting of current Assistive Technology funding schemes in terms of Assistive Technology, funded by them, and to make recommendations for any changes based on a review of local feedback, national and international research.

**Objectives**
The review had 6 key objectives:

1. To identify the strengths and weaknesses of LWDEG program
2. To identify prioritized unmet needs
3. To identify Assistive equipment and technologies not currently funded but which merit funding, as identified through
   - Western Australian stakeholder feedback
   - Best practice funding schemes and evidence based research in Australia and Internationally
4. To identify the funding gaps within the Western Australian community and how the funding gaps could be addressed
5. To identify the need for further research and advise Lotterywest which areas should be a priority for further research
6. To make policy and planning recommendations based on the evaluation findings.
4.0 Methods

Information was sought from a variety of sources that would assist in the review of the LWDEG program. Information sources included grant recipients, their families and carers, grant management agencies, disability service providers, ILC administrative data, electronic databases, internet sites and a list serve posting.

A range of different data collection methods was involved and a mix of both qualitative and quantitative research methodologies was adopted. The six components of the data gathering process were:

1. Literature review
2. LWDEG administrative data extraction
3. Questionnaire surveys
4. Focus group discussion
5. Expert consultation
6. Posting on list serve

4.1 Literature Review

Appropriate electronic databases were searched to identify examples of best practice and evidence based data pertaining to the funding of Assistive Technology. They included:

- Cinahl
- Medline
- Proquest
- Austhealth
- Social Work Abstracts
- Cochrane Database of Systematic Reviews
- National Health Economic Assessment
- TRIP: Turning Research into Practice
- Health Technology Assessment
- OT Seeker
- PEDRO

Appendix 9.4 details the bank of subject headings and keywords used in the search process. Only articles from 1998 onward were included in the review given the constant change in technological development and need to consider current funding policy and initiatives.
4.2 LWDEG program administrative data
Deidentified routinely collected LWDEG administrative data was provided to the researchers. Data items provided included Applicant ID number, date of birth, sex, applicant's locality, postcode and disability, applicant's supporting agency, AT item requested, date of application, date request granted and value of grant,

4.3 Questionnaire surveys
A series of survey questionnaires were designed to capture both qualitative and quantitative information from volunteer participants within four disability stakeholder target groups:
- LWDEG recipients
- LWDEG management agencies
- Other (community) disability stakeholders
- Families/carers of LWDEG recipients

Consent and ethical approval
The survey protocol and practices were approved by the Sector Advisory Group. By completing the survey protocol, participants consented to the provision of data and its publication in aggregate form.

Information about the purpose of the surveys and how to participate were circulated to stakeholders via telephone, emails, newsletters, newspaper articles and websites. Respondents completed a mailed questionnaire returning by stamp addressed envelope or where necessary opted to complete the survey with a researcher by phone.

Survey participants completed the following questionnaires:

Grant Recipient Questionnaire
Individuals who had received a LWDEG between December 2003 – September 2004 were asked to complete a questionnaire.

Agency Questionnaire
All agencies who had assisted LWDEG recipients to make their grant application between December 2003 – September 2004 received an Agency Questionnaire.

Stakeholder Questionnaire
Members from the following seven groups were contacted to participate in the Stakeholder Questionnaire survey.
- Disability organizations
- DSC Local Area Co-ordinators (LAC's)
- Health Department allied health staff
- Interested disability community stakeholders
- General Practitioners
- Local Government Associations
- Interested members in the general community
Family/Carer Questionnaire
The families and/or carers of all individuals who had received a LWDEG between December 2003 – September 2004 were invited to complete a Family/Carer Questionnaire.

4.4 Focus group discussion
Individuals identified as representatives of the disability sector and of AT grant recipients, and considered to have knowledge or special interest in this area were invited to a focus group to identify their perspectives on unmet equipment needs within the West Australian community. Twelve people accepted an invitation to participate in a three hour focus group held at the ILC on the 17th February 2005. Before the meeting, each focus group member was provided with background information (including the LWDEG project outcome measures, the evaluation aims and the expressed unmet needs of survey respondents) to guide the proposed discussion and encourage further reflection on AT unmet needs. The discussion was facilitated by an external facilitator. Two assistants acted as advisors/observers and recorders. Comments were recorded as written notes and on audio. All information recorded at the focus group was tabled and sent to participants to check veracity.

4.5 Expert consultation
Consultations were held with Industry specialists in including
- Occupational therapists from the Independent Living Centre (n=3)
- Curtin Occupational Therapy School (n=1)
- CAEP Manager, Individual Development Program Service, Purchasing and Development Directorate, DSC (n=1)
- Other disability sector agencies (n=1)

4.6 ARATA posting on list serve
Information was posted on the ARATA (Australian Rehabilitation & Assistive Technology Association) list serve about the Pilot Project evaluation. ARATA is a national Australian association whose purpose is to serve as a forum for issues in rehabilitation and Assistive Technology. Members were requested to give advice and information on best practice/evidence based equipment funding schemes within Australia and Overseas.

4.7 Sampling and analysis
The survey and focus group populations were selected by non-probability quota sampling method. The researcher chose the following groups as representing all stakeholders:
- Lotterywest DEGMP recipients including individuals and their supporting agency.
- people with disabilities, their families
- disability agencies and organizations
- health professionals
- local government
• general community

Descriptive statistics were used to analyse questionnaires responses and administrative data.
5.0 Literature review

There was little information about funding of Assistive Technology that was considered to be best practice apart from the loan financing schemes in the US. Most of the AT funding systems were fragmented and under funded with a range of problems including lack of co-ordination, lack of training and awareness amongst health professionals on available Assistive Technology, slow or inadequate assessment/prescriptive practices, inadequate access to trial equipment, insufficient training and support for the client using the equipment.

In terms of evidence based research most of the evidence is non experimental descriptive studies or expert committee reports, opinions and/or experience of respected authorities. There are few examples of randomized controlled trials for AT’s. The most relevant information related to funding was an understanding of the issues of equipment non-use and assessment of AT outcomes to justify benefits and costs in the funding of equipment.

Australia

In Australia, research conducted by Ernst and Young (1996) found that the available disability equipment schemes were fragmented and did not provide adequately for people in need. The AIHW (2003) reported that many people with a disability miss out on equipment provision and outlined some of the systemic problems. They include:

- The range of equipment is limited and supply from traditional dispensing units such as hospitals is declining. Funding for schemes is insufficient to both increase the number and range of aids available and cover the cost of maintenance, repair and replacement of loan equipment.

- There are particular problems with the cost, availability and shortage of referral services in remote areas of Australia

- Eligibility criteria for some schemes are too restrictive. The exclusion from schemes (other that CRS Australia) of people with a disability who are employed and the absence of alternatives, causes financial hardship particularly for those who require high-cost or numerous equipment items

- Because of waiting lists, aids and equipment are often provided only after a lengthy delay. Children and young people, with their particular developmental and sudden growth patterns, can urgently require a number of expensive items in rapid succession. Sometimes the delay in provision is so great that they outgrow their original prescriptions before the required item becomes available
• Many people with a disability have low income (many rely on the Disability Support Pension), leaving little capacity to pay for items of aids or equipment.

ACROD (2004) reported that this situation has not improved and that there is a need for national reform with particular consideration of the following strategies as outlined by Dowling (2002):

• Boosting private health contributions as well as public funding

• Providing holistic packages of items that meet long-term needs in a timely manner

• A separate funding stream for high-cost, low-volume items

• Training in the selection and use of appropriate aids and equipment

• Strategies to build stronger national purchasing power in the equipment market, while retaining local individualized clinical assessment prescription

• A reduction of long waiting periods while applications are reviewed and processed in a number of agencies

• More inclusive and consistent eligibility criteria

• Re-use of recycled equipment

West Australian Research
Research conducted by Smith & Mitchell (2003) at Rocky Bay (not for profit organisation providing services to children and adults with neuromuscular conditions) in Perth, Western Australia discussed the potential positive influence on functional independence and quality of life which Assistive Technology can provide. They investigated use of computers and environmental controls (both not funded under CAEP) and found a minimum of two or more difficulties in their usage. The authors discussed that to achieve successful implementation of this technology it is essential to have easily accessible resources for trial, careful prescription, training and ongoing support as well as a funding commitment.

AT funding options for WA individuals with a disability

Loan financing
In Australia the No Interest Loans Scheme (NILS) offers an alternative for low income consumers who face barriers in gaining access to credit for the purchase of basic and essential household generally less than $1000. The definition of the term "low-income" includes anyone in receipt of a government benefit, pension or allowance and anyone who holds a Commonwealth Health Care Card.
There is a network of 104 NILS agencies operating throughout WA from Kununurra to Esperance. The network is run as a centralized processing/administration model. The agencies have a direct relationship with the client.

The primary purpose of loans offered by NILS organisations are for whitegoods, browngoods (e.g. televisions and videos) and other household goods/furniture. Other purposes included medical equipment, car repairs and registration and education expenses. The most common repayment amount is $20 per fortnight with others ranging from $20 to $30 per fortnight. The funds are paid directly to the supplier of the goods. Minimum repayments are $2.50 per fortnight per $100 borrowed. The average term of the loan is 12-15 months. The agency assists participants to examine their finances, develop a budget and determine whether they have sufficient funds to service a WANILS loan. (Around 5% of clients return for a second or third loan and often, different members of the same family apply for a loan). To further develop their skills, clients must be involved in the application process. They must put together the paperwork including their Centrelink statement, residency agreement and obtain a minimum of two quotes for the item they intend to purchase. WANILS evolved from the WA Government whitegoods scheme. When established, WANILS received $500 000 in State Government funding for the first four years of operation, of which 30% was for administration and the remainder for loans. WANILS now manages around $1.7 million. From 2007-08 the WA Government will fund only administration costs. WANILS operates as a commercial business with a loans committee that meets each Wednesday to assess applications. WANILS has a 96-97% repayment rate, secured through a direct debit from the recipients’ Centrelink payments through Centrepay. Tasmania has also just started a NILS scheme based on the WA model.

CAEP Funding
The Community Aids and Equipment Program (CAEP) in Western Australia funds the purchase of basic and essential aids and equipment to assist people with disabilities to manage at home. People who are eligible for services from Disability Services Commission, hold either a Pensioner Concession card, Health Care Card or Commonwealth Seniors Card who have a long term disability and who are living in the community may apply. CAEP Service Providers are allocated a base budget from which to fund equipment for their client base. They have the opportunity twice each year to apply for growth funding. This is allocated based on demonstration of unmet need and priority. This growth funding is then added to the base budget of the service provider. Service providers may also apply for one off funding and this is provided based on availability of funds and priority.

Commonwealth rebate
For individuals not eligible for CAEP funding the Commonwealth rebate of 18% for prescribed medical expenses that are greater than $1,250 includes
wheelchairs, orthotics, prescribed appliances and ancillary equipment. However, few people with disabilities are aware and consequently do not apply for it in their tax return. The Physical Disability Council of NSW in 2004 called on the Commonwealth Government to

- Increase the rebate rate on disability goods and services from the current 18% applied to medical costs to 100%.
- Decrease the rebate threshold for essential disability aids and appliances from $1,250 to $300.

International

**United Kingdom**

On 27 June 2002, the Audit Commission published *Fully Equipped 2002 — Assisting Independence* which was a follow-up to a similar report in 2000. Both reports were critical of five services for disabled people: audiology; community equipment; wheelchairs; prosthetics, and orthotics. The 2002 report found the AT service to be unsatisfactory with confusion, inequality and inefficiency although it was acknowledged some progress had been made with community equipment and audiology since the first report in 2000. The recommendations of the 2002 report focused on actions that commissioners of services need to take to improve the lives of older and disabled people. The passing of UK legislation since the 2002 report, to remove the power of councils to charge for equipment loan or supply removes a significant impediment to AT acquisition.

Stead (2002) also discussed the inadequacies of AT provision in the UK concluding that further research into the benefits of AT and a comprehensive national strategy were essential to give services a clear sense of direction.

The Audit Commission (2004) examined the role Assistive Technology plays in supporting older and disabled people to maintain independence focusing on Telehealth and Telecare. It pointed out ‘the value of AT in alleviating dysfunctions and preventing health and social problems’ as demonstrated by studies in UK and overseas.

Despite the recommendations of the Audit Commission’s 2002 report (*Fully Equipped 2002 — Assisting Independence*) the Audit Commission (2004) noted that at least one third of community equipment services were still not delivering an integrated AT service within the UK.

**Funding AT Services**

In the UK, AT services have a low financial profile with baseline funding less than one percent of personal social services expenditure (Audit Commission 2004). AT services were being impeded by the following funding obstacles:
• only one quarter of AT projects have recurrent funding
• the need to modernise services, but most health and social care communities having many other demands on their block capital
• a concern that provision of AT equipment will simply lower hospital admissions for AT recipients and subsequently lead to higher costs overall; the savings derived from using AT as a substitute for existing services may simply be swallowed up by more demand because of the very large measure of remediable disability and undiagnosed chronic conditions that are currently left untreated.

Possible solutions discussed in the report included:

• investing in AT services while taking capacity out of the acute hospital sector
• government providing non-recurrent funding via grant mechanisms to pump-prime AT services.

Research into cost effective provision of AT
Lansley, McCreadie and Tinker (2004) measured the feasibility and costs of home adaptations and AT and the scope for these to substitute and supplement formal care. They concluded that ‘appropriately selected adaptations and AT can make a significant contribution to the provision of living and environments which facilitate independence. They can both substitute for traditional formal care services and supplement these services in a cost-effective way’.

United States
The US National task Force on Technology and Disability (2004) identified lack of funding as one of the major barriers to the acquisition of Assistive Technology. In the United States, Medicaid (state funded system matched by the federal government for those in financial need) and Medicare (funds people over 65 for durable medical equipment - rarely Assistive Technology products) are ‘limited in scope to provide durable medical equipment like wheelchairs, prosthetics and orthotics and augmentative communication technologies’. The report indicated that recommendations were usually limited by the agencies’ budget for particular items or by the categories of AT as stipulated by the agencies’ mandates.

Hammel and Finlayson (2003) outlined some of the future US trends that will influence disability policy including the ageing population, increasing immigration, changes in the labour market, and the dramatically increasing role technology plays in our society.

Loan financing
Several states in the US have loan financing schemes to assist in the purchase of AT. These programs include public and private partnerships usually involving
a community based organisation, a nonprofit entity and a lender. Program operation and administrative responsibilities is usually undertaken by the nonprofit group with the lender providing credit review, loan distribution and collection functions. Loan review committees involve consumers, non profit and other community representatives (Wallace, 2003). According to Sauer (2000) these partnerships are based on the following characteristics:

- Full inclusion of all stakeholders from the outset, including the end user (joint collaboration and ownership is the result)
- Careful examination and validation of needs from the customer’s perspective
- Involvement of all parties in the design of the program/response
- Secured resources
- Assurance that the program/response is easily and readily accessible
- Delivery and evaluation of the product/service in a timely manner
- Redesign of program, if needed

Wallace (2003) concluded that loan programs demonstrate ‘that people with disabilities are a viable market for credit across ages, incomes and geographic locations’. Examples of other successful loan financing programs were also described by Hammond (2003), Adams (2003), Dalto (2003) and Scione (2003). It is acknowledged that loan financing is just one strategy for meeting the Assistive Technology funding needs of people on low to middle incomes that are not eligible for federal or state government schemes (Wallace, 2003).

Assessing AT outcomes
Mann et al (1999) researched the effectiveness of AT and environmental interventions in maintaining independence. The authors found that although the frail elderly persons exposed to these interventions experienced decline over time, institutional and certain in-home personnel costs were reduced.

Jacobs, Hailey and Jones (2003) discussed the tools for economic evaluation analysis and how they can be used to evaluate technologies and make policy recommendations in the Assistive Technology field.

Canada
The Canadian Association of Occupational Therapists (Miller Polgar, 2002) has comprehensively reviewed the uptake of AT in that country. The following factors were identified as the chief cause of limited AT uptake: the cost of technology, lack of outside funding (government or a third party payment systems), limited access to AT suppliers particularly outside large metropolitan areas, limited access to experts for assistance in the selection and use of AT (mainly in rural and remote areas) and lack of recognition for the need or the availability of AT, as well as fear of stigmatization when using AT.
Non-use of AT
Additionally, amongst owners of AT, there are reported high rates of non-use (Cushman and Scherer, 1996). The researchers identified that abandonment of use of AT was associated with the following factors:

- Problems with devices that did not provide the type or extent of assistance required (Mann, Hurren and Tomita, 1993)
- Technology that resulted in unwanted attention to the user (Mann et al., 1993)
- The client’s perceived need for the technology
- The degree of fit between the client’s environment and the Assistive Technology (Hastings, Kraskowsky and Finlayson, 2001). Evidence suggests that a visit to the environment in which the device is to be used can reduce non-use (Finlayson & Havixbeck, 1992).
- Whether users’ opinions are considered in the selection process and if training is provided in the clients’ usual environment. AT use increases with consideration of opinions and training of users (Phillips & Zhao, 1993).

Assessing AT device outcomes
Fuhrer et al (2003) developed a framework for the conceptual modelling of Assistive Technology device outcomes. This framework could facilitate development of device specific causal models and assist in research examining AT outcomes.

Other research examining AT outcome measures includes:

- Psychosocial Impact of Assistive Devices Scale (PIADS) looking at impact of AT on users quality of life (Jutai and Hy Day, 2002; Jutai and Campbell, 2002).
- The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0) measuring user satisfaction of AT device(s) and services (Demers, Weiss-Lambrou and Ska, 2002).

Shone Stickel et al (2002) researched consumer satisfaction and the value people with degenerative neuromuscular conditions placed on electronic aids to daily living (EADL). They found that consumers were quite satisfied with their EADL’s but expressed concern re the cost of the technology and associated services. The authors concluded that using outcome measurement tools will assist service providers to justify costs associated with prescription and supply of EADL’s. The measurement of user satisfaction is considered to be very important in the management of AT outcomes and represents a shift from a medical assessment model to a client centered perspective. Ongoing research
and refinement of instruments is focused on measuring AT outcomes in a structured and systematic way (Demers et al, 2002).

The Netherlands

Assessment of AT outcomes, effects and costs

Gelderblom and Witte (2002) discussed the importance of assessing outcome of AT ‘to demonstrate the efficacy of the application of new technology, to establish the effectiveness of Assistive Technology over time or to steer the development of new Assistive Technology’. The authors reported on eight instruments that assess part of the overall outcome of AT and one that assesses costs. They pointed out that the field of AT is developing and to improve the quality and applicability of outcome instruments there needs to be further development, standardization and international collaboration.
6.0 Results

6.1 LWDEG program administrative data - Client demographics

Disability Diagnosis of LWDEG applicants
In Table 1 below, LWDEG program administrative data for the period October 2003 – August 2005 shows a wide range of disability groups are making funding applications. It should be noted that the figures shown are for individual grant applications except for the disability diagnosis categories of Multiple Sclerosis and vision impairment where the Multiple Sclerosis Association and the Association for the Blind respectively apply for block grant funding on behalf of multiple clients.

Table 1. Disability diagnosis of individual funding applications

<table>
<thead>
<tr>
<th>Disability Diagnosis</th>
<th>Applications n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quadraplegia, paraplegia, hemiplegia</td>
<td>61 (13.0)</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>49 (10.4)</td>
</tr>
<tr>
<td>Multiple sclerosis*</td>
<td>42 (8.9)</td>
</tr>
<tr>
<td>Amputee</td>
<td>40 (8.5)</td>
</tr>
<tr>
<td>Other Congenital disability conditions (Down's syndrome [5], Prader-Willi syndrome, Sanfillipo, Shy-Dragger, Pallister mosaic, Dravet’s, Holoprosencephaly sequence)</td>
<td>36 (7.6)</td>
</tr>
<tr>
<td>ABI, CVA</td>
<td>35 (7.4)</td>
</tr>
<tr>
<td>Multiple disabilities</td>
<td>34 (7.2)</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>33 (7.0)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>25 (5.3)</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>24 (5.1)</td>
</tr>
<tr>
<td>Poliomyelitis</td>
<td>21 (4.5)</td>
</tr>
<tr>
<td>Arthritis, athrodesis, hereditary paralysis</td>
<td>19 (4.0)</td>
</tr>
<tr>
<td>Vision impairment *</td>
<td>15 (3.2)</td>
</tr>
<tr>
<td>Other disability diagnoses</td>
<td>12 (2.5)</td>
</tr>
<tr>
<td>Motor Neurone disease</td>
<td>11 (2.3)</td>
</tr>
<tr>
<td>Autism</td>
<td>9 (1.9)</td>
</tr>
<tr>
<td>Lymphodema</td>
<td>5 (1.1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>471 (100%)</strong></td>
</tr>
</tbody>
</table>

* includes group applications
Agencies supporting applications for LWDEG funding
There were 73 agencies supporting grant applications between October 2003 and August 2005. The ILC supports more than a quarter (29%) of all individual grant applications during that period.

Equipment funded
Table 2 below shows the number and percentage of AT items granted within the four available categories of Lotterywest funded equipment from October 2003 to August 2005. Vehicle modifications and air conditioning together comprise the majority (76.8%) of grant applications.

Table 2. AT funded by LWDEG program Oct 2003 - Aug 2005

<table>
<thead>
<tr>
<th>Category of AT funded by LWDEG</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vehicle Modification</td>
<td>244</td>
<td>42.2</td>
</tr>
<tr>
<td>Air conditioning</td>
<td>200</td>
<td>34.6</td>
</tr>
<tr>
<td>Adaptive Technology for people with vision impairment</td>
<td>122</td>
<td>21.1</td>
</tr>
<tr>
<td>Augmentative and Alternative Communication (AAC)</td>
<td>12</td>
<td>2.1</td>
</tr>
<tr>
<td>Total</td>
<td>578</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 3 below shows by category of AT, the number of grants, number of agencies and LWDEG funds for financial years 2001-2005 inclusive.

Table 3. Number of grants, agencies and LWDEG funds for financial years 2001-2005 inclusive

<table>
<thead>
<tr>
<th>Year</th>
<th>Air Conditioning</th>
<th>Vehicle Modifications</th>
<th>Adaptive Technology</th>
<th>AAC</th>
<th>Agencies No.</th>
<th>Amount $</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001/01</td>
<td>32*</td>
<td>62</td>
<td>3#</td>
<td>2</td>
<td></td>
<td>574,720</td>
</tr>
<tr>
<td>2001/02</td>
<td>39*</td>
<td>44</td>
<td>12#</td>
<td>3</td>
<td>40</td>
<td>537,019</td>
</tr>
<tr>
<td>2002/03</td>
<td>52*</td>
<td>60</td>
<td>9#</td>
<td>6</td>
<td>40</td>
<td>594,575</td>
</tr>
<tr>
<td>2003/04</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2004/05</td>
<td>92*</td>
<td>131</td>
<td>8#</td>
<td>3</td>
<td>47</td>
<td>-</td>
</tr>
</tbody>
</table>

*Includes Multiple Sclerosis Society block grants
#includes Association for the Blind block grants
**Sex and age of applicants**

There are significantly more males (57%) than females (43%) making LWDEG applications (binomial significance p<0.02).

Table 4 below shows the age category distribution of funding applicants compared to their distribution in the WA population. The majority (65.8%) of funding requests was for adults between the ages of 20 and 65 years. The representation of adolescent, adult and elderly LWDEG applicants is similar to that in the WA population however, amongst children 0-4 yrs there is a lower representation in comparison to their numbers in the general population (2.8% vs 13.0%).

**Table 4. Age categories of LDWEG grantees compared to the WA population**

<table>
<thead>
<tr>
<th>Age Categories</th>
<th>Grantees (%)</th>
<th>WA population (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children (0-4yrs)</td>
<td>2.8</td>
<td>13.0</td>
</tr>
<tr>
<td>Adolescents (5-19yrs)</td>
<td>18.0</td>
<td>14.4</td>
</tr>
<tr>
<td>Adults (65 and under)</td>
<td>65.8</td>
<td>61.0</td>
</tr>
<tr>
<td>Elderly (65+)</td>
<td>13.4</td>
<td>11.6</td>
</tr>
</tbody>
</table>

**Post code – distance/remoteness as a measure of access**

Application of the ABS standardised remoteness classification index ARIA+ (Accessibility/Remoteness Index of Australia – ARIA+) to grant recipient post codes is considered to provide a de facto measure of access (Glover and Tennant, 2003). Table 5 below shows the ARIA+ distribution of grant requests from across WA. The vast majority (87.5%) of LWDEG funding request are from individuals and organisations located in major WA cities and from inner regional WA. Fund applications from outer regional, remote and very remote WA comprise 12.5% of all applications made during 2003-2005. The WA population distribution for the same area is 16.8%. A proportion of grant applications remain unclassified in terms of remoteness/access due to missing post codes. They comprise individual applicants with unrecorded post codes and block grants to the MS Society and the Association for the Blind.
Table 5. Location of LDWEG grantees by ARIA+ Remoteness Index

<table>
<thead>
<tr>
<th>Location</th>
<th>Grantees 2003 – 2005</th>
<th>WA population 2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major cities of WA</td>
<td>307</td>
<td>71.1%</td>
</tr>
<tr>
<td>Inner regional WA</td>
<td>71</td>
<td>16.4%</td>
</tr>
<tr>
<td>Outer regional WA</td>
<td>34</td>
<td>7.9%</td>
</tr>
<tr>
<td>Remote &amp; very remote WA</td>
<td>20</td>
<td>4.6%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>432</strong></td>
<td><strong>100%</strong></td>
</tr>
<tr>
<td>Missing post code*</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>Group applicants**</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

* Individual’s post code not recorded in database
**Includes 9 instances of block grants made to the MS Society and Association for the Blind where individual post codes are not recorded in the ILC database

Table 6 below shows the majority of grant applications received (79.1%) are from individuals in the lowest income category.

Table 6. Number of grant applications per LWDEG income category

<table>
<thead>
<tr>
<th>Individual applicant - income category</th>
<th>Number of grants</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1 – up to $14,000</td>
<td>353</td>
<td>79.1</td>
</tr>
<tr>
<td>Level 2 – up to $33,000</td>
<td>86</td>
<td>19.3</td>
</tr>
<tr>
<td>Level 3 – over $33,000</td>
<td>7*</td>
<td>1.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>446</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

*only 1 application was granted in the level 3 income category
6.2 Questionnaire survey

6.2.1 Grant Recipient Questionnaire
One hundred and eighty nine questionnaires were distributed to LWDEG recipients. There was an overall return rate of 44% (84/189) with the following distribution:

- 41.5% - ILC managed (42/101)
- 48% - Association for the Blind WA managed (35/73)
- 47% - Multiple Sclerosis Society managed (7/15).

The disability of the 84 recipients is shown in figure 1 below.

![Figure 1. Grant recipient disability groups](image)

The disabilities in the 'Other' category included transverse myelitis, upper body paralysis, Charcot Marie Booth, Alzheimer's Disease, Cerebellar Ataxia, Dystonia, Motor Neurone Disease, Myasthenia Gravis, Epilepsy, Metabolic Disorder, Chronic Fatigue, Spino cerebellar Ataxia, RSD.

There were approximately equal numbers of males (51%) and females (49%) with the following age ranges:

- Children 2%
- Adolescents 6%
- Adults 48%
- Elderly 44%

Of this group 67 (80%) had not received LWDEG funding in the past. The remainder received items from between 1987 and 2000 some of these items being replacement or for different equipment needs.
**Need for equipment**
Figure 2 reflects the need for equipment.

**Figure 2. Grant recipients - equipment needs**

![Pie chart showing equipment needs]

- 42% for Temperature control
- 32% for Print/picture magnification
- 21% for Increased mobility
- 4% for Bed chair mobility
- 1% for Increase mobility and temp control

Print/picture magnification included using email/internet/computer, writing letters/memoirs, reading books/letters/articles, viewing photos/artwork.

Temperature control was required for stabilizing blood sugars, improving chest problems, reducing Multiple Sclerosis symptoms, reducing seizures and pain and improving quality of life.

**Equipment Funded**
Equipment categories previously funded to LWDEG recipients are shown in figure 3 below.

**Figure 3. LWDEG funded equipment (Grant recipient Questionnaire)**

![Pie chart showing funded equipment]

- 41% for adaptive technology
- 36% for air conditioning
- 23% for vehicle modification
How did Grant recipients find out about grants?
Grant recipients found out about grants from the following sources;

- Local Area Coordinators (LAC's) -26% (22)
- Association for the Blind WA – 26% (22)
- Grant Recipients themselves 11% (9)
- Friend 9.5% (8)
- Hospital 6% (5)
- Rocky Bay 4.8% (4)
- TL Engineering, 2.4% (2)
- No response, 2.4% (2)
- ELBA, Spinal Bifida Assn, Canning Shire Council, Neurologist, ILC, MND Association, Stroke Group, Cancer Foundation, Adventist Residential Nollamara all 1.2% (1)

Grants approved
With regard to the grants approved many respondents did not give information or indicated they were unsure of the accuracy of their information. The information received indicated that grants approved by LWDEG ranged from $926.60 to $7,500. Supporting organizations provided funds for two recipients and 25 (30%) recipients also provided funds. One recipient received funds from other sources (Wearne Trust).

Agencies Supporting Applications
The following agencies supported the grant recipients to make the LWDEG application:

- Association for the Blind WA 39% (33)
- MS Society 12% (10)
- No response 7% (6)
- ParaQuad 4.8% (4)
- Lions Clubs, Rocky Bay, 3.6% (3) each
- Spinal Bifida, Southwest family support group, LAC, Brightwater Care Group, ILC, CPA, 2.4% (2) each
- ELBA, Canning Shire Council, DEAC, Alzheimer’s Association, My Place Foundation, Motor Neurone Disease, Northern Suburbs Stroke Group, Cockburn HACC, Recreation Network, Hurty Family Support, Karen Wild, City of Cockburn 1.2% (1) each
**Assistance with the application**
The following agencies assisted grant recipients complete their LWDEG application forms:
- Association for the Blind WA 32% (27)
- No response 13% (11)
- LAC 12% (10)
- Family member, GP’s 7% (6) each
- MS Society and Hospitals 4.8% (4) each
- Carers, ILC, Brightwater Care Group 2.4% (2) each
- Rocky Bay, Shire Council, Alzheimer’s Association, My Place Foundation, ParaQuad, Self, OT, Southwest Family Support Association, Adventist Residential Care Nollamarra 1.2% (1) each

**Vehicle advice and driver assessment**
Of the 21 Vehicle Mobility grants 43% (9) sought ILC advice 28.5% (6) did not and 28.5% (6) did not give a response. There were 33.3% (7) who had driver assessment, 33.3% (7) were not assessed and 33.3% (7) did not give a response.

**Equipment Trials**
- Vehicle Mobility
  - 31.6% (6) trialed equipment,
  - 68.4% (13) did not
- Air-conditioning
  - 6.9% (2) trialed equipment,
  - 76% (22) did not and
  - 17% (5) did not respond
- Adaptive Technology
  - 77% (27) trialed equipment,
  - 20% (7) did not and
  - 3% (1) did not respond.
  - Of those who indicated trialing the equipment 48% (13) trialed for up to 2 hrs, 18.5% (5), 2 weeks - 1 mth 18.5% (5), 2 mths – 4 mths 14.85% (4), greater than 4 mths 11% (3).
- Bed chair mobility did not trial equipment
Problems supporting application
Most respondents 89% (75) did not experience difficulty gaining support for their LWDEG; 8% (7) did not respond. Of the two respondents that reported experiencing problems, one reported difficulty working with the supporting agency and the other did not elaborate.

ILC Project Officer assistance
There were approximately 17(20%) respondents who received help from the ILC Project Officer. Of these, assistance was given for the following grant applications

- Vehicle Modifications 41% (7)
- Adaptive Technology 41% (7)
- Air conditioning 11.8% (2)

Problems with training and support
Most respondents 88% (74) did not experience any difficulty with training and support. There were five commendations of support for the Association for the Blind WA and one for TL Engineering from respondents. Of the 5% (4) that did experience problems two had air conditioners (one had trouble reading the manual; the other did not elaborate). The other two problems involved adaptive technology grants - one was waiting for a computer class and the other for a volunteer assistance to begin.

Timing for applications
Respondents reported the following processing times from the commencement of application to receipt of equipment.

- <one month - (14%) 12
- <2-3 months - (40.5%) 34
- <3-6 months - (33.5%) 28
- <6 months + - (9.5%) 8
- no response - (2.5%) 2
**Satisfaction with process**

Satisfaction was measured on a scale from 1 (not satisfactory) to 5 (highly satisfactory). Results were as follows:

- 5  66% (55)
- 4  19% (16)
- 3  11% (9)
- 2  2% (2)
- no response 2% (2)

The two grant recipients that rated 2 on the satisfaction scale both received air conditioners: one after 2-3 months wait and the other after 3-6 months wait. The 9 grant recipients that rated 3 on the satisfaction scale received air conditioners (6), adaptive technology (2) and vehicle modification (1). The waiting times were: one waited 6 months +, six waited for 3-6 months and two waited for 2-3 months.

**Still using the equipment**

Most grant recipients 96% (81) were still using their grant equipment, 2% (2) did not respond and the 1% (1 recipient) who was not using the equipment was given details to return the adaptive technology to the Association for the Blind WA.

**Other equipment needs**

A total of 61% (51) respondents reported no further equipment needs, 12% (10) did not respond, 5% (4) were not sure and 23% (19) indicated the following unmet equipment needs:

- **Care Items**
  - Special bedding including electric bed and postopaedic bed 3
  - Incontinence pads
- **Mobility aids general**
  - Electric scooter and Electric wheelchair 2
  - Pool hoist 2
  - Walking frame
  - New van
  - Cheaper transport
  - Special chair
  - Tilt table
  - Exercise equipment
  - Hand controls car
- **Adaptive equipment for vision impaired**
  - Adaptive Technology to Scan material with a screen reader 2
  - Read newspaper and books
  - Software for vision impairment
- **Grants for education and learning and educational software**
- **Computer and home training**
- **Telephone large numbers and loud ring**
**Quality of Life**
Grant recipients were asked to comment on how the granted equipment had impacted on their quality of life. Some of the respondents (37%) described quality of life changes in all seven of the listed quality of life domains. Several respondents made no comments, whilst the remainder (59%) commented on at least one domain. The respondents’ comments are tabulated in Appendix 9.5. The impact of granted equipment on each quality of life domain is summarized below.

**Health**
Reduction of stress levels, happier outlook, improved health and stabilising of medical conditions leading to reduced infection and better sleep.

**Home**
Ability to read books recipes and to keep in touch with others, more comfortable, more independent in the home with energy to get things done.

**Personal Goals**
Improvement in independence and confidence, increased work and leisure options such as ability to do more computer work, read more, study and be more active in the community.

**Family and Friends**
Better and more enjoyable with more mobility to visit and network, improved contact because less tired or can email and write letters.

**Community**
More access to community social activities and awareness, as well as an opportunity for volunteering.

**Work/school**
Ability to access further education, study made easier due to better sleep and health and ability to see print.

**Leisure**
Increased access to reading, getting to entertainment and new activities as the quality of life improvement.
Other feedback

- Pleased with the help received and everything was satisfactory (n=27)

Respondents made the following suggestions to improve the grant application process and its outcomes:

- Decrease waiting times (n=9)
- Decrease red tape (n=2)
- Prefer to apply directly to ILC as have other needs apart from MS (n=3)
- Problems finding out about the funding (n=3)
- Promote LWDEG. E.g. Staff education for people at retirement villages, community care facilities, care visitors, public libraries, doctors surgeries and local government
- More contact and follow up
- Make documentation easier to fill out
- Increase funding limits
- Modify process where you could email/fax information or attend grant making decision group to find out there and then of successful grant application
6.2.2 Agency Questionnaire
Of the 44 LWDEG management agencies sent a questionnaire 20 responded resulting in a 45% return rate. Of this group 75% were disability providers.

Equipment funded by LWDEG
Figure 4 below shows the range of equipment funded by grants to agency clients.

**Figure 4. Equipment funded by LWDEG (Agency Questionnaire)**

- Airconditioning (16) 53%
- Vehicle Modifications (8) 27%
- Adaptive Technology (3) 7%
- Augmentative and Alternative Communication (2) 3%
- Other (1)

How Grant recipients found out about grants
Figure 5 below shows how clients found out about grants.

**Figure 5. How clients found out about grants**

- Disability Services Commission including Local Area Coordinators (10) 31%
- Agencies (10) 30%
- Therapists/advisers (4) 12%
- Other families (3) 9%
- Publications (3) 9%
- Networking (2) 6%
- Seminars/presentations (1) 3%
Assessing need for equipment
Figure 6 below shows the frequency distribution of various reported modes for assessing equipment need.

![Figure 6. Mode of assessing equipment needs](image)

- Doctor (6)
- LAC (7)
- Allied Health (7)
- Agency (5)
- Shire (1)
- TL Engineering (1)

Assistance with the grant application
Figure 7 below shows who assisted with Application form

![Figure 7. Assistance with LWDEG application](image)

- Agency (10)
- Doctor (5)
- LAC (4)
- Allied Health (3)
- Shire (1)
- TL Engineering (1)

Problems completing the LWDEG application
The majority of agencies (17/20) reported no difficulties completing the Grant application forms. One agency did not respond. Problems experienced by two agencies included

- Difficulty accessing means test information for clients
- Difficulty within the agency obtaining required signatures from president/chair and
- Clients experiencing difficulty in obtaining quotes and arranging visits to doctors when housebound

Accessing support to complete grant application
Twenty five percent (5) of agencies reported they did not need support to complete the application. Another 25% (5) accessed the ILC LWDEG Project Officer's support, 10% (2) used LAC’s, 5% (1) sought Lotteries help, 5% (1) sought Shire help and 5% (1) sought Anglicare help to complete the application forms.
Time to process LWDEG applications
Agencies reported the following processing times from the commencement of the application to receipt of equipment.

- less than two weeks 10% (2)
- less than one month 20% (4)
- less than 2-3 months 45% (9)
- between 3-6 months 10% (2)
- No response 10% (2)

The majority (75%) of the twenty agency respondents reported LWDEG grants being processed within 2-3 months:

ILC Advice and Information
Two agencies reported all their clients received advice and information from the ILC. Five did not know and 13 did not respond.

Equipment trials
Agencies reported that grant recipients for adaptive technology and AAC equipment trialed equipment in each case. Vehicle equipment trials were unknown.

Satisfaction with process
Using a rating scale from 1 to 5 where 1 = not satisfied and 5 = highly satisfied, the majority of agencies (70%) rated a satisfaction level of 4 (45%) or 5 (25%). The remainder rated level 3 (30%).

Those rating level 3 satisfaction were granted air conditioners (4) and vehicles modifications (3) and experienced a waiting time of either 2-3 mths (4) or 3-6 mths (1).

Quality of Life
Agencies were asked to comment on the impact the granted equipment had on their clients’ quality of life in the areas of health, at home, with people, work or education, leisure and community. Although comments made were all positive in terms of improving their clients’ quality of life many agencies did not comment on all aspects. There were 30% (6) who commented on six aspects, 50% (10) made at least one comment with 20% (4) making no comment. Detailed comments on quality of life can be seen in Appendix 9.6.

Orientation training and ongoing support
The majority of agencies (75%) did not comment regarding the importance of the influence of orientation, training and support for the successful use of equipment. Those agencies that did comment indicated the following:
Air conditioning
Ten percent of agencies suggested that for this item parents were responsible for correct use and that generally only good orientation was required with minimal need for training and support.

Vehicle modifications
Fifteen percent of agencies commented that assessment, orientation, training and support were essential for satisfactory outcomes.

Adaptive Technology
Five percent of agencies commented that although labour intensive; orientation, training and support were all equally important to ensure equipment was suitable and would be used by the individual.

Augmentative and Alternative Communication
Five percent of agencies indicated that AAC orientation, training and support were all necessary.

Problems providing orientation, training or ongoing support
In response to ‘did agencies experience problems providing orientation, training or ongoing support?’
• fifty five percent (11)of agencies indicated that they experienced no difficulties
• ten percent (2) indicated that the companies providing equipment for air conditioning and vehicle modification orientated, trained and supported families and that generally there was no need for the agencies to provide ongoing support
• Five percent (1) involved with the provision of adaptive technology indicated it was a resource stretch
• five percent (1) did not know.
• forty percent (8) of agencies did not respond.

Equipment still being used
Ninety percent of agencies indicated that all of the equipment granted was still being used. One piece of adaptive technology had been abandoned and was to be returned to the agency, another agency reported the death of a client. One agency involved with neurological degenerative conditions reported two pieces of equipment were no longer being used due to exacerbation of the disease in one case and unrealistic expectations in the other.

Unmet needs
When asked to comment on unmet equipment needs currently not covered by government grants or the Lotterywest grant fifty five percent of agencies did not respond, ten percent indicated that there were no unmet needs in their client group and five percent said they did not know. Table 7 below, lists the unmet needs identified by the thirty percent of agencies who responded.
### Table 7. Unmet equipment needs identified by supporting agencies

<table>
<thead>
<tr>
<th>Care Items</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electric hospital beds</td>
<td>4</td>
</tr>
<tr>
<td><strong>Mobility Items</strong></td>
<td></td>
</tr>
<tr>
<td>Lift chairs</td>
<td></td>
</tr>
<tr>
<td>Recliner lift chairs</td>
<td></td>
</tr>
<tr>
<td>Rocker recliner</td>
<td></td>
</tr>
<tr>
<td>Hoists agency use in a house</td>
<td></td>
</tr>
<tr>
<td>More than one mobility aid</td>
<td></td>
</tr>
<tr>
<td>Electric wheelchairs</td>
<td></td>
</tr>
<tr>
<td>Scooter</td>
<td></td>
</tr>
<tr>
<td>Occupant restraint systems</td>
<td></td>
</tr>
<tr>
<td>Vans ? loan library</td>
<td></td>
</tr>
<tr>
<td>Leisure aid e.g. bookstand</td>
<td></td>
</tr>
<tr>
<td>Feeding aid e.g. neater eater</td>
<td></td>
</tr>
<tr>
<td>Quality of life issues not addressed by CAEP</td>
<td></td>
</tr>
<tr>
<td>Computers – hardware not covered and software needs certain criteria to run</td>
<td></td>
</tr>
<tr>
<td>Adaptive Technology for people with dementia. Monitor clients at home and assist in locating lost clients. Available but prohibitively expensive</td>
<td></td>
</tr>
</tbody>
</table>
- MND report from care advisors should suffice in lieu of doctors report
- Repeated information regarding therapy focus and corporate information on each application.
- Three months acquittal process can be difficult due to family circumstances and wellness of child.
- Take less time processing application
6.2.3 Stakeholder Questionnaire
Forty three people responded from the Disability sector; 44% (19) were from Allied Health, 42% (18) were Local Area Coordinators and 14 % (6) were from Disability organizations. All of the respondents provided services for clients with disabilities. There were no responses from General Practitioners, Local Government Authorities or from the general community.

The respondents assisted clients within the following age categories:
- 25% (11) 0 – 59 years
- 23% (10) 0 – 60+ years
- 16% (7) 19 – 59 years
- 5% (2) 0 –12 years
- 5% (2) 13 – 59 years
- 5% (2) 13 – 60+ years
- 5% (2) 19 – 60+ years
- 5% (2) 60+ years
- 2% (1) 0 – 12 years, 19-59 years
- 2% (1) 0 – 12, 60+ years
- 2% (1) 0 – 18 years
- 2% (1) 0 – 18, 60+ years

Most respondents (98%) working with these client groups reported that they required aids and equipment.

More than two thirds of stakeholder respondents (67%) were aware of the Lotterywest DEG. They were made aware through DSC and LAC networks (26%) or through ILC including website (12%), work and colleagues (10%), allied health (5%), emails and circulars (5%), word of mouth (5%), and other families (5%). Most of the respondents (97.5%) were aware that they could assist with equipment funding and in fact 80.5% had been requested to support funding applications.

Unmet Needs
Respondents identified the following unmet AT needs:

- Mobility Aids general (5%)
  - Electric scooters and wheelchairs for community access (12%)
  - Walkers (5%)
  - Standing frame (2.4%)
  - Electric easy chairs/ postural support easy chairs (2.4%)
  - Lightweight pram (2.4%)
- Vehicles
  - Modified Vehicles purchase or more assistance with modifications (12%)
  - Specialized car seats and restraints (5%)
- Environment Control (9.75%)
- Security safety systems (2.4%)
- Integrated Controls (2.4%)
- Computers
  - Computer access (2.4%)
  - Laptop and special software (communication devices) (2.4%)
  - General computer equipment (2.4%)
- Mobile phone access (2.4%)
- Care Items
  - Suction unit (2.4%)
  - Electric/hospital beds (9.75%)
  - Incontinence pads (2.4%)
- Therapeutic training equipment
  - Switches (single/latch/powerlink) (2.4%)
  - Portable sensory room equipment (2.4%)
- Other adaptive equipment for vision impaired (screen readers) (2.4%)
- Cognitive prosthetics – external prompting system (2.4%)
- Air conditioning
  - other rooms in home (2.4%)
  - Shade window film (2.4%)
- Recreational (24%)

**Other feedback**

**Positive**
- Lotterywest application process is more streamlined thank you. Positive grant application process experience. Nicki is very helpful.

**Suggestions/comments/concerns**
- Great program but restrictive on what can be funded.
- Means test for DEG is very low especially for a family on moderate income ($60,000) with high vehicle modification costs
- Mobility in the community is a problem. Someone who can walk in their own home is not eligible for a wheelchair, yet not be able to negotiate the community without one.
- CAEP budget is tight with only basic items - needs to broaden scope of equipment on offer.
- More exposure to funding sources at University for undergraduate health professionals
- Favoritism exists within Lotterywest DEG for vision impaired where some people are not given access to grants or others receive grant equipment and then sell it.
- Acquired Brain Injury clients need powerful computers to run specialised software programs and lots of hands on training to achieve competency.
- Consideration for unlisted items that are therapeutic for mobility e.g. treadmill
- Top up CAEP applications where funding ceiling doesn’t cover the best equipment to meet the clients’ needs.
6.2.4 Family/Carer Questionnaire
About three quarters (64/84) of grant recipient respondents also completed a Family/Carer Questionnaire. Most (56%) were aged above 60 years with 42% aged between 19 – 60 years and 2% aged between 13-18 years.

Figure 8 below summarises the relationship of the respondent to the grant recipient.

Figure 8. Respondents relationship to grant recipient

Quality Of Life
The majority (59/64) of respondents provided comments on ‘how the granted equipment had impacted on the quality of life for the family.’ A majority of respondents (64%) commented on at least one of the quality of life domains listed, whilst about one third (28%) addressed multiple quality of life domains.

A small proportion of respondents (11%) also mentioned the impact on the clients’ quality of life. The Family/Carer comments are tabulated in Appendix 9.7.

Below is a summary of the impact of granted equipment on each quality of life domain.

Health
Decreased stress levels, less stress on backs due to decrease in lifting, more relaxed with better health and sleep. Three family members indicated no change in their quality of life.

Home
Making life easier and more comfortable for all with more freedom due to fewer demands on time.

Personal Goals
Family respondents indicated the equipment had assisted them by increasing their family member’s independence and lifestyle.

Family and Friends
Good and excellent.
Community
Some families commented that there was no effect, whilst others indicated that there was more time to be involved in community activities and that they had an ability to go places that they were unable to before.

Work/school
For most families their was little impact but for some it impacted on work in that they were now on time and less tired.

Leisure
Mostly families did not comment but some expressed more freedom and time to do activities.

Other feedback
Many positive comments were made:

- 12.5% expressing appreciation and thanks
- 14% commenting on the independence the equipment (mainly vehicle modifications and adaptive technology) had provided giving them confidence, a social life, an ability to maintain work and not rely on others to read for them or assist in transport
- 8% commented on improved quality of life making reference to improved general health and self esteem, ability to maintain community work and communicate with family and friends

6.2.5 Limitations
It is recognised that the relatively low response rate for the survey questionnaires component of this review and an over representation by vision impaired respondents, means the current findings may not be representative of all disability stakeholders residing in Western Australia. However, the themes which emerged from respondent data were not unexpected based on other research reports from Australia and elsewhere and thus the recommendation arising from the data merit attention and action.
6.3 Focus group
Participant feedback is grouped and reported under each of several discussion issues.

Issue 1
What are the unmet equipment needs within the West Australian community? Prioritize the unmet needs and justify the priorities.

The focus group participants indicated that the majority of equipment identified in the category of unmet need by survey respondents was important depending upon the individual needs of the person with a disability. Although some of the identified equipment needs may not be considered basic and essential they nonetheless had a significant positive impact on quality of life of clients and their families.

The following represent the priority unmet needs discussed on the day.

- Quality of life equipment – basic communication systems and environmental controls
- Mobility aid as a second aid and/or for community access
- Car seats and restraints
- Electric beds
- Low income, non-CAEP eligible people

Issue 2
Is there current or past funding for these items. What funding bodies/organizations could potentially fund these items?

Information regarding previous, current and possible future funding for a wide range of unmet AT needs was recorded and discussed. A summary of this discussion is contained in Appendix 9.8.

Issue 3
What are the priority equipment/Assistive Technology items that Lotterywest is currently not funding that could be considered for funding?

The summary at Appendix 9.8, lists focus group priority 1 & 2 and other items and indicates how they could be funded in the future.
6.4 Expert Consultation
Consultations were held with Industry specialists in Assistive equipment and technology including
- Occupational therapists from the Independent Living Centre (n=3)
- Curtin Occupational Therapy School (n=1)
- CAEP Manager, Individual Development Program Service Purchasing and Development Directorate, Disability Services Commission (n=1)
- Other disability sector agencies (n=1)

6.5 ARATA posting on list serve
Four responses were obtained from the information posted on the ARATA (Australian Rehabilitation & Assistive Technology Association) list serve about the Pilot Project evaluation. Members were requested to give advice and information on best practice/evidence based equipment funding schemes within Australia and Overseas. There were responses from:
- An Australian Capital Territory Equipment Loan Service manager
- A lecturer whose students had completed a Critically Appraised Topic (CAT) on “What is the evidence that providing Assistive Technology and Environmental Intervention (AT-EI) positively impacts upon functional independence in elderly people?”
- An interested professional commenting on the keywords used in the CAT search
- A US researcher wishing the evaluation researcher luck given the limited research in this area.
7.0 Discussion and Recommendations
The issues summarised below and the recommendations made to address them should contribute to greater awareness and action to address the future AT needs of individuals with a disability in WA.

7.1 Strengths and weaknesses of Lotterywest DEGM program

7.1.1 Funding of equipment grants pre and post ILC managing LWDEG program
Grants were administered though Lotterywest prior to December 2003 when the ILC assumed management. Since then the number of agencies seeking LWDEG grants and the numbers of grants have steadily risen from 40 agencies supporting 127 equipment grants in 2002/2003 to 47 agencies supporting 234 grants in 2004/2005. Over this period Lotterywest funding resources have also risen from $650k to $800k.

The increasing number of grants and the granting agencies involved could in part be due to the streamlined grant management process in existence since the ILC has operated the grant scheme under the direction of a dedicated project officer as well as the additional funding resources.

The role of the project officer and the assistance available was seen as a valued component of the grant management scheme by individual grant applicants, granting agencies and other stakeholders involved in equipment assessment and grant application process. Indicative comments about the Project officer’s role included:

‘The ILC Project Officer is very helpful’
‘Project Officer is doing a good job’

[Recommendation 5]

7.1.2 Access and equity
Compared to their distribution in the West Australian population, children aged four and under are under represented amongst grant recipients (2.8% vs 13.0%) The remaining age groups are adequately represented with the bulk of applications (65.9%) being for adults aged 20 to 65 years; eighteen percent (18%) of applications are for 5-19 year olds and 13.4% for those 65 years and over. Fewer very young applicants may be explained by the majority of the primary disabilities being acquired rather than congenital and the fact that children in this age group do not require the types of equipment funded in LWDEG e.g. vehicle modifications. Examples of the acquired diseases (many of which begin in adulthood) included degenerative neurological conditions (Multiple Sclerosis, Muscular Dystrophy, Motor Neurone Disease, Alzheimer’s Disease, Friedreich’s Ataxia, Spinal Muscular Atrophy), Quadriplegia and Paraplegia and vision impairment conditions such as Macular Degeneration.
The LWDEG data show there are significantly more male than female applicants (57% vs 43%). Possible explanations for this may include the relatively large proportion of quad, tetra and paraplegias as well as ABI grant applicants, who as a group tend to have a greater male representation.

Close to ninety percent (87.5%) of AT grant applications were from people residing in major WA cities and inner regional WA. The AIHW (2003) stated that cost, availability and shortage of referral services in remote areas of Australia is a major barrier to the acquisition of AT for this population. In regional and remote WA the Health Department Telehealth videoconferencing initiative is contributing to improve AT service provision and the ILC has up to date videoconferencing equipment available as does ACROD and NHA. The ILC will however need to monitor the possibility of under representation from outer regional and remote areas of WA which is suggested by the figures to date (Table 5). Bias associated with small number samples and unrecorded postcodes for some grant applications thus far however, make it difficult to comment conclusively on the true representation of outer regional, remote and very remote AT grant applicants. More complete future recording of post code information will improve monitoring and evaluation of accessibility to AT throughout WA.

[Recommendation 7]

Currently, data regarding Culturally and Linguistically Diverse background (CALD) or Indigenous status is not sought from grant applicants. Ethnic people with disabilities make up approximately 25% of Australia’s disable population. While the Australian population as a whole is ageing, the population of people from CALD backgrounds is ageing at a more rapid rate. Evidence shows that older people from CALD communities are not accessing health and aged care services commensurate with their proportion of Australia’s ageing population (Partners in Culturally Appropriate Care, 2004).

There are indications that disability in the Indigenous population may be substantially more than the non-Indigenous population (O’Neill, Kirov & Thomson, 2004). The AT needs of this group will therefore be proportionately higher also. However there remains a very high degree of unrecognized disability within Aboriginal communities. Several factors contribute to this including some people with disability being ‘hidden away’, or simply not able to access the wider community. Additionally Aboriginal people with disability are often unaware of important information relating to rights and entitlements including social security entitlements and availability of disability services (O’Neill, Kirov & Thomson, 2004).

At present it is not possible to say whether eligible members of these two demographics are adequately represented amongst LWDEG applicants apart from seven presumed applications from CALD and Indigenous agencies. Some Indigenous people with disabilities may be being assisted by Aboriginal specific services. Knowledge about the LWDEG program’s reach and the ability to
monitor trends in funding applications from diverse geographic locations and populations within WA should be an integral part of the LWDEG program.  

[Recommendation 7]

According to survey responses about one third of grant recipients contributed to the cost of AT purchases and 80% of LWDEG respondents reported not receiving LWDEG funding in the past. Funding to previous grantees was for purchase of replacement items or different equipment needs. The size of grants to individual applicants ranged from $350 - $10000; the average grant being $2300. As expected the greater portion of grants (79.1%) went to level 1 income recipients (Individual up to $14,000; families up to $26,000) with 19% to income level 2 recipients (Individual up to $33,000; families up to $55,000). One grant was approved to a recipient with level three income (Individual over $33,000) on the grounds of exceptional circumstances following approval by the SAG clinical review panel.

Routinely collected LWDEG data show a wide range of disability groups and agencies have made funding applications since late 2003. Two agencies receive annual block grants; ($225,000 to Association for the Blind per annum; and between $30,000 – 60,000 to the Multiple Sclerosis Society per annum). This is a historical arrangement with Lotterywest prior to administration of the program by ILC. In this regard Lotterywest may need to defend criticism that access to AT may be more difficult for some individuals and that clear priority is not evident. It was also the perception of one disability stakeholder that ‘favoritism exists within LWDEG program for vision impaired where some people are not given access to grants or others receive grant equipment and then sell it’.

[Recommendation 8]

The ILC was itself the supporter of more than a quarter of all individual grant applications; a fact not apparent from survey responses that covered a 10 month period. Thus individuals who are not allied to a particular disability group, or prefer not to be, are utilizing the ILC to support their funding applications. It is likely however that there remain individuals in this category who are not aware of the availability of the LWDEG. This may include those clients who have age related disabilities and whose technology needs increase as they age.

7.1.3 Funding application process
Overall the funding application process is not seen as overly burdensome by the vast majority of agencies and individuals. Where two agencies reported difficulty gathering information requested on their clients’ financial status, this was identified as an internal administrative matter readily amenable to change. Provision of corporate information, mentioned by an agency is now less onerous with LWDEG program requiring annual provision of information and an update only of banking details for each application. It was also explained to this agency that the acquittal process has always been flexible with agencies having an
option to negotiate the three months time frame. The agency noting difficulties faced by housebound individuals in satisfying some of the requirements of the application process (such as arranging equipment quotes and attending medical appointments) can recommend their clients utilize the services of LAC’s to assist in the gathering of information for funding applications.

Individual seeking LWDEG funding generally do so with the support of an agency specific to their area of disability and most surveyed individuals (89%) reported being able to readily gain support for their application through a variety of agencies. Only two people reported a problem gaining support; one of which was not explained whilst the other cited ‘difficulties’ with the supporting agency. Where an individual has no specific affiliation with a disability agency the ILC can support individual grant applicants and as previously noted, to end of August 2005, 29% of all individual grants have been supported by the ILC.

Several respondent agencies required clarification of issues encountered making applications that pertain to important funding policy and guidelines:

- **Restricted range of equipment being funded by LWDEG (one agency)**

  The role of the LWDEG is to provide funding for equipment that is not provided through another government agency and to regularly review the funding of equipment to ensure that the program keeps pace with changing needs and priorities for people with disabilities and new developments in technology.

- **Low means testing (one agency)**

  The means testing for Lotterywest DEG was seen to be very low especially for a family on a moderate income ($60,000) with high vehicle modification costs. There is an exceptional circumstances clause in the information package provided by LWDEG that states the individual or family whose income is Level Three may be eligible for funding. They need to contact the LWDEG project officer to discuss their situation.

- **Top up CAEP applications (one agency)**

  There was a request to top up CAEP applications where the funding ceiling did not cover the best equipment to meet the clients’ needs. Top up funding through LWDEG is only available to people purchasing AAC equipment that exceeds the CAEP ceiling. However, CAEP does have an Advisory Committee where application can be made to consider funding for other equipment that is more expensive than the CAEP ceiling.

[Recommendation 9 &15]
7.1.4 Grant processing

According to agency respondents, the majority of applications (75%) were processed in less than 2-3 months, with approximately one third taking less than a month. Although the individual respondents reported processing times that appeared longer than the agencies this possibly could be explained by sample bias of respondents. Analysis of all recorded grant processing times between 2003 and 2005 showed a reduction in the mean waiting time from 63 days ± 59 days in 2003 to 38 days ± 26 days in 2005. The mean however masks application waiting times extending two or more times beyond the average waiting time. A perception that grant application times were too long was the most common concern in respondents’ feedback about the application process. Applicants and their supporting agencies should be aware that application waiting time are impacted by a number of variables, some common to all AT requests and others specific to the category of AT requested. Variables which need to be factored into application waiting times include sponsor agency time, ILC time, assessment, trialing, ordering of equipment, vehicle modification applications pending successful passing of a driving test and priority of funding in the case of air conditioning requests (e.g. an air conditioner may be applied for in June but may not be funded until October if cooling only is requested).

To avoid the perception that application times are unnecessarily lengthy or delayed recommendations are proposed to refine the application process with adjustments to systematically track applications and provide clients with progress updates at specified times. In the future the ILC may wish to provide grant applicants with indicative waiting periods which reflect best practice guidelines for grant processing times. To support this, the ILC should adopt a system for systematically monitoring waiting times and flag those whose wait extends beyond a designated cut off.

It is understood that time hold ups in the application process may be beyond the control of the ILC LWDEG Project Officer. The cause of hold ups in waiting times amongst survey respondents were found to be:

- within the agency (especially smaller agencies with volunteer staff that may close during the Christmas period (when air conditioners are in high demand),
- with individuals themselves,
- while waiting on additional information necessary for the application.

One agency expressed concern that air conditioning requests are often urgent and need shorter processing time; the ILC is able to process urgent requests quickly.

[Recommendation 12]
7.1.5 Satisfaction

The majority of individuals (85%) and agencies (70%) expressed high or very high satisfaction with the grant application process. Many individuals (27) reported positive comments about the LWDEG program. A commonly expressed sentiment was:

‘pleased with the help received and everything was satisfactory’

Agencies also provided positive feedback, describing:

‘the process was straightforward’, ‘process working well’, ‘expedient’ and ‘prompt’.

However, a number of respondents (11) expressed lower levels of satisfaction with the grant application process. They were in the main people who had applied for air conditioners and who waited for at least 2-3 mths for equipment to arrive. Low levels of satisfaction amongst agency respondents were also linked to applications for air conditioners, which had similar waiting times. Perhaps these lower levels of satisfaction are related to the processing time. This explanation for low levels of satisfaction may also apply in the remainder of the small number of cases of agencies and individuals applying for other equipment including adaptive technology and a vehicle modification where the common feature was also a wait of at least 2-3 month. As discussed in grant processing, time hold ups in the application process may be beyond the control of the ILC LWDEG Project Officer.

[Recommendation 5 & 12]

Other valuable feedback and commentary offers the opportunity for ILC to reflect on the need and/or possibility for adjustments to its activities. Respondent’s comments included:

- Problems finding out about the funding (3)
- Decrease red tape (2)
- More contact and follow up
- Modify process where you could email/fax information or attend grant making decision group to find out there and then of successful grant application.
- Promote LWDEG. E.g. Staff education for people at retirement villages, community care facilities, care visitors, public libraries, doctors surgeries and local government
- More exposure to funding sources at University for undergraduate health professionals
- Favoritism exists within LWDEG program for vision impaired where some people are not given access to grants or others receive grant equipment and then sell it.

[Recommendation 9, 10 & 15]
7.1.6 Equipment assessment, advice, trial, training and support

Assessment
Assessing equipment need for individuals with a disability is an important first step in ensuring a proper person equipment match to achieve maximum benefit, ongoing use and satisfaction with the chosen AT support(s).

One agency raised a valid concern that the grant application process was promoting over assessment by requesting a doctor’s report when it was felt a MND report from a care advisor should suffice. The ILC may wish to assess the extent of this perception via future evaluation studies. However, the need to maintain transparency of the granting process by having designated professionals provide client assessments should be stressed. In the current survey assessments were reported from a variety of sources including LAC’s (7) Allied Health (7), doctors (6), agencies (5), Shire (1) and a supplier (1). It is also important to ensure straightforward processes are in place which can expedite the granting process with minimal demands of clients, carers and families.

Advice
The survey findings indicate a need for more agencies to actively promote the role of the ILC as a source of advice and information about their clients’ prescribed equipment. Only two agencies reported that all clients received advice and information from the ILC and the rest did not know or respond to the question. The ILC too, needs to ensure that there is sufficient information available to agencies and individuals about the knowledge and expertise the centre can offer and that there is more encouragement to use this valuable resource.

Equipment trialing
The importance of equipment trialing is recognized as a major factor in achieving a good person to equipment fit which leads to improved usage rates, satisfaction with equipment choice and subsequent reduced risk of early abandonment.

There was a lack of awareness by agencies as to whether or not granted equipment had been trialed. Where two agencies could comment on equipment trialing, both adaptive technology and AAC was trialed 100%. There may be some confusion as to what constitutes an adaptive technology trial since about a quarter of respondents claimed not to have trialed the equipment. This appears to be where equipment was trialed for less than two hours and the session was seen as an assessment rather than a trial.

It should be noted that of 21 individuals receiving vehicle modification grants only nine reported seeking ILC advice prior to making their grant application and of these only seven reported requesting a driver assessment. Specialist OT driver assessment is advised for people seeking to drive a modified vehicle. The LWDEGMP has funding available to assist clients with this assessment.
Air conditioners are a large part (43%) of granted equipment. Since the most important factors are correct assessment by the installing company and that the individual/family has capacity to operate the equipment this may explain some agencies lack of knowledge about trialing.

**Orientation, training and ongoing support**
The importance of the influence of orientation, training and support in the successful ongoing use of Assistive Technology and equipment is repeatedly stressed in the published literature.

Most (88%) individuals’ perception was that training and support for the use of granted equipment was readily available. Some provided commendations for the support given by the Association for the Blind WA (5 individuals) and for a supplier (one individual).

From an agency perspective, about a half reported no difficulty providing orientation, training or ongoing support. Two agencies noted that it was the companies providing the equipment (air conditioning and vehicle modification) together with LAC’s that provided the necessary support to families and that the agency didn’t need to be involved in this aspect.

However, for the agency supporting adaptive technology, this activity, was found to be “a resource stretch”.

‘Acquired Brain Injury clients need powerful computers to run specialised software programs and lots of hands on training to achieve competency’.

It is not known whether other agencies share this experience. Perhaps fewer than anticipated agency responses on their perception of the importance of orientation, training and support may indicate some agencies’ unwillingness to espouse this view when currently it could be difficult to implement. This matter should be examined further in view of the importance of incorporating assessment, training and support in the process to ensure suitable equipment is recommended, unrealistic expectations avoided and a satisfactory outcome is achieved.

[Recommendation 10, 11 & 14]

7.1.7 **Equipment use and maintenance**

**Equipment use**
It is pleasing to note that the vast majority of grant recipients (96%) reported ongoing use of granted equipment; a finding corroborated by agency respondents. Whilst it is hoped that the WA survey figures are a true reflection of ongoing AT use, the possibility of sample bias should be borne in mind. Abandonment or non use of equipment are a frequently reported feature in the
AT arena with quoted rates as high as 30%. The two reported explanations for non use in this survey (unrealistic expectations; and abandonment) may warrant further examination in the light of concerns mentioned above, regarding agencies’ inability to provide necessary orientation, training and support for AT.

[Recommendation 14]

**Maintenance**

The issue of maintenance was not specifically raised with survey respondents and nor were there any comments made regarding the costs associated with upkeep or repair of AT. It is an important aspect of acquiring AT and has been raised as an issue in previous Australian research (Ernst and Young, 1996; AIHW, 2003). The UK literature also reports that individuals struggle to maintain and repair equipment thus jeopardizing their independence (Audit Commission, 2004).

[Recommendation 14]

7.1.8 **Quality of Life Outcomes for grantees as a result of equipment provision.**

Individuals and their family/carer(s) made numerous positive comments about the impact of granted equipment on their QOL. Many reported how the granted equipment had successfully addressed limitations imposed by their condition on the types of activities they could undertake. Common themes emerging from equipment use were greater independence, more confidence, increased opportunities and less stress for individuals and their families and / or carer(s). Other responses as well as those of agency supporters related to QOL improvements affecting health and comfort in the home, personal goals, interaction with family, friends and the community, and their leisure, work and educational and activities. Some indicative comments reflecting positive QOL responses included:

‘Life a bit easier’
‘Less frustration’
‘Able to set personal goals as life has become manageable’
‘My son’s independence in transport will enable him to seek work or further education’
‘Interact with neighbors’
‘Less stress better relationships’
‘Life is fuller’
‘People can visit again due to improvement in depression’
‘Family now travel as a unit’

[Recommendation 5]
7.2 Unmet equipment needs

Australia wide there has been official documentation of unmet AT needs commencing with the 1996 CSDA review of Australian equipment schemes (Ernst and Young, 1996) and the AIHW report on unmet need for disability services in Australia (AIHW, 2002. Much anecdotal evidence about unmet AT need is also available from disability advocacy groups (Carers Australia, 2001, ACROD, 2002/2004, Physical Disability Council of NSW, 2001 /2004). This review is sadly a confirmation of those previously published findings.

An extensive list of AT equipment was identified as unmet need by disabled individuals, supporting agencies and other disability stakeholders. The top four priority items articulated by survey respondents and matching those identified by focus group members were:

- electric beds
- electric scooters and wheelchairs for community access
- vehicle modifications
- environmental controls

This is a reassuring finding that enhances the validity of the prioritized equipment needs identified by the current research. A second mobility aid and specialized car seats and restraints (currently not eligible under CAEP) were also mentioned by respondents. Focus group participants noted that whilst there are priority demands, other identified unmet equipment need was equally valid depending upon the specific needs of the individual with a disability. Whilst some equipment might not be considered basic and essential (and therefore not eligible for CAEP funding) it nonetheless enhanced their independence and improved their quality of life.

Individuals on low incomes that fall outside the CAEP funding limits are also identified as a category with unmet equipment needs. Although there is ample evidence of the benefits of utilizing Assistive Technology, this group includes some of the many individuals with disability who are unable to access the aids and equipment necessary to realize those benefits (AIHW, 2003 chapter 2). Rethinking of existing funding structures may be required to make needed AT available to these individuals. The needs of low income, non CAEP eligible individuals are further discussed Section 7.5: ‘Other unmet need – funding gaps and issues within the Western Australian disability community’.
7.3 WA stakeholder feedback of currently unfunded AT equipment that could be considered for funding

It was the collective opinion of survey respondents that there are funding shortfalls for individuals with a disability which prevent their AT needs being met in a holistic manner with the inevitable consequence that their independence is not being fully supported.

The section below discusses the unfunded priority needs of people with a disability that were considered to merit funding by focus group discussion. The rationale and options provided for their proposed funding is based on demonstrated need evidenced by stakeholder feedback; equipment type requested in recent Equipment for Living (EFL) grant distributions; and consideration and interpretation of current funding policy and its intended coverage. Also of relevance is the need to keep abreast of new developments in technology and to match the widespread use of and greater reliance on new technologies occurring in the wider community.

The EFL grants were the result of additional non recurrent funding provided by the WA Government in 2005 for individuals with disabilities to purchase essential AT not currently available under the CAEP scheme. The grants were administered by the ILC (with a total of $1,425,000 being granted in two funding rounds) for equipment for individuals to enhance participation in their homes and the community. Uptake of these funds provides some measure of current level of AT need amongst people with disability in WA. Specific EFL grant amounts and the category of equipment funded are described in the following discussion on currently unfunded AT items. A recommendation is made for broadening granting policy to include these specific unfunded AT priority items.  

[Recommendation 16]

AT equipment to be considered for funding is discussed according to the focus group priority listing:

Priority one  - Environmental controls and basic communication systems/devices  
- car seats and restraints  
- second mobility aid

Priority two - electric beds

Also merits funding - specialized seating  
- agency requiring hoist in the home
a) Priority one

**Environmental controls**

Environmental controls allow the user to independently access and operate appliances in their home environment. They can assist with security and safety issues such as for example leaving doors unlocked for carers to enter the home when the disabled person cannot manage this function. Homeswest have provided some switches for disable individuals to manage the entrance door independently. However, because this area has not been funded in the past the disability community (including consumers and service providers) lack information on the availability of many of these products.

Some measure of the expressed need for this category of AT is revealed by the recent one off funding rounds of the EFL program. Between 24/12/2005 – 1/4/2005 the EFL received applications for:

- 8 electric door openers
- 4 scanning bed controllers
- 2 mobile base units and
- 1 page turner

Other environmental control options for people include those for turning lights on and off, controlling TV and stereo systems and opening and closing curtains.

In Australia schemes such as New South Wales Program of Appliances for Disabled People (PADP) and The Victorian Aids and Equipment Program provide funding for some environmental controls based on funding scheme eligibility criteria with cases being assessed on their merit.

**Potential Funding Options**

- Currently environmental controls are not included on the CAEP imprest list and therefore are not funded. They could be considered basic and essential and CAEP could potentially accommodate them, providing additional funding was allocated.

**Communication systems/devices including recreational and communication systems (excluding voice output devices)**

This category of AT includes communication systems/devices that enable individuals to participate in leisure, educational, work and business activities they would otherwise be excluded from. For example equipment to enable the individual to write to other people or access books (unable to access printed material due to restricted mobility or vision) or that enables access to a computer and the internet (allowing them to shop, bank, communicate via email, and pursue leisure interests such as audio and electronic books). This equipment
includes specialized keyboards, mice and software, e.g. (speech recognition software).

Computer literacy has developed within the community and is seen as a common place activity in daily lives of many people. It is important that people with disabilities especially those restricted physically in their home environments can avail themselves of similar computer technologies accessed by the wider community. This often enables people to access services and undertake communication that would otherwise not be possible.

The NSW PADP funds technological aids, for example equipment to access a computer including mounting device, special mice or keyboard and specialized software (e.g. speech recognition software).

**Potential Funding Options**

- Lotterywest has been funding some communication items and could consider broadening the criteria in this area to fund additional communication systems/devices e.g. alternative communication call systems designed to address safety issues in the home.

**Car seats and restraints for adults and children**

Whilst new technology has provided better choices for specialised car seating and restraint, they are costly. This equipment is not currently funded. It has been funded by CAEP in the past, but this ceased in approximately 2000 as these items were not used in the home and therefore ineligible for CAEP funding. Variety WA has occasionally funded these items for children. The NSW PADP funds specialized car seats and the Victorian Aids and Equipment Program fund car seats for children according to their eligibility criteria.

Currently there is a demonstrated need for this equipment: The EFL program has between 24/12/2005 – 1/4/2005, funded 32 car seats and/or restraints at a cost of $83,000.

**Potential Funding Options**

- Consideration could be given to broadening the CAEP eligibility criteria to fund not only items used in the home but also to facilitate community access. For example it is essential for people with disabilities to be able to access medical and therapy appointments to maintain a level of health and function thereby enabling them to be maintained in the home environment. The NSW PADP has a more inclusive criteria wherein
**Items must support and/or enhance participation in and/or independence in the community (e.g. medical and therapy appointments) and quality of life.**

- Lotterywest could consider expanding the list of equipment funded in the Vehicle Hoists and modifications category of AT to include the addition of car seats and restraints for adults and children.

- An additional potential funding source worthy of investigation is the Department of Planning and Infrastructure which could be involved in the provision of grants/funding for car seats and/or restraints for people with disabilities.

**Mobility aid as a second aid and/or for community access**

Currently CAEP funding provides a mobility aid for use in the home but not for community access. For example this means that someone who has been provided with a wheelchair but is developing skills to use a walker will not be provided with one. Also if an electric wheelchair breaks down there is currently no provision within CAEP to allow for the funding of a back up manual chair. There is also the scenario where there is no funding for someone who can walk independently within the home but not manage to do this in the community. The NSW PADP scheme’s policy provides broader coverage of funding for mobility aids. PADP describes these mobility aids as items ‘that are provided to access and mobilize within the consumer’s community, including the home, leisure and recreational environments’. The program’s eligibility criteria recognize that both a powered and a manual option or two manual options may be necessary to adequately cover mobility needs.

- Current CAEP eligibility criteria does not fund a second mobility aid despite it being a legitimate need to adequately promote independence and participation in the community. Some indication of the current level of need for this category of AT is revealed by the funding activities of the EFL program. There have been two EFL program funding rounds between 24/12/2005 – 1/4/2005 in which the following items were funded at a cost of $270,500:
  - 54 manual wheelchairs
  - 9 powered wheelchairs
  - 21 walker/standing frames and
  - 15 scooters

**Potential Funding Options**

With increased funding
- CAEP could potentially consider broadening its granting policy on mobility aids to allow funding of a second mobility item.
Lotterywest which currently does not fund any mobility items could potentially fund a second mobility aid.

b) Priority two

**Electrically adjustable beds**

The focus group indicated that electrically adjustable beds have not previously been government funded. There has been some occasional charitable funding; for example Variety club funding for children. These beds are expensive to hire in the private sector and there are currently no cheaper hire schemes operating in WA. In 2005, the West Australian State Government has provided short term funding for electrically adjustable beds through the EFL Program. However this is only a short term measure.

Electric beds are funded by the NSW PADP and the Victorian Aids and Equipment Program. This latter scheme cannot be applied for until 30 days post discharge up until which the existing DHS agreement deems hospitals to be responsible for providing electric beds.

Recent funding activities of the EFL program provide an indication of the level of need for this item in WA. The EFL program had two funding rounds between 24/12/05 – 1/4/05 and funded 127 electric beds at a cost of $462,000. A high level of demand for this item is also reported by the VA&E program where there are wait list of the order of 6-12 months.

**Potential Funding Options**

- Currently electric beds are not included on the CAEP imprest list and therefore not funded. They could be considered basic and essential and therefore potentially fundable by CAEP; providing additional funding was allocated.
- Given the cost of electrically adjustable beds, consideration could also be given to leasing arrangements with bed suppliers as happens in New South Wales.

c) Also merits funding

**Specialised seating e.g. electric recliner/lift chairs and symmetrikit chairs**

These items are occasionally funded through CAEP if considered to be basic and essential or through service clubs eg Rotary. There are safety and liability issues with regard to the resale market (people selling these items at swap meets) and recycling of this equipment, which are a disincentive for funding organizations. In NSW funding for specialized seating in the home and recreation environment is provided by the PADP.
Evidence of actual need for this category of AT is demonstrated by the EFL program which had two funding rounds between 24/12/05 – 1/4/05 and funded 73 specialised seats at a cost of $290,000.

**Potential Funding Options**

This item could also be considered basic and essential and thus covered by existing providers of basic and essential equipment. Funding sources would include

- CAEP when the individual has a mobility problem and

- The Health department when there is a medical problem e.g. respiratory and the aged.

- Lotterywest may also wish to consider funding this category of equipment to assist individuals who are not eligible for DSC services. As there is a large ageing population there is a need to set criteria with multiple funding bodies.

**Agency required hoists in the home**

Portable hoists are provided by CAEP for unpaid carers in the home. When the person with the disability lives alone and has a paid carer, the provision of the hoist is usually seen by CAEP as the responsibility of the carer agency. Although some Home and Community Care (HACC) packages provide a hoist many do not. This causes difficulties when family and friends come to visit as they are unable to assist the person in their care.

Other schemes in Australia such as NSW PADP fund hoists for disability consumers except when they live in residential aged care facilities.

**Potential Funding Options**

Funding bodies need to review care packages and where appropriate consider including hoist and other AT provision as part of the care package and training in its use. Funding sources would include:

- HACC through other care packages

- Commonwealth

- Other provider agencies

[Recommendation 16 & 17]
7.4 Other unmet need – funding gaps and issues within the Western Australian disability community

The focus group was concerned about a range of other unmet need and issues affecting AT service provision within the WA community. They are discussed below with possible solutions for addressing them.

**Equipment that is needed short term or for consumers who have a short/medium life expectancy**

People who are learning new skills, are improving medically or have a degenerative disease such as Motor Neurone disease may need different equipment for short periods due to improvement or worsening of their function. An example of this need is the person in a wheelchair who progresses to a walker or the individual who uses a wheelchair and then needs an electric wheelchair. There is also a need for short term use if equipment breaks down.

Some loan equipment is available for hire from the ILC Hire service (low cost and offering non biased clinical expertise) or through private operators. Organisations such as the Motor Neurone Disease Association offer a loan service to their client group and include power chairs and communication devices. The health system has responsibility for post hospital discharge equipment, but there are variations in the level of assistance provided. CAEP will fund costs associated with short term trial of equipment eligible through the LWDEG program. There is also no funding available for short term hire of equipment for CAEP ineligible individuals. Technology Assisting Disability in Western Australia (TADWA) recycle equipment to hire in Western Australia but they do not have the expertise to prescribe.

In developing a short term hire scheme, consideration would need to be given to ensure there is effective co-ordination, minimisation of red tape and that economies of scale are present. For example, the Motor Neurone Disease equipment loans service in Western Australia, (although not able to meet consumer range of equipment or demand), effectively utilizes the equipment it does have. For larger equipment such as electric beds and hoists it is also worth considering leasing schemes as, for example NSW PADP have recently developed leasing arrangements with suppliers.

[Recommendation 18]

**Old and unused equipment – other than CAEP equipment**

It was noted by the focus group that some equipment no longer used is sold via newspapers or through community swap meets. In particular the recycling of LWDEG funded equipment is problematic since it has been gifted to the grant recipient (although people are advised that they can return the equipment to the funding agency for recycling). It may be worth some West Australian service providers considering systems such as electronically tagging and barcoding equipment. The United Kingdom Audit Commission (2002) found that
electronically tagging and bar-coding equipment improved equipment recycling rates.  

[Recommendation 19]

**Medical equipment including suction, medical consumables and continence items**

*Suction equipment*

The focus group identified provision of suction equipment as an area of concern because whilst some hospitals have loan equipment, it is generally old, large and noisy and there is no consistency to the funding of these items.  

[Recommendation 20]

*Medical consumables*

Medical consumables such as respiratory consumables are only provided for 3 months post discharge. Following that there is no further funding with subsequent costs to the family or individual of approximately $70 per week. The focus group suggested that a service entity akin to the ILC could bulk purchase and on sell these items at reduced cost, for example small amounts of plastic tubing.

[Recommendation 21]

*Continence*

For people with continence issues, requiring equipment, funding is provided from different sources for the following ages

- 3 - 16 years - Lotterywest funding (having taken over from the State government)
- 16 - 65 years - Commonwealth funding
- Over 65 years - no funding

The focus group identified that both children and adults are under funded in this area and that there is a great need to address the continence products and equipment problem with the over sixty age group where presently no funding is provided.  

[Recommendation 22]

*Commonwealth funded consumers*

Equipment for Commonwealth-funded residential care consumers (in a nursing home or hostel environment) to meet individual needs such as mobility, seating, standing and quality of life needs is not ear marked and is an area currently of unmet need.

The focus group identified this situation is severely affecting many people who do not have the capacity to pay for this equipment and is impacting quality of life at a time when people often have a reduced capacity to identify and/or express this need. For example, people tend to be left in bed during the day because of inadequate seating options, or their comfort is compromised due to poor seating posture. Often, families may not be aware of this problem or understand the need for appropriate seating. There is a need for increased awareness amongst
consumers and their families of the existence and impact of this AT funding gap within residential care facilities. This gap limits their ability to access the community. On these grounds there is merit in advocating for and considering the funding of unmet needs in this group and how it can be achieved.

Action will need to be taken on a number of fronts including consultation between Commonwealth and State governments and other disability stakeholders (including consumers, families, disability service providers, organisations and communities). It will also be necessary to ensure client assessments address any specialized equipment needs e.g. special seating and mobility aids arising in residential care clients. [Recommendation 23]

**Low income non CAEP eligible people**

Individuals and families on low incomes who are eligible for CAEP funding under the program’s financial hardship provisions will often not use this or other funding programs such as the LWDEG. This may be because they find the process invasive or prefer to be independent.

At the federal level the government shows some support for AT by providing compensation for the cost of disability goods through tax relief. A rebate of 18% for prescribed medical expenses greater than $1,250 is available for people who cannot access CAEP. Wheelchairs, orthotics, prescribed appliances and ancillary equipment are eligible for the rebate, but many people with physical disabilities are unaware of the rebate and therefore do not apply for it in their tax return. Including these individuals within the scope of AT services provision is a challenge that must be pursued for them to achieve an independent lifestyle within the community. [Recommendations 24]

**Assessing and specifying equipment for CAEP funding**

Currently when CAEP funding is sought, health professionals assess and specify equipment for clients. These health professional are either from the Disability Services Commission, DSC non government organizations, or Health Department therapists. However there can be delays in assessment and the specification stage due to human resource shortages in all these funded areas. Additional issues can arise for

- Health Department clients where there is sometimes a waiting list, thus increasing the overall waiting time for equipment.
- People who aren’t linked with an agency as they must access a service provider for assessment because funds do not go directly to an individual.
Addressing these deficiencies to provide a more effective response to the AT needs of this client group will require better joint arrangements between the relevant AT service areas.

[Recommendation 25]

The information discussed in the previous sections (7.2 – 7.4) indicates there is a strong need to reassess the scope of AT service provision and funding in WA. Getting the scope right is essential for achieving a more comprehensive AT service system to meet the needs of people with a disability. This will require reaffirming contemporary concepts of disability and exploring how AT can support as far as possible independent lifestyles in the community. The input of key disability stakeholders via an AT Task Force is recommended as a first step toward achieving this aim.

[Recommendation 1, 2 & 4]

This review’s findings support the recommendation that the ILC continue in its management role of the LWDEG program with consideration to the recommended changes for enhancing and strengthening its operations. A prime focus of the recommended changes is the expanded evaluation and monitoring of its service activity which is seen as essential for supporting future evidence based AT service developments.

[Recommendation 3]
7.5 Need for or further research - Alternative approaches for meeting unmet need.

Finite AT funding and narrowing eligibility criteria demand alternative approaches to help provide AT to underserved individuals. A variety of AT service provision models is the most practical way to address and maintain service delivery in an environment of constant technological change and many contextual variables such as fluctuating symptoms and rapidly changing needs.

Low cost no interest loans
There are precedents both in the US and in Australia for the adoption of low cost or no interest loans to assist individuals with purchase of essential goods.

The US has a well structured system of loan financing programs across most states offering a range of low or no interest lines of credit to eligible applicants for assistance in purchasing AT. These programs include public and private partnerships usually involving a community based organisation, a nonprofit entity and a lender (Wallace, 2003). Program operation of administrative responsibilities is usually undertaken by the nonprofit group with the lender providing credit review, loan distribution and collection functions. Loan review committees involve consumers, non profit and other community representatives. In summarizing a review of successful US loan financing programs Wallace (2003) stated that people with disabilities are a viable market for credit across ages, incomes and geographic location. Currently there is no precedent in Australia for the involvement of financial institutions in providing credit for AT purchases to people with a disability.

Australia has however been successfully providing non banking credit to eligible Centrelink clients for the purchase of basic and essential household items generally less than $1000. The No Interest Loans Scheme (NILS) which evolved from the WA Government whitegoods scheme operates outside the banking sector via participating goods suppliers. In WA there is a NILS network of 104 agencies operating from Kununurra to Esperance. The network is run as a centralized processing and administration model and the agencies have a direct relationship with the client. The WANILS has a 96-97% repayment rate, secured through a direct debit from the recipients’ Centrelink payments through Centrepay.

In the UK the Motability Charitable Fund operates the Motability scheme which helps disabled people to use their Disability Living Allowance (DLA) to buy a car, scooter or electric wheelchair. Anyone receiving the higher rate of the mobility component of DLA or a War Pensioners Mobility Supplement can apply. The Motability Equipment Fund provides help for severely disabled people who require complex and expensive adaptations to their mobility purchase.
Adoption of similar schemes for financing AT equipment purchases or expansion of the WANILS model to include provision of AT equipment would allow low income individuals in WA to plan the acquisition of their AT needs.

**[Recommendation 26]**

**Short term hire/loan scheme**

Reference to the need for short term hire of equipment has already been made in section 7.4 where examples of existing hire schemes, either free or user pay are referred to. Schemes already in place can serve as useful models and should be used as a basis for improving existing hire loan arrangements so that the needs of all individuals who require AT equipment for short term use can be addressed.

**[Recommendation 18]**
7.6 Disability policy

A number of obvious opportunities exist in the way of policy reform to significantly assist future provision and funding of AT. Strategies should focus on utilizing the findings of this report to support appropriate advocacy and representational activities from key disability stakeholders to achieve desired enhancement of existing policy.

State and Commonwealth policy development activities should target the following areas:

1. Commonwealth/State Disability Agreement
2. National Strategy for an Ageing Australia
3. Commonwealth Medicare rebate

[Recommendation 27, 28 & 29]
8.0 References


9.0 APPENDICES
Appendix 9.1

Equipment currently funded by LWDEG program

- **Vehicle Hoists and Modifications**
  Including Wheelchair or scooter carrier, Modified vehicle controls, Raised vehicle roof or other modifications

- **Adaptive Technology - Vision Impairment**
  Including Specialized Software, Print Magnification System, Braille related equipment, Text to speech scanning systems

- **Augmentative Communication Equipment**
  Equipment manufactured specifically for a person with a disability
  Eg: Macaw or specialised computer program.

- **Air conditioner**
  For one area of respite from the heat or cold, in person’s primary place of residence.
Appendix 9.2

Equipment currently funded by CAEP

- **Mobility** e.g. wheelchairs
- **Seating** e.g. inserts and modified chairs
- **Positioning** e.g. positioning boards and wedges
- **Orthoses** e.g. splints, surgical footwear
- **Prostheses** e.g. wigs
- **Transfer Aids** e.g. hoists and transfer boards
- **Bed Equipment** e.g. bed rails
- **Personal Care Items** e.g. commodes
- **Home Modifications and Installations**
- **Communication** e.g. switches and devices
Appendix 9.3

ASSISTIVE TECHNOLOGY CATEGORIES

Communication Aids
- Speech and Augmentative Communication Aids
- Writing and Typing Aids

Computer Access Aids
- Alternative Input Devices
- Alternative Output Devices
- Accessible Software
- Universal Design

Daily Living Aids
- Clothing and Dressing Aids
- Eating and Cooking Aids
- Home Maintenance Aids
- Toileting and Bathing Aids

Education and Learning Aids
- Cognitive Aids
- Early Intervention Aids

Environmental Aids
- Environmental Controls and Switches
- Home-Workplace Adaptations

Ergonomic Equipment

Hearing and Listening Aids

Mobility and Transportation Aids
- Ambulation Aids
- Scooters and Power Chairs
- Wheelchairs
- Vehicle Conversions

Prosthetics and Orthotics

Recreation and Leisure Aids
- Sports Aids
- Toys and Games
- Travel Aids

Seating and Positioning Aids

Vision and Reading Aids

Services
Appendix 9.4

Bank of Subject headings and keywords used in literature search

<table>
<thead>
<tr>
<th>A. POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disabled</td>
</tr>
<tr>
<td>Disability</td>
</tr>
<tr>
<td>Disab*</td>
</tr>
<tr>
<td>Independent living</td>
</tr>
<tr>
<td>Impaired</td>
</tr>
<tr>
<td>Impairment</td>
</tr>
<tr>
<td>Impair*</td>
</tr>
<tr>
<td>Physically challenged</td>
</tr>
<tr>
<td>Activity restriction</td>
</tr>
<tr>
<td>Immobility</td>
</tr>
<tr>
<td>Immobil*</td>
</tr>
<tr>
<td>Severe restriction</td>
</tr>
<tr>
<td>Profound restriction</td>
</tr>
<tr>
<td>“Assistance with core activity”</td>
</tr>
<tr>
<td>Improve* function*</td>
</tr>
<tr>
<td>Disabled/</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. INTERVENTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technology</td>
</tr>
<tr>
<td>Technol*</td>
</tr>
<tr>
<td>Technological innovations</td>
</tr>
<tr>
<td>Assistive technology</td>
</tr>
<tr>
<td>Adaptive technology</td>
</tr>
<tr>
<td>Equipment</td>
</tr>
<tr>
<td>“Supplies and equipment”</td>
</tr>
<tr>
<td>Independent living equip*</td>
</tr>
<tr>
<td>Medical equip*</td>
</tr>
<tr>
<td>Assistive equipment</td>
</tr>
<tr>
<td>Aids</td>
</tr>
<tr>
<td>Aid*</td>
</tr>
<tr>
<td>Communication aids</td>
</tr>
<tr>
<td>Daily living aids</td>
</tr>
<tr>
<td>Environmental aids</td>
</tr>
<tr>
<td>Computer access aids</td>
</tr>
<tr>
<td>Transfer aids</td>
</tr>
<tr>
<td>Material aids</td>
</tr>
<tr>
<td>Hearing aids</td>
</tr>
<tr>
<td>Mobility aids</td>
</tr>
<tr>
<td>Transport* aids</td>
</tr>
<tr>
<td>“Seating and positioning aids”</td>
</tr>
<tr>
<td>“Vision and reading aids”</td>
</tr>
<tr>
<td>Listening aids</td>
</tr>
<tr>
<td>“Recreational and leisure aids”</td>
</tr>
<tr>
<td>Self care aids</td>
</tr>
<tr>
<td>Devices</td>
</tr>
<tr>
<td>Assistive devices</td>
</tr>
<tr>
<td>Health devices</td>
</tr>
<tr>
<td>Low-tech devices</td>
</tr>
<tr>
<td>High-tech devices</td>
</tr>
</tbody>
</table>
C. COMPARISON

<table>
<thead>
<tr>
<th>Fund</th>
<th>Funds</th>
<th>Funding</th>
<th>Fund*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Philanthropic fund*</td>
<td>Commercial fund*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public fund*</td>
<td>Private fund*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited fund*</td>
<td>Funding policy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding system</td>
<td>Funding issue*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding stream</td>
<td>Effectiveness of fund*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Cost*
Economic*
Payment*
Budget*
Purchas*
Sponsor*
Money

Costs and cost analysis
Cost benefit

financial support/
financing, organized/
funding source/
Fund raising/
Financing, government/
Grants/
Public policy/
Public assistance/
Cost benefit analysis/
"costs and costs analysis"/
Health care costs/
Rehabilitation/ec
Economic aspects of illness/
outpatient service/ec
Cost savings/

health services purchasing/
health resource utilization/
Health resource allocation/

Medicaid/
D. OUTCOME

Best practice
Evidence based
Quality of life
Improved functioning
Activities of daily living
Independence
Autonomy
Unmet need*

Quality of life/
Outcomes (health care)/ev
Consumer satisfaction/
Consumer attitude/
## Appendix 9.5

Comments on quality of life – Grant recipient perspective

<table>
<thead>
<tr>
<th>Health</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased stress and tempers, generally better health</td>
<td>9</td>
</tr>
<tr>
<td>Independence makes me mentally happy</td>
<td>5</td>
</tr>
<tr>
<td>Stabilised blood sugar and muscle weakness, controlled epilepsy</td>
<td>4</td>
</tr>
<tr>
<td>Better health and control of my body, less infection and dehydration</td>
<td>4</td>
</tr>
<tr>
<td>Improved sleeping at night and in the afternoon</td>
<td>3</td>
</tr>
<tr>
<td>Can now read correspondence</td>
<td>3</td>
</tr>
<tr>
<td>Helped breathing</td>
<td>2</td>
</tr>
<tr>
<td>Helps temperature control</td>
<td>2</td>
</tr>
<tr>
<td>Saves my and families back as don’t have to lift the wheelchair</td>
<td>2</td>
</tr>
<tr>
<td>Good</td>
<td>2</td>
</tr>
<tr>
<td>Increased independence</td>
<td></td>
</tr>
<tr>
<td>Relieved chest complaints</td>
<td></td>
</tr>
<tr>
<td>Solved humidity problems</td>
<td></td>
</tr>
<tr>
<td>Decreased spasms and increased comfort</td>
<td></td>
</tr>
<tr>
<td>Wonderful</td>
<td></td>
</tr>
<tr>
<td>Decreased driving stress</td>
<td></td>
</tr>
<tr>
<td>Feel 50% better have something to live for.</td>
<td></td>
</tr>
<tr>
<td>Can now exercise on walking machine all year round</td>
<td></td>
</tr>
<tr>
<td>Can now sit with family at table</td>
<td></td>
</tr>
<tr>
<td>Positive especially at night</td>
<td></td>
</tr>
<tr>
<td>Stimulated my brain</td>
<td></td>
</tr>
<tr>
<td>More comfort</td>
<td></td>
</tr>
<tr>
<td>Relaxation and sleep better, decreased discomfort from allergic reactions</td>
<td></td>
</tr>
<tr>
<td>More relaxed</td>
<td></td>
</tr>
<tr>
<td>More content to be on my own</td>
<td></td>
</tr>
<tr>
<td>Helps to avoid decline in overall attitude, feel not isolated from society</td>
<td></td>
</tr>
<tr>
<td>Assist MS remain in remission</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal Goals</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence and confidence</td>
<td>12</td>
</tr>
<tr>
<td>Do more computer work eg. memoirs</td>
<td>6</td>
</tr>
<tr>
<td>Read more</td>
<td>4</td>
</tr>
<tr>
<td>Volunteer work</td>
<td>2</td>
</tr>
<tr>
<td>Can think about a career</td>
<td></td>
</tr>
<tr>
<td>Study books and keep in touch with family via email</td>
<td></td>
</tr>
<tr>
<td>Study at ECU and home</td>
<td></td>
</tr>
<tr>
<td>More active in the community</td>
<td></td>
</tr>
<tr>
<td>Keep healthy</td>
<td></td>
</tr>
<tr>
<td>Walk as often as possible</td>
<td></td>
</tr>
<tr>
<td>Energy to do things</td>
<td></td>
</tr>
<tr>
<td>More incentive eg. collect mail</td>
<td></td>
</tr>
<tr>
<td>Live comfortably in own home</td>
<td></td>
</tr>
<tr>
<td>Live long with wife</td>
<td></td>
</tr>
<tr>
<td>Buy house with airconditioning or take mine with me</td>
<td></td>
</tr>
<tr>
<td>Carer be more loving, better and supportive parent</td>
<td></td>
</tr>
<tr>
<td>Do more as less tired</td>
<td></td>
</tr>
<tr>
<td>Can now set future goals and continue with current activities</td>
<td></td>
</tr>
<tr>
<td>Manage condition better</td>
<td></td>
</tr>
<tr>
<td>Do farm jobs successfully</td>
<td></td>
</tr>
<tr>
<td>Pay bills on time</td>
<td></td>
</tr>
<tr>
<td>To feel more cheerful</td>
<td></td>
</tr>
<tr>
<td>Sing recite, do talks at ladies meetings</td>
<td></td>
</tr>
<tr>
<td>Upgrade to a new and better piece of equipment</td>
<td></td>
</tr>
<tr>
<td>Continue interests – now stimulated</td>
<td></td>
</tr>
<tr>
<td><strong>Home</strong></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Can now read books, recipes, keep in touch, read important information</td>
<td>16</td>
</tr>
<tr>
<td>Comfortable</td>
<td>9</td>
</tr>
<tr>
<td>More independent don’t have to ask for help</td>
<td>5</td>
</tr>
<tr>
<td>More energy to get things done</td>
<td>3</td>
</tr>
<tr>
<td>Can assist in home tasks eg. cooking, pottering, gardening</td>
<td>3</td>
</tr>
<tr>
<td>More freedom and independence</td>
<td>2</td>
</tr>
<tr>
<td>Run errands</td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td></td>
</tr>
<tr>
<td>Cooler</td>
<td></td>
</tr>
<tr>
<td>Continue to be active and independent</td>
<td></td>
</tr>
<tr>
<td>Managing well</td>
<td></td>
</tr>
<tr>
<td>Communicate family and friends via email</td>
<td></td>
</tr>
<tr>
<td>Cope better with children’s needs</td>
<td></td>
</tr>
<tr>
<td>Decreased stress</td>
<td></td>
</tr>
<tr>
<td>Buy goods on internet</td>
<td></td>
</tr>
<tr>
<td>Easy temperature control</td>
<td></td>
</tr>
<tr>
<td>Mental alertness and quality time has greatly increased</td>
<td></td>
</tr>
<tr>
<td>Looks like normal furniture</td>
<td></td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td></td>
</tr>
<tr>
<td>More community social activities e.g attend shopping centres as its safer and not stuck at home</td>
<td>10</td>
</tr>
<tr>
<td>Very strong enables continued working for the community and being active e.g. volunteer mentor and art teacher, printing tickets for retirement local club</td>
<td>5</td>
</tr>
<tr>
<td>More involved in groups eg. writing newsletter for local community</td>
<td>2</td>
</tr>
<tr>
<td>Now have increased awareness , read local news, minutes of meetings</td>
<td>2</td>
</tr>
<tr>
<td>Able to run strata affairs in home units</td>
<td></td>
</tr>
<tr>
<td>Maintain mobility and independence</td>
<td></td>
</tr>
<tr>
<td>Now attend dad’s playgroup weekly</td>
<td></td>
</tr>
<tr>
<td>Borrow books from local library</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td></td>
</tr>
<tr>
<td><strong>Family and Friends</strong></td>
<td></td>
</tr>
<tr>
<td>More mobile to visit and to network</td>
<td>6</td>
</tr>
<tr>
<td>Good better</td>
<td>5</td>
</tr>
<tr>
<td>Improved due to decreased dependency. Don’t rely on them to help</td>
<td>3</td>
</tr>
<tr>
<td>More contact e.g. email connection</td>
<td>3</td>
</tr>
<tr>
<td>Enjoying activities and relationships with friends</td>
<td></td>
</tr>
<tr>
<td>Talk more and alert to visitors – not sleeping in bed</td>
<td>2</td>
</tr>
<tr>
<td>Easier letter writing – able to check spelling errors and read of letters</td>
<td>2</td>
</tr>
<tr>
<td>Positive outcomes</td>
<td>2</td>
</tr>
<tr>
<td>Less tired</td>
<td></td>
</tr>
<tr>
<td>Talk about joy of driving with family and friends</td>
<td></td>
</tr>
<tr>
<td>Reduced stress on carer re my health</td>
<td></td>
</tr>
<tr>
<td>Improved due to decrease in mood swings</td>
<td></td>
</tr>
<tr>
<td>Decreased stress helped relationships. Other children happier to visit – increased social relationships</td>
<td></td>
</tr>
<tr>
<td>Hoist means more outings with family and friends who have the confidence in my safety</td>
<td></td>
</tr>
<tr>
<td>Communicating and interacting more frequently with both written/photographic and renewed friendships</td>
<td></td>
</tr>
<tr>
<td>Family can now help, less of a chore moving from bed to chair</td>
<td></td>
</tr>
<tr>
<td><strong>Work and Education</strong></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Get to study eg. ECU, TAFE</td>
<td>4</td>
</tr>
<tr>
<td>Maintain knowledge base using computer and print magnification</td>
<td>2</td>
</tr>
<tr>
<td>Enabled me to achieved satisfactory clerical position</td>
<td></td>
</tr>
<tr>
<td>More alert and brighter at school and making progress</td>
<td></td>
</tr>
<tr>
<td>Homework done better sleep better and more alert</td>
<td></td>
</tr>
<tr>
<td>Improved reading and spelling</td>
<td></td>
</tr>
<tr>
<td>Assisted school work tremendously</td>
<td></td>
</tr>
<tr>
<td>Now have the energy to apply for computer from TADWA to learn how to use it.</td>
<td></td>
</tr>
<tr>
<td>Read articles and do voluntary work in schools</td>
<td></td>
</tr>
<tr>
<td>Email and internet opens new options</td>
<td></td>
</tr>
<tr>
<td>Do volunteer work for fisheries in comfort</td>
<td></td>
</tr>
<tr>
<td>Bible study programmes</td>
<td></td>
</tr>
<tr>
<td>Now drive to work and transport others</td>
<td></td>
</tr>
<tr>
<td>Mum transport me to/fro school – more convenient than using taxi’s</td>
<td></td>
</tr>
<tr>
<td>Better</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Leisure</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased book reading, newspapers</td>
<td>6</td>
</tr>
<tr>
<td>Get to entertainment more easily</td>
<td>4</td>
</tr>
<tr>
<td>Enjoying new activities meeting new groups, taking leisurely drives</td>
<td>3</td>
</tr>
<tr>
<td>Can now paint, watch tv, videos and DVD’s</td>
<td>2</td>
</tr>
<tr>
<td>More positive, better</td>
<td>2</td>
</tr>
<tr>
<td>Maintain outside activities in summer as I can come home to a cool house</td>
<td>2</td>
</tr>
<tr>
<td>Enjoy more</td>
<td></td>
</tr>
<tr>
<td>Do activities in comfort and aircon aids concentration</td>
<td></td>
</tr>
<tr>
<td>Now join in more social activities</td>
<td></td>
</tr>
<tr>
<td>Enjoy computer type leisure</td>
<td></td>
</tr>
<tr>
<td>Graphics on computer much easier to see</td>
<td></td>
</tr>
<tr>
<td>More leisure time with mum instead of at University</td>
<td></td>
</tr>
<tr>
<td>Easier to read plans for model truck and trailer</td>
<td></td>
</tr>
<tr>
<td>Helped sculpture and artwork greatly</td>
<td></td>
</tr>
<tr>
<td>Access to information eg. reading public transport timetables, events and notices</td>
<td></td>
</tr>
<tr>
<td>Out each evening not reliant on transport help</td>
<td></td>
</tr>
<tr>
<td>Can go on family outings with electric chair, have greater independence</td>
<td></td>
</tr>
<tr>
<td>Feel more secure in going and doing what I want now</td>
<td></td>
</tr>
</tbody>
</table>
### Health

<table>
<thead>
<tr>
<th>Health</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response</td>
<td>5</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
</tr>
<tr>
<td>Health more stable</td>
<td>3</td>
</tr>
<tr>
<td>Air conditioning assists control of epilepsy especially during summer</td>
<td>2</td>
</tr>
<tr>
<td>Cope better with health conditions</td>
<td>2</td>
</tr>
<tr>
<td>Sleeping better</td>
<td>2</td>
</tr>
<tr>
<td>Air conditioning assisted health comfort greatly</td>
<td></td>
</tr>
<tr>
<td>Decreased stress with respite from heat much improved</td>
<td></td>
</tr>
<tr>
<td>Adaptive technology – can now see medication</td>
<td></td>
</tr>
<tr>
<td>AAC improved well being and subsequent behaviour</td>
<td></td>
</tr>
<tr>
<td>Vehicle modification improved psychosocial health greatly through community access</td>
<td></td>
</tr>
<tr>
<td>Mobility easier</td>
<td></td>
</tr>
</tbody>
</table>

### Home

<table>
<thead>
<tr>
<th>Home</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response</td>
<td>10</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
</tr>
<tr>
<td>Function in home improved to do tasks and resting better (air conditioning)</td>
<td>3</td>
</tr>
<tr>
<td>Improved mobility (air conditioning)</td>
<td>2</td>
</tr>
<tr>
<td>Huge improvement, whole family benefits, client not irritable and can rest comfortably (air conditioning)</td>
<td></td>
</tr>
<tr>
<td>Decreased stress for carers (air conditioning, vehicle modifications)</td>
<td></td>
</tr>
<tr>
<td>Assists access to health professionals (vehicle modifications)</td>
<td></td>
</tr>
<tr>
<td>Manage own business and care for selves longer, staying independent longer (Assistive technology and vehicle modifications)</td>
<td></td>
</tr>
<tr>
<td>Assists in clients care and being maintained at home (AAC)</td>
<td></td>
</tr>
</tbody>
</table>

### Work and Education

<table>
<thead>
<tr>
<th>Work and Education</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response</td>
<td>14</td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
</tr>
<tr>
<td>Increased opportunities - ability to access work/education (vehicle modification, air conditioning)</td>
<td>2</td>
</tr>
<tr>
<td>Better sleep/rest assists energy levels to participate in work/education if desired (air conditioning)</td>
<td></td>
</tr>
<tr>
<td>Enabled one person to remain gainfully employed part time (vehicle modification)</td>
<td></td>
</tr>
<tr>
<td>Allows people to job search, be more competitive, increase skill/independence and allows many to undertake study (adaptive technology, vehicle modification)</td>
<td></td>
</tr>
</tbody>
</table>

### Family and Friends

<table>
<thead>
<tr>
<th>Family and Friends</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response</td>
<td>11</td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
</tr>
<tr>
<td>Stable (air conditioning)</td>
<td></td>
</tr>
<tr>
<td>Less cranky (air conditioning)</td>
<td></td>
</tr>
<tr>
<td>Improved significantly, mood swings associated with discomfort and fatigue eliminated (air conditioning)</td>
<td></td>
</tr>
<tr>
<td>Decreased stress in families and promotes family communication (air conditioning)</td>
<td></td>
</tr>
<tr>
<td>More confidence and greater ability to interact (vehicle modifications, air conditioning)</td>
<td></td>
</tr>
<tr>
<td>Satisfaction in being able to transport child safely in community with family (vehicle modifications)</td>
<td></td>
</tr>
<tr>
<td>Get out see new things and mix more (vehicle modifications)</td>
<td></td>
</tr>
<tr>
<td>More interaction with community (vehicle modifications)</td>
<td></td>
</tr>
<tr>
<td>Less reliant on others to read, frees up carers/neighbours family and friends time (adaptive technology)</td>
<td></td>
</tr>
<tr>
<td>Leisure</td>
<td>Community</td>
</tr>
<tr>
<td>------------------------------</td>
<td>--------------------------------</td>
</tr>
<tr>
<td>No response</td>
<td>No response</td>
</tr>
<tr>
<td>Assisted greatly in activities at home (air conditioning)</td>
<td>Increased ability to access (vehicle modification)</td>
</tr>
<tr>
<td>Allows friends to visit and want to interact (air conditioning)</td>
<td>Greatly assists (vehicle modification, air conditioning, AAC)</td>
</tr>
<tr>
<td>Increased opportunities (air conditioning, vehicle modification)</td>
<td>Decreased stress involved in planning outings vehicle modification)</td>
</tr>
<tr>
<td>Greatly assists (vehicle modification, air conditioning, AAC)</td>
<td>Increased (vehicle modification)</td>
</tr>
<tr>
<td>Gave one person back independence to visit friends, shop and attend community groups (v/m)</td>
<td>Keep up community roles eg. church, clubs sports, despite vision impairment (adaptive technology)</td>
</tr>
<tr>
<td>Greater involvement in community (vehicle modification)</td>
<td></td>
</tr>
<tr>
<td>Endless uses reading, crafts, computing, letter writing etc (adaptive technology)</td>
<td></td>
</tr>
<tr>
<td>Increased options (vehicle modification)</td>
<td></td>
</tr>
<tr>
<td>Playground equipment accessible by broad range of children with disabilities</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 9.7

#### Comments on quality of Life – Family/Carer perspective

<table>
<thead>
<tr>
<th><strong>Health</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased stress levels</td>
<td>6</td>
</tr>
<tr>
<td>Have a bad back now life is easier</td>
<td>6</td>
</tr>
<tr>
<td>Life a bit easier</td>
<td>4</td>
</tr>
<tr>
<td>No change</td>
<td>3</td>
</tr>
<tr>
<td>Wonderful</td>
<td>3</td>
</tr>
<tr>
<td>Relaxed better health</td>
<td>2</td>
</tr>
<tr>
<td>Better sleep</td>
<td>2</td>
</tr>
<tr>
<td>Don’t have to take daughter to doctors so much</td>
<td></td>
</tr>
<tr>
<td>Mental state improved don’t help in out of the car</td>
<td></td>
</tr>
<tr>
<td>Wife less tired great help</td>
<td></td>
</tr>
<tr>
<td>More time for myself</td>
<td></td>
</tr>
<tr>
<td>Everything super</td>
<td></td>
</tr>
<tr>
<td>Protects my back</td>
<td></td>
</tr>
<tr>
<td>Health generally improved</td>
<td></td>
</tr>
<tr>
<td>Improved my asthma</td>
<td></td>
</tr>
<tr>
<td>Chest cleared no longer using wood burning fire</td>
<td></td>
</tr>
<tr>
<td>Peace of mind</td>
<td></td>
</tr>
<tr>
<td>More comfortable</td>
<td></td>
</tr>
<tr>
<td>More peaceful</td>
<td></td>
</tr>
<tr>
<td>See more</td>
<td></td>
</tr>
<tr>
<td>Less frustration</td>
<td></td>
</tr>
<tr>
<td>Great relief</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Personal Goals</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Continue working towards child/wife being independent</td>
<td>4</td>
</tr>
<tr>
<td>Make life good as can be for wife/son</td>
<td>2</td>
</tr>
<tr>
<td>Nil no impact</td>
<td></td>
</tr>
<tr>
<td>Can now consider activities for self as I have more time and work more hours at p/t job</td>
<td></td>
</tr>
<tr>
<td>To get a job</td>
<td></td>
</tr>
<tr>
<td>Able to set personal goals as life has become manageable</td>
<td></td>
</tr>
<tr>
<td>Now able to have some goals and ‘me’ time</td>
<td></td>
</tr>
<tr>
<td>Able to do other things</td>
<td></td>
</tr>
<tr>
<td>Stay positive and keep an open mind</td>
<td></td>
</tr>
<tr>
<td>Gain confidence in activities outside the house and at home positive</td>
<td></td>
</tr>
<tr>
<td>To be healthy and look after my disabled child</td>
<td></td>
</tr>
<tr>
<td>Care for husband as long as possible</td>
<td></td>
</tr>
<tr>
<td>Assist couple stay in their own home as long as possible</td>
<td></td>
</tr>
<tr>
<td>Continue in caring role</td>
<td></td>
</tr>
<tr>
<td>Get daughter walking</td>
<td></td>
</tr>
<tr>
<td>Remain independent on farmlet as long as possible</td>
<td></td>
</tr>
<tr>
<td>Stay well and enjoy grandchildren growing up</td>
<td></td>
</tr>
<tr>
<td>Start incorporating husband into family life again (a/c)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Work and Education</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not appropriate</td>
<td>2</td>
</tr>
<tr>
<td>Nil affects</td>
<td>3</td>
</tr>
<tr>
<td>Better environment to do it in</td>
<td>2</td>
</tr>
<tr>
<td>Now get to work on time</td>
<td></td>
</tr>
<tr>
<td>Non drowsiness at work and university</td>
<td></td>
</tr>
<tr>
<td>My sons independence in transport will enable me to seek work or further education</td>
<td></td>
</tr>
<tr>
<td>Not into it yet</td>
<td></td>
</tr>
<tr>
<td><strong>Home</strong></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Made easy for me</td>
<td>4</td>
</tr>
<tr>
<td>Life more comfortable for all</td>
<td>3</td>
</tr>
<tr>
<td>More freedom don’t have to be available to assist, read letters etc</td>
<td>2</td>
</tr>
<tr>
<td>More time to complete tasks at home</td>
<td></td>
</tr>
<tr>
<td>More pleasant to do all therapies</td>
<td></td>
</tr>
<tr>
<td>More relaxed less concerned for husbands breathing</td>
<td></td>
</tr>
<tr>
<td>Feel brighter more alert, gain confidence day to day living</td>
<td></td>
</tr>
<tr>
<td>Helped my sight</td>
<td></td>
</tr>
<tr>
<td>Spend more time with daughter in comfort</td>
<td></td>
</tr>
<tr>
<td>Easier making joint decisions with husband as he can read for himself</td>
<td></td>
</tr>
<tr>
<td>More time to be independent of husband</td>
<td></td>
</tr>
<tr>
<td>Can now step back and let daughter take more control</td>
<td></td>
</tr>
<tr>
<td>Children don’t have to be kept as quiet therefore decrease in stress to all</td>
<td></td>
</tr>
<tr>
<td>Furniture blends in doesn’t look like hospital</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Family and Friends</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not appropriate</td>
<td>3</td>
</tr>
<tr>
<td>Good and excellent</td>
<td>9</td>
</tr>
<tr>
<td>See more of them more frequency ie. Other children and grandchildren</td>
<td>2</td>
</tr>
<tr>
<td>More enjoyable relationship with daughter</td>
<td></td>
</tr>
<tr>
<td>Less stress better relationships</td>
<td></td>
</tr>
<tr>
<td>Family now travel as unit</td>
<td></td>
</tr>
<tr>
<td>Life is fuller</td>
<td></td>
</tr>
<tr>
<td>Involved in community and social activities</td>
<td></td>
</tr>
<tr>
<td>Freedom, less restrictions on us</td>
<td></td>
</tr>
<tr>
<td>Can discuss daughters school progress now she can read information</td>
<td></td>
</tr>
<tr>
<td>Can be taken places by my son</td>
<td></td>
</tr>
<tr>
<td>People now visiting again due to improvement in depression</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Leisure</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not applicable</td>
<td>4</td>
</tr>
<tr>
<td>Nil effects, no time F?T carer</td>
<td>3</td>
</tr>
<tr>
<td>Go out anytime</td>
<td></td>
</tr>
<tr>
<td>Never had time in past 8 years can now consider</td>
<td></td>
</tr>
<tr>
<td>Much safer to transport</td>
<td></td>
</tr>
<tr>
<td>Daughter can now go out with us without too much trouble now we have the hoist</td>
<td></td>
</tr>
<tr>
<td>Daughter now starting to join me in hobbies during the day and I enjoy this</td>
<td></td>
</tr>
<tr>
<td>Enjoy gardening activities with husband. I work he watches</td>
<td></td>
</tr>
<tr>
<td>Air con helps when I come back from the gym</td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td></td>
</tr>
<tr>
<td>Able to share things like photos with mother</td>
<td></td>
</tr>
<tr>
<td>Able to do own thing</td>
<td></td>
</tr>
<tr>
<td>Priority</td>
<td>Past/Current Funding</td>
</tr>
<tr>
<td>----------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Electric beds</td>
<td>Not funded since 1996 – except more non-profit/hospital, expensive to hire in private sector. Not for hire (eg by ILC). Variety has occasionally funded for children. EFL (Equipment for living) program providing some short term funding grants – look at demographic information.</td>
</tr>
<tr>
<td>Equipment for Commonwealth-funded consumers – for individuals needs eg. Mobility, seating and QOL</td>
<td>Not funded – never has been? Gaping hole people are isolated within the nursing home environment</td>
</tr>
<tr>
<td>Short term to medium/short life /changing needs (eg, addressed by hire?) Maintenance, tracking and recycling issues.</td>
<td>ILC Hire, private (cost x4, no expertise) hospital has post-op responsibility, some CAEP, TADWA – recycles (don’t have expertise to prescribe but in other states they do), non CAEP get nothing</td>
</tr>
<tr>
<td>Old/unused equipment – other than CAEP</td>
<td>Quokka, Sunday Times, Privately purchased (swap meets) Lotterywest Recycling problem as equipment is gifted although people advised that they can return equipment to funding agency for recycling.</td>
</tr>
<tr>
<td>Car seats and restraints – adults and children</td>
<td>Nowhere – used to be CAEP: 1999/2000 (stopped because not used in the home) Legal problems/policy/nursing homes. Variety has funded for children.</td>
</tr>
<tr>
<td>Medical equipment (suction, continence, specialised feeding)</td>
<td>Some hospitals have loan equipment old large &amp; noisy. Variety has funded portable ones for chln.. PMH-DSC-DCD(Dept of Community Dev’t. Three way agreement: “CATCH” – technically dependent children (could generate savings!) High Spinal cord/head injury – problems</td>
</tr>
<tr>
<td>Priority</td>
<td>Past/Current Funding</td>
</tr>
<tr>
<td>---------</td>
<td>---------------------</td>
</tr>
<tr>
<td>“Quality of life” equipment - recreational and communication (not voice) as well as environmental controls ✓ ✓</td>
<td>Some Homeswest (eg, switches manage the door independently but not for carers)</td>
</tr>
<tr>
<td>Basic communication systems/devices eg, being able to write to other people or reading aids to access books (ie can’t hold book, vision impaired)</td>
<td>Environmental controls eg, safety and security (safety issues here re leaving doors unlocked for carers to access as disabled person can’t open and close),</td>
</tr>
<tr>
<td>Environmental controls eg, safety and security</td>
<td>Occasional CAEP if considered to be basic and essential. resale market, links to ageing…hire? and recycle</td>
</tr>
<tr>
<td>Rotary/service clubs</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Electric recliner/lift chairs</td>
<td>Not funded</td>
</tr>
<tr>
<td>standing equipment for people who are Non-CAEP eligible eg Easy-stand</td>
<td>Rarely– same ‘package’ (Aged Care EACH) agencies ie, HACC</td>
</tr>
<tr>
<td>Some donations; portable hoists provided by CAEP for unpaid carers</td>
<td>Commonwealth</td>
</tr>
<tr>
<td>Agency required hoists in home</td>
<td></td>
</tr>
<tr>
<td>Priority</td>
<td>Past/Current Funding</td>
</tr>
<tr>
<td>------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td><strong>Two ticks</strong></td>
<td></td>
</tr>
<tr>
<td>Quality of life equipment</td>
<td></td>
</tr>
<tr>
<td>2nd mobility aid</td>
<td></td>
</tr>
<tr>
<td>Car seats and restraints</td>
<td></td>
</tr>
<tr>
<td><strong>One Tick</strong></td>
<td></td>
</tr>
<tr>
<td>Electric beds</td>
<td></td>
</tr>
<tr>
<td>Low income, non-CAEP eligible people</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Continence</th>
<th>CAS – Commonwealth – covers 16 – 65 State – then Lotterywest (but stepped in) for 3 – 16 yrs), PADP, eg NT!</th>
<th>Funding for Over 65- commonwealth Existing under-funding – Commonwealth State supplementary? Explore PADP funding in NT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respirator consumables</td>
<td>3 months post discharge only – then $70/week No funding</td>
<td>Cost benefit for Health Dept ILC type service eg. Plastic?</td>
</tr>
<tr>
<td>Low income, non-CAEP eligible people</td>
<td>Financial hardship often not used (choice?) People often fiercely independent and don’t to give details Disadvantage of working! Some Lotterywest (for those eligible)</td>
<td>Program issue</td>
</tr>
<tr>
<td>Specifying /assessing/CAEP future</td>
<td>Health for Health, CAEP DSC for CAEP NGO, (private). Problems for people aren’t linked with an agency. CAEP scheme there is a gap within those waiting as there art two waiting lists • Waiting for specification • Waiting for funding</td>
<td>Principle: can’t have care without the other. Need to build in assessment as part of the process costs etc</td>
</tr>
<tr>
<td>Infrastructure for future programs</td>
<td>Special grant programs/one-off – Lottery grants Rotary, Lions DVA</td>
<td>Lotterywest?</td>
</tr>
<tr>
<td>Second piece of mobility equipment eg. wheelchair and scooters/w/chairs for community use.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 10.0 Glossary

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT</td>
<td>Assistive Technology</td>
</tr>
<tr>
<td>AAC</td>
<td>Augmentative and Alternative Communication</td>
</tr>
<tr>
<td>ACROD</td>
<td>Australian Council on Disability</td>
</tr>
<tr>
<td>CAEP</td>
<td>Community Aids and Equipment Program</td>
</tr>
<tr>
<td>DSC</td>
<td>Disability Services Commission</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>EFL</td>
<td>Equipment for Living Grants (State Government one off funding)</td>
</tr>
<tr>
<td>ILC</td>
<td>Independent Living Centre</td>
</tr>
<tr>
<td>LAC</td>
<td>Local Area Coordinator</td>
</tr>
<tr>
<td>LWDEG</td>
<td>Lotterywest Disability Equipment Grant</td>
</tr>
<tr>
<td>LWDEGMP</td>
<td>Lotterywest Disability Equipment Grant Management Program</td>
</tr>
<tr>
<td>MND</td>
<td>Motor Neurone Disease</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>PADP</td>
<td>Program of Appliances for Disabled People</td>
</tr>
<tr>
<td>SAG</td>
<td>Sector Advisory Group</td>
</tr>
<tr>
<td>VA&amp;EP</td>
<td>Victorian Aids and Equipment Program</td>
</tr>
<tr>
<td>WA</td>
<td>Western Australia</td>
</tr>
</tbody>
</table>