Assistive technology solutions
as mediators of equal outcomes for people
living with disability

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Doctor of Philosophy

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This thesis owes its existence to many supporters.

My fellow explorers in this life of human diversity: the members of the Aids and Equipment Action Alliance and the individuals who participated in The Equipping Inclusion Studies.

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This thesis is for my father Udo, who is my inspiration, and my mother Beverley, who is my unflagging supporter.

I thank you David for being my rock, and James and Charlotte, who have lived with this for a good part of their lives and encouraged me every step of the way.

Finally, the academics, occupational therapists and AT practitioners who have taught and mentored me over my career: how fortunate I am to have known you all.

This thesis was professionally edited by Dr Margaret Johnson of The Book Doctor, to whom I am grateful for her calmness, meticulous support and sense of humour.
Publications related to this study


Abstract

The thesis is concerned with equality of outcome for Australians living with impairment. From my standpoint as a practicing occupational therapist, assistive technology (AT) and environmental interventions (EI) as well as personal care or support (PC) can bring about equal outcomes by mediating the ‘gap’ caused by the effects of impairment and/or disabling environments. Despite the efficacy of these strategies, a range of pragmatic constraints limit their effective provision. Three key inquiry areas, each with a set of research questions, have emerged from my practice:

1. How are impairment and disability understood?
   1a. In what ways is disability different from the absence of disability?
   1b. Does the presence of impairment or disability impact upon people’s life aspirations?
   1c. What is the role of impairment effects and environmental barriers in creating disablement?

2. How do mediators bring about outcomes?
   2a. Which strategies mediate impairment effects and disabling environmental barriers, and what relationship do they have to each other?
   2b. What is the effectiveness of identified mediators?

3. What is the social contract between society and its citizens with impairments?
   3a. How effective is government in delivering equality of outcome through the provision of mediators?
   3b. What does government need to do to realise its obligations?

The thesis intent is to generate useful knowledge with which to lever change, and thus improve equality of outcome for individuals requiring mediators to live their lives.
METHOD: The perspective of individuals with impairments was sought to fill an evidence gap as to the actual outcomes of mediator provision within existing policy boundaries, and how this might be improved. Based on the premise that researchers should seek epistemologically just methodologies which validate and privilege the view of people living with impairment, the thesis utilised a participatory methodology, within an interpretive tradition. Literature reviews and conceptual analyses considered author standpoint and specifically sought material from the standpoints of those living with impairment. Empirical data were collected and analysed from a medium-scale, mixed-methods study conducted by myself and colleagues of 100 Victorians living with impairment and who used AT or other mediators in their daily lives. An AT policy case study investigated current policy on a number of levels, and identified a range of potential policy solutions.

FINDINGS: From a methodological perspective, the thesis demonstrates that people living with impairment have held a marginalised position in relation to the production of knowledge about them, and the delivery of services for them. Impairment and disability were found to be contested concepts, subject to socio-political forces. Contemporary disability theory, and the voices of study participants, presents a nuanced picture of life within the universal spectrum of human diversity, where people move in and out of independence/interdependence. Both impairment effects: that is, the embodied experience of human variation, as well as disablement brought about by societal structures, were found to be factors in the individualised experience of disability. The locus of disablement was demonstrated to occur in the space between individuals' capabilities, the tasks they aspire to, and the environments in which they operate.

The valued life outcomes and aspirations of people generally and people living with impairment specifically, were found to be the same. Equality of outcome was therefore identified as an important concept with which to evaluate the experiences for individuals using mediators such as AT. People living with impairment are likely to experience multiple costs of disability, a thinner margin of health, and high rates of poverty and social exclusion. Environmental barriers and the limited supply of mediators was found to magnify the experience of disablement. Without effective equity measures on the part of society, the thesis
findings show that most people with impairment experience key differences in their capacity to reach these outcomes, best described as ‘capability gaps’. Such factors contribute to the capability gap which renders outcomes less achievable than for the population generally.

The literature analyses, and empirical data from ‘The Equipment Study’, identified a range of interventions which mediate the effects of impairment and environmental barriers. Found to be effective in terms of participation, satisfaction with participation, ameliorating difficulty and saving a range of economic costs, the case is made for provision of key mediators AT, EI and PC in relation to each other, that is, in an AT solution.

Tailored provision of mediators in the form of AT solutions and inclusive community environs were demonstrated to narrow the capability gap, minimise the experience of disablement, and enable the achievement of, potentially equal, outcomes. At an individual level, the thesis demonstrates that AT solutions effectively mediate the effects of impairment such that people can participate in a range of life outcome areas. At an environmental level, a range of mediators were found to be effective in removing barriers and facilitating access for all.

Current government policy intent was found to align with key human rights tenets. Analysis of the empirical data against UN Convention on the Rights of Persons with Disabilities (CRPD) and social exclusion frameworks however demonstrates the realisation of this intent in AT service delivery falls short. Australia’s commitments in terms of the CRPD (United Nations 2006), and its own disability policy strategies across government demonstrably fail to deliver equal outcomes.

CONCLUSION: The conceptual and empirical studies conducted in the thesis led to a range of suggested policy solutions. These include adopting a universalised perspective of human variation; realigning policy goals with valued outcomes; enshrining flexible delivery of services and funding in the form of individualised support for AT solutions; and increasing and extending the role of a range of duty holders. These policy solutions are proposed to reconceptualise impairment within the social contract and to reframe the mediators which are effective in delivering the potential of equal outcomes.
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<th>Description</th>
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<tbody>
<tr>
<td>AAATE</td>
<td>Association for the Advancement of Assistive Technology in Europe</td>
</tr>
<tr>
<td>AAC</td>
<td>Augmentative and Alternative Communication</td>
</tr>
<tr>
<td>AQoL</td>
<td>Assessment of Quality of Life Measure</td>
</tr>
<tr>
<td>ABI</td>
<td>Acquired Brain Injury</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>A&amp;E</td>
<td>Aids and Equipment</td>
</tr>
<tr>
<td>A&amp;EP</td>
<td>Aids and Equipment Program</td>
</tr>
<tr>
<td>AEAA</td>
<td>Aids and Equipment Action Alliance</td>
</tr>
<tr>
<td>AIPC</td>
<td>Australian Institute for Primary Care</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>AQoL</td>
<td>Assessment of Quality of Life Measure</td>
</tr>
<tr>
<td>AS</td>
<td>Australian Standards</td>
</tr>
<tr>
<td>AT</td>
<td>Assistive Technology</td>
</tr>
<tr>
<td>BiPAP</td>
<td>Bivalve Positive Airway Pressure (machine)</td>
</tr>
<tr>
<td>CACP</td>
<td>Community Aged Care Package</td>
</tr>
<tr>
<td>CDC</td>
<td>Consumer-directed care</td>
</tr>
<tr>
<td>CPAP</td>
<td>Continuous Positive Airway Pressure (machine)</td>
</tr>
<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>DHS</td>
<td>Department of Human Services</td>
</tr>
<tr>
<td>EACH</td>
<td>Extended Aged Care Package</td>
</tr>
<tr>
<td>ECU</td>
<td>Environmental Control Unit</td>
</tr>
<tr>
<td>EI</td>
<td>Environmental Interventions</td>
</tr>
<tr>
<td>eFHROM</td>
<td>Electronic Functioning and Health Related Outcomes Module (AIHW)</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GPS</td>
<td>Global Positioning Device</td>
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<tr>
<td>HRQoL</td>
<td>Health-related Quality of Life</td>
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<tr>
<td>ICCPR</td>
<td>International Covenant on Civil and Political Rights</td>
</tr>
<tr>
<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
</tr>
<tr>
<td>ICER</td>
<td>Incremental Cost effectiveness Ratio</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<tr>
<td>ICT</td>
<td>Information and Communication Technology</td>
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<tr>
<td>ILC</td>
<td>Independent Living Centre</td>
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<td>ISO</td>
<td>International Standards Organisation</td>
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<tr>
<td>ISP</td>
<td>Individualised Support Package</td>
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<tr>
<td>QOL</td>
<td>Quality of Life</td>
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<tr>
<td>Acronym</td>
<td>Full Form</td>
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<tr>
<td>NDS</td>
<td>National Disability Strategy</td>
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<td>NGO</td>
<td>Non-government Organisation</td>
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<tr>
<td>PC</td>
<td>Personal Care or Support</td>
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<tr>
<td>PWD</td>
<td>People or Persons with Disability</td>
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<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
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<tr>
<td>TGA</td>
<td>Therapeutic Goods Act</td>
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<tr>
<td>TAD</td>
<td>Technical Aid to the Disabled</td>
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<tr>
<td>TTY</td>
<td>Teletypewriter</td>
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<tr>
<td>VAEP</td>
<td>Victorian Aids and Equipment Program</td>
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<tr>
<td>UPIAS</td>
<td>The Union of the Physically Impaired Against Segregation</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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Chapter 1: Introduction

The Problem

As a health professional I have spent my professional life working to mediate the effects of impairment for people living with disability or the effects of aging. I do not currently experience significant impairment myself, but subscribe to the view that human variation and changes over the lifespan is likely to bring varying experiences of disability and interdependence to us all.

In my occupational therapy practice across the health, disability and aging sectors, two key interventions are assistive technologies (AT, also known as assistive devices, or aids and equipment) and adapting the environment (specifically home modifications and community access, here termed EI or environmental interventions). The term ‘mediators’ will be used to collectively describe these interventions which impact upon, or mediate, the demands of tasks, impairment and/ or environments, to enable people living with impairment to participate more fully in life.

Despite the observed effectiveness of mediators, pragmatic constraints limit their availability to people living with disability, and prevent the realisation of good practice. These constraints, from my practitioner perspective, include wait lists, workloads, and the limited scope of practice imposed by the service setting. From a broader structural perspective, the primary constraint upon effective practice in the field of AT and EI would appear to be resourcing. There is a dissonance between promising government policy rhetoric, which appears to support adequate resourcing, and its delivery in practice, which does not. Essentially, the budget is insufficient to meet demand, resulting in programs that ration mediators (such as AT and EI), and program guidelines that exclude many individuals.

Different perspectives have informed my thinking about these issues, and I have found great value in seeking a diverse set of views to widen my horizon as a health professional. Key among these is the perspective of individuals living with impairments. Examining the views of people with disability reveals concerns not just about rationed resources but also about the seemingly narrow focus on
basic instrumental accomplishments or outcomes which is a feature of many funding programs. This limited focus raises broad questions as to the outcomes that people living with impairment are ‘afforded’ in terms of the social contract, and the outcomes to which they may have rights as citizens. As my colleagues living with disability point out, people generally do not define a successful day as one in which they manage to get out of bed in the morning. Such a basic outcome is important in that it may be fundamental to accomplishing anything else that day, but it does not represent the human endeavours to which citizens in general aspire. In practical terms, a mismatch is evident between potential outcomes of value to people (enacting family roles, participating in chosen leisure pursuits, volunteering and so on) and a very different set of outcomes (safety, function, independence) against which funding applications must be written to justify provision of AT and related mediators. In the words of one research participant, a retired physicist living with polio and post-polio syndrome,

Now that I need to use the manual wheelchair all the time, I can’t get it under the kitchen bench to make a cup of coffee as the drawers and cupboards are in the way. That’s really frustrating, because what I should be doing is working on the issue of carbon sequestration in the southern oceans. [S80]

Such problems raise fundamental ontological questions about impairment, disability, and what it is to be a citizen. While Australia’s broad policy and human rights context demonstrates a positive and inclusive vision for individuals living with impairments, there are substantial gaps between intent and realisation. Articulation of these gaps is emerging, with two contemporary Australian publications authored by people living with disability: Goggin and Newell’s 2005 Disability in Australia: Exposing a Social Apartheid; and the 2009 National People with Disabilities and Carers Council’s Shut Out report. These texts identify the role of society and the concept of a norm as major disabling factors in the lives of individuals living with impairments in Australia today. Both groups of author contend that the way in which issues are viewed, even the way in which ‘disability’ is viewed, greatly affects the analysis and framing of the issue, and of any potential solution. To illustrate:

If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses, and if the community was completely accepting and
accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have Spina Bifida. (National People with Disabilities and Carers Council 2009: 12)

From my perspective, mediators such as AT and EI are effective in a number of ways. At an individual level, AT and EI may mediate the effects of impairment such that people can get on with life (for example, whether you walk or wheel, you are still ‘mobilising’ to the destination). At an environmental level, mediators can remove barriers and create facilitators so all people have access: for example, kerb ramps and public civility may render a destination accessible to all. Theoretically, should environmental barriers exist, and should adequate or sufficient mediators not be available, the effects of impairment are magnified and the person experiences disablement; therefore, it appears that the locus of disablement occurs in the space between individuals’ capabilities, the tasks they aspire to, and the environments in which they exist.

These observations led me to consider what could be done to change the experience of disablement reported by Australians living with impairment, at any level. Given budgetary constraints, effecting change necessitates arguing strongly for effective resourcing of AT and EI. Despite emerging evidence of the cost effectiveness of AT provision, and despite promising policy rhetoric, actual program delivery is governed by discourses of welfare and rationing, and fails to enable optimal outcomes. There appear to be dissonances between the social contract underpinning the provision of support such as AT and EI within civil society, its articulation in policy, and its delivery in practice.

Others, particularly people living with disability and health professionals, have had similar experiences and observations to my own and have also sought change. These concerned individuals and organisations came together through the public launch of two Victorian reports into high levels of unmet need for AT, and the perceived inadequacy of public AT and EI funding mechanisms in 2006 (Wilson, Wong and Goodridge 2006; Pate and Horn 2006), subsequently forming the Aids and Equipment Action Alliance (AEAA) in 2006 (see Appendix A). The AEAA is a non-profit, multi-member group consisting of people with disabilities, advocates, health professionals and service providers, engaging in information sharing, research, and lobbying in order to improve the availability of
aids and equipment in Victoria. My role as a founding member of both the AEAA in Victoria, and several national and international AT-related collaborations\(^1\), provided additional insights into some of the multiple perspectives or standpoints involved in AT systems locally, nationally, and internationally.

**Research questions**

This thesis more thoroughly investigates the assumptions or ‘reality’ described above, offering an opportunity to critique and evidence this more thoroughly. Such an investigation necessitates engagement with ideas on a range of levels. To contextualise the fine grained detail of assistive devices and home modifications and their use, a high level, theoretical discussion of disability and impairment is necessary. To evaluate the policy and service delivery context, mid level engagement with program documentation is required.

The thesis asks how individuals living with impairment might achieve equal outcomes, drawing conclusions by integrating granular data on consumers and their mediators with a range of literature. This is accomplished by examining three broad questions:

1) **How are impairment and disability understood?**
   1a. In what ways is disability different from the absence of disability?
   1b. Does the presence of impairment or disability impact upon people’s life aspirations?
   1c. What is the role of impairment effects and environmental barriers in creating disablement?

2) **How do mediators bring about outcomes?**
   2a. Which strategies mediate impairment effects and disabling environmental barriers, and what relationship do they have to each other?
   2b. What is the effectiveness of identified mediators?

\(^1\) National Aids and Equipment Reform Agenda or NAERA (2011); AT Collaboration (2009)
3) What is the social contract between society and its citizens with impairments?

3a. How effective is government in delivering equality of outcome through the provision of mediators?

3b. What does government need to do to realise its obligations?

**Thesis structure**

Each research question is informed by reviews of current literature from a variety of fields including rehabilitation, sociology, political science, and health economics. Literature from the disability academy, that is, authors with disabilities, has been specifically sought. The main source of original empirical data for each inquiry was ‘The Equipment Study’ (Layton and Wilson 2010). The thesis author was the main researcher, responsible for the design, collection and analyses of data, and was the lead author. This study of life for 100 AT users in Victoria was one of a series of studies known as *The Equipping Inclusion Studies* (Layton, Wilson, Colgan, Moodie and Carter 2010). This independently funded research was sponsored and heavily informed by the AEAA. ‘The Equipment Study’ (Layton and Wilson 2010) was a mixed methods study of 100 Victorians with disabilities, their use of AT and related supports, aspirations, and outcomes. Data gathered for ‘The Equipment Study’ were also used for a cost consequence analysis of the impacts of AT in ‘The Economic Study’, authored by Colgan, Moodie and Carter (2010); the key findings and policy implications were presented in the third report (Layton Wilson, Moodie and Carter 2010). All three documents were subsequently published together as *The Equipping Inclusion Studies* (Layton et al. 2010).

Data from the study series, particularly ‘The Equipment Study’, is re-analysed and incorporated with other data sources and analysis processes into a broader inquiry addressing the thesis research questions.

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2 The thesis candidate and her primary supervisor were colleagues and members of the AEAA at this time, and participated in the creation of this research agenda, prior to the candidate’s PhD enrolment and the establishment of a candidate–supervisor relationship.
Figure 1 contains a depiction of the relationship between *The Equipping Inclusion Studies* (Layton et al. 2010) and the PhD.

**Figure 1: Relationship of *The Equipping Inclusion Studies* and the PhD Inquiry**

Organisation of thesis

Chapter 1 sets the scene for the overall thesis inquiry regarding how Australians living with impairment might achieve equal outcomes, from my perspective as an occupational therapist. The terms impairment, as a primary descriptor of human variation, and disability, as the nuanced term most prevalent within the literature, are discussed and variably used as applicable throughout the thesis. The methodological stance adopted to address the thesis research questions is described in Chapter 2, while Chapter 3 identifies the mixed methods used. Chapter 4 addresses how impairment and disability are understood and, in the discussion of impairment effects and disablement, introduces the key role that mediators can play.

Chapter 5 outlines a range of interventions or mediators, focusing on three (AT, EI and PC) and proposing relationships between them in the form of the AT solution. Chapter 6 considers evidence for the effectiveness of these mediators. Further analyses of the literature and data occurs in Chapter 7 in the form of an AT policy case study to address the role and effectiveness of government in...
delivering equality of outcome through the provision of mediators. These analyses generates a set of potential policy solutions which are presented in Chapter 8. Chapter 9 (Conclusion) summarises the new knowledge presented throughout this body of work, and Chapter 10 (Addendum) reflects upon the thesis and identifies its limitations.

Concluding comments

This chapter has identified a range of pragmatic constraints under which health professionals work, and the observed limitations these place upon individuals living with disability. These provide a background to the set of research questions which have emerged from the author’s practice. In order to explore the questions, a methodological framework was needed which empowered the research by aligning with inclusive research principles, yet also yielded robust conclusions to influence the real-world policy-makers and decision-makers who allocate resources. It is hoped that the focus on user experience of services which are currently delivered will fill a knowledge gap concerning the nexus between practice and policy: that is, build evidence as to the actual outcomes of mediator provision within existing policy boundaries, and how these might be improved from the perspective of individuals with impairments. The thesis intent is to generate useful knowledge with which to lever change in order to improve equality of outcome for individuals requiring mediators to live their lives.
Chapter 2: Methodology

The overarching research question of this thesis asks how individuals living with impairment might achieve equal outcomes. Three areas of inquiry underpin this broad question: firstly, the nature of impairment and disability per se, and their relationship to outcomes; secondly, the impact of mediators upon outcomes for individuals living with impairment and disablement; and thirdly, the role of society in relation to citizens with impairment, in terms of delivering equality of outcome via mediators which support the achievement of outcomes. To answer these questions, it is first necessary to establish the frame of reference which will be used to inform the concept definition, scope and focus of the inquiry areas, and the nature of evidence to be collected.

The intent of this chapter is to examine major research paradigms to ascertain their influence over accepted knowledge regarding life with impairment or disability, mediators, and the role of society. From these a methodology will be developed to underpin both the formation and the exploration of the thesis research questions.

Positivist versus interpretivist research paradigms

Different methodologies bring different evidence to the table, or at least cause evidence to be seen differently. The ontological and epistemological position of researchers is critically influential:

Belief functions as evidence at every stage of scientific enquiry: in the selection of problems, the formulation of hypotheses, the design of research (including the organization of research communities), the collection of data, the organizing and sorting of data, decisions about when to stop research, the way results of research are reported, and so on. (Harding 2004: 136)

The two major paradigms from which impairment and disability have been examined can be described as positivist and interpretive. The traditional positivist research paradigm is characterised by assumptions that research can be ‘value-free’, that the knowledge and causal explanations obtained can be independent of the methods used, and that the social world can be studied in the same way as the natural (Peat, 2001). This is challenged by interpretive
paradigms, which posit that all knowledge is socially constructed and that the social world differs from the natural in that those studied are active participants rather than passive objects. In this view, research should try to understand the meaning of events, not just their causes (Becker 1996), and the lived experience of the individual is elicited as a form of truth (Barnartt and Altman 2001). Interpretive paradigms recognise, and take steps to manage, the fact that knowledge and understanding obtained from research will be influenced by the researchers’ values and are not independent (Löfgren et al. 2011).

It is clear from the range of publications regarding impairment and disability that positivist approaches have dominated the research agenda. This is likely to be an expression of the epistemological values of the professions and domains in which research into human variation occurs. Research from health and medical perspectives typically centres upon individual impairment and medical intervention, largely using research methods which follow these positivist tenets (Peat 2001; Rice and Ezzy 2002). A key reason is that, for research to be funded and published within peer-reviewed health, medical, rehabilitation and disability journals, it is required to adhere to specific standards of evidence.

Rioux identifies an underlying economic conservatism as influential upon research, noting that there is a strong cultural bias in industrialised countries towards scientific positivism in research and policy making, and that ‘rationality and objectivity are valued as necessary conditions for the social and economic well-being of society’ (1997: 108). The primary evidence hierarchy for interventions or treatments is mandated by the National Health and Medical Research Council (NHMRC 2009), a major source of research funding in Australia (see Table 1 Column 1).

<table>
<thead>
<tr>
<th>NHMRC levels of evidence (NHMRC 2009)</th>
<th>Hierarchy for assessing qualitative health research (Daly et al. 2007)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic reviews (level 1)</td>
<td>Generalisable (level 1)</td>
</tr>
<tr>
<td>RCT (level 2)</td>
<td>Conceptual (level 2)</td>
</tr>
<tr>
<td>Comparative studies with controls (level 3)</td>
<td>Descriptive (level 3)</td>
</tr>
<tr>
<td>Case series (level 4)</td>
<td>Single case studies (level 4)</td>
</tr>
</tbody>
</table>
This hierarchy is limited to quantitative methods only and does not address qualitative research. NHMRC itself notes the levels of evidence are restrictive, particularly where ‘areas of study do not lend themselves to research designs appropriate to intervention studies (i.e. randomised controlled trials)’ (NHMRC 2009: 8). Ongoing work is examining how to critically appraise ‘non-randomised and non-interventional evidence’, including qualitative evidence (Merlin et al. 2009). A recent hierarchy for assessing qualitative health research, by Daly et al. (2007), is presented for comparison in Table 1 (Column 2). Both hierarchies sit within a positivist methodology; critiques of their ‘mechanistic/epidemiological approach rooted in a traditional compliance paradigm’ (Löfgren et al. 2011: 16) suggest they do not represent best quality evidence when it comes to researching lived experience.

In a recent position paper on the challenge of evidence in disability and rehabilitation research and practice, Johnston et al. (2009) echo this concern, noting that existing evidence grading systems do not address all the research methods used to evaluate mediators of impairment, in this instance AT. The limited perspective on permissible evidence in mainstream research may explain the many major evidence gaps in relation to the lived experience of disability (Andreson et al. 2000; Lutz and Bowers 2005; Sunderland et al. 2009). Research questions which require a mix of approaches to be fully examined may be seen as too complex to explore, and may entail ‘designs and methodologies [which] may be considered less rigorous under most current evidence grading methods’ (Johnston et al. 2009: 4). It is, however, critical to ensure that research is relevant to the lives and values of people with disabilities:

- to reach a comprehensive understanding of the complexity of the overall usefulness of a particular technique or technology in daily life, methods other than laboratory or functional testing are required. Whilst it is accepted that the empirical techniques provide reliable factual results, their inherent reductivistic scope does not allow an adequate representation of the complexity of the human–technology–environment system. (Levy 1987: 230)

One evidence gap noted over ten years ago is the lack of ‘empirical research as to the fundamental question of how intrinsic features of an individual interact
with features of the social environment to produce disablement’ (Bickenbach et al. 1999: 1174); it remains a gap today (Bickenbach et al. 2012).

A further impact of methodology upon disability research relates to the role of the researched. From an interpretivist perspective, the criteria used to obtain high-quality evidence are narrow in focus, and exclude a number of key aspects of value to the disabled stakeholder. Critiques of the research literature in disability and rehabilitation note a propensity to ‘research upon’ rather than ‘research with’ people with disabilities (Stone and Priestly 1996).

The research approach is particularly important given the implications for the accurate portrayal and engagement of individuals with disability – a group who hold the marginal role of ‘the researched’. My colleagues who live with disability point out a failure to prioritise research into elements that are critical from their standpoints as individuals living with impairment. This may be due in part to the mismatch between the agendas of professionals or researchers and those of people with disabilities (Erdtman et al. 2012; Fawcett and Hearn 2004). Failure to examine or reflect upon the perspective of those with disabilities may lead to research which is irrelevant or oppressive as it fails to align with their views (Petersen 2011; de Leeuw 2007; Barnes 1996). As Ripat and Woodgate assert,

Disability theorists have described research as a dominant means of upholding and perpetuating oppressive and discriminatory practices and contend that the use of positivist and qualitative traditions of inquiry to study disability issues serves to create further disablement by alienating those researched from the process of research. (2011: 88)

Substantial negative experiences of individuals living with impairment result from the framing and depiction of disability as a problem for the individual rather than for society, both in research and in service provision:

For disability, rehabilitation is not necessarily a useful vehicle for participation and inclusion. Indeed, rehabilitation could be considered to be an exclusionary technology because it validates the normative body and determines a restorative health trajectory toward which the disabled body is projected. (Hodgkins and Baility 2009: 216)
Selecting a research methodology for the thesis is therefore a critical step, as it will both illuminate and limit the evidence that is produced.

Methodological choices for the thesis

As do all humans, individuals living with impairment have nuanced and situated identities (Thomas and Corker 2002; Shakespeare 2006). The challenge for researchers is to hold and privilege multiple factors, knowing that they are partial representations of a whole. Research methods, to be capable of transcending specific truth claims, must be designed to attend to multiple aspects of the phenomena under study. Mixed methods were therefore selected for this study, within an inclusive research framework.

Mixed methods research is seen as a contemporary and realistic approach to investigate aspects of phenomena at many levels (Merlin et al. 2009; Peat 2001; Pentland et al. 1999; Pope and Mays 1995; Pyett 2003; Rice and Ezzy 2002; Silverman 2010). The primarily qualitative and quantitative methods were selected within an interpretive approach, insofar as individuals with disabilities and other stakeholders influenced their selection and analysis. The intent of employing this range of methods was to encompass multiple realities: that individuals living with impairment are experiencing individualised impairment effects; they are subject also to social forces; and they are to be identified well beyond these impairments and barriers. Such an approach adheres to the tenets of critical realism and postmodernism, theoretical constructs which will be explored in Chapter 4 but are mentioned here as acknowledgment of the position that ‘there cannot be “pure” measures of people’s contexts and characteristics as, inevitably, to arrive at “purity” involves the distorting practice of filtering out the normal social context of a person’s life’ (Corker 1998: 223).

Inclusive research refers to the practice of including, to varying degrees, ‘the researched’ in the mechanisms of research production. Inclusive research principles will be described in the following sections, but first the issue of identifying and prioritising stakeholder standpoints will be addressed.

Johnston et al. define evidence as the knowledge which connects research to practice, and suggest that evidence-based practice (EBP) involves ‘using the best available evidence – integrated with clinical expertise and the values and
experiences of people with disabilities and other stakeholders – to guide decisions about clinical and community practices’ (2009: 2). As this thesis is committed to disability perspectives, a critical view is taken regarding the source and positioning of evidence. Researchers’ and authors’ vantages in regard to the nature of impairment and other disability-related issues colour their approaches to the lived experience of disability, and this matters when considering research questions, methods, and the interpretation of results. Despite efforts at reflexive practice and despite positioning themselves as humans likely to have impairment at some stage or another, non-disabled researchers do not research from within the lived experience of impairment effects and disablement. The question then arises as to whether non-disabled researchers possess sufficient insight to research and write without partnership and collaboration with people who live with disability.

Epistemologies are required which will make explicit the various perspectives at play, including those of the author. While I predominantly hold the role of researcher/author in relation to the thesis, I am by profession an occupational therapist, a position historically allied with the medical model and professionalisation. As a member of groups such as the AEAA, I am a collaborator and an activist, giving me the status of privileged insider or observer in a number of disability contexts. This is perhaps akin to the position of a ‘participant observer’ (Kawulich 2005; Petersen 2011). Naming these roles acknowledges my situated position, and indicates the bias they imply; however, they have proved essential in informing my knowledge of the marginalised standpoints I am seeking. My explicit alignment, as a professional and a collaborator, with people living with impairment enables me to identify the literature which resonates or contrasts with their experiences. Indeed, the virtual absence in the literature of the voice of people living with impairment becomes recognisable only when contrasted with the verbalised lived experience of disabled people.

Scholars from a number of disciplines offer concepts useful in exploring the notion of viewpoints and their limitations. Social sciences use terms such as ‘selective screens’ or ‘filters’ to describe the process by which we learn how the social world works and how other people behave (Oliver 1990; Petersen 2011). A useful concept from health economics is that of bounded rationality, where,
‘without surveying all possible options, people adopt some more-or-less arbitrarily defined subset of the universe to consider’ (Goodwin et al. 2003: 13). At an individual level, a person’s positioning, selective filters, or bounded rationality may be explicit or implicit, and relate to position, training, experiences, role, and the nature of the constructs within which the person operates: as a person with a disability, AT practitioner, academic, researcher, and so on. In exploring the ways differing stakeholders arrive at shared views, Gadamer (1975) uses the concept of the ‘fusion of horizons’ for visualising common ground. This idea encapsulates the ideal scenario, where key players are sufficiently reflexive to perceive their own positions and filters, and can appreciate the positions (and the limits) of others. A range of approaches take a systems view in the analysis of standpoints (Buckley 1967; Salmon 2003; Wadsworth 2008), or systematically applying a mix of methods to research the self, others, and the world in relation to a problem, in order to build a coherent view of the whole (Esbjorn-Hargens 2006; 2009). A theoretical framework to realise this fusion yet privilege the vantage point of the person living with disability is found in standpoint theory.

**Standpoint theory**

In order to analyse the relationship of a phenomenon of interest in relation to other factors (its situated meaning), it is essential to identify the viewpoint of the author. This study required a methodology that privileges the view of people with disability and their situated knowledge. Standpoint theory is therefore adopted as a theoretical foundation congruent with inclusive research in the area of disability.

Feminist standpoint theory has been described as a recontextualisation of Marxist understandings of power and knowledge, in that it takes Marx’s conceptualisation of social marginality and transforms it into an epistemic privilege (Harding 2004; Haraway 2004; Hekman 2004): that is, a person’s understanding will be influenced by their location within social hierarchies, which implies that ‘those who have experienced a particular form of discrimination are likely to see things others will miss’ (Phillips 2004: 14). As Harding suggests, ‘starting off thought’ from the lives of marginalized peoples . . . will generate illuminating critical questions that do not arise in thought that begins from
dominant group lives . . . marginalized lives are better places from which to start asking causal and critical questions about the social order. (2004: 130)

Standpoint theory offers a means to privilege the disabled person's standpoint as a form of situated knowledge, and also offers an alternate view of objectivity (Haraway 2004: 86). Opposing the assumption that research can be conducted from a god-like, external position and be conducted without influencing the researched, situated knowledge recognises the politics and epistemologies of location, positioning, and situating, where partiality and not universality is the claim of being heard to make rational knowledge claims. These are claims on people’s lives, the view from a body, always a complex, contradictory, structuring and structured body versus the view from above, from nowhere, from simplicity. (Haraway 2004: 92)

Standpoint theory resists the mainstream objectivist demands of empiricism which underpin much of the rehabilitation literature. The notion of objective, value-free research is considered a flawed concept, largely due to its failure to account for the broad, historical social desires, interests, and values that have shaped the agendas, contents, and results of the sciences as much as they shape the rest of human affairs . . . The methods of science – or rather, of the social sciences – are restricted to procedures for the testing of already formulated hypotheses. Untouched by these methods are those values and interests entrenched in the very statement of what problem is to be researched and in the concepts favoured in the hypotheses to be tested. Recent histories of science are full of cases in which broad social assumptions stood little chance of identification or elimination through the very best research procedures of the day. (Harding 2004: 137)

Reflexivity and use of liberatory research methods are the principle methods by which researchers enact standpoint theory. Reflexivity attends to the presence of the research as part of the ‘world being studied and the ways in which the research process represents, and is part of, that study’ (Owens 2007: 302). To be reflexive, researchers are challenged to examine the construction of ‘others’ in society and understand their own positions:
this approach challenges members of dominant groups to make themselves ‘fit’ to engage in collaborative, democratic, community enterprises with marginal peoples. Such a project requires learning to listen attentively to marginalised people; it requires educating oneself about their histories, achievements, preferred social relations, and hopes for the future . . . it requires critical examination of the dominant institutional beliefs and practices that systematically disadvantage them; it requires critical self-examination to discover how one unwittingly participated in generating disadvantage to them. (Harding 2004: 135)

Standpoint theory is highly applicable to disability:

collectively disabled people have accumulated a significant body of knowledge with different standpoints from those without disabilities and … this knowledge, ignored and repressed in non-disabled cultures, should be further developed and articulated. (Fawcett and Hearn 2004: 210)

While it is acknowledged in this thesis that all methodological standpoints have something valid to offer, it is suggested that what has been missing is the reflexivity necessary to locate knowledge produced in its — necessarily limited — context. From a systemic perspective, the loudest voices (as evidenced by the quantity and calibre of the AT literature) are those of researchers and practitioners, not of disabled individuals (despite their centrality to the issue) or even of the policy-makers and funders who are critically influential in terms of achieving any outcomes. This reveals the sustained absence of the actual (not interpreted) standpoint of individuals with disability. The view adopted in this thesis considers from whose standpoint research has been conducted, whether it includes disabled researchers and authors, and whether the study design includes data on the direct experience of the subjects being studied, including their valued outcomes. Standpoint theorists from the feminist tradition provide methods which require reflexivity on the part of the researcher, and position the researched, in this case users of AT, in a central role with regard to their views and in naming measurements or outcomes of importance to them.

**Inclusive research**

Inclusive research is the methodology proposed to realise the legitimacy of knowledge of people with disability. Disability campaigners point out ongoing
low levels of involvement of disabled people in framing research questions and
designing projects, and the failure of research adequately to capture and convey
the lived experience of people with disabilities, of carers, and of non-disabled
people working with disabled colleagues (Christie and Mensah-Coker 1999;
Stone and Priestly 1996). Regardless of whether positivist or interpretive
research paradigms were used, criticisms focus on the issue that research is
carried out by relatively powerful *experts* on relatively powerless ‘subjects’.
Despite the liberal trappings of the qualitative paradigm, the ‘social relations
of research production’ [have] not changed. Hence, there [is] a need for an
‘emancipatory’ research paradigm: one which places people with disabilities
and their concerns centre stage at every point in a research process aimed at
facilitating their empowerment. (Rioux and Bach 1994: 31)

Inclusive research builds on a history of alternative approaches variously termed
emancipatory, liberatory or participatory. These terms emerged from literature
on critical social research by black writers, feminists, and educationalists who
positively allied themselves with oppressed groups (Barnes 2001). Emancipatory
scholarship by individual scholars with disabilities has generated
analyses of political action and developed an understanding of disablement that
supports arguments for social change (Abberley 1992; Oliver 1990). Demands
for emancipation in the research process by ‘the researched’ have met with
equivocal responses, however, within the ‘professional’ research community
(Albrecht et al. 2001). One explanation for this is that the status quo of research
is hard to shake:

Medical sociologists, comfortable with their own research ethics, practices
and methods, have not shared in the enthusiasm for ‘emancipatory research’
on disability or chronic illness … the aspiration to be seen as ‘objective’ and
‘balanced’ retains a powerful disciplinary hold. Moreover, ethical standards
and ‘independence’ are believed to be held in check by UK Research Council
guidelines, professional codes of practice and academic peer review
processes. (Thomas 2007: 163)

Critics have also questioned the partiality of emancipatory researchers,
concerned that their overt socio-political positions will lead to an exercise of
power likely to recolonise research findings in line with the researchers’ ideologies (Danieli and Woodhams 2005).

The thesis methodology aligns with the latest iteration of inclusive research principles based upon several decades of work on emancipatory approaches, detailed below.

The ongoing development of inclusive methodologies continues to aim for inclusion of persons with disabilities in the design and conduct of research, in order to draw upon their experiences while addressing such criticisms. Barnes (2001) outlines emancipatory principles whereby researchers must attend to issues of accountability to the disabled community; must adhere to the social model of disability; must manage the problem of objectivity by making their ontological and epistemological positions clear; must justify the choice of methods, particularly given the failure of quantitative methods to capture fully the complexity of everyday experiences; must recognise the role of experience but report this within broader contexts; and must seek to produce practical outcomes. These calls were reframed in 2004 to include reflecting critically on the knowledge production process, building research agendas grounded in the experiences of subordinate groups, finding ways to judge some knowledge claims as better than others, acknowledging diversity and contradictions in subordinate groups, recognising that knowledge (about disability) is generated by a historically specific community, and espousing liberatory knowledge (Barnes and Mercer 2004: 130).

In Australia, underpinned by the National Disability Strategy (Commonwealth of Australia 2011) and the National Disability Research Agenda (National Disability Research and Development Working Group 2011), these principles were recently synthesised in the form of a Quality Statement to guide inclusive research (Disability Inclusive Research Collaboration 2012). These principles state that research should be informed by, led, consented to or owned by people with disability; should use inclusive and participatory research process and methodologies; should include materials that are accessible and a range of types of activities in research design; should conduct research that transfers through to real life and the chance to re-define what research is; should include opportunities for co-presenting; and should feature ‘the right people asking the
right questions and getting the right answers’ (Disability Inclusive Research Collaboration 2012: 1). This approach, whereby research methods are expected to meet the needs of research recipients, is endorsed by the Cochrane Collaboration (Hill 2011).

Variations on the combination and extent of emancipatory principles enacted in research will produce various forms of inclusivity. French (1992) observes that contemporary inclusive research can be conceptualised as a continuum. Participatory research lies at one end, with the meaningful involvement of people with disabilities and the opportunity for mutual learning between researcher and researched; emancipatory research lies at the other. A fully emancipatory approach occurs when ‘disabled people themselves … are controlling the research and deciding who should be involved and how’ (French 1992: 185). It may be difficult to realise inclusive research as fully as researchers and people with disabilities may wish, but, where possible, building inclusive features into research practice is a key mechanism for changing the social relations of research production to ensure its relevance to the lives of disabled people (French 1992). Wherever the conduct of research is positioned along this continuum, ultimately the potential of research to empower disabled people rests with their using evidence to argue for the dismantling of disabling barriers (Danieli and Woodhams 2005).

It remains, however, critically important that people with disabilities who are being researched are involved at many levels of the research process. It is apparent from the conceptual review of impairment and disability, as reported in Chapter 4, that underlying ontological and epistemological assumptions on the part of professionals, including researchers, can limit the capacity of research to engage fully with life as individuals living with impairment experience it. These represent critical limitations. The choice of research methods for this thesis was partly predicated on the desire to avoid these limitations and to achieve epistemological justice.

**Epistemological justice**

The long history of marginalisation of individuals with impairment at the hands of professionals renders it understandable that ‘disabled people and their organisations should be wary of researchers’ (Barnes 1996: 107). Abberley
echoes this warning in his 1992 critique of government survey methods: ‘disability is a social construct, and definitions depend upon the interests, intentions and presuppositions of those with the power to define’ (1992: 139). Barnes warns that ‘quantitative data collection strategies . . . can never capture fully the complexity of the everyday experiences of disabled people’ (2001: 12).

Epistemological justice occurs through the ‘emancipation of the experiential knowledge of patients and their supporters from the hegemony of the expert knowledge of the medical and managerial professionals’ (O’Donovan 2011: 5). Thomas, a disabled academic, encapsulates these notions of standpoints and epistemological justice when she asks,

What would be the consequences if the feminist position that all knowledge is ‘situated’ were taken seriously in disability studies? At the very least it would mean acknowledging that all knowledge about disability (and not just the knowledge of the medical modellists) is profoundly related to the conditions of its own production. It would also require of all authors that they ‘write themselves’ into their work, at least in the sense of intellectual biography, so that the scaffolding on which their knowledge claims are built is made explicit. As a result, apparent scientific ‘truths’ about disability would be identified for what they are: ‘situated’ attempts to interpret social reality which can be contested and debated. (Thomas 1999: 120)

This thesis seeks to explore the mediators of impairment and equality of outcome in a way that is epistemologically just to the subjects of the research. Emancipatory or liberatory methodologies enable researchers to recognise and select a viewpoint, and allow diverse views to be heard and understood (Haraway 1988; Harding 2004; Sherry 2004). Such methodologies require reflexivity on the part of the researcher, and position the researched, in this case people with impairment, in a central role with regard to their views and in naming measurements/outcomes of importance to them. Achieving epistemological justice in this inquiry into mediators of equal outcomes requires research methods, systems, policies, procedures, and outcomes to be based in the disabled person’s perspective, and to be representative of the needs of individuals living with impairment (Hill 2011; Löfgren et al. 2011).
Methodological tensions

To establish the role of assistive technology solutions in mediating equal outcomes, a wide terrain is covered. Spanning diverse scholarly traditions as this thesis does, it is not surprising that contradictory and conflicting sets of ideas emerge. Understandings of impairment, disability and the nature of outcomes are broadly drawn from medical sociology, rehabilitation and disability studies literature; the nature of mediators is found across a range of literatures including rehabilitation, design, housing and policy studies. The inquiry as to the social contract, specifically the role and effectiveness of government, brings sociology and human rights, as well as economic theory, into the mix.

While a range of perspectives is evident across these literatures, in general they have been discussed, and to some extent synthesised, using standpoint theory. Two tensions are singled out for discussion here: the epistemological contrasts between disability ‘values’ and the standpoints of mainstream economic methods and rehabilitation-based measures of participation. The importance of these dissonances cannot be underestimated, given the reliance on formal outcome measurements to evaluate interventions, and the influence of economic thought over the policy context within which disability is managed.

The intent of these discussions is to provide an example of the ongoing contradictions implicit in methodological approaches to generating and using ‘evidence’ in relation to the thesis topic.

Measuring participation: objective and subjective tensions

The importance of participation as a life goal or outcome valued by people with disabilities is articulated within the disability literature (Goggin and Newell 2005; National People with Disabilities and Carers Council 2009). However, a review of rehabilitation, policy or disability literature demonstrated that health professionals, governments, and people living with disabilities have different ideas about the definition, extent, and areas of participation, and about which activities lead to participation. Measurement of participation, based as it is within an extensive body of outcomes research, has focused upon indicators of function, independence, and focal activities (Andreson and Meyers 2000; Andreson et al. 2000; Bruyere et al. 2005). This is problematic: while aspects of
functional independence measures such as the performance of or engagement in various activities might be included in the concept of participation, the reverse is not true since participation encompasses significant additional components (Desrosiers et al. 2006).

Salter et al. (2007: 341) reviewed 1721 study outcomes from 491 randomised control trials of stroke rehabilitation and determined that ‘fewer than 6% of all measurement citations could be classified as pertaining to participation’, and a recent systematic review of instruments assessing participation concludes that most instruments that aim to measure participation do so only to a limited extent (Eysen et al. 2011). Although social participation is acknowledged as a much stronger factor affecting subjective quality of life than is impairment or function related to activities of daily living, this has poor uptake in the service delivery arena where, as Dijkers et al. note,

> payers of health care typically devalue social outcomes in using ‘medical necessity’ as the primary criterion for funding, rejecting many services that would enhance social health, rather than physical health. (Dijkers et al. 2000: S75)

Objective measures are argued to do injustice to the values and goals of the person served, leading to calls for ‘patient-perceived measures of participation’ (Cardol et al. 2002: 28). The notion that understandings of participation need to be grounded ‘within the insider perspectives of people with disabilities’ (Hammel et al. 2008: 1446) has been taken up, with a range of researchers agreeing that subjective measures of participation might be better than objective ones (Whiteneck and Dijkers 2009). To operationalise the concept of participation it is necessary to consider what the term actually means in relation to the life actions available to humans. In general, participation is seen as a critical social outcome with a strong relationship to overall health and wellbeing:

Research has shown consistently that participation in meaningful occupations, particularly work and leisure, has an important, positive influence on health and well-being . . . The presence of disability has been found to lead to participation that is less diverse, is located more in the home, involves fewer social relationships, and includes less active recreation (Law 2002: 641).
In terms of method, Brown et al. argue that in order to represent the voice of individuals living with impairment, subjective measures of participation must be developed to ‘more adequately reflect the perspective of the disability insider, whose life it is’ (2004: 460). A range of theoretical aspects related to participation are emerging and contributing to the validity of participation measures; one such aspect is autonomy:

‘Choice’ and ‘importance’ are two equally important concepts. The knowledge that one has the choice to participate encourages feelings of autonomy and empowerment, increasingly important themes for people with disabilities. Importance is also worth considering since participation, deemed vital to those without disabilities, might carry different levels of significance to those with disabilities, or at least for certain participation elements (Bricknell and Madden 2002: 6).

Another is the concept of participation enfranchisement, as a way to capture the extent to which people perceive the community as restricting or enabling participation in terms of valuing, respecting, and fully including them (Heinemann et al. 2011; Mallinson and Hammel 2010; Whiteneck et al. 2011). This new domain focuses on a person’s perceptions of whether one has choice and control over participation, contributes to society, and feels valued (Heinemann et al. 2011; Whiteneck et al. 2011). Scherer suggests an idiographic approach, where the person is the unit of analysis and serves as their own control, as preferable to normative approaches and in keeping with social model and consumer-directed perspectives of outcomes assessment, proposing

one means of assessing a consumer’s ‘stake’ or perspective is to have individual prioritize their own desired outcomes and then rate over time the progress in achieving them … in this way, outcomes are measured in terms of changes in the person’s satisfaction in being able to get to where he/ she wants to go, whether by walking or some other means, rather than just by the functional capability to do so. (2002b: 171)

Any evaluation of the outcomes literature on participation therefore must critically assess the means by which participation is defined and captured. Successful measurement of participation, for example as an outcome of
mediator use, will clearly depend upon the calibre of tool used and, at a minimum, dual measurement of the objective and subjective aspects of participation is required to approach epistemological justice.

**Applying mainstream economic methods to disability - the case of health related quality of life**

This thesis attempts to generate useful evidence that resonates with the perspectives of individuals living with impairment yet can be understood and valued from the perspective of policy and economics. While a range of arguments can be made for a particular strategy or intervention to be resourced by government, for example quality of life or human rights and social justice arguments, economic arguments are stronger drivers of change as, at the end of the day, governments view outcomes in economic terms (Banta and De Wit 2008).

In economic evaluations, interventions are evaluated against a comparator (usually current practice), and consideration is given to both costs and benefits. Difficulties in measurement arise when costs and benefits are not fiscal but relate to aspects of life, for example health related quality of life (HRQoL). These ‘intangibles’ were largely ignored in mainstream economic evaluations until the development of the quality adjusted life year (QALY) as ‘the unit of output for health benefits’ (Hawthorne, Richardson and Osborne, 1999: 209). A quality of life score provides a mechanism for quantifying life quality in numerical terms. The premise of the quality adjusted life year is that interventions are valued because of the contribution they make to both length and quality of life (Mooney 1992) This is useful to economists and policy-makers needing a numerical measure of ‘benefit’ to counterbalance cost, and the QALY has become a widely accepted measure of health-related quality of life. The QALY, which calculates a dollar value through health-related quality of life assessment, is benchmarked to norms for health expenditure (Carter and Harris 1999). There is wide acceptance that ‘health interventions with cost-utility ratios under approximately $50,000 per QALY saved are ‘cost-effective’ and are within the range of economic efficiency that society usually funds’ (Pinkerton et al. 2002: 75).
The epistemological framework of QALY methodology is, however, criticised as exclusionary in method and in vision (Cummins 2005). Three main areas of critique are as follows.

Firstly, this economic method focuses upon the (limited) aspects of life which are able to be captured statistically (Dobes 2009: 45), even though social scientists argue that ‘methodological pluralism’ is required in the assessment of quality of life, as well as an awareness of the effects of different data collection strategies in measuring outcomes (Shalock 2004). A range of broad-based fundamental conditions have been documented as necessary for a ‘good life’, well beyond HRQoL (Johnson and Walmsley 2010; Shalock 1996). In terms of key variables, Coast questions the methodological appropriateness of ‘funnelling multiple outcomes into one simplistic outcome such as the quality adjusted life year’ (2004: 1234). International evidence suggests that ‘the assumption that the value assigned to a QALY is the same no matter who receives it, is too simple’ (Nord et al. 1995: 1430).

Secondly, from a standpoint perspective,

how someone attempts to ‘measure’ QOL says more about their own values, priorities and fundamental orientation to life than it does about the QOL of the people whose lives are ostensibly being studied. (Whalley-Hammell 2007: 128)

Richardson and Nord, economists, acknowledge that

Perspective can significantly alter the values incorporated in a QALY instrument . . . Different perspectives exist . . . perspectives are not right or wrong; rather, each represents a different ethical position with respect to the appropriate basis for the evaluation of health states . . . The issue of the (morally) appropriate perspective has received remarkably little attention in the literature. (1995: 40)

For example, it is suggested that overemphasis is placed upon functional dependency and activities of daily living (ADLs) in relation to quality of life, and that this emphasis is aligned with the ‘traditional medical model that views positive outcomes in light of physical abilities’ (Frain et al. 2009: 33). This brings
a third criticism into play: the conflation of independence and the absence of disease with life quality.

An inherent bias is evident against people with disabilities in the techniques for calculating quality adjusted life years (Nord et al. 1995). The bias in question means that positive states can only be achieved by those without impairment. Termed ‘double jeopardy’, this occurs when quality of life measurements are norm referenced, meaning that ‘perfect’ scores represent total unimpaired capacity in a range of domains. Given that, even with the best interventions, many people with disabilities will retain core impairments, their scores will always remain lower than the ‘norm’ and the outcomes of any intervention will be limited when judged by such narrow criteria (Drummond et al. 1997; Street and Richardson 1992). Current population weightings rate impairments such as lack of mobility, blindness, and deafness so low that multiple impairment may lead to a ‘state worse than death’ score (Franic and Pathak 2003). Overall, then, this method ‘discriminates against people with disabilities by placing less value on saving the lives of people with pre-existing disabilities’ (Ubel et al. 1999: 745), and the focus of QALYs on aggregate benefit ‘fails to account for other ethical values which society would wish to incorporate in determining the allocation of health care resources’ (Street and Richardson 1992: 127).

There exists then a significant tension in using of QALY methodology here, as the thesis privileges the perspective of individuals living with disability in determining valued outcomes but QALY methodology demonstrably does not. The application of standpoint theory to evaluate underpinning perspectives, and of inclusive research principles, specifically the involvement of a stakeholder reference group comprising individuals with disability and others, for ‘The Equipment Study’ were strategies engaged to manage a method which is, in many ways, epistemically unjust. HRQoL results were considered in context, in line with the belief that ‘the perspectives individuals with disabilities have regarding their quality of life is more relevant than objective indicators of this construct’ (Scherer and Cushman 2001: 387). In fact, engaging in HRQoL research methods opened up a valuable discourse between researchers advocating QALY methodology and ‘recipients’ who could articulate its impact and limitations. Such exchange is aligned with the catalytic validity goals of emancipatory research (Lather 1986).
Concluding comments

This thesis inquiry is based on the premise that people living with impairment have held a marginalised position in relation to the production of knowledge about them, and the delivery of services for them. The voices of those living with impairment have been muted, and influenced by the disabling structures about which they speak (Hunt 1966; Swain et al. 2004). When sought out, the standpoint of people living with impairment appears to be both ‘the same’ in embracing a universalising perspective whereby the notion of ‘other’ is rejected and the stance of human diversity is adopted; yet ‘different’ to mainstream discourse in that ‘disabled people do affirm disabled lifestyles and provide a counter-narrative to that of non-disabled people’ (McCormack and Collins 2012: 158).

Ethically, researchers in the arena of impairment and disability must seek methodologies which validate and privilege the (multiple and nuanced) views of people living with impairment, and methods which are epistemologically just. Standpoint theory provides a methodology that validates and privileges their views. Additionally, to address issues of role and power in relation to knowledge produced, inclusive research principles (a combination of participatory and emancipatory approaches) are utilised. These, together with a methodology justified by standpoint theory, provide a form of epistemological justice. Key methodological principles used include the role of people living with disability in controlling research questions and method; involvement in the research process; opportunities for reflection and knowledge-sharing; and a commitment to ensure that the products of research empower and do not alienate.

The thesis inquiries have been designed with these methodological issues in mind, and these are operationalised within the research questions and methods presented in Chapter 3.
Chapter 3: Research inquiry structure and research methods

The thesis inquiry concerns how individuals living with impairment might achieve equal outcomes. Three key research questions, each with a range of sub-questions, are identified. The three research questions are:

1. How are impairment and disability understood?
2. How do mediators bring about outcomes?
3. What is the social contract between society and its citizens with impairments?

These questions represent three inquiries, with attendant sub-questions, detailed below. Each inquiry uses two data sets: literature review data, and original empirical data collected as part of ‘The Equipment Study’. Methods of data collection for the empirical study are presented at the end of this chapter. Conducted at the outset of the thesis research, the design of ‘The Equipment Study’ was informed by initial results of literature reviews undertaken for the thesis, and was published as a discrete study in its own right.

For each of the three inquiries, methods for literature review and analysis, along with methods of empirical data analyses, are detailed. The chapter therefore comprises four sections: one on each research question, and one presenting the empirical data collection method of ‘The Equipment Study’. This latter section, as well as Appendix E contains detail of the mix of methods and decision trails followed.

SECTION 1 Research question 1: How are impairment and disability understood?

To commence, it is critical to explore the ontology, or nature, of impairment and disability, and the relationship to other factors such as social and environmental elements, as these affect how the ‘problem’, and therefore the solution, is understood. Understandings and assumptions about impairment and disability are likely to be reflected in social responses which include policy and provision
of public resources. These observations were formulated into three specific sub-
questions which ask:

1a. In what ways is disability different from the absence of disability?

1b. Does the presence of impairment or disability impact upon people’s life
    aspirations?

1c. What is the role of impairment effects and environmental barriers in
    creating disablement?

Method: literature search

The primary research method was a literature review, searching for conceptual
articles which addressed one or more of the thesis questions. Search terms
search reviewed key texts used in Australian disability studies, and included
hand searches of the full indexes (with no date limit) of disability and medical
sociology journals such as Disability and Society, Disability and Rehabilitation,
Journal of Intellectual Disability Research, Social Science and Medicine, Journal
of the American Geriatric Society, Gerontologist, and Sociology of Health and
Illness. The search terms were also applied to key journals and texts in the
areas of clinical practice, clinical reasoning, health economics, policy and
service provision, and human rights.

Abstracts and indexes were scanned for relevance to one or more of the
research questions, with relevant items read and their reference lists reviewed
for any additional relevant content. The literature search commenced in early
2007 and continued until early 2013, with texts added to an Endnote library and
to interim literature syntheses to inform each thesis chapter.

A key focus of the literature review was the explicit collection of material from
the standpoint of persons identifying as living with impairment or disability. A
notable lack of published material by individuals living with impairment exists,
compared with professionally generated peer-reviewed literature. In keeping
with the tenets of inclusive research approaches, and the privileging of the
standpoint of individuals living with impairment, work by disabled authors was
explicitly sought. In the main, academic literature by such authors and pertinent
material from the ‘grey’ literature, i.e. blogs and other media formats, was included. Grey literature was identified through engagement with disability networks (such as AEAA and international disabled persons organisations), and periodic open web searches using the key words above. Publications located in this way were evaluated against authorship and parent institution credentials.

**Method: literature analysis**

A conceptual review was carried out, in which literature was explicitly organised and analysed in terms of standpoint. This was done in order to elicit differences between people with and without disability regarding understandings of disability and impairment. The ontological positioning of all texts was critically appraised for their understandings and assumptions about impairment and disability.

**Method: analysis of empirical data from ‘The Equipment Study’**

As outlined above, original empirical data available from ‘The Equipment Study’ underwent a number of analyses to answer the research questions pertaining to understandings of impairment and disability. These will be outlined following the synopsis of ‘The Equipment Study’ response set out below.

**Response Characteristics**

- **Type of disability**

While all participants had an impairment of some sort, most identified themselves as having a disability while others identified themselves as chronically ill or undergoing the effects of ageing. Of the 79 survey participants completing these demographic questions, nearly 60 separate diagnoses were reported, the majority relating to physical disability (59%), followed by multiple (14%) and sensory (14%) disabilities (see Figure 2). This contrasts with the overall Victorian population of adults with disabilities that comprises 12.9% physical disability and 4% sensory disability (ABS 2003). Study participants overall identified as having between one and twelve disabilities or long-term health conditions. This multiple disability rate is slightly higher than data on the full Australian population, where 10% of people with disabilities report the presence of multiple disabilities.
The spread of impairments found in ‘The Equipment Study’ population is broadly representative of the WHO ICF body function and structure categories (WHO 2001), and AIHW categories of disabling conditions (AIHW 2006a; 2009b). This suggests a level of validity for accepting the study population as a cross-section of persons with a disability, although sample sizes within each diagnosis category varied and were small in most cases.

- **Age, gender and living situation**

Seventy-eight survey participants completed questions related to age, gender and living situation. Of these, 41% were male and 59% female; 8% of the participants were aged 18–24, 26% aged 25–44, 50% aged 45–64, and 16% of whom were aged over 65 (ABS 2003). This compares with Victorian averages of 49.8% male and 50.2% female. In terms of age, 17.7% of Victorians with disabilities were aged 18–24, 37% were between 45–64, and 13% were aged over 65 [data drawn from the closest cohort match: the Victorian population with disabilities over 15 years (ABS 2003)]. No significant difference was found between participants across these variables either in activity across life domains, the demand for and uptake of mediators, or perceived barriers to further outcome achievement: that is, aspirations and mediator use spanned age and gender divides.
The living situation of participants differed, with the majority living in private dwellings (92%, compared with 90% of the Victorian population with disabilities over age 15, the closest cohort match) (ABS 2003) (see Figure 3). Of these, 65% of study participants lived with a spouse or partner, or with family members (27%). Two percent of survey participants lived in a supported group home, and a further 2% lived in a larger congregate care residence, compared with ABS figures of 10% of people with disabilities living in non-private dwellings including aged care facilities (ABS 2003). Participants across all living situations identified a wide range of mediators and life outcomes to be important to them.

![Figure 3: Living situation of participants](image)

Analyses of the study population against Australian Bureau of Statistics data on the broader population of Victorians with disabilities indicates the broadly representative nature of the sample.

Based upon this empirical data, in order to address research question 1 concerning how impairment and disability are understood, thematic analyses drew on major concepts from the literature review. Two major Australian texts authored by people living with disability (Goggin and Newell 2009; National People with Disabilities and Carers Council 2009) were used to triangulate the experiences of ‘The Equipment Study’ cohort and draw conclusions as to the generalisability of findings. Narrative data were extracted from all open text questions within ‘The Equipment Study’ survey response set (n-100). The thesis
author conducted deductive manual coding for key words and inductive manual coding for key themes.

Analyses for research sub-question 1a, concerning the ways in which disability is different from the absence of disability, focused on thematic analysis around key ideas from the literature by reviewing the data in relation to the themes of normal and normative and autonomy and independence. Additionally, demographic data were analysed against ABS data and the ICF (2001) framework to identify factors implicated in disablement, specifically evaluating the cohort against poverty, social inclusion/ exclusion and impairment indices.

Research sub-question 1b asks if the presence of impairment or disability impacts upon people’s life aspirations. In order to examine commonalities and differences across life aspirations, ‘The Equipment Study’ open text survey responses (that is, narratives) against each life area were analysed. To examine the basic question of what people value, data were evaluated through the filter of generic quality of life theory, specifically Shalock’s comprehensive quality of life scale for the general adult population (1996), as well as for aspirations across a set of eight life areas geared to diverse populations, specifically those living with disability (Wilson 2006). Data were further analysed in relation to instances of met and unmet need for mediators identified as necessary to achieve outcomes in life areas. The factors perceived as limiting achievement were then analysed through the lens of capability gaps.

Finally, research sub-question 1c concerned the role of impairment effects and environmental barriers in creating disablement. The impact of impairment upon the experience of disablement was established through thematic analyses of ‘The Equipment Study’ data using ICF (2001) and ISO 9999 (2007) definitional matrices. This identified a range of experiences ascribed to impairment effects and to a range of societal barriers.

**SECTION 2 Research question 2: How do mediators bring about outcomes?**

To understand how citizens might achieve equality of outcomes despite the effects of impairment, it is necessary to define those strategies which can
mediate impairment effects and to determine their effectiveness. Literature, and data from the empirical study, was gathered around two questions:

2a. Which strategies mediate impairment effects and disabling environmental barriers, and what relationship do they have to each other?

2b. What is the effectiveness of identified mediators?

Assistive technology (AT), as a key mediator of impairment, was the initial focus of interest in this study for a number of reasons. My occupational therapy ‘horizon’ was one, as occupational therapists have a primary role in prescribing AT within Australia. In this role, I identified particular constraints upon the supply of AT devices, in the context of Victorian policy and resourcing, which led to activism by people with disabilities alongside others in the formation of the Aids and Equipment Action Alliance. In this regard, the priorities of people living with disabilities set the path of enquiry, locating AT as the central issue, with environmental modifications or interventions (EI) as a related but less central area. On reflection, environment now seems to me a more theoretically sound starting point. Firstly, AT devices are necessarily used in an environmental context; and the substantial relationship between AT and EI has been conceptualised as a ‘technology chain’ (AAATE 2003). For example, provision of AT devices such as a bathseat will not be required if the shower-over-bath is replaced with a stepless recess: in other words, the barriers or facilitators which environments present create or obviate the needs for a specific AT device or aspect of personal support. Secondly, from a theoretical perspective, social model perspectives are embedded in environments, thereby encompassing broad concepts of disablement.

However, the pragmatic realities of altering environments (permanency, cost, and the hurdles of multiple duty-holders in respect to structural or public alterations) have inevitably skewed current practice towards the introduction of AT devices (and personal care) targeted at modifying the capacity of the individual to interact with the environment, rather than the other way around. Notably, this is resonant with a medical model of the ‘problem’ of disability being located within the individual.

These considerations have led me to include a focus on AT, EI and PC in my investigation of mediators of impairment.
Method: literature search

Literature reviews were conducted using EMBASE and PUBMED search facilities, to locate evidence from CINAHL, MEDLINE, Psychlit and related databases. No limitation was imposed upon years, as earlier evidence was useful in illustrating changes in both approaches to delivery of mediators and attitudes to disability and outcomes. As well as published texts and refereed articles, conference proceedings, government and NGO reports, and some grey literature (such as consumer newsletters and blogs) were considered.

Search terms included AT (e.g. aids, equipment, appliances, durable medical devices, assistive devices), EI (e.g. environmental interventions, modifications, home, access, adaptable, community); personal care/ support/ attendant care; and a range of terms regarding effectiveness (e.g. outcomes, effectiveness, efficacy, independence). In terms of exclusions, while a substantial literature base was identified around caregiving (Hoenig et al. 2003), literature was only included if it related to personal care in relation to AT, EI, or the experience of disability. Searches were conducted in August 2007 and repeated with additional keywords relating to health economics and priority setting in March 2008. A final search in November 2011 also included search terms related to human rights, social inclusion/ exclusion, and policy making. These additional key words and search terms were introduced as the thesis inquiry developed and refined its focus over four years, particularly in relation to my developing awareness of stakeholders and standpoints. Newly published literature identified through regular journal alerts was included until November 2012.

The rehabilitation field provided the largest source of AT and EI evidence, featured in publications such as Disability and Rehabilitation, American Journal of Physical Medicine and Rehabilitation, International Journal of Language and Communication Disorders, Brain Injury Rehabilitation Management, British Medical Journal, The Gerontologist and others. However compared with research upon other interventions, the body of literature regarding AT, EI and PC is fairly sparse. For example, a review of the contents pages of Archives of Physical Medicine and Rehabilitation in the decade 2001–2011 found that less than 10% of the original papers concerned AT, EI or PC, while over 90% focused on therapeutic or surgical interventions, in line with the perspective of the medical model.
Despite varying terminology, the mediators, supports or interventions brought to bear upon people experiencing impairment do fall into the recognisable categories of AT, EI, and PC which resonate with lived experience (Lutz and Bowers 2005; Ottmann et al. 2009). A number of journals dealing specifically with AT and EI were located, publishing a mix of quantitative, qualitative and mixed methods research studies, and some conceptual articles. These included various journals of occupational therapy, *Technology and Disability, Journal of Assistive Technology, Assistive Technology*, and others. Related publications contained some literature, such as *Age and Ageing, Building and Environment, Journal of Rehabilitation Medicine, Journal of Architectural and Planning Research, Housing, Care and Support, Housing Studies*, and the *Journal of Telemedicine and Telecare*.

Articles identified and reviewed related to AT (536 articles); environments and environmental interventions (135); clinical practice (specifically, the use of mediators by practitioners in health and disability settings) (138); health economics as relating to AT, EI or PC (55) and personal care as related to AT, EI and/ or disability (14).

**Method: literature analysis**

Due to the broad methodological stance adopted in the thesis, inclusion criteria considered but did not hinge on rigour of evidence. Rather, literature was evaluated on its disability focus, whether it attended to issues of resourcing and service delivery, and any inclusive research credentials. To determine this, all titles were considered, and abstracts reviewed if indicated. Works by people living with disability, reviews, texts and non-research based literature were also collated, based on relevance to the thesis questions, even if they did not fit into the two hierarchies provided in Table 2. Literature analysis demonstrates the varied methodological calibre of the studies reviewed according to mainstream scientific evidence hierarchies. While studies of AT, EI or PC, either singly or in combination, have been conducted on a wide range of populations, a minority of the articles reviewed rated highly on either evidence hierarchy.
Table 2: Studies relating to AT, EI and PC according to levels of evidence

<table>
<thead>
<tr>
<th>NHMRC levels of evidence (NHMRC 2009)</th>
<th>Hierarchy for assessing qualitative health research (Daly et al. 2007)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic reviews (level 1)</td>
<td>Generalisable (level 1)</td>
</tr>
<tr>
<td>1 stroke rehabilitation outcomes</td>
<td>&lt;12 (by diagnosis, outcome, or specific AT/ EI/ personal care and support or PC)</td>
</tr>
<tr>
<td>1 mobility outcomes</td>
<td></td>
</tr>
<tr>
<td>1 systematic review of impact of AT on</td>
<td></td>
</tr>
<tr>
<td>family caregivers of young children</td>
<td></td>
</tr>
<tr>
<td>3 clinical practice guidelines</td>
<td></td>
</tr>
<tr>
<td>RCT (level 2)</td>
<td>Conceptual (level 2)</td>
</tr>
<tr>
<td>6 (falls; AT and EI with frail elders)</td>
<td>22 (by diagnosis, outcome, or specific AT/ EI/ PC)</td>
</tr>
<tr>
<td>Comparative studies with controls</td>
<td>Descriptive (level 3)</td>
</tr>
<tr>
<td>(level 3)</td>
<td></td>
</tr>
<tr>
<td>&lt;20 (by diagnosis, outcome, or specific</td>
<td>48 (by diagnosis, outcome, or specific AT/ EI/ PC)</td>
</tr>
<tr>
<td>AT/ EI/ PC</td>
<td></td>
</tr>
<tr>
<td>Case series (level 4)</td>
<td>Single case studies (level 4)</td>
</tr>
<tr>
<td>&lt;35 (by diagnosis, outcome, or specific</td>
<td>&lt;65 (by diagnosis, outcome, or specific AT/ EI/ PC)</td>
</tr>
<tr>
<td>AT/ EI/ PC</td>
<td></td>
</tr>
</tbody>
</table>

A range of limitations and complexities was found to attend this literature set. This is not surprising, given the diversity of approaches and foci of the literature overall. The critical summary below identifies key issues in researching AT-related interventions in order to contextualise the evidence that was found.

One of the most troublesome aspects of the evidence base for AT-EI is the fact that, ‘as a discrete variable AT appears to be absent from much of the rehabilitation literature’ (Rust and Smith 2005: 103). This limits the extent of available evidence as to its efficacy because it is likely to be present yet unaccounted for in rehabilitation interventions, as it is commonly used alongside other interventions. In order to ‘isolate’ or describe AT-EI as a variable, the pervasive yet often ‘invisible’ AT use must be recognised and the nature or extent of the mediator present (e.g. the actual components of an AT intervention) must be defined. Terms delineating the extent of provision across the literature included basic, minimal, least costly, usual treatment, or intensive, comprehensive, supportive and tailored; yet detailed operationalisation of these terms was rarely found. Additionally, differences emerged between laboratory
studies, clinical and inpatient settings, and community or consumer-focused reports.

A number of studies (such as RCTs) with high evidence rankings utilise methods that eliminate confounding factors more rigorously, for example by testing wheelchair performance in a laboratory or clinic; but results are then reported against specific functional subsets and conclusions are substantially removed from actual life for the device users themselves. Similarly, treatment plans in clinical settings are likely to delineate pathways for AT-EI, but in everyday life AT-EI and PC are frequently used in a blended and partial manner, and their use is influenced by such diverse factors as the knowledge of options, the availability or supply of particular solutions, and the person’s psychological stage of adjustment.

When reviewing 100 rehabilitation outcome measures, Rust and Smith found that only 22% incorporated the use of AT, while 30% ignored the impact of AT and 44% reduced scores if AT was utilised. It is likely therefore that the effectiveness of AT and to some extent EI is substantially underreported, and the potential of meta-analyses of literature in this field is limited.

Despite these noted limitations, the literature set was analysed in relation to the two sub-questions of research question 2 (as discussed below). In addition, the literature, particularly that dealing with the measurement of effectiveness of mediators, informed the development of data collection approaches for ‘The Equipment Study’ discussed at the end of this chapter.

- Analysis for sub-question 2a. Which strategies mediate impairment effects and disabling environmental barriers, and what relationship do they have to each other?

Method: literature analysis

The range of mediators or strategies reported in published studies were analysed for definitions, then compared with and aligned against relevant taxonomies. Several key concepts influencing the identification and definition of mediators emerged. For AT, the notion of everyday technologies (Patomella et al. 2011) and inclusion of the human factors or ‘soft technology’ aspects of AT (Cook and Hussey 2008) arose, alongside a body of literature concerning
technology and stigma. Contemporary developments in design (Dong 2007; Hocking 1999; 2008) influenced conceptualisations of both AT and EI. The EI literature also featured discussions of local through to systemic environmental factors of a physical or psychosocial nature, being influential as barriers or as facilitators. Personal care or support literature focused upon a range of care types, and delivery methods for formal care (Stout et al. 2008; Ottmann et al. 2009). These various ways of conceptualising and defining interventions were considered, and underpinned the decision to consider AT, EI and PC as in scope.

A need to focus upon interrelationships soon became evident. Many studies do not capture relational aspects of the causal factors contributing to outcomes; for example, Rabiee et al. interviewed parents and children from 50 families, and noted the dependence of outcomes upon the presence of key mediators:

Inaccessible environments and lack of equipment to support a child’s mobility were frequently mentioned as important barriers impeding opportunities for socializing, being active, learning skills and promoting independence (2005: 485-486).

In this example, mediators are clustered together in relation to an outcome but the integrity of the mediating solution as a whole is not addressed. Across the literature, 15 articles were located which either clustered or investigated two of the three mediators of interest together; only two investigated all three. This limited literature set was analysed for evidence to explore the research question, and so conducting the empirical study was critical to providing a more substantial data set.

Method: data analysis

‘The Equipment Study’ dataset (n-100) included numbers of and types of support or mediator used or desired against a range of life areas. These counts, and the free text field narratives accompanying each life area, were analysed to identify mediators used by respondents and any relationships between them.

Mediators in focus comprise three elements: AT (aids and equipment/ devices), EI (or environmental modifications within the home and in the community), and
PC. The method for identifying the mediator used involved analysing data against the following codes:

- an instance of AT device usage;
- an instance of environmental adaptation; or
- an instance of personal care.

Prevalence, that is, instances both of use and of unmet need, was established by counting the number and type of mediators reported. Thematic analysis was also conducted on the accompanying narratives. In terms of categorisation, mediators were analysed against 'ISO 9999 Assistive Products for persons with disability—classification and terminology' (ISO 2007) as a taxonomy of assistive devices. Additionally, the environment chapter of ICF was included as a complementary taxonomy of environmental factors in order to augment the product-focus of ISO and represent environmental factors more broadly. To operationalise these mediator sets, a matrix was constructed for each of AT, EI and PC, using subchapters of ISO 9999 and WHO ICF (see Taxonomy of Mediators Appendix C). These classification systems reflected differing degrees of detail: for example, the WHO subchapter dealing with personal indoor and outdoor mobility (2001: e120) did not differentiate between powered and manual wheelchairs; but when used together the systems presented a finely distinguished set of definitions that matched the majority of the data (see Table 3).

Table 3: ICF/ ISO definitional matrix for mediators

<table>
<thead>
<tr>
<th>Key concept:</th>
<th>Definition includes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT Devices</td>
<td>ISO 9999 Assistive Products for Persons with Disability (2007)</td>
</tr>
<tr>
<td></td>
<td>Products and Technology Chapter 1 (WHO 2001)</td>
</tr>
<tr>
<td>Environment</td>
<td>Furnishings and adaptations to homes and other premises &amp; Assistive products for environmental improvement, tools and machines (ISO 9999 2007: 40; 55)</td>
</tr>
<tr>
<td></td>
<td>Natural Environment and Human Made Changes to Environment Chapter 2 (WHO 2001: 182)</td>
</tr>
<tr>
<td>Personal Care</td>
<td>Support and relationships Chapter 3; Attitudes Chapter 4; Services, systems and policies Chapter 5 (WHO 2001: 187; 191; 192).</td>
</tr>
</tbody>
</table>

The ICF/ ISO matrix proved exhaustive in terms of classifying the diverse range of mediators reported in the data, including unique non-commercial and
infrequently used products identified by respondents. This approach in both data
collection and analysis methods enabled a diverse set of mediators to be
documented and classified. Having scope within a survey to list other supports
overcomes the methodological risk of failing to capture important aspects
through applying a limited question set (Ryan, Campbell, Rigby et al. 2009:
195). This classification system enabled all reported mediators to be classified
and analysed. Many participants identified the same items as mediators in a
number of life domains (a wheelchair being utilised, for example, across
Personal Life, Social Life, and Economic Life). These instances of multiple use
were noted but not counted for the primary analysis, in which each individual
element of a participant's mediator set, both current and desired, is counted as a
single instance of met need or unmet need.

Finally, analysis of the combined use or desire for mediators (that is,
participants' identification of multiple mediators to address a desired outcome)
was also captured to evidence any relationship of AT, EI and PC to each other.

- **Analysis for sub-question 2b: What is the effectiveness of identified mediators?**

  **Method: literature analysis**

  Outcomes derived from AT, EI and PC use, or outcomes denied when these
  mediators are not fully available, are focal areas of this inquiry. In order to
  understand and evaluate notions of 'efficacy', the literature was analysed to
  identify the outcomes areas (i.e. indicators of efficacy) related to use or denial of
  mediators, and to establish evidence of the effectiveness of mediators in relation
to the identified outcomes.

  A range of literature, including focal studies (Mann et al 1999, 2002),
government reports (Audit Commission 2002, Connell et al. 2008) and clinical
practice guidelines speaks to the impact of these mediators and their
effectiveness on a wide range of parameters (as reported in Chapter 6). The
scope of outcomes attributed to AT, EI and PC varied widely, from narrowly
defined outcome measures to very broad outcome concepts. Mediators have
been researched for their impact upon body functions and structures or areas of
activity or participation, either singly or in combinations, using indicators such as
independence, participation, satisfaction, and difficulty. A subset of studies
evaluates the impact of individual AT devices in terms of uptake, usage and satisfaction with the AT device, and the impact of AT devices upon social costs represents another cluster of outcomes for AT, EI and PC.

A number of the outcome areas outlined above are economic in nature, and the economic outcomes of these mediators represent a complex yet under-researched area of enquiry. Economic outcomes for AT and EI are measured or framed in varying ways, and outcomes indicators can be found related to healthcare costs (frequency of admissions, cost of bed days); cost saving (prevention of secondary medical complications; alleviating carer burden; injury prevention); health related quality of life; time use and time saving; and the relationship between these items.

In 2005, Lenker, Scherer, Fuhrer, Jutai and Deruyter found the major outcome domains used across 82 studies of AT outcome from 1980–2001 to be device useability, user satisfaction (with the AT device), quality of life, social role performance, functional level, and cost. Of the 162 studies reviewed for the thesis, only five focused on outcomes to do with overall life participation (broadly defined), quality of life or subjective wellbeing. The majority of the studies reviewed focused on narrowly defined outcomes, such as applying standardised assessments to specific outcomes within specific diagnostic groups rather than whole of life outcomes or those related to participation and quality of life. The literature review failed to identify any stand-alone instruments of data collection suitable for capturing whole-of-life outcomes (related to the provision of AT and related mediators) or to comprehensively explore outcomes defined by people with disability.

Clearly, evidence regarding effectiveness, in the form of outcomes, is conceptualised in many different forms, and the methods applied to capture ‘effectiveness’ differ widely. A host of complexities in relation to exploring the effectiveness of mediators arises from the literature review as summarised below.

Firstly, perceptions of ‘valued outcomes’ are not stable, appearing to alter over time based on research trends and other developments. Which outcomes are selected or deemed to be of value appears to relate to the perspective and values of the stakeholders seeking evidence. As Stineman et al. argue, ‘The
difference among and between patient satisfaction measures and outcome measures illustrates the history of whose standpoint these tools are usually devised from’ (2008: 679). This observation is echoed by Gibson et al., who, in revisiting therapy assumptions in children’s rehabilitation, noted ‘discrepancies between performance outcomes and patient satisfaction’ (2009: 1446).

Outcomes discourse has shifted over the last decade from function and independence towards activities and participation. This is probably due to the publication of the World Health Organizations' International Classification of Functioning, Disability and Health (ICF) in 2001 which provides a common definitional understanding of these terms and has been accompanied by the uptake of the language of participation and broader perspectives upon human rights (Hurst 2003).

Secondly, the focus of the outcome measure may fail to pinpoint the effectiveness of the intervention due to disjuncture between measurement focus, method, and outcomes actually experienced. Some methods designed to capture statistically significant outcomes fail to capture clinically significant outcomes. For example, in one study, staff and people living with disability provided positive qualitative responses about an AT device that enabled individuals to switch on a TV independently, as this had been identified as a desired outcome; however, no significant measurable difference in quality of life was recorded by the measurement scales used, even though they had been tailored to the population being studied (Perry and Beyer 2009). It is also difficult if the particular ‘lens’ used to identify outcomes obscures the presence of related outcomes, as mediators may have impacts beyond those captured by the outcome measures being applied. Such unnoticed impacts may occur concurrently or subsequently, and will not be captured unless the outcome tools are sufficiently sensitive, multifactorial, and used over time. Rabiee et al. (2005) note repeated utility where the same support contributes to the achievement of different outcomes, as well as identifying the hierarchical and interdependent nature of outcomes, leading to ‘outcome chains’ where

Achievement of some outcomes depends on other, more basic and intermediate outcomes having been met first, creating ‘outcomes chains’. For example, maximizing a child’s communication ability opens doors to
opportunities to socialize and be active. Conversely, barriers to achieving one outcome also inhibit the achievement of another outcome. (2005: 485-486)

In another example, Ryan, Campbell, Rigby et al. introduce AT in the form of adaptive seating devices to young children with cerebral palsy. The outcome measures used were sufficiently sensitive to identify outcomes that extended beyond the original focus on the individual child, demonstrating that AT also had ‘a significant positive effect on the lives of families’ (2009: 31). Such examples highlight the critical need to both capture outcomes in the real world and use evaluative methods that are able to respond to novel or unexpected outcomes from a broad perspective.

This short critical discussion of the complexities and limitations of outcomes literature in this field tends to suggest that evidence may underestimate rather than overstate outcome results, and under-report outcomes related to whole of life participation.

Method: data analysis

To determine the effectiveness of mediators, several analyses were conducted using ‘The Equipment Study’ quantitative dataset (n=100). This included an analysis of demographics, a health-related quality of life measure, and numerical data regarding participant-identified impacts. Qualitative data regarding participant-identified impacts (captured in the open text responses to all questions related to current and optimal situations) were also utilised. More extensive quantitative and qualitative data including expert-identified impacts (n=8) from the interview series were also utilised in the following analyses:

1. analysis of diversity of AT users by disability category to evidence breadth of AT efficacy;
2. analyses against the outcome measures adopted for this study: participation in life areas, satisfaction with participation, difficulty, HRQoL, and time use.

These outcome areas and methods of data analysis against them are described below.
i. Participation in life areas

The Equipment Study’ method sought data collection processes that would encompass human endeavour broadly, going beyond the level of ‘activity’ which is overly privileged in rehabilitation and medical literature, and therefore used two congruent frameworks from WHO (2001) and Wilson (2006).

Wilson’s (2006) framework offers an overarching set of eight life areas applicable to all humans, encompassing all functions and activities within aspirational areas. All domains focus on areas of human participation, and component activities sit within these; hence, communication, mobility and other ‘sub-domains’ are found nested within the life areas of personal wellbeing, social life, political life, cultural life, recreational and leisure life, economic life, educational life, and spiritual life. This range of inclusions was felt to be comprehensive in providing a ‘classification of all areas of human life, from the mundane (taking care of one’s physical appearance) to the highest planes of human existence (education, employment, spirituality and cultural, social and political involvement)’ (Bickenbach et al. 1999: 184). Impacts of AT solutions were readily mapped into categories; for example, ‘Personal and Family Wellbeing’ is inclusive of mobility, communication, and self-care, yet names the meta-goal rather than the elements or functions within it. This relatively recent framework, developed in Victoria, is currently undergoing validity and reliability studies (Wilson 2006). The domains are listed and explained in Table 4.

The second framework of analysis is the WHO ICF (2001), which has the advantage of being internationally recognised and adopted. The ICF is congruent with the epistemological approach of the thesis in that it embraces ‘impairment effects’ alongside understandings of the environment as barrier or enabler (WHO 2001). The ICF identifies nine sub domains of ‘Activities and participation’ (WHO 2001: 125–170). This classification framework identifies both what could be considered a number of ‘foundational’ life areas such as communication, mobility and self care, as well as broader areas identified as ‘Interpersonal interactions and relationships’, ‘major life areas’ (including education, work and economic life), and ‘community, social and civic life’ (including recreation and leisure, religion and spirituality, human rights, political life and citizenship). The AEAA stakeholder reference group for ‘The Equipment Study’ found the articulation of ‘Activities and participation’ within the ICF,
particularly Chapter 8, ‘Other life areas’ and Chapter 9 ‘Community, social & civic life’, to be welcome affirmations of the broad array of outcomes to which people living with disability can aspire. Of key importance was the understanding that the activities and participation chapters reflect the goals and aspirations of society at large.

Despite these positives, the ICF Activity and Participation Framework was criticised by the stakeholder reference group for positioning underpinning functions such as mobility and communication at the same level of importance as, for example, community, social, and civic life. Another flaw in the framework is its failure to capture the presence of underpinning functions in every chapter: for example, it is hard to imagine participating in major life areas without addressing the communication or self-care activities that necessarily underpin these, such as participation. While communication and mobility are clearly crucial elements of performance in life, people generally do not define them as end goals (Layton and Wilson 2009): in other words, positioning underpinning activities (or ‘sub-categories’) such as ‘mobility’ and ‘self-care’ alongside much broader, ‘meta’ participation areas such as ‘Major life areas’ and ‘Community, social and civic life’ was perceived by the stakeholder reference group as an overprivileging of underpinning but largely functional tasks as ends in themselves, resonating with traditional rehabilitation approaches. This set of considerations led to the decision to use both the ICF and Wilson Life Domains frameworks to guide analysis of outcomes resulting from AT, EI or PC use, or outcomes denied through the absence of these mediators.
The relationship of ‘sub’ or underpinning domains to overarching domains is depicted in Figure 4, while the conceptual relationships between the two frameworks is identified in Table 4.

**Table 4: Relationship between ICF Chapters and Wilson Life Domains**

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Learning &amp; applying knowledge; Mobility; Self-care</td>
<td>Personal Life</td>
</tr>
<tr>
<td></td>
<td>health and function, happiness, wellbeing, safety, sense of independence and choice.</td>
</tr>
<tr>
<td>Communication</td>
<td>Social Life</td>
</tr>
<tr>
<td></td>
<td>friendships and relationships, community involvement and sense of belonging.</td>
</tr>
<tr>
<td>Major life areas</td>
<td>Recreation &amp; Leisure Life</td>
</tr>
<tr>
<td></td>
<td>being involved in recreational or leisure activities at any level. This might be through attending activities, playing an active part or doing what you enjoy.</td>
</tr>
<tr>
<td></td>
<td>Economic Life</td>
</tr>
<tr>
<td></td>
<td>finances, employment or business.</td>
</tr>
<tr>
<td>Community, social &amp; civic life</td>
<td>Educational Life</td>
</tr>
<tr>
<td></td>
<td>relates to your education, training, personal or professional development.</td>
</tr>
<tr>
<td></td>
<td>Political life</td>
</tr>
<tr>
<td></td>
<td>having a say about things that affect you (e.g. in a local service or community group, about your local area, funding</td>
</tr>
</tbody>
</table>
From a data collection perspective, instances were classified as outcomes achieved or denied according to response categories: that is, whether data was entered (on the survey) or narrated (during interview) in response to specific life domains. A validity check of the response theme by the primary researcher verified the life domain and the nature of the outcome. The methodological choice to locate mediator use within life domains such as educational life or civic life, rather than among underpinning activities (such as mobility) proved valuable as it provided detailed evidence of the repeated utility of such devices as wheelchairs in the whole of life context.

**ii. Satisfaction with life participation**

While satisfaction with a particular AT device or service represents one set of uses for this term (Iwarsson and Wilson 2006; Wessels et al. 2003, 2004), for ‘The Equipment Study’ method, satisfaction relates to the extent of life participation (Bricknell and Madden 2002). As ‘The Equipment Study’ utilised the electronic Functioning and Health Related Outcomes Module (eFHROM) (AIHW 2005), a data collection format organised against the ICF framework, participation, difficulty and satisfaction were operationalised as per this tool. Bricknell and Madden (2002) of the Australian Institute of Health and Welfare were tasked with constructing eFHROM, and note that choice and satisfaction were critically important both in their consultations with people with disabilities, their carers, and service providers, and in the quality of life literature, in order to indicate ‘whether the level of participation experienced by the respondent is personally fulfilling and appropriate’ (Bricknell and Madden 2002: 6).

Data on satisfaction with life participation was not explicitly sought for ‘The Equipment Study’ survey cohort, although the theme of satisfaction/dissatisfaction arose within the open-ended comments captured by the survey tool. Satisfaction with participation was elicited from interview participants both...
at baseline (current situation) and post-provision of the hypothetical optimal AT solution (see scales in Table 5). A pre–post comparison was therefore conducted, as well as analysis of the qualitative interview data.

**iii. Difficulty**

Within the survey, participants were asked to report their degree of difficulty with each life area on a six-point rating scale, then to re-rate the projected difficulty level per life domain with hypothetical improvements. The subset of interviewees was asked to rate pre- and post-change in difficulty levels on a five point scale provided by eFHROM, by activity and participation domain. Analyses of both sets of data related to difficulty were conducted, as well as an analysis of the narratives concerning difficulty.

For both satisfaction and difficulty as captured by the eFHROM tool, it was noted that the scales provided (see Table 5) did not capture change noted to be of significance to the participants, as the percentage jumps within the scales were substantial. For this reason, interviewees were additionally offered an open percentage rating in order to capture more nuanced degrees of change.

**Table 5: eFHROM scales for difficulty, satisfaction and extent of participation, and personal assistance**

<table>
<thead>
<tr>
<th>Difficulty</th>
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</tr>
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<tbody>
<tr>
<td>0 No difficulty in this life area 0-4%</td>
<td></td>
</tr>
<tr>
<td>1 Mild difficulty 5-24%</td>
<td></td>
</tr>
<tr>
<td>2 Moderate difficulty 25-49%</td>
<td></td>
</tr>
<tr>
<td>3 Severe difficulty 50-95%</td>
<td></td>
</tr>
<tr>
<td>4 Complete difficulty 96 -100%</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal Assistance</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0 Does not need help or supervision 0-4%</td>
<td></td>
</tr>
<tr>
<td>1 Sometimes needs help/ supervision 5-24%</td>
<td></td>
</tr>
<tr>
<td>2 Always needs help/ supervision 25-49%</td>
<td></td>
</tr>
<tr>
<td>3 Unable to do this life area, even with assistance 50-95%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Extent of Participation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0 Full participation</td>
<td></td>
</tr>
<tr>
<td>1 Mild participation restriction: restricted in their participation less than 25% of the time</td>
<td></td>
</tr>
<tr>
<td>2 Moderate participation: restriction less than 50% of the time</td>
<td></td>
</tr>
<tr>
<td>3 Severe participation restriction: participates rarely and/ or with an extreme effect on functioning</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Satisfaction with Participation</th>
<th></th>
</tr>
</thead>
</table>
0 High satisfaction
1 Moderate satisfaction: reasonably satisfied in terms of duration, frequency, manner and outcome
2 Neither satisfied nor dissatisfied
3 Moderate dissatisfaction: two or three criteria (duration, frequency, manner or outcome) are not fulfilled
4 Extreme dissatisfaction: all criteria (duration, frequency, manner and outcome) are not fulfilled
5 Complete restriction and dissatisfaction: not participate in this life situation in line with his or her own goals
(Sykes et al. 2007)

iv. Data related to economic indicators: health related quality of life (HRQoL), costs and time use

‘The Equipment Study’ method collected data against each economic indicator, as described below, with accompanying analysis strategies.

As outlined in Chapter 2, a measure of HRQoL and the costs of a proposed intervention (as well as the costs of the current intervention) are necessary ingredients to identify an incremental cost-effectiveness ratio (ICER) to demonstrate the effectiveness of an intervention. As the benefits of many health interventions are non-fiscal, quality adjusted life years (QALY) is the preferred measure of utility (Gold, Siegel, Russell and Weinstein 1996). The QALY is calculated using data collected via a measure of HRQoL. ‘The Equipment Study’ utilised Assessment of Quality of Life (AQoL) 6d (Hawthorne and Osborne 2005) as an instrument for this.

‘The Equipment Study’ survey invited all participants to complete the AQoL as a measure of current HRQoL. The AQoL was readministered for a subset of interview participants (n=8), enabling a comparison of HRQoL states with and without a hypothetical optimal set of mediators. Interview participants also had current and optimal sets of mediators costed, to enable the economics team to conduct an ICER, specifically a cost consequence analysis.

Of the survey participants, sixty-seven participants provided complete AQoLs, while 33 returned incomplete AQoLs. In analysing the AQoL data, standard procedures for handling any missing data were followed whereby scores can be
imputed if fewer than three are missing, as long as no two are missing from a single domain (Franic and Pathak 2003). This enabled a total of 77 AQoL scores to be obtained from the survey population of 100. All but one interviewee underwent two AQoL ratings. Data analysis protocols were followed (Richardson Day, Peacock and Iezzi 2004) as outlined in Colgan et al. (2010: 152). This generated quality of life scores across six different domains of HRQOL (independent living, social functioning, mental health, coping, pain and sensory perception), and captured life quality in a standardised format. As a result, analysis could compare the AQoL scores of participants with those of the rest of the Australian population. Additionally, costs of current and optimal mediator sets underwent economic analyses against a current QALY benchmark of $50,000 (Colgan et al. 2010). This analysis is published in Colgan et al. and presented here.

The final data analysis for economic indicators entailed thematic analysis of both survey and interview question sets regarding time use, reported in Chapter 6. Inductive line by line narrative analysis of all text related to time use resulted in four emergent themes: ‘wasted time’; fatigue and ‘crash recovery’; quality of time; and productivity.

SECTION 3 Research question 3: What is the social contract between society and its citizens with impairments?

The policy environment significantly influences the lives of AT users. To describe the policy context for living with disability and attaining mediators, a range of policy literature was appraised, that is, academic literature and government publications, including programme guidelines. This focus on a specific policy context is referred to throughout as a policy ‘case study’.

This policy case study asks: What is the social contract between society and its citizens with impairments? It investigates these through two sub-questions:

3a. How effective is government in delivering equality of outcome through the provision of mediators?
3b. What does government need to do to realise its obligations?

Literature was sought to fulfil the following aims:
• A theoretical review of key concepts like ‘social contract’, ‘equality’ and related concepts such as ‘human rights’, particularly as discussed in relation to people with disability and associated theories;

• a review of literature relating to policies re assistive technology provision to people with disabilities in Australia. This included grey literature such as policy documents, evaluations, research, and advocacy documents.

Literature from the fields of human rights, political science, and health economics was searched during the broad literature searches related to mediators and disability/impairment, as described above. Several seminal texts were used as foundation material for the concept of a social contract (Rawls 1971; Smith 1812). Additional searches were conducted in the grey literature. These included internet searches of Victoria and Australian government, NGO, and consumer/DPO sites to collect data on current AT programmes and their policy context, as well as to establish current statistical information regarding disability in Australia. Additional internet searches reviewed international human rights and health sites such as websites of the United Nations and the World Health Organisation, seeking key legislative and policy documents pertaining to AT and consumer funding within the last 11 years (2001–2013) since the publication of ICF (WHO 2001).

Literature was analysed in relation to both sub-questions 3a and 3b as described below.

-Analysis for sub-question 3a: How effective is government in delivering equality of outcome through the provision of mediators?

Method: literature analysis

Key concepts from the literature review included minority groups versus universalising policy approaches, equality and equity (in relation to the notion of a social contract), and capability gaps (in relation to the differential capacity of individuals to achieve equal outcomes). Several analysis frameworks were developed based upon human rights documentation and social exclusion indices relevant to mediator use, in order to contrast the reported experience and outcomes of the study cohort with theoretic rights. Additionally, literature
reflecting the perspectives of individuals upon the social contract in relation to their expectations of the AT service system was explicitly sought.

**Method: data analysis**

Analyses of the data in relation to the overarching question of the social contract between participants and government was as follows. The cohort underwent demographic analysis against poverty, affordability, and social exclusion indices.

Concurrent, line by line analysis of all narrative responses within ‘The Equipment Study’ survey set pertaining to the theme of policy and provision coded a range of policy limitations identified by respondents. A range of evaluations of the scope and effectiveness of the VAEP were then conducted by comparing the levels of cost subsidy and gap requirement for applicants with the levels of income and financial disadvantage of applicant groups, comparing the range of eligible items listed within VAEP policy with the range identified as used or needed by respondents. Further analysis regarding the range and extent of mediators provided was conducted using ISO 9999 as a benchmark for scope of coverage.

The experience reported by participants was considered in relation to the ingredients or desired elements of AT policy from the perspective of people living with disability (AEAA 2011; De Jonge, Layton and Vickery 2009)

**- Analysis for sub-questions 3b. What does government need to do to realise its obligations?**

To address this sub-question ‘The Equipment Study’ dataset is considered against key ideas from the literature: in particular individualised service delivery approaches, equity measures and weights, and the role of duty holders, generating a range of suggested policy solutions.

**Method: literature analysis**

The human rights context, internationally, within Australia, and within Victoria, was identified as a key mode of analysis for the performance of AT policy. Overall policy analyses sought and compared key policy ideas across policy levels and jurisdictions, as well as identifying key program and funding details to develop a summary of AT funding provision in Australia. A range of policy
material (international human rights-based documents, national disability policy, and State-based AT related policy) was then analysed against human rights tenets. Elements of the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006) pertaining to AT, EI and PC, as well as to general indicators of the right to support, were identified and formed an analysis framework against which to map current policy initiatives and programmes.

SECTION 4 Empirical study: ‘The Equipment Study’ design and data collection method

‘The Equipment Study’ is the primary source of original empirical data for the three inquiries of the thesis discussed above. With the support of another researcher (the thesis supervisor), the study was led by the thesis author, who was primarily responsible for the design of methods and data collection, along with the subsequent data analyses for ‘The Equipment Study’ as well as the thesis (Appendix D presents the role of the thesis candidate in relation to the ‘The Equipment Study’). The study was implemented in the initial stage of the thesis.

‘The Equipment Study’ researched the experience of Victorian adults with a disability using AT, and the impact of AT in their lives. The study sought to identify the range of AT used, the life domains enabled by this use, and levels of difficulty, participation and satisfaction with current use. In addition, the study investigated AT required by participants and the impact this provision would have on life participation, difficulty and satisfaction, and explored the role played by current AT policy in relation to participants’ experiences.

As identified previously the study was commissioned by the AEAA and utilised a participatory or inclusive methodology. This section provides a brief overview of the study design and data collection processes, to inform the data analyses above. ‘The Equipment Study’ sequence is presented in Figure 5; fuller explanations of the study method can be found in the published work (Layton and Wilson 2010) and in Appendix E.
Figure 5: The Equipment Study sequence

The Study utilised an online survey method with both quantitative and qualitative responses, and in-depth interviews with a smaller subset of respondents consisting of both quantitative and qualitative items. Data collection methods are presented below, commencing with the strategies utilised to enact an inclusive methodology (see Appendix E for further details).

**Inclusive research strategies**

1. **Partnership with the AEAA**

Chapter 2 outlined some theoretical perspectives about the role of ‘subjects’ in research and the intent to conduct research ‘with’ and not ‘on’ people living with impairment (Disability Inclusive Research Collaboration 2012). *The Equipping Inclusion Studies* (Layton, Wilson, Colgan, Moodie and Carter 2010), of which ‘The Equipment Study’ is a part, were founded upon a stakeholder-driven research agenda largely developed by Victoria’s Aids and Equipment Action Alliance. This is a non-profit group consisting of people with disabilities, advocates, health professionals and service providers working to improve the availability of aids and equipment to aged and disabled Victorians’ (AEAA 2011: 1). AEAA membership comprises a range of stakeholders within the AT arena, and has features of a consumer group (Löfgren et al. 2011): for example, half of
the board positions are filled by individuals living with impairment (AEAA 2011). As the AEAA had sought and won philanthropic funds to conduct studies into the need for, cost burden, and impact of existing aids and equipment programs on people with disability in Victoria, an emancipatory aim was also partly realised whereby ‘disabled people themselves … are controlling the research and deciding who should be involved and how’ (French 1992: 185). The AEAA Board functioned as the steering group to administer and oversee the rollout of *The Equipping Inclusion Studies*, including ‘The Equipment Study’, while a stakeholder reference group drawn from the membership advised the researchers on the conduct of the research.

2. Stakeholder reference group

Formation of a stakeholder reference group was a key strategy enabling ‘The Equipment Study’ to engage with stakeholders rather than to enact research upon them, and served to fulfil one element of participatory research, namely the exchange of ideas between researcher and stakeholder regarding the research process (Barnes 2001; Stone and Priestly 1996).

Drawn from the existing AEAA evidence and research sub-group, with invitations extended to AEAA members generally, eight individuals formed the core stakeholder reference group. With some crossover where individuals with disability held professional positions, including a social worker with a vision impairment, an AT purchasing officer who had a spinal cord injury, and a speech pathologist with a vision impairment, the group broadly represented individuals living with impairment (3), workers in allied health (2), and policy and advocacy workers from disability organisations (3). This group met at key stages to advise on piloting the accessible on-line survey and the interview tools, to consider the validity and meaningfulness of the methods and data analysis frameworks, and to provide a user perspective on study direction and findings. As well as providing ongoing advice and opinion throughout the research design, execution, analyses and documentation, this core group assisted the researchers in accessing the AEAA membership at several stages to:

1. comment on the review of assessment tools (24 participants in February 2008);
2. comment on research design (18 participants in May 2008);
3. advise and respond to initial analysis of results (20 participants in October 2009); 
4. comment and triangulate in relation to key themes (15 participants in May 2010).

Advice from the stakeholder reference group furnished key inputs for four focal aspects of the research: identifying ‘whole of life’ outcomes to capture the reality of AT issues for people with disabilities in Victoria; recruiting and sampling to define AT users widely and ‘not miss anyone out’; acting as a focus group to triangulate primary analysis; and disseminating results.

**Data collection methods**

Three methods of data collection were used in ‘The Equipment Study’:

1. a survey method (online and paper based), completed by 100 adult Victorians with a disability using AT;
2. a series of in-depth interviews, completed by a subset of 8 respondents;
3. assessment of interview data by a panel of assistive technology experts.

**Survey**

The survey tool comprised 97 questions (see Appendix F). The bulk of the data collection was in relation to six questions seeking detailed descriptions of mediators (AT, EI and PC) used to enable participation in eight life areas (Wilson 2006), any desired improvements, and the impact of any such improvements. These questions formed the first section of the survey. Open-ended questions aimed to elicit broad understandings of mediators by asking ‘what do you use?’ and ‘what else helps?’ in relation to each life domain, with a set of prompts around ‘AT’, ‘EI’, ‘PC’ and ‘other’ (based on the Wilson Life Domains, Wilson 2006). ‘The Equipment Study’ used the ICF definition of participation, ‘involvement in a life situation’ (WHO 2001: 10), and considered participation as it occurs across broad life areas. The eight life domains from Wilson (2006) included in the survey encompassed human endeavour broadly, going beyond the level of ‘activity’ which is overly privileged in rehabilitation and medical literature.
The final survey section included demographic questions, and the middle section comprised the HRQoL question set in the form of the Assessment of Quality of Life (AQoL) 6D quality of life measure (Hawthorne, Richardson and Day, 1999). Developed by Australian researchers, this instrument straddles six dimensions and has standard psychometric properties in terms of validity and reliability (Hawthorne and Osborne 2005). The set of 20 standardised closed-ended questions formed the second section of the survey, and was re-administered to the interview participants after provision of the hypothetical optimal AT solution, to capture projected change.

At the pilot stage, several issues were noted with the AQoL 6D. Firstly, pilot participants criticised the broad scaling that equated functional limits with poor quality of life. Secondly, for individuals using wheeled mobility, the ‘walking’ question (‘thinking about how well you can walk …’) needed to be rephrased into a ‘mobility’ question (‘thinking about your mobility, including using any aids or equipment such as wheelchairs, frames, sticks …’) to render it meaningful. This was done in consultation with the Monash Centre for Health Economics, which authored and maintain the AQoL (http://www.aqol.com.au/). It is understood that utility measures will be undertaken to weight this amendment and it will become part of the tool in future (personal communication with A. Iezzi by telephone and email, 18 June 2009).

While the survey tool was the primary form of data collection for the study cohort, a subset of participants (n-8) were selected for an interview series. The interview tool was designed to capture more in-depth pre-and post-data, and was structured according to the ICF (2001) activity and participation chapters as described below.

**Interview**

Interviews were conducted with eight participants (selected for maximum diversity across body structure and functions, life situations, age, and living situations – see Appendix B) to capture more in-depth pre-and post-data. ‘Pre’ or first interviews recorded detailed descriptions of various ratings of life participation, HRQoL, and time use, as described below, and were a measure of the current outcome levels given current AT, EI and PC use. Interview data were then de-identified and presented to a panel of AT experts who recommended
both ‘basic’ and ‘optimal’ level AT solutions for each interviewee. The literature concerning optimal provision is reported in Chapter 5 of this thesis and an operational definition constructed for optimal provision in the Australian context: the best combination of enablers including any solution, regardless of cost, currently on the market and available in Australia. These detailed but hypothetical solutions were returned to interviewees who then participated in a second or ‘post’ interview to re-rate their predicted participation outcomes with the hypothetical AT solution.

From a methodological perspective, a hypothetical intervention has inherent limitations and any findings must be viewed as indicative only. It does however offer a means to explore potential outcomes, particularly relevant in service delivery contexts where ‘usual treatment’ is known to be limited, and where resources do not allow provision of optimal solutions, particularly without any exploratory work as to potential impacts.

Interviews were structured according to the ICF (2001) activity and participation chapters by utilising the eFHROM (AIHW 2005) as previously outlined. Appendix G presents the standard interview protocol, and the amended protocol for the Deafblind participant. Refer to Appendix H for the expert panel selection and procedure. The eFHROM indices of measurement include difficulty, the extent of assistance needed, the extent of participation, and satisfaction with participation (an example of the eFHROM tool can be found in Appendix H).

The eFHROM tool enables a rating of the individuals’ level of difficulty, need for personal assistance, extent of participation, and satisfaction with participation against each subchapter of the ICF of relevance to the participant; the eFHROM scaling is outlined in Table 5. All parameters were rated by the participant with the exception of ‘extent of participation’, which was rated by the interviewer. While an external rater can be seen as an epistemological compromise in research that aims to be emancipatory, it was adopted in this limited instance in order to provide an additional perspective on the dimension of participation. The perspective of the occupational therapist researcher as an external rater aimed to ensure that ‘universalism has been captured by setting the norm of full participation as at a level of participation that could be experienced by an individual with no disablements’ (Bickenbach et al. 1999: 5). This intent is
echoed by the eFHROM authors, who point out that the third party rating is to attain objective and subjective measures of participation, with the interviewer taking into account participation ‘norms’ (AIHW 2003; 2005).

Having identified a range of parameters to guide data collection in ‘The Equipment Study’, data analysis is discussed below, followed by ethics, sample and recruitment methods.

**Ethics Approval**

Ethics approval was obtained to recruit a sample of 100 survey participants. Inclusion criteria for the survey included being a person with a disability, a user of AT, a Victorian, an adult, and having sufficient English and cognitive capacity to complete the questions without the need for proxy reporting (use of scribing or other physical assistance was not an exclusion criterion). Ethics approval was granted by Deakin University Human Research Ethics Committee (Project EC 5-2009) in February 2009, with a subsequent June 2009 amendment to approve both the on-line survey format and the reinterview of participants based on the results of the pilot stage, as reported below. A July 2010 amendment provided the opportunity for interview participants to confirm or withdraw consent regarding publication of contextual data pertaining to them.

**Sample and recruitment**

One hundred adult Victorians living with disability were sought. While not large enough to be representative of the population living with disability in Victoria, it was hoped this would be large enough, and sufficiently diverse, to illuminate a wide range of experiences of life with AT and other enablers across a broad range of living situations and demographics. The survey was directed at adults using AT (using the colloquial term ‘equipment’ as a non-labelling attempt to target users of AT).

Despite recognition of the AT needs of children and families by the stakeholder reference group and researcher, the decision was taken to focus on over-18-year-olds in ‘The Equipment Study’. The rationale for this was primarily methodological: children’s participation needs required a different set of outcome areas (DHS 2001; Oladeji et al. 2007; Raghavendra and Lane 2006; Rentinck et al. 2009). The scope of this study did not allow for additional
development or parallel use of children and youth tools such as children and youth tool ICF-CY (WHO 2007). Further, in order to strengthen the reliability of the self-report and to simplify the ethics process, proxy reporting was not included as a response method, and it was thought likely that the inclusion of under-18s would have led to substantial proxy reporting by family members.

An information flyer (see Appendix I) was distributed through 34 member organisations of the Aids and Equipment Action Alliance (AEAA) and 11 other community and age-related organisations. Recipients of the survey flyer were invited to forward the information to any other Victorian organisations or individuals who fitted the inclusion criteria. Many organisations like the Australian Quadriplegic Association, the Chronic Illness Alliance and the Polio Network advertised the survey via their newsletters and publications. The survey was also promoted by word of mouth through case managers, hospital social workers, community occupational therapists, and people living with disability themselves. Particular efforts were made to identify individuals who might not engage with health or disability organisations and services, such as the delegates to the Art of Difference International Deaf and Disability Arts Event (2009). Appendix J (Recruitment and Sample) contains a full list of agencies through whom the survey was distributed.

Response Size

One hundred paper copies of ‘The Equipment Study’ survey were distributed with reply paid envelopes, and approximately 1,000 hits were recorded on the on-line survey site between September and December 2009. Thirteen completed paper versions were mailed back and 92 online surveys were uploaded, giving a response rate of approximately 10% for both online and paper versions of the survey tool. It is likely the snowball distribution would have continued to generate additional responses, but the survey was closed on 31 December as the project had fulfilled the participant quota for which there was ethics approval, and had expended the research monies set aside for reimbursing survey participants. Of the 105 surveys returned, five completed surveys were excluded as they were from respondents who did not fit the inclusion criteria (not within Victoria, or not over the age of 18).
Eighty surveys were complete in all three sections (97 questions). Five participants availed themselves of recompense for their support needs, and one requested the researcher to physically scribe survey responses. As survey responses were not forced, the extent of completion of each question varied. Altogether, 100 returned surveys contained information able to be used within ‘The Equipment Study’: in other words, data pertaining to some (if not all) of the survey question set, beyond demographic data. The demographic questions were placed in the final section so participants had to scroll through all other questions first. Had they been positioned at the front, possibly a higher completion rate would have been achieved, but it is also likely client experience in the form of the ‘stories’ of AT use would have been fewer; this is one of the trade-offs of survey design.

**Concluding comments**

In drawing this section on methods together, the chapter will return briefly to the ontological and epistemological ideas of Chapter 2. The formulation of disability, whether expressed in individual pathology methodologies (typified by biomedical and functional approaches) or socio-political methodologies (such as the environmental approach and the rights-outcome approach) plays a key role in articulating the overarching complexity of life with impairment. Rioux calls on thinkers to analyse their own standpoint, particularly in relation to the horizon of those ‘hearing’ and using work in disability across disciplines:

> The research community in the field of disability has created a world of ‘disability facts’, but has been relatively unconscious about the judgements it has made in doing so. In creating the world of facts, we have assumed that the place of judgement belongs to the advocates, the policy-makers, the politicians and the courts ... we need to recognise the very real forces that shape the questions we ask and the criteria of validity we adopt. Recognising the relative nature of disability found in the different approaches should provide an opportunity to address the reductionism common to disability research and scientific findings. (1997: 109)

Critiques of the literature from both disability theorists (Shakespeare 2006) and AT researchers (Fernie 2008) note the dominance of positivist approaches and call for more user-focused and user-driven research which both encompasses
meaningful outcomes and captures effectiveness in the real world. The limitations of the literature base point to the need to further explore and rethink the potential outcomes of AT, EI, and PC, particularly to find the outcomes valued by people living with impairment. Outcome measures which represent an atomised view of functional elements, selected for the standardised properties of the outcome tool, raise questions as to the authenticity of the link to the lives of individuals with disabilities (Hammel, Magasi, Heinemann, Whiteneck, Bogner and Rodriguez 2008). Applying this frame or view justifies the inclusion of broad evidence sources and highlights the limited horizon of many studies deemed rigorous on other criteria. As Hoenig et al. state,

The vital next step in AT research is to understand the effects of AT in the daily lives of typical consumers. This requires a change in the approach used for the preceding half-century, which was one of rapid development and deployment of new devices with limited evidence of efficacy. (2007: 167)

A need is evident for more nuanced research designs which will evidence outcomes of AT, EI, and PC which are ‘unseen’ due to the pervasive and integrated nature of AT solutions and therefore are likely to have been underestimated in terms of their impact (Djikers et al. 2000; McInnes et al. 1994; Whiteneck and Djikers 2009). Examining the role of environment in relation to impairment is essential to ascertain the extent of social model and critical realist assertions regarding sources of disablement and the ways to mediate them. Whiteneck et al. argue that

data on measures of societal participation will test an underlying tenet of disability rights that environmental barriers reduce full participation in society, above and beyond the impact of impairments themselves ... research can be a step toward improving the lives of people with disability by turning environmental barriers into environmental facilitators. (2004a: 1325)

Particularly important, then, is research which encompasses outcomes emerging from the person–occupation–environment interaction (Wilcock 2006). Given that EI and AT are not single measures in themselves but ‘parts of an ongoing transactional process influencing occupational performance’, their effect upon the individual’s experience of participation and disablement is the key
outcome (Ivanoff et al. 2006: 115). It is clear that Australians with impairments currently describe significant barriers at both environment and individual levels:

There is much talk of community involvement and participation, but when individuals don’t have access to the necessary mobility and communication tools to partake, then it is not possible. (National People with Disabilities and Carers Council 2009: 26)

Turning to the measurement of HRQoL, as foreshadowed, from a disability perspective substantial criticisms can be made of such standardised measures. These focus upon oversimplifying multiple outcomes into a single measure (Coast 2004: 1234); limited vision regarding the ingredients of a quality of life (Dobes 2009; Garcia-Gutierrez and Salvador-Carulla 2011; Manns and Chad 2001; Scherer and Cushman 2001; Shalock 2004); an overly medicalised focus upon parameters of functioning (Frain et al. 2009; Richardson and Nord 1995; Whalley-Hammell 2007) and a calculation method which is insensitive to valued changes for disability (Drummond et al. 1997; Nord et al. 1995). The dilemma of using a potentially marginalising instrument was taken to the AEAA stakeholder reference group, who reiterated their commitment to engage with economics and its methods in order to generate much-needed economic evidence regarding life for people needing AT. The opportunity to examine and to critique the AQoL and QALY methodology was seen as a beneficial outcome of the process, and indeed has led to a revision and improvement in method among the AQoL authors.

For research to be meaningful, it must ‘address issues within large social systems that involve consideration for the social, physical, and/ or economic environment ‘(Johnston et al. 2009: 5). The three inquiries of this thesis, then, focus upon the standpoint of the person whom the research is about and take a broad perspective of outcomes. Methods are intended to capture outcomes valued by individuals living with disability, and the impact of mediators in the broadest sense, to establish a body of evidence which, as far as possible, is not subject to the limitations described in much of the literature.
Chapter 4: A conceptual review of impairment and disability

The first step in determining how individuals living with impairment may achieve equal outcomes is to investigate how impairment and disability are understood (research question 1), and specifically, whether (and in what ways) disability may be different from the absence of disability (sub-question 1a). The exploration presented below informed two further sub-questions: whether the presence of impairment or disability impacts upon people’s life aspirations (sub-question 1b); and the role of impairment effects and environmental barriers in creating disablement (sub-question 1c). These questions will be addressed through a conceptual review of impairment and disability based upon the literature review method outlined in Chapter 3 and triangulation with data from ‘the Equipment Study’. Particular attention is paid in this chapter to the identification of the views of people living with disability in line with the principles of epistemological justice.

Introduction

Assertions about the nature of impairment and disability spring from ontological beliefs about the nature of being. Different understandings of disability and impairment inform the production of research evidence. Rioux describes the implications of this knowledge:

Ways of viewing disability, of developing research questions, of interpreting research results, of justifying research methodology, and of putting policies and programmes in place are as much about ideology as they are about fact ... to understand the field, it is useful to explore the social and scientific formulations of disability which underpin the research agenda, and the ways of knowing disability. (1997: 109)

A key discourse influencing the topic of this thesis is the nature of impairment and disability in the context of the social world. Policy is crucially underpinned by understandings of impairment and disability. Conceptualising disability as a disease, for example, may lead to service responses based on the presence and legitimacy of ‘need’ for remediation, via AT or related means; while
conceptualising it as oppression may raise human rights-based arguments about the legitimate demands of individuals to live in a barrier-free environment. Clearly, differences in view will determine societies’ responses towards individuals living with impairments. Indeed, even the selection of terminology is loaded: for example, the term ‘disabled person’ remains popular in the UK as it reflects a belief that people ‘are disabled’ by the environment (French 2012), a concept which is not captured by the alternate term ‘people with disability’ used by ISO (2007). Australia does not generally use the term ‘disabled person’. ‘People/ person with disability’ (PWD) is the most commonly used Australian term, which also captures the disabling effects of environments. ‘Living with impairment’ most accurately depicts the presence of impairment effects as one aspect of a person’s identity and one which captures human variation broadly; for example, members of the study sample living with chronic illness identified with this term where they might not have not identified themselves as disabled.

For this thesis, the terms ‘individuals’ or ‘persons’ living with disability’ or ‘living with impairment’ are used interchangeably. Additional relevant language is the term healthcare ‘consumer’ (Löfgren et al. 2011) and, more specific to the thesis topic of mediators, ‘AT user’ (De Jonge et al. 2007). These terms will also be used where relevant. Establishing the various discourses relating to impairment and disability is a fundamental step towards understanding today’s policy and resourcing context, which are likely to be premised on such foundations.

Discourses of impairment and disability

**Disability as disease: the medical model**

The context of any writing is necessarily societal. The binary of deviance versus normality has pervaded writings concerning impairment from early history until the current day (Annison et al. 1996; Charlton 1998; Deal 2003; Kristiansen et al. 2009). Religious, political and economic forces influence perceptions of impairment, contributing to the ongoing problematising of disability (Calder and Newell 2004; Sussman 1965). For example, Thomas proposes that the transition from feudalism to capitalism in the West brought about ‘causal economic mechanisms (that) worked to generate disability’ (2004: 572), due to the focus on productivity and individualism. This brought about the rise of ‘an
ideological context in which being dependent on others came to be seen as problematic in ways it had not been before’ (Goble 2004: 41).

A widely held Western view has disability framed as a personal tragedy (Crashaw 1994), thereby creating an opportunity for the dominance of disability professionals within what came to be termed the medical, latterly the rehabilitation, model. Discourses of disability were informed by the ideologies of these professionals, even though the professionals’ world view might ‘contrast sharply with that of a disabled person using the professional’s service’ (McCormack and Collins 2012: 156). Within medical and rehabilitative models, support for vulnerable people was premised on the belief that disablement of people was a result of illness and disease and existed in the domain of the body (Annison et al. 1996). Professionals hold perceived power to normalise the individual ‘through corrective rehabilitative, re-educative and orthopaedic interventions’ (Gzil et al. 2007: 1618).

The implications of a medical view of disability are twofold. Firstly, the presence of impairment is framed as deviance from a norm (Stowe et al. 2007), and serves to identify the person as ‘other’. The early disability literature describes this as a ‘dilemma of difference’, first articulated by Goffman (1963) in his seminal work on stigma and asylums. Goffman foreshadowed the disability movement’s later challenge to norms: ‘The question of social norms is certainly central, but the concern might be less for uncommon deviations from the ordinary than for ordinary deviations from the common’ (Goffman 1963: 152). ‘Otherness’ is a multifaceted concept, explored variously by feminist, postcolonial and disability theorists. In disability, the process of categorisation according to impairment can be seen as a mechanism of othering, a process that ‘established and reinforced notions of the boundaries between normalcy and aberrance in Western society’ (Albrecht et al. 2001: 13).

A second effect of the medical approach is that people living with the effects of impairment are effectively marginalised from mainstream life on a variety of fronts, compounding the experience of disability. As Crashaw explains,

Disabled people came to be seen as having problems, in that there was something ‘wrong’ with them so the medical profession moved in to try and cure them. If they were not cured, disabled people were, and still are, set
aside from the rest of society, as second class citizens, denied access to many areas of life. (1994: 27)

This denial of access to life areas manifests as a separation of outcome expectations (Goffman 1961, 1963; Wolfensberger 1975), leading to a situation where not only are people living with impairment absent from many aspects of human endeavour, but their absence goes unremarked (Goggin and Newell 2005; Thomas 2004). The preoccupation with normality is such 'that illness and disability become separated from everyday life and constructed as forms of individual pathology' (Fisher and Goodley 2007: 67). As Albrecht et al. put it,

Perhaps the most intrusive, violating, and invalidating experiences for disabled people emanate from the policies, practices, and interventions that are justified and rationalized by a personal tragedy view of disability and impairment. The tragedy is to be avoided, eradicated, or the disabled ‘normalized’ by all possible means ... there is an assumption that disabled people want to be ‘normal’. However, disabled people who know themselves that disability is a major part of their identity rarely voice this. Disabled people are subjected to many disabling expectations, for example to be ‘independent’ and ‘normal’ as well as to ‘adjust’ and ‘accept ‘their situation. It is these expectations that are disabling, rather than the impairment itself (737).

It was in this context that the range of therapeutic interventions controlled by professionals came about (De Jonge et al. 2007; Gibson et al. 2009). Professionals have come to exert jurisdiction over the ‘process of categorizing persons with disabilities into the minutiae of their impairments [which] resulted in the development of specialized treatments’ (Albrecht et al. 2001: 13).

There is, however, an emerging recognition that varied perspectives of ‘truth’ are absent from professional discourse (Fisher and Goodley 2007: 67). Authors living with disability point out that when the prime goal of intervention is normalising the impaired body, ‘No space is left for an exploration of how variation, even when experienced as disability or disease, can be understood not in terms of suffering and deficit, but as a dynamic, sometimes satisfying engagement with corporeal difference’ (Scully 2002: 54).
Identifying people as ‘other’, or as ‘deviating’ from a supposed homogeneous norm both springs from and feeds into negative attitudes, labelling, and many other exclusionary and marginalising actions experienced by individuals living with impairment (Oliver 1990; Price and Shildrick 2002; Wolfensberger 1992). In a major study of attitudes to, and experiences of, disability in Britain, Grewal et al. (2002) identify four such attitudes, including labelling, attributing characteristics on the basis of a disability, fear and avoidance of disability, and the assumption that the ability to live life fully, or a person’s quality of life, is diminished by disability. They note that

People’s accounts of their social lives were at variance to non-disabled people’s beliefs about the lives of disabled people. Disabled people frequently described highly active and connected social lives at odds with the isolated world often imagined by non-disabled people. (2002: 100)

Exclusionary attitudes about disability can be found in the population at large, but also among the professionals from the health and disability field (Swain et al. 2004). Coining the term ‘the disability paradox’, Ubel et al. describe this phenomenon as one where ‘patients frequently report higher levels of well-being than what is imagined by healthy people under similar circumstances’ (2005: 60). While this phenomenon is discussed in the literature, a striking aspect of articles such as this is the author’s position or response to the issue. As pointed out by colleagues living with impairment, and also noted by Cummins and Lau (2006), Ubel et al. assert that the capacity of people living with impairment to enjoy good quality of life is surprising: they find that people experiencing a wide range of illnesses and disabilities report ‘paradoxically high’ evaluations of quality of life and mood measures (2005: 62) and note that people are ‘understandably sceptical’ regarding the accuracy of such self-reports:

However, to date, across a wide range of studies, the best available evidence suggests that such self-reports are largely accurate. Even when care is taken to explore for scale recalibration, and even when great effort is taken to collect data on moment-to-moment mood rather than relying on global self-reports, the disability paradox persists: people experiencing chronic illness and disability are happier than what healthy people predict they would be under similar circumstances. (2005: 62)
Limited researcher reflexivity is perhaps apparent here, as Ubel et al. do not appear to question their position in assuming a paradox. Rather, they conclude that ‘focusing illusions’ may cause the general public to overestimate and focus narrowly on life domains which will be affected by disability (2005: 61). The disability paradox has been identified as a factor likely to skew population weighting methods used in, for example, economics (Colgan et al. 2010), and represents a major epistemological issue.

Moreover, treating chronic illness and disability as medical problems, and identifying people as recipients of welfare, effectively ‘dis-enfranchises a large segment of society by making them permanent objects of social beneficence, a status that few if any members of our society would wish to occupy’ (Pope and Tarlou 1991: 245). This approach is identified as the charitable model, which ‘defines disability as a personal tragedy which can be overcome through the help of non-disabled people and through the personal courage of disabled people’ (Grewal et al. 2002: 4). The pervasive impacts of this approach can be seen in the dominant media portrayals of people living with impairment as either ‘supercrips’, as bravely ‘coping’ with their disability, or as the objects of charity (Goggin and Newell 2005).

History is dominated by a ‘personal tragedy’ perspective of disability within society, coupled with a perceived need for charity, whether in the guise of religious succour in medieval times, or the welfarist approaches of modern societies (Kristiansen et al. 2009). Goggin and Newell note the medical model of disability has ‘particular power in our health system, controlling people’s very bodies, but [it] finds its way, too, into questions of welfare and who society chooses to support and how it does so’ (2005: 41).

Medical model perspectives appear to have a powerful influence on the separation of life (and outcomes) according to disability status. The discourse of normality is such that, in both professional practice and society at large, it is assumed that people living with impairment will have sets of priorities ‘other’ than their fellow citizens’, and that these priorities are likely to relate to safety, independence, and achieving ‘normalcy’ (Goble 2004). This issue of valued outcomes is a critical one, and one of the most pervasive examples of dissonance is the value placed upon independence. The binary of dependence
and independence represents a cornerstone of the medical and rehabilitation models, where being normal is conflated with being independent. This notion has been progressively challenged by disability advocates and political theorists (Shakespeare 2006; Arneil 2009), and will be taken up in human rights contexts later in the chapter. From within the health professions, it is interesting to note a shift from the rehabilitation-based focus on restoring physical function, increasing functional ability and reducing the supports needed to complete activities of daily living, towards self-reliance and autonomy (Russell et al. 2002). Some authors go further, suggesting practitioners of rehabilitation need to reflect on current practice and tacit assumptions which emphasise autonomy and independence (Gibson et al. 2012). Indeed, in many cultures where the societal role and interconnectedness are highly valued, the liberal and individualist idea of independence fails to resonate (Iwama 2003; Pollard et al. 2008). Medicine and rehabilitation particularly are identified as dominant discourses emphasising independence:

The valorization of independence has as its starting point the assumption that we are separate and distinct from other beings and things. Independence as a taken-for-granted goal of rehabilitation is slowly being modified by the notion of ‘interdependence’. Interdependence emphasizes the reciprocity and mutuality that pervades human existence. (Gibson et al. 2012: 1895)

The interdependence of humans within networks of people, systems and services represents emerging postmodern understandings, but remains at odds with commonly-held definitions which still hold sway in health and disability policy. As Russell notes, independence is most frequently defined as ‘the ability to complete activities of daily living without assistance, which frequently dictates discharge criteria in hospitals and other health service programmes’ (Russell et al. 2002: 189). Gibson et al. suggest a way forward:

We would like to be clear that we are not suggesting that rehabilitation stop providing valuable interventions, but rather that we view what we do and what patients experience through different lenses. Disability and dependence reconceived as connectivities have much to teach us about the limits of independence for all persons. Dependence does not have to be viewed negatively, and independence is not always the goal. (Gibson et al. 2012: 1898)
Extending these ideas with what is essentially a postmodern perspective, Gibson et al. challenge the focus upon autonomy and independence in the case of an adolescent powerchair user with severe disability, concluding that ‘Connectivity can be embraced to explore multiple ways of being-in-the-world for all persons and problematises the goals of independence inherent in rehabilitation practices’ (Gibson et al. 2012: 1894). Perspectives of individuals living with disability, as captured in ‘The Equipment Study’, support notions of interdependence and of agency and are reported in Chapter 6. The critical importance of then enshrining these understandings in policy is taken up in Chapter 7, which addresses the imperative for policy to recognise the complexity of people’s lives and the intersection and interdependence of many areas. (National People with Disabilities and Carers Council 2009: 7)

The medical discourse as described above demonstrates many tensions for people with disabilities, and sets the scene for the paradigm shift described as the social model of disability.

**Disability as oppression: social models of disability**

In resistance and response to the viewpoint described above, social oppression theories, encapsulated in social models of disability, emerged in the latter half of last century from disabled authors and activists themselves (Tremain 2002). Mirroring civil rights and feminist developments and debates, people living with disabilities articulated their experiences of marginalisation and called for inclusion and control in spheres previously dominated by professionals (Charlton 1998). The Union of the Physically Impaired against Segregation located disability within social structures when they declared that ‘In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society’ (UPIAS 1975: 1).

The social model became both a ‘research construct and a political challenge to health care professionals who ... have historically dictated who qualifies as a disabled person and what social response is appropriate’ (Albrecht et al. 2001: 1176). The individualistic and normative nature of a medical and functional rehabilitative model was questioned and critiqued for its failure to take into
account social and political issues (Gzil et al. 2007). Acknowledgement of the social and environmental causes of disability (Bickenbach 2009a; Gray et al. 2003; Iwarsson and Stahl 2003) issued a contemporary challenge to the definition of disability per se, concerning the extent to which the locus of disablement sits with the individual, or with disabling structures and environments. Locating disability within the social and structural barriers causing disadvantage and exclusion to people living with impairments (Swain et al. 2004), the social model proved a powerful force for social and political change to address public attitudes, interpretation of disability, and architectural, legal and educational barriers (Albrecht et al. 2001; Goggin and Newell 2005; Shakespeare and Watson 1997; Wolfensberger 1975, 1992).

In terms of the interpretation of disability, the notion of norms has been progressively challenged by theorists working towards paradigms beyond disability and impairment (Patston 2007). If human variation is understood to be a common feature of human diversity then variations may cease to be seen as deviations. That aim is partially realised in the latest iteration of the International Classification of Functioning, Disability and Health (WHO 2001). The product of extensive international consultation, building from the critiques of its predecessor, the ICF is recognised as ‘an important moment in the (re)conceptualisation of the nature of disability’ (Imrie 2004: 301). Key to its development and uptake is the engagement of disabled people’s organisations in its creation. As Hammel et al. warn, if such a classification schema is ‘created and institutionalized by public health, medical, rehabilitation and other professionals, it can perpetuate disability ideologies related to deficit and dysfunction, and further promote professional dominance’ (2008: 1446). The ICF makes explicit its attempt to integrate the ‘medical model [which] views disability as a problem of the person’ with the ‘social model of disability [where] disability is not an attribute of the individual, but rather a complex collection of conditions, many of which are created by the social environment’ (WHO 2001: 20). The ICF classification system ‘mainstreams’ disability as a universal human experience, shifting from classifying the “consequences of disease” to the “components of health”, and making explicit that it encompasses all people, not only people with disabilities’ (WHO 2001: 7). Impairments are defined as problems in body function or structure associated with health conditions; and disability becomes an umbrella term for impairments, activity limitations or participation restrictions,
encompassing aspects of the previous term ‘handicap’ (WHO 2001). In the previous WHO edition, the term ‘handicap’ was used to denote a disadvantage for a given individual that limits or prevents the fulfilment of a role that is normal, depending on age, sex, and social and cultural factors (WHO 1980).

Despite some criticism, largely around perceived compromises (Hemmingsson and Jonsson 2005; Levasseur et al. 2007), the ICF represents a collective endeavour on the part of international stakeholders in health and disability, including organisations of disabled people. The claim of neutrality is not intended as an ontological one – rather, the multilayered historical discourses of stigma, identity and dependence attached to disability and handicap are avoided and difference is identified merely as variation or diversity. The approach of the WHO ICF is therefore consistent with the philosophy of universalisation, as described below.

**Disability as universal versus disability as minority group**

A universalising perspective assumes all humans will experience impairment at some stage of life, and that, ‘disability is part of the human condition and almost everyone will be temporarily or permanently impaired at some point in life’ (WHO 2012: 1). Unlike other demarcating human attributes such as race and gender, Bickenbach describes disability as

an infinitely various but universal feature of the human condition. No human has a complete repertoire of abilities, suitable for all permutations of the physical and social environment. Scientifically speaking there are no inherent or intrinsic boundaries to the range of variation in human abilities; ability-disability is a continuum and the complete absence of disability, like the complete absence of ability, is a limiting case of theoretic interest only. (Bickenbach et al. 1999: 1182)

Accepting that some of the barriers experienced by people living with impairment are experienced by other groups among the population, and indeed that people currently without impairment forget their dependence upon services which support their independence, brings about a mutuality perspective. Paul Hunt, an early proponent of the social model, speaks to the notion of universality:
If everyone were as disabled as we are there would be no special situation to consider. This focus on the ways in which we are set apart from the ordinary does not mean that I see us as really separated from society. In fact the reverse assumption underlies everything I write. We are society, as much as anybody, and cannot be considered in isolation from it. I am aware of the danger of concentrating on the ways in which disability makes us like each other and unlike the normal, and thus being trapped into the common fault of viewing people in terms of one characteristic to the exclusion of all others. Disabled people suffer enough from that kind of thing already. But whatever the differences between us we do have certain sets of experiences in common. In dealing with this aspect of our lives I have tried not to forget two others – our uniqueness as persons and the human nature we share with the rest of mankind. (Hunt 1966: 146)

A tension within universalising perspectives is articulated here. On one hand is the notion that the lived experience of disability affords particular insights or ‘insider knowledge’. People without direct experience of disability are likely to be without these insights (Haraway 1988). Therefore individuals, authors and academics without disability may fail to perceive nuances, or to recognise that nuances are worthy of note, worth conserving, and worth remembering (Foucault 1991). The implications of this may be that the reality of being ‘the same but different’ is subverted by power differentials, and a resulting identification and separation of groups from each other (Fawcett and Hearn 2004).

This critically important point forms the cornerstone of the argument for a universalising disability policy and for the discussion of policy realignment. Removing the lens of difference will position individuals living with impairment with the rest of the human population. By extension, in democratic settings, social policy must be applicable to all people (Bickenbach et al. 1999).

Bickenbach, who has written extensively on this topic (Bickenbach 2009b; 2009a; Bickenbach et al. 2012), suggests,

Universalizing disablement policy begins by demystifying the ‘specialness’ of disability. Rather than identifying special needs that require special attending to (and special legislation, special agencies and special experts), we need to see that all people have needs that vary in roughly predictable ways, over the
course of their life span ... Disablement policy is therefore not policy for some minority group, it is policy for all. (Bickenbach et al. 1999: 1183)

This is not yet the case in Australia according to Goggin and Newell, who ask,

Is our social contract, and our other deepest imagining of our polity and its political institutions, premised on the figure of able-bodied citizens? In its assumptions about who may belong, participate and govern, does our polity only conceive the polity who is not deformed, who is ‘normal’, who is ‘abled’ – overlooking and overruling those who are considered ‘disabled’? ... Our society’s places and practices of exercising, sharing or wielding power systematically exclude people with disabilities. Indeed, we suspect that people with disabilities have long been on the margins of Australian political life – although there has been a conspicuous lack of interest in and research on this topic. (Goggin and Newell 2005: 142)

A universalising perspective appears therefore to offer an alternative to ‘othering’. Yet on the other hand a number of disabled authors warn it runs the risk of denying that one’s identity as an impaired person is unique and separate (Swain et al. 2004; Thomas 2007):

While it may constitute a theoretical means of ameliorating the existential negativity associated with being disabled it does so at the expense of disability identity. What is required is a critical social ontology that problematises non-disablement and exposes the forms of invalidation that lie at the heart of disabling culture ... I do not have a quarrel – on empirical grounds – with the view that impairment is ‘the normal condition of humanity’ ... but because we are all impaired or will all become impaired does not mean that we are all treated in the same way. (Hughes 2007: 677)

The critical point here is that the concept of universality does not translate into equal opportunities or life conditions for everyone. In other words, universality is a valid concept, but in reality people living with impairment experience differential treatment. Despite the vision of universal policy presented by Bickenbach, policy does not treat people living with impairment as ‘universal’. Indeed, policy and service delivery are based on a ‘disabled identity’ as a minority group eligible for identified services. The term ‘minority group’ was
coined by Wirth in 1947 to identify ‘a group of people who, because of their physical or cultural characteristics, are singled out from the others in the society in which they live for differential and unequal treatment, and who therefore regard themselves as objects of collective discrimination’ (Wirth 1945: 347). The minority group model serves as ‘an explicit basis for much disability policy’ (Scotch and Schriner 1997: 150). A number of problems result from a minority definition. If individuals elect to avoid a ‘disability identity’, they stand to miss out on services, given services are structured along minority group model lines. To identify as disabled is to concede to a minority group positioning. It is to risk the characterisation of disability as ‘a pathological individual attribute inevitably linked to incapacity and dependence’ (Scotch and Schriner 1997: 151). It is to risk being ascribed one static, single-sided identity which is privileged above other personal attributes such as gender, class, ethnicity or sexuality (Priestly 2004: 96). The minority group approach is likely to reinforce stigma and marginalisation as, by measuring impairments, it reinforces aspects of the medical conception of disability (Christie and Mensah-Coker 1999). Such negative identity markers have led to calls for ‘transforming disability policy and programs away from deficit models … a necessary condition for democracy, particularly in the minds of disability advocates and their supporters’ (Baker 2008: 572).

This conflict became apparent when a minority group identity emerged during ‘The Equipment Study’. That is, analysis found the study participants were marginalised according to a range of socio-economic and participation indicators, and could therefore be identified as a discrete ‘minority group’. To be in a marginalised group is to be in a position of exclusion from full participation in society, or to live on the margins of society, which is the experience of many groups, including individuals living with impairments (Baker 2008). Using such a term creates tension between the negative nature of this minority group label in the context of universalising arguments, and the pragmatic fact that identifying this group as having special needs enables economists and government service providers to single out the impaired population as being in need of particular decision rules (Ong et al. 2009; Carter et al. 2008). Identifying the cohort as a ‘special needs’ group (Colgan et al. 2010), permits arguments to be made for tailored levels of resourcing.
There is an inherent tension between the apparent equality offered by a universal approach and the need to make visible the differences between people. Particularly significant is the differentiated experience that people living with impairment are likely to have, given the breadth of bodily variation inherent in impairment, and the different environments in which these play out. The focus of the minority group approach overemphasises features of impairment beyond their actual impact upon a fully contextualised life. Universalisation, on the other hand, may overlook a critical element of identity and cause needed supports to be rendered invisible. These ideas will be taken forward in Chapter 7’s analysis of policy.

**Disability as fluid and multiple**

Over the last decades, medical and social models have come to be viewed as binary opposites:

> the concepts of the medical model and the social model have been polarized and reified. The medical model … means much more than a simple set of definitions: it has become a proxy for all that it is wrong with traditional attitudes to disability. It stands for research and practice developed by non-disabled people, without the participation of disabled people. It stands for the dominance of professionals. It stands for the idea that disabled people are defined by their physical or intellectual deficits. It stands for medicalisation. (Shakespeare 2006: 18)

The ontological belief that the disability lay within the individual or was a function of the social environment led to a schism within disability studies. Disability studies ‘proper’ is based on the idea that disability is structured by social oppression, inequality and exclusion. In contrast, the ‘sociology of chronic illness and disability’ is a branch of medical sociology and operates on the basis that disability may entail suffering and some social disadvantage, but is caused by illness and impairment (Thomas and Corker 2002). The dichotomy lies in the content focus of research, on the one hand focusing on the experience of oppression, and on the other, the experience of illness (Thomas 2004). This results in partial horizons within both literatures. As Bury points out, ‘the separation of a medical view of impairment and illness from a social view of
disability fails, finally, to articulate the complex interplay between the two’ (Bury 2000: 177).

The world has moved forward substantially since the advent of the social model of disability, in terms of both socio-political events as well as in the progression of philosophies of knowledge. Emerging thought from these philosophies has over time furnished additional vantages from which to view and revise ideas about disability and impairment. The movements of modernism, postmodernism, structuralism, poststructuralism and critical realism represent ‘points of departure’ from the world as it was previously understood – and although they are dynamic and contested, they provide useful reference points in understanding emerging perspectives of disability. Most significant is contemporary philosophical thought, which revises and replaces the previous tenets of structuralism and modernism which came before (Lopez and Potter 2001). Lopez and Potter refer to postmodernism, which rejects the notion of universal laws and deconstructs theories, ideologies, and contentions (Lyotard 1984), and to critical realism, which replaces traditional scientific dualist approaches to social systems with ‘both–and thinking’ (Danermark 2002).

Based within postmodern thought, a ‘second wave’ of writers in disability studies is now critically examining social model assumptions (Bury 2000; Reeve 2002). Substantial literature from authors with disabilities has critiqued the social model (McCormack and Collins 2012). These authors are refocusing and moving beyond the binary opposition of the social versus medical model, to encompass the reality that ‘people are disabled both by social barriers and their bodies’ (Deal 2003: 677). One of the key logical flaws to have been pointed out is the loss of early acknowledgements of the presence of impairment and human social relatedness (Hunt 1966), as more radical iterations of the social model allocated blame entirely to social structures (Bickenbach et al. 1999). By dissociating the question of disability from its functional limitations, the social model disembodies disability and denies it corporeal and subjective dimension. It therefore disregards the importance of the judgment disabled persons themselves have on their own impairments, their activity limitations, environmental factors or the response they get from society. In other words, it
disregards the subjective evaluation of the notion of disability. (Gzil et al. 2007: 1620)

From a postmodern perspective, then, previous models of disability can be critiqued:

Both the medical model and the social model seek to explain disability universally, and end up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people’s lives and of their knowledge. The global experience of disabled people’s lives is too complex to be rendered within one unitary model or set of ideas. Considering the range of impairments under the disability umbrella; considering the different ways in which they impact on individuals and groups over their lifetimes; considering the intersection of disability with other axes of inequality; and considering the challenge which impairment issues to notions of embodiment, we believe it could be argued that disability is the ultimate postmodern concept. (Corker and Shakespeare 2002: 15)

In terms of disability, the idea of a central identity has been problematic, given the broad sweep of impairment and related factors which make up an individual’s disability experience as well as major demarcations between various diagnoses (Deal 2003), and between illness conceptualisations (disability versus chronic illness, for example) (Löfgren et al. 2011). Theories emerging from postmodernism have the potential to support the development of a more eclectic model of disability, which would be seen by many within the disability community as a welcome paradigm shift which might

move the heated debates about disability/impairment forward, thereby freeing us to concentrate on models (again, loosely defined) that account for the material reality of living with physical bodies that might not work perfectly while also actively resisting the oppression of disablement. (Gabel and Peters 2004: 588)

One such thread is the application of critical realist thinking to disability. Shakespeare, an academic with disabilities both congenital and acquired, is a proponent of the ‘critical realist’ approach. He positions impairment as an individual predicament to be managed as the ongoing work of living occurs,
describing disability as 'So variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure.' (Shakespeare and Watson 2001: 19)

Disablement also occurs due to societal factors, but removal of societal barriers will not remove corporeal impairment. It can be said that contemporary disability perspectives in Australia adhere to this nuanced view; for example, the National People with Disabilities and Carers Council states, ‘How we view impairment and disability has changed dramatically over recent years ... although the impairment a person has is a reality, the disablement is caused by environmental and social barriers’ (National People with Disabilities and Carers Council 2009: 14). Shakespeare describes disability from a critical realist view:

Critical realism means acceptance of an external reality: rather than resorting to relativism or extreme constructionism, critical realism attends to the independent existence of bodies which sometimes hurt, regardless of what we may think or say about those bodies. Critical realists distinguish between ontology (what exists) and epistemology (our ideas about what exists). They believe that there are objects independent of knowledge; labels describe, rather than constitute, disease. In other words, while different cultures have different views or beliefs or attitudes to disability, impairment has always existed and has its own experiential reality. (2006: 54)

Deconstructing the metanarrative of disability in line with these philosophies allows impairment to be uncoupled from the notion that it is ‘always and only negative’ (Shakespeare 2008: 240). Postmodern thinking refutes the encompassing narrative of disability as negation and renders it less meaningful to regard one’s disability as one’s sole and significant identity, in the context of wide human diversity. Postmodernist thought allows that which has been ignored or undervalued to be revealed and explored (Lyotard 1984). The critical realist perspectives allow space for ‘and–and’ thinking, recognising that for some, as well as presenting disabling predicaments, impairment gives an experience of corporeal difference which may be satisfying (Smith 2009).

**Disability as diversity: impairment effects**

The concepts of disability and impairment remain conflated (Thomas 2004), and represent a ‘problematic binary’ (Sherry 2004: 770). Thomas and Corker proffer
the term ‘impairment effects’, to describe what in their view is a lost dimension of difference defined as ‘the non-socially imposed restrictions caused by impairments and chronic illness’ (Thomas 1999: 581). Specifically, impairment effects are defined as

The direct effects of impairment which differentiate bodily functioning from that which is socially construed but not normal or usual. The lives of people with impairment are profoundly shaped by the interaction of disability and impairment effects, and in lived experience these join together with other dimensions of individuals’ social positioning (gender, ‘race’, age, class, sexuality). (Thomas and Corker 2002: 20)

‘Impairment effects’ are an accepted contemporary concept from the disability literature, and fit into a critical realist frame where the corporal body exists and represents a facet – but not the entirety – of human experience. Medicine is therefore seen to have a partial role in addressing biology, but otherwise to be a limited frame through which to view life with impairment:

The central point that arises from the social model critique of medicine is that medicine is impotent when it comes to the amelioration of disability. It may have some efficacy in relation to impairment. It cannot, however, be regarded as an ally when it comes to the abrogation of disabling barriers and the discrimination, exclusion and oppression that arises from them. (Hughes 2009: 678)

Closely linked to early ideas of universality as described by Goffman (1961, 1963) and Hunt (1966), Thomas explains that ‘everyone is impaired, in varying degrees. This perspective ... offers an important insight into human experience, and can be used as a springboard for dismantling socially constructed divisions between “the disabled” and “the normal”’ (2004: 574). Representing impairment as a characteristic of human difference rather than as a defective or functionally limited body (McCormack and Collins 2012) effectively reconceptualises the norm. To do so identifies disablement as ‘the normal condition of humanity’ (Sutherland 1981: 18), setting the scene for population approaches which embrace diversity (Winance 2007) and which help “normal” people to see the quotation marks around their assumed state’ (Davis 1995: 777). Described as an affirmative model, this approach ‘represents a viable alternative to dominant
cultural discourses, and challenges the negative connotations typically associated with a disabled life’ (McCormack and Collins 2012: 158). Several thinkers have further developed these ideas in relation to public policy (DePoy and Gilson 2009; Zola 2005); these will be considered in Chapter 7.

The impaired rights bearer: human rights perspectives

The equal treatment of humans is a benchmark of civil society, one enshrined in human rights frameworks (United Nations 1948). Human rights, then, represent another useful lens through which to explore understandings of disability and impairment. This lens is useful theoretically, as human rights are the basic civil, political, social, economic, and cultural rights belonging to all people regardless of race, religion, culture, geographical location or other distinguishing attribute. The human rights lens is also useful practically, as a number of human rights instruments are designed to redress disability and inequality.

Blueprints articulating rights and offering tools for rights-based evaluation are found in the form of international conventions (Office of the High Commissioner for Human Rights, 2010). Australia is a signatory to the Universal Declaration of Human Rights (1948), to conventions addressing freedom from discrimination and torture, and to a range of economic, social, cultural, civil and political human rights such as the International Covenant on Civil and Political Rights (ICCPR) (1966) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966).

In the language of human rights, the individual is primarily a rights bearer whose rights may either be upheld or fail to be realised in part or in full. From the perspective of disability, however, these human rights instruments have historically assumed that possessors of human rights have an able body capable of enacting any rights provided (Megret 2008; Rioux et al. 2011 ). The fact that disability disrupts this central tenet of the human as rights bearer is seen as both a complexity and a challenge to contemporary human rights law. It is possible that this is why human rights remain so poorly realised for people living with impairment. As Rioux et al. explain, ‘To bring real change through law, and to bring human rights into daily operation, what is needed is political will coupled with a sophisticated understanding of disability … this involves a radical disruption of the status quo’ (2011: 489). To achieve this sophisticated
understanding requires a major shift, given the deficit-based ‘normal/ abnormal’ binary conceptualisation of disability which has dominated political and economic theory (Arneil 2009; Sen 2009). In theorising the effects of economic and political circumstances upon society, the heuristic of the rational citizen has been taken as a reference point (Smith 1812). The rational citizen is taken to be capable and independent, able to exert agency upon, and benefit from, the economic opportunities of the day, and is envisaged as the opposite of the ‘lunatick’, ‘ideot’, ‘mentally handicapped’, ‘disabled’, or ‘ill’ person”, who is instead provided succour (Arneil 2009: 221).

The idea of an archetypal ‘rational citizen’ is problematic, however, in that it is based on a normative assumption of the essential nature of ‘man’. According to contemporary disability theory, this heuristic is flawed in that it fails to encompass human diversity (Megret 2008; Patston 2007). The archetype of the rational citizen does not, for example, encompass individuals whose cognition or mobility precludes ‘rational choice’ (Arneil 2009), and therefore fails to take into account ‘the inherent and ultimate value of each and every person’ (Basser 2011: 17).

These ideas illuminate the underpinnings of much economic and political thought which has run parallel to the positioning of disability within the medical model as previously described, and have contributed to the current problematic policy and funding contexts in which people living with disability are seeking support today (Goggin and Newell 2005, National People with Disabilities and Carers Council 2009).

A number of scholarly efforts have been made to accommodate a ‘human diversity’ view of impairment more fully in contemporary political thought, focused on a reconceptualisation of the ‘rational citizen’ and rethinking the concept of independence. Examples of philosophical examinations of human diversity include Nussbaum’s (2006) rejection of rational agency as the basis of personhood, instead focusing on the central principle of human dignity and capability. Kittay proposes the universality of human dependency, taking the perspective of human moral worth which arises from being ‘some mothers’ child’ (Kittay 2005). Dependency has been further reframed in the context of human interdependency, where dependence does not infer the relinquishing of agency
to the care of others but is an element of a constellation of interrelations, whose ultimate trajectory is independence (Davidson 2007).

The question of in/dependence, previously raised in the discussion of the medical model of disability as a key outcome, requires further consideration here from the standpoint of human rights. From a disability rights perspective, autonomy, rather than self-sufficiency, is a critical outcome, yet one which has been at odds with priorities within rehabilitation (Goble 2004). Shakespeare identifies a vital distinction between physical dependency (not being able to do particular tasks) and social dependency, where the goal should be ‘not to learn skills and abilities, but to gain independence through being able to control how tasks are performed’ (2006: 39). Goggin and Newell observe that if, due to impairment, individuals cannot ‘do’ for themselves, autonomy can be retained if people are in a position to direct the care they receive (2005). In other words, personal autonomy can be facilitated despite receiving personal assistance if ‘the carer replaced the participant’s “hands” and followed the choices and preferences of the participant when providing assistance’ (Meyer et al. 2007: 595).

Empirical support for this concept, variously defined as autonomy or control, can be found in the spinal cord injury literature. Here, perceptions of life quality are strongly coupled with the opportunity to be in control of one’s own life; ability is defined by the extent of control people have over their lives rather than the number of activities the participants can accomplish without assistance; and a sense of autonomy springs from the ability to determine daily activities (Whalley-Hammell 2007). Reeve describes the tension between personal independence or autonomy, and independence, as understood from within the rehabilitation model:

As part of the rehabilitation process within spinal injury units, people with spinal cord injury are taught the principles of good bowel management, and instructed how to check their bodies daily for signs of abrasion or pressure sores. Whilst I acknowledge that this returns autonomy to the disabled person for care of the self, literally to become a ‘doctor of oneself’, failure to maintain an adequate level of self-care is considered by others to be irresponsible. From personal experience, it seems to me that the (usually)
non-disabled people who criticise my failure to adhere to apparently simple self-surveillance tasks fail to appreciate the emotional costs of having to carry out tasks that they do not have to do themselves. These tasks are yet another reminder of my ‘abnormality’ and I am held responsible for failing to contain and render invisible that difference from the norm. (Reeve 2002: 500)

Returning to human rights theory, in Arneil’s view, normalising dependence (and being depended upon) as one pathway to autonomy serves to refocus the lens ‘away from “the disabled” as a site of “dependency” to look more closely at the “autonomy” of the “nondisabled”’ (2009: 236). Arguing for an alternative theory of personhood and citizenship based upon interdependence, Arneil calls for redefinition of disability, autonomy and dependence in the political arena:

Ultimately, if we accept the principle that we are all interdependent to varying degrees (including at different points within any given lifespan) disability becomes a dimension of human diversity across space and time rather than a tragedy, deficit, or abnormality. Interdependence allows us to excise the many negative images so central to modern political theory and replace them with a positive set of images and an alternative theoretical basis upon which to develop social arrangements (accommodations and supports governed by the principle of human dignity) that facilitate independence even as they support dependence in varying degrees across the life cycle. (Arneil 2009: 237–238)

The mechanisms governing the ‘social arrangements’ described by Arneil are underpinned by governments, with core obligations expressed in legislation. A key development in 2006 was publication of the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006). The CRPD (United Nations 2006) has re-expressed existing anti-discriminatory, economic, social, cultural, civil and political rights from a disability perspective, acknowledging that ‘despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world’ (United Nations Preamble 2006).

The CRPD (United Nations 2006), as the most recent iteration of disability rights, has resonance with contemporary theory regarding the interdependence
of humanity (Lord et al. 2010). It articulates the seeming tension between dependence and independence, and acknowledges the simultaneous need for autonomy and inclusion. Promisingly, it also articulates a range of outcome-oriented mechanisms to address issues of community, vulnerability, support, agency, and care (Megret 2008) and to enact rights at the level of lived experience (Bickenbach et al. 1999; Lutz and Bowers 2005; Rioux et al. 2011).

Human rights, as expressed through such conventions, offer an inclusive view of personhood as well as a description of life outcomes common to all.

This conceptualisation is therefore a valuable way to understand ‘disability’ as well as to guide socio-political responses to it and, in part, provides a cogent answer to research question 1a regarding the way in which disability differs from the absence of disability. Contemporary human rights thought resonates with the conceptualisation of impairment as diversity. The diversity which impairment may bring can be linked to ideas of ‘intrinsic traits’, and impairment effects can be understood within this frame:

all manner of ‘external’ or ‘environmental’ factors can influence how one’s life is led or how one’s panoply of intrinsic traits plays out in the world [and therefore] we must remove, modify or otherwise alter all those extrinsic sources of human inequality that are within the control of our social and political institutions. Those extrinsic factors that are realistically out of our control but produce individual differences which may require a compensatory state response, in the form of additional social resources to compensate the individual for limits on his or her capacity to participate in basic human and social activities (Bickenbach 2009b: 108).

Human rights for Australians with disability, and some key concepts within human rights, will now be explored, to set the scene for human rights-based analyses of data from ‘The Equipment Study’ in Chapter 7.
Comments on the human rights of Australians with impairment

Although equal treatment of humans is a benchmark of civil society, and one which is enshrined in human rights frameworks (United Nations 1948), many Australians living with impairment are highly critical of the support they receive, finding services and programs are a barrier rather than a facilitator to participation in daily and community life (National People with Disabilities and Carers Council 2009). Reporting on findings from more than 750 submissions and 2,500 consultations with individuals living with impairment and their carers, the Shut Out Report concludes,

In a democratic country as wealthy as Australia, many found it absolutely unacceptable that they are unable to access the support and services required to achieve even a basic quality of life ... They argued that the service system needs to move away from a welfare model of service provision to a person-centred approach that sees services not as charity but as a social investment in realising the potential of people with disabilities. (National People with Disabilities and Carers Council 2009: 5)

This statement demonstrates the tension between the conventional basis of social obligation which has entailed ‘beneficence and privilege as a consequence of charity by governments and the public’ (Rioux and Riddle 2011: 47), and the idea of rights to the resources needed to achieve a person’s potential (or to achieve equality of outcome). Basser describes this as the ‘deservedness versus entitlement’ continuum (2011: 28), where rights approaches may dictate a fair distribution of those goods between members of the society; but more traditional values of economic and social self-sufficiency limit the social obligation of equality for persons with disabilities.

The history of disability previously outlined leads to the conclusion that the moral priorities (Sen 1999) of Australian society which influence policy and resource distribution are based on concepts of ‘normality’ and able-ness (Arneil 2009). Medical and charitable models of disability are the dominant theories that have influenced the theories of justice and distribution upon which the social contract is based, according to political philosopher Martha Nussbaum (2011). This fact has led to policy choices which result in the continued exclusion and de-valuing of people living with disability (Corker and Shakespeare 2002; Oliver 1990). This
is a critical point in understanding the disability and AT policy and resourcing landscape.

**Human rights as a basis for understanding equality of outcome**

In the contemporary human rights paradigm, society’s moral priorities are re-directed to concepts of human rights, including those for people with disabilities (Megret 2008). Human rights provide a powerful discourse and language regarding equality. In examining the language of human rights, it is apparent that there are various ‘types’ of rights. One key differentiator is the negative/positive binary where, for example, ‘negative rights’ typically entail fundamental freedoms from certain actions (such as freedom of speech, freedom from torture), and positive rights represent second- or third-order rights ‘provision’, such as steps to ensure that economic, social and cultural rights are realised (Baker 2008; Gruskin and Tarantola 2005). Outcomes for individuals living with impairment are intricately linked to the extent of positive steps taken towards rights realisation (Rioux and Riddle 2011), as will be outlined below.

**Equality**

A key concept of interest in this thesis is that of equality. Equality can be measured in terms of equal opportunity to have one’s human rights fulfilled: an approach which French notes has been entrenched in disability policy for some decades (2012). Equality of outcome (of condition or of results) represents another way of determining if equality of opportunity has been realised (Phillips 2004). Exploring equality of outcome in relation to ethnic and gender groups, Phillips observes, ‘we can only be confident that opportunities were equal when the outcome is equal too. Any systematic disparity of outcomes … alerts us to a likely inequality in initial opportunities’ (2004: 20). Equality of outcome is felt to be a sound concept to capture ideas of universalised aspiration. This idea answers research question 1b in refuting the notion that the presence of impairment or disability impacts upon people’s life aspirations; it will be carried forward across the thesis inquiries.

Turning to define equality itself: formal understandings of equality accord each person identical treatment independent of any personal characteristics, and imply equal allocation of public resources (Jones 2009). Rights can be thought of as either positive or negative in the way they are achieved, as identified
above. To enact negative rights, states merely need refrain from certain conduct; however,

because persons with disabilities are often the victims of structural discriminations, having the state simply ‘abstain from positively violating their rights’ is the surest way of condemning them to only marginal respect for their rights. At the very least, granting access requires the active removal of barriers. (Megret 2008: 264)

For people living with impairment, then, provision of negative rights has proven an ineffective tool for equality:

While simple or negative equality ignores inherent differences and promotes equality as equal treatment, complex or positive equality provides provisions and recognizes differences as valuable and individuals as requiring different treatment to arrive at a similar result or outcome. (Rioux and Riddle 2011: 44)

Such ‘active removal of barriers’ infers positive rights, where individuals are entitled to have the state take steps to secure those rights. Expressed in terms of equality, this complex or positive equality recognises differences as valuable and provides for individuals requiring different treatment to arrive at similar outcomes. Both concepts are important in examining the roles or actions of state parties in addressing inequalities. Indeed, both negative and positive measures may be required to achieve rights enjoyment. This is because the impact of an individual’s circumstances upon their outcomes, whether due to impairment effects or disablement resulting from non-inclusive environments, may prevent rights being realised.

While the focus upon state parties’ actions in providing negative (lack of obstacles) and positive (steps taken towards realisation) rights is valuable, perhaps more critical is the experience of rights realisation from the perspective of the rights bearer. Provision of positive rights is seen as a crucial facilitator of equality in the context of disability, where

Due to the entrenchment of ableist social and economic structures, poverty is experienced by the vast majority of people with disabilities ... If the goal is substantive equality, then treating all alike, including those with demonstrable
social advantage, does not achieve the objective. (Rioux and Riddle 2011: 44)

Such identical treatment is clearly problematic, given understandings of human diversity and the substantial disadvantage this has brought about when society is structured according to narrow definitions of normal (Albrecht et al. 2001; Bickenbach et al. 1999; Goggin and Newell 2005; Oliver 1990; Rioux 2003; Swain et al. 2004). The assumption that people start from an equal position has been described as false, and one which leads to the further entrenchment of inequality and further injustices (Rioux and Riddle 2011). For example, the child getting to school or adult getting to work via a wheelchair is likely to have far greater expenditure of effort (transfers and so on), more limited options (requiring accessible transport) and cost (time-costs and perhaps personal support) in engaging in school or work, compared with non-wheelchair users. While all individuals desire the similar ends, it is more difficult, costly or complex for the person living with impairment to attain these ends. Should all individuals have access to the same income or funding base, it will cost more of the impaired person’s resources to accomplish the same outcome: that is, in the presence of impairment more resources than usual are likely to be required to achieve an outcome (Kimberlin 2009). This phenomenon has been described as a conversion handicap (Sen 1999). Arguing that what should be distributed equally is, in fact, capability, Sen explains,

what use we can respectively make of a given bundle of commodities, or more generally of a given level of income, depends crucially on a number of contingent circumstances, both personal and social. In analysing social justice, there is a strong case for judging individual advantage in terms of the capabilities that a person has, that is, the substantive freedoms he or she enjoys to lead the kind of life he or she has reason to value. (Sen 1999: 87)

Sen’s ‘capability’ is defined as ‘substantive freedoms’ to achieve aspirations (Sen 1999: 87). It is not equated with, although it includes, the ability/impairment dichotomy. Certainly ‘capability’ will be affected by impairment effects and other disabling elements, as well as a range of social and economic barriers and contexts.
This critical point establishes that, in reality, not everyone achieves human rights to the same degree despite theoretical equality. A range of literature points to the fact that equality is experienced differently as people are differently situated, and that some people require additional resources to achieve an equal experience due to circumstances of marginalisation, including the presence of impairment (Rioux et al. 2011). These understandings are brought together in the concept of equity, which addresses the realisation of equality in the context of differing needs and capabilities.

**A capabilities approach: universally applicable capability gaps**

To realise equality of outcome, Phillips (2004) suggests the capabilities approach as realised by Martha Nussbaum. Nussbaum’s work is based upon the human development approach in developmental economics, and largely theorised around populations from developing nations. Here, the capabilities approach adopts basic social justice principles alongside mechanisms for evaluating quality of life for each person in society. In a capabilities approach, the focus is not on deficit but on what each person is able to do and to be (Nussbaum 2011: 18), and the role of society is to provide those elements that will ensure ‘substantial freedoms’ for a population. This view accepts the ‘complexities of human life and human striving’ (Nussbaum 2011: x), and understands that the quality of a human life involves multiple elements whose relationship to one another may be complex. True to its foundation in developmental economics, a starting point concerns the role of society (or, to adopt ICF terminology, the barriers and facilitators present) in creating opportunities for people to realise their potential: the capacity to vote, for example, rests upon whether society provides education about voting to its populace, allows women (or people with disability) to vote, and whether there is transport to the polling booth if the right to vote does exist. Additionally, it is noted that people have ‘internal capabilities’, described by Nussbaum as personal characteristics such as ‘personality traits, intellectual and emotional capacities, states of bodily fitness and health, internalised learning, skills of perception and movement’ (2011: 23). In the instance of political voting, an individual might additionally require specific accommodations in order to comprehend and to enact voting if they use a wheelchair or have a visual impairment. The combination of these (internal capabilities and opportunities) is necessary for voting to occur. These ‘combined capabilities’ represent the
totality of opportunities for choice and action across a person’s ‘social, economic, familial and political environments’ (Nussbaum 2011: 23).

Capability ‘gaps’ may arise between one’s internal capabilities and the opportunities presented societally. When this occurs, governments are required to focus explicitly on how to enable people’s capabilities to function, in any domain, both by the direct provision of supports and by ensuring there are no impediments to capabilities being enacted.

I propose that the capabilities approach is applicable to disability. Although there is scant literature making these links, the notion of a performance gap is congruent with current perspectives in AT:

*disablement* should be not looked at as an attribute of a given individual, but rather a situation that may affect any individual in case a gap exists between individual capabilities and environmental factors, and this gap restricts the quality of life and hinders fullest exploitation of the individual's potential in society. (AAATE 2003: 2)

‘Capability gap’, then, is a term which can apply to the spaces between impairment effects, desired outcomes, and the disabling impacts of environment. To adopt such language from human development theory into political philosophy and economics may alter the identity politics with which disability struggles. While it is beyond the scope of this thesis to explore this idea fully, it will be taken forward throughout. Further, the notions of universalised aspiration and of equality of outcome will be used as principles against which to measure both the scope of ‘disability’ outcomes and the realisation of outcomes thus far.

**Equity**

Equity adds a moral dimension to the idea that people should be treated as equals by asking whether distribution is fair and leads to equal life chances (Jones 2009). The concept of equity introduces a normative element: in other words, how one person’s experience stacks up against that of others. The equity lens recognises that people are not necessarily in equal situations. The presence of impairment or the lack of financial resources may lead to unequal need, and unequal capacity or capability (Sen1999) to address that need,
creating an imperative to address these inequalities with equity measures (Culyer 1995). In response, vertical equity measures work to ensure equitable access to resources is provided to those with ‘unequal need’ (Ong et al. 2009). Strategies to achieve vertical equity effectively provide a safety net to the most marginalised within society.

The concept of equity explains why it is critical to go beyond the notionally ‘fair’ idea of providing like treatment for all. Applying positive equity principles argues that to level the playing field, some individuals will require additional or different resources. Equity approaches challenge historically conservative ideals of economic and social self-sufficiency, which value notions of efficiency and fairness within the context of merit (Pinkerton et al. 2002) and where resources are distributed upon a horizontal equity basis: in other words, on the basis of equal access for equal need among a population (horizontal equity is therefore closely related to the rights-based notion of negative equality). Such merit-based ideals have served to entrench charitable beneficence by governments and the public (Rioux and Riddle 2011).

The current shift in discourse from charitable benevolence towards human rights and social justice offers challenges to both the conception of disability and the prioritisation of resource provision. However, Lofgren et al. (2011) note that despite the equity argument, many other factors, particularly economic systems, continue to limit the impact of this shift. This is perhaps one reason for the dissonance between policy intent and policy resourcing, and will be considered in Chapter 7.

**Equity-based resource allocation to address capability gaps**

Australia is a free market economy, yet as in many countries, government intervenes to provide ‘merit goods’ such as healthcare as commodities which citizens are provided based upon their adjudged needs, rather than their ability to pay (Musgrave 1957). In countries like Australia, without clearly legislated rights to actual service levels or standards for the merit goods AT and EI, government priority setting and resource allocation is influenced by many factors, including the values and perspectives of policy-makers, the recent research agenda, and current affairs (Goggin and Newell 2005; Kingdon 2003). The most common non-economic approach to resource allocation is a historical
one, where funding decisions are based on what has been funded in previous years – notable for a lack of ‘explicit priority setting’ (Carter et al. 2008: 598).

Resource allocation has been described as a ‘highly complex process’ integrally linked to policy (Persson et al. 2002: 119). Health economics proffers a range of models to control limited supply (or ‘rationing’). These include resource allocation based upon economic evaluation as critiqued in Chapter 2: that is, cost and subsequent utility, benefit, or effectiveness measured incrementally against a comparator, usually current practice (Drummond et al. 1997; Mooney and Scotton 1998). An alternative method of resource allocation is found in decision-making techniques which, to some extent, recognise and address the shortcomings of mainstream economic evaluations (Coast 2004; Coast et al. 2002).

Decision-making techniques acknowledge that decisions in health and welfare must go beyond technical efficiency (Campbell et al. 2007), and that ‘ethical concerns (such as equity and fairness) are critical to any discussion of real-world resource allocation decision making’ (Pinkerton et al. 2002: 25). However, few economic methods or studies appear to directly tackle ethical or human rights concerns, the impact of rationing upon those who have to implement policy – or, indeed, to take into account the views of those who are affected by the rationing of care (Coast et al. 2002; Wilkinson and Pickett 2009). The risk of failing to embrace community perspectives, with all the standpoints this entails, is significant (Schwartz et al. 1993: 276). Some authors argue that issues related to wellbeing ought to influence policy decisions more heavily at the organisational, corporate, and governmental levels, as ‘domestic policy currently focuses heavily on economic outcomes, although economic indicators omit, and even mislead about, much of what society values’ (Diener and Seligman 2009: 201).

A key issue with economic outcomes is their failure to represent societal values fully (Cummins 2005). Indeed, the general public have been found to ‘place less emphasis on costs than economists might deem appropriate’ (Nord et al. 1995: 1436). Nussbaum developed the seminal ideas of Sen into a capabilities approach as a ‘counter theory’ to this failure of mainstream economics, which in her view has guided policy choice in ways which are ‘deeply mistaken ... toward
choices that are wrong from the point of view of widely shared human values’ (2011: xi). From a disability perspective, Goggin and Newell also challenge the priorities of mainstream economics:

Our pessimistic and inaccurate preconceptions of the cost of disability are not helped by the fact that Australia is a country in which public debate and policy formulation is dominated by narrow neoclassical economic frameworks (‘economic rationalism’, as it is popularly termed). Such an economic discourse, and its ethical correlates, lacks the values, concepts and methods to comprehend – and allow – the full benefits as well as costs of disability, and the complex issues posed in resource allocation, consumption and production. In Western societies more generally, and specialised bioethical debates, we see the rise of utilitarian calculus premised upon the tragedy of disability. The concept of disability deployed in such economics and ethics derives from a coupling of the medical models’ account of disability as defect, and the charitable discourse that sees people with disabilities as passive recipients of societies’ munificence, while being exorbitant consumers of its scarce resources. (2005: 32)

Goggin and Newell call for the replacement of charitable and medical models of resource allocation with entitlement or human rights approaches. This entails determining allocation via decision making that identifies capability gaps and uses equity weighting as mechanisms of resource allocation.

Given the human rights context, definitions of disability, and the relative disadvantage of people living with impairment, equity is an important resource allocation principle. A contemporary economic method to incorporate equity into economic evaluation of interventions is the equity weight. Here, the additional resource required to reach a nominated outcome is calculated on the basis of the capability differential. In other words, the real costs of delivering an intervention equivalent in quality and outcome is sought for particular groups whose circumstances cause a conversion handicap (Nussbaum 2003).

In order to establish equity weights, researchers canvass the views of stakeholders from ‘government, health, non-government organizations, academia and service providers’ (Voss et al. 2010: 1). Added to the usual technical cost-effectiveness results, these views, taken together with other
policy relevant considerations such as acceptability, feasibility, and equity, represent a filter to ensure sensitivity to the specific needs of the population (Voss et al. 2010). As an example, in indigenous health researchers have ascertained that delivering an intervention such as a medical consultation with a general practitioner (GP) will cost double the ‘standard’ cost of a GP consultation for the general population (Ong et al. 2009). The magnitude of the equity weight was determined by comparing the costs of specific interventions via both indigenous primary health services and mainstream services, taking into account the additional costs of remote travel and the evidenced need for aboriginal health workers to mediate the GP visit. Establishing the additional needs of a specific group ‘makes comparisons with mainstream more equitable when applied during economic evaluation’ (Ong et al. 2009: 2). While equity weights are a relatively new concept, Ong et al. believe that

Cost-based weights have the potential to provide a pragmatic method of equity weight construction which is both understandable to policy makers and sensitive to the needs of target groups. It could improve the evidence base for resource allocation decisions, and be generalised to other disadvantaged groups who share similar concepts of equity (Ong et al. 2009: 3).

Epistemologically, this returns the argument to one of ‘special needs’ (Colgan et al. 2010) or minority groups, yet equity weights, from a conversion handicap perspective, have the potential to recognise and address capability differences. What is required to balance this tension is the adoption of a broader epistemological position that privileges notions of human diversity, human rights, and entitlement to universal aspirations and outcomes. Equity and equity weights have the potential to address those elements that disable, including impairment effects, social and economic contexts, and disabling environmental barriers.

Findings from ‘The Equipment Study’ regarding impairment and disability

Having examined impairment and disability from the perspective of the theoretical literature, the chapter now turns to examine these ontological premises by drawing on empirical data from ‘The Equipment Study’.
As presented in Chapter 3, while the study population all identified as AT users, their demography was extremely broad, mapping across all body structure and function chapters of the WHO ICF. The discourses of impairment and disability presented above also demonstrate a wide demography for human diversity, where impairment can be seen as a feature of human variation and part of the universal human condition. Individuals living with impairment have ‘and/ and’ identities, where the unique experiences which may be brought about by the effects of particular impairments are just one aspect of identity. Further, drawing on a social model perspective, the term ‘disability’ has come to describe the articulation of impairment effects with environmental barriers of all descriptions. The empirical data and the literature present a picture in which disablement can be seen as a mismatch between individuals’ capabilities (based upon impairment effects and personal factors), the particular environments in which they live, and the occupations which they enact.

**Impacts of impairment upon lives: on being ‘the same but different’**

In the context of the vexed history of separate treatment (Albrecht 2001; Annison 1996) including low expectations and support (Goffman 1963; Wolfensberger 1975), it is important to examine the basic question of whether life aspirations are universal, or distinguished and differentiated by disability or impairment. Here, the empirical data is analysed to examine aspirations, and experiences of difference from citizens living with impairment.

**The same: universally desired life outcomes**

Data analyses support the contention that the valued life outcomes of individuals living with impairment are the same outcomes of value to citizens in general. Participants sought to ‘go out into the community ... to live, rather than merely exist’ [S43]. This statement from a profoundly impaired, non-verbal adult living with quadriplegia and locked-in syndrome articulates the autonomy and choice he desires, the difference it would make to his life, and the extraordinarily affirming fact that being in and participating in the community can make life worthwhile. This participant also reported substantial participation limitations through restricted personal care hours, noting that he is only able to access the community for ‘one shopping/ coffee afternoon a week’ [S43], thereby foreshadowing key difficulties in attaining these universal outcomes. A diversity of ‘The Equipment Study’ participants expressed essentially universal desires
and aspirations around achieving wellbeing, and participating in the world around them:

Live an independent and inclusive life [S106 45-64 year old with late effects of polio & secondary conditions]

A fuller life & a garden [S105 45-64 year old with multiple sclerosis]

To illustrate these commonalities across life aspirations, data were evaluated through the filter of generic quality of life theory. Quality of life has been previously discussed in the methods chapter in light of health economic measurement. Given the conceptual and methodological limitations of the health-related quality of life approach discussed there, a more encompassing conceptualisation of quality of life is utilised here for this task. Amongst the many QOL measures available, Cummins’ ‘Comprehensive Quality of Life Scale’ (1997) is devised for the adult population overall and identified as a suitable benchmark for the population as a whole, including those living with impairment (Gomez 2011; Shalock 2004). In order to test commonality of quality of life aspirations, qualitative data from ‘The Equipment Study’ was categorized using the seven quality of life domains of this scale and examples presented in Table 6.

Table 6: What do people want from life?

<table>
<thead>
<tr>
<th>Multidimensions of Quality of Life for Adult Population (Cummins 1997)</th>
<th>Sample statements by participants.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age bracket and diagnosis included (where reported) to demonstrate demographic diversity across dimensions</td>
<td></td>
</tr>
<tr>
<td>1. Material wellbeing</td>
<td>Now that my partner also has a disability, we are struggling to maintain the house, and we need to pay cleaner and sometimes gardener. [S10] have more money to live and pay for basic needs. [S39 25-44 year old female with cancer] [supports required to] More of a chance to catch up with friends at the cafe over a hot drink, equally, instead of straight there/ home and 4 walls syndrome … would make living more of a leisurable [original text], pleasurable and safer effort on my part. [S35 45–64 year old female with myopathy]</td>
</tr>
<tr>
<td>2. Health</td>
<td>one thing that would make a huge difference to health and wellbeing would be swimming pools that are totally and independently accessible for wheelchair users in Ballarat and more wheelchair friendly gym facilities with better trained</td>
</tr>
<tr>
<td>Multidimensions of Quality of Life for Adult Population (Cummins 1997)</td>
<td>Sample statements by participants. Age bracket and diagnosis included (where reported) to demonstrate demographic diversity across dimensions</td>
</tr>
<tr>
<td>---</td>
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</tr>
<tr>
<td></td>
<td>staff. [S17 45–64 year old female with paraplegia]</td>
</tr>
<tr>
<td>3. Productivity</td>
<td>Computer setup for making websites for a small income. Online banking enables me to move money around. [S24 25–44 year old female with multiple chronic illnesses] I would love to return to some paid consultancy work; organize my time and my appointments ... it would keep me busy and occupied, I wouldn’t be bored, my brain would be active. [S110 45–64 year old male with multiple sclerosis]</td>
</tr>
<tr>
<td>4. Intimacy</td>
<td>Have independent access to home and return to a normal husband/ wife relationship with carer [S9] If the money was available I would like to have enough care so that my young daughter would not have to care for me at night and weekends, this would take the responsibility of me from her. [S26 45–64 year old female with PTSD and chronic vestibular disturbance]</td>
</tr>
<tr>
<td>5. Safety</td>
<td>Be confident that when I go out, I’ll not have to turn around and go home again; Be safer on the street. [S10 45–64 year old with multiple sclerosis] Having street lights wait until I cross the street before it turns red would put me in a safer environment in the busy main roads. [S35 45–64 year old female with myopathy]</td>
</tr>
<tr>
<td>6. Place in community</td>
<td>Be able to be more independent … able to join in social events [S107 45–64 year old male with C5/ 6 quadriplegia] go out more and be involved in community … to spend more time outside my home. [S59 15–24 year old male with Duchennes Muscular Dystrophy] Be able to access things I enjoy doing in life … Go out and do things with people or on my own and feel like I’m part of something, part of the community, part of life … have a say in the community in which I live in. [S61 25–44 year old female with multiple chronic illnesses]</td>
</tr>
<tr>
<td>7. Emotional wellbeing</td>
<td>To socialise with neighbours, get exercise … participate socially with friends … get around more freely … depend on others a lot less, and be more independent [S88 25–44 year old male with quadriplegia] Plan for the future, not live hand to mouth – massive decrease in stress, resulting in improvement in overall wellbeing … More ability to plan short and long-term … spare time for fun! [S32 female with chronic pain, PTSD, anxiety and depression]</td>
</tr>
</tbody>
</table>
This data echoed that of the *Shut Out Report* which concluded from over 750 submissions and 2,500 consultations that people living with disability are ‘just like all other Australian citizens, individuals with their own needs, abilities, ambitions and priorities. They are united only by the experience of living with disability’ (National People with Disabilities and Carers Council 2009: iv). These data sets also verify the claim that ‘People with disabilities clearly value social outcomes – the extent to which they are active, productive members of society, well integrated in family and community life’ (Djikers et al. 2000: S75).

The stakeholder reference group noted some irony when study participants affirmed that the goals of citizens living with impairment are in fact those of the citizenry in general. They commented that a sense of difference and exclusion was generated in contemplating that their lives might in fact be seen as separate, different and not ‘normal’. The fact that discourse from the disability and rehabilitation literature needed to say this reinforced for the stakeholder reference group the essential task of articulating this ‘sameness’ based in evidence.

That said, the fact that individuals living with impairment seek a life shaped by ‘everyday ordinariness’ rather than ‘exclusion and oppression’ (National People with Disabilities and Carers Council 2009: vii) points to a difference in the experience and ‘starting point’ for citizens with disability.

*The same but different: the impact of disability upon extent of and realisation of aspirations*

Having recognised the universality of life aspirations across the spectrum of human diversity, the question arises: what makes life different for individuals living with impairment? In the words of the *Shut Out Report*, people living with disability ‘desire to have the same opportunities as everyone else for a fulfilling and productive life’ (National People with Disabilities and Carers Council 2009: vi). Such human aspirations speak to a desire for equality of outcomes with fellow citizens. These desires are not different in nature from other citizens’, but have particular resonance with other marginalised groups such as caregivers (Cummins et al. 2007), refugees and asylum seekers, and some indigenous populations (Kronenberg et al. 2005; Pollard et al. 2008). It is notable that many of the elements of quality of life named by participants in Table 6 were described
as not realised: in other words, phrased as aspirations rather than achievements.

A further analysis explores the extent of realisation of life outcomes for ‘The Equipment Study’ cohort through the lens of capability gaps: that is, identifying the missing ingredients which would render people, despite the presence of impairment effects, able to achieve equal outcomes. Table 7 demonstrates the areas of human endeavour in which participants participated using the supports available to them, across a set of eight life areas geared to diverse populations, specifically disability (Wilson 2006). Table 7 contains the percentages of survey participants who identified activity in each life area, illustrated by narratives demonstrating the methods or strategies participants used to participate.

Table 7: Life area engagement by ‘The Equipment Study’ participants

<table>
<thead>
<tr>
<th>Participation in Life Area (Wilson 2006)</th>
<th>Capability resources – illustrative quotes re. mediators used to enable realisation of participation in life area</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of respondents</td>
<td></td>
</tr>
<tr>
<td><strong>Personal Life Outcomes</strong> (health and function, happiness, wellbeing, safety, sense of independence and choice)</td>
<td>‘Being bedridden [I use] environmental controls to let visitors in’ [S24]</td>
</tr>
<tr>
<td>98% of respondents</td>
<td></td>
</tr>
<tr>
<td><strong>Social Life Outcomes</strong> (friendships and relationships, community involvement and sense of belonging)</td>
<td>‘Designated seating for wheelchair and companion make a huge difference. Means you don’t have to sit on your own. [S30]</td>
</tr>
<tr>
<td>80% of respondents</td>
<td>(I use) carer support, bicycle and aids to assist my vision … I don’t have anything that I can’t do. [S57]</td>
</tr>
<tr>
<td><strong>Recreation &amp; Leisure Life</strong> (being involved in recreational or leisure activities at any level. This might be through attending activities, playing an active part or doing what you enjoy)</td>
<td>I love to paint; I love going to the theatre too. I use my wheelchair. [S86]</td>
</tr>
<tr>
<td>73% of respondents</td>
<td>I have braille playing cards as well as board games. [S72]</td>
</tr>
<tr>
<td></td>
<td>[a] partly modified 25 foot yacht for bay sailing and staying overnight. [S101]</td>
</tr>
<tr>
<td><strong>Economic Life Outcomes</strong> (finances, employment or business)</td>
<td>I use a smart view magnifier to read what mail has come in the letter box. [S29]</td>
</tr>
<tr>
<td>68% of respondents</td>
<td>I use a Lightwriter to communicate, I also do volunteer work at a local opportunity shop. [S55]</td>
</tr>
</tbody>
</table>
Participation in Life Area (Wilson 2006)  
% of respondents | Capability resources – illustrative quotes re. mediators used to enable realisation of participation in life area
---|---
I breed Australian Miniature Ponies … I have a motorised chair I use to get around the paddocks. [S97]

Educational Life Outcomes (relates to your education, training, personal or professional development)  
66% of respondents | Tertiary study completed in 1990s at specifically selected University which was accessible. [S30]

Political Life Outcomes (having a say about things that affect you (e.g. in a local service or community group, about your local area, funding etc.))  
65% of respondents | I advocate for our rights, write to politicians, participate in local committees. [S32]
I assist on two committees/ boards, I use my wheelchair and vehicle. [S45]

Cultural Life Outcomes (being involved in cultural activities (e.g. arts, music, theatre, dance at any level). This might be through attending activities or playing an active part, or through being part of your own cultural group)  
69% of respondents | [user of Etran communication board] I wrote and produced a play. I write a lot on computer – something that doesn’t need carers. [S43]

Spiritual Life Outcomes (any aspect of your religious or spiritual activities)  
54% of respondents | I use my electric chair to travel to church on Sundays. [S74]
Modifications to the church would be the ideal but not practical. This has been overcome somewhat by a church worker bringing communion to me. [S26]

‘The Equipment Study’ data presented in Table 7 demonstrates participation achieved across a range of life areas. ‘The Equipment Study’ data presented in Table 8 depicts desired participation and the factors limiting its achievement. The 100 survey participants described a range of mediators identified as necessary to achieve outcomes in these areas: these have been conceptualised as ‘capability gaps’ in column 2.

| Table 8: Life areas aspirations by ‘The Equipment Study’ participants |
|---|---|
| Unmet need for participation in Life Area (Wilson 2006)  
% respondents identifying unmet need | Illustrative quotes re. capability gaps and the mediators anticipated to enable realisation of participation in life area |
<p>| Personal Life Outcomes (health and function, happiness, wellbeing, | a mobile phone would mean I could be out in the community on my own with greater safety. |</p>
<table>
<thead>
<tr>
<th>Unmet need for participation in Life Area (Wilson 2006)</th>
<th>Illustrative quotes re. capability gaps and the mediators anticipated to enable realisation of participation in life area</th>
</tr>
</thead>
<tbody>
<tr>
<td>% respondents identifying unmet need</td>
<td></td>
</tr>
<tr>
<td>safety, sense of independence and choice)</td>
<td>[S26] With the right equipment I could do far more than I do now. [S53]</td>
</tr>
<tr>
<td>68% of respondents</td>
<td></td>
</tr>
<tr>
<td>Social Life Outcomes (friendships and relationships, community involvement and sense of belonging)</td>
<td>[I] wish I could get out into the community – once a week isn’t enough. [S41] Everyone tells me I need 2 carers and there isn’t enough funding for this. [S41]</td>
</tr>
<tr>
<td>48% of respondents</td>
<td></td>
</tr>
<tr>
<td>Recreation &amp; Leisure Life (being involved in recreational or leisure activities at any level. This might be through attending activities, playing an active part or doing what you enjoy)</td>
<td>[desires] new adapted saddle for riding [to] ride my horse with more independence and safety; modified reins for riding; cheaper access to adaptive skiing. [S87] the built environment limits recreation and leisure pursuits by denying access. [S21] Go swimming more access the football more often and go out with other people. [S19] Would love an accessible shed. [S101]</td>
</tr>
<tr>
<td>38% of respondents</td>
<td></td>
</tr>
<tr>
<td>Economic Life Outcomes (finances, employment or business)</td>
<td>[desires] Less effort in running around finding accessible banks or embarrassing myself by yelling from the front door and having to be a dependent disabled person, reliant on people’s good will. [S25] Most banking done online. Local branch has very high, wide counters and need to shout to person behind security glass. [S30]</td>
</tr>
<tr>
<td>32% of respondents</td>
<td></td>
</tr>
<tr>
<td>Educational Life Outcomes (relates to your education, training, personal or professional development)</td>
<td>Professional development opportunities reliant on venue and accessible parking being available. [S30] To have less people marching through my life just so I can go to uni. I would feel like less of a problem. [S69] [desires] removal of increased TAFE fees to allow me to continue with Ceramics course … do another diploma, now financially and physically out of reach. [S51]</td>
</tr>
<tr>
<td>27% of respondents</td>
<td></td>
</tr>
<tr>
<td>Political Life Outcomes (having a say about things that affect you (e.g. in a local service or community group, about your local area, funding etc.)</td>
<td>Again it’s access, access, access … my local member’s office is inaccessible … parliament House Vic has a back door accessible entrance … governments hold a lot of power over our lives so access to them is essential. [S25] Our town hall is not wc [wheelchair] friendly –</td>
</tr>
<tr>
<td>24% of respondents</td>
<td></td>
</tr>
<tr>
<td>Unmet need for participation in Life Area (Wilson 2006)</td>
<td>Illustrative quotes re. capability gaps and the mediators anticipated to enable realisation of participation in life area</td>
</tr>
<tr>
<td>-------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>% respondents identifying unmet need</td>
<td>the buttons for the lifts are too high! [S26]</td>
</tr>
<tr>
<td></td>
<td>I need help in the voting booth, my husband does this. If I wanted to, I could get pre-voting ballots, but [I] like to go to vote. [S15]</td>
</tr>
<tr>
<td><strong>Cultural Life Outcomes</strong> (being involved in cultural activities (e.g. arts, music, theatre, dance at any level). This might be through attending activities or playing an active part, or through being part of your own cultural group) 22% of respondents</td>
<td>[desires] recognition that PWDs can and will be involved as practitioners of the arts as well as watchers—recognising this in venue planning and design. Better informed staff at venues and booking services. [S25] [improvements?] enjoy the arts and culture and not feel denied access to events or have to make endless enquiries, and know that everything at the event is accessible, affordable and not located in a crumby position because of my disability … Be able to access things I enjoy doing in life. [S61]</td>
</tr>
</tbody>
</table>
| **Spiritual Life Outcomes** (any aspect of your religious or spiritual activities) 10% of respondents | Assistance with getting to temple … (for) greater participation and attendance; improved peace of mind [S32]  
If I could have carers when I needed them I would be able to attend the church service that I want to … allow me to go to church and be involved as I want to be. [S11]  
I have been invited to four spiritual Christmas events as a member of support groups and can access none of the venues so will not attend. [S106] |

While the population generally could be expected to enjoy these activities and freedoms captured within Wilson (2006) life areas, the data presented above illustrates the particular limitations that participants experience in relation to their non-impaired counterparts (Saunders et al. 2007). These limitations relate to discourses of normal and normative, particularly in relation to independence and interdependence, choice and control, and barriers and facilitators. These themes will be addressed below.
The same but different: normal and normative

In describing similarities and differences between life for those with and without impairment, understandings of ‘the same’ are underpinned by notions of normal as previously discussed. The following narrative from Goble (2004) discusses the focus of health professionals upon independence as a desired outcome, and foregrounds several tensions around the conceptualisation of normal and the problematisation of dependence:

The functional capacity, or more often incapacity, of the disabled person is assessed using scales and tools that measure their performance against ‘normative’ standards. Programmes are then drawn up which aim to reduce the gap between the performance of the disabled individual and the normative standard as far as possible. Success is achieved when the professional expert judges that the performance of the individual has moved significantly in the desired direction … The assumption is that the problem lies with the individual, and the response is technical intervention by skilled ‘expert’ professionals to help the person overcome it and return to an approximation of ‘normality’. (Goble 2004: 42)

Independence was certainly mentioned by study participants but was rarely coupled with a need for rehabilitation or remediation. The term ‘independence’ appeared interchangeable with ‘autonomy’: in a number of instances people identified a desire to be ‘be more independent and rely on others less’ [S88]. For example, a young woman with cerebral palsy stated more carer support would enable her to ‘go places and do things with friends without mum. I would just be more independent and like any other 21 year old’ [S69]. In this instance, more or different supports or mediators were hoped to bring about feelings of independence.

‘Being normal’ was a term frequently used to explain the control and flexibility people desired:

Have a bit more flexibility and do things when I want, sleep in sometimes … be a bit more normal and just do things when I want to. [S34]
One would feel more ‘normal’ because like other people I would not have to plan every step according to where I can or can’t get in or where I can get down the street or find parking. [S25]

Being able to access more tour buses for holidays, more money to employ more paid carers to go places on weekends like normal people do. [S81]

Spend time on my own doing what I want. [S95]

Have choices about how I spend my time … Doing things I want to do, try new things. Enjoy life. [S61]

As well as control and flexibility, a range of other concepts contribute to the nature of ‘normality’, including autonomy and independence (Arneil 2009; Reeve 2002; Shakespeare 2006). Emerging from ‘The Equipment Study’ dataset were many examples which verify a view of autonomy that involves ‘being’ rather than ‘doing’. For example, one bedfast participant positioned her hospital bed in her lounge room, adjacent to a veranda door so she could view her garden, and sufficiently close to direct and engage with garden activities, stating ‘I love gardening … well it’s my bossing and other people’s gardening’ [S24]. This participant also wished to engage in cooking: that is, if her kitchen could be remodelled, her carers could prepare meals in her line of sight and with her direction. These perspectives upon normality, autonomy and independence arising from the data reinforce the importance of individuals defining desirable outcomes for themselves, although, as Goble warns,

it should be remembered that human service professionals often can, and do, work in alliance with disabled people to achieve emancipatory ends, [but] it is clearly the case that many disabled people experience this professionalized approach to the issue of independence as irrelevant and oppressive. (2004: 43)

The same but different: barriers to achieving an ‘ordinary life’

Participants desired the same diversity of life choices ‘enjoyed by others in the society’ (Senate Community Affairs Reference Committee 2004: 2.4) but these appear insufficiently valued and realised. The National People with Disabilities and Carers Council describe this as the ‘constant struggle to obtain what the
rest of the community would consider to be an ordinary life’ (2009: iv). While the outcomes described above resonate with human aspirations as articulated in human rights frameworks like the CRPD (United Nations 2006), their limited enjoyment on the part of study participants raises the issue of realisation, and whether resources to ensure the overarching intent of legislative frameworks are delivered:

society often fails to take seriously the autonomy of persons with disabilities … their life choices are not perceived to be as worthy of social support as those of the non-disabled. Low expectations have led to neglect of the material conditions that people with disabilities need to take control of their lives and live as they wish … it is one thing to have the ability to study astrophysics despite disability – it is another to be able to do so in the absence of accessible transportation. (Quinn and Degener 2002: 16)

Selecting how to expend resources and mediators can be seen as an enactment of choice and control; however, frequently the choices are ones which affect health and participation in ways which contravene human rights principles. While it is the human condition to progressively work towards valued outcomes, the data indicates a particular set of barriers for people living with impairment, which serve to restrict their lives substantially beyond those of their non-impaired colleagues. Several participants, for example, limited their fluid intake so they could get through 12 hours until personal care was available to assist them to the toilet. The commentaries about people’s lives and desired changes captured in ‘The Equipment Study’ revealed the common theme of hardship in getting by, and lack of resources to meet life goals. As one respondent stated,

Hours a day are used up trying to manage to support the most basic of life’s tasks that would not need to be used if the [equipment] changes were implemented. [S106]

Choices and trade-offs between life areas were evident throughout the data, where limited access to mediators influenced possible outcomes:

I am able to access the community on Monday, Wednesday, Thursday and Friday as these days I have the longest hours. I give up having washes so that I can get out. [S26]
if I had more than 19 hours per week support hours, my family could have a break and could do more … I could socialise with neighbours; get exercise; relieve stress etc … I would a lot more time and flexibility to do things that I otherwise couldn’t. [S88]

40 hours a week [of provided personal care] seems a lot but divide it by 7 and it shrinks!! To go to the theatre I must give up some personal care!! [S26]

Participants described prioritising their participation opportunities where there were insufficient resources to engage in all life areas. Frustration was expressed regarding the inability to change current situations, as one adult living with quadriplegia describes:

Another hour [of personal care] per day would enable me to save some for holidays. I also want to hire direct and stop giving $350 per week to an ISP [individual support package broker] for nothing. [S11]

Participants in the research demonstrated having particular difficulties in accessing or achieving the life outcomes that they value. See Figure 6 for the proportion of met need (i.e. activity in each life area) to unmet need (i.e. specific instances/activities that participants wished to undertake but could not).
Figure 6: Met and unmet needs across Life Domains (Wilson 2006)

Research question 1c asks: Is it impairment effects, or disablement resulting from environmental barriers, that restricts outcomes? To examine this question, ‘The Equipment Study’ data were analysed to determine the impact of impairment effects, as compared with the impact of identified barriers.

The impact of impairment effects upon participation

‘The Equipment Study’ provides key evidence that severity of disability does not preclude participation, demonstrating that impairment effects of themselves are not necessarily experienced as barriers to participation. One participant with a disability level bordering on profound (no voluntary movement and no speech) described significant achievements in his life, including living alone independently, made possible via a suite of eight major AT devices including communication devices and specialised computer peripherals operated via eye gaze:

I did a university degree off-campus using the Blind mob’s talking books. I wrote and produced a play … I voice for myself – I participate in a communication advisory group [S43]

Satisfaction with participation in life for many study participants was linked to the presence of a tailored set of mediators aligned to the desired outcomes of the individual rather than to the degree of disability. A young adult with paraplegia stated,

I do need to have a chair that I can easily get into the car and that is comfortable and works for me. I have one currently funded by a private foundation. Couldn’t get A&EP [Victorian Aids and Equipment Program] to fund one for me and I’d be stuffed without it. My main hobby is theatre and performing … The chair is crucial to these activities. [S25]

These findings demonstrate that severity of impairment need not exclude participation in desired life domains. A respondent with Huntingdon’s Chorea described her social life as follows:

[I use a] Lightwriter; alphabet or yes/no board; I love going out. I go to concerts and to see sport events I go in my wheelchair and special van. The
staff help to move me in my wheelchair and airchair … rec [recreation] staff and my daughter help me to go to different places. Sometimes people find it hard to understand me. I can get frustrated. I appreciate it when people stop to chat to me … I would not make any changes I have a great life. [S86]

Narratives from three participants have been selected to illustrate the impact of mediators upon capability gaps: that is, the way in which a range of supports mediate between impairment effects and environmental and task demand, to enable desired participations. First, a mother living with chronic illness describes her set-up:

I receive 40 hours paid care per week. My carers [do] my shopping, I used to have a helper from the council till it was decided I was too young … this was very difficult for me. I do not use a credit card so even computer shopping was very difficult. Now I can shop at the green grocer, baker, and small food shop on my own, the people know me and the shops are accessible. My daughter does the banking and pays our bills on the phone so I can know what is going on and participate. [S26]

The second participant is an adult with paraplegia:

I work full time, drive my own modified car. As I age, getting in and out of the car is getting more difficult. I may need further modification to the car to make it easier to get into. I do my personal banking online which is easy. I own my own home. [S17]

The third participant, an adult with a degenerative condition:

As I mainly use public transport I spend time planning on internet the route and means of transport (timetables) and how they connect. Often 1 bus and 2 trains or 2 buses and 1 train to get somewhere; can be limited by access and the time of day/ night travelling. I use the internet a lot for planning. A hand held GPS for navigating my way around the streets and electronic diary for planning, organising and remembering. Telephone and mobile phone. Computer with accessible technology [such as] screen reader. [S47]

In these three examples, access to the online environment is a powerful mediator to eliminate physical access issues, without which the need for EI, PC
or AT would increase. For example, the first respondent is limited by the level of her carer support, but enabled by the presence of friendly local shops, although issues of choice and lack of capacity to shop around for bargains are likely to be trade-offs. The second respondent is affected by the limited application of assistive technologies (i.e. vehicle modifications) to her vehicle and the absence of a powered wheelchair. The third is enabled by current mainstream technologies (GPS, internet access) which require self-funding, but is limited by community-based elements (timetables and public transport availability).

These examples validate contemporary, critical realist views of disability. Participants explain their lives in relation to impairment, but from the perspective of active agents in their own unique existence, engaging in a wide diversity of life areas and activities. Impairment is just one of the threads of individuality making up the whole person, alongside identities as student, parent, volunteer, retiree, community dweller and so on. These examples also indicate the profound impact of mediators upon their lives. Notably, computers and internet costs are non-funded items on government equipment schemes, although specialised peripherals do attract a subsidy. ‘Inclusive community’ elements of AT solutions also come into play; namely aspects of the broader social, attitudinal and built environment which are beyond the scope of AT funding schemes. These observations will be further discussed below and in the AT policy analyses within Chapter 7.

**The impact of societal barriers upon participation**

According to the *Shut Out Report*, people living with impairment ‘just want the barriers removed so they can get on with living’ (National People with Disabilities and Carers Council 2009 iv). Beyond impairment effects, aspects of the environment are identified by ‘The Equipment Study’ participants as critical barriers to, or facilitators of, valued life outcomes. One participant described her disability as ‘Cerebral Palsy and the “built environment”’ [S15]. Frequently, physical barriers, rather than the effects of impairment per se, were described as preventing these outcomes: for example, a 61-year-old with multiple medical conditions related pain and social participation to the need for accessible public transport:
Accessible low floor regular public transport that will take me to where I need to go rather than having to take 3 forms of public transport on a crappy Sunday timetable [in order to] Attend Mass regularly where my friends go … It would save me sooooo much time and stress trying to get connecting public transport and then arriving there in a lot less pain. [S61]

**Factors implicated in disablement: the built environment**

A range of responses clearly shows the link between impairment and environmental barriers in creating disability, with participants identifying many possibilities for removing current environmental barriers and providing extensive data of potential outcomes should these occur. Societal barriers manifest in a variety of forms, and frequently participants reported a mix of both barriers and facilitators, providing concurrent experiences of inclusion and disablement:

> Being able to do my own shopping is a great pleasure and an independence event [but] when a shop is only partly accessible and the specials are in an area where there is no accessibility then I have to go home without a moment of equality. [S35]

The following comments from respondents are typical of issues they face in public urban spaces and the unmet need for modifications:

> If the environment was more accessible I wouldn’t need any carer help. I don’t use any now but sometimes it is difficult and I rely on friends to drag me up steps etc. [S25]

> Easy access to buildings would save huge amounts of time and stress. The good footpaths would mean I did not get tired so quickly and therefore could be out in the community doing what I wanted for longer periods of time. Good public transport is obvious. [S26]

> Counters at a usable/ accessible/ reachable level in govt and private offices and businesses. Microphone podium accessibility. Lifts that work and don’t stop a few centimetres off or below the floor level. Better emergency escape plans regulated. [S35]

> [I need] street changes – I use a chin-controlled chair and when I try to move the chair along street paths and cross the road, poorly constructed bumpy
and steep crossovers are extremely difficult to navigate with my chin. When paths are not flat and smooth, my head moves too much for my chin to remain on the chin control, it makes it nearly impossible for me to get out in most areas locally like to the park or shop. Roads are more smooth than paths. The use of blue stones for crossovers is appalling for wheelchair users. [I need] better access into some buildings, venues and shops that haven't provided access for the disabled in wheelchairs. [S89]

One participant described the differential experience of inclusion based upon the nature of the environment:

I stayed in Seattle where it is more physically accessible. I realised I felt different and the difference was that I felt more like I used to feel before my accident when I lived in an environment that was built to include rather than exclude me. [S25]

Factors implicated in disablement: non-physical environments

Aspects of social and attitudinal environment were also described as integral to the outcomes of participation and inclusion and the experience of disablement. One young adult with vision impairment who used a wheelie walker to mobilise described her life as follows:

I am extremely competent with public transport – however I don’t go to large events such as the football and concerts on my own – it is too easy for me to be knocked over in large crowds … I get assistance from bus-drivers and others as I go about my day … I go to TAFE and my counselling course, the gym and other local things on my own. I also visit my friend at Cheltenham as often as I can. [S38]

In this instance, public transport is used with support from public transport staff to access a range of activities and venues. Participating independently in major events, however, is avoided for safety reasons. Others commented on more global experiences:

An impossible change – people’s attitudes, just because I am in a chair I am not stupid!!!! [S26]
Misinformation in relation to what some venues/locations call ‘accessible’ e.g. ‘It only has one small step’, ‘there is just a step into the shower’, ‘Parking is close by’ etc. [S30]

Government awareness of what the needs are for people with disabilities in the community. At this stage the only group well supported are those with a vision impairment. [S26]

Acceptance of the ‘companion card’ needs to be made compulsory by law, I can not attend activities if I have to pay for my carer to take me. I have been accused of trying to ‘rob’ a company by asking for free admittance for my carer!!!!!! UNTIL THIS IS MADE LAW [capitals in original] there will be companies etc who will not comply. [S26]

This theme of disablement coming about through non-inclusive environments, both social and physical, is consistent with social model perspectives. Such data upholds Scotch and Schriner’s (1997) premise that if environments fully accommodate a condition it ceases to be a disability. The term ‘inclusive community environs’ has been coined in this thesis to express the combined impacts of built and non-tangible aspects of environments capable of creating, or eliminating, the experience of disablement. The components of inclusive community environs will be explored further against the major taxonomies of ISO and ICF, in Chapter 5.

Factors implicated in disablement: poverty causing lack of access to mediators of impairment effects

If open markets and adequate resources are in place within society, citizens typically purchase needed goods and services for themselves. Exceptions to this are goods related to public welfare: for example, an individual cannot be expected to finance the running of a hospital or the police force, services needed for the benefit of all. Goods and services relating to health also form a special case; these are seen as merit goods in economic terms. In the case of merit goods, specific resourcing or provision may be provided depending on the welfare obligations of society (Drummond et al. 2005; Mooney and Scotton 1998). However, there appears to be substantial dissonance between the outcomes known to be possible with a range of mediators and the reality of current experience for those living with disabilities, captured both in “The
Equipment Study’ sample and in the wider literature. Key to this is the capacity of individuals to obtain the mediators they require, which raises the issue of resources and the related issue of poverty.

Data presented below indicates that the study participants were likely to experience poverty and high costs of disability, rendering them less likely to be able to mediate capability gaps themselves. The AIHW identifies 64% of people aged 18–64 who have severe or profound core activity limitations as receiving income from government pensions and allowances (AIHW 2009b: 156). As the tables below demonstrate, 75% of study participants relied on government support (including housing support), held marginal employment, and were less likely to be living with partners in established households.

Compared with the population of Victorians not identified as having disabilities, the study cohort fared far worse on all indicators. Income and employment are key indicators of poverty or affluence. As noted by the Productivity Commission, ‘disability exacerbates disadvantage. People with a disability and their carers often also experience low levels of income, educational attainment, employment, superannuation, health and wellbeing’ (2011: 9). Almost all respondents had an annual income below $58,000 per annum, with most well below $21,600 (see Table 9).

Table 9: Main income source of participants compared to the Victorian population (ABS 2003)

<table>
<thead>
<tr>
<th>Category</th>
<th>The Equipment Study Participants</th>
<th>ABS Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>government pension/ allowance</td>
<td>75% (N - 60)</td>
<td>53%</td>
</tr>
<tr>
<td>wages or salary</td>
<td>19% (N- 15)</td>
<td>29%</td>
</tr>
<tr>
<td>other income</td>
<td>9% (N-7)</td>
<td>18%</td>
</tr>
</tbody>
</table>

NB ABS Data refers to 15-64 year olds living in Victorian households

Five participants identified their primary funding source as insurance. Four of these received Traffic Accident Commission (TAC) funding and one identified ‘other insurance’. Incomes were variable across these participants, with one receiving less than $6,000 per annum, two receiving between $6,001 and $21,601, and one with income between $21,601 and $58,000 (see Figure 7). The insured group therefore did not necessarily have substantially higher
incomes, but did report significantly increased support in terms of mediators provided.

Figure 7: Annual gross personal income of participants

Survey questions pertaining to employment were completed by 78 participants. Twenty-one participants (27%) identified themselves as being in employment, compared with the 2003 ABS population data of 50% for adults with disabilities. Of those in employment, six were full-time (29%); ten part-time (48%); and five (24%) were employed on a casual or ad hoc basis (see Figure 8).
Figure 8: Type of employment of participants

Many participants commented that their disability influenced their employment status, particularly with regard to lack of accommodation of their workplace needs:

Due to my disability I had to retire from paid work much earlier than anticipated. [S56]

Due to lack of building and toilet access [there are] less jobs available. One can only work in an accessible building. Also due to attitudes about disability and perceived difficulties by employers about access among other things. [S25]

If more workplaces were wheelchair friendly then maybe people with disabilities would be more easily included in work! Even DHS does not know how many people with disabilities they employ. [S24]

[I need] support to make access viable. My attendant carer attends every lecture I give, sets up the room and all educational aids, supports the learner where the access is not possible. I am also a Celebrant and my attendant carer provides access to every venue and does all of the physical work to allow me to perform and take part in educational and celebrancy life. [S106]

Participation poverty and social exclusion

The impacts of poverty upon participation can be clearly seen when data is analysed through a social exclusion lens (Saunders and Wong 2009). Several data sets point to the link between disability and poverty, resulting from low incomes and few employment opportunities, either for people with disabilities or for their family carers who might otherwise contribute to household income. Thirty-six percent (36%) of people aged 18–64 with severe or profound core activity limitations in Australia are identified as living in households in the lowest 20% of income distribution (AIHW 2009b: 156).

Overall, people with disability are among the three most vulnerable populations in terms of social exclusion, only marginally better off than sole parents and unemployed people: 32% of Australians with a disability and 39% of Victorians with disabilities do not participate in community activities; and 81% of
Australians with a disability and 61% of Victorians with disabilities do not have $500 in emergency savings (Saunders and Wong 2009). A recent study of emergency relief recipients found the highest proportion were disability pensioners, suggesting significant economic hardship and deprivation among this group (Engels et al. 2009).

Along with low incomes, people living with disability have been identified as sustaining a high disability-related cost burden, related to ‘the high cost of medication, the purchase of special equipment or aids, and access to appropriate housing, transport and services related to personal care or maintenance of a person’s home’ (Senate Community Affairs Reference Committee 2004: 363). For example, one ‘Equipment Study’ participant described her difficulties in affording a particular support which was unfunded by any AT scheme, yet would save costs and improve outcome into the future:

Elastic stockings are expensive but necessary. No elastic stockings= swollen legs= leg infection= hospital. [S42]

The presence of added health conditions and multiple disabilities is of note given the documented link between the extent and multiplicity of disability (Kinne et al. 2004) and the need for mediators. People living with disability have a ‘thinner margin of health’ than people without impairments (Löfgren et al. 2011). As the AIHW notes, ‘The more disabilities people had, the more likely they were to need help with “core” daily activities of self-care, mobility and communication … access to aids and equipment is critical to older people with multiple disabilities’ (2009a: v).

Poverty in affluent nations such as Australia is generally conceived in relative rather than absolute terms, defined ‘not in terms of a lack of sufficient resources to meet basic needs, but rather as lacking the resources required to participate in the lifestyle and consumption patterns enjoyed by others in the society’ (Senate Community Affairs Reference Committee 2004: 2.4). The evidence presented above points to the overall context of dependency on government income support, which is unlikely to adequately meet the costs of living with a disability. It can therefore be argued that some of the study population experience both absolute and relative poverty.
While this study did not explicitly ask about experiences of participation poverty or social exclusion, a number of the findings speak to current indicators of social disadvantage. ‘The Equipment Study’ data were collated against some of the indices of social exclusion utilised by the Social Policy Research Centre in 2009 to determine deprivation or social exclusion i.e. an ‘inability to afford essential items’ (Saunders and Wong 2009: vii):

- Does not have a week’s holiday away from home each year;
- Does not have $500 savings for emergencies;
- Does not participate in social and community activities;
- Lacks access to key services when needed (medical or dental treatment if needed);
- Has restricted access to economic resources and low economic capacity (range of indices) (Saunders and Wong 2009).

While this data cannot be quantified to determine levels of participation poverty or social exclusion among the study population (as not all respondents chose to discuss these topics and their experience of them), the experiences documented by some respondents provide some evidence that this group experiences both deprivation and social exclusion. The following table provides some selected examples of experiences of the study sample against these five indices.

Table 10: Examples of deprivation and social exclusion in the study population

<table>
<thead>
<tr>
<th>Issue</th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week’s holiday away from home each year</td>
<td>[I need] more paid care, maybe one holiday a year as I cannot go on my own and I cannot afford to pay a carer and I desperately need a holiday . . . to see some of Aussie before I die. [S81]</td>
</tr>
<tr>
<td></td>
<td>Sometimes I’ve asked for a 6am shift [for paid carers] … it’s a hassle … you know … I wanted to get to Warrnambool by train (early start) but it’s after hour’s rates … you wonder, for people working, how would they get on? [S34]</td>
</tr>
<tr>
<td></td>
<td>I live with my ageing parents and we don’t have holidays very often. Logistically there is a lot to consider and I cannot expect my parents to take on that work load … if there was support available to take you on a holiday with or without your parents it would be ideal, but you cannot expect carers to give up their lives to go on holidays with you … perhaps take a holiday with the help of a paid worker who could care for me … it would give my parents a break. [S93]</td>
</tr>
<tr>
<td></td>
<td>Yes we saw the wheelchair accessible caravan at Yooralla … yes we went in to it, it was good … just totally out of our price range. [S34]</td>
</tr>
</tbody>
</table>
### $500 savings for emergencies

It would be most beneficial if the waiting period for financial assistance for equipment was not so lengthy … The charges for home modifications are so costly; it takes such a long time to save for these needs. [S56]

We are always trying to find money for things like taxis and continence products and carers and we need to fix the house and get a new car. [S69]

We don’t think about things like that [safer kitchen appliances] because we know darn well we can’t afford it. [S35]

### DISENGAGEMENT

Lack of participation in social and community activities

Would love to do another diploma, now financially and physically out of reach. [S51]

Sadly, unable to afford further education … [Cultural life] Sadly, unable to afford these activities. [S56]

I have the time but not the carers and funding for them [i.e. social activities]. [S38]

If I could have carers when I needed them I would be able to attend the church service that I want to. I cannot do it at present. [S11]

### SERVICE EXCLUSION

Lack of access to key services when needed

I don’t have enough money to go to the dentist. [S42]

Instances of deprivation and social exclusion from the data, as measured against five indices used by the Social Policy Research Centre (Saunders and Wong 2009)

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Poverty, then, can be seen as a key factor in disablement. Data from ‘The Equipment Study’ participants aligns with other evidence of unmet need related to income; for example, Desai et al., in their US study of 2,700 elders needing support to perform one or more activities of daily living, found over 20% of participants had one or more unmet needs, with nearly 50% reporting negative consequences as a result. Unmet need was found to be associated with ‘lower household income, multiple ADL difficulties, and living alone’ (Desai et al. 2001: 82). In Australia, the *Shut Out Report* relates the costs of disability and the costs of mediators to limited resources and to conversion handicap:

*The costs of mobility aids (like wheelchairs or scooters), communication aids, specifically designed therapies, paid carers and supports, home renovations, etc, are all very costly to ordinary people living on pensions or benefits. The extraordinary gap between the level of income support and the cost of disability was seen as restricting the ability of people with disabilities both to live independently and to enjoy a decent standard of living. Gaps in the service system mean that many people with disabilities and their families,*
friends and carers are forced to meet the cost of essential services and support themselves. As many noted, this leaves little discretionary income to meet basic living costs. (National People with Disabilities and Carers Council 2009: 35)

In response to the question posed above, as to whether removal of barriers would enable the achievement of outcomes desired by ‘The Equipment Study’ participants, the evidence demonstrates that, above and beyond impairment effects, a range of factors create disablement. Further, the lack of material resources, compounded by higher costs of disability and a thinner margin of health, serve to increase the capability gap between those living with impairment and those without.

Evidence for an equity weighting

A tool for calculating equity is proffered by ‘The Economic Study’ (Colgan et al. 2010), based upon data from ‘The Equipment Study’. As outlined previously, an equity weighting is a calculation based on the real cost of meeting the needs of specific groups and specific interventions, considering the range of factors which concerned stakeholders identify as contributing to capability gaps. The economics team conducting ‘The Economic Study’ established the evidence base for a disability equity weighting by identifying the costs and outcomes of providing an optimal package of assistive technology to a subset of respondents (n-8). This involved estimating the costs of service and support, and comparing these to outcomes as measured with a Quality of Life data collection instrument (Hawthorne, Richardson and Day 1999). This data was translated into a cost per Quality Adjusted Life Year (QALY). The current QALY rate for Australia is $50,000 (George, Harris and Mitchell 2001). Outcomes improved in all cases as a result of optimal provision, and the cost of provision of the optimal AT was small (under $7,000) in half of the cases. In the other 50% of cases, the actual cost of AT was moderate to high (between $11,000 and $30,000), which made the supply of AT cost-ineffective as it required expenditure of more than the threshold of $50,000 per quality adjusted life year gained (Colgan et al. 2010: 180). ‘The Economic Study’ offers a preliminary calculation of a 2- to 3-fold equity weighting to achieve parity with fellow citizens (Colgan et al. 2010). The potential of an equity weight as a policy solution will be addressed in Chapter 8.
Concluding comments

A number of core understandings regarding the nature of impairment and disability will be carried forward through the thesis. In response to the overarching question regarding how impairment and disability are understood, it appears the term ‘disability’, as used in common parlance, in fact refers to two related (but conflated) concepts. Specifically, the embodied variations in body structure and function with which we all live and which are a feature of human diversity; and the disabling mismatch between an individual’s capabilities, participation goals, and environments. This thesis has therefore operationalised the concept of disability into impairment effects (variations in body structure and function) and disablement (societal barriers which prevent or limit participation).

In terms of the way in which disability might be the same or different (research question 1a), human variation is found to be universal; however, societal understandings of disability remain influenced by the historical coupling of impairment with notions of deficit, abnormality, and disease. This both explains certain socio-political responses to impairment and points to the need for ontological repositioning. Postmodern thought, in particular critical realism, repositions disability, stating that ‘Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality’ (Shakespeare and Watson 2001: 19). Shakespeare and Watson illuminate the constructed nature of disability, including human bodily variation as well as the impacts of inadequate societal response to impairment.

Research question 1b asks whether the presence or experience of impairment or disability might impact upon life aspirations: conclusions thus far indicate that human aspirations are universal, and well articulated in human rights conventions, yet impairment does influence the degree of achievement of human aspirations. Australians living with impairment report they have not, as yet, attained equality of outcome with Australia’s citizens generally: the current situation is one where individuals living with impairment ‘may be present in the community but most do not enjoy full participation in it’ (National People with Disabilities and Carers Council 2009: 2). ‘The Equipment Study’ data portrays 100 Victorians living with impairment aspiring to universal human endeavour, yet limited by a range of barriers ‘beyond’ their impairment effects.
Thus far, the thesis has established the need for ontological repositioning and provided evidence that people with disability aspire to but do not achieve equal outcomes. It is therefore timely to explore the role of mediators such as AT, EI and PC further as ‘capability gap mediators’ or bridges towards equal outcomes.
Chapter 5: Assistive technology, environmental interventions and personal care or support as mediators

Having explored understandings of disability and impairment, Chapter 5 investigates what might mediate or mitigate disablement, as expressed in research question 2:

2. How do mediators bring about outcomes?
   2a. Which strategies mediate impairment effects and disabling environmental barriers, and what relationship do they have to each other?
   2b. What is the effectiveness of identified mediators?

The nature of mediators and their role in achieving valued outcomes for people living with disability is the focus of the chapter, which seeks to investigate and define mediators in relation to each other as a foundation for a discussion of their effectiveness in Chapter 6, and the AT policy case study to follow in Chapter 7.

The previous chapters have established that classifying ways to manage and minimise the impact of disability upon life is likely to be influenced by the ontological position of the classifier. Context of use also frames the language and focus of classifications, and this perhaps explains the predominance of the term ‘interventions’ to describe mediators within medical and rehabilitation settings (Smith and Benge 2004). A widely accepted framework with an ontological positioning congruent with the thesis principles is provided by Smith:

- interventions to reduce the impairment or compensate for the impairment;
- the redesign of life activities;
- the use of assistive devices;
- the redesign of life environments;
- the use of personal care work, otherwise known as attendant care or support (2002).
To illustrate these various strategies Smith and Benge (2004) provide the example of an individual living with cerebral palsy and speech impairment, engaged in the task of ordering food in a restaurant. Here, ‘reducing the impairment’ entails rehabilitating dysarthric speech in order to achieve functional vocalisation. ‘Compensating for the impairment’ bypasses dysfunctional speech by pointing to a menu or using gestures. ‘Redesigning the activity’ might entail using a set menu, while ‘Using AT devices’ might involve use of a speech synthesiser or communication board. ‘Redesigning the environment’ could be going to a cafeteria-style restaurant and ‘Using personal assistance’ would have an attendant order the food or perhaps interpret the vocalisations (Smith and Benge 2004). Other definitional frameworks frequently combine several of these five core elements, as, for example, the inclusion of environmental interventions within assistive technology (Cook and Hussey 2008; ISO 2007; WHO 2001), but no frameworks have been identified which acknowledge the relationship between the various elements. Frequently, actual definitions of what constitutes AT or EI encompass a range of strategies. For example, several authors identify EI as including changes or additions to structures, the introduction of AT, the reorganisation of space, and the adjustment of tasks (Cumming et al. 1999; Pynoos et al. 1988).

Impairment-reducing and compensatory interventions such as surgical intervention, rehabilitation programs and prosthetic training fit within the ‘compensating for the impairment’ category, and are delivered primarily via health and rehabilitation settings at focal points in the impairment trajectory (Smith 2002). The remaining strategies of assistive technology devices (AT), environmental interventions (EI) and personal care (PC), within the context of redesign of activities, are applicable throughout the individual’s lifespan. These are the primary strategies by which people with disabilities manage their situations and maximise their capacity to accomplish life tasks (Cook and Hussey 2008). AT, EI and PC are selected as the categories of mediator which best reflect the thesis inquiry intent.

Literature reviews for AT, EI and PC are presented below, but first a commentary from a disability perspective is offered to contextualise the discussion. While Litvak and Enders are talking about AT devices in this instance, the principle is consistent across all the constructed boundaries that
definitions and taxonomies create: ‘that which enables a desired outcome’ is a mediator.

From a grassroots disabled person’s perspective, it does not matter what the technology is, just that it fits, works, and is useful … in other words, if the products selected require you to consider your disability issues first, then they are assistive technology – even if they are widely available, mundane, mass-market products. If you did not have a disability you would not have to think about these product features when you make your choices. When your disability is defining or narrowing your product choices and options, you are buying assistive technology, whether you are calling it that and whether it was designed to be AT. (Litvak and Enders 2001: 711)

Assistive technology

Defining assistive technologies

AT can be broadly divided into devices and services. WHO defines AT as ‘an umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed’ (WHO 2001: 10). An assistive device is further defined in the ICF as ‘equipment that enables an individual who requires assistance to perform the daily activities essential to maintain health and autonomy and to live as full a life as possible’ (WHO 2001: 173). ISO 9999, which provides standards for assistive products for persons with disability, defines AT as ‘Any product (including devices, equipment, instruments and software), especially produced or generally available, used by or for persons with disability’ (ISO 2011: 2). This recently released definition updates the previous version; as ‘The Equipment Study’ data were analysed based on the 2007 version, it is provided here:

any product (including devices, equipment, instruments, technology and software) especially produced or generally available, for preventing, compensating for, monitoring, relieving or neutralizing impairments, activity limitations and participation restrictions (ISO 2007: 2).

For the AT user in Australia, available technology is more limited than the international listing ISO 9999 would suggest, for several reasons. Because the
actual AT supply sector in Australia is ‘small and fragmented, and dependent largely on imported products from overseas-based companies’ (Hobbs et al. 2009: 153), design, manufacture and import of AT devices are ad hoc and subject to many systemic variables including market forces (Dong et al. 2006). The relatively small Australian market limits the range of products imported, and while AT users may be able to purchase products privately over the internet, some trade- and standards-related barriers do exist (Association for Children with Disability 2006). Hansson notes that ‘The quality of life of people with disease or disability depends to a large extent on the availability of enabling technology’ (2007: 265). This infers a limitation for Australian AT users as decisions on such technologies are noted to be ‘partly made in the healthcare sector, partly in other sectors of society’ (Hansson 2007: 265).

**Hard and soft technologies**

AT can also be usefully classified using Odor’s concepts of ‘hard and soft technologies’ (Odor 1983, cited by Cook and Hussey 2008). Here, AT devices represent ‘hard’ technology, while related activities such as clinical advice, customising, and training represent ‘soft’ technology. Provision of the actual device alongside or embedded with relevant soft technology elements is identified as critical to outcomes (Scherer and Sax 2009). For example, successful matching of AT devices such as environmental controls or wheelchairs to an individual requires a comprehensive understanding of the hard technology (the device), and a systematic application of the soft technology (needs assessment, set-up, trial, training and follow-up) for optimal outcomes (Cook and Hussey 2008; McDonald 2010). Soft technology expertise usually sits with experienced AT suppliers or an AT practitioner such as an occupational therapist, physiotherapist, speech pathologist or rehabilitation engineer (Waldron and Layton 2008). A key issue in obtaining AT is that, while ‘hard’ technology is able to be purchased or provided through funding bodies, the necessary ‘soft’ technologies of assessment and fit, customisation and training, are not always coupled with the device.

Evidence for the effectiveness of soft technology is reported by Kayes and McPherson (2012), who synthesised the substantial body of clinical reasoning literature from occupational therapy, psychotherapy, and physiotherapy to identify the nature of the relationship or connection between the practitioner and
patient. Defining this connection as the 'therapeutic alliance', they describe this phenomenon as a 'human technology' (2012: 1911). Research in these fields has found that the therapeutic alliance has the potential to positively contribute to the disparate responses to treatment observed in individuals (Kayes and McPherson 2012: 190).

When is technology not ‘assistive’?

Over 19,000 AT devices were listed as commercially available in 2011 by the world’s largest AT database, based in USA (ABLEDATA n.d.). Other national AT databases (for example, Europe’s database, EASTin 2007), reflect similar product ranges. Australia’s Independent Living Centre database comprises approximately 6,000 products (ILC 2012), reflecting both limited imports into and limited manufacture within Australia.

AT devices can be categorised in a number of ways: for example, Hansson (2007) classifies AT into four technology types which may alleviate the impact of disease or disability (see Table 11):

<table>
<thead>
<tr>
<th>Technology Type</th>
<th>Purpose</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic technology</td>
<td>reduces restrictions by reducing disability</td>
<td>Implants and technology used for surgery</td>
</tr>
<tr>
<td></td>
<td>Restores the original biological function that has been lost, or prevents further losses</td>
<td></td>
</tr>
<tr>
<td>Compensatory technology</td>
<td>reduces handicap by providing new abilities that compensate for the disability</td>
<td>Eyeglasses, hearing aids, speech synthesis systems, walking sticks, crutches, wheelchairs, orthotic appliances, ventilators, and equipment for total parenteral nutrition</td>
</tr>
<tr>
<td></td>
<td>Replaces (fully or in part) a lost biological function with a new function of a general nature</td>
<td></td>
</tr>
<tr>
<td>Assistive technology</td>
<td>makes it possible for the individual to perform a task or activity despite an (uncompensated) disability or lack of function</td>
<td>Devices with which disabled persons can perform tasks or activities that most persons can perform without these devices: knives that require less strength, appliances for dressing; remote controls for doors; adaptive interfaces of software products; household robots</td>
</tr>
<tr>
<td></td>
<td>Makes it possible for the individual to perform a task or activity despite an (uncompensated) disability or lack of function. Assistive technology provides abilities of a more specialised nature than compensatory technology does</td>
<td></td>
</tr>
</tbody>
</table>
**Universal technology**
designed on principles for all users

Intended for general use, not only for persons with a specific disease or disability

Devices and environments designed according to UD principles such as flexibility of use, perceptible information, low physical effort eg lever action door handles, large doorbells.


In addition to Hansson, other writers have differentiated between types of AT by using terms such as low to high technology, general versus specific technology, and everyday versus specialist technology. These classifications are explained in Table 12.

**Table 12: Terms used to refer to AT**

<table>
<thead>
<tr>
<th>Typology</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low to high technology</td>
<td>Inexpensive devices that are simple to make [versus] expensive, more difficult to make, and harder to obtain (Cook and Hussey 2008: 6)</td>
</tr>
<tr>
<td>Minimal to maximal technology</td>
<td>Minimal technologies generally augment rather than replace function e.g. orthotic devices [versus] all devices that provide a functional replacement (prosthetic devices) (Cook and Hussey 2008: 7)</td>
</tr>
<tr>
<td>General versus specific technologies</td>
<td>Used in many different applications or intended for specific applications e.g. seating system used across wide range of applications [versus] performance in one unique application area e.g. hearing aid, feeding devices (Cook and Hussey 2008: 7)</td>
</tr>
<tr>
<td>Everyday technologies (ET) versus specialist technologies e.g. stove; electric kettle; TV; remote; micro; press button telephone; coffeemaker; washing machine; dishwasher; radio; stereo; computer; cell phone; DVD</td>
<td>ETs are an important part of the environment in which we live and interact (Patomella et al. 2011: 243)                                                                                             ETs: made for the average user, unlikely to be paid for by health insurance [versus] Specialist technologies: durable, often high cost, made for those with complex needs (Scherer 2012: 180)</td>
</tr>
</tbody>
</table>

Common sense suggests it is difficult to determine any element of technology which is not ‘assistive’, as assisting humans to function is the purpose of
technology. However, identifying the scope and boundaries of technology are not merely semantic exercises in wording. Postmodern readings argue that concepts are brought into being through socially constructed discursive formations (Foucault 1991). The social model serves to disturb the idea that impairment per se is disabling, by linking features of the environment to the experience of disablement. This key understanding is taken up in the notion of the technology chain, the relationship between assistive technologies and environmental interventions (AAATE 2003). Here, accessible environs such as a stepless shower may eliminate the need for AT devices such as a shower stool.

Taken further again, the normal/abnormal or mainstream/assistive divide is further blurred by developments from the design field regarding technology definitions and population norms. The rapidity of technological change and AT device mainstreaming is likely to influence understandings of AT in the near future, and may in part address the impact of naming ‘special’ interventions and devices discussed below.

**Technology, stigma, and the de-stigmatising promise of inclusive and universal design**

A range of factors influences the uptake, use and effectiveness of AT, according to studies into AT abandonment and non-use (Wessels et al. 2003). Among these factors are ‘personal meanings’ associated with AT devices which ‘influence the integration of assistive technology into daily activities’ (Pape et al. 2002: 5). AT devices have the potential to preserve or damage the self-image of the user insofar as they draw attention to a deficit, highlight a lost skill, provide low aesthetic choice and value, or have negative peer group connotations (Hocking 1999). An example of identity related to AT devices is that of hiking poles versus a walking stick: both provide a point of support for walking, but one presents an image of outdoor recreation while the other is more likely to be associated with age or infirmity. Watson and Woods, writing from the perspective of medical anthropology, highlight this when they note that a wheelchair (a common AT device) ‘disables the users in that they are themselves medicalised’ (Watson and Woods 2005: 103). Echoing Foucault’s (1991) medical gaze, Reeve points out that using technology serves to render an impairment visible; this then ‘presents the observer with privileged information and therefore power about the body. This gaze is influenced by the
stereotypes and prejudices about disabled people’ (Reeve 2002: 499). Historical images of assistive technology devices (variously termed equipment, invalid aids, or appliances) include leather and buckle callipers, medical implements and ‘specially’ adapted homes. Current and future images include robotics and innovative designs such as the iBOT wheelchair or exoskeletal products. The rapid diversification of enabling technologies holds implications for AT users which go beyond traditional medical ethics yet are seldom discussed in bioethics, the ethics of technology, or other branches of applied ethics (Hansson 2007). Impacts of the pervasive use of technology include the risks that technology will replace human contact (particularly pertinent in replacing personal care usage) and that disabled people’s needs and autonomy become subordinated to the technologies in use.

Effectively, then, AT represents a strategy which can either ‘enable’ or ‘disable’. Goggin and Newell describe the impetus to ‘fix’ disability with technologies:

Technology has become an important part of modern medicine, and nowhere is this more apparent than the glamorous field of biotechnology where real possibilities for creating and modifying human beings are emerging. It is commonly assumed that people with disabilities are the natural beneficiaries of such technology. (Goggin and Newell 2005: 42)

It is interesting therefore to consider the phenomenon of ‘patient reluctance to use compensatory and assistive technology’ (Hansson 2007: 264). Probably this speaks to the fact that AT devices are seen as markers of illness and loss, identity and stigma (Connell et al. 2008; Cook and Hussey 2008; Hocking 1999, 2008). AT devices have typically been designed, manufactured and marketed by niche suppliers for the disabled ‘other’ (Hobbs et al. 2009) and the resulting lack of consultation and consideration regarding the views, attitudes and tastes of individuals correlated with AT non-use and abandonment (Wessels et al. 2003).

In order to understand what drivers shape definitions, there is a need to understand the use to which definitions are put, and the needs of those doing the defining. Definitional differences greatly affect what governments and private insurance will provide, and are frequently based upon custom and practice (Masso et al. 2008). Obtaining AT devices frequently involves a transaction mediated through professionals as gatekeepers of equipment funds (Barbara
and Curtin 2008). In this transaction, individuals with impairments are in a position of requiring the appropriate ‘label’ to match the device, effectively reducing the person to a disability identity (Riou et al. 2011). The scope of AT, as defined by AT funders and health insurers, is frequently restricted to items that are ‘medically necessary’ – a criterion itself subject to interpretation based upon the ‘narrowest administrative definition of clinical need’ (Barbara and Curtin 2008: 58). AT is defined by many funding systems as a ‘medical device’. This becomes problematic because it perpetuates the medical model view of disability rather than the alternate conceptualisations of disability, and may prevent recognition of AT as technology that supports independent living (Ripat and Booth 2005).

**Contemporary definitions of AT**

The existence of the international taxonomy *Assistive Products for People with Disability* or ISO 9999 (ISO 2007, 2011) can be seen to delineate or to draw a line around ‘assistive technology’ as specific to people with impairment and separate from that used by ‘everyone else’ (Cook and Hussey 2008), a critical departure from previous definitions (technical aids, invalid appliances’) in that it includes generally available devices when they serve as assistive products for persons with disability (ISO 2007). Any assistive device can theoretically be classified within the classification system of ISO 9999 (Hoenig et al. 2007), which offers 650 device categories across 11 classes as follows:

- **04** Assistive products for personal medical treatment
- **05** Assistive products for training in skills
- **06** Orthoses and prostheses
- **09** Assistive products for personal care and protection
- **12** Assistive products for personal mobility
- **15** Assistive products for housekeeping
- **18** Furnishings and adaptations to homes and other premises
- **22** Assistive products for communication and information
- **24** Assistive products for handling objects and devices
Three levels of classification are offered: for example, class 12 denotes assistive products for personal mobility, with 14 subclasses including walking products, cars, cycles, wheelchairs, transferring and turning, plus additional divisions for powered wheelchairs, foot driven wheelchairs, and so on (ISO 2007: 7).

Devised with reference to ISO 9999, the ICF also categorises devices, describing Products and Technology over twelve subchapters within its Environmental Factors section (WHO 2001). Chapter 1, for example, identifies ‘Products and technology for personal indoor and outdoor mobility and transportation’ as a discrete subchapter (coded e 120) (WHO 2001: 173). Within this, the third-level classification delineates ‘General products and technology for personal indoor and outdoor mobility and transportation’ (e1200) including non-adapted buses, cars etc., and ‘Assistive products and technology for personal indoor and outdoor mobility and transportation’ (e1201) including adapted or ‘specially designed equipment’ (WHO 2001: 174).

Together these taxonomies present a full array of mediators, particularly in light of the ISO exclusions (installation of assistive products, assistive products and instruments used exclusively by healthcare professionals, non-technical solutions such as personal assistance and guide dogs, financial support, implanted devices and medicine) (ISO 2007: 1). The reason for a number of these exclusions is that they are dealt with in other standards; thus, while they may be useful strategies to mediate disability, procedural or historic structures govern their inclusion or exclusion in taxonomies.

Finally, turning to the future, inclusive design realises ideas of human diversity as discussed in Chapter 2 of this thesis. Inclusive design moves away from the conventional human factor ergonomics approach of ‘norms’ and outliers, and is

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3 Although a subsequent version of ISO 9999 has been released (2011), at the time of study construction and data analysis, the 2007 version was current, and therefore it is used here.
based on a ‘deep understanding of diversity’ (Dong 2007: 70). Such inclusivity has the potential for a paradigm shift from ‘designing special aids and equipment for disabled people (an assistive technology approach), to designing mainstream products for as many people as possible (a universal design approach)’ (Dong 2007: 67).

The philosophy of universal design has typically conceptualised a population bell curve, featuring a centralised ‘norm’ and outliers. Design can encompass the needs of these outliers if universal design principles (equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for approach and use) are successfully implemented (Steinfeld and Danford 2006). Universal design tenets are, however, shifting towards an inclusive view of the population, in response to advances in models of the disablement process (Steinfeld 2010). Thus, from an inclusive design perspective, the traditional bell curve population is now characterised as a circular entirety (Dong 2007: 70). In this conceptualisation, a series of ‘segments’ captures the ergonomic diversity of the population. To use the example of an assistive device, a small moulded pistol grip potato peeler suits both adolescents and older people with weakened grip caused by arthritic conditions; while a heavier cylindrical grip potato peeler suits adults with large hands but poor dexterity such as labourers or those with athetosis: differently tailored designs meet the diverse needs of the population, where a single design might approximate the needs of 80 to 90% of that population. In this case, the ‘special’ aspects of the designs are marketed in a way that does not distinguish disability but rather distinguishes particular design features.

Conceptualisations of the mediator that is AT can be seen to be influenced by standpoint: both historical, and related to the role of the viewer (AT user, AT funder and so on). Definitions must be flexible enough to encompass unprecedented technological change, and the possibilities presented through inclusive and universal design trends. As described in methods, for this thesis ISO 9999 is utilised as a flexible, contemporary taxonomy for AT.

**Environments**

Human performance is inextricably linked to ‘the physical, social and attitudinal environment in which people live and conduct their lives’ (Schneider et al. 2003:...
Environments are variously conceptualised as overlapping spheres of home and community (Ainsworth and De Jonge 2011), and both built and social elements (Imrie and Hall 2001; Steinfeld 2010; WHO 2001). A number of publications in the field of environmental interventions take a particularly broad perspective by addressing relevant psychological aspects of environmental interventions such as the psychological attachment to home (Beer and Faulkner 2009); the fit between person and environment (Wahl et al. 2009); and the economic costs as well as psychosocial responses to changing and modifying dwellings (Tinker and Lansley 2005).

Several theories speak to the critical impact of the environment upon disablement, such as the competence-environmental press model (Lawton and Nahemow 1973), the disablement process model (Verbrugge and Jette 1994), and the person-environment fit model (Wahl and Gitlin 2003). Lawton and Nahemow link the psychological constructs of adaptive behaviour response with the idea of ‘environmental press’, which represents forces in the environment that, together with individual need, evoke a response (Lawton and Nahemow 1973). The competence-environmental press model introduces the idea that there are optimal combinations of environmental facilitators and personal competencies that result in the highest possible functioning for that person (Wahl and Gitlin 2009). The disablement process model also draws intrapersonal and external factors together in describing how conditions (impairments) affect functioning alongside the personal and environmental factors that may speed or slow disablement (Verbrugge and Jette 1994). The person-environment fit model (Wahl and Gitlin 2003) draws on both these theories, viewing a person within their environment as a system.

It is widely acknowledged that the environment or milieu as a whole will mediate the experience of disablement (Ainsworth and De Jonge 2011; Letts et al. 2003; Sanford 2012; Scherer 2005). As Whiteneck et al. point out, the impact of environment cannot be overstated:

physical, attitudinal, and policy barriers in the environment are viewed as having as great an impact, or greater, than the underlying organ system impairments in determining a person’s activity limitations, participation

A disability perspective on issues of environment is provided by Reeve, who presents a view of environment as both structural and psychosocial:

One important aspect (of psycho-emotional aspects of disability) includes the way in which disabled people respond emotionally to social exclusion and physical barriers (structural disability), such as feelings of anger and frustration when faced with inaccessible buildings. Another dimension of this form of disability includes the emotional responses to the social reactions of other people, for example, feeling ashamed when being stared at in the street. An important element of this type of emotional disablement is called internalised oppression and is a feature of any marginalised group within society (Reeve 2002: 495).

Indeed, environments with an absence of infrastructure such as pavements or transport routes prevent many people from accomplishing their daily activities. As built environments have historically been designed around the theoretical norm of an upright adult male (Hunter 2003), they can be experienced as ‘disabling’ for many other individuals, such as parents with prams. The ‘disabling nature of everyday design’ compounds the presence of impairment effects or the effects of aging; and builders, designers and developers are complicit in this situation (Sanford 2012: 19). The marginalised status of individuals living with impairment is reflected in the lack of environmental accommodation: ‘The oppression and domination of disabled people underpins the (development) processes which give shape to the built environment’ (Imrie and Hall 2001: 145).

While the social model explicitly links the environment with disablement, in practical terms the person continues to be identified as the locus of disablement, as can be seen in Heywood’s definition of environmental modification: ‘any permanent alteration to a building carried out with the intention of making [it] more suitable for a disabled person’ (2004: 134).

**Defining environmental interventions**

In its broadest sense, environment encompasses natural and physical aspects of the landscape, including terrain, air quality, temperature, and so on. The broadest taxonomy of environment is provided in the ICF’s ‘Environmental...
Factors’ section (WHO 2001). This includes Chapter 1 (Products and Technology), where three categories offer fine differentiations between home and community environs. Private dwellings are covered by ‘design, construction and building products and technology for buildings for private use’ (Chapter 1 e155). A further two categories cover the environment beyond the garden gate. ‘Design, construction and building products and technology for buildings for public use’ (Chapter 1 e150) addresses public buildings, while ‘products and technology for land development’ (Chapter 1e160) includes kerb cuts, pathways, lighting and signage, and other aspects of the wider environment. Psycho-social aspects including the societal milieu or attitudinal environment are captured within Chapter 2 (Natural environment and human-made changes to environment); Chapter 4 (Attitudes) and Chapter 5 (Services, Systems and Policies).

The WHO ICF also offers the concept of barriers and facilitators, which provides a lens through which to view the impact of the environment upon an individual. The ICF recognises that the way in which certain factors are experienced by individuals makes them into either facilitators or barriers: ‘Environmental factors are to be coded from the perspective of the person whose situation is being described. For example, kerb cuts without textured paving may be coded as a facilitator for a wheelchair user but as a barrier for a blind person’ (WHO 2001: 171). In recognising the central role played by environmental factors, the ICF can be said to enact the social model of disability as the locus of the problem and, hence, the focus of intervention is shifted from the individual to the environment in which the individual lives (Schneider et al. 2003). The ICF’s position normalises environmental barriers as an experience for people with and without disabilities. The impact of environmental barriers for those living with impairment effects, such as the presence or absence of features like kerb cuts, wayfinding and signage, ramps, lifts, and continuous paths of travel, can effectively enable or bar individuals from participating: ‘people with disability experience more frequent and/ or more problematic barriers than people without disabilities and … the nature and severity of the disability relates to the frequency and magnitude of the barriers encountered’ (Whiteneck et al. 2004b: 1329).
The language of environmental barriers and facilitators is designed to capture experiences across both tangible and non-tangible aspects of environments, and identifies potential interventions at local and systemic levels (Ivanoff et al. 2006). Generally, however, environmental interventions are directed at a local, not systemic, level. While it is recognised that multiple elements within environments may present barriers or facilitators to human functioning, some are seen to have limited capacity for adaptation.

Research about environmental interventions has largely focused upon physical access issues with little attention to measures of the psychosocial experience of environments. Priestly et al. (2009) begin to articulate broader views on EI when they argue that:

A holistic approach to the ‘useability’ of physical environments needs to be applied … which goes beyond technical requirements for physical access. Confidence, security, information and forms of social interaction and assistance are all relevant to the useability of physical space. (2009: 78)

Perhaps unsurprisingly, from a rehabilitative perspective, the locus of intervention within environments is taken to be aspects of the natural or built environment which are amenable to building adjustments on an individual basis. This view of environment as narrowed to tangible elements affecting one individual is also reflected in the detailed but narrow taxonomy of environmental elements in ISO’s Chapter 18, ‘Furnishings and adaptations to homes and other premises’ (ISO 2007).

In keeping with this more narrow definitional focus, formal definitions found in policy or practice standards tend also to be narrow. ‘Environmental interventions’ (AAATE 2003) is the umbrella term for modifications to homes or to the built environment more widely, used in Europe and North America. In Australia, environmental intervention practice is commonly known as home modifications or adaptations, and is usually limited to the process of modifying a home (Ainsworth and De Jonge 2011). The intent of modifications is to improve the fit between person and environment by increasing access and minimising barriers. Examples of common home adaptations include alteration of access in and out of the home with ramps, handrails, or doorway widening; provision of showering equipment and kitchen redesign for wheelchair access or for use of a
propping stool to enable self-care or domestic tasks; and hazard reduction to minimise the risk of falls by removing trip hazards, enhancing lighting, and building continuous paths of travel (Ainsworth and De Jonge 2011: 20). Emerging environmental strategies include ambient technologies embedded within the home environment, such as telemonitoring and robotic technologies (Ainsworth and De Jonge 2011; Soar 2010).

In this thesis and in ‘The Equipment Study’ both ICF and ISO taxonomies were utilised to analyse the environmental elements used by participants in ‘The Equipment Study’. These taxonomies provided scope for the emergent themes of home and community environs, as will be reported shortly.

**Personal care or support**

*Defining personal care*

The giving of care, or provision of support from one human to another, is variously defined and, as one might expect, definitions reflect several dominant ontological approaches. ‘Caregiver’ or ‘carer’ tends to denote unpaid support within family and kinship networks. ‘Personal care assistant’ is the term used to describe a person employed to provide assistance to others in health contexts (ILO 2010; WHO 2010); both classifications embed a rehabilitation-oriented approach to the role.

In the context of Australian physical disability, ‘attendant carer’ is a common term; for home and community tasks ‘home care workers’ may be used; and in intellectual disability, ‘support worker’ is preferred. These terms can be seen to be congruent with a social model of disability, specifically moving away from the term ‘care’ and its connotations of dependency (Arnold et al. 2009). The term ‘personal care’ is selected to capture the aspect of care from an economic perspective, whereby care work is a sub-category of work that includes all tasks that directly involve care processes done in the service of others (ILO 2010). This is congruent with the language of WHO ICF, which identifies eleven categories of ‘support and relationships’ including ‘personal care providers and personal assistants’ (e340) (WHO 2001: 187–189).

Engagement with human support is a fundamental transaction for individuals with impairment. Each occasion of support is a dynamic interaction, in contrast
to engagement with tangible and ‘fixed’ supports such as AT devices or EI. Comprehensive personal support represents a ‘central component in the realization of societal inclusion and personal freedom guaranteed to persons with disabling conditions’ (Stout et al. 2008: 44).

**Delivery of personal care**

Numerous studies have investigated personal care assistance, but as Meyer et al. note, there is a ‘paucity of research on the experience of receiving personal assistance delivered by formal services’ (Meyer et al. 2007: 595). Formal care schemes feature many models of delivery and financing (Henman and Foster 2011), although care work, while crucial to society, is notably undervalued and underpaid (Laragy and Naughtin 2009). Whether privately funded or via government packages of care, the personal care worker is typically used to assist with personal or domestic care work in the home or community. Personal care is usually provided separately from modifications and devices in terms of funding and service delivery. In Australia, government provision is frequently linked with the replacement of institutional care, such as community aged care packages (CACP) targeted to those at risk of admission to residential care (Fisher et al. 2010); and other schemes to provide work-based attendant care (Ottmann et al. 2009).

There is evidence of substantial unmet need and suboptimal provision (Stout et al. 2008); the impact of insufficient personal support is to severely curtail personal freedoms:

> In the action of waking up we are confronted with the very brutal realities of inadequate access to personal care support, to get out of bed and have our breakfast, or of a user pays system that increasingly requires ‘co-payments’ (as if many of us with disabilities have sufficient discretionary income). (Goggin and Newell 2005: 50)

Research question 2a asked which key strategies mediate impairment effects and disabling environmental barriers. The above discussion has explored and defined the strategies that are used to attain human aspirations in the context of impairment, focusing on the mediators AT, EI and PC as identified through the literature review and empirical study. This chapter now turns to consider the combined or interrelated use of mediators, but first presents the perspective of
Individuals living with disability regarding the relationship between mediators and outcomes, and their capacity to identify those mediators which will lead to outcome attainment.

**Linking mediators to outcomes**

People with disabilities clearly see mediators as delivering outcomes, as evidenced by ‘The Equipment Study’ cohort. Study participants identified the mediators which they felt would enable their desired outcomes to be achieved, as outlined in Table 13. Logical links are evident between the mediators listed in Table 13 and the hoped-for outcome (such as fewer environmental barriers leading to increased possibilities for wheelchair travel, more personal support freeing up time for hobbies, or a communication device enabling connections with others). Column 2 of Table 13 indicates the proportion of unmet need and unrealised outcomes reported by study respondents, suggesting that in many instances the potential of mediators is not fully realised.

**Table 13 Linking mediators to outcomes**

<table>
<thead>
<tr>
<th>Mediators and potential outcomes</th>
<th>% unmet need</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT devices</td>
<td>70% required additional and/or replacement AT devices</td>
</tr>
<tr>
<td>Try to have some sort of communication aid able to let people know how I am feeling or what I would like to eat or do. [S19]</td>
<td>70% required additional and/or replacement AT devices</td>
</tr>
<tr>
<td>If I had a wheelchair accessible vehicle I would be able to go further afield and visit friends and relations who do not live near stations. It would also mean that I could do more of my disability related activities eg. attending more schools to talk about living with a disability. [S106]</td>
<td>70% required additional and/or replacement AT devices</td>
</tr>
<tr>
<td>Environmental Interventions</td>
<td>46% required home modifications</td>
</tr>
<tr>
<td>(To) move into a home closer to family with others I choose to live with. Be around others without disabilities for a change. [S69]</td>
<td>46% required home modifications</td>
</tr>
<tr>
<td>Also many of the restaurants and shops in my area have a big front step; not having this would be good. [I would like] no stairs, plenty of places to sit and rest, public transport stops closer together, wider and more accessible toilets (not just disabled ones), disabled toilets not being ‘key available on request’. [S32]</td>
<td>52% noted community-level barriers</td>
</tr>
<tr>
<td>Access in my neighbourhood is very poor and I’m not confident at all getting around. Some places are too steep and some places don’t have footpaths. [S88, outer suburban user of power wheelchair]</td>
<td>52% noted community-level barriers</td>
</tr>
<tr>
<td>Personal care and support</td>
<td></td>
</tr>
</tbody>
</table>
Mediators and potential outcomes

<table>
<thead>
<tr>
<th>Mediators and potential outcomes</th>
<th>% unmet need</th>
</tr>
</thead>
<tbody>
<tr>
<td>My wife is becoming less able to do some activities that allow us to live where we do, so assistance would enable us to live longer in the place we love. [S94]</td>
<td>24% desired additional personal support</td>
</tr>
<tr>
<td>The support that I get is just enough for the everyday things to live my life. I can’t get away and that make me extremely angry. As far as weekends go, I hit barriers. I have a very busy week but weekends are a problem. Sometimes I want a support worker on a Sunday and I have to pay double or triple. [S106]</td>
<td></td>
</tr>
<tr>
<td>If I had more than 19 hours per week support hours, my family could have a break and could do more … I could socialise with neighbours. get exercise. Relieve stress etc … I would have a lot more time and flexibility to do things that I otherwise couldn’t. [S88]</td>
<td></td>
</tr>
<tr>
<td>Where it now takes me 1/2 hour to get my PJs on a car[r] could do this in 5 mins I would have more time knitting as its my hobby. [S34]</td>
<td></td>
</tr>
<tr>
<td>Have less people marching through my life just so I can go to uni. I would feel like less of a problem. [S69]</td>
<td></td>
</tr>
<tr>
<td>Some hours a day are used up trying to manage to support the most basic of life’s tasks that would not need to be used if the changes were implemented. [S106]</td>
<td></td>
</tr>
</tbody>
</table>

Other evidence from ‘The Equipment Study’ attests to the validity of people with disabilities’ identification of appropriate mediators to achieve outcomes. An expert panel review of the subset of eight interview participants provided an additional level of analysis of the solutions identified, and also confirmed the appropriate coupling of mediator with outcome by participants. The eight participant-generated ‘optimal’ situations were evaluated by the expert panel, who ratified the majority of participant suggestions, at times introducing additional or alternative solutions. Panel members identified a high correlation between need and solution: noting a high level of participant expertise in perceiving their own needs, linking them to potential solutions, and identifying the impact on goal attainment. They noted that, far from requesting ‘gold plated wheelchairs’, aspirations were both realistic and achievable in terms of human goals and potentially available mediators. These observations support the notion of individuals as experts in their own condition (Hill 2011); or, in terms familiar to the AT sector, the idea of the expert user (ARATA 2012). These ideas of consumer expertise will be reconsidered in Chapter 7.
The second part of research question 2a concerns the relationship these mediators have to each other; it will be discussed below, followed by a review of the effectiveness of the identified mediators.

**The emerging concept of AT solutions**

Chapter 3 foreshadowed the limitations of the literature concerning the relationships of mediators to each other. While a number of studies provide a foundation for hypothesising such relationships, there is little systematic evidence to assess the relative roles of various mediators, or the most effective combinations (Verbrugge and Sevak 2002).

The majority of studies located investigated the efficacy of one mediator. Examples include single AT devices such as the hoist provided for patients being returned home from an acute hospital in the UK (Benton and Ellis 2008); AT devices relevant to specific areas like workplaces, such as augmentative and alternative communication users (McNaughton et al. 2002); or home modifications as a single intervention (Petersson et al. 2008: 40). Some studies explored the impact of one mediator upon another, such as provision of a mobile hoist to bring a two-person transfer down to a one-person assist, or provision of a stairclimber to replace an assistant (Andrich 2002b). Even in these relatively straightforward studies, definitional differences are noted; for example, a portable ramp may be treated as an AT device or an EI, or a mobile hoist requiring the assistance of one carer may be classed as an AT device or as an element of PC.

Several studies consider AT combined with EI but without PC (Goodacre et al. 2008; Lansley et al. 2004), while others focus on AT with PC (Down 2006). Commonly, studies ostensibly of AT include elements of EI (such as handrails) in their definitions of AT (Hoenig et al. 2003; Verbrugge, Rennert and Madans 1997).

Two studies incorporate elements of all three mediators in the study definitions, yet only report on the efficacy of two mediators: Verbrugge, Rennert and Madans (1997) include some EI (structural modifications) in the definition of AT; while Hoenig et al. do not mention the environment at all in their extensive (N-
2368) study into personal assistance and technological assistance, describing PC and AT as the ‘two basic modes of coping with limitations’ (2003: 330).

Other studies demonstrate a broad definitional approach which appears to consider all three mediators. Goodacre et al. (2008) define adaptations (in other words EI) as a component of AT, and cost various packages of ‘adaptations, AT and care’ for seven notional users, while a series of studies encompassing AT and EI as elements of a ‘technology chain’ also make mention of PC (Lansley 2006; Lansley et al. 2004; Tinker and Lansley 2005).

The lens of the researcher and the taxonomies used can be seen to delineate and limit the range of interventions and thus the conclusions which can be drawn. However, despite limited theoretical exploration and limited evidence regarding the relationship of mediators to one another, there are grounds to envisage a relationship between the three. As Hartke et al. note, it is unlikely only one mediator is in use, so researchers need to look ‘beyond simple device use to consider multiple-device use and expressed need’ (1998:114).

A collaboration of AT researchers (including the author) has previously observed that AT, EI and PC are components of ‘enabling’ solutions for people, mediating impairment and reducing experiences of disability. This collaboration developed the following definition to capture the ingredients of an optimal AT response:

An AT solution is an individually tailored combination of hard (actual devices) and soft (assessment, trial and other human factors) assistive technologies, environmental interventions and paid and/ or unpaid care. (AT Collaboration 2009)

This definition is empirically tested against ‘The Equipment Study’ data in the remainder of Chapter 5.

*Findings from ‘The Equipment Study’ regarding AT solutions*

Data from ‘The Equipment Study’ provides a snapshot of what AT, EI and PC elements are used by 100 Victorians, as well as the demand for, and outcomes resulting from, use of these mediators.
- *Use of AT devices*

A total of 725 AT devices were in use, and participants demonstrated an appreciation of the presence of AT in their lives:

With the great use of the hoist I can now get on my shower chair and have a shower safely. [S11]

With the electric wheelchair I can get around independently to the shops … use bus, trains or maxi taxis to travel. [S42]

AT clearly means a wide range of things to AT users. Respondents reported using AT across a wide range of areas of ISO 9999, illustrating both the breadth of AT device usage, and the robustness of ISO 9999 as a taxonomy. Figure 9 contains total device numbers against major categories of the ISO 9999.

![Figure 9: Total AT device numbers by ISO category](image)

As well as this wide range of AT types, the data reveals how much AT was needed by this cohort. On average, eight AT devices were used by each participant. This implies that AT users require multiple items of equipment simultaneously as part of their mediator solution. Little comparable data from other studies regarding the number of AT devices used by individuals was
found. In 1998, Hartke et al. found almost one in four older adults were users of AT devices; of these, one third reported using multiple devices, but did not specify a number. Another study reported upon 57 adult community dwellers who used a total of 188 items post-hospital discharge in the UK – an average of three items each (Chamberlaine et al. 2001). Additionally, Mann et al.’s 1999 study compared an intervention group with unlimited AT access (on average 14 devices each) with a control group who accessed two devices each under ‘standard care’.

As shown above, the breadth of assistive technology devices in use was analysed against ISO 9999, the relevant international standard, and this taxonomy provided an exhaustive matrix to classify every AT device identified by ‘The Equipment Study’ participants, including all AT devices made or modified to suit individual needs (see Table 14).

**Table 14: Examples of custom-made/ modified devices against ISO 9999**

<table>
<thead>
<tr>
<th>Device</th>
<th>ISO 9999</th>
</tr>
</thead>
<tbody>
<tr>
<td>[In car] slippery plastic bag to swivel on in order to look left and right [S32]</td>
<td>ISO 2007: 12 31 Assistive products for transfer and turning</td>
</tr>
<tr>
<td>Calibrated earmuffs to stop loud noises [S26]</td>
<td>ISO 2007: 27 03 09 Devices for noise reduction</td>
</tr>
<tr>
<td>Self-designed foam scaffold to support legs in bed [S26]</td>
<td>ISO 2007: 06 12 Lower limb orthotic system</td>
</tr>
<tr>
<td>A tenor recorder, a book stand for use in my bed, a large tray for working with clay and other “creative” pursuits. A tiny little plastic sewing machine small and light enough to sit on bed and tray [S26]</td>
<td>ISO 2007: 24 24 Assistive products for positioning &amp; 30 18 Handicraft tools, materials and equipment</td>
</tr>
<tr>
<td>Modified quad bike [S92]</td>
<td>ISO 2007: 12 16 09 Four wheeled mopeds and motorcycles</td>
</tr>
<tr>
<td>Hoist to get into the family boat [S92]</td>
<td>ISO 2007: 24 30 Assistive products for repositioning and hoisting</td>
</tr>
</tbody>
</table>
The comprehensive classification system offered by ISO was demonstrated to embrace AT diversity through the inclusion of mainstream (commercially available) products, others marketed specifically as ‘specialist disability’ products, and custom-made products – suggesting that this standard is a useful, inclusive and relevant guide to AT devices.

This analysis of both off-the-shelf and individualised or modified AT emphasises that a comprehensive definition of devices is required if appropriate AT solutions are to be provided. Substantial data demonstrated that, from the standpoint of the AT user, the corraling of devices into ‘specialist’ versus ‘mainstream’ categories has no bearing on their usefulness, but substantial bearing upon whether they are deemed legitimate inclusions on equipment funding lists. Recognition of the diversity of AT allows for appropriate and individualised responses, just as the data illustrates that a wide diversity of individuals with impairment (beyond narrow definitions of disability) use and benefit from AT.

- Use of EI

Eighty percent of the respondents made explicit mention of the environment as a barrier, facilitator, or both. Two clear categories emerged from the data in environments: the home and inclusive community environs. EI data is presented against these two areas below.

- Use of EI: the home

The primary context of use for current AT and other enablers is the home environment, identified as both a constraint and a refuge. ‘The Equipment Study’ participants predominantly lived in private housing with others, although dwellings included flats, houses, government housing and relocatable homes in caravan parks. Modifications to the home were utilised by 39 respondents (43%), who listed a total of 332 home modifications as illustrated in Figure 10.
EI was an area of substantial unmet need, both in the home and in the community in general. The effectiveness of EI is evidenced by the lost outcomes identified through lack of provision. A significant number of participants described being ‘stuck’ in their dwellings without resources to adapt or change to more appropriate living situations:

I have lived here for 7 years and need a ceiling hoist, [and a] proper bathroom for my carers but this house is all that mum and dad can afford at the moment and we can’t do it here unless we renovate properly. And I think we can only get home modifications once and that means me and my family could never move house. [S69]

As I get older my needs change. As my house is heritage listed it is difficult to change things inside. I would love to have wider doors, some rooms I cannot enter and the others I have a 2 cm leeway. [S26]

One participant over 75 years of age with multiple conditions (postpolio syndrome; cardiomyopathy; spinal injury) states,
since the death of my husband I desperately require a modification to the hoist in my vehicle to enable me to use the wheelchair without assistance, as it is I am virtually housebound because of my inability to walk or stand for any length of time … My home is totally inconvenient and unsustainable by me, however, my financial circumstance prevents me from moving to more suitable accommodation … The computer is my main means of contact and I use it constantly, but it is expensive to run and keep pace with technology. [S40]

Another participant who lives with a high degree of impairment as an adult with C7 quadriplegia identifies the link between suitability of dwelling type, appropriate assistance for home maintenance and engagement in other life activities, providing empirical proof of the impact of mediators upon the experience of disability:

[I would like] funding for home maintenance [so] I would get jobs done that terrain and access prevent me from doing because of mobility … It would get those things done that you can see need doing but I am unable to do. This would allow more funds/ time for living life … If you can look after your permanent residence it then allows you time and energy to participate more in the community making access issues become smaller. [S80]

Forty-two respondents (46%) named 64 instances of unmet need for home modifications. While many of these were desired as a result of changing circumstances such as ageing or a change in lifestyle and health, some were required as a result of poor architectural planning and poor regulation. One respondent, a wheelchair user, described his home environment (an apartment in a new city apartment block) as requiring no internal adaptation at all as the contemporary bathroom was designed with a rimless shower, but reported that he had to enter the building through the basement carpark as the public entrances all had steps or inaccessible doors [S92].

- Use of EI: inclusive community environs

Inclusive or accessible community environs emerged as a discrete category and theme from the data (see Table 15). Participants named only 22 instances where the environment beyond the garden gate facilitated participation, including non-physical aspects such as the companion card, half-price taxis,
disabled parking spots, respite care, and community attitudes. This was the only category, however, in which the level of unmet need exceeded current instances of provision: environmental barriers were identified in 125 instances.

Table 15: Inclusive Community Environs Examples by ICF category

<table>
<thead>
<tr>
<th>Environments: Physical</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ch 2 Natural environment and human-made changes to environment (WHO 2001)</td>
<td></td>
</tr>
<tr>
<td>Physical environment as barrier</td>
<td>Physical environment as facilitator</td>
</tr>
<tr>
<td>Access in my neighbourhood is very poor and I'm not confident at all getting around. Some places are too steep and some places don't have footpaths … neighbourhood access for wheelchairs would make things a lot easier. [S88]</td>
<td>I can shop at the green grocer, baker, and small food shop on my own, the people know me and the shops are accessible. [S26] Physical access can be provided by my portable ramp. [S9]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environments: transport</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ch 1 Products and Technology; Ch 2 Natural environment and human-made changes to environment (WHO 2001)</td>
<td></td>
</tr>
<tr>
<td>Transport as a barrier</td>
<td>Transport as facilitator</td>
</tr>
<tr>
<td>Belong to the local Interfaith network. My church is in Melbourne and no trams there yet – got the stops but no accessible trams on that line! [S15]</td>
<td>If I fly to a destination the airlines are very good they arrange a wheelchair and a person to assist with all my needs. [S55]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environments: social/attitudinal/bureaucratic</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ch 3 Support and Relationships; Ch 4 Attitudes; Ch 5 Services, systems and policies (WHO 2001)</td>
<td></td>
</tr>
<tr>
<td>Attitude as a barrier</td>
<td>Attitude as facilitator</td>
</tr>
<tr>
<td>The station staff could be more willing and ready to help, if they see the person with the disability is having trouble getting a ticket out of the ticketing machine! [S44]</td>
<td>I don’t use a communication aid at home, because everyone knows me. However, I DO use one when I am out in the Community. [S86]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environments: online</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ch 1 Products and Technology (WHO 2001)</td>
<td></td>
</tr>
<tr>
<td>Online environment as a barrier</td>
<td>Online environment as facilitator</td>
</tr>
<tr>
<td>I want to provide training and education to people. I would love a notebook computer so I could take it with me when I went out … take information out with me, not be stuck in my room. [S110]</td>
<td>My computer is my window to the world. I use it to keep in touch, to do research, pay bills, order groceries and buy from ebay. [S42] I use my lightwriter for communication. I go shopping with my mother weekly using my walker, I use telephone banking. [S55] As I mainly use public transport I spend time planning on internet the route and means of transport (timetables) and how they connect. [S47]</td>
</tr>
</tbody>
</table>
Barriers in the broader community environs were reported by over half the participants (forty seven people: 52%). Of these, the need for universal design of and physical access to outdoor environs and buildings accounted for 37% of unmet requirements; accessible public transport and public space each accounted for 25% of unmet requirements; and public information and support (9%) and income support (5%) were also identified. Statistical breakdowns are presented in Table 16.

Table 16: Description of unmet needs for Inclusive Community Environs

<table>
<thead>
<tr>
<th>Inclusive community environs: elements</th>
<th>Examples of unmet requirements as described by ‘The Equipment Study’ participants (n=47)</th>
<th>Number of meditating elements required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public buildings</td>
<td>Universal design of buildings, including stepless entry, easy doors, presence of accessible toilets, appropriate height reception/ sales desks at shops and other venues, seating, accessible swimming pools/ gym</td>
<td>46 (37%)</td>
</tr>
<tr>
<td>Public transport</td>
<td>More low floor buses, accessible tram stops, large print and talking timetables</td>
<td>31 (25%)</td>
</tr>
<tr>
<td>Public space</td>
<td>Footpaths, kerb access, tactile street signage, street crossings, accessible parking (presence of disabled parking spots, proximity to destination)</td>
<td>31 (25%)</td>
</tr>
<tr>
<td>Public information and support</td>
<td>Accessible information on websites including information as to whether access is possible at venues written in accessible formats, helpful and trained staff</td>
<td>11 (9%)</td>
</tr>
<tr>
<td>Income support and supplements</td>
<td>Increase in pension and allowances, savings, recourse to top-up funds</td>
<td>6 (5%)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>125</strong></td>
</tr>
</tbody>
</table>

The environment is the context for human endeavour and is a critical variable to be considered in relation to AT and more broadly disability. ‘The Equipment Study’ data suggests that environments encompass built and human elements, with attitudinal aspects of the milieu identified as enormously important to the experience of inclusion, by people living with disability.

- **Use of personal care**

Seventy-four participants (81% of respondents) used some form of paid or unpaid personal care in its broadest sense, naming 160 instances, an average of two forms of personal care per person. They identified a high use of
immediate family (47% of current instances of care), with a further 19% of instances of friends, neighbours and others providing unpaid care. There were only two identified instances of family members being paid for providing care. Respondents also identified a high use of home care workers on a regular basis (47% of instances). A further 43% of instances of current care were provided by personal care providers, indicating some delineation of care tasks between personal support and domestic or community support. Narratives described the use of informal care to supplement formal care:

I get assistance from carers three times a week for 15hrs. This is to assist me with p/c [personal care] and dressing as I am no longer able to do this by myself … I am fully dependent on all aids and use commode chair, walking frame. My wife assists me with all aspects of my care … I am still able to make my own decisions however I need help to get out of my home … 24/7 unpaid care. [S63]

Figure 11: Met and unmet need for aspects of personal care use

The diverse types of care identified by participants and mapped to the WHO ICF (2001) classification system for Support and Relationships (part of the
Environment Section) in Figure 11. Once again, this data illustrates the relevance of broad definitions of personal support, including animals and strangers.

Personal care needs were identified as not being fully met in one or more ways by 22 participants (24%) in ‘The Equipment Study’. This group described 30 instances (47%) of unmet need, including a desire for more flexibility and more hours for home care and home maintenance; more hours of personal care time, case management time and community support worker time (comprising 40% of the instances of unmet need); availability of professional support such as a financial adviser or employment support worker (10%); and more volunteer friends (3% of the instances of unmet needs).

Participants raised the challenge of finding flexible support which fits with lifestyle. Two respondents identified the following needs:

- Competent, reliable carers who could come when needed rather than just at set times, it can be very hard to make appointments when carers are available. [S26]

- Flexibility of carers would mean I would not waste so much time trying to arrange appointments at convenient times … less frustration would make my life more tranquil and definitely less exhausting. [S40]

This level of unmet need echoes the findings of Desai et al. in their study of older adults, which found that ‘over 20% of those needing help to perform one or more ADL reported receiving inadequate assistance … Nearly half of those with unmet needs reported experiencing a negative consequence as a result of their unmet need’ (2001: 82). The observation that difficulty in accomplishing activities, in this case activities of daily living, is related to the need for personal care, raises the close relationship between care needs and AT. The availability of AT is a known factor which can supplement the need for personal support or even substitute for it (Hoenig et al. 2007). As Hoenig et al. state, ‘Many severely disabled people own no assistive equipment, and substantial unmet needs are reported; this lack of equipment may play a role in the substantial disparities noted by others in use of personal assistance’ (2003: 336).
- Data on the relationship between mediators

‘The Equipment Study’ found few participants used AT alone. For 66% of this cohort, the mix of elements making up an AT solution consists of a combination of AT devices, environmental interventions and personal care. A further 16% of respondents used AT devices and personal care combinations; 15% used AT devices and environmental interventions together; and 2% used AT devices alone.

Overall, the total number of mediators used (1251) or required (377) can be seen in Table 17 below. This equates to an average of 13 different items (or elements) currently used by each respondent in their AT solution.

Additionally, 74% of participants identified unmet needs for various elements of AT solutions: additional AT devices, environmental interventions, or elements of personal care. It is likely that in situations of optimal provision, the number and combination of mediators would rise.

Table 17: Number of elements of AT solution (i.e. mediators) used or required by participants (n-100)

<table>
<thead>
<tr>
<th>Elements of AT solutions currently in use or required</th>
<th>Currently in use (ie. met need)</th>
<th>Currently required (ie. unmet need)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. of elements/items</td>
<td>No. of respondents</td>
</tr>
<tr>
<td>Assistive Technology devices</td>
<td>725</td>
<td>100</td>
</tr>
<tr>
<td>Environment:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home modifications</td>
<td>332</td>
<td>42</td>
</tr>
<tr>
<td>Community environs</td>
<td>26</td>
<td>18</td>
</tr>
<tr>
<td>Personal care</td>
<td>168</td>
<td>78</td>
</tr>
<tr>
<td>TOTALS</td>
<td>1251</td>
<td>377</td>
</tr>
</tbody>
</table>

‘The Equipment Study’ findings link a wide range of AT devices, elements of EI (both home and community-based) and personal support to achievement of life outcomes. The diverse cohort demonstrated use of multiple mediators across each mediator type, and significant unmet need was established.
There is sufficient evidence in the literature and data from the empirical study to show that the impact of and relationship between the mediators AT, EI and PC are significant, supporting the following definition:

An AT solution is an individually tailored combination of hard (actual devices) and soft (assessment, trial and other human factors) assistive technologies, environmental interventions and paid and/or unpaid care (AT Collaboration 2009).

To draw together the term mediators, used in the early sections of this thesis, and AT solutions as introduced here, these terms will be used interchangeably and encompass the three elements AT, EI, and PC.

**How good is the mediating solution? – defining optimal**

As well as counting instances of mediator usage, ‘The Equipment Study’ cohort provided data regarding the calibre or quality of mediators used. This includes the performance of single elements such as personal care time or an AT device, and the overall quality of a mediating solution, based on all the component parts. To contextualise the quality of provision, the following example is drawn from Palmer and Seale (2007) who explored attitudes to environmental control systems (ECUs) of people with physical disabilities. This grounded theory study of 14 AT users uncovers key themes regarding the quality of performance of AT devices. The theme of ‘utility’ represents a basic level of provision, where the ECU delivers necessary functions such as opening essential doors. ‘Utility transcended’, however, occurs when the AT is carefully tailored to perform all the desired tasks of the user in a seamless manner, and therefore becomes ‘more than a tool’ (Palmer and Seale 2007: 24). The third theme, ‘transcendence of utility denied’, reflects the dissatisfaction of users when potentially optimal solutions are not delivered. For example, one user was able to let visitors in the front door with his ECU, but there were insufficient ECU ports to enable him to close his bathroom door; visitors walked past his bathroom and could view his commode. The fact that he could control some (but not all) of his environment, exerting partial mastery yet limited by technical factors, was experienced as particularly dissatisfying.
In discussing potential mediators of impairment and disablement, it is critical not to establish just what is provided, but how much, and under what conditions. This raises the issue of defining the extent, and indeed the optimal nature, of mediators.

Studies which introduce AT, EI, PC or a combination of mediators as a comparator to usual treatment might be expected to define the nature of that provision, but this is typically described without substantive detail. It is difficult to establish effectiveness across studies without details about which mediators are present. For example, EI might be prescribed by an ‘experienced occupational therapist’ (Hoenig et al. 2007: 1397), or consist of ‘eleven home modifications interventions’ (Petersson et al. 2008: 40). Mann et al. (1999), on the other hand, provide details of provision at the level of a clinical encounter, describing ‘intensive AT-EI services [including] comprehensive functional assessment of the person and the home by an occupational therapist, recommendations for needed AT–EI’s, provision of the devices and modifications, training in their use, and continued follow-up with assessment and provision of AT–EI’s as needs changed’ (Mann et al. 1999: 211).

‘Optimal’, defined as ‘best or most favourable’ (OED 2009), has been selected as the term to delineate provision which goes beyond basic requirements. The concept of optimal can be found in the AT literature, but working definitions of optimal AT interventions were not located. The term is generally used as a descriptor: for example, Wessels et al. suggest AT devices might be adapted ‘more optimally’ to meet individual needs (2003: 234) while De Crean et al. note that the current presence and use of assistive devices is ‘not optimal’ (2006: 202). A case study I published in McDonald (2010) offers a description of both optimal and sub-optimal AT provision of wheeled mobility for an individual with SCI; no other study has been located which provides optimal AT or assesses the relative merits of this approach.

The concept of best practice provides a further set of parameters which may contribute to a definition of ‘optimal’. Evidence of what constitutes best practice in AT can be found in a number of published theoretical models of practice applicable to AT interventions (see Bain and Leger 1997; Cook and Hussey 2008; Fuhrer et al. 2003; Law et al. 1996; Scherer 2002a, 2005). Although no
model has yet been adopted universally in the field of AT, all models, despite differing terms used to describe them, encompass the same elements within their constructs, namely the individual, the task or occupation, device or intervention, and the environment or milieu. The holistic nature of these models supports the contention that best practice in AT requires multifactorial assessment of the AT user and of the AT itself, thus encompassing hard and soft technology elements in the context of environment.

Optimal AT provision can be said to occur when there is ‘no better technology option available’ (Scherer 2005: 26). The Audit Commission describes optimal provision as a situation of ‘unlimited access to the equipment of their choice’ (2002: 59). For the purposes of the thesis, optimal AT solutions, in the Australian context, are defined as the best combination of mediators including any solution, regardless of cost, currently on the market and available in Australia.

Optimal provision, however, cannot be assumed, given the constraining influence of pragmatic and situational factors upon outcomes described in the clinical reasoning literature (Boyt Schell and Schell 2008; Chapparo and Ranka 2004; Unsworth 2004). AT provision in Australia occurs in an environment of restricted resources and bounded options (Barbara and Curtin 2008). This is likely to cause a perpetually limited horizon for both AT users and the AT practitioners working with them. The compromise of best practice ideals due to resource constraints is pervasive, and found to ‘affect many organisations that provide therapy and equipment for people with CP and like disabilities in Australia today’ (AIHW 2006b: 184).

**Concluding comments**

This chapter has explored and established definitions of key mediators, and identified comprehensive taxonomies that appear to match well with actual experience of AT users (‘The Equipment Study’ cohort) so has clear validity of use. Strong conceptual and empirical reasons have been identified for the mediators AT, EI and PC to be considered in relation to each other and provisionally named AT solutions. Chapter 6 now considers evidence from the literature and ‘The Equipment Study’ data regarding the effectiveness of AT, EI and PC as mediators of impairment.
Chapter 6: Effectiveness of mediators

Having identified the key mediators, it is now important to evaluate how effective they are in delivering valued life outcomes to people living with impairment (research sub-question 2b). Chapter 6 considers the effectiveness of AT, EI and PC across impairment types and outcome areas. Their effectiveness is further examined according to the six selected indicators described in Chapter 3: participation, difficulty, and satisfaction in life areas; and costs, time use and HRQoL. Evidence is then presented for the effectiveness of the AT solution.

Methodological issues related to effectiveness of mediators

A range of methodological issues arose during critical appraisal of the literature, and has been described in previous chapters. In terms of methods, these can be summarised as variable and inconsistent definitions of mediators and mediator combinations within studies, particularly in relation to extent of provision, the range of outcome indicators used, and methods which may fail to fully capture impacts and outcomes.

In terms of methodology, the impact of the specific horizon of researchers is noted, and sometimes found to be at odds with the values of those using mediators, whose voices are rarely directly heard within research articles. In their recent critique of AT research in relation to emancipatory research ideals, Ripat and Woodgate note that conventional AT research creates ‘a wide separation between the researcher and the AT user, where researchers have determined the research agenda and the AT user has been the object of that research’ (2011: 89). Institutional influences are likely also to frame the dominant view of AT as ‘serving to replace or augment function which is more closely aligned with the biomedical model than a model that seeks to address an oppressive environment’ (2011: 89). The authors suggest that the limited use of emancipatory disability research methodologies in the field of AT is the result of the location of service provision within biomedical institutions.

The only critical appraisal of AT in Australia uses a biomedical hierarchy, and notes that there is ‘limited high-quality research on the effectiveness of assistive technology’ (Lovarini et al. 2006: 9). That is, according to the NHMRC evidence
hierarchy, most studies reviewed had low rankings in terms of strength of research method (see Table 2, Chapter 3). However, as determined previously, a wider valuing of evidence has been utilised for this thesis as the potential of AT, EI and related mediators appears not to be fully captured by many methods, despite their credentials in terms of strength of evidence. Available evidence which addressed the thesis questions regarding use and effectiveness of mediators is presented below; but first the range of human diversity for which AT, EI and PC have been found to be effective, is considered.

**Outcome areas in which the effectiveness of mediators has been researched**

Mediators are effective across a wide diversity of impairment types. The breadth of application of AT, EI and PC, as theorised by Cook and Hussey (2008) and Smith (2002), is evident from the range of populations to which these mediators are applied in the literature.

All studies located through the literature review demonstrated positive results for the efficacy of AT and related mediators: while some populations had few studies, this is more likely to reflect the lack of research initiative across population breadth than a lack of efficacy. The span of studies demonstrates the applicability of these mediators across body function and structures, and throughout the lifespan. Populations that were the focus of research studies about the efficacy of mediators were diversely constructed: some used broad categorisations like elders and aging (17), or overall physical disability (5); some used more specific identification of populations such as amputees (1), intellectual disability (7), or cerebral palsy (6); others used a combination of markers, including disabled migrants (1) young people in nursing homes (2), or veterans (3). In terms of interventions, studies addressed single mediators, individual aspects of these mediators, and aspects of the relationships between them. Sample sizes ranged from single figures to cohorts of several hundred and varied in strength, but no meta-reviews were located. The variability in populations minimises any opportunity to aggregate findings or perform meta-analysis, and this is likely to be one reason that systematic evaluations of the existing empirical evidence have been 'rare and selective' (Wahl et al. 2009: 356).
Similarly, ‘The Equipment Study’ respondents represented a population with diverse impairments, and all reported the effectiveness of AT, EI and PC as mediators of impairment. As described in Chapter 3, ‘The Equipment Study’ participants reported nearly 60 separate diagnoses, demonstrating a span of human variation across the full extent of the ICF body structure and function categories. Diagnostic categories identified by two or more participants included circulatory disorders (2); Deafblind (2); ABI (3); arthritic conditions (3); ME/CFS (2); amputations (3); muscular dystrophy (2); multiple sclerosis (8); polio (11); spinal cord injury (14) and cerebral palsy (8). The use of mediators by this wide diversity of participants demonstrates their wide applicability.

**Effectiveness of mediators across outcome areas**

Establishing the outcome areas in which efficacy has been researched is the first task. Data in Table 18 depicts key studies identified within the literature reviews which found AT, EI and/or PC to have a role in delivering the following broad outcomes:

<table>
<thead>
<tr>
<th>Preserved independence, decreased functional decline and reduced hospital admission rates</th>
<th>Agree and Freedman 2003; Bateni and Maki 2005; Chamberlaine, Evans, Neighbour and Hughes 2001; Charness and Schaeie 2003; De San Miguel 2008; Mann, Ottenbacher, Fraas, Tomita and Granger 1999; Logan et al. 2008; Lysack et al. 2007; Mann, Llanes, Justiss and Tomita 2004</th>
</tr>
</thead>
</table>
ii. shoulder integrity (Boninger et al 2005; Collinger et al. 2008; )  
iii. aspiration pneumonia, contractures and postural deformity (Winkler, Sloane and Calloway 2007) |
| Alleviating carer burden | Audit Commission UK, 2002; Blyth and Gardner 2007; Chhokar et al. 2005; Goodacre, McCreadie, Flanagan and Lansley 2008; Hoenig, Taylor and Sloan 2003; Ryan and |
In terms of the tools used to evaluate outcomes, more than two dozen published outcome parameters were located within the literature, summarised in Table 19 against outcomes and indicators.

**Table 19: Measurement scales and approaches**

<table>
<thead>
<tr>
<th>Meta category</th>
<th>Outcome Areas and Indicators</th>
<th>Sample Tools</th>
<th>No of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific body functions and structures</td>
<td>Function or Independence (e.g. falls prevention)</td>
<td>FIM (UDS 1999)</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td></td>
<td>London Handicap Scale outcome measure for chronic disease (Harwood et al. 1994)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>The Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck et al. 1992)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Community Integration Questionnaire (CIQ) (Willer et al. 1994)</td>
<td></td>
</tr>
<tr>
<td>Areas of activity or participation</td>
<td>Life Domains Frameworks (indicators: participation, satisfaction, difficulty in life areas)</td>
<td>Activity &amp; Participation Chapters (WHO 2001)</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wilson Life Areas (Wilson 2006)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Life habits (LIFE-H) (Noreau et al. 2002)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>PAR-PRO: measure of home and community participation (Ostir et al. 2006)</td>
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<tr>
<td></td>
<td></td>
<td>Functioning and Health Related Outcomes Module (FRHOM) (AIHW 2005)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participation Objective, Participation Subjective Measure (Brown et al. 2004)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Measure of Participation</td>
<td></td>
</tr>
</tbody>
</table>
| Combined aspects of body structure & function; and activity & participation | Quality of life & Wellbeing | Enfranchisement (Heinemann et al. 2011)  
Problem Impact Rating Scale (PIRS)  
Preference based assessment of the quality of life of disabled persons (Persson et al. 2002)  
Quality of Life Core Domains (Shalock 2004)  
Subjective Wellbeing Index (Cummins and Lau 2006) | 3 |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Global impact of AT devices</td>
<td>Matching Person and Technology</td>
<td>AT Device Predisposition Assessment (Scherer and Sax 2009)</td>
</tr>
</tbody>
</table>
| Evaluation of individual AT devices | Effectiveness of individual AT devices (uptake and usage; satisfaction with AT device) | PIADS Psychosocial Impact of Assistive Devices Scale (Jutai and Day 2002)  
QUEST Quebec User Evaluation of satisfaction with Assistive Technology (Demers et al. 2000)  
IPPA: individually prioritised problem assessment. (Wessels et al. 2002) | 20 |
| Economic impact of AT devices (prevention of secondary medical complications; alleviating carer burden; injury prevention) | SCAI Social Cost Analysis Inventory (Andrich 2002b)  
HTA Health Technology Assessment (Banta 2009) | 10 |

The data in Table 19 demonstrate the majority of studies (63) located focused upon body structures and functions, with indicators including function and independence. The second largest group of studies (20) evaluated the effectiveness of individual AT devices, largely through a focus on user satisfaction. Ten studies considered the economic impact of AT devices, while three examined impacts upon quality of life and wellbeing. Of the literature discussing aspects of activity and participation in relation to certain populations (particularly in relation, for example, to ICF core sets), only five studies were located which directly reported on the efficacy of AT and related mediators in terms of activity and participation. Literature types included clinical practice guidelines (synthesising available evidence), summative statements in
government reviews and reports, and individual empirical studies which
demonstrate aspects of the impact of AT, EI, and PC upon specific outcomes for
individuals. A range of clinical practice guidelines finds mediators effective for
the prevention of secondary medical complications, for example recommending
AT, EI, and PC in the form of the prescription of lightweight wheelchairs,
pressure equipment, modifications to the environment and targeted use of
personal support (Boninger et al 2005; National Guideline Clearinghouse 2000).

The effectiveness of broadly defined AT and EI to support and engender
wellbeing and quality of life is identified in several major reviews from the UK
(Audit Commission 2004; Priestley et al. 2009). In Australia, key recent studies
into the effectiveness of AT were conducted by the Australian Institute of Health
and Welfare (AIHW) (2006), and Connell et al (2008) for the Department of
Health and Aging (DOHA). The AIHW review investigated the nature and extent
of met, partially met, and unmet needs for therapies and AT for people with
cerebral palsy and like disabilities. The review also estimated the effects of
provision in terms of functioning, participation, and reduced social costs. The
study demonstrated strong support for equipment provision as an enabling
support, and drew conclusions regarding adverse outcomes if AT were not
supplied:

Unmet need appears to be high … Long waiting times for therapy and
equipment are a major concern, particularly in the light of focus group
evidence that lack of timely access to appropriate therapy and equipment can
exacerbate problems and result in greater future need for services. (AIHW
2006b: 184)

The study commissioned by DOHA considered the use of AT by frail older
people living in the community (Connell et al. 2008). The scope of AT was
broad, encompassing environmental adaptations, telehealth and remote
monitoring devices. The authors reviewed a range of available Australian and
international literature and interviewed a range of stakeholders. Despite noting
variable study quality and some major evidence gaps, overall the authors
concluded that there is

strong evidence that assistive technology can enable: improved safety and
reduced falls; reduced hospitalisation; improved independence, mobility and
physical function; improved well-being and quality of life, including an enhanced sense of safety and increased opportunities to continue living at home. (Connell et al. 2008: 6)

Connell et al. also note that the potential of AT remains unrealised due to barriers such as affordability and the lack of soft technologies, including lack of access, information and assessment points, and of follow-up home-based training and maintenance.

The voices of Australians living with impairment heard via consultations (n=2,500) and submissions (n=750+) to National People with Disabilities and Carers Council’s *Shut Out Report* identify AT as ‘essential to daily functioning [and the] ability to lead an independent life’ (2009: 25). Likewise, the UK Office of Disability Issues found choice and control to be key outcomes for those using AT and EI:

> the impact of home adaptations can be so dramatic that service users talked of their lives being transformed or prolonged by the restoration of independence, dignity and the removal of fear of accidents and of strained personal relations in the home. (Priestley et al. 2009: 42)

While AT and, to some extent, related mediators are identified as having enormous potential to improve quality of life, mobility and independence, poor provision has been linked to a range of adverse participation outcomes by several reports from the UK (Audit Commission 2002; 2004; Heywood and Turner 2007). This finding is echoed in Australia: in over 20% of submissions, The *Shut Out Report* reported that ‘a lack of aids and equipment acted as a barrier to their participation in the community’ (National People with Disabilities and Carers Council 2009: 25).

**Effectiveness of mediators upon participation in life areas**

*a. Literature analysis*

A number of efficacy studies related to mediators undertook research related to participation as an outcome area. Henderson et al. reviewed 54 studies to determine the impact of AT devices on the components of functioning defined by the ICF (including participation), concluding that ‘The impact of these devices
was found to be overwhelmingly positive’ (2008: 89). Scherer, Sax and Gluekauf (2005), and Scherer and Gluekauf (2005) assessed the benefits of AT for activities and participation overall, reporting good evidence of the effectiveness of AT across activity and participation domains, while noting that ‘Understanding and assessing the influences of AT use on [ICF] domains is an understudied area’ (Scherer and Gluekauf 2005: 132).

All studies which evaluated the impact of AT and EI with the ICF concepts of activities and participation reported positive outcomes. Regarding AT, participation in university study was positively related to the provision of AT and mainstream products (Bauer and Lane 2006). Copley and Ziviani (2004) reviewed the literature pertaining to school participation by children with multiple disabilities and found AT to be a key mediator, albeit costly and difficult to obtain. A systematic review by Nicolson, Moir and Millsteed (2012), into the impact of AT on family caregivers of children with physical disabilities, identified the role of AT in increasing the quality, quantity and duration of participation for children in the areas of play, leisure, mealtimes and self care. For EI, Hollingsworth (2010) established the role of environment as a mediator of leisure participation for 604 people with mobility limitations, while Hammel, Jones and Smith et al. (2008) identified a range of environmental supports as critical to the participation of people with developmental and intellectual disabilities.

b. Data analysis

Within The Equipment Study, participation was demonstrated to be a key concept, as operationalised into ‘activities you can/ wish to do’ across the eight life areas identified in the Wilson (2006) framework. Data presented in Figure 12 demonstrate the number of instances of respondents participating in each life area (Wilson 2006) and the types of mediators used for this participation.
Figure 12: Instances of participation across life areas

Over 900 instances of participation across life domains were reported by participants and linked to mediating elements. In terms of AT, 94% of people reported mediators as being used to enable participation in Personal Life (including such devices as mobility devices, hoists, adjustable beds and alphabet boards), while 92% identified EI such as ramps, roll-in showers and PC including family members and attendant care as also supporting participation in Personal Life. For Social Life, 80% of participants used mediating devices including white canes, computers and power wheelchairs, while other mediators, including universal design of buildings (EI) and physical assistance from friends (PC) were identified by 61% of respondents. Recreation and Leisure Life participation had 73% of participants using AT such as orthotics and computers, while EI such as fenced children’s playgrounds, accessible toilets and hearing loops and PC including family, paid carers and supportive vendors were identified by 50% of respondents. Economic Life had 68% of respondents utilising AT such as mobility devices, laptops, CCTV to read bills, while 42% utilised family or council help and accessible banks and shops. Sixty six percent of respondents identified AT including communication devices and software as essential to participation in Education Life, along with EI (for example accessible public transport) and PC (such as library assistance and paid note taking) was
identified by 33% of respondents. For Political Life, 65% utilised AT such as a maxi taxi or reading glasses while 38% used EI such as accessible voting booths, or, in several instances, PC when the environment featured barriers. For example, S38 stated, ‘I get someone to help me fill in the voting card’, while S26 described being 'escorted … through the very negative public to the entrance as my local polling station has a stair case to get out'. For Cultural Life, 59% of participants were enabled in their participation through AT including Braille books and adapted driving controls. PC, such as family and friends to attend events with, and EI facilitators, such as accessible parking spaces and public transport, were reported by 42% of respondents. Finally, 54% of respondents used a range of AT including wheelchairs, audio loops and large print prayer books to support Spiritual Life participation, and 21% reported EI including sealed footpaths en route to temple, and PC in the form of visiting volunteers from various churches.

In terms of the life areas completed, it must be noted that cultural, political and spiritual life were towards the end of the question set, and response fatigue may have influenced the completion of these areas. That said, many respondents repeated 'as previously stated', allocating previously identified mediating factors to engagement in the various life areas. It is also worth noting that these figures are likely to underrepresent participation potential, as many respondents described making choices and trade-offs, effectively prioritising their participation opportunities when there were insufficient resources available.

While the examples provided above demonstrate the range of mediators used, in many instances participants forecast that the provision of one or two pieces of AT would lead to identified outcomes across the whole of life. One adult male with a hearing impairment described the anticipated outcomes of the provision of new technology hearing aids and hearing loops:

**Personal Life:** Subsidised hearing aids are merely amplifiers that increase the volume of ALL sound. New technology filters out background noise and focuses specifically on voices but these aids are not subsidised. Making this technology available to me would increase my quality of life. [I could then] socialise more and attend group discussion without embarrassment …
Spending more time on things I’d like to do. Spending less time asking people to repeat themselves.

**Social Life:** Currently I avoid social situations. I believe that provision of better quality hearing aids would reverse this … Less time spent alone and greater community involvement.

**Recreation and Leisure Life:** Technologically upgraded hearing aids [and] more ‘Hearing Loops’ installed in public places (e.g. cinema, community centres) [would enable me to] interact with others more … Potential to spend more time outside my home.

**Economic Life:** Better subsidised hearing aids [would enable me to] manage my life more efficiently … Enormous advantages in time management.

**Educational Life:** Improved hearing aids and ‘Hearing Loops’ provided on TAFE etc campuses [would enable me to] undertake campus courses rather than online or distance education. I recently completed a diploma using the Distance Education model and would like to avail [myself] of the greater opportunities offered in a classroom environment.

**Political Life:** Better hearing aids [would enable me to] attend more events across this sphere … Expand the time devoted to participation in the community.

**Cultural Life:** More sophisticated hearing aids, more hearing loops in public buildings [would enable me to] participate to a greater extent in cultural events [currently] my hearing impairment virtually excludes meaningful enjoyment of cultural activities. [S60]

Data from the eight interview participants provides further evidence of the impact of mediators upon participation outcomes. The eFHROM tool was used to re-rate their anticipated experience in each life activity area following the identification of their optimal AT solution, providing pre- (current situation) and post-(accepted optimal AT solution) ratings for a number of indices including difficulty in activities, level of personal care needed, level of participation, and satisfaction with life participation. Results demonstrated an average 12% increase in participation (range 0–28%) when provided with the hypothetical
optimal AT solution, indicating that participation levels were likely to rise with additional mediators. In expressing how well these participation needs were fulfilled, the notion of satisfaction again had resonance with the cohort discussed below.

**Effectiveness of mediators upon satisfaction with participation in life areas**

*a. Literature analysis*

The term ‘satisfaction’ in this field usually refers either to satisfaction with a device or solution, or satisfaction with participation. Ten refereed articles were located which utilised satisfaction as a key outcome indicator in AT, while one was located in the literature on EI, and none in the field of PC.

Tailored provision of a range of mediators under the broad headings AT and EI can bring about satisfaction (Brandt, Iwarsson and Stahl 2003; Demers, Weiss-Lambrou and Ska 2000; Iwarsson and Wilson 2006; Ward et al. 2010), with multiple factors found to contribute to the subjective experience of satisfaction overall. Insufficient or inappropriate provision creates dissatisfaction and correlates with abandonment of AT (Kittel, Marco and Stewart 2002, Mann et al. 2002, Wessels et al. 2003, 2004).

*b. Data analysis*

‘The Equipment Study’ cohort was not specifically asked about satisfaction with their current or proposed suite of mediators. Satisfaction was, however, elicited from interview participants in describing their subjective experience of participation: that is, the interview cohort rated current satisfaction with life participation and then re-rated their anticipated satisfaction with participation considering expected change with provision of optimal AT solution (see Table 20).
Table 20: Comparison of pre- and post satisfaction with participation for interview participants

<table>
<thead>
<tr>
<th>Satisfaction with Participation Scale from eFHROM (AIHW 2005)</th>
<th>Complete restriction &amp; dissatisfaction</th>
<th>Extreme dissatisfaction</th>
<th>Moderate dissatisfaction</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Moderate satisfaction</th>
<th>High satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current rating: % of life activities/areas rated in each level (67 life activities/areas rated as identified by 7 participants)</td>
<td>5%</td>
<td>12%</td>
<td>22%</td>
<td>13%</td>
<td>34%</td>
<td>13%</td>
</tr>
<tr>
<td>Post hypothetical change rating (i.e. provision of optimal AT): % of life activities/areas rated in each level (54 life activities/areas rated as identified by 7 participants)</td>
<td>0%</td>
<td>2%</td>
<td>4%</td>
<td>20%</td>
<td>44%</td>
<td>30%</td>
</tr>
<tr>
<td>Total overall change pre to post</td>
<td>-5%</td>
<td>-10%</td>
<td>-18%</td>
<td>+7%</td>
<td>+10%</td>
<td>+17%</td>
</tr>
</tbody>
</table>

Interview participants identified moderate or extreme dissatisfaction/complete restriction on participation in 39% of life activities prior to the provision of optimal AT, as compared with only 6% dissatisfaction post AT provision. In total, this cohort rated a total of 74% of life activities as moderate to highly satisfying in terms of participation with the hypothetical provision of optimal AT, as compared with only 47% prior to the optimal AT solution. In terms of satisfaction with participation, interview participants experienced an average of 19% increase in satisfaction with participation levels (range 8–33%) when provided with the hypothetical optimal AT solution.

While this evidence demonstrates that AT, EI and PC are able to increase satisfaction with life participation, a number of issues in measuring and analysing satisfaction must be mentioned. The findings identified above may over-simplify the range of results for each interview participant across differing life activities and areas (with participants identifying both improvements and increased problems across their lives).

Both interview and survey participants reported that satisfaction is not a clear term and does not mean that all problems in life or with AT provision are
overcome. Concepts which emerged as related to satisfaction included dissatisfaction and frustration, as discussed below.

In terms of dissatisfaction, several respondents described a state of being ‘less dissatisfied’ as more realistic than a state of satisfaction with anticipated changes, yet the circumstances in which satisfaction or less dissatisfaction might occur were substantially different from each other. In one example, S24 described her dissatisfaction with the current situation whereby she performed a slide-transfer onto a bedside commode. Usually bedfast in her lounge room, this participant was extremely dissatisfied with this institutional-looking AT device next to her bed, clearly recognisable to visitors. She had located a more discreet corner commode via the internet which was available in Victoria, but its cost was beyond the funding limit for a basic commode. She described her dissatisfaction with the current situation as having increased, knowing there was an alternative yet not being able to afford it. In a contrasting example, again related to self-care, S27 elected to use the toilet only twice a day (7am and 7pm) in an effort to utilise her personal support workers for other tasks, such as the administrative aspects of completing her PhD thesis. She expressed satisfaction at having managed to ‘get away’ with this and to maximise productive time, but was anxious that age-related changes and health issues arising from her restricted fluid intake would require her to change.

Turning to frustration, this concept appeared closely linked to ‘dissatisfaction’ and was raised by many participants. Frustration was a key concept used in describing the mismatch of supports and aspirations; for example:

I make all my own decisions but it can be frustrating arranging supports. [S45]

Lower height of counters in banks made lower which would reduce frustration help with stress levels. [S7]

Frustration was also the term used to describe a lack of control and efficacy in anticipating, building, and maintaining a set of needed mediators in a timely fashion. For example, one participant explained the following:
[improvements?] less frustrated by complex eligibility criteria and service systems. [S65]

My son would be less frustrated by repairs to wheelchair if he knew that he could always obtain a replacement wheelchair. [S65]

This conflation of concepts may in part explain why some interview participants identified lower scores in areas such as difficulty and satisfaction following the hypothetical intervention.

Overall, it appears satisfaction with life participation is not a stable measure and is highly subjective (one person may be satisfied to forfeit some areas of life participation for others; another may not). The process of reviewing one's situation and supports as part of the research process was described as painful by several respondents: the process of envisioning 'optimal' was exciting but rendered the current situation 'more dissatisfying'. In reacting to an optimal solution, some participants were cautious, one noting 'it may not work out, you never foresee all the problems'; and, despite optimal solutions, 'life would still be hard'.

**Effectiveness of mediators upon difficulty in life areas**

*a. Literature analysis*

Difficulty as a concept is embedded, but rarely made explicit, within the AT and EI literature. Those studies investigating difficulty per se usually discuss difficulty in relation to focal activities. For example, reporting on a major population health survey (n=9526), Verbrugge, Rennert and Madans (1997) identify a positive role for personal assistance and 'equipment assistance' (defined as inclusive of structural modifications) in alleviating 'difficulties in doing everyday tasks' (1997: 384). The concept of difficulty may be complex to isolate and address; for example, Gottlieb and Caro focus on difficulty and satisfaction with devices issued for self care and meal preparation in a study of the provision of low-cost assistive devices through home care services (n-196), finding increases in satisfaction with devices, and some increased functional independence, yet no change to expressed difficulty levels for this group of frail community dwelling elders (2000). Multiple accommodations which may alter the experience of satisfaction, participation, difficulty and overall outcomes are not uncommon in
managing daily life with impairment, as the following contextual vignette illustrates:

One way in which people adapt is to find ways to physically deal with their new circumstances. A patient with rheumatoid arthritis finds new kitchen utensils to make it easier for him to work around the house and purchases clothing that is easier to get on and off with painfully swollen hands. In addition, people adapt psychologically by shifting their goals and priorities in life. They reduce their expectations for what they can accomplish in domains of their life that have been influenced by illness or disability. They find meaning and purpose in other aspects of their lives. They may even redefine, to themselves, what it means to be happy. (Ubel et al. 2005: 61)

In summary, the concept of difficult receives little attention in research studies, and is patently problematic to define and measure.

b. Data analysis

The survey cohort (n-100) was asked to anticipate the changes in their lives should required AT solutions be provided, and then to re-rate their life experience on the index of level of difficulty, based on the anticipated effect of the provision of the required AT. Data in Figure 13 show the overall level of current difficulty experienced within each life area (‘pre’) and the level of difficulty envisioned by survey participants with the improved enablers they identified in place (‘post’). The provision of an identified change in their equipment, environment, care or other factor led to a significant improvement or lessening of difficulty in respondents’ lives of an average of 19% for the survey cohort (n-100). Interview participants experienced an average 14% decrease of difficulty (range 4–20%) based on the eFHROM results. This suggests that, overwhelmingly, survey respondents identified tangible improvements in their lives and decreased difficulty resulting from the provision of AT.
Some respondents identified problems with rating life in terms of ‘difficulty’, arguing that this did not capture their aspiration or experience. Average difficulty in engaging across life domains was between 3 and 4 on a 6-point scale, where ‘0’ was no difficulty and ‘5’ was complete difficulty. For some respondents, the provision of suitable AT would enable them to achieve a greater range of life outcomes although difficulty in performing them would increase. This was seen as a desirable outcome by a number of respondents, who valued participation and independence over difficulty levels. In one case, proposed improvements were likely to increase the individual’s independence from personal care – a desired outcome – but would increase the level of difficulty of the activity, as the person would be able to complete the activity themselves but would expend more time and effort doing it. The equivocal nature of difficulty, and the desire not to lead a life less difficult, but to accomplish more, is illustrated in the following comment:

Time would be spent doing more of the things I love that I cannot do at all now. The quality of my time would be better. Difficulty level might change [from 4] to (3) not because things would be less hard but because more stuff would be achieved. [S24]

This suggests that aspiring to reduce difficulty levels as an outcome of AT provision is not a suitable outcome measure.
Effectiveness of mediators based on economic measures: HRQoL, costs and time use

a. Literature analysis

As we have seen, health interventions including AT, EI, and PC represent costs, in terms of resources used (to enact the intervention) as well as opportunities lost (the alternate intervention that could have been implemented with these resources) (Drummond et al. 2005). Economic outcomes focus upon the effective use of resources (Drummond et al. 1997). From an economic and policy perspective, then, evidence is sought to ensure that resources are well utilised (Mooney and Scotton 1998).

The literature concerning economic outcomes for mediators can be broadly divided into full economic evaluations and studies which use elements of economic method. A paucity of primary research evidence exists for the economic impact of AT and EI using full economic evaluation methods. In the only Australian literature review on economics and AT, conducted as part of the Equipping Inclusion Studies, Colgan et al. (2010) consider 55 studies in their literature review of economic evidence for AT; only 15 were judged to have merit in an economic hierarchy of evidence, and only one reported a full cost effectiveness evaluation. This study compared microprocessor controlled prosthetic knees with non-microprocessor controlled knees (n-20), taking into account a range of costs and using QALY as a measure of health outcome, and concluded that the more expensive (microprocessor controlled) AT device delivered positive health outcomes at an acceptable cost (Brotkorb et al. 2008).

Colgan et al. (2010) note that not only have very few AT interventions been subjected to economic analysis, but there has been no priority-setting within an AT context. In other words, there has been no attempt to determine the ‘best buys’ for persons with disabilities, despite the economic impact of such resources being of great interest to AT funders and policy-makers, by providing, for example, the potential to reduce the costs of care.

Turning to the studies which do not represent full economic evaluations yet tackle the effectiveness of AT and related mediators from an economic perspective, Colgan et al. (2010) note some positive results but a number of
methodological problems, including difficulty accounting for confounding variables and the lack of valid, AT-specific outcome measures. Several articles investigated the economic actors involved in AT provision (Schraner et al. 2007) and considered the cost implications of AT and universal design for society as a whole (Schraner and De Jonge 2010), suggesting the cost of a range of accommodations such as kerb cuts and accessible public transport should be allocated over a whole community of potential users (e.g. parents with prams and residential care dwellers), rather than allocated to the individual living with disability. A series of studies from Italy inform a social cost analysis inventory tool for use by AT practitioners, which models the social costs and outcomes of AT provision (Andrich 2002b; Andrich and Caracciolo 2007b; Andrich et al. 1998), whereby the initial outlay for an AT device is compared with overall societal savings over a period of years. Here, Andrich and Caracciolo (2007a) incorporate potential earnings over time on the part of carers in a social cost analysis, calculating the point at which an AT device, replacing such care, becomes cost-neutral or cost-saving. In this study, the most costly device evaluated (an in-home lift) proved cost effective within several years because of a range of cost offsets (Andrich 2002a).

Several government reports have utilised audit data and conducted systematic reviews of the available evidence to establish the economic credentials of expenditure, and support arguments for early investment in AT device purchase (Connell et al. 2008). In 2002, a UK Audit Commission report evaluated a range of evidence and identified that ‘optimal’ provision was found to be more cost-effective than standard provision:

Participants who had unlimited access to the equipment of their choice – on average 14 devices each – cost $14,000 per person in total healthcare costs over the next 18 months. On the other hand, users given ‘standard care’, which amounted to only two devices each, cost over $30,000 in total healthcare costs per person during the same period. (2002: 59)

A subsequent major review by the Audit Commission found judicious provision of AT and EI demonstrated potential for high levels of cost-saving (Heywood and Turner 2007).
As can be seen, the concept of costs is a broad one, and three measures, HRQoL, ‘costs’ (with definitions arising from thematic analysis of data), and time use, were selected for this inquiry. Health-related quality of life is a narrower concept than overall quality of life (Moons et al. 2006; Verdugo et al. 2005). Data related to quality of life on other indices, such as social inclusion/ exclusion and participation poverty, is presented elsewhere in the thesis; for the current discussion, HRQoL is specifically considered. No research was located which investigated HRQoL specifically in relation to AT or EI, although health-related quality of life outcomes of AT are noted to be a vital area of enquiry (Seale and Turner Smith 2003).

b.1. Data analysis: HRQoL

As identified previously, HRQOL was evaluated for ‘The Equipment Study’ cohort through the Assessment of Quality of Life (AQoL) instrument (Hawthorne, Richardson and Osborne 1999). AQoL scores are reported between 0 (death) and 1 (excellent health). Scores approaching 1 are deemed high, representing high life quality and excellent health; scores below zero are categorised as ‘states worse than death’ (Hawthorne and Osborne 2005). The survey population achieved a mean score of 0.32 in relation to the population’s current health-related quality of life (Table 21). This contrasts with an Australian population mean of 0.80 (Hawthorne and Osborne 2005). Survey respondents reported mean AQoL scores lower than half those of the Australian reference population for both genders. They demonstrated a large range in AQoL scores, from -0.1726 to 0.885. These results demonstrate an overall struggle for the population with disabilities to achieve the quality of life of the general Australian population, and a lower level of functioning across the six domains of the AQoL than is the Australian norm.

**Table 21: Comparison of survey participants’ AQoL scores with Australian population norms**

<table>
<thead>
<tr>
<th>Australian Population Norms by Gender (Hawthorne and Osborne 2005)</th>
<th>Survey Sample by Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number (N)</td>
</tr>
<tr>
<td>Female</td>
<td>654</td>
</tr>
<tr>
<td>Male</td>
<td>393</td>
</tr>
<tr>
<td>All</td>
<td>1047</td>
</tr>
</tbody>
</table>
The wide diversity of initial AQoL scores for eight interview participants, ranging from 0.03 to 0.73, are presented in Table 22. Of the seven who provided a second AQoL score in response to the hypothetical 'optimal' solution, all but one produced scores that evidenced a positive change in their health and life quality; four made gains of 10% to 33%. These improvements were considered significant. Overall, participants were at different points along a trajectory of acclimatisation to the disability but most had conditions of a chronic nature (more than two months’ duration); the exception was participant number 7, whose disability (a spinal cord injury) was recently acquired. This may explain the decrease in AQoL score on second administration in this one case, as the person was still in the early days of adjustment to the effects of impairment and was progressively gaining insights into the reality of life back at home (identified elsewhere as the rehabilitation through transition towards community life phase) (APIC 2007; Djikers 2005). The AQoL score for this participant is therefore unlikely to reflect an accurate evaluation of outcomes of the provision of AT, EI and PC, particularly when taking into account the qualitative commentary during interview.

Table 22: Extent of change of AQoL as a result of hypothetical provision of optimal AT solution for interview participants

<table>
<thead>
<tr>
<th>Interview participant</th>
<th>a) pre-score in current situation prior to optimal AT solution</th>
<th>b) post-score with envisioned optimal provision</th>
<th>Percentage improvement in score between two time points</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0.4969</td>
<td>0.5362</td>
<td>4%</td>
</tr>
<tr>
<td>2</td>
<td>-0.0366</td>
<td>0.0640</td>
<td>10%</td>
</tr>
<tr>
<td>3</td>
<td>0.5408</td>
<td>0.5862</td>
<td>5%</td>
</tr>
<tr>
<td>4</td>
<td>0.4850</td>
<td>0.6215</td>
<td>14%</td>
</tr>
<tr>
<td>5</td>
<td>-0.0346</td>
<td>0.1772</td>
<td>21%</td>
</tr>
<tr>
<td>6</td>
<td>0.2059</td>
<td>0.5357</td>
<td>33%</td>
</tr>
<tr>
<td>7</td>
<td>0.7346</td>
<td>0.4543</td>
<td>-28%</td>
</tr>
<tr>
<td>8</td>
<td>Not administered a second time; so no comparison</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mean AQoL score of pre intervention interview participants: 0.3417
Mean AQoL score of post intervention interview participants: 0.4250
b.2. Data analysis: costs

Data from ‘The Equipment Study’ was utilised for a cost consequence analysis within ‘The Economic Study’ (Colgan et al. 2010). This study adopted a health sector perspective (i.e. considering costs and cost offsets from any source) in evaluating the cost-effectiveness of a move from current to ‘optimal’ AT solutions for each of the eight case studies, with the optimum determined by a panel of experts and approved by the interview participant. From the perspective of government affordability, ‘The Economic Study’ notes the potential for cost offsets with the judicious provision of AT solutions, and concludes that substantial improvements could potentially be achieved at modest cost for many AT users (Colgan et al. 2010).

b.3. Data analysis: time use

The other evaluative parameter which offers a perspective upon cost is that of time use. Time use, as assessed through the eFHROM tool for interview participants (n=8), indicated a prospective 7% decrease in personal assistance required (range 2.5–14%) with an optimal AT solution.

Thematic data emerged from the survey participants (n=100) who were asked the following questions for each of the eight life areas where participants nominated potential changes to their current mediator use:

- What impact on your time would these changes have?
- Describe what the impact on your time would be. This may be through more efficient use of time or spending time on things you want to do.

Two hundred and sixty-four responses were made to this question, and data analyses identified four major thematic categories including ‘wasted time’, fatigue and ‘crash recovery’, quality of time and productivity (Table 23).
Table 23: Impact of mediators upon time use

<table>
<thead>
<tr>
<th>Theme from Time Use data</th>
<th>Responses (no. of instances)</th>
<th>Supporting examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Wasted time’</td>
<td>43</td>
<td>Less time wasted and less appointments missed. [S101] Less time isolated at home, more time out, about and enjoying life. [S32] Less effort devoted to booking with specially designated officers at booking services and waiting for long periods on the phone for them to answer. Less effort devoted to finding out if venues are accessible and really do have accessible toilets. Less wasted time with inaccurate and wrong information about access [S25].</td>
</tr>
<tr>
<td>Fatigue and ‘crash recovery’</td>
<td>20</td>
<td>Would help increase the time I am able to function [S7] As always easier accessibility means less stress and wasted energy, therefore I would be able to do more in my day. [S26]</td>
</tr>
<tr>
<td>Quality of time</td>
<td>55</td>
<td>I would have a much richer life. [S26] Would allow me to feel part of life and increase self esteem. [S39] It would fulfill some of my dreams as I feel my spare time is very poorly managed at the moment making me depressed. [S81] Give more choice of activity to undertake in a meaningful way due to more time. [S6] I would be able to be outside some of the time instead of inside all of the time. [S42] Enjoying life more, doing things other people do. [S61]</td>
</tr>
<tr>
<td>Productivity</td>
<td>14</td>
<td>With work I cannot sit at the desk for very long so it impacts on how much I can complete, with adjustments I could spend longer at work. [S36]</td>
</tr>
</tbody>
</table>

These data provide both qualitative and quantitative evidence as to the effectiveness of AT, EI and PC in terms of time costs and time savings.

**Evidence for the ‘AT solution’**

*a. Literature analysis*

As described in Chapter 5, the calibre of evidence regarding the effectiveness of combinations of AT, EI and PC is highly dependent upon the definitions used and the outcome measures selected. Many studies appear to investigate two or more of the mediators as defined for this thesis, but do not identify them as
separate. This leads to difficulties in determining which of the three mediating elements are in fact present. Further, it means a systematic review or meta-analysis of the effectiveness of mediators in combination is not possible, given the variations in published studies.

The most commonly examined combinations of mediators are AT combined with PC. An early population study (n=9526) demonstrated the ‘great efficacy’ of AT and PC (Verbrugge et al. 1997). A study of 2368 ‘disabled elderly’ community dwellers concluded ‘both technological and personal assistance are contextual factors that act to modify the disablement process, reducing the severity of disability’ (Hoenig et al. 2003: 335). Many subsequent studies and reviews conclude that AT is a cost-effective substitute for PC in the medium to long term (Agree and Freedman 2000; Allen et al. 2001; Audit Commission 2002; Bricknell 2003; Down 2006; Heywood and Turner 2007; Molenda 2006; Tinker and Lansley, 2005).

Considering AT with EI, Mann et al. (1999) conducted a landmark study in the US in 1999, demonstrating the effectiveness of AT and EI in maintaining independence and reducing home care costs for the frail elderly. One of the few RCTs in the field, this study used medical and economic outcome indicators to determine the effectiveness of systematic provision of AT and EIs. This widely cited study includes a broad population and broad set of mediators and reports highly specific outcomes, including a slowing of the rates of functional decline and reductions in institutional and certain in-home personnel costs. A similar RCT published by Gitlin et al. (2006) in the USA demonstrates that multicomponent interventions targeting modifiable environmental and behavioural factors result in life quality improvements in community-dwelling older people. Individualised interventions at home were provided (including cognitive interventions such as problem-solving and reframing; behavioural interventions such as pacing; and environmental interventions such as handrail installation) to address specific areas of participant concern. This study is of particular interest in terms of agency, as it focuses on increased efficacy to minimise the disablement process, based on theories of personal control. The interventions employed were low cost and resulted in less difficulty with a variety of activities of daily living, greater self-efficacy, and decreased fear of falling, sustained at 12 month follow-up (Gitlin 2006). Additional important evidence for
the effectiveness of AT and EI comes from a series of studies of 82 homes, incorporating understandings of the ‘technology chain’; they conclude that adapting the homes of older people and providing AT are cost-effective strategies (Lansley 2006; Lansley et al. 2004; Tinker and Lansley 2005).

The efficacy of single mediators has been proved in a variety of studies, such as the provision of hoists enabling patients to return home from an acute hospital in the UK (Benton and Ellis 2008); augmentative and alternative communication users successfully participating in the workplace due to a range of AT devices (McNaughton et al. 2002); and increased independence and less personal care support in a range of daily living activities for ECU users (Palmer and Seale 2007). In a study of wheelchair access, Meyers et al. 2002 articulate the need for multiple layered responses to environmental barriers, responding to the lived experience of wheelchair users and considering a nuanced set of mediators:

At a substantive level, the data supports the suggestion that efforts to mitigate and eliminate barriers and facilitate social participation by wheelchair-users and others with mobility impairments should continue to focus upon the built environment: streets and sidewalks, entrances and exits, and interior design … at the same time, there is also a clear need for other kinds of social policy interventions – for example, personal assistance and assistive technology, health promotion and fitness. Finally, there is a clear need for programs that teach civility – that is, the ability to provide assistance to people with mobility impairments without conveying (and perhaps, to accept this assistance without inferring) condescension or contempt. (Meyers et al. 2002: 1445)

Only one study was located which considered AT, EI and PC together. Goodacre et al. (2008) in the UK examined the costs of substituting and supplementing care with AT. They defined adaptations (in other words EI) as a component of AT, and costed various packages of ‘adaptations, AT and care’ for seven notional users, concluding that ‘some AT and adaptations are cost-effective, enabling savings in the cost of formal care as well as improving the quality of life’ (Goodacre et al. 2008: 139). Overall, evidence from such studies provides specific and useful data, but does not provide a full picture regarding the interrelationships of the mediators of interest or the effectiveness of such combinations.
b. Data analysis

‘The Equipment Study’ validated the notion of AT solutions as tailored combinations of a range of mediators. As reported in Chapter 5, only 2% of study participants reported use of one mediator alone (an AT device); all others described using elements from two or more mediator categories (16% for AT and PC; 15% for AT and EI), and a high proportion of participants (66%) utilised elements from all three mediator categories.

The critical ingredient rendering AT solutions effective, above and beyond efficacy of individual elements, is the fact that, for the majority of the study cohort, tailored combinations of mediators were used to address the complex capability gaps which arise in the daily business of living. Extensive qualitative data from survey and interview respondents as reported throughout illustrates the impact and interrelatedness of these ‘suites’ of mediators or ‘AT solutions’.

Several diverse AT solutions, alongside the outcomes they facilitate, are outlined below by way of example:

A 65–74-year-old female respondent living with post polio sequelae described her AT solution as consisting of a range of small yet important mediators used together:


(EIF) Stepless shower. Grab rails in shower and toilet. Ramps from carport to front door and paths all around the house.

[PC] I don’t get daily help. I have home help for 1 & 1/2 hours a fortnight and the shire provides 4 hours once a year Spring Cleaning service. Grocery delivery. A friend who comes for a couple of hours once a fortnight to do needed small tasks. Next door neighbour who puts out my rubbish bins and other friends who are available for small tasks like posting letters or getting odd items of shopping. [S42]

With this AT solution, this individual is able to engage in a range of personal, domestic, work-related and cultural activities. She identifies potential extensions to her capability with several additions:
[AT] An electric wheelchair; Broadband internet connection
[EI] A letter box I can reach to empty from the car. Ramps instead of steps. Shorter ramps – at the moment all ramps are geared to wheelchair users and not walkers. Disabled parking closer to entrances so that I am not totally exhausted getting from the car park to where I am going.
[PC] A gardener; Occasional handy man/ window washer for outside windows, moving furniture, hanging pictures etc.

With these additional mediators, she anticipates,

I might be able to go on public transport again and go to places like the theatre. Genealogical research would be easier and quicker with broadband. Go out more. Go to the library/ Public Record Office/ Genealogical Society/ computer classes. Attend functions. Do some gardening seated in the wheelchair. I would be able to be outside some of the time instead of inside all of the time.

The following example from a 25–44-year-old respondent demonstrates use of a key mediator across multiple environments (a manual wheelchair) as well as the range of other tailored devices and modifications required for an overall solution to render him able to live, work and play:

I have … paraplegia. I use intermittent self catherisation, about 6 times a day, using KY gel, this I take with me in my manual wheelchair. I live … in a rented flat in Melbourne, with a shower transfer bench to wash, and a padded toilet seat. Apart from that, a normal flat. I work … and drive to work daily with hand controls. We have an accessible toilet … at work. On weekends I go to my parent’s farm, and use a modified quad motorbike to get around when on a farm, and my dad made up a hoist to get me into a boat. I have a modified bathroom when up on the farm. I get no paid or unpaid assistance. [S92]

In this example, six disability-specific AT devices (catheterisation equipment, manual wheelchair, shower transfer bench, hand controls to car and quad bike, boat hoist) combined with three mainstream devices (car, quad motorbike, boat) are augmented by three elements of EI (padded toilet seat, accessible toilets and bathrooms) as well as an absence of environmental barriers (i.e. accessible workplace). While he identifies ‘no paid or unpaid assistance’, support from his
father (e310: immediate family: WHO 2001) has enabled use of the boat. His list of improvements focuses on elements of inclusive community environs, for example:

‘Less steps, more ramps … Maybe better disabled car parks in the city for meetings … not have to plan social arrangements around toilet availability … can have that second drink if there is a toilet I can use!’ [S92]

This respondent demonstrates a set of aspirations likely to resonate with many young men, expressing a desire to ‘Do more adventure stuff … ’ and responding to the survey prompt regarding improvements as follows:

Ok. Since you asked I’d like a hand cycle, tennis wheelchair, kayak or canoe, place to get into/ out of it on Melbourne’s waterways, sailing clubs with accessible sailing boats and access. [S92]

All in all, this participant describes a life of diverse participation including work and recreation, in which his AT solution effectively augments his capability gaps.

When the detailed nuance of daily life and desired participation for each of these respondents is considered, clearly a tailored response in the form of a relevant set of mediators is the one that is most effective. To provide a generic suite of supports, or a pool of commonly utilised mediators, to either of these individuals would fail to fit their individualised environments and needs. These examples are just two from the dataset of 100, all of which demonstrate similarly individualised AT solutions related to particular environments and goals, and realised fully or partially depending on a number of factors, including resourcing. Within each AT solution identified for ‘The Equipment Study’ cohort, multiple AT devices (an average of eight) within a set of up to 13 mediating elements in total, were used.

The presence of the components of AT solutions, particularly when provided according to need and in relation to other components, can and does facilitate participation across all life domains for ‘The Equipment Study’ participants. The presence of the range of mediators which form each individual AT solution were reported to deliver outcomes on a range of indices including participation, satisfaction, decreased difficulty, and improved HRQoL and time use. The
causal link between identified mediators and reported outcomes was found to be robust, based on my analysis as an occupational therapist and AT prescriber: that is, nominated mediators were appropriately coupled with the outcomes they potentiated. Robustness was further established through the process of an expert panel review of eight participant datasets. Such data provide clear empirical support for the notion of the AT solution, and adds to the efficacy argument for these mediators.

**Concluding comments**

Chapter 6 examined the efficacy of mediators in the context of the larger thesis question: how might Australians living with impairment achieve equal outcomes?

The literature identified good, if atomised, evidence for the efficacy of AT, EI, and PC in terms of cost savings and functional status, using indicators such as carer burden, functional decline, fewer hospitalisations and later admission to residential care, and certain health outcomes. This was despite a range of methodological shortcomings, which makes it likely that the full efficacy of the mediators in question is not captured.

‘The Equipment Study’ data demonstrate that AT, EI and PC can mediate the effects of both impairment and the environmental barriers which may cause disablement. Respondents detailed the way in which the desired AT and related mediators would expand participation and enable the achievement of life aspirations across all eight life domains (Wilson 2006). Effectiveness was demonstrated on the parameters of satisfaction, decreased difficulty, improved time use and health-related quality of life, and increased participation in a wide range of life areas.

The data provide confirmation that these mediators are effective and most commonly used in tailored combinations (AT solutions). Because it explicitly captures the range of AT, EI and PC in place, the construct of the ‘AT solution’ provides a way to capture the effectiveness of mediator ‘sets’. Effectiveness of AT solutions is best captured at the level of participation rather than at the level of focal or discrete efficacy measures. This is because as the components of AT solutions influence each other, a wholistic view across multiple domains of use is embedded. Unlike, for example, examining the impact of a hoist (upon
transfers) or wheelchair (upon mobility), considering the suite of mediators in use refocuses attention onto the person, their tasks, environments and aspirations more broadly. Repeated and detailed evidence shows that AT solutions enable participation for individuals with a diversity of impairments and in a range of life areas and situations.
Chapter 7: AT policy case study

Introduction

The following chapters consider the social contract between society and citizens with impairments, through two sub-questions:

3a. How effective is government in delivering equality of outcome through the provision of mediators?
3b. What does government need to do to realise its obligations?

Chapter 7 addresses the first sub-question considering the current effectiveness of government according to a range of benchmarks, while Chapter 8 builds the case for a range of actions to enable government to meet its obligations.

Having established a key role for mediators in enabling Australians living with impairment to augment capability gaps and achieve a range of outcomes, the next question concerns the role of society in bringing this about. Realising equality of outcome is theoretically within reach, given these powerful interventions or mediators, yet substantial barriers prevent their availability:

There is a failure to recognise many social circumstances which disable or enable people. For example, a small amount of personal care can make all the difference – comparatively cheap, low tech, non-medical intervention can support someone living in the community. Yet, so often the care is either denied to people or charged at a prohibitive cost, such that a person’s condition and quality of life may well worsen. Yet, paradoxically we are prepared to fund extremely expensive and inappropriate accommodation for people with disability if this is philosophically consonant with the medical model of disability … The implication of our analysis is that power makes all the difference. Not only are those we regard as having a disability systematically and economically disadvantaged, our situation is in part created by the very healthcare system which is supposed to nurture us. We are certified as to what we can and cannot do. All this is based on inflexible notions of capacity, work, communication and physical access. Such dominant norms tell us who is valued in society and who is not. (Goggin and Newell 2005: 73)
This observation speaks of the profound and ongoing impact of disparate views of disability which are evident in the policy and service delivery covering AT, EI, and PC from a disability perspective.

In asking what it takes for individuals with impairments to achieve equality of outcome, it is argued that policy, as the expression of societal intent, is part of the answer. This inquiry into policy uses human rights concepts as a critical lens through which to view the impaired rights bearer, and the role of society in realising a range of rights for that bearer. Policy is an instrument for enacting human rights, and as such sets up directional parameters for the provision of resources (de Leeuw 2007).

Understandings established in the previous chapters are brought forward to inform the policy analyses. These include a nuanced view of the relationship between impairment and disablement; particularly in relation to the influence of mediators and structural barriers. Also important is the universal nature of life aspirations as demonstrated by people living with disability in the empirical study, and captured in human rights frameworks.

The potential of equity measures to address the challenge of achieving equal outcomes in the context of human rights arguments was introduced in Chapter 4, which found that simple or negative equality implies equal allocation of public resources, with a view to according people identical treatment regardless of personal characteristics and circumstances (Jones 2009). Such ‘identical treatment’ is problematic given the diverse nature of humanity, including impairment effects (Bickenbach et al. 1999; Goggin and Newell 2005; Rioux 2003; Rioux and Riddle 2011). Positive equality, on the other hand, infers the taking of active steps towards rights realisation in order to achieve equality of outcome (Phillips 2004; Rioux et al. 2011; Sen 1999). Equity approaches are a means of enacting positive equality, as they specifically address the conversion handicap inherent in achieving outcomes with impairment effects (Kimberlin 2009; Nussbaum 2003).

After outlining the nature of the social contract between society and its citizens with impairments, this chapter draws on policy documentation, ‘The Equipment Study’ data and a range of literature to analyse how effectively society and
government currently facilitate equality of outcome through the provision of mediators of impairment, from the perspective of equality and of equity.

Australia’s policy context will be outlined in relation to AT and related mediators, to contextualise the Victorian Aids and Equipment Program (VAEP) and the experience of the research participants. The VAEP program will be the focus of this chapter, as it is the primary funding source for ‘The Equipment Study’ cohort and provides an example of how AT funding schemes currently deliver on their policy intent.

**The social contract as expressed in Australian policy**

The human rights imperative is a legal and moral expression of our social contract and sets the context for public policy, including policies for people living with impairment. Human rights are social tools for the achievement of a just society (Jones 2011: 65) increasingly recognised as a mechanism by which people living with disability can be heard (DLA Piper 2012; Frohmader 2011). In the delivery of human rights, rights are generally positioned at either end of an ‘immediate obligation’ (ensure; shall undertake) to ‘progressive realisation’ (take measures) continuum. Many civil and political rights are recognised as absolute, such as the right to privacy or participation in public life, while others are subject to ‘progressive realisation’ to the maximum of a State’s available resources (United Nations 2006).

Translating this to the Australian context means that, while acknowledging that full realisation may take some time to achieve, the Australian government must take immediate steps to work towards the goals expressed in the international human rights charters and conventions to which it is a signatory. Importantly, progressive realisation also requires that the government does not take any retrogressive steps regarding any right.

Over the past forty years Australian policy and resourcing has been described as operating along neo-liberal and welfare-reformed lines (Bigby and Clement 2009), with disability services in particular being subject to limited vision brought about through managerialism (Head 2008; Löfgren et al. 2011) and economic rationalism (Annison et al. 1996). The emerging legislative framework governing policy for individuals with impairment in Australia, however, is based upon
human rights approaches and presents a strong rationale for the application of human rights principles to this inquiry.

A number of pieces of Australian legislation, both nationally and at state level, sit beneath the international benchmark offered by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006). On 17 July 2008, Australia became the thirtieth country to ratify the CRPD, which created an obligation on the part of the Australian government to deliver on its intent. Other Australian legislation dealing with the rights of people living with impairment includes the *Disability Discrimination Act (1992)* and the *Age Discrimination Act (2004)*. These pieces of legislation are enacted and realised through a variety of means: for example, their principles are re-expressed in related policy areas such as Australian Telecommunications regulations, or Human Rights and Equal Opportunity Commission Action Plans, and most recently the National Disability Strategy 2010–2020 explicitly recognises and builds upon this legislation (Commonwealth of Australia 2011). Identifying human rights, social justice and economics as the three imperatives of the next decade, the Commonwealth government explicitly states that the key aims of its National Disability Strategy (NDS) will be aligned with the principles of the CRPD (United Nations 2006), envisioning that people with disability and their carers will have an enhanced quality of life and participate as valued members of society. To this end, core outcome areas are named:

1. People with disability live in accessible and well designed communities with opportunity for full inclusion in social, economic, sporting and cultural life.
2. People with disability have their rights promoted, upheld and protected.
3. People with disability, their families and carers have economic security, enabling them to plan for the future and exercise choice and control over their lives.
4. People with disability, their families and carers have access to a range of supports to assist them to live independently and actively engage in their communities.
5. People with disability achieve their full potential through their participation in an inclusive high quality education system that is
responsive to their needs. People with disability have opportunities to continue learning throughout their lives.

6. People with disability attain highest possible health and wellbeing outcomes throughout their lives. (Commonwealth of Australia 2011: 27)

Turning from national to state jurisdictions, the Victorian State Disability Plan 2002–2012 identifies key goals as ‘Pursuing individual lifestyles’, ‘Building inclusive communities’, and ‘Leading the way’ (State Government of Victoria 2002: 11). The State Disability Plan is attended by a Quality Framework for Disability Services that identifies outcomes expected of funding and supports provided to people with disabilities (DHS 2007b). In Victoria, outcomes focus on sixteen life areas such as ‘being part of community’, ‘doing valued work’, and ‘having fun’ (DHS n.d.: 12–13). This policy framework is broadly consistent with both the National Disability Strategy and the thrust of the CRPD (United Nations 2006). As with the National Disability Strategy, provision of the components of AT solutions is implied rather than explicit. Key goals, such as ‘Pursuing individual lifestyles’ and ‘Building inclusive communities’ (State Government of Victoria 2002: 11), are likely to require facilitators such as AT and EI in order to achieve these, but strategies to enact the goals remain vague.

Each Australian State and Territory has flagship government-funded assistive technology programs or ‘equipment schemes’ which, while they differ in name and budget, have many program elements in common. The discourse of Commonwealth and State government policy and programs continues to use the somewhat dated term ‘aids and equipment’ (Commonwealth of Australia 2011) which, while including limited funding for home modifications, suggests a somewhat narrow focus on devices rather than on the broader environments and supports that interface with them. Within Victoria, the policy that actually addresses AT services and resourcing to individuals is the Victorian Aids and Equipment Program (VAEP).

In Victoria, the VAEP is the fallback scheme should people be ineligible for other funders. The VAEP aims to provide ‘people with a permanent or long-term disability with subsidised aids and equipment to enhance independence in their home, facilitate community participation and support families and carers in their role’ (DHS 2010). The stated intent regarding support, independence and
community participation is noticeably narrower than the outcome areas of the overarching policy context within which VAEP sits. Nevertheless, many survey respondents acknowledged they would be unable to live in the community at all without the support of VAEP and other government and non-government services:

It’s marvellous, getting all this support, I couldn’t manage without it. [S86]

Eligibility is limited to Victorian residents who have a permanent disability and do not have access to AT through other means such as hospitals (if recently discharged) or private health insurance, and require ‘aids and equipment or home or vehicle modifications from the aids availability list on a permanent or long-term basis’ (DHS 2010). A limited range of allowable AT devices, vehicle modifications and elements of EI are subsidised by the VAEP: this availability list is colloquially known as the ‘equipment list’.

The social contract as identified by AT users

The grey literature contains several sets of AT user priorities regarding AT policy and provision that have emerged from stakeholder groups in recent years. The Aids and Equipment Action Alliance has been active in documenting user views on AT provision in Victoria since 2006, and generated a set of agreed principles from stakeholders regarding good features of AT policies and programmes at the Equipping Inclusion Forum held in 2006 (Wilson 2007) and revised in 2011 (AEAA 2011):

Any system for allocating aids and equipment should meet the following principles:

1. A fair balance of government and private expenditure: Government investment in aids and equipment should be consistent with levels of need, and should be regularly adjusted to reflect demographic and technological changes.
2. Government funding guaranteed against clear eligibility guidelines: Any individual who needs aids and equipment should have security of entitlement if they are eligible, and eligibility criteria should be transparent.
3. Meets individual needs: Access to government funding for aids and equipment should be responsive to individual need and recognising the needs of families and carers, allow for choice and the timely allocation of equipment that is appropriate to the individual.

4. Allows for life changes: Provision of aids and equipment must be timely and responsive to changes in the life situations, needs and aspirations of individuals, families and carers and which reflect improvements in technology.

5. Efficient systems: Systems for the provision, maintenance and recycling of equipment should be designed to maximise the efficient use of government resources (AEAA 2011: 2).

A further list of AT user requirements from their AT funding schemes was identified at a national workshop of consumers and other stakeholders in 2008 (De Jonge and Layton 2008). This list has since been triangulated with several disability groups (Aids and Equipment Action Alliance; Queenslanders with Disabilities Network), and continues to be refined (De Jonge, Layton and Vickery, 2009). Broadly consistent with the thrust of the AEAA principles, the requirements are listed as:

- The best combination of equipment, personal care and environmental design to meet needs in every area of life;
- Access to sufficient funding to pay for good quality and long lasting equipment;
- Having needs looked at holistically, so that each piece of equipment works well and does not interfere with other equipment or supports;
- Having equipment needs considered across the lifespan, as needs change;
- Access to support through the whole process of getting equipment, including equipment trial, training and maintenance;
- Access to resources when needed;
- Being actively involved in deciding on the best option;
- Having personal preferences and identity considered when identifying equipment to suit lifestyle and participation;
- Gaining knowledge of AT and the processes involved in accessing it;
• Having access to skilled AT practitioners who can work across life domains. (De Jonge, Layton and Vickery, 2009)

From the standpoint of AT users, then, the social contract between citizens who require AT and the government features tailored and flexible provision of broadly defined mediators and skilled soft technology support, at time of need. Resourcing must be sufficient to meet demand, but also must be efficiently administered and effectively spent, demonstrating an understanding that AT users also have responsibilities as citizens. Choice (of goals and mediators), control (over processes), and autonomy (including the capacity to gain skills and extend roles in the AT delivery process) are underpinning principles which resonate with the literature as presented in Chapter 4.

The role of society and effectiveness of government in delivering equality of opportunity through the provision of mediators

A number of areas are analysed to explore the role of government in delivering mediators. The first step in this analysis of policy is an evaluation of the experiences of the 100 ‘Equipment Study’ participants against the benchmarks provided in the CRPD (United Nations 2006). This analysis will determine what outcomes in terms of life participation are being supported or denied by provision of AT, or lack thereof. An examination of the AT policy overall, and a specific evaluation of policy pertaining to AT in Victoria (VAEP) provides further data as to mediator provision by government.

The UN Convention on the Rights of Persons with Disabilities (United Nations 2006) presents a set of human rights against which current policies and programmes can be evaluated (Bickenbach 2009a; Watchorn and Layton 2011): that is, human rights, as expressed in CRPD (United Nations 2006) articles, are used as a measure of equality of outcome. In terms of the components of AT solutions with which this thesis is concerned, AT and the accessibility of environments and services are explicitly named within multiple articles of the CRPD (United Nations 2006). The ‘General obligations’ section (article 4) requires signatories to

    undertake or promote research and development of, and to promote the availability and use of new technologies, including information and
communications technologies, mobility aids, devices and assistive technologies (Article 4 g).

Article 9 on accessibility requires signatories to:

take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

Further articles, including ‘Living independently and being included in the community’ (Article 19), ‘Personal mobility’ (Article 20), ‘Freedom of expression and opinion, and access to information’ (Article 21), ‘Education’ (Article 24), ‘Habilitation and rehabilitation’ (Article 26), and ‘Participation in political and public life’ (Article 29), explicitly identify rights to access appropriate assistive technology and related enablers in relation to each of these areas of life.

**Analysis against CRPD benchmarks**

The principles expressed in these Articles formed an analysis framework against which ‘The Equipment Study’ data could be analysed to identify the number and type of instances where respondents reported unrealised participation in a desired life activity that is identified as a human right in the CRPD (United Nations 2006).

Coding protocols for ‘The Equipment Study’ data as meeting or failing to meet CRPD (United Nations 2006) Articles were as follows: an instance of unrealised participation was recorded if it met two criteria. Firstly, participation was experienced as unrealised if it was difficult to the extent that participants were subjected to undue effort to participate or relinquished the task altogether. For example, an adult with a spinal cord injury discussing her economic life described her inability to access banks as follows:

Effort in running around finding accessible banks or embarrassing myself by yelling from the front door and having to be a dependent disabled person, reliant on people’s good will. [S25]
Secondly, data was included if the activities being described mapped directly to human rights expectations as expressed in the CRPD (United Nations 2006). Some instances constituted actual breaches of the CRPD, where the continued presence of barriers are illegal in that they contravene laws or regulations as in this example where aspects of the building code have been breached:

My rented flat has steps to get in the main entrance, so have to drive into downstairs carpark, or come in the car entrance on the wheelchair. Ensuring all new apartment blocks with lifts have an entrance with no steps would be a big bonus! Also the apartment has a huge (20cm) lip to get onto the balcony, so need to build a ramp. [S92]

Figure 14 represents a summary of the 138 instances of unrealised participation identified in the study data relating to articles from the CRPD (United Nations 2006).

**Figure 14: Failure to realise participation in life activities as defined in CRPD**

Articles with the highest level of non-compliance related to lack of AT provision are ‘Accessibility’ (Article 9) with 32 instances of unrealised participation; ‘Living independently and being included in the community’ (Article 19); ‘Adequate standard of living and social protection’ (Article 28), and the combined elements
of Article 4 ‘General Obligations’ (together totalling 25 instances). Illustrative quotes are listed in Table 24. It is recognised that while these quotes highlight particular element of each Article, their scope often links to other Articles of the Convention.

**Table 24: Illustrative participant quotes regarding unrealised participation in CRPD articles**

<table>
<thead>
<tr>
<th>Article or Section (UN 2006)</th>
<th>Example from data of life areas not realised leading to failure to fulfil CPRD principles</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Article 4 - General obligations</strong></td>
<td></td>
</tr>
<tr>
<td>(f) To undertake or promote research and development of universally designed goods, services, equipment and facilities…</td>
<td>[I need] low floor public transport; sufficient seating on public transport; disabled access at venues, ie no stairs [in order to] go out and do things with people or on my own and feel like I’m part of something, part of the community, part of life. I’d have choices about how I spend my time. [S61]</td>
</tr>
<tr>
<td>(g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;</td>
<td>Since our son has moved into his own unit, we have had to change agencies three times to obtain an agency that listens to our son’s aspirations and our family dreams, upholding an appropriate attitude toward our son’s ability to learn new skills while making his own choices. Some staff at some agencies have very old ideas regarding care and support—requires retraining and updating attitudes. [S76]</td>
</tr>
<tr>
<td>(h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;</td>
<td></td>
</tr>
<tr>
<td>(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognised in this Convention so as to better provide the assistance and services guaranteed by those rights.</td>
<td></td>
</tr>
<tr>
<td><strong>Article 9 – Accessibility</strong></td>
<td>Accommodation venues state that they are accessible but they are not or do not meet the Standards. In my case, I will not now go to a venue unless I see photographs of the toilet and shower to ascertain if I will be able to manage when I get there. [S17]</td>
</tr>
<tr>
<td>1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.</td>
<td>Access in my neighbourhood is very poor and I’m not confident at all getting around. Some places are too steep and some places don’t have footpaths… neighbourhood access for wheelchairs would make things a lot easier. [S88]</td>
</tr>
<tr>
<td>Article 19 - Living independently and being included in the community</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.</td>
<td></td>
</tr>
</tbody>
</table>

| I wish I could get out into the community - once a week isn’t enough. [S81] |
| At the moment I do not have any of the aids nor equipment to make it possible for me to join in socially without assistance from others. [S107] |
| [Deafblind individual who travels alone on public transport:] It is so stressful to have nothing - if only I had a mobile - there are so many barriers. Hearing people can buy a cheaper phone, fitting their budgets; less expensive mobiles will not work with the Connie [refreshable Braille peripheral]. [A] mobile phone will enable me to contact the person I’m meeting if I have an emergency… it would just enable me, if I’m sick or have been attacked, if the electricity is out I’m unable to contact anybody, the mobile would get rid of all those barriers. We need to argue with government that this is our right to have equal access to communication. [S109] |

<table>
<thead>
<tr>
<th>Art 20 – Personal mobility</th>
</tr>
</thead>
<tbody>
<tr>
<td>States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:</td>
</tr>
<tr>
<td>Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;</td>
</tr>
<tr>
<td>Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;</td>
</tr>
<tr>
<td>Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities.</td>
</tr>
</tbody>
</table>

| I’d like a lift in my work place so I could access other offices and the cafe to eat. [S45] |
| A cut in path in my nature strip near my front door as the nearest cut in the gutter is up the road which when getting a taxi I get rather wet, council will not let me do it even though I was willing to pay. [S81] |

<table>
<thead>
<tr>
<th>Article 21 – Freedom of expression and opinion, and access to information</th>
</tr>
</thead>
<tbody>
<tr>
<td>On-line meetings with chat or voice hook-up for people with disabilities as</td>
</tr>
<tr>
<td>a. Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost</td>
</tr>
<tr>
<td>Article 26 – Habilitation and rehabilitation</td>
</tr>
<tr>
<td>Article 25 - Health</td>
</tr>
<tr>
<td>Article 29 Participation in political and public life</td>
</tr>
</tbody>
</table>

AT users in Victoria, as captured in this study, aspire to included lives, and currently live them to varying degrees. This study identified a strong match between the policy goals at international, national, and state levels in regard to disability and inclusion, and the aspirations of people with disabilities using AT in Victoria. However, the experiences of the participants in ‘The Equipment Study’ led to the conclusion that insofar as provision of AT and EI are concerned, Australian policy fails to meet its human rights commitments. This confirms the findings of the Shut Out Report, which concludes that ratification of the CRPD (United Nations 2006) has not ensured its realisation:

The gap between the principles enshrined in the legislation and the lived experience of many people with disabilities was a recurring theme … People with disabilities reported experiencing discrimination in every aspect of their lives. (National People with Disabilities and Carers Council 2009: 14)
**Analysis of current AT policy**

The current expenditure (both public and private) on AT, equipment and related products in Australia is estimated to be $4.5B (Summers 2010). Much of this is incurred by individuals living with the effects of age and/or disability who are likely to have low incomes and high health-related expenditure (ABS 2004; AIHW 2009a; Engels et al. 2009; Hill 2011), including the need for AT and other mediators (Wilson et al. 2006).

Equality, defined as equal treatment, is not achieved within current systems of AT provision. An explanation for the limited supply evidenced in Australia is simply insufficient budgets for AT (Coalition for Disability Rights 2006; Summers 2010). Constrained budgets lead to a variety of rationing measures which limit the realisation of programme intentions. Current policy guidelines effectively ‘ringfence’ programme eligibility with a range of eligibility hurdles. The reality that people receive different levels of supports based on categorisation of disability type and cause, rather than need, is evidenced in ‘The Equipment Study’ data as will be demonstrated below. Differential treatment, described as a ‘cruel lottery’ (NDIA 2012), occurs on the basis of a range of personal, demographic, historical, or regional factors and delivers variable realisation of rights in terms of access and outcome. Respondents identified a complexity of funding schemes which provided partial solutions yet were reportedly hard to identify and access, due in part to restrictive eligibility criteria. These barriers will be outlined, followed by an examination of VAEP as the main AT funder for Victoria.

**Barriers: complexity of funding sources**

Of the 100 Equipment Study participants, 30 identified the primary funding source for their AT as self (30%); 41 (41%) identified the primary funding source as VAEP; and eight received other funding, including insurance payouts. Twenty-one (21%) did not identify their primary funding source.

A multiplicity of services and funding schemes was found to be part of the lives of the study population. Participants volunteered information on a variety of sources of funding. These included compensation schemes (war veterans, traffic accident and workplace injury); government-funded specific purpose schemes (employment and primary, secondary, tertiary or further education);
and disability-specific schemes (government, non-profit or blended funding). Participants also identified a wide range of specific purpose schemes such as respiratory AT services, continence schemes, wound care, a national relay service for hearing impairment, half price taxi schemes, disabled parking permits, medical cooling concessions, companion cards and mobility allowances, note-takers for college, guide dogs and service dogs. Some of these provide services; others provide funds. While many of these options were valued, the plethora of schemes was confusing and time-consuming to work with for many respondents:

We are always trying to find money for things like taxis and continence products and carers and we need to fix the house and get a new car. And we spend a lot of time filling in forms and getting the doctor to fill in forms because every place wants their own forms, not just one for everyone, and they need it filled in every few months, not just when it changes. [S69]

[What’s needed is to] reduce red tape and streamline the service system. [S84]

The literature identifies that Australia has an ‘ad hoc and uncoordinated patchwork of over 100 aids and equipment programs’ (Summers 2010: 1), many of which were primarily devised to provide other sorts of support (for example health, social services, or education) but extended into AT because of the limits of the main State funding programme (Cook and Hussey 2008). The number of funding sources and service providers described by participants supports this contention, and demonstrates, in part, the range of agencies with which AT users are required to interact in order to gain their AT solution and achieve desired life outcomes. The wide range of players brings additional complexity to navigating the AT service system, and compounds the experience of inequity when people do not have full information on their options or rights to various resources. Additionally, despite this large range of funding sources, many respondents were unable to access needed services. Such fragmentation demonstrates a failure, as yet, to realise the goal of eliminating ‘service silos’ via coordination across multiple services and the building of joined-up services, as stated in the Commonwealth Social Inclusion Principles (Australian Public Service 2009). As the Shut Out Report concludes:
Disability services are intended to provide people with disabilities and their families, friends and carers with the assistance they need to fully participate in daily and community life. More than half of the submissions received during the consultation process (56 per cent) said that services and programs act as a barrier to, rather than a facilitator of, their participation (National People with Disabilities and Carers Council 2009: 5).

Barriers: factors rendering respondents ineligible for public funding

Far from having equal access to mediators, the source of an impairment, the location of the individual, and employment status profoundly affect the policy context in which people living with impairment must attempt to construct their AT solutions. Individuals find themselves defined out of services, a situation of rationing which creates a ‘shadow army of individuals who exist on the margins and who cannot meet strict eligibility criteria for support despite real and pressing needs’ (National People with Disabilities and Carers Council 2009: 20). Illustrative data regarding the limitations on accessing public AT funding is depicted below.

1. Employment status

Several individuals found their eligibility status for publicly funded AT to be a barrier to participation in work-related life outcomes. One participant, who ran a website business from her hospital bed at home, was ineligible for essential computer and communications technologies as she was self-employed. Another participant with Deafblindness required a mobile phone with refreshable Braille interface, to be able to communicate with others when away from an interpreter or adapted computer. She found she was ineligible to apply as a jobseeker as she needed to be in work. In these two instances, none of the AT required was within the scope of provision of the VAEP, and nor was it available through the Commonwealth’s employment-related AT funding program for the reasons provided.

2. Cause of impairment: compensable/ non-compensable status

Compensable versus non compensable status is a substantial cause of inequality. Victoria’s Traffic Accident Commission (TAC) is an example of a compensation scheme where AT is provided alongside EI, attendant care and
therapy support, and provided on an ongoing, assessed need basis. AT solutions, provided by such schemes, are uncapped. As TAC support is designed to address whole-of-life domains and provides individually tailored combinations of AT, EI and PC (AIPC 2007), this scheme can be said to most closely provide optimal AT solutions.

Within ‘The Equipment Study’ cohort, five participants identified their primary funding source as insurance. Four of these received Traffic Accident Commission (TAC) funding and one ‘other insurance’. This subset of participants reported more extensive ranges of AT in comparison to VAEP recipients: for example, provision of both manual and powered wheelchairs (VAEP subsidises only one); lowered light switches throughout the home; and multiple ramped entrances (VAEP subsidises only one). Differences were most apparent in the extensive availability, and use of, PC:

- Carers, 38.5 hours per 24 hrs, at times 2 carers work together to bath/toilet, dress me. [S89]

- Attendant care about 9.5 hours/day plus sleepovers; cleaner 2 hrs/week; gardener 3 hrs/fortnight (when they come!) – all paid. [S90]

In contrast, many non-compensable participants described receiving limited amounts of PC, with associated limited outcomes:

- 2.5 hours per day to do everything I need in my life. [S11]

- Another hour per day would enable me to save some for holidays. [S111]

This finding perhaps indicates likely unmet needs for PC among recipients of other schemes which do not provide this mediator. However, the TAC-funded participants shared a desire for inclusive community environs with their VAEP-funded and self-funded counterparts, demonstrating the impact of community barriers beyond the AT solution used by each individual.

3. Residential status

Residential status also significantly impacts upon access to mediators. In theory residential care facilities must attend to the needs of the resident, including their
need for AT. However, state funding schemes exclude residential care dwellers such as residents of nursing homes (AIHW 2010). The limited provision which typically results has been demonstrated to increase morbidity and mortality (Dearn 2011; Winkler et al. 2007); for example in the provision of generic equipment such as a transit wheelchair or tub chair instead of a customised powerchair with postural supports. In response to this ineligibility for public funds, several survey participants who resided in specialist facilities for progressive neurological impairment described receiving specialised tailored AT from philanthropic funds or loan schemes co-ordinated by organisations such as the Motor Neurone Disease Association and facilitated by allied health staff.

All schemes present differing eligibility criteria and require individuals to apply separately and repeatedly to gain access. Such variable provision fails to meet the intent of core outcome area 4 of the National Disability Strategy (Commonwealth of Australia 2011), or indeed the general obligations set out in Article 4 of the CRPD (United Nations 2006).

This analysis of the factors rendering respondents ineligible for government AT funds demonstrates that, rather than being driven by AT user need, access to the elements of AT solutions is governed by service structures across government sectors (Barbara and Curtin 2008; Disability Investment Group 2009; National People with Disabilities and Carers Council 2009; Productivity Commission 2011). The government itself critiques the current disability support system, of which AT systems are a part, as ‘underfunded, unfair, fragmented, and inefficient, [giving] people with disability little choice and no certainty of access to appropriate supports’ (Productivity Commission Feb 2011: 2).

The observations from ‘The Equipment Study’ participants echo calls for an ‘integrated approach to policies, programs and services [and] broadening the aims of disability-specific programs and services from function and independence to social inclusion and community participation’ (National People with Disabilities and Carers Council 2009: 14).

**Analysis of the Victorian Aids and Equipment Program**

As stated, the intent of the VAEP is to provide to people with a permanent disability ‘subsidised aids and equipment to enhance independence in their
home, facilitate community participation and support families and carers in their role’ (DHS 2010). The data analyses provided below demonstrate that the VAEP fails to meet the AT needs of Victorians in a number of ways. Scheme limitations include an unaffordable subsidy requirement against a narrow list of eligible mediators. It will be argued that the range of observed ‘disincentives’ to participate in the scheme are a result of resourcing which is inadequate to meet demand. Such constrained supply leads to a narrowed focus upon ‘basic’ provision. VAEP prioritises supply of AT for reasons first of safety and then of independence: although community participation is a stated goal, it is less likely to be delivered given competing demands (Barbara and Curtin 2008; Waldron and Layton 2008).

Limitations of VAEP: lack of affordability

While many state equipment funding schemes (for example NSW) apply a means test for access, the VAEP does not. However, at present the VAEP is designed as a subsidy program. In this respect it does not fund the full cost of many approved AT devices or environmental modifications. The subsidy rate available via VAEP represents an average of 60% of device cost, according to Wilson et al. (2006), leaving a substantial proportion of the purchase price (an average of 40%) to be raised by other means. This has been noted as a significant barrier to actually attaining AT because of the financial hardship sustained by the client group (Wilson et al. 2006). This finding is echoed in the only one of several recent government-commissioned reviews of the VAEP to be made public, based on data from 2005–2006 (KPMG 2006). KPMG’s review clearly acknowledges that provision of equipment subsidies may fall short of actually delivering an AT outcome:

This subsidy level has remained unchanged for a number of years, despite increases in the cost of aids and equipment. For many clients, this increasing gap between the subsidy and the full cost of the item is impacting on their capacity to afford necessary items. To access an alternative funding source a client, their case manager or the prescribing therapist may be required to submit an application to another government funded program, a community service organisation, a charitable organisation or a trust fund, or secure funding from a private source. These processes can cause significant delays in the provision of equipment. This process adds significantly to the workload
of the case manager or prescribing therapist … delays in securing this funding may also lead to the need to reassess the client, as their circumstances may have changed over time such that the original item prescribed is no longer suitable. (KPMG 2006: 24)

The report identifies a budget of $21 million subsidising 26,619 Victorians, but estimates unmet demand to be at least $3.3 million annually. In 2006 it was estimated that an additional $20 million budget allocation for the VAEP was required, along with

A minimum $10 million recurrent injection of new funding for the Victorian Aids and Equipment Program in order to reduce waiting times; improve subsidy levels for all VAEP aids and equipment items to reduce the prohibitive ‘gap’ costs between VAEP subsidy levels and the actual cost of aids and equipment. (Coalition for Disability Rights 2006: 15)

Repeatedly, respondents in ‘The Equipment Study’ discussed their difficulty in affording items of AT in terms of funding the ‘gap’ amount between the subsidy level provided by VAEP and the actual purchase price or cost of the item, confirming the high cost burden caused by the significant gaps between actual cost and VAEP subsidy suggested by Wilson et al. (2006) and KPMG (2006). In order to meet their AT needs, participants frequently used more than one source of support and funding:

I have one [manual wheelchair] currently funded by a private foundation. Couldn’t get VAEP to fund one for me and I’d be stuffed without it. [S25]

If multiple items were required, participants often needed to pay for them themselves:

[I need] many rails around house so combined with crawling I can get about my flat eg. open fridge door … I get approx 20 hours help a week [paid care] includes paper work, cleaning, shopping, access to exercise, and banking and medical appointments etc … for 20 years I have systematically had kerbs and recessed rails installed, had to pay for much of it myself. [S105]

At times, an individual was placed at risk of injury as a result of inability to afford co-payments for AT:
[I] need a transfer pole to steady myself when transferring from bed to commode. A&EP option is too costly [gap funding] so still using moveable trolley which is potentially unsafe. [S24]

An analysis of VAEP subsidy levels (DHS 2010) and the actual mean cost of comparable items catalogued in the Independent Living Centre Victoria database identifies significant subsidy gaps on most items. Actual and subsidy costs across the types of AT devices and modifications eligible for and excluded from funding by the VAEP are compared in Table 25.

Table 25: Level of subsidy gap between VAEP subsidy and actual mean cost of item (selected items)

<table>
<thead>
<tr>
<th>Category</th>
<th>Item example</th>
<th>Mean cost (ILC, 2007)</th>
<th>VAEP subsidy cap (DHS 2010)</th>
<th>Gap $</th>
<th>Gap % of total actual cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility Aids and Equipment</td>
<td>Walking frame</td>
<td>$412</td>
<td>$300</td>
<td>$112</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>Manual wheelchair – basic</td>
<td>$1371</td>
<td>$1000</td>
<td>$371</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>Manual wheelchair – lightweight</td>
<td>$2147</td>
<td>$1250</td>
<td>$897</td>
<td>42%</td>
</tr>
<tr>
<td></td>
<td>Powered wheelchair</td>
<td>$6,739</td>
<td>$6,000</td>
<td>$739</td>
<td>11%</td>
</tr>
<tr>
<td></td>
<td>Scooter</td>
<td>$3,200</td>
<td>$4,000</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Personal Aids and Equipment</td>
<td>Powered bed</td>
<td>$2,882</td>
<td>$2,000</td>
<td>$882</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>Bedstick</td>
<td>$220</td>
<td>$200</td>
<td>$20</td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>Portable ramp</td>
<td>$618</td>
<td>$400</td>
<td>$218</td>
<td>35%</td>
</tr>
<tr>
<td></td>
<td>Static pressure mattress</td>
<td>$1,493</td>
<td>$1,070</td>
<td>$423</td>
<td>28%</td>
</tr>
<tr>
<td></td>
<td>Dynamic pressure mattress</td>
<td>$2,133</td>
<td>$1,070</td>
<td>$1,063</td>
<td>49%</td>
</tr>
<tr>
<td>Environmental control units</td>
<td>PROG© ECU</td>
<td>$4,200</td>
<td>$3,000</td>
<td>$1,200</td>
<td>29%</td>
</tr>
<tr>
<td>Personal use items</td>
<td>Wheeled commode</td>
<td>$1,038</td>
<td>$1,000</td>
<td>$38</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td>Mobile hoist</td>
<td>$3,145</td>
<td>$2,600</td>
<td>$545</td>
<td>17%</td>
</tr>
<tr>
<td>Home modifications</td>
<td>Permanent ramp (to eliminate 3-4 steps)</td>
<td>$9,000</td>
<td>$4,400</td>
<td>$4,600</td>
<td>51%</td>
</tr>
<tr>
<td></td>
<td>Bathroom modifications</td>
<td>$19,750</td>
<td>$4,400</td>
<td>$15,350</td>
<td>78%</td>
</tr>
</tbody>
</table>
The widespread significant subsidy gaps include a 51–78% shortfall on home modifications; 27% for walking frames, 42% for manual wheelchairs, a 31% shortfall for beds, 35% for portable ramps; 17% for mobile hoists, and 49% for some pressure care equipment. Given this, some respondents have felt it was ineffective to enter a scheme characterised by delays and uncertain outcomes.

Calculated on the above list of selected items, the VAEP subsidy provides an average of 66% of the purchase price of an item. Appendix K contains a full comparison of current VAEP subsidy levels with current market costs.

Significant hardship was reported by many respondents due to lack of responsiveness of VAEP. A narrative from one participant identifies the adverse effects of wait times and limited subsidies, based on his experience in accessing the scheme in order to leave hospital after a spinal cord injury:

VAEP, they won’t let you do anything … they are only paying for a third, less than a third of the cost of this [wheel]chair but they won’t let you put the order in … and they won’t do it until right at the end so now it’s taken 6 weeks to put the order in, another 6 minimum to get the chair … so I probably won’t see my chair to January now. It does not make sense to work that way … now why, when I found out which chair I wanted over 10 weeks ago, why couldn’t I have just put in the order, paid the whole chair, then if VAEP deemed that I am due $1500 pay it back to me … I would have had my chair by now. Now they won’t let you out of [the hospital] unless you are set up to be able to go to the bathroom and everything, right, so . . . I had to gut my bathroom … You have to go and get the report from Archicentre … they say that you have to get two quotes, and it was a monstrous amount of money they came in at, you know, $20,000 or something, and VAEP were going to take an untold amount of time to … approve it and to pay someone that $4,500 or something, which meant I was going to have to stay at [the hospital] all this time … [The hospital] is struggling for beds … I got my licence for a hand-controlled car and I wanted to go out [of hospital] to come home, to be totally independent … but VAEP they would not pay for the
hand-controls. I couldn’t do the hand-controls until they approved it which was going to be about 8 weeks … so I was going to have to wait 8 weeks … and if I went and did it on my own they would not reimburse me at all … I thought ‘they are sending me out, they want me to go out to work as normal and get independent, but instead they are causing hurdles that should not be there’, as it turned out [the social worker] managed to get me the funding via another avenue within 2 days … it went straight to the [company doing hand conversions] and I was absolutely independent in about a week and a half and back to work and doing my normal thing. [S84]

Effectively, the VAEP system denied this participant a range of outcomes, all of which would have enhanced his health and quality of life, and many of which would actually have saved costs within the system.

Essentially, the VAEP fails to render AT affordable. The particularly low socioeconomic status of ‘The Equipment Study’ cohort, described in earlier chapters in the context of generally low resource levels, high costs of disability and thin margins of health for those living with impairment, suggests that substantial conversion handicaps are experienced by this population. Clearly a public or social policy response is needed, one that fits this user group with their specific levels of economic disadvantage. Such a group is unlikely to afford the shortfalls representing 33% or more of AT device costs, or 51–78% of home modification costs.

Limitations of VAEP: inadequate range of mediators

This study has demonstrated mediators to be AT, EI and PC, used together as a proven effective ‘AT solution’ that mediates impairment and potentially prevents ‘disability’. ‘The Equipment Study’ empirically establishes ‘AT solutions’ as a useful intervention and one which is essential to realising, or failing to realise, a range of human rights benchmarks. However, the availability of the components of AT solutions has been demonstrated to be restricted, limiting the achievement of outcomes.

As discussed in Chapter 5, ISO 9999 provides a comprehensive, and contemporary, taxonomy for AT and EI. A comparison of the 650 AT devices categories in ISO 9999 (2007) with the 82 device categories of the VAEP demonstrates that the VAEP, as it currently stands, provides funding for only
13% of currently available AT device categories on the market, identified by the ISO. This illustrates the ad hoc nature of VAEP provision, where some AT devices are funded – and some not – despite all having a role in supporting activity and participation aligned with VAEP and DHS funding principles. For example, mobility and self care are core VAEP areas, yet mobility devices allowed by VAEP represent less than 20% of the devices listed in this category on ISO, and self-care represents 13% of the total devices listed on ISO as available to enable function in this key area.

It should be remembered that the list of AT provided within the VAEP does not currently aim to provide products in all categories of the ISO. Some of these other categories are partially provided through other funding sources (for example prosthetic limbs, funding sources dealing specifically with sensory loss, workplace accommodations, or school-based AT). This, by extension, points to the complexity for AT users, having to navigate more than one funding system to access all the components of their required AT solution. Moreover, there appears to be little rationale for the omission of many items of value from the VAEP. The data within Figure 15 identifies the extent of VAEP provision against each category of ISO 999, demonstrating that overall the VAEP provides subsidies for fewer than 10% of items listed in most chapters of the ISO.

**Figure 15: ISO 9999 Assistive Product chapters and number of devices, compared with devices available on the VAEP**

NB This does not include items listed in the ISO chapters 05 ‘Assistive products for training in skills’ or 28 ‘Assistive projects for employment and vocational training’ which are entirely excluded from VAEP funding.
The data within Figure 16 identifies the number of AT devices as well as home and vehicle modifications identified by ‘The Equipment Study’ respondents (AT devices currently in use = met need, or AT devices required = unmet need) that were eligible for a VAEP subsidy. In addition, the data presented within Table 26 documents the number of items that were not currently eligible for VAEP subsidy (i.e. devices and items not on the VAEP list of approved items). Overall, 65% of currently used AT devices and home/vehicle modifications within ‘The Equipment Study’ population were eligible for VAEP funding.

Figure 16: Total number of AT devices currently in use or required, according to VAEP eligibility

Participants described a significant level of need which had not been met. Unmet need fell into two categories: firstly, a proportion of the AT devices which participants used or needed but which were currently ineligible for VAEP funding; and secondly, a number of AT users not receiving funding for which they are eligible. In other words, study respondents were not receiving, or not accessing, VAEP funding despite being eligible for this subsidy and despite the items resolving elements of unmet need for AT solutions.

In total, 73% of current unmet AT device needs were on the VAEP ‘Equipment List’. Sixty five per cent of all devices and modifications used by or required by participants were technically eligible for funding under VAEP; the remainder were not. Respondents reported self-funding 386 devices not eligible for VAEP: this represents 30% of all AT devices (in use and required).
Many devices may be described as mainstream or generic items likely to be of use across the wider Victorian population; some are consistent with universal design principles and therefore have a wide accessibility and value across different needs groups. For example, 32% of items currently in use by the participants in ‘The Equipment Study’ were communication devices such as computers and mobile phones with add-on applications or adaptations that enable more customised use. However, these devices were ineligible for VAEP funding. Some items were within the eligible device ‘scope’ of the program but ineligible for other reasons: for example, wheelchairs were frequently identified as an ineligible VAEP item, as VAEP does not fund second or backup wheelchairs for use in different locations. This may account for the level of mobility devices currently in use although they are ineligible for VAEP funding. Mobility devices represent 9% of all used ineligible items.

Table 26 contains data that totals both met and unmet needs in order to show the type of items considered necessary by study respondents (whether currently in use or identified as required) that are VAEP eligible.

### Table 26: Used and required AT Devices identified by participants, according to VAEP eligibility

<table>
<thead>
<tr>
<th>VAEP Category</th>
<th>VAEP Inclusions</th>
<th>VAEP Eligible</th>
<th>VAEP Ineligible</th>
<th>VAEP Exclusions (AT devices identified as required yet unavailable on the Scheme)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mobility Aids</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking aids</td>
<td></td>
<td>136</td>
<td>27</td>
<td>Walking sticks; elbow crutches; pool wheelchair; beach wheelchair; wheelchair accessories; powered bike; shoes for different sized feet</td>
</tr>
<tr>
<td>Wheel-chairs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scooters</td>
<td></td>
<td>33</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Orthoses</td>
<td></td>
<td>31</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Person Aids and Equipment</strong></td>
<td></td>
<td>38</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Powered beds</td>
<td></td>
<td>35</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Bed equipment</td>
<td></td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Continece</td>
<td></td>
<td>18</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Seating: specialised</td>
<td></td>
<td>19</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Portable ramps</td>
<td></td>
<td>11</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Pressure care</td>
<td></td>
<td>31</td>
<td>5</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 26: Used and required AT Devices identified by participants, according to VAEP eligibility
<table>
<thead>
<tr>
<th>Section</th>
<th>VAEP Eligible</th>
<th>VAEP Ineligible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobile commodes</td>
<td>55</td>
<td>4</td>
</tr>
<tr>
<td>Fixed commodes</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Specialised seating</td>
<td>19</td>
<td>4</td>
</tr>
<tr>
<td>Upright seats; desk seating</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Electronic voice aids and communication</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Communication</td>
<td>4</td>
<td>125</td>
</tr>
<tr>
<td>devices</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Mobile phone; computer; software; peripherals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>accessible desk</td>
<td></td>
<td></td>
</tr>
<tr>
<td>communication boards</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TTY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>customised pens and typing splints</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual aids (himark; magnifiers; cane;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>proximity monitor; GPS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>glare resistant sunglasses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environmental control units</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Simple ECU (e.g. doorbell; touchlights;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>remote garage door)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>commercially available intercoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Modifications</td>
<td>263</td>
<td>60</td>
</tr>
<tr>
<td>Ramp to second entrance; remodelled</td>
<td>69</td>
<td>4</td>
</tr>
<tr>
<td>laundry; remodelled kitchen; accessible</td>
<td></td>
<td></td>
</tr>
<tr>
<td>garden (raised beds); wider doors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vehicle Modifications</td>
<td>32</td>
<td>8</td>
</tr>
<tr>
<td>Seating for car (lumbar cushions;</td>
<td>25</td>
<td>8</td>
</tr>
<tr>
<td>pressure cushion); Vehicle suitable for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>wheelchair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excluded categories:</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>recreation, domestic, personal medical,</td>
<td>118</td>
<td>21</td>
</tr>
<tr>
<td>small aids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual aids; clothes dryer/ front loader;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>bath insert; suction mat; adapted cutlery &amp;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>crockery; elastic stockings; dosette &amp;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>medication management; tilt tables;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>tracheostomy equipment; PEG feed equipment;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>pick up sticks; urinals; adapted saddle;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>adapted skis; modified yacht; bowling arm;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>handbike</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTALS</td>
<td>645</td>
<td>158</td>
</tr>
<tr>
<td>52%</td>
<td></td>
<td>386</td>
</tr>
<tr>
<td>13%</td>
<td></td>
<td>60</td>
</tr>
<tr>
<td>30%</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total VAEP Eligible: 803(65%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total VAEP Ineligible: 446</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
This analysis of the range of devices deemed eligible for VAEP funding demonstrates that its narrow parameters constrain the life activities and capabilities of people with disabilities. Although there is a heavy dependence on VAEP to fund needed AT, restrictions in terms of eligible items places a burden on individuals to find alternative funding for other needed items. Respondents provided many narratives of the difficulties of gaining funds for needed AT devices, including often going without necessary items. In addition, the Scheme does not provide soft technologies, and unmet need for professional support was evident. Given the complex interaction between multiple elements of an effective AT solution (multiple devices, environmental changes, and personal care), it is not surprising that AT users may require expert knowledge to assist with the identification of solutions:

Don’t know what’s available that would be helpful!! Lower cupboards, assistance with household and garden maintenance … Knowledge of what cost-effective resources are available to assist. [The impact of these would be that I could] reach my cupboards and access storage space, enjoy my garden … I would be in less pain generally and be able to do more and have a better quality of life as a result. [S61]

Life outcomes are constrained by the substantial restriction of identified equipment eligible for funding, as whole fields of life (for example recreation and leisure) are omitted from approved VAEP funding, with participation narrowly supported in other areas such as mobility and environmental interventions. Underpinning these limitations is a focus upon independence and a narrow range of participation evident in VAEP policy (DHS 2010): this is contrary to both
the named aspirations of people with disabilities and the moral priorities of human rights conventions.

Limitations of VAEP: disincentives

The above issues of lack of affordability due to limited subsidy and limited range of mediators in themselves are disincentives to participate in the Scheme. Data from participants suggests that a further range of disincentives operates to prevent eligible applicants from receiving funding for eligible items from VAEP. Participants’ comments indicated a range of reasons for this, including disincentives of the VAEP system: red tape, long wait times, and inadequate subsidy levels leading to high cost burdens. Some disincentives are bureaucratic hurdles:

[VAEP] said I’d have to go back on the list … so I said no to the electric wheelchair and to blazes with it … Well they [VAEP] try to help but they try to save money … you can’t do both, you are doing one or the other. [S80]

Other disincentives pertain to rationed provision and limited subsidies which, while potentially providing an ‘output’ from the scheme, do not translate into an ‘outcome’ for the individual:

I had no compensation for my falling accident. I had to use my superannuation to fund my kitchen to make it accessible. [VAEP] would only fund little bits of it and the process was so bureaucratic I gave up. [S25]

Analysis of the data also suggests a lack of responsiveness to changing circumstances and needs, and evidences reduced productivity, independence, and life quality as a result. A key concern was changing needs, particularly ageing or dealing with changes in the immediate social environment. Many described a range of changes at all ages of life; this was captured by one person who pointed out that ‘As I get older my needs change’. For others, changing personal contexts led to changed needs:

Now that my partner also has a disability, we are struggling to maintain the house, and we need to pay cleaner and sometimes gardener. [S51]

Many participants described a sense of helplessness because, despite perceiving the need for future changes, clear paths of action did not exist to plan
given uncertainties related to VAEP application and wait times. Changing circumstances often meant increased cost burdens rather than increased government support. In some cases, VAEP guidelines contain restrictions on what may be applied for: once-in-a-lifetime funding is a VAEP program component (e.g. for home modifications). Additionally, many participants described additional financial burdens and participation restrictions caused by limitations to supply and maintenance. Respondents identified the issues of such restrictive program guidelines:

Home modifications are only done once and as mine were done 20 years ago, it needs to be redone but no provision for this. [S17]

I believe that a change over of wheelchairs more frequent then 7 yrs would be better. And an increase of funds to get a better quality wheelchair would be a huge improvement as we all require different things with our chairs so that they are suitable for our needs. [S18]

My wish list – a wheelchair that does not break down all the time. A backup chair with suitable restraints to use when my chair is not working. [S26]

Repairs to tyres and wheels are becoming a costly item in a pensioner’s tight budget – these need to be covered by government [in order to] be assured of having access to a wheelchair for mobility at all times. [S56]

These disincentives appear to function both as barriers to the acquisition of AT by those who need it, and as incentives for people to self-fund items (if they can afford to) when they are in fact eligible for VAEP subsidy.

Concluding comments

Research question 3a asked: How effective is government in delivering equality of outcome through the provision of mediators?. The AT policy case study undertaken in Chapter 7 reveals that, despite high level policy rhetoric which resonates with the life aspirations of people living with disability, a number of program inefficiencies limit the realisation of outcomes.

Insufficient resourcing limits the use of best practice guidelines. Despite published evidence of the potential of high-quality AT devices to minimise
downstream costs and cost offsets, the pragmatic interpretation of program guidelines and severe budget shortfalls mean such options cannot usually be prescribed unless the individual has been demonstrated to experience the secondary complications that the prescription is endeavouring to avoid.

Resourcing is poorly aligned with the reality of life with disability. High costs of disability and low incomes means that even when AT-EI are approved, if the person cannot meet the subsidy shortfall, the device or modification may not be obtained. As the Productivity Commission’s Draft Report into Disability Care and Support notes,

In addition to the costs of supports and aids and appliances, several participants pointed to the additional costs of everyday living they face. Examples include higher electricity costs due to the use of medical equipment or to provide temperature control, and higher water costs for washing clothes (Productivity Commission Feb 2011: 4. 9).

Similarly, in relation to personal support, people living with disability reported being waitlisted for packages of care such as individual support packages (ISPs), despite demonstrating technical eligibility and substantial opportunity for cost offsets, because available packages were fully utilised.

This is significant evidence that the government is not currently meeting its social contract in providing the mediators necessary for people living with impairment to achieve equal outcomes. The current level of provision of AT solutions is not sufficient to enable achievement of stated policy goals. There is an urgent need to enact policy in program guidelines, to question the amount of resources allocated at a government level (Borsay 1986), and to realign the multiple, fragmented schemes and services according to the government’s own principles (Commonwealth of Australia 2011; Australian Public Service 2009).

Chapter 8 now presents a range of potential policy solutions addressing what government needs to do to realise the social contract more fully.
Chapter 8: Policy Solutions

Introduction

This chapter draws together the key ideas and main findings of previous chapters to inform a range of potential policy solutions. This thesis is concerned with the embodied variations in body structure and function with which we all live and which are a feature of human diversity, and the disabling mismatch between an individual’s capabilities, participation goals, and environments. Chapters 1 and 2 identified the critical nature of standpoint in naming and understanding current issues for people living with impairment in obtaining mediators and participating in valued life outcomes. Standpoint analysis of the literature identified several applicable theoretical frameworks from the fields of international human rights, and from international health developments, namely the CRPD (United Nations 2006), and WHO ICF (2001). These frameworks were validated through analyses of ‘The Equipment Study’ data. The CRPD (United Nations 2006) offers a rights-based identity to citizens living with impairment and experiencing disablement, and WHO ICF provides a congruent framework for articulating impairment, life outcomes, and the role of environmental barriers and facilitators. The empirical study also provided evidence of the effectiveness and interrelatedness of the mediators AT, EI and PC, verifying the concept of the AT solution. The conceptual review of impairment and disability in Chapter 4 concluded that society (with a focus on policy as the expression of societal will) has a large role to play in addressing disablement, both through enabling access to effective mediators (the AT solution) and by providing a range of other strategies such as inclusive design and creating inclusive environments. The role of duty-holders within society therefore must be identified in order to address the multiple causes of disablement, and this includes examining the role of policy itself as a disabling factor.

The health economics literature provides the notion of the ‘health sector perspective’, which considers outcomes from across different parts of the health sector, and at different times (Mooney 1992; Mooney and Scotton 1998). A ‘societal perspective’ captures outcomes more broadly again, encompassing impacts across a person’s whole system, and providing a wholistic view of the
effectiveness of mediating solutions. This thesis contends that taking a societal view of the complexity of people’s individual circumstances enables realistic modelling of costs (the resources used) and cost offsets (savings in other areas, including in the future), and can capture more fully the effectiveness of AT solutions.

Chapter 8 integrates understandings of effective mediators, the desired outcomes of individuals living with impairment, and the critique of current government service delivery, in order to determine what governments need to do to deliver equality of outcome more effectively.

**What does government need to do to realise its obligations?**

Government undoubtedly has the key responsibility for enacting society’s contract with citizens who happen to live with impairments (Australian Public Service 2009; NHMRC 2009). The government is charged with the generation and fair distribution of resources (Disability Investment Group 2009; Smith 1812), and is expected to enact the CRPD (United Nations 2006) beyond rhetoric into policy:

> Without a strong strategy, many participants feared that the Convention [CRPD] would fail to change the lives of Australians with disabilities and become just another piece of meaningless rhetoric (National People with Disabilities and Carers Council 2009: 8).

This leads to the need to identify specific social policy and other government interventions that will be effective. A range of data have been presented on the problems with current Victorian service provision and the policy that supports it, demonstrating that ‘the person who should be at the centre of the system is forgotten in specifying the system outcomes’ (Goggin and Newell 2005: 72). By what mechanisms, and to what extent, can equality of outcome in the outcome areas desired by individuals be achieved?. Bickenbach provides a starting point when he writes,

> We must remove, modify or otherwise alter all those extrinsic sources of human inequality that are within the control of our social and political institutions. Those extrinsic factors that are realistically out of our control but
produce individual differences may require a compensatory state response, in the form of additional social resources to compensate the individual for limits on his or her capacity to participate in basic human and social activities. (2009b: 108)

A range of policy solutions emerging from these ideas are presented below.

**Policy solution 1: universalising policy**

Disability is more than impairment, is constructed by a range of factors, and is subject to varied societal responses. It is proposed that an underpinning premise of all policy must be the understanding that, within the universal experience of human diversity, each person's impairment is a unique element of their identity, and will be differently experienced. The capabilities approach, which addresses both impairment effects (capability gaps) and societal barriers (opportunities) offers a way forward in terms of policy construction which is individualised and universal (non-stigmatising). The solution is therefore universalised policy and adequate provision of resources, based upon an evaluation of the capability gap an individual experiences, as argued below.

The range of factors at community and societal levels which impact upon the experience of disability mean that the circumstances of people living with impairment have largely been rendered invisible by the limited expectations allotted them, governed by the social, legal and economic policies in place at any given time (Rioux et al. 2011). Substantial literature documents the consistent marginalisation on all human rights vectors of people living with impairment, and the (largely unspoken) expectations that individuals living with impairment may not expect to be afforded the 'adequate' or 'usual' life afforded to others in that society (Cummins et al. 1997; Oliver 1990). ‘The Equipment Study’ demonstrates that identity is rich and varied among those living with impairment effects: participants with chronic illness, acquired impairment, and congenital issues described themselves variously, but named their common experience as related to the structural barriers they faced. Participants provided evidence of broad human aspirations which resonate with current human rights principles. Scotch and Schriner contend that this understanding of human diversity which is inclusive of disability needs to be acknowledged in social structures. They write:
Building on the perspective of disability as human variation, disability can be viewed as introducing complexity and disequilibrium into individual lives, family relationships, and the various social systems in which people live, learn, play, and work … by focusing attention on how systems respond to the variation introduced by disability, a new model of disability might help us address issues of how to best design institutional responses to such variation. (1997: 156)

Relating these observations to the universalising versus minority group argument of Chapter 4, it can be said that AT policy is currently premised around ‘legitimate category membership’ (De Poy and Gilson 2009: 37) as an expression of the minority group model. Disability policy historically addresses defined populations in a segregated manner, with multiple criteria differentiating between individuals despite their common position of living with impairment and requiring AT solutions to participate in life areas (Scotch and Schriner 1997). As proposed by DePoy and Gilson,

Rethinking disability policy (and other population-categorical policies) on a foundation of celebrating diversity can move us towards policy that creates universal rights, resources and privileges on the basis of human description and need, rather than on tacit and nomothetic assumptions about individual embodied worth. Our charge is to analyse, rethink and implement policies that shape our world as one that is welcoming of all. (2009: 46-47)

The ‘legitimate category model’ is demonstrably inequitable as, rather than providing the mediators required to achieve equality of outcome, categorisation becomes the key factor in resource access and allocation (NAERA 2011; Summers 2011). Disability continues to be labelled as other, and competition for resources is enforced between disadvantaged groups (Bickenbach 2009a). Governments, and therefore policies, must deal with the tension between universalising and minority group approaches. The comments from people living with impairment presented throughout this study articulate an overarching desire for inclusion and citizenship. However, there are risks when policy is de-differentiated.

Recent critiques of the impact of de-differentiated human services policy upon the population of individuals with intellectually disabilities in Victoria indicate that
universalising policy approaches fail to address the particular nuances of diverse populations (Bigby and Fyffe 2010). Relinquishing a ‘special’ but stigmatising identity may not be ‘worth it’ if one’s individualised and specific needs are no longer delineated in population or resourcing contexts (Bigby and Clement 2009). From an ontological perspective, however, ‘special’ law and ‘special’ policy is of itself exclusionary and marginalising: it ‘others’ recipients and pits them against other ‘special’ groups. Bickenbach et al. argue that social policy in a democratic setting must be applicable to all people, not merely to those who fall within an artificially created, narrow range of normality … if a group of people are forced to label themselves … in order to qualify for resources that will meet their needs, they are immediately in competition with others who are similarly set aside as ‘special interests’. (1999: 1183).

Reconceptualisations of disability appear to be moving towards a more nuanced view of the intersection of impairment effects and environments, and towards universal understandings of human diversity. Advocates suggest a need for policy that respects difference and widens the range of the ‘normal’ (Grewal et al. 2002; Zola 2005). Moves to universalise definitions of impairment and disability offer the opportunity to consider whether any policy is one we would like applied to us, and leads us to understand that, potentially, we are all disabled (Megret 2008). Recent reconceptualisations of the disability/aging divide, for example, provide a possible blueprint for replacing ‘disability’ with ‘human variation’ (Bickenbach et al. 2012: 2). Such a reconceptualisation locates the notion of impairment effects universally (a feature of the human condition, rendering us equal), yet allows differential provision without the stigma of minority group positioning. The lens of capabilities and capability gaps is a way to enable differentiation within a universal approach. This notion requires assessment of the capability gap of each individual and the response required to mediate that so as to achieve equal outcomes across human diversity. Such a policy, based upon an individual’s capability gaps, must provide that which makes a difference in attaining outcomes against human rights benchmarks.

In terms of identifying these benchmarks, there is strong concordance between valued elements within the contemporary high-level policy frameworks above
and the life domains and outcome areas selected for this study, although less so at the programme level where the aims are more limited. This is encouraging, and indicates that, compared with the public policies of the mid-20th century, government and the disability academy are approaching a point of convergence and agreement on aspirations to do with citizenship and a good life in the community, despite or across diversity.

Policy solution 2: aligning policy goals with valued outcomes

It is proposed that an overarching outcomes framework, consonant with the principles expressed by people living with disability (AEAA 2011; De Jonge, Layton and Vickery 2009) and with the fact that human aspirations are common across the continuum of human diversity, is enshrined within policy at all levels. This must include a broad view of human participation, as proffered by the WHO ICF. The CRPD (United Nations 2006) is suggested as a companion framework, as it articulates a contemporary vision of the scope of life outcomes expected for and valued by people with disabilities, and provides a benchmark for achievement of participation goals.

The CRPD principles have strong correlations with stated disability policy at state level (Victorian State Disability Plan 2002–2012; State Government of Victoria 2002), Commonwealth level (National Disability Strategy 2010–2020; Commonwealth of Australia 2011); and international level (United Nations 2006). There is, however, a demonstrable difference between policy (principles to guide decisions) and procedures or protocols which are intended to implement policy at a programme level, such as VAEP. At this operational level policy intent falls down in delivering outcomes. Therefore, it is suggested that the critical next step involves embedding WHO ICF outcome areas within program guidelines, along with sufficient resourcing to support their achievement.

Policy solution 3: Flexible service delivery: the AT solution

Policy solution 3 has two elements: a broad and adaptable definition of mediators such as is encompassed by the AT solution, and individualised funding models enabling this breadth and adaptability to be realised in service delivery.
'The Equipment Study' evidence demonstrates that AT solutions are critical to achieving outcomes identified in government policy frameworks, and that a lack of provision leads to a failure to achieve these policy mandates. This evidence also suggests there is a much wider scope of benefit from the provision of AT than previously documented in government AT policy. Flexibility, control, choice and the capacity for tailored solutions have been identified by AT users as priorities for AT policy, as outlined previously. Two suggestions proffered are a broader definitional matrix for mediators; and the introduction of individualised funding approaches for AT solutions.

As AT solutions require combinations of interdependent elements, the effectiveness of any AT provision is compromised whenever one or more elements of the integrated solution are denied. The attainment of AT solutions that are customised for 'best fit' for individual needs is clearly at risk in a system governed by a rigid and narrow delineation of items eligible for government subsidy, undermining the effectiveness of the program by excluding needed components of AT solutions. Government funding of AT would be more effective if it adopted the definition of AT solutions along with procedures to support a co-coordinated response to funding and provision.

Historical typologies of AT as described in Chapter 5, particularly the divide between 'specialist' and 'mainstream' devices, must be addressed. The dynamic nature of AT developments reinforces the need for government to construct more flexible understandings of AT. AT identified as used/ required but ineligible for VAEP subsidy includes both highly customised items as well as generic devices used in a range of applications by the broader public. Generic devices are likely to be lower in cost due to the higher volume of their sales, as they have diverse markets. Universal design principles mean more generic devices have wider application for special needs groups without additional modifications. Government policy would ideally foster this kind of industry development via universal and inclusive design principles, as it is likely to be more sustainable and meet a wider range of needs than a focus on highly specialised items. The presence of the dichotomous, overly medical and 'special needs' thinking regarding disability and impairment explored earlier in the thesis will clearly limit the potential of policy to adapt to universalising perspectives, if not overtly addressed. ISO 9999, capturing as it does mainstream and specialist mediators,
and verified as an exhaustive taxonomy against AT devices utilised by ‘The Equipment Study’ participants, is suggested as a suitable list for AT funding schemes like the VAEP. The use of this international standard, which undergoes regular revision in line with WHO ICF, is a far better benchmark than the current lists in place (like that used by VAEP).

In individualised funding models, contemporary service delivery approaches suggest people should receive individualised support, delivered in their environment (AIPC 2008; Blyth and Gardner 2007; DHS 2007a; Meyer et al. 2007; Productivity Commission 2011; Ratzka 2002). It is clear from the range of disparate schemes which ‘The Equipment Study’ participants navigated that no single scheme addresses the range of known mediators of impairment; therefore, attention must be paid at a back-end policy level to how to articulate personal care and inclusive community environments, the other two components of AT solutions, into tailored and seamless packages for individuals living with impairment.

Individualised funding approaches resonate with the desire for choice and control over supports as identified in Chapter 4’s review of consumer literature and disability theory (National People with Disabilities and Carers Council 2009; Shakespeare 2006). Consumer advocates ‘agree that people receiving assistance are best able to evaluate, manage and direct the providers of the services they need, particularly as they have the most detailed knowledge of their disability’ (Meyer et al. 2007: 599). In terms of AT and EI, evidence gaps remain regarding the ways in which soft technology is purchased or otherwise integrated into direct funding arrangements, where a health professional may no longer be gate-keeper of the AT device purchase or the construction of the AT solution. However, several decades of trialling consumer-directed personal care services have produced a valuable body of knowledge which can be applied to provision of other mediators such as AT. This evidence suggests that, in circumstances where people self-manage funds, AT has been prioritised and purchased, although sometimes this has been at the expense of other elements of AT solutions, for example trading care hours to purchase AT (Ottmann et al. 2009; Victorian Auditor-General’s Office 2011). Unintentionally, then, it appears that policy regarding self-managed, individual, consumer-directed expenditure
leads to the potential to buy ‘AT solutions’ valued by the individual, if funds are sufficient.

Policy solution 4: increasing the number and extending the roles of duty holders

This thesis argues that the concept of an AT solution usefully describes the necessary mix of mediators, including AT, EI and PC, required to bridge capability gaps to achieve equal life outcomes for people with disability. ‘The Equipment Study’ data have shown that the responsibility for the provision of these mediators, especially EI, is often unclear or even non-existent. In human rights language, those responsible are ‘duty holders’ and need clearer identification in policy.

This policy solution suggests that there is a need to identify duty holders to take action to support provision of AT solutions; that the notion of duty holders needs to be broadened beyond government; and that the role of government can be extended beyond that of funding provider, to include responsibility for ensuring other duty holders act. These points are expanded below.

Recognising that ‘rights of persons with disabilities are in practice mediated by a host of other actors, either directly or indirectly’ (Megret 2008: 267) acknowledges the unique vulnerability which people with disabilities experience in relation to their treatment from a range of others or ‘duty holders’. The thesis has demonstrated that access to AT solutions as mediators of impairment is indeed influenced by a range of players, who may or may not perceive themselves to be duty holders. The work of feminist scholars has been said to influence the broadening of the duty-holder horizon within contemporary human rights documentation, well beyond the traditional notion of ‘state parties’ to include ‘individuals, society as such, communities, and the international system’ (Megret 2008: 267). Lord and Brown suggest duty holders include

the State, employers, education providers, health care providers, testing and qualification bodies, providers of goods and services and private clubs. The duty requires these actors to reasonably adjust policies, practices and premises that impede the inclusion and participation of persons with disabilities. (2011: 279)
It has been established that governments have obligations to act to address sources of inequality, and a critical point for engendering change is through the identification of duty holders. Failing to do so exposes rights as vulnerable to ongoing violation, because ‘When demand for meeting needs has no “object”, nobody has a clear-cut duty to meet needs’ (Jonsson 2003: 20). Redefining and extending the role of duty holders is therefore a key strategy for change. It is proposed that government, as the main duty holder, must enact responsibility by being accountable to and engaging with stakeholders.

To realise governments’ obligations, the role of duty holders must be examined and extended. AT is a named human right and, as seen in the previous chapter, underpins the realisation of a wide range of life outcomes. The discussion of duty holders will examine the range of players and consider the obligations or accommodations they might be expected to deliver.

**Role for AT users**

There are various potential extensions to the role of the individual living with impairment who requires AT solutions. AT users should be the most important stakeholders of all, yet they are generally afforded such limited roles in controlling or directing their AT solutions that ‘passive recipient’ (Goggin and Newell 2005: 32) appears to be an accurate descriptor. Analyses of ‘The Equipment Study’ data identify a role hitherto invisible in the literature: that of navigating funding and support systems to pull together the elements of an AT solution. Some participants demonstrated substantial expertise in locating and connecting disparate elements of the AT system, but their roles remained limited to providing this information to the AT practitioner, the person required to complete assessment forms and make actual funding applications. This study found that persons with disability who are AT users remain marginalised and powerless within the system designed to support them, and this leads to a dissonance between goals across system levels (de Jonge et al. 2009b; Masso et al. 2008).

It is suggested therefore that AT policy-makers consider development of roles for AT users. A substantial body of consumer literature supports the utilisation of consumer expertise (Löfgren et al. 2011; Silverstein 2010). User involvement in planning and policy decision-making has become the policy of choice for
governments as well as health and social care service providers, and is based upon a growing body of research evidence regarding the impact of active engagement of users of the program, and on the impact of the policy design process upon better policy outcomes (Ottmann and Laragy 2010).

‘Disability policy change agent’ roles (Silverstein 2010: 173) identified by the disability community in Australia include monitoring shortfalls and engaging in systemic advocacy activities. For example, shadow reports produced by disabled people’s organisations regarding the performance of governments, for submission to the United Nations, represent a course of action that bridges the gap between high-level rhetoric, program policy, and the actual delivery of mediators (Lord et al. 2010; Megret 2008). This has occurred in Australia, and the Equipping Inclusion Studies contributed to the data set presented in such activities (DLA Piper 2012).

In terms of AT, extended roles may include a recognition for peer mentors, some form of credentialing for ‘user experts’, and possibly a competency-based framework to enable AT users to self-assess for elements of their AT solutions in a risk-based individualised way; this might provide a valid basis for funding provision by government (ARATA 2012).

The role of AT users should also extend into the design and testing of AT products, a strategy that will address a long history of exclusion from research, design and development (Dong 2007; Dong et al. 2006). Such inclusion strategies have the potential to ameliorate, in part, the abandonment and non-use of AT devices, and to normalise and universalise ‘disability’ technologies (Hansson 2007; Pape et al. 2002; Scherer et al. 2005; Wessels et al. 2003).

Role of AT practitioners

There is evidence that AT practitioners see AT policy as a major impediment to AT access (Barbara and Curtin 2008; Curtin 2008). The main role of AT practitioners (occupational therapists, physiotherapists, orthotists and prosthetists, speech pathologists, rehabilitation engineers and others) is to prescribe and tailor AT provision to AT users. Despite this pivotal role, these practitioners appear to have little influence upon AT policy (Pollard et al. 2008; Whiteford and Wright-St Claire 2005). As duty-holders, AT practitioners have
conflicting roles. While the literature outlines the ingredients of good practice as providing assessment, set-up, trial, training, support, evaluation and review within the context of person-centred evaluation tailored to the individual, the task, and the environment (Bain and Leger 1997; Cook and Hussey 2008; Fuhrer et al. 2003; Scherer 1998), there are pragmatic practice constraints which limit the effectiveness of the AT provision process such as wait lists, lack of funds, and lack of clinical time (Chapparo and Ranka 2004; Waldron and Layton 2008). The policy environment experienced by AT practitioners is more an immovable factor to be managed than a dynamic structure to be influenced (Boyt Schell and Schell 2008; Chapparo and Ranka 2004; Schell 1998; Unsworth 2004). Critical reflection upon the influence of policy and politics upon practice is, however, becoming more prevalent, as are calls for increased systemic advocacy to address the policy and political elements needed to enact change on behalf of consumers (Barbara and Curtin 2008; Kronenberg et al. 2005). It is these activities that AT practitioners as duty holders need to take up.

*Role for duty holders responsible for inclusive community environs*

A broad approach must be taken to identify duty holders in respect to creating enabling environments. Many study participants described the intractability of community attitude or market support, yet the CRPD (United Nations 2006) addresses duty holders as persons and organisations beyond the public sector including private enterprises, and supports action on a number of practical fronts.

‘The Equipment Study’ demonstrates that the barriers faced by people living with impairment are frequently systematic and structural. Substantial data relates to the inclusive community environs, where there appears to be no co-ordinated plan to measure, or systematically address, barriers within the environment ‘beyond the garden gate’, which is currently the remit of the limited home modification programmes available. Many participants provided evidence demonstrating that ‘inaccessible and poorly designed built environments are an infringement of disabled people’s civil liberties’ (Imrie and Hall 2001: 1). As is described in Chapter 2, the environment is actually a series of overlapping and interlinking physical, cultural and social spaces, and includes tangible and non-tangible elements (WHO 2001; Steinfeld 2010). From the standpoint of the person with a disability, all parts of a path of travel within a community must link
if users are to actually get somewhere, but users’ functional demands are rarely heard and are viewed as less important than other, often financial, criteria in constructing built environments (Imrie and Hall 2001).

The impact of disability can be lessened if environments are built, or adapted, to enable participation:

Building codes, principles of barrier-free design, adapted curricula, targeted policy and funding commitments are being shown in policy research to be useful tools to this end. Research shows that these tools enable modifications and supports to be made in home, school, work and leisure environments which increase the participation of people with disabilities in society and limit the disadvantages they otherwise would face. (Rioux 1997: 105)

It is worth noting that retrofitted solutions may not be necessary if accessible design is a feature of new buildings. Research into the limited uptake of access standards and inclusive housing shows that property developers, architects and builders are reluctant to engage with accessibility solutions which are linked to disability (Gray et al. 2003). Hitch et al. argue that ‘disability discourse’ for universal design is a barrier to its more widespread implementation. Good design benefits everyone and should not be seen merely for the paternalistic benefit of one section of the community. Such an approach not only continues to marginalise people with a range of health conditions and impairments, but turns its back on the opportunity for a broad range of people, regardless of ability, to benefit from good design. (Hitch et al. 2011: 7)

Analyses of data pertaining to barriers demonstrate the presence of multiple stakeholders, including local government authorities, state government, departments of infrastructure and transport, and individual businesses. Addressing environmental barriers typically occurs in a fragmented or segregated manner: for example, local council action on footpaths ceases at the door of retail establishments and at the roadside, as other duty holders (private businesses and the roads authority) are under different jurisdictions and may be governed by different legal requirements.
Regulation is a potential avenue of change, but it has limited effectiveness, with some literature suggesting that more multilayered strategies, rather than increased directives and regulations, are needed (Ward 2011). Particularly concerning is the observation that regulation positions inclusion as a compliance problem, which creates extra barriers in convincing stakeholders to make needed changes (Forrester and Davis 2011). International moves to work towards a more universally accessible housing stock are being replicated in Australia in order to decrease the need for major, individually initiated interventions. However, builders and property developers have challenged Universal Housing initiatives intended to mandate ten adaptable features in a percentage of new housing in Victoria (Nissim 2008), querying cost, saleability and necessity. In creating rules regarding accessibility, disability may in fact become problematised still further, which will work against attitude changes in key stakeholders such as architects (Hitch et al. 2011). Further, Megret points out that tackling barriers through legal action may result in ‘isolated legal victories [which] will provide little correction to what are otherwise entrenched manifestations of societal exclusion’ (Megret 2008: 273).

What is required are approaches which turn the emphasis from individual to collective responsibility, and focus the lens upon the cost of non-social (Fouarge 2003) and non-inclusive or universally designed environments (Iwarsson and Stahl 2003; Nissim 2008; Schneider et al. 2003). Recent work outlines a ‘reversed’ position of dutyholders with respect to access and inclusive communities, most recently termed the ‘economics of inclusiveness’, where costs are calculated over all community members (parents with prams, elders with shopping trolleys and so on) who may benefit from interventions such as kerb cuts and accessible transport (Schraner and Bolzan 2009; Schraner and De Jonge 2010). Such a shift would mean, for example, that architects conceive access not as a constraint upon design, but as a ‘major perceptual orientation to humanity’ (Imrie and Hall 2001: 112).

The extended role of duty holders in terms of inclusive environments, then, is to co-ordinate action on environmental barriers at many levels, focusing on the standpoint of the person with disability in the first instance and addressing the multiple tangible and intangible aspects of environment which influence their
outcomes. Government is the first point of responsibility to co-ordinate and require action from a much wider pool of duty holders for AT solutions.

**Policy solution 5: providing entitlement and equity**

Data and analyses presented thus far demonstrate that people living with disability are indeed ‘discriminated against as a result of the lack of vigorous policies to ensure that their rights are guaranteed, be it through effective application of the law or policies that fill the gaps left by the law’ (Megret 2008: 272). Here Megret foreshadows a role for law and for ‘vigorous’ action on the part of government. It is proposed that government must act to address documented evidence of under-resourcing which leads to unmet needs and unrealised outcomes for AT users (Coalition for Disability Rights 2006; KPMG 2006). Three suggested mechanisms are a legislated right to support, improved priority-setting measures, and equity-based distribution of resources, as outlined below.

Chapter 4 discussed the case for government to intervene, via legislation, in the provision of merit goods. As in the UK where ‘many disabled people experience social and economic deprivation the consequences of which are seriously under-estimated and understood’ (Grewal et al. 2002: 10), ‘The Equipment Study’ cohort demonstrated evidence of the significant disadvantages experienced by Victorians who require AT solutions in order to live their lives, yet struggle to afford them. The participants in the study were noted to have lower rates of employment and lower incomes than Australians with disabilities generally; relative poverty and deprivation are common across disability groups. This evidence suggests there is a need for government intervention for AT solutions, to address disadvantage manifesting as relative poverty (Senate Community Affairs Reference Committee 2004), and experienced as participation poverty and social exclusion (Engels et al. 2009; Saunders et al. 2007). Recent scrutiny by the Productivity Commission acknowledges that, despite limited resources, resourcing change needs to occur:

> societies have scarce resources, which mean that there must be tradeoffs between what can ideally, and what can actually, be achieved for any person … however, it is widely accepted in Australia that governments and society
must increase resourcing for disability and that they should address discrimination where it arises. (Productivity Commission 2011: pp98-99)

Several international examples demonstrate policy approaches to manage the distribution of finite resources to meet multiple, competing needs for merit goods such as health care (Carter et al. 2008). The Netherlands, Oregon and Israel specify ‘core services’; Norway and Sweden identify broad principles within legislation enshrining the right to support for individuals with disabilities (Ratzka 2003; Waldron 2006), and New Zealand and the UK utilise evidence-based guidelines in rationing access to healthcare (Carter et al. 2008). The impact of these varying approaches is profound: the individual living with a disability but without health insurance in the USA is without essential resources (Field and Jette 2007; Hoffman et al. 2010; Pope and Tarlou 1991; Russell 1998). This contrasts with individuals in Denmark who, thanks to principles of solidarity and compensation, have their needs financed through public sector taxation, and where a ‘sector responsibility’ principle renders each ministry of government responsible for ensuring their services are accessible to all (Waldron 2006).

A legislated right to support is firstly proposed as a strategy to address resourcing at the highest level. Similar to other merit goods such as pharmaceuticals, in an entitlement approach identified need renders the individual eligible for provision. This differs substantially from the current resourcing situation with VAEP where recipients must wait for provision because of budget shortfalls.

A second approach concerns improved priority setting on the part of government. In lieu of the historically governed budget allocations to AT funding schemes, it is suggested policy must move to provide differential support which is sensitive to conversion handicaps and to markers of vertical inequity, and which targets AT solutions towards achieving equality of outcome.

Standard economic program evaluations are moving to adopt priority setting approaches (Carter et al. 2008; Schwartz et al. 1993). For economic methods to work in the real world, genuine consultation with the community or society is good economic practice, and this includes consideration of health values and testing against social justice and ethical standards, as well as considering issues important to policy-makers such as equity, acceptability, and feasibility.
(Carter et al. 2008: 604). Priority setting aligns resource allocation with societal intent in a transparent and ethical manner (Carter et al. 2008: 604). It entails structured and iterative consultations with the wider community, particularly consumers of health and disability services. It is proposed that priority setting approaches should be integrated into policy development. As a starting point, policy could consider the several sets of principles described by AT users and presented above (AEAA 2011; De Jonge, Layton and Vickery 2009).

A final element of achieving equity is that of equity-based distribution of resources. Evidence was presented in Chapter 4 regarding the 2- to 3-fold equity weighting necessary to achieve parity with fellow citizens for participants of ‘The Equipment Study (Colgan et al. 2010): that is, the expenditure benchmark of $50,000 for a quality adjusted life year needs to be doubled or tripled in order to compare the outcome of the intervention against the outcome for an individual who does not live with disability. Based upon these findings, an equity argument is proposed as a tool to inform budget allocations for AT users as an identified group with specific capability gaps (aka ‘special needs’ group) more fairly. This is required for several reasons. Firstly, from a demographic point of view, the study population experiences significantly low incomes, high levels of unemployment, a high reliance on government support, low health-related quality of life, and high levels of participation poverty. These identify the group as an ‘equity’ group with significant levels of disadvantage. Secondly, the phenomenon of double jeopardy means the standard measure of QALY works against individuals with impairment because, regardless of the health intervention provided, their disability will continue to prevent them from scoring highly on generic health-related quality of life instruments (Drummond et al. 1997). Such lower quality of life outcomes result in poorer cost-effectiveness compared with other client groups who are able to achieve higher quality of life outcomes. This is likely to bias government resource allocation decisions against them, as outcomes appear to be comparatively poor returns on investment. Imposing an equity weighting is therefore intended to counter both socioeconomic disadvantage and methodological bias.

This solution ensures policy recognises the requirement for differential and substantially higher expenditure for this population in order to overcome capability gaps and achieve equal outcomes.
Concluding comments

There is an established social contract between individuals living with disability and society. Dissonance is, however, evident between the overarching principles enshrining the ingredients of a good life for Australians, the scope of the actual programs intended to deliver these ingredients, and the resourcing available to realise the programs' intents. A range of limitations including marginalising definitions of disability, inadequate resourcing, poor priority setting, and narrow program boundaries render the government inefficient in its role, in relation to AT solutions.

Mediators of impairment effects and the disabling effects of environments, such as AT solutions, are tools for achieving equity. By addressing the gap between individuals’ capabilities, their environments, and the tasks in which they engage, tailored AT solutions have been demonstrated to ‘level the playing field’, attested to by a range of literature and by ‘The Equipment Study’ data.

In terms of what the government needs to do to realise its obligations, the range of policy solutions which have been proposed are underpinned by a human rights discourse of individual as rights bearers and society as duty holder.

Contemporary human rights-based conceptualisations of human life and the outcomes humans can aspire to affirm both the shared humanity of individuals living with impairment and their rights to outcomes beyond the bounded medical and rehabilitative outcomes ascribed for disability (Megret 2008). Positioning individuals living with impairment as rights bearers in this way also aligns with contemporary perspectives of disability in several key ways. Firstly the seeming tension between dependence and independence and the simultaneous need for autonomy and inclusion (Shakespeare 2006) is theoretically reconciled by the philosophies of the interdependence of humanity (Arneil 2009) as expressed in the CRPD (United Nations 2006). Secondly, approaches that focus upon human rights have the potential to surmount disability labels altogether, in that they refute the current casting of people with disabilities as ‘passive recipients of societies’ munificence, while being exorbitant consumers of its scarce resources’ (Goggin and Newell 2005: 32). Moving from benevolence and ‘paternalistic concepts of charity’ (Taket 2012: 1) towards rights approaches infers the bearer of human rights has a right to support and is not regarded as a
cost to society. Policy then should actively reconceptualise the notion of
disability away from deficit notions and towards capabilities, and utilise a range
of strategies to embed relevant mediators, outcomes, and mechanisms of
resource allocation.
Chapter 9: Conclusion

This thesis topic emerged from the experience of practitioners and people with disabilities in Victoria, Australia. It asked how individuals living with impairment might achieve equal outcomes, and used a combination of literature reviews, a mixed methods empirical study with multiple data analysis methods, and a policy case study, to answer the research question and sub-questions:

1. How are impairment and disability understood?
   1a. In what ways is disability different from the absence of disability
   1b. Does the presence of impairment or disability impact upon people’s life aspirations?
   1c. What is the role of impairment effects and environmental barriers in creating disablement?

2. How do mediators bring about outcomes?
   2a. Which strategies mediate impairment effects and disabling environmental barriers, and what relationship do they have to each other?
   2b. What is the effectiveness of identified mediators?

3. What is the social contract between society and its citizens with impairments?
   3a. How effective is government in delivering equality of outcome through the provision of mediators?
   3b. What does government need to do to realise its obligations?

Research Approach

A key concern of the thesis is epistemological justice (O’Donovan 2011), expressed as respect for, and the seeking of, lived experience and knowledge of those living with impairments. The voices of those living with impairment have been muted, partially by the disabling structures about which they speak (Hunt 1966; Swain et al. 2004). When sought out, the standpoint of people living with impairment is notably different to mainstream discourses on a number of fronts,
as ‘disabled people do affirm disabled lifestyles and provide a counter-narrative to that of non-disabled people’ (McCormack and Collins 2012: 158).

The voices of individuals with disabilities are largely absent in published literature related to AT and the construction of outcome measures for people with disability. Individuals living with impairment have limited choice and control within policy and service delivery in this arena. Methodologies were therefore sought which enabled research knowledge to be partly co-produced with people with disabilities, and which privileged disability perspectives within the research itself. The potentials of ‘lay’ knowledge are actively discussed within the health and medical literature (Hill 2011; Prior 2003). Such texts clearly identify consumer input, and indeed consumer leadership at all levels of research, as beneficial to the production of research. Recent moves within the rehabilitation literature call for wider engagement of stakeholders (Silverstein 2010); for multidisciplinary perspectives to advance research, development, and outcomes measurement (Mendelsohn et al. 2008), wider consideration of valued outcome domains (Rist et al. 2008), and further research into lived experience from the perspective of individuals with disability (Andreson et al. 2000; Brown et al. 2004; Mallinson and Hammel 2010). Writings within the disability academy (Barnes 2001; Lutz and Bowers 2005) and the field of human rights (Bickenbach et al. 1999; Megret 2008; Rioux et al. 2011) also acknowledge that the centrality of lived experience must be addressed in considering steps to ensure equity for people living with disability.

For these reasons, principles of inclusive research (a combination of participatory and emancipatory approaches) were used in the empirical study (‘The Equipment Study’) from which data for analyses were drawn. Inclusive principles include a role for people living with disability in controlling research questions and method, involvement in the research process, opportunities for reflection and knowledge-sharing, and a commitment to ensure that the products of research empower and do not alienate (see Figure 17).
Figure 17 Enacting Inclusive Research Principles

Co-production
‘a partnership between citizens and public services to achieve a valued outcome.’

Consent
The right people asking the right questions and getting the right answers.

Ownership
Lynne addresses PM via tactile communication

Inclusive & participant
Heather advises PM via tactile communication

Co-presenting
Heather and colleagues addressing Treasury

Materials that are accessible

Re-defining what research is

Research that transfers to real life

Policy-focused research

A range of types of activities

Mapping ‘The Equipment Study’
inclusive research experiences to
Disability Inclusive Research Principles (DIRC: 2012)
It is felt that this thesis achieves epistemological justice to some degree, through the engagement of a stakeholder reference group at key steps in the research conceptualisation, design, analysis and dissemination, and the careful choice of research methods. A challenge for the thesis method was to ensure the truth claims of the chosen methodology were understood, and of relevance, to the breadth of stakeholder audience. This thesis attempts to elicit data that may be used for mainstream research purposes (understandable and valued in policy and economic terms), and that also resonates with the perspectives of individuals living with impairment. The mix of methods selected attempts to both provide epistemic justice for people with disabilities and meet the data needs of economists and policy-makers. Broadly speaking, trade-offs were found across the various methods used. These could be conceptualised as points along a continuum with qualitative, difficult-to-generalise individualised experiences at one end and quantitative, categorical data with standardised scales, limited sensitivity and limited capacity to capture valued outcomes at the other. These general observations support the use of mixed methods as a way of capturing multiple truth horizons and ensuring that the need for both data tractability and resonant findings are met, at least in part.

The other major theoretical orientation for this thesis was drawn from standpoint theory (Harding 2004), as a key approach to privilege people living with impairment and their experience, and to bracket myself as a researcher without disability. Standpoint theory provides a methodology that validates and privileges consumer views by ‘starting off thought’ from the perspective of the individual, and provides a critical lens through which to view the literature, the policy, and the means of research production which underpins all evidence.

As a PhD student, researcher, occupational therapist, and person without overt impairment, researching with and on behalf of people with impairment, I hold certain positions in relation to the research which provide a particular vantage point and yet are also likely to obscure knowledge of the lived experience of disability. From an epistemological point of view, this lack of neutrality can be regarded as bias, or as a valid and informative standpoint. Within the disability academy, researchers are called upon to manage the problem of objectivity by making their ontological and epistemological positions clear (Barnes 2001). The following strategies were felt to be effective for this thesis: the process of
reflexive subjectivity (Lather 1986; Owens 2007) using reflective journal keeping and regular supervision; triangulating methods, data sources and theories (Lather 1986); and considering the epistemological positioning and resulting truth claims of a wide range of others, including the health and medical establishment, the disability academy, health economics, policy, and human rights literature.

Overall it is felt that these orientations, and the methods employed to conduct this thesis, were successful in addressing issues of role and power in relation to knowledge produced, and meeting the aims of epistemological justice. The ongoing use of findings from *The Equipping Inclusion Studies* (Layton et al. 2010) by a range of people with disabilities and other stakeholders to evidence their calls for improved AT provision can be seen to be a validation of the project in terms of practical outcomes (Barnes 2001) and catalytic validity (Lather 1993).

**Research question 1: How are impairment and disability understood?**

In asking about equal outcomes with fellow citizens despite the presence of impairment, it is important to understand what impairment and disability actually mean. A conceptual review of impairment and disability found that discourses of disability and impairment differ widely through time and across such groups as authors with disability, the rehabilitation literature, political philosophy, and economics. The history of disability and its themes of disease, charity and oppression are critically important because different approaches to disability – what it is, what ‘causes’ or contributes to it, views about personhood, citizenship and life aspirations of people living with disability – inform and predict stakeholder standpoints. These dominant narratives are found to have a potent negative effect on how disability is viewed societally, and may explain in part why disability has been so poorly explored, until very recently, within the fields of economics and justice in Western society.

Moving beyond the binary discourses of medical versus social models of disability, the literature review demonstrates substantial momentum towards more nuanced views which acknowledge impairment as a reality but see disability as an interaction between someone with an impairment and the social,
political, cultural, and physical environment (Shakespeare 2006, 2009): that is, disability comprises both essentialist and socially constructed elements (Nagi 1991; Sanford 2012). These essentialist elements are also known as impairment effects (Thomas and Corker 2002) or internal capabilities (Nussbaum 2011), and are congruent with theories of human variation (Patston 2007) and universality (Bickenbach 2009a).

Research sub-question 1a asks in what ways disability is different from the absence of disability. In other words, are people the same, or different, if they happen to have disabilities? The thesis concludes that living with impairment does not alter one’s humanity or occupational nature, and, broadly speaking, does not change the life participations valued by the society of which that person is a part. As with all humans, people with impairment are somewhere on a continuum of independence/ interdependence with others. Therefore, many aspects of life for people with disability are just part of the universal human experience.

Yet, in line with critical realist perspectives (Shakespeare 2006, 2008), the effects of impairment do indeed exist and form one part of a person’s identity and being. Impairment effects may bring about satisfying experiences of human diversity or ‘predicaments’ that need to be managed, or both (Shakespeare 2009). Life with impairment also potentially brings a thinner margin of health, increased costs of disability, and a vulnerability to environmental barriers. Substantial evidence from the literature (Goggin and Newell 2005; National People with Disabilities and Carers Council 2009) and from ‘The Equipment Study’ cohort concerning participation poverty, unmet and undermet need, and constrained aspirations, demonstrates that these factors present an experience of disablement above and beyond that experienced by people without impairments. Therefore, in answer to research sub-question 1b, the presence of impairment or disability does impact upon people’s opportunities and outcomes. While aspirations appear to be common across the diversity of people with and without disability, many disabled people experience a disabling mismatch between their capabilities, their participation goals, and their environments. This gap between aspiration and realisation, termed a capability gap, effectively renders people ‘the same but different’.
Research sub-question 1c asks what the role of impairment effects and environmental barriers is in creating disablement. The theoretical space created by this question enabled a range of theories to be considered from ontological and epistemological perspectives, including health and the environment (WHO 2001), economics and priority setting (Carter et al. 2008), justice and human rights (Arneil 2009; Megret 2008), policy and universalisation (Bickenbach 2009b; Patston 2007), and society (Goggin and Newell 2005; Phillips 2004; Shakespeare 2008).

Despite differing language and standpoints in the way ‘disability’ is defined and addressed, much of the above theory acknowledges a role for both impairment effect and environmental barriers in creating disablement. Recent international and national human rights moves have enshrined many of these understandings, and outlined an imperative to realise more fully the rights of people living with disability (Commonwealth of Australia 2011; United Nations 2006; WHO 2001).

This conceptual review concludes that the range of literature which addresses this question, and the language in which it is expressed, is as diverse as the perspectives of its authors. For the purpose of this thesis inquiry, a broad definition of impairment and disability has been offered in line with contemporary approaches to human diversity and universalisation. Disability is envisaged as an outcome of the interaction between impairment effects and environmental factors. Disablement may be mediated through a range of supports (Cook and Hussey 2008; Smith 1996) including AT, PC, EI and elements of inclusive environments, collectively termed mediators (Layton and Wilson 2009).

Profound implications for policy arise from these conclusions, related to the naming and problematising of the need for support (Arneil 2009; Foucault 1991). Political theory suggests problems should be framed according to the language and priorities of key stakeholders and decision-makers (Banks 2009; Campbell et al. 2007; Kingdon 2003). A muted but persistent theme from the sparse consumer-generated literature articulates the substantial and ongoing marginalisation of Australians with disabilities who require some type of assistance in order to participate fully in daily and community life:
The disability service system was characterised as broken and broke, chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need. Services were unavailable or infrequent, unaffordable or of such poor quality as to be of little benefit. Respondents felt that more effort went into rationing services than improving them. Programs and services were built around organisational and system needs rather than the needs of clients. In a democratic country as wealthy as Australia, many found it absolutely unacceptable that they are unable to access the support and services required to achieve even a basic quality of life (National People with Disabilities and Carers Council 2009: 5).

Given the imperative of creating change it may be wise to adopt discourses of human rights, and more specifically of political economics. An alternate expression of disability and disablement is therefore offered, in line with the capabilities approach (Nussbaum 2003). Here, required supports are a mediating solution to the problem of capability gaps: that is, the differences between a person’s capacity and the human goals and aspirations they endeavour to achieve. The aim of mediating capability gaps, whether these are caused by internal capabilities or lack of opportunities within the environment, is to achieve equality of outcome with other citizens. While the capabilities approach has yet to be applied fully to disability, it is found to be congruent with popular discourses which are shifting from the ‘cost’ of disability towards a focus on rights and outcomes.

**Research question 2: How do mediators bring about outcomes?**

Individuals living with impairment may experience limitations in their capabilities and capacity for participation due to the effects of their impairment per se, because of disabling barriers within the environment, or because of both. The question therefore arises: which mediators or supports address capability gaps arising from impairment effects or environmental barriers so that valued outcomes to be achieved?

Analysis of the literature pertaining to AT, EI, and PC through the critical lenses of standpoint theory and inclusive research uncovered a number of methodological limitations which, it is felt, understates the effectiveness of these
mediators. These will be discussed prior to presenting the available evidence as to the use and effectiveness of mediators.

From the vantage of mainstream research hierarchies of evidence (NHMRC 2000), the existing AT evidence base is characterised by the limited number, quality, and scope of studies (Lovarini et al. 2006). Yet research in mainstream hierarchies typically limits its investigations to one variable (such as a power wheelchair) in a homogeneous population (such as adults with tetraplegia), applying limited outcome measures. Despite the prominence of such evidence, it fails to meet inclusive research standards, excluding critical aspects of life with AT and related mediators for people living with disability. Commonly used outcome domains such as function, safety and independence have been strongly criticised by disabled individuals (Goble 2004; Goggin and Newell 2005). They are found to be ‘partial’ in scope, insofar as overall life goals and outcomes are not addressed. The conclusions of such literature are frequently limited due to the difficulty in managing confounding variables (other AT devices, personal factors and environments of use inevitably differ). Research designs provide low generalisability (the more rigorous the call for homogeneity, the smaller the sample); and for failing to make the leap from efficacy (what works in perfect conditions) to effectiveness (what works in the real world). From the perspective of lived experience, such studies invariably fail to capture the diversity of disability or the highly individualised, client-centred interventions which can be ‘tailored to particular configurations of impairment or to personal and contextual factors’ (Johnston et al. 2009: 4). Indeed, applied studies with broad scope (in terms of mediators and populations) and breadth of outcome were found to have more resonance with the outcomes valued by people with disabilities than many studies with high psychometric values.

Disparate and limited perspectives are evident regarding the impacts and outcomes of AT and related mediators, and may not fully reflect the actual effectiveness of AT (Johnston et al. 2009). Specific evidence gaps include evaluating the impact of AT, EI, or PC upon whole-of-life outcomes; the relationship of multiple elements to each other and to potential outcomes; and a lack of best practice indicators regarding the provision and planning of mediators (Lutz and Bowers 2005; Johnston et al. 2009). That said, some shifts are evident in the rehabilitation literature as a whole, with recent empirical
studies finding ‘empowerment variables’ (self-efficacy, self-advocacy, self-perceived stigma and competence) to be valid predictors of rehabilitation outcomes, leading to a critique of traditional ‘unidimensional’ outcome goals such as functional status and a call for ‘superordinate, or overriding rehabilitation goals’ (Frain et al. 2009: 27).

From the perspective of resource allocation, the economic impact of AT and EI was noted to be under-researched despite the economic impact of such resources being an important factor in AT funding and policy. Critical analysis of economic method speaks to the need to reorient outcome measures to the specific needs of AT users as a group living with impairment. This includes consideration of a range of methodological issues with health-related quality of life (HRQOL) measures for disability, including the problematic nexus between quality of life and health or functional status.

Virtually no research studies included people living with disability as part of the production of research. Such exclusion may ‘bias the choice of outcomes, the effectiveness of evaluation of rehabilitation interventions, and ultimately the adoption of “best practices” and intervention guidelines’ (Kroll 2011: 67). It has been suggested that if research is to have a beneficial impact then it must look outwardly and do more than audit ‘need’, because ‘Research addressing disabled people’s choices should acknowledge both objective and perceived constraints, but it is also important to consider aspirations, dreams and ideal worlds alongside “real life” decisions’ (Priestley et al. 2009: 104).

These methodological points are made to contextualise the findings of the literature and of ‘The Equipment Study’. The chapter now turns to the findings related to research question 2.

Sub-question 2a sought to define the strategies or interventions which mediate impairment effects and disabling environmental barriers, and to delineate their relationship to each other. The rehabilitation literature was the major source of research evidence pertaining to outcomes for people with disability in relation to the mediators AT, EI, and PC. Substantive evidence of impacts and outcomes was identified in the following areas:
preserved independence, decreased functional decline and reduced hospital admission rates;
• prevention of secondary medical complications;
• prevention of falls; maintenance of occupational roles via enabling environments;
• alleviating carer burden;
• reduced residential care placement;
• enablement of activity and participation in specific life domains;
• positive health and community life outcomes;
• improved quality of life.

The literature furnished good, if atomised, evidence that AT and the related mediators EI and PC can mediate impairment effects so that the experience of disability is minimised. It could therefore be hypothesised that a range of mediators under the broad headings of AT, EI, and PC have the potential to address capability gaps and minimise environmental barriers so that outcomes can be achieved.

A substantial dataset from ‘The Equipment Study’ provided evidence as to the mediators used and sought by adults living with disability in Victoria; and as the cohort broadly shared demographic characteristics with the broader Victorian population of people with disability, some generalisation of these findings is possible. Analysis of mediators against ISO 9999 found this classification system to be an exhaustive and detailed taxonomy for the mediators AT and EI. Personal care and support were able to be classified according to the ICF chapters (WHO 2001), and an additional emergent category, that of inclusive community environs, was also captured by the ICF. Data analyses indicate that a combination of these frameworks is required to fully explicate supports within and across peoples’ lives. Despite a survey design which identified each of the three mediators separately, the delineation between these mediators was, practically speaking, less clear from the perspective of users of AT themselves. This was consistent with the concept of the ‘technology chain’, where AT devices are nested within environments (AAATE 2003).

‘The Equipment Study’ data provided empirical evidence supporting an interrelationship between the mediators AT, EI, and PC, with an average of eight
elements combining to form a tailored solution. This evidence verified the definition encompassing this relationship as ‘an individually tailored combination of hard (actual devices) and soft (assessment, trial and other human factors) assistive technologies, environmental interventions and paid and/or unpaid care’ (AT Collaboration 2009). The vast majority of participants in ‘The Equipment Study’ demonstrated the ability to construct AT solutions tailored to their impairments, environments and goals, suggesting the capability exists within this consumer group to assume more control and self-efficacy when it comes to arranging supports, such as in individualised funding contexts.

Sub-question 2b considered whether mediators are in fact effective. Again, the absence of consumer-generated effectiveness measures was noted. From the perspective of the AEAA stakeholder reference group, the focal outcome areas reported in the literature were flawed. Outcomes like staying out of hospital, being safe, avoiding falls or maintaining the ability to manage a certain task were understood by the reference group to be both useful and important, but in no way represented their overarching concerns and aspirations. In the same way, the examination of one focal element of the interlinked set of mediators in use was seen as likely to fail to capture the ‘whole story’ of what works and doesn’t work in the complex business of living despite impairment.

The methodological variability of evidence found within the literature review did not allow meta-analysis or systematic review, but did provide a range of evidence for the effectiveness of AT, EI and PC as separate interventions or in combinations of two mediators; and some economic evidence regarding substitution of one mediator for another. The inclusive methodology and mixed methods used for ‘The Equipment Study’ were constructed to address these limitations, with an active stakeholder reference group and the capacity to capture participant-generated priorities and outcomes. Selected methods focused upon the integrated results of the suite of mediators in use (the AT solution) upon whole of life outcomes as captured by WHO ICF. This approach met the needs of the consumer stakeholders engaged in directing the research, and met the criteria for inclusive AT-related research articulated by a range of consumer groups (AEAA 2011; De Jonge, Layton and Vickery, 2009; Disability Inclusive Research Collaboration 2012).
A diverse sample (all adult users of AT), broad outcomes frameworks and a range of outcome measures (participation, difficulty, satisfaction, time use and HRQoL) were utilised. This study demonstrated that the life outcomes of people living with impairment are aligned with the aspirations of the population in general, yet subject to significantly more barriers to realisation. Provision of a suite of AT was found to contribute to or underpin outcomes across a wide range of life domains, including personal wellbeing and social, political, economic, educational, cultural, recreational and leisure, and spiritual life. Participants reported improved satisfaction, higher health-related quality of life, more effective time use and increased participation in a wide range of life areas, due to the presence of AT and other mediators. Participants therefore anticipated fuller AT solutions as highly enabling, suggesting that their lives would be transformed. It must be noted that this construction of optimal AT solutions is based upon hypothetical rather than empirical method: that is, solutions and potential outcomes were envisioned rather than actually provided and tested. This renders the data exploratory in nature. Whether and to what extent such expectations would be met is difficult to say in view of the hypothetical nature of the intervention, nevertheless this represents valuable indicative evidence.

The literature review and subsequent empirical study demonstrate that, from the standpoint of people living with disability, effectiveness measures should take a societal perspective to capturing inputs and outcomes.

Research question 3: How effectively does government facilitate equality of outcome?

Having found that equal outcomes are possible and that the AT solution is a key way to deliver these, the final research question considers government’s obligations and roles in delivering equality of outcome through provision of mediators, and its effectiveness in doing so.

The language of human rights is a powerful one, framing as it does roles for both ‘rights bearers’ and ‘duty holders’. Rights range from an ‘immediate obligation’ (ensure; shall undertake)’ to ‘progressive realisation’ (make measures) divide (United Nations 2006). Attempts to enshrine both obligations in the form of ‘reasonable accommodation’, are an obligation ‘at the intersection of the desirable and feasible’ (Megret 2008: 270). Here, the state owes
‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’ (United Nations 2006). This statement contains both absolute requirements and relative standards. At this interface the reality of reasonable accommodation must be realised by all actors – a challenge, given disparate standpoints, but essential for effective change.

The overarching question concerns the nature of the social contract between society and its citizens with impairments. In terms of human rights and social justice, societies are evaluated according to their treatment of all sections of that society (Rawls 1971). That said, the actual realisation of change is noted to be complex in practice (Lord et al. 2010; Lord and Brown 2011; Masso et al. 2005; Megret 2008). From the standpoint of those living with disability, the literature review provides ample evidence of what ‘a just society’ currently looks like, and might be envisioned to look like. The following illustrative comments are drawn from the key disability texts used in the thesis:

Rather than seeing disability as inherently uncivil, uncivilising and deeply distressing, we need to encounter disability as an inevitable, normal and indeed positive part of the diversity of Australian society, to be celebrated. In every aspect of Australian society, the situation of people with disabilities provides us with a significant challenge to understand our lived values and even dare to ask: how can we embrace people with disabilities as part of the civil society and society in general? (Goggin and Newell 2005: 43)

We desire a place within the community! This place is not just somewhere to lay down our heads, but a place which brings comfort and support with daily living, friendship, meaningful work, exciting recreation, spiritual renewal, relationships in which we can be ourselves freely with others. And out of this great things may flourish … And from there will flow all the delights and tragedies of a life lived in the community, shaped not by exclusion and oppression but by everyday ordinariness (whatever that might be)! (National People with Disabilities and Carers Council 2009: vii).
The thesis has demonstrated that humans, as rights-bearers, have differential capacities to realise their capabilities despite equal treatment (negative rights and horizontal equity) and the absence of barriers. For people living with disability, ‘even when their entitlement to rights has been formally recognized and uncontentious, their disability has often effectively excluded them from rights enjoyment’ (Megret 2008: 263). Research question 2 demonstrates that mediators such as AT and EI can be considered accommodations or ‘distributive justice measures, due to societal acknowledgment of inequality’ (Bickenbach 2009b: 109), and concludes that AT solutions are proven mediating solutions to the problem of capability gaps.

Based on these conclusions, research sub-question 3a, concerning the effectiveness of government in delivering equality of outcome through the provision of mediators, can be addressed. In terms of societal resourcing of AT, here termed ATDs or AT devices, Scherer notes,

> Regardless of the country in which we are located, we live and work in a broad social environment consisting of expectations, priorities, and regulations that have resulted in large part from the enactment of laws and policy decisions at various levels of government. Laws and policies can affect the availability of ATDs … and the ways in which they are made known and provided to consumers (AT service delivery). Insufficient funding for ATDs … can result in inadequate resources to achieve a good match of person and technology. (2002b: 4)

This was found to hold true for Victoria where ‘The Equipment Study’ data findings demonstrate significant undermet need on an individual level, with the VAEP found to partially cover only a fraction of required mediators. All in all, participants had their human rights realised at a ratio of less than one in four, against CRPD (United Nations 2006) principles. The data analyses indicate that updating or extending AT solutions were likely to expand participation, but that improving or building on current AT, EI and PC was frequently beyond the scope of existing government funding in Australia, and specifically of the VAEP. Given that individuals show that they require multiple elements of AT (multiple AT devices, multiple environmental modifications, and episodes of care), and that the effectiveness of these is achieved or maximised when used together, the current piece-by-piece approach to the assessment and funding of AT makes
little sense. The availability of AT solutions to Victorians with impairment represents a tangible indicator of whether policy has the wherewithal to comprehend, to resource and therefore to enact inclusion: ‘If we are going to fulfil the aspirations of the Convention and the intentions of the disability movement, then the fair and just provision of assistive technology is essential’ (Curtin 2008: 120). The government is found to be less than effective in its current role: analysis of policy literature and the AT policy case study based upon ‘The Equipment Study’ data have demonstrated that current government policy and provision for AT, EI, and to some extent PC is not ‘fair and just’, and does not meet a range of equality or equity standards.

To address the question posed in to research sub-question 3b, regarding what government needs to do to realise its obligations, a number of policy solutions are suggested, emerging from the thesis findings. The most profound shift, that of the universalisation of policy (policy solution 1) is an ontological one, grounded in the discussions of concepts of disability and impairment presented throughout this thesis. This approach may effectively address the ‘and/ and’ nature of human identity – where impairment comprises one aspect but not the whole of a person (Löfgren et al. 2011). Further, a capabilities approach will direct governments to work to universal outcomes on an individual basis (Nussbaum 2011; Nussbaum and Sen 1993). A capabilities approach overcomes potentially stigmatising identity issues in that it applies to all citizens and may address capability gaps in other spheres, such as lack of education. Thus, for those with impairment, policy would address requirements beyond categorisations such as age, diagnosis or other markers, sparing individuals the experience of labelling particular identifying (and disabling) aspects of themselves.

In terms of applying the capabilities approach to impairment, policy solution 2 suggests the WHO ICF activity and participation chapters are a globally applicable outcomes framework which resonates with international benchmarks (CRPD) (United Nations 2006). Structuring policy goals according to universal outcome frameworks (WHO ICF) lifts life expectations for people living with impairment, offering a broad canvas of opportunity. This counteracts decades of marginal expectations, and ensures people do not merely ‘accommodate
themselves to whatever they perceive as the options before them’ (Phillips 2004: 19).

Policy solution 3 suggests the construction of flexible service delivery options, including broadening the definitional matrix of mediators and offering individualised funding models. Here, AT user experts inform and direct the construction of their tailored AT solution, regardless of whether the ingredients are specialised or mainstream devices, and across the life outcome areas important to them. Consumer-focused priority-setting within the context of choice and control by individuals living with impairments and their circles of support will be necessary ingredients for such a paradigm shift in service delivery.

Finally, policy solution 4 identifies extended roles for a range of duty holders including AT users and practitioners, government, and those implicated in inclusive community environs. Legislating the right to support, and supporting the known mediators that lead to valued outcomes – in other words, resourcing AT solutions – will address internal capabilities (impairment effects). Extending and strengthening the role of duty holders will address environmentally-based opportunities (or barriers).

Resourcing is critical: the use of equity weights in redressing current inequities of funding due to capability gaps may also address the differential capability gap for individuals to achieve equal outcomes. Achieving the paradigm shift towards a capabilities approach would embed two final policy elements.

Measuring whether outcomes for people with disability are equal to those of citizens without disability remains a major task. Clearly, from the evidence presented in the consumer and disability literature and ‘The Equipment Study’, people living with impairment experience major and pervasive barriers at many levels of participation. Phillips observes that eventual outcomes must become the measure of the opportunities available, because ‘if the outcome is not equal, we can be reasonably certain the opportunities were not so’ (Phillips 2004: 13).

All in all, there is reason for optimism in considering the position of people living with impairment in Victoria today. Kingdon (2003) posits that government action depends upon the alignment of problems, acceptable policy alternatives, and
political will. A number of these levers are now in place. Australia is a signatory to the CRPD (United Nations 2006), and resulting obligations provide ‘a philosophical and moral statement and framework guiding integrated and strategic policy’ (Madden et al. 2011: 1). Strategies to enact CRPD principles sit within the National Disability Agreement (among the national and state governments) and the National Disability Strategy. Importantly, the Australian Human Rights Commission, responsible for the Disability Discrimination Act, has substantial responsibilities in relation to the CRPD (United Nations 2006). Finally, the voice of people with disabilities is raised as never before (National People with Disabilities and Carers Council 2009), with a significant national campaign lobbying for national disability insurance (Every Australian Counts n.d.), and adequate provision of AT solutions within it.

These factors all contribute to provide a rare opportunity to redefine the boundaries applied to, and the mediators available to, diverse Australians. A fundamental shift in policy approach towards capability, with associated steps to tailor necessary resources to realise diverse individual capabilities, brings equality of outcome within the reach of all.
Chapter 10 Addendum: Reflections and limitations

Chapter 10 contains additional explanation and detail about some of the methodological and method-related issues which arose during the completion of the thesis. It also comments on the thesis limitations.

Managing the problem of objectivity

It is critical to design and conduct research in such a way that its truth claims are defensible. While terminology differs, this is recognised across paradigms: scientific approaches aim to eliminate bias and maximise rigour in quantitative studies (Peat 2001); qualitative studies call for reliability and trustworthiness (Rice and Ezzy 2002); and feminist authors discuss weak and strong objectivity (Harding 2004). Emancipatory writers refer to this as ‘managing the problem of objectivity’ (Barnes 2001: 11).

What follows is a description of steps taken to maximise the truth claims of ‘The Equipment Study’. While this thesis is committed to an inclusive research approach, the development of methods of data collection and analyses were influenced by the funding of the two research investigations, ‘The Equipment Study’ and The Economic Study’, as part of The Equipping Inclusion Studies by the Aids and Equipment Action Alliance (via the William Buckland Foundation). As the second of these studies was an economic analysis and utilised data from the first study, a mixed methodology was required to meet the need for rigour in collecting data for the economic analysis and to ensure the privileging of the experiences of those with disabilities, including the capacity to capture consumer-determined outcomes. Encompassing the multiple and varied perspectives of ‘reality’ from an emancipatory, post-structural research paradigm while also engaging with a positivist, scientific research paradigm was challenging. Methods such as triangulation, member checking, and stakeholder reference groups and expert panels were used, explicitly to address objectivity (Harding 2004). Tensions do exist between a reflexive approach and the positivist frame of reference underpinning some tools and approaches necessary to fulfil the data requirements of ‘The Economic Study’. A substantial fusing of horizons was required on the part of the researcher in order to make sense of the demands of each paradigm, and to uphold the research intent. The
use of mixed methods allowed ‘multiple lenses’ to be used in the study method and data, and to elicit meaning according to the various research approaches which were being used (Koch 1994).

For data to be robust in positivist terms, the risk of bias must be minimised (Peat 2001). Risk of bias could be perceived in the steps taken to elicit the required level of detail regarding AT solution use and need. Here, the research design involved detailed clinical discussions of needs and suitable AT between myself as occupational therapist, AT practitioner and researcher, and the interview participants in administering the case interview series. Steps were taken to minimise researcher influence, including use of formal measures such as eFHROM, and bracketing and debriefing regarding my occupational therapy identity within the researcher role. The process of reflecting upon and describing life with AT clearly affected a number of interview participants, many of whom had not had any sort of AT review for some years. One interview participant’s satisfaction scores decreased on second interview; this probably resulted from ‘looking with fresh eyes’ at the 27-year-old wheelchair. Another said it was painful but good to look at her life through the means of the eFHROM and Activity Log, commenting that unexpected solutions offered by the expert panel were ‘worth it’. These observations are resonant with qualitative understandings of the research process as a transaction (Lather 1993; Manderson 2010; Pope and Mays 1995). While the effect of the researcher appeared to be a positive element of the research method based on participant response and feedback, the role of researcher and the effect on participant responses is, of course, open to other interpretations.

Practical outcomes and catalytic validity

Working towards practical outcomes is a tenet of disability-congruent research (French 1992; Oliver 1990). This was taken to include communicating findings widely and effectively to key stakeholders, in line with the best evidence on achieving policy change (Banks 2009; Kingdon 2003). Arguably, a benchmark of the meaningfulness of research is its catalytic validity, whereby the research process leads to ‘insight, and, ideally, activism on the part of the respondents’ (Lather 1986: 78). Several instances of what can be described as catalytic validity resulted from ‘The Equipment Study’ data collection processes. Five percent of respondents used the email contact provided for interview follow-up,
to seek further information about AT and related mediators in Victoria, and to discuss impending policy changes such as the National Disability Insurance Scheme. As the survey material and interview correspondence carried both University and AEAA logos, two participants became interested in the AEAA organisation, attended meetings, and then joined. One was subsequently elected to the board of the AEAA. The author was invited to speak at several Polio network meetings as well as at Polio Day in Victoria in 2010, all events organised and run by the Polio community, and has since been co-opted onto the Polio Clinical Advisory Group to 'spread the word' about AT needs. Several participants subsequently accompanied the author on trips to State and Federal politicians and to Productivity Commission hearings to discuss AT. One bedfast interview participant mentioned a lifelong wish to present at a conference, elicited during the interview process under the education sub-domain of eFHROM. She subsequently co-authored a paper and DVD script which enabled her to present at several conferences (Buchanan and Layton 2010b; Layton et al. 2012) and be published in an industry journal (Buchanan and Layton 2010a). Another interview participant invited the author to speak at a regional Disability Advisory Committee and, as part of her activities on behalf of the Every Australian Counts lobby group, co-authored an update on the proposed National Disability Insurance Scheme for Occupational Therapy Australia (Layton and Foreman 2012); co-presented at an inclusive research conference (Layton et al. 2012); and has begun to publish independently in the AT arena (Foreman 2012). A number of AEAA colleagues with disabilities co-authored and co-presented on a variety of aspects of ‘The Equipment Study' since its completion (see Table 27).
<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Type of Dissemination or Change Activity</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumers</td>
<td>Engagement on research advisory panels for new projects</td>
<td>2.0</td>
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| AT consumers and practitioners | Plain language articles  
Workshop                                                                 | 4.0 |
| AT practitioner | Case study of ‘optimal’ in book chapter  
Articles for industry journal  
Conference workshops  
Conference papers  
Keynote address                                                                 | 1.0 |
| AT practitioners; Researchers; Policy and program staff | Engagement in working groups (ARATA industry group, OT Australia professional body)  
Refereed journal articles  
Published conference abstract  
Present at research/ industry seminar  
Keynote addresses  
Invited workshops                                                                 | 2.0 |
| Government: funders | Invited plenary paper  
AT funder conference paper  
AT funder invited workshop  
Represent AEAA on Vic equipment funding review                                                                 | 1.0 |
| Government: politicians | Visits to state, federal politicians and parliamentary secretaries                                                                 | 5.0 |
| ALL          | DVD of AT solutions across life domains                                                                | 2.0 |

From the perspective of research, mutual exchange and change processes such as these are hallmarks of community-building, and of meaningful and emancipatory research (Barnes 1996; Barnes and Mercer 2004; Freire 1972; Lather 1986). From the perspective of public policy, these are examples of co-production, ‘partnership between citizens and public services to achieve a valued outcome’ (Think local act personal downloaded 4 May 2012; Department of Human Services 2010).

**Personal factors and the impairment trajectory**

Several observations regarding the impact of the study upon participants spoke to psychological and therapeutic aspects of adjustment and expectation. As with
practitioner/patient collaborations in therapy or treatment settings, a discursive process takes place around envisioning potential goals. Here, individuals impart knowledge of their individual contexts and aspirations, and the practitioner brings information about possible mediators and possible change (Chapparo and Ranka 2004); it is a dynamic relationship, and adjustment is ongoing. This is felt to be an explanation for the responses of several interview participants to the study process. For example, envisioning positive change was viewed with trepidation and ambivalence: ‘it may not work out’. In most cases, interview participants carefully selected options for their optimal AT solution, although some rejected recommendations because of their cost (to government or self). In some cases, there was a ‘make do’ attitude where solutions were considered too expensive or not required immediately, despite the likely risk of injury in the future as a result of not having the AT required. One interview participant at 60 years of age had sustained a recent spinal cord injury. His response to the expert panel’s recommendation of a vertical lift installation in his double-storeyed home captures some of these issues:

it’s out of the question. No one is going to afford that. I expect to have to use my shoulders [to propel a manual wheelchair along a lengthy external ramp to move between housing levels and to transport] – take the most economically reasonable option for everyone … At the moment I don’t need it … maybe in 5 or 10 years … at the moment I wouldn’t expect it of anybody.

[S84]

From a practitioner perspective, strong clinical, productivity, safety and downstream-cost arguments could be made for a lift, including the need to preserve shoulder function (an issue this newly injured individual may not have yet perceived), the need for fire egress from his rural property, and access to his studio and office as he worked from home.

Another example relates to the notion of ‘optimal’. Exploring this concept required a fine balance between raising hopes and increasing dissatisfaction, both of which were observed to occur in ‘The Equipment Study’. For example, one interview participant described as painful the process of being presented with optimal solutions that felt unachievable, particularly those that required the removal of funding barriers or societal change:
A lot of this has made me dream big … but then I think about getting halfway there and find some different solutions. I don’t regret this process and taking part at all, you made me think bigger and get out of the boxes or limitations in my thinking, and we have really got somewhere with some of these ideas I think. [S24]

These observations in some ways challenge one aspect of method: that is, the assumption that measures can be taken at finite points within the research and will ‘hold true’. Such an observation can, however, be made with many research methods that examine human behaviour, where it is important to capture an aspect of the therapeutic encounter.

**Identifying mediators**

The taxonomy of mediators was used successfully, exhausting all responses to the enabler categories offered and to the open-ended prompts (‘what else enables you?’). Possibly individuals who did not ‘fit’ the concept of mediators did not engage with the survey; however, even those for whom AT was a minor component of their lives made responses in the environment categories, or named more temporal and technique-based enablers in the space provided: for example, one participant described rolling around her garden to avoid falling due to her poor balance.

**Bias and administration**

Researchers involved with ‘The Economic Study’ advised that administering the AQoL, a standard measure, should be done in the researcher’s absence as a strategy to minimise bias. In practice this created some physical difficulties for participants, and prevented the collection of a potentially useful set of triangulating data. Two participants wished to complete the repeat AQoL forms and hand them to the researcher immediately after the second interview, as their level of disability made it difficult to insert the completed form into the envelope provided or to access postal services. These AQoL forms were presented in large print so that two participants, one of whom had ataxia and the other difficulty gripping a pen, could complete them with a rubber stamp. Positioning and turning the sheets was physically difficult, and time-consuming without support. As well as imposing this additional burden upon respondents, the requirement of researcher absence meant that an additional source of data
was missed regarding respondents’ opinions of the AQoL question set. Precedents do exist, however, to capture narratives during standardised form completion. In one study, participant narratives were captured during completion of the SF36 and the additional data enabled researchers to triangulate the meanings of question responses (Warren et al. 2008). During ‘The Equipment Study’ the researcher absented herself while the AQoL forms were completed, and lost this additional opportunity to collect data.

**Specific methodological issues with the AQoL 6D**

Observations from the use of a HRQoL measure in ‘The Equipment Study’ reveal a substantial dissonance between the views of people living with impairment and those of the health economics community. Health-related quality of life, as measured by the Australian Quality of Life Measure (AQoL 6D) (Hawthorne and Osborne 2005), was selected to obtain economically useable data from ‘The Equipment Study’. Analysis of the survey population’s scores, along with additional interview data from the subset of interview participants who completed the prospective AQoL based upon optimal AT solutions, raised questions about the capacity of this tool in two ways. Firstly, the predominance of function and health-state categories within the question set failed to capture the subjective experience of life quality and wellbeing reported across other, open-ended sections of the survey. Secondly, a disparity was evident between improvement levels when the difficulty, satisfaction and participation improvements described with qualitative measures were compared with measures derived using other tools (eFHROM and time use). The AQoL was seen to be an insufficiently sensitive measure of change, as disability per se did not change based upon interventions.

This specifically relates to the way questions are framed and weighted. Particularly problematic is the previously unaddressed confounding of ‘walking’ with ‘mobility’, and the fact that a Deafblind participant, by virtue of her continuing low scores on the vision and hearing questions, was rated as enjoying a ‘state worse than death’ despite a number of substantial gains in participation with an optimal AT solution. Specifically, the Deafblind participant had to rate her AQOL as ‘6’ (most severe) for the vision and hearing categories, but describes her life as quite satisfying. Likewise, ‘bedbound’ was the ‘most severe’ category on the mobility question, yet this score was at odds with other
findings from a bed-bound participant for whom ‘getting mobile’ was actually a low priority in relation to her activities in cultural, economic and educational life domains.

These methodological issues for a population living with impairment may be due in part to the disability-exclusionary population weighting methods used to construct the AQoL (South Australian Health Omnibus Survey 1999). The current framing of the instrument overly equates health and quality of life with a biomedical model of functioning and ability, and the question set has not been evaluated in the light of disability (Iezzi et al. personal communication 18 June 2009). While this tool did measure some change, it can be assessed as epistemically unjust due to its question set and health bias.

**Commentary on ICF perspectives**

The eFHROM is a useful tool for systematic evaluation of daily activity (ADL) but the ICF taxonomy was found to overly privilege some domains. Foundation activities such as mobility and self-care were afforded the same importance as much larger clusters of higher-order domains such as major life areas and community, social, and civic life. In contrast with the survey tool’s use of the Wilson life domains (2006) which provide a ‘top down’ approach in which activities contribute to performance and achievements in meta-domains, the Activity and Participation chapters of WHO ICF (expressed through eFHROM and used with interview participants) identify activities at up to four levels of detail.

Clinically significant changes (such as capacity to use a cup to drink, with appropriate AT) were found to be effective through participant narratives, but were not picked up on the eFHROM rating scales. These scales did not capture changes even of 20–30%, because the percentage jumps within the scales were substantial. For this reason, an additional piece of data-gathering as the interviews progressed captured degrees of change via an open percentage rating from participants; the open percentage rating was reported against the categories.
Limitations

People with disabilities are largely absent from the disability discourse, and lack centrality within the current AT service system. This absence is found to relate to a historical marginalising of those with disability as ‘other’. A major endeavour for the thesis overall has been the search for approaches and methods which will capture and privilege disability perspectives while producing conclusions of sufficient mainstream rigour to communicate with key stakeholders: in other words, to meet the data needs of economists and policy-makers in disability and AT. A critical realist frame of reference was selected to encompass multiple understandings of disability as a construct, and to centralise the human experience of impairment.

Literature review

The commitment to disability perspectives requires a critical view of the positioning of evidence: from whose standpoint is it written? Does the authorship include disabled researchers? Does the study design include data on the direct experience of the subjects being studied, including their valued outcomes? If the outcome measures represent an atomised view of functional elements, selected for the standardised properties of the outcome tool, how authentic is the link to the lives of individuals with disabilities? Applying these analyses highlights the limited horizon of many otherwise rigorous studies. Within this thesis, I have defended the decision to attend to a diversity of research evidence rather than filtering the available data through a quantitative evidence hierarchy.

Limited horizon of author

The topic for this thesis emerged from the author’s practice as an occupational therapist and from advocacy and research activities with disabled stakeholders. As such, it was constructed on the author’s multiple roles as clinician, researcher, advocate, student and, as part of the human condition, an individual with potential impairment. Efforts were made to address the limitations of this author-centric horizon by convening a supervisory cohort including sociology and health economics experts, building the input of colleagues with disability into the research design via the stakeholder reference group, using critical friends from occupational therapy and policy arenas, and directing enquiries across multiple bodies of literature.
**Catalytic validity**

Lather defines research as having catalytic validity when it leads to ‘insight, and, ideally, activism on the part of the respondents’ (1986: 78). Collaborating with AT users to establish their standpoints is, in some ways, an extension of the collaborative, person-centred approach used in occupational therapy and related disciplines. In other ways it has been a transforming experience for my practice. Familiar professional boundaries fell away as the transactional research and dissemination process developed, and my preferred method now involves co-partnership with people with disabilities in presenting and publishing, and in advising politicians and others in the sector. Whether this approach is reflexive and epistemologically sound, or biased and limiting, is for the reader to decide.

**Research paradigms**

A strength of this thesis is its attempt to encompass a range of research paradigms in seeking to understand its topic fully. Such a wide focus risks a ‘shallow’ engagement with specific topics. There is also a risk that the language, concepts and beliefs common to one paradigm will not be perceived or valued by another. It is felt that the attempts to reconcile disparate research perspectives from economics, sociology, and policy in some cases did not result in a fully realised alternate position.

**‘The Equipment Study’ limitations**

The horizon of this thesis limited itself to three key mediator types, widely defining the variations within each. Similarly, of the outcome measures available, only two sets of life outcome measures were utilised. Limiting the variables and measures in this way necessarily excludes the potential that other tools and interventions may have to offer. The underpinning methodology privileged the views and experiences of people with disabilities using AT: specifically, by enabling AT users to define the domains important to them. While this has merit from the perspective of participatory research, the choice limits the ability to match the data with similar studies in a way that might enable further correlation or analysis.

Obtaining the views of AT users necessitated the participation of a sample of people with a diverse range of disabilities (rather than one diagnostic group) in
the research. The self-selected sample of 100 respondents represented a fraction of AT users in Victoria, and while the breadth of respondents was intended to capture a wide range of individual experiences which could be mapped to policy, it may not be feasible to extrapolate findings to a wider population with similarities to the sample group. In order to assess optimal AT provision, a smaller sample of eight was purposefully selected to provide archetypes to be interviewed in detail, and to have customised AT solutions designed for them and provided in a hypothetical scenario. Archetypal method has been used in similar studies, but its limitations are similar to those of case study research: in other words, richly detailed vignettes have limited capacity for generalisability. Likewise, the strategy of eliciting hypothetical change is less powerful than a pre- and post-evaluation of actual change, and is therefore a weaker method.

Finally, as ‘The Equipment Study’ was part of a funded study on behalf of a stakeholder group, from which data were utilised for this thesis, see Appendix D for a description of my role as primary researcher in relation to ‘The Equipment Study’ research stages.

**Need for future research**

A number of extensions to the work of this thesis present themselves.

From a ‘clinical’ or practice perspective:

- Personal factors (such as impairment stage and adjustment) were noted to have an influence upon goal-setting and expectations. It is suggested that these factors require further investigation for their impact upon the life goals and societal expectations of people with disabilities.

- Consumer expertise was noted to range from novice users unsure ‘what would help’, to expert users who could clearly articulate their AT needs. From a policy and program perspective, it would be valuable to develop frameworks for coaching and educating AT users, with the development of formal mentoring or self-management roles for expert AT users.

- The role of AT practitioners has not been closely examined in this thesis, although it has been suggested that practitioners are influenced both by clinical and ethical principles in working with people with disabilities, and
by the institutional settings which employ them. A further examination of the motivations and incentives of practitioners would illuminate some of the identified tensions between consumer-identified goals and priorities, and those of the rehabilitation sector.

From the perspective of mediators, a number of further research questions present themselves:

- ‘The Equipment Study’ asked participants to define optimal AT solutions and envision their outcomes. This study could be run again, this time providing the optimal AT solutions and evaluating them against participant projections. To do so would enable further economic (cost consequence) analysis, as well as providing valuable data on the accuracy of participant and expert panel projections.
- Investigating the interrelationships between AT and EI and the impact of EI on outcomes.
- Establishing different AT solutions, subjective experiences, and outcomes, for individuals in receipt of individual support payments or for a more substantial cohort with insurance cover, would provide a more detailed picture of the impact of resourcing policies upon life for Victorians requiring AT.

This thesis affirms the value of co-production for all concerned, and supports the production of research based on inclusive principles. Doing inclusive research is likely to challenge the standpoint of AT practitioners, and also to disturb the conventional locus of research as based around the individual:

Assistive technology researchers need to collaborate with disabled people as co researchers, and provide them with opportunity to empower themselves through knowledge and capacity building. Researchers need to answer the questions that are meaningful to the disabled community, enable disabled people to create the research agenda, and simultaneously support efforts to address oppressive environmental barriers. To do this requires a paradigm shift by many health care providers and researchers, who require further knowledge of the social model of disability, need to reframe language in terms of AT provision, and must continue to expand their focus beyond
individual needs to consider the AT users interaction within society. (Ripat and Woodgate 2011: 90)

Ultimately, future research needs to include direction from those whom the research is about.
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Appendix A: Aids and Equipment Action Alliance

History of the Alliance
The Aids and Equipment Action Alliance was developed following joint work by the Association for Children with a Disability, Melbourne Citymission, Scope, and Disability Justice Advocacy, with involvement from Yooralla, to hold the Equipping Inclusion Forum in October 2006.

This initial group of organisations came together due to their shared concern about the high level of unmet need for aids and equipment in Victoria. Two research reports (one by Melbourne Citymission and one by Scope) were published to highlight these issues. The Equipping Inclusion Forum was held to explore policy options for an improved aids and equipment system and involved a very wide range of stakeholders from the disability sector, including people with a disability. The Forum coincided with the Victorian Government Review of the Victorian Aids and Equipment Program.

The Aids and Equipment Action Alliance was formed in response to the high level of interest expressed at the Forum. The Alliance aims to achieve real change around the provision of aids and equipment to people with a disability. It is expected that the Alliance will have a long-term advocacy role on a range of issues including investment, systemic improvements, and mechanisms for promoting choice and control for people with disabilities.

* Aids and equipment for Victorians with disabilities – entitlement or hand-out? Recommendations for an effective Victorian Aids & Equipment Program for the 21st Century, Anne Pate and Michael Horn, Research & Social Policy Unit, Melbourne City mission, October 2006 and: Too little, too late: Wait times and cost burden for people with a disability in seeking equipment funding in Victoria, Scope, 2006
Who are we? A wide range of stakeholders have joined the Alliance, including people with a disability, advocacy organisations, community service organisations which support people with a disability, and representatives from key health and allied health providers.

Together, Alliance members will share knowledge and advocate to achieve increased investment in the Victorian Aids and Equipment Program and to promote greater choice and equity for people with a disability and their carers.
Appendix B: Interview Participants: selection and participant summaries

The intent was to sample for diversity, to elicit a wide range of lived experience across the body structure and function categories of WHO ICF, and where possible across living situations, gender, age brackets and life roles. Seventy-one survey participants indicated their willingness to participate in the interview stage of the research by providing a phone number or email address for contact. Six female and two male participants were selected across three age categories and matched to broad ICF and diagnostic categories sets (Table 28).

Table 28: Interview participants by WHO ICF body structure and function category

<table>
<thead>
<tr>
<th>WHO ICF mapped to interview participants</th>
<th>Body Structures</th>
<th>Match to interview participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental functions, e.g. memory function, intellectual functions</td>
<td>Structures of the nervous system</td>
<td>Cognitive issues</td>
</tr>
<tr>
<td>Sensory functions and pain</td>
<td>The eye, ear and related structures</td>
<td>Visual acuity deficits, Blindness and deafness</td>
</tr>
<tr>
<td>Voice and speech functions</td>
<td>Structures involved in voice and speech,</td>
<td>Dysarthric speech</td>
</tr>
<tr>
<td>Functions of the cardiovascular, haematological, immunological and respiratory systems</td>
<td>Structures of the cardiovascular, immunological and respiratory systems</td>
<td>Respiratory issues</td>
</tr>
<tr>
<td>Functions of the digestive, metabolic and endocrine systems, e.g. ingestion</td>
<td>Structures related to the digestive, metabolic and endocrine systems</td>
<td>GI issues related to posture, Swallowing issues</td>
</tr>
<tr>
<td>Genitourinary and reproductive functions e.g. menstruation functions</td>
<td>Structures related to the genito-urinary and reproductive systems</td>
<td>Continence issues</td>
</tr>
<tr>
<td>Neuromusculoskeletal and movement-related functions, e.g. mobility of joint functions</td>
<td>Structures related to movement</td>
<td>Athetosis, Spinal lesion, Neuromuscular junction disorders</td>
</tr>
<tr>
<td>Functions of the skin and related structures</td>
<td>Skin and related structures</td>
<td>Pressure care, Amputation</td>
</tr>
</tbody>
</table>

NB Some participants are listed in more than one category. Each category has at least 2 participants.
Interview Participants: Participant summaries

Interview Participant 1

Body Structures and Functions Ingrid is in her late fifties, and identifies her disability as ‘cerebral palsy and the built environment’. She has restricted hand function in both limbs, although can use a joystick and keyboard with her left hand if she stabilises herself. She habitually has large involuntary athetoid movements occurring in upper and lower limbs even when at rest, and increasing with exertion or speech. Ingrid is of Ceylonese descent and jokes that her girlfriends say her accent, as well as her dysarthric speech, account for any trouble in understanding her. Ingrid has recently been told that her shoulders are ‘beyond repair’ and therefore is facing significant change in her current functioning, particularly challenging as Ingrid describes herself as ‘a busy person … I am always out’.

Personal Factors Ingrid lives with her husband who is a therapist and runs a practice from their home. He also provides part of Ingrid's personal care. The couple lives a 'wholistic' lifestyle, using meditation, herbal remedies, optimum diets and integrative health practitioners as much as possible to keep themselves in good shape. They are active volunteers, despite the common experience of Ingrid having to go to the toilet using a portable commode in the back garden of inaccessible homes when they attend working bees to help others, due to lack of access. Ingrid runs a small part-time office for a volunteer organization behind the kitchen of the local organic bulk food shop with cafe and is resourceful in getting a couple of friends who work at the local DHS and her husband to assist her with any toileting issues that come up when she is out and about on her own.

Environment Ingrid lives with her husband and owns a double fronted weatherboard home in an industrial area of a regional centre. Home modifications include a portable chequerboard aluminium ramp permanently positioned at front door, and internal doors removed and a built ramp leading to the back garden. Ingrid can control some aspects of her home for example uses an m-lak key handle to unlock and push front door open and can operate the light and heating switches, but kitchen appliances are almost always operated by either carers or her husband. VAEP provided initial modifications, although Ingrid states ‘they said it’s the back door ramp and either kitchen or bathroom,
but not both’. Ingrid’s bathroom has an accessible toilet and an in-bath height-adjustable ‘lifter’. Adjustments to the kitchen mean she is able to get a wheelchair under the kitchen rangehood. She is also able to sit at the kitchen table and open the fridge but cannot use other kitchen areas. She has a HomeFirst Individual Support Package.

Aspirations Ingrid hopes to maintain her participation despite her age-and use-related shoulder issues, and continue to work for change for people with disabilities and environmental sustainability for her community. Ingrid desires greater control over her Home First package, looking towards direct payments as an option. ‘I’d get to have a look at my budgets every month, to see where the money and hours are going’. She also would like her support workers to get paid after every fortnight instead of in the middle of it, and have blank timesheets that she and her carers fill in and sign as this is a system that would suit all members of her in-house ‘team’ including herself.

Interview Participant 2

Body Structures and Functions Ricky is in her early thirties, with several severe metabolic/ systemic disorders which became incapacitating during her university years. Orthostatic intolerance and hyper-mobile joints confine Ricky to bed (supine or elevated less than 30%), apart from swivel transfer to commode adjacent to bed, and occasional short trips in reclined power wheelchair (less than once per week and only to medical appointments). Ricky lives with severe fatigue, sensory sensitivity (vision and hearing) and fluctuating cognitive issues such as word finding difficulties and an inability to finish tasks. Ricky has normal hand dexterity but her fluctuating systemic functioning means she fatigues quickly and experiences overuse symptoms when typing or doing other activities such as hand sewing for moderate periods of time.

Personal Factors Ricky actively seeks opportunities within her limited physical capacity and occupationally deprived environment, to engage with the world. She runs a number of websites and small enterprises connecting her to others via the internet and engages in on-line dialogue and system advocacy regarding disability and human rights issues. She builds meaning through small engagements and projects for example craft projects, organising feed for the birds outside her window, and taking every opportunity to read, learn and engage with the world.
**Environment** Ricky receives an individualised support package of 45 hours per week attendant care. During a period of homelessness, she was placed in a ground floor, inner city Ministry of Housing flat, 45 minutes from her family and far from the semi-rural, outer suburban area in which she grew up. She has her electrically adjustable bed in the living room, with a view of the hallway, and living room window. The flat is wheelchair accessible but circulation spaces are too narrow for the bed to be moved into any other rooms. A wall between the living room and the kitchen prevents Ricky from viewing the kitchen or participating in kitchen-related activities including supervising the carers. Ricky has a cat and grows many climbing plants.

**Aspirations** Ricky desires to participate in cooking and gardening, and to have a bath. She wishes to spend less time and energy negotiating and navigating through different funding bodies and services, and to participate in more formal education. Ricky wants to have some choice over where she lives and to be in closer proximity to family and friends to increase the ease with which they can visit. She wishes to administer money more easily (legal problems with attendant carers handling cash and autobank cards), to shop more easily (e.g. buying material online is not possible), and to enjoy current cultural events (shows, books, movies) from her bed.

**Interview Participant 3**

**Body Structures and Functions** Margaret is a professional woman in her mid 60's who has lived with severe polio for many decades and now also the effects of post-polio syndrome. She has a past history of three spinal fusions and partial removal of her left hip joint. Margaret is able to readjust body position in seating and lying by small amounts through leverage of head/shoulders against firm surfaces such as a shower chair surface or firm polystyrene pillow block. Margaret is of small physique such that she sits forward of the front wheel of her electronic wheelchair. A previous wheelchair capsized because the front-mounted bars and safety wheels were too small. Margaret sustained a hyperextension injury to her neck/cervical spine which resulted in increased impairment of her (R) arm function. Now she notes a slow deterioration in reach range and physical function generally due to post-polio effects and to possible effects of ageing. Margaret requires a full torso orthotic jacket and orthotic knee high boots for her lower limbs. She is able to move her arms within an inner range only, and the capacity of her right arm for lifting objects is 1-1.5 kg only.
Margaret has more strength and function of her left arm and shoulder but almost no function in her left hand. Because of her scoliosis she leans to the left or falls to the right unless supported by the wheelchair, seat belts or, when in bed, a left side bed rail and a polystyrene block.

**Personal Factors** Margaret is just completing a PhD and preparing for a cruise with her elderly father. She brings a lifetime's experience of coping with disability to this, her current situation of managing the deterioration brought about through post-polio syndrome and ageing. She is active in community and political arenas for example voluntary roles supporting human rights and equal opportunity for people with disabilities. Her carefully tailored longstanding AT solutions are now ageing themselves (e.g. wheelchair, shower/commode) and she perceives many hurdles ahead in readjusting and in locating additional enablers.

**Environment** Margaret lives with two cats in an attractive single story unit which she purchased via a Victorian supported housing scheme about 8 years ago; the package funded approximately $40K worth of home modifications. The unit has level access entry front and back; accessible bathroom and toilet, and a custom modified kitchen. As Margaret is unable to go to the toilet without a disability support worker to assist with hoist transfers, she engages in careful management of her fluid intake to reduce the occurrence of having to go to the toilet during day-times or night-times. A 1 hour callout cost occurs if she does go to the toilet outside the daily care hours of 7.30-9.30 am and 7.30 - 9.00 pm. ISP funding provides these care hours, with an additional 4 hours on Sat (food preparation for the week) and extra 30 minutes two days per week for other domestic tasks such as putting away shopping. Linkages provide 4.5 hours a week for a disability support worker to assist Margaret in hydrotherapy at a heated public pool.

**Aspirations** Margaret hopes to maintain her level of independence in her home. She may be at risk of admission to an aged care facility if her changing physical status is not offset by more technology or disability support worker support hours. Margaret wishes to continue her support to her elderly father and psychiatrically impaired sister. She plans to continue some consultancy and voluntary work and to enjoy leisure pursuits.
Interview Participant 4

Body Structures and Functions Lynne is a woman in her fifties who has Arthrogryposis Multiplex Congenita, an arthritic condition. This manifests through multiple joint contractures (hips and knees are fused into extension), generalised muscle weakness and fibrosis. Lynne has partial amputation of both feet, therefore requires purpose-built orthotics and orthopaedic shoes. Her standing balance is significantly impaired given her small base of support, especially when transferring from bed without footwear. She also has several missing metacarpal joints in her hands. Lynne has used crutches for most of her life in order to walk short distances but in the last year has been advised that her shoulders can no longer sustain this weight-bearing activity due to RSI, and therefore she needs to look at other transfer methods, and to use a power wheelchair. Pain is a significant factor for Lynne.

Personal Factors Lynne and her husband state ‘over this year, everything has changed’ and they are feeling anxious about what the future holds.

Environment Lynne, her husband and their small dog live in a modern housing commission unit on the outskirts of a regional centre. The unit was previously modified for someone with a disability and minor adjustments were made to fit it to her requirements such as removal of adult sized fold down change table, and installation of quarter turn taps at all sinks. Chequerboard aluminium ramps are permanently fixed at front and back entrances. Her current attendant care comprises 15.5 hours per week and the couple are awaiting a Home First package but have been advised Lynne is ‘not bad enough’. Lynne uses PWC indoors and outdoors, and as her hips and legs are fused into extension, she cannot reach doors or appliances easily. She uses a pickup stick to pull the front door open from within, but must ask cab drivers and others to unlock it. Likewise, the sliding rear door has a low handle on it for gripping and pulling but the fly-screen door is not accessible. Lynne has difficulty reaching light switches but can manoeuvre her powerchair close to the heater in the lounge to light it. Lynne is a regular volunteer with the community visiting program and is a member of a number of access committees. She attends Boci and swimming weekly where possible.

Aspirations Lynne and her husband describe occasional holidays and short breaks as significant in them maintaining their quality of life and sense of
enjoyment as a couple. Relinquishing crutches however means Lynne cannot now access their small caravan.

**Interview Participant 5**

**Body Structures and Functions** Peter is 60 years of age and has recently retired from work due to the effects of post polio syndrome. Peter describes being limited by shortness of breath, specifically difficulty in exhalation, as well as fatigue and loss of muscle strength in arms and legs. He is a tall man, approaching 100 kg in weight, and previous back and (L) shoulder injuries also limit his capacity. He can walk around home and garden, requires a single point stick to walk in the street, but describes severe effects if he walks for more than 5 minutes (fatigue, twitching, cognitive impact) ‘I could walk to the end of the street and back but I would pay for it tomorrow’.

**Personal Factors** Peter describes his journey as a man of working age with a young family, in adjusting to a progressive disorder after a lifetime of high level work in management, and high levels of fitness. He attends counselling to manage depression related to his circumstances, and describes a high level of reward from his community visits to people in nursing homes, and running the local polio network. He has just accepted the necessity of applying for DSP, and self-funded his scooter last year. Peter intersects with the health/ service system e.g. outpatient connections with physicians and OT at local hospital, but has not utilised the public funding system so far, other than specialised shoes. Peter describes a reluctance to address his equipment needs as he feels others may need such equipment more than he does. He frequently deflects concerns for his own status into discussion of those ‘worse off’, and is an active advocate for increased enablers for others.

**Environment** Peter lives in an unrenovated brick single storey dwelling in need of some maintenance, with wife and school aged children. Minimal modifications to date include the back entrance has been made level to garden, scooter which is stored in garage, and path to side of house, via self-laid house bricks (somewhat uneven). ‘When I knew this was happening I put the bricks out the back, a single handrail adjacent to shower-over-bath, but no alteration to the single step at front patio’. Peter uses a pickup stick around the house, and a CPAP (continuous positive airways pressure) machine overnight. He wakes every 1-2 hours due to discomfort with CPAP functioning: this causes residual
fatigue due to suboptimal lung function as well as disturbed sleep. In 2008 a BiPAP (bi-level positive airways pressure) machine was trialled for one month on the advice of the respiratory physician, and gave undisturbed sleep (approx 5-6 hours without waking), ‘improved lung function and therefore improved endurance, alertness and feeling of wellbeing.’ It cost $100 for the trial through the local chemist, but it made ‘an enormous difference … instant pleasure. I have difficulty breathing out, the CPAP blows air in and it stays in’. Peter’s respiratory physician recommended he purchase one as it could improve his health. Peter felt that he is ‘not severe enough’ to be funded a BiPAP machine. Peter is not clear about the funding rationale, but describes invasive, regular and ongoing tests scheduled at the acute hospital to monitor him until such time as he deteriorates sufficiently for a BiPAP machine, oxygen or any other interventions.

**Interview Participant 6**

**Body Structures and Functions** Jenny was diagnosed with MS in 1979 whilst she was in full time work. She is now retired and in her sixties. Jenny is mobile around her unit and local community in her power tilt-in-space wheelchair, and requires mobile hoist and carer support for all transfers. She has severe paraesthesia in her lower limbs; moderate weakness and severe tremor in her arms as well as some lack of sensation in her hands. Jenny is able to manage gross tasks such as pulling towels from dryer, but cannot use her hands to eat with cutlery or to write. She is unable to do many other fine tasks such as open containers or unlock doors. Jenny is able to drink through cups of water left at bench-height with a straw, but requires physical assistance to eat. Therefore she requires 30 minutes of attendant care at lunchtime and for the evening meal. She has mid-range dynamic sitting balance, mild swallowing problems, and mild dysarthria is evident in her speech.

**Personal Factors** Jenny lives alone and manages her own affairs. In between the carer support visits that occur two or three times daily, she enjoys travelling around the local community to shop or have a lunch of finger food at accessible venues. Given the outer suburban area in which she lives, locating an accessible path of travel is a problem, ‘It’s much better travelling on the road: there are no footpaths around here’. Jenny receives the aged pension, ISP funding, some hours from Qual-Care and a weekly ISP community access worker. She is very positive about the support she obtains from many sources
which enables her to live independently, but comments ‘for care agencies to align policies would be great’. Jenny has a supportive daughter who works, and two beloved grandchildren; she describes her daughter as being able to provide friendship rather than care thanks to the presence of the ISP package and case manager. ‘Previously my daughter did everything but my case manager is terrific … now she does everything … when I didn’t have enough money for the door she said maybe we can put some money towards it … I’d be lost without the case manager because there are so many areas of help and money and you just don’t know … ’

**Environment** Jenny owns an attractive outer suburban single storey unit, with many toys present for grandchildren’s visits. She describes paying $15,000 herself to render the unit accessible prior to moving in, and accesses the unit through the garage and back door if no one is with her to open the front door. Modifications included wooden ramps at front and rear, stepless shower base, space beneath vanity in bathroom, lower kitchen benches, and the pantry was relocated to increase circulation space in passage and kitchen. ‘When I bought this unit it was just set up for an ordinary person, I was very aware of this and paid to have things done so it wasn’t looking like oh you are disabled’ Several aspects of the modification were VAEP funded such as remotely operated back door ‘it was cheaper to put the remote control on the sliding door (rear) than front door’, and ISP funds are periodically used for modifications or maintenance. Jenny self-funded a variety of small aids.

**Aspirations** Jenny hopes she can continue to stay in her home as she ages and as her abilities change. She is aware that her swallowing and positioning capacities are changing, but chooses to maintain her independent lifestyle and the dignity of risk inherent in that. Jenny is positive and adventurous, making the most of opportunities to explore new places with the community access worker, and working out ways to continue to do things as her abilities alter. It is likely that additional AT would make life easier for the long periods Jenny is alone, for example an environmental control unit, ‘that would be very good because a couple of weeks ago I dropped my remote control well I thought I would be sleeping with the TV blaring … it took me 2 hours to get it with a wooden backscratcher … every now and then someone leaves a light on and I just cant sleep’
Interview Participant 7

Body Structures and Functions  Yanni recently experienced severe back pain and disc compression, with the outcome of permanent neural damage to his spine causing L1 paraplegia. He returned home less than six weeks prior to interview, following rehabilitation, with partial home modifications.

Personal Factors  Yanni describes himself as a pragmatic man. His impairment had a catastrophic rather than a gradual onset thus he is at a very early stage of adjustment to the disabling impact of a spinal cord injury and its effect upon his life situation. Yanni feels it is unreasonable for ‘the state’ to pay for expensive equipment and alterations, although they would make a significant difference to his independence and life quality. He does however express deep concern about the system inequities he perceived when in hospital, where different resources and therefore different levels of assistive technologies and other enablers are available based on an individual’s compensable status. System inefficiencies are also of great concern to Yanni, who, observed that hospitalisation and recovery were delayed by funding constraints for both him, and many others on the ward.

Environment  Yanni is a man in his 50s who lives rurally. He runs a small home-based business, while his wife who works fulltime away from the house, and teenage children attend local schools. The family live in a split level home on a steep block which is located part way along a single lane, dead end dirt road. The dirt driveway to the house is very steep decline – approx 1: 4 gradient, which sweeps down to a carport and the only access point currently suitable for wheelchair use. This is a threshold ramp at single step to first floor (living, sleeping, and kitchen). There is currently no access via stairs or steep raked garden to lower floor (office, BBQ, children’s bedrooms, utilities, outdoor basketball court). Yanni notes that, as he cannot reach the ground floor area, ‘I have no ability to fight a fire... up here I am totally defenseless ... if I could get down could access my water, access the pump ... I could do something’

Minimum modifications were made in order to get home ... these include the accessible bathroom and hand controls for a vehicle. Yanni paid for this himself or with the support of alternative funding sourced by social worker; otherwise he states ‘I’d still be taking up a hospital bed, waiting for VAEP’.
Aspirations Yanni resumed his home-based work having reorganized his workspace for access with the help of friends, and has refined this through trial and error since his return home. In terms of mobility, some storage and other aspects of work remain downstairs in the previous work area, which remains inaccessible to a wheelchair. Yanni must also transfer into his car in order to leave the property given its access issues. Although aware of the benefits of available technology solutions such as stair lifts or four wheel drives/quad bikes, Yanni feels attaining funding for them is 'out of the question. No one is going to afford that'.

Interview Participant 8
Body Structures and Functions Grace is a woman in her fifties who lives with Ushers Syndrome, a genetic disorder affecting hearing and sight. She has lived with complete deafness all her life, and lost her sight in her twenties. Grace explains, 'Being Deafblind is very difficult and isolating and I am always determined to make my life the best as I can'.

Personal Factors Grace lives in the outer suburbs of a large city, having moved from the country in order to be close to Deafblind services. She is therefore some distance from her family including two siblings also living with Deaf/blindness. Grace works hard to structure her days and her weeks, 'I don’t need any help for showers or things like that … I have my shower, eat my breakfast, open the computer to see if I’ve received any emails … go outside and check the weather. All though the day … sometimes I’m quite bored, I put the computer on and I’m backwards and forwards checking for emails, I play with the cat, I do many laps of the block with my white cane'. Grace describes her life journey as follows, ‘Satisfaction over the years has increased from very, very dissatisfied. (interviewer: why?) Because I have more control now, I am not as passive as I was before!’ Grace also has an awareness that life may change as she ages, and different enablers may be required. Cultural and leisure media such as music, television and radio are inaccessible. Accessing current news online is navigationally complex and involves a screen reader alongside a refreshable Braille keyboard. Once away from a desktop computer with these specialised peripherals, this avenue of communication is lost. Another key enabler at home is a Braille TTY rented via Telstra, used ‘to make calls to make appointments to see doctor, taxi, train stations to organise for assist when meet staff, taxi, contact any professional in some agencies, etc. However Braille TTY
may disappear in future due to no more parts for repairs. Grace undertook a
course of study at CAE recently, completing a Certificate in Community Service.
The following mediators all came from different sources:
-  2 Auslan tactile interpreters (Sign-On Employment);
-  interpreter table ‘I left my interpreter table in class room for two years … I
  have to leave it in classroom because I can’t carry it home or bring it to
  classroom’. Interpreter tables are not designed for portability which is a barrier to
  their use.
-  Tutors (Smith Family);
-  Textbook translation into Braille (Vision Australia). Grace describes
  some compromises that were made, ‘TAFE covered the note taker and
  translating books into Braille. Braille is quite expensive – some books had to be
dropped’.

Environment As the world around is tangible only through touch and smell,
vibrating alerts (e.g. clock, doorbell, smoke alarm, vibrating pager with four
different alerts for phone) and tactile input via human or via computer, are the
ways in which Grace can receive and impart communication. Grace received an
ISP (28 hours per week) and Council home care (5 hours per week) and lives
independently in the company of her cat, in a house purchased with support
through a housing association. She describes her situation as follows,
I have been very privileged to have some government funding to make my life a
bit easier. Yes, I have government funding but not enough for me to make
impromptu choices that many people take for granted. For example, if the
weather is warm and sunny on a weekend, I am stuck as I cannot go out on my
own to new places without making any prior arrangements with volunteer, friend
or support worker. This is a frustrating for me. Also with the government funding
for the unit I live, I was again restricted by the limit of funding level as I am
currently living in suburb outside of a major city. I find travelling very tiring as I
need to concentrate all the time where I am going or often I am stuck in rain and
it is not comfortable for me.

Grace describes a lifelong journey towards this current situation of autonomy
and independence, ‘Really I ’m quite skilled with how I navigate my world, for
people with less skills, less experience, who are less assertive, its harder.’
Grace describes her joy at having space and an outdoor area, compared with former dwellings. ‘I lived in … a little box, I had to stay inside, and there was no yard. It was like a prison’.

Simple labelling procedures at home such as Hi Mark (tube of quick hardening raised putty) on the microwave and washing machine; Dymo Braille tape or magnets on food ingredients, enable Grace to manage her domestic life.

The known environs are easily managed by Grace, who is familiar with her dwelling, able to walk around the block with a white cane, perform transactions at known shops, and able to take the train to the city independently. Crossroads and unfamiliar terrain especially if uneven and with poor tactile signage, are barriers. AT such as the Mini-Guide (vibrating alert which detects objects in vicinity) helps to identify barriers such as traffic, but does not help in negotiating it.

**Aspirations** The independence and autonomy Grace values so highly is enabled through self-managed ISP funding, ‘The ISP, I can use whatever they have allocated to me for anything in my life’. The financial cap on this funding means there is little capacity to plan any sort of break, or even get through the weekend. Grace states, ‘The support that I get is just enough for the everyday things to live my life. I can’t get away and that make me extremely angry. As far as weekends go, I hit barriers. I have a very busy week but weekends are a problem. Sometimes I want a support worker on a Sunday and I have to pay double or triple. The weekends are very difficult for me I don’t have a choice to get a taxi, if I need to get out of the house and talk. I’m very alone’. Grace values ‘regularity and personal activity’ in her life and longs to be more physically active but needs support to engage in any physical pursuits such as running as ‘Being Deafblind I do not have opportunity and access to do all that stuff’ Grace elects to use some ISP support to enable her to swim ‘I do swim and feel fantastic after that’ but also describes having to make choices and use the support worker hours for more basic needs, ’ I may need to cancel my swimming to make contact calls, … (to read) snail mail if it doesn’t come through email’. Grace is an active volunteer in the community: she is taking part in a fundraising relay for life and sits on advocacy committees all of which are facilitated through computer-based communication or tactile communication with
another. Grace is seeking funding for a mobile phone and refreshable Braille peripheral but no funder covers this. She states,

I was told that the only way to use my current ISP funding to cover but I strongly feel that it is not fair because the ISP funding is really for my everyday use not for any special equipment as I maximise my level of funding support. Why am I being penalised for being Deafblind?? People need to understand how expensive it is being Deafblind.

Grace recently approached JobAccess but was informed their $5000 funds for AT are only available to people in full or part-time employment, not people doing voluntary work. This is frustrating for Grace, as, with the AT, she may be able to seek paid work.
## Appendix C: Taxonomy of Mediators

International Classification of Functioning, Disability and Health (ICF) 2001 |
|-----------|---------------------------------------------------------------------------------------------------|
| PERSONAL CARE | Top level classification  
CHAPTER 3 SUPPORT AND RELATIONSHIPS  
Second level classification  
Paid Care  
Unpaid Care | Detailed level classification  
e310 immediate family  
e315 extended family  
e320 friends  
e325 acquaintances, peers, colleagues, neighbours and community members  
e330 people in positions of authority  
e335 people in subordinate positions  
e340 personal care providers and personal assistants  
e315 strangers  
e350 domesticated animals  
e355 health professionals  
e360 other professionals |
| | Top level classification  
CHAPTER 4 ATTITUDES | Detailed level classification  
e410 Individual attitudes of immediate family members  
e415 Individual attitudes of extended family members  
e420 Individual attitudes of friends  
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members  
e430 Individual attitudes of people in positions of authority  
e435 Individual attitudes of people in subordinate positions  
e440 Individual attitudes of personal care providers and personal assistants  
e445 Individual attitudes of strangers  
e450 Individual attitudes of health professionals  
e455 Individual attitudes of health-related professionals  
e460 Societal attitudes  
e465 Social norms, practices and ideologies  
e498 Attitudes, other specified  
e499 Attitudes, unspecified |
| ENVIRONMENT | Top level classification  
CHAPTER 5 SERVICES, SYSTEMS AND POLICIES | Detailed level classification  
e510 services, systems and policies for the production of consumer goods  
e515 Architecture and construction services, systems and policies  
e520 Open space planning services, systems and |
<table>
<thead>
<tr>
<th>ENVIRONMENT cont’d</th>
<th>Top level classification</th>
<th>Detailed level classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Furnishings and adaptations to homes and other premises</td>
<td>18 Furnishings and adaptations to homes and other premises</td>
<td>e1500 Design, construction and building products and technology for entering and exiting buildings for public use</td>
</tr>
<tr>
<td>18 03 Tables</td>
<td></td>
<td>e1501 Design, construction and building products and technology for gaining access to facilities inside buildings for public use</td>
</tr>
<tr>
<td>18 06 Light fixtures</td>
<td></td>
<td>e1502 Design, construction and building products and technology for way finding, path routing and designation of locations in buildings for public use</td>
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<td>18 09 Sitting furniture</td>
<td></td>
<td>e1508 Design, construction and building products and technology of buildings for public use, other specified</td>
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<td>18 12 Beds</td>
<td></td>
<td>e1509 Design, construction and building products and technology of buildings for public use, unspecified</td>
</tr>
<tr>
<td>18 15 Assistive products for height adjustment of furniture</td>
<td></td>
<td>e1550 Design, construction and building products and technology for entering and exiting of buildings for private use</td>
</tr>
<tr>
<td>18 18 Support devices</td>
<td></td>
<td>e1551 Design, construction and building products and technology for gaining access to facilities in buildings for private use</td>
</tr>
<tr>
<td>18 21 Gate, door, window and curtain openers/closers</td>
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<td>e1552 Design, construction and building products and technology for way finding, path routing and designation of locations in buildings for private use</td>
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<td>18 24 Construction elements in the home and other premises</td>
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<td>e1558 Design, construction and building products and technology of buildings for private use, other specified</td>
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<td></td>
<td></td>
<td>e1559 Design, construction and building products and technology of buildings for private use, unspecified</td>
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<tr>
<td>ENVIRONMENT cont’d</td>
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<tr>
<td>18 30 Assistive products for vertical accessibility</td>
<td>e160 Products and technology of land development) Eg. kerb cuts, ramps, signposting, street lighting, pathways, wildlife trails, planning and development of space, park signage</td>
<td>e1600 Products and technology of rural land development Products and technology in rural land areas, as they affect an individual's outdoor environment through the implementation of rural land use policies, design, planning and development of space, such as farm lands, pathways and signposting</td>
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<tr>
<td>18 33 Safety equipment for the home and other premises</td>
<td>e155 Design, construction and building products and technology of buildings for private use</td>
<td>e1601 Products and technology of suburban land development Products and technology in suburban land areas, as they affect an individual’s outdoor environment through the implementation of suburban land use policies, design, planning and development of space, such as kerb cuts, pathways, signposting and street lighting.</td>
</tr>
<tr>
<td>18 36 Furniture for storage</td>
<td>e150 Design, construction and building products and technology of buildings for public use</td>
<td>e1602 Products and technology of urban land development Products and technology in urban land areas as they affect an individual’s outdoor environment through the implementation of urban land use policies, design, planning and development of space, such as kerb cuts, ramps, signposting and street lighting.</td>
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<tr>
<td>ENVIRONMENT cont’d</td>
<td>Second level classification</td>
<td>Detailed level classification</td>
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<tr>
<td>(e165 Assets)</td>
<td>e165 Assets</td>
<td>e1603 Products and technology of parks, conservation and wildlife areas Products and technology in land areas making up parks, conservation and wildlife areas, as they affect an individual’s outdoor environment through the implementation of land use policies and design, planning and development of space, such as park signage and wildlife trails.</td>
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<td>e1650 Financial assets eg money or financial investments</td>
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<tr>
<td>ASSISTIVE TECHNOLOGY</td>
<td>Top level classification</td>
<td>Second level classification</td>
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<tr>
<td>Top level classification</td>
<td>04 Assistive products for personal medical treatment</td>
<td>04 30 Assistive products for heat or cold treatment</td>
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<td>e1151 Assistive products and technology for personal use in daily living</td>
<td>04 33 Assistive products for pressure-sore prevention (antidecubitus)</td>
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<td>ASSISTIVE TECHNOLOGY cont’d</td>
<td>Top level classification</td>
<td>05 Assistive products for training in skills</td>
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<td>06 Orthoses and prostheses</td>
<td>06 03 Spinal orthoses</td>
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<td></td>
<td>e1151 Assistive products and technology for personal use in daily living</td>
<td>06 04 Abdominal orthoses</td>
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<td>ASSISTIVE TECHNOLOGY cont’d</td>
<td>Top level classification</td>
<td>06 06 Upper limb orthoses (body-worn)</td>
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<td></td>
<td>09 Assistive products for personal care and protection</td>
<td>06 09 Upper limb orthoses (non-body-worn)</td>
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<td></td>
<td>e115 Products and technology for personal use in daily living</td>
<td>06 12 Lower limb orthotic systems</td>
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<td>ASSISTIVE TECHNOLOGY cont’d</td>
<td>Top level classification</td>
<td>06 15 Functional neuromuscular (electrical) stimulators (FNS) and hybrid orthotic systems</td>
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<td>09 Assistive products for protecting the body (body-worn)</td>
<td>06 18 Upper limb prosthetic systems</td>
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<td>e115 Products and technology for personal use in daily living</td>
<td>06 21 Cosmetic upper limb prostheses</td>
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<tr>
<td></td>
<td>09 06 Assistive products for stabilizing of the body (non body-worn)</td>
<td>06 24 Lower limb prosthetic systems</td>
</tr>
<tr>
<td></td>
<td>09 07 Assistive products for dressing and undressing</td>
<td>06 27 Cosmetic lower limb prostheses</td>
</tr>
<tr>
<td></td>
<td>09 12 Assistive products for toileting</td>
<td>06 30 Prostheses other than limb prostheses</td>
</tr>
<tr>
<td></td>
<td>09 15 Assistive products for tracheostomy care</td>
<td>06 33 Orthopaedic footwear</td>
</tr>
<tr>
<td></td>
<td>09 18 Assistive products for ostomy care</td>
<td>09 03 Clothes and shoes</td>
</tr>
<tr>
<td></td>
<td>09 21 Products for skin protection and skin cleaning</td>
<td>09 06 Assistive products for protecting the body (body-worn)</td>
</tr>
<tr>
<td></td>
<td>09 24 Urine diverters</td>
<td>09 07 Assistive products for stabilizing of the body (non body-worn)</td>
</tr>
<tr>
<td></td>
<td>09 27 Urine collectors</td>
<td>09 09 Assistive products for dressing and undressing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>09 12 Assistive products for toileting</td>
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<td></td>
<td></td>
<td>09 15 Assistive products for tracheostomy care</td>
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<td>09 18 Assistive products for ostomy care</td>
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<tr>
<td></td>
<td></td>
<td>09 21 Products for skin protection and skin cleaning</td>
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<td></td>
<td></td>
<td>09 24 Urine diverters</td>
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<tr>
<td></td>
<td></td>
<td>09 27 Urine collectors</td>
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<tr>
<td></td>
<td></td>
<td>09 03 Clothes and shoes</td>
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<td></td>
<td></td>
<td>09 06 Assistive products for protecting the body (body-worn)</td>
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<td>09 07 Assistive products for stabilizing of the body (non body-worn)</td>
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<td></td>
<td>09 09 Assistive products for dressing and undressing</td>
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<td>09 12 Assistive products for toileting</td>
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<td>09 15 Assistive products for tracheostomy care</td>
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<td>09 18 Assistive products for ostomy care</td>
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<td></td>
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<td>09 21 Products for skin protection and skin cleaning</td>
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<tr>
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<td></td>
<td>09 24 Urine diverters</td>
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<tr>
<td></td>
<td></td>
<td>09 27 Urine collectors</td>
</tr>
<tr>
<td>ASSISTIVE TECHNOLOGY cont’d</td>
<td>Top level classification</td>
<td>Second level classification</td>
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<tr>
<td>-----------------------------</td>
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<td>-----------------------------</td>
</tr>
<tr>
<td>12 Assistive products for personal mobility</td>
<td>12 03 Assistive products for walking, manipulated by one arm</td>
<td></td>
</tr>
<tr>
<td>e120 Products and technology for personal indoor and outdoor mobility and transportation</td>
<td>12 06 Assistive products for walking, manipulated by both arms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12 07 Accessories for assistive products for walking</td>
<td></td>
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<td></td>
<td>12 10 Cars</td>
<td></td>
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<tr>
<td></td>
<td>12 12 Car adaptations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12 16 Mopeds and motorcycles</td>
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<tr>
<td></td>
<td>12 18 Cycles</td>
<td></td>
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<tr>
<td></td>
<td>12 22 Human-driven wheelchairs</td>
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<td>12 23 Powered wheelchairs</td>
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<td></td>
<td>12 24 Wheelchair accessories</td>
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<td>12 27 Vehicles</td>
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<td></td>
<td>12 31 Assistive products for transfer and turning</td>
<td></td>
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<tr>
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<td>12 36 Assistive products for lifting</td>
<td></td>
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<tr>
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<td>12 39 Assistive products for orientation</td>
<td></td>
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<tr>
<td></td>
<td>15 Assistive products for housekeeping</td>
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<tr>
<td>e125 Products and technology for communication</td>
<td>15 03 Assistive products for preparing food and drink</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15 06 Assistive products for dishwashing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15 09 Assistive products for eating and drinking</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15 12 Assistive products for house-cleaning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15 15 Assistive products for making and maintaining textiles</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22 Assistive products for communication and information</td>
<td></td>
</tr>
<tr>
<td>e125 Products and technology for communication</td>
<td>22 03 Assistive products for seeing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22 06 Assistive products for hearing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22 09 Assistive products for voice production</td>
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<tr>
<td></td>
<td>22 12 Assistive products for drawing and writing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22 15 Assistive products for calculation</td>
<td></td>
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<tr>
<td></td>
<td>22 18 Assistive products for handling audio, visual and video information</td>
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<tr>
<td></td>
<td>22 21 Assistive products for face-to-face communication</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22 24 Assistive products for telephoning (and telematic</td>
<td></td>
</tr>
<tr>
<td>ASSISTIVE TECHNOLOGY cont’d</td>
<td>Top level classification</td>
<td>Second level classification</td>
</tr>
<tr>
<td>----------------------------</td>
<td>--------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td></td>
<td>24 Assistive products for handling objects and devices</td>
<td>24 04 Marking materials and marking tools</td>
</tr>
<tr>
<td></td>
<td></td>
<td>24 06 Assistive products for handling containers</td>
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<tr>
<td></td>
<td></td>
<td>24 09 Assistive products for operating and/or controlling devices</td>
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<td></td>
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<td>24 13 Assistive products for controlling from a distance</td>
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<tr>
<td></td>
<td></td>
<td>24 18 Assistive products to assist and/or replace arm and/or hand and/or finger function</td>
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<tr>
<td></td>
<td></td>
<td>24 21 Assistive products for extended reach</td>
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<td></td>
<td>24 24 Assistive products for positioning</td>
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<td></td>
<td></td>
<td>24 27 Assistive products for fixation</td>
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<tr>
<td></td>
<td></td>
<td>24 30 Assistive products for repositioning and hoisting</td>
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<td></td>
<td></td>
<td>24 36 Assistive products for carrying and transporting</td>
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<tr>
<td></td>
<td></td>
<td>24 39 Industrial transportation vehicles</td>
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<tr>
<td></td>
<td></td>
<td>24 42 Conveyors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>24 45 Cranes</td>
</tr>
<tr>
<td>ASSISTIVE TECHNOLOGY cont’d</td>
<td>27 Assistive products for environmental improvement, tools and machines</td>
<td>e135 Products and technology for employment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>27 03 03 assistive products for climate control</td>
</tr>
<tr>
<td>ASSISTIVE TECHNOLOGY cont’d</td>
<td>30 Assistive products for recreation e140 Products and technology for culture, recreation and sport e145 Products and technology for the practice of religion and spirituality</td>
<td>30 03 Toys</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30 06 Games</td>
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<tr>
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<td></td>
<td>30 09 Assistive products for exercise and sport</td>
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<tr>
<td></td>
<td></td>
<td>30 12 Musical instruments</td>
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<tr>
<td></td>
<td></td>
<td>30 15 Assistive products for producing photos, films and videos</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30 18 Handicraft tools, materials and equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30 21 Tools, materials and equipment for outdoor and indoor gardening</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30 24 Assistive products for hunting and fishing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30 27 Assistive products for camping and caravanning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30 30 Assistive products for smoking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30 33 Assistive products for pet care</td>
</tr>
</tbody>
</table>
## Appendix D: Role of Thesis Candidate (Primary Researcher) in Relation to Research Stages

<table>
<thead>
<tr>
<th>Step</th>
<th>Research Stage</th>
<th>Conducted by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Selected</td>
<td>Sample selection</td>
<td>Primary researcher</td>
</tr>
<tr>
<td>Conduct Interview</td>
<td>Data gathering</td>
<td>Primary researcher with Participant (N=4)</td>
</tr>
<tr>
<td>Transcribe handwritten Activity Log data (scenario 1: current practice)</td>
<td>Data management</td>
<td>Primary researcher</td>
</tr>
<tr>
<td>- Check Activity Log details with economists</td>
<td>Member checking</td>
<td>Primary researcher with Participant; Economist</td>
</tr>
<tr>
<td>- Clarify any details with participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Transcribe data into Expert Panel format</td>
<td>Clarify data requirements for analysis</td>
<td></td>
</tr>
<tr>
<td>Data management</td>
<td>Data formatting</td>
<td></td>
</tr>
<tr>
<td>Send to expert panel members with reply paid envelopes</td>
<td>Expert review</td>
<td>Primary researcher</td>
</tr>
<tr>
<td>- Collate individual expert panel responses received by mail</td>
<td>Data collection</td>
<td>Primary researcher</td>
</tr>
<tr>
<td>Convene expert panel meeting (1)</td>
<td>Facilitate expert review of 4 cases</td>
<td>Chaired by Primary researcher</td>
</tr>
<tr>
<td>- Transcribe expert panel findings</td>
<td></td>
<td>Primary researcher</td>
</tr>
<tr>
<td>Re-format expert panel findings for re-interview with participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct Interview 2</td>
<td></td>
<td>Primary researcher with Participant (N=3)</td>
</tr>
<tr>
<td>Conduct adapted interview Deafblind participant</td>
<td>Data gathering</td>
<td>Primary researcher, tactile interpreter, AT for dual sensory loss expert (N=1)</td>
</tr>
<tr>
<td>Transcribe handwritten activity log data in scenario 2,3,4 (optimal, moderate, basic)</td>
<td></td>
<td>Primary researcher provide to Economists</td>
</tr>
<tr>
<td>Generate eFHROM comparative charts and activity logs for economics study</td>
<td></td>
<td>Primary researcher</td>
</tr>
<tr>
<td>- Check Activity Log details with economists</td>
<td>Member checking</td>
<td>Primary researcher with Participant; Economist</td>
</tr>
<tr>
<td>- Clarify any details with participant</td>
<td>Clarify data requirements for</td>
<td></td>
</tr>
<tr>
<td>Task</td>
<td>Analysis</td>
<td>Responsibility</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>----------</td>
<td>----------------</td>
</tr>
<tr>
<td>Transcribe data into Expert Panel format</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Send to expert panel members with reply paid envelopes</td>
<td>Expert review</td>
<td>Primary researcher</td>
</tr>
<tr>
<td>Collate individual expert panel responses received by mail</td>
<td>Data collection</td>
<td>Primary researcher</td>
</tr>
<tr>
<td>Convene expert panel meeting (2)</td>
<td>Facilitate expert review of 3 cases</td>
<td>Chaired by Primary researcher</td>
</tr>
<tr>
<td>Formulate feedback to Expert Panel for triangulation</td>
<td></td>
<td>Primary researcher</td>
</tr>
</tbody>
</table>
Stage 1 – Pilot

A pilot of the survey via mail (n-4) and the interview (n-1) was conducted in early 2009 with three individuals with disabilities from the AEAA stakeholder reference group, plus two individuals with specific access needs, as advised by the Evidence Sub-committee. The latter two individuals worked for organisations that are members of the AEAA, but they themselves were not members. They were approached independently of their employers, by the researcher.

The intent of the pilot was to establish the quality of the survey and interview tools, ensuring they would capture the data required, and also to ascertain the completion burden. Conducting the pilot was an essential step in that it identified the need to refine the study design by commissioning a bespoke, accessible online survey (including the capacity to save and return) as described below; and amending the AQoL (as previously described). It was also found necessary to extend the proposed single interview into an interview series as will be outlined in Stage 3 of the research design.
**Stage 2 – Survey**

Despite the prevalence of people living with impairment within the population, they are likely to be substantially under-sampled due to limited flexible or alternative access methods (Kroll 2011). Specifically, anyone using alternative or augmentative communication methods is likely to be excluded from on-line or paper-based surveys unless personal support is used, and institution-dwellers are unlikely to be sampled at all (Kroll 2011). Gottliebsen et al. note that ‘the voices of a proportion of people living with disability are absent from the data collected by surveys, and ‘current accessibility guidelines, even where implemented, still fall short of assuring useable survey tools’ (Gottliebsen et al. 2010: 401).

*The Equipment Study’s accessible survey tool*

A core element of the method design was that of accessibility, given that it was imperative to enable respondents with a wide range of impairments and communication modes to participate. Owens (2007) articulates the epistemological justification for such strategies:

> If we contextualize research within a disability rights perspective, then excluding people who are unable to verbalize, are inarticulate, unable to provide a coherent account or stick to the interview topic means that the researcher is reproducing the inequalities in a non-disabled world that denies opportunities to and oppresses disabled people … Deciding not to research individuals because they are vulnerable could actually increase their vulnerability because people will remain in ignorance about their circumstances and treatment. Furthermore, exclusion from research may also denude the knowledge base of marginalized groups concerning their health, education, welfare and quality of life, etc. (Owens 2007: 307)

Given that the sample size was 100 and geographically diverse, it was felt an online method of surveying was most appropriate. In seeking an accessible survey tool it became clear that commercial online products, and indeed the survey options used by peak health, disability, aging and government institutions nationally and internationally, excluded people with impairment who required alternate access such as screen readers or switching software. A number of commercially available online surveys were trialled, and efforts were made to
contact and consult academics, researchers, and organisations, both within Australia and internationally, who might be expected to run accessible surveys of their membership, to ascertain the best options. However, despite accessibility claims, no pre-existing online survey formats were sufficiently ‘useable’ for the diverse population being surveyed. A full report on the analysis of accessibility of survey instruments was subsequently published (Gottliebsen et al. 2010). Writing, piloting, revising and running a bespoke equipment survey was a successful strategy in eliciting participation from individuals unable to access standard surveys. This approach was accessible to participants who used alternate switching methods or screen-reading technologies.

To widen the range of accessible formats, surveys were also printed in hard copy and mailed to individuals on request. Participants requiring assistance to scribe were encouraged to participate by being offered support to complete the survey in the forms of reimbursement for attendant care or support to scribe. Hard copies were also bulk mailed to organisations who had identified themselves as willing to provide support to complete surveys for individuals requesting it. A $20 Coles Myer voucher was posted in recognition of participants’ time, to the five pilot participants and the first 105 survey participants.

Survey structure

The survey comprised 79 questions (see Appendix F). In Section A, participants were asked to indicate the range of things they use, other help they get in open-ended categories, and their degree of difficulty, on a six-point rating scale. If participants felt improvements could be made to their situation, they were asked to identify ‘the best equipment solutions … irrespective of cost’; they were prompted to consider equipment changes, changes to environments such as home modifications, street changes, workplace changes, changes to carer supports and other factors. Finally, participants were asked to identify the likely resulting changes in their lives from such improvements, and to re-rate the projected difficulty level in undertaking activities in the relevant life domains. These questions were repeated for each of eight life areas. Section B comprised the 20-question set of AQoL 6D; and nine demographic questions formed Section C. Table 29 depicts the survey structure.
Table 29: The Equipment Study survey structure

<table>
<thead>
<tr>
<th>Survey Sections</th>
<th>Format</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Section A</strong></td>
<td>Open-ended questions and ordinal scales for the variables of difficulty and time use (structured into 8 Life Areas (Wilson 2006))</td>
</tr>
<tr>
<td>‘Equipment use in your life’ survey questions 1-8 (6 subquestions)</td>
<td></td>
</tr>
<tr>
<td><strong>Section B</strong></td>
<td>Forced choice ordinal scale</td>
</tr>
<tr>
<td>Australian Quality of Life Measure (AQoL 6D) (20 questions)</td>
<td></td>
</tr>
<tr>
<td><strong>Section C</strong></td>
<td>Tick-the-box standardised questions and open-ended questions</td>
</tr>
<tr>
<td>Demographic questions (11 questions)</td>
<td></td>
</tr>
</tbody>
</table>

Stage 3 - Sub-set of interview participants

Eight individuals were selected for interviews, a feasible number to make in-depth investigations given the resources available for this study. This purposeful selection was based on a protocol-seeking archetypal representation (AIHW 2006b) of key variables that characterise assistive technology users. These included a range of diagnoses (spread across body function and structure categories of the ICF (WHO 2001), a range of assistive technologies used, then spread of age, gender, living situation, and urban versus rural dwellers.

Interviews were semi-structured and included viewing the participant’s home and current AT set-up. Data was collected during interviews using the electronic Functioning and Health Related Outcomes Module (eFHROM) (AIHW 2005). The interview schedule included questions regarding current and prospective time use and the mix of AT and formal or informal care used to perform activities.

Interview 1 represents an initial data-gathering interview. Interview 2 took place subsequent to an expert panel having reviewed and provided commentary on each interview participant’s current situation, as will be detailed shortly.

Table 30: Interview format

<table>
<thead>
<tr>
<th>Method</th>
<th>Format</th>
<th>Life Areas Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview 1</td>
<td>Ordinal scales for eFHROM (WHO 2001) Open ended commentary regarding themes emerging from use of eFHROM</td>
<td>WHO ICF Activity and Participation chapters</td>
</tr>
</tbody>
</table>
### Interview 2

<table>
<thead>
<tr>
<th>Time-use tool/ activity log</th>
<th>Expert Panel recommendations</th>
<th>WHO ICF Activity and Participation chapters</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ordinal scales for eFHROM (WHO 2001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Open ended commentary regarding themes emerging from use of eFHROM</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time-use tool/ activity log</td>
<td></td>
</tr>
</tbody>
</table>

Interviewees rated their experience against eFHROM scales by considering both their current level of AT provision and the hypothetical ‘optimal’ AT solution. The overall intent of these interviews was to explore and compare the differences in outcomes that might occur between three scenarios:

1. ‘usual treatment’: that is, current situation;
2. provision of ‘basic’ AT solutions: that is, devices or environmental modifications currently listed as eligible for Victoria’s Aids and Equipment Program subsidy (SWEP);
3. provision of ‘optimal’ AT solutions.

Scenario 1 represented each participant's actual situation, while scenarios 2 and 3 were hypothetical, as it was beyond the resources of the study to provide identified AT and then evaluate its actual impact. This approach was designed to enable a comparison of outcomes of AT available within current government policy, with AT define as optimal, thereby exploring in what ways current policy might restrict outcomes, as per research inquiry 3.

Two interview protocols were used for interview participants (see Appendix G). The standard protocol was used for seven of the eight participants, and an amended protocol was adopted to suit the communication needs and to minimise the participants burden of the eighth participant, who described herself as fully Deafblind. Specifically, a tactile interpreter and interpreting table were required, with certain questions and phrases modified to be understood in tactile Auslan. Initial interviews in participants' homes of between one and two hours' duration were conducted with seven participants during October and November 2009. A single interview with the modified protocol for the individual who was Deafblind was conducted with the relevant AT expert present, in February 2010.
A payment of $40 in Coles Myer vouchers was provided to participants at the end of Interview.

Stage 4 – Expert Panel

Precedent exists for the use of expert panels in research. Experts are usually identified on the basis of years of practice in specific areas and can be used to provide key perspectives (Ryan and Campbell 2009). NHMRC (2009) lists expert panel consensus as acceptable evidence, and, in a similar design to ‘The Equipment Study’, AIHW convened expert panels to review archetypal cases of the therapy and equipment needs of people with cerebral palsy and similar disabilities (2006b).

The Equipment Study expert panel design

The seven members of the expert panel were selected on the basis of expertise in identifying AT solutions, and for their ability to contribute significant clinical judgement and experience to the process of forecasting the effects of any AT proposed. Experts were identified across a number of relevant disciplines and AT services. The selection process is described in Appendix H. The panel consisted of four clinicians from private practice, one from a specialist state-wide AT centre, a state equipment funding co-ordinator, and a representative from an AT facility. The panel was convened after Interview 1 in order to analyse the data generated from each interviewee. Interview data was summarised into ‘case study’ format for use by the expert panel. The term ‘case study’ is used interchangeably with ‘interview’ for this methods outline.

The panel had two main tasks:

1. to identify a range of mediating solutions for each interviewee to reflect ‘basic’ and ‘optimal’ assistive technology provision and environmental modification;
2. to analyse case studies to determine functional and participation effects of current, basic and optimal levels of assistive technology provision.

Their information was then taken to the second interview with respondents as discussed in Stage 5.
The protocol concerning the operation of the expert panel, outlined in Table 31, ensured that individual and group-based recommendations were captured, and clearly identified whether the basic AT solutions were included as part of the optimal solution to be presented to the participant at the second interview.

**Table 31: Expert panel procedure**

<table>
<thead>
<tr>
<th>Step</th>
<th>Procedure</th>
<th>Steps taken to minimise bias and confounding</th>
</tr>
</thead>
</table>
| 1    | Each panel member provided with: **Definitions:**  
      - Optimal: defined as the best combination of enablers including any solution, regardless of cost, currently on the market and available in Australia.  
      - Assistive Technology (www.ilca.org.au; ISO 9999)  
      - Environment (chapters 1-5 WHO ICF)  
      **Parameters for AT selection:**  
      - Available on the market (international or Australia)  
      - OR previously manufactured by TAD and not yet to market  
      - No reference to cost  
      - Not necessarily TGA/AS approved. | Provide consistency of definition from peer reviewed sources.  
Provide consistent parameters to all.  
This information mailed to panel members independently. |
| 2    | Email/post initial 4 case studies to each panel member:  
      - Experts engage in separate coding at level 1 (broad level) activity and participation chapters.  
      - Experts generate a list of ‘optimal’ recommendations including their rationale. | No contact between panel members or dialogue with the researcher at this point, to ensure independent rating and decision-making. |
| 3    | Convene expert panel for a morning for discussion and consensus building re each case.  
      **Consensus rules:**  
      - all experts to share their individual recommendations and scores, and be heard in turn;  
      - discussion of any variable or conflicting scoring or recommendation chaired by researcher;  
      - determine consensus recommendation or score via unanimous agreement or, in absence of this, include variation in | Researcher collected hard copies of independent ratings/recommendations prior to commencing consensus session.  
Researcher made explicit the rules for achieving consensus.  
Researcher chaired the session, writing consensual recommendations and scores via electronic whiteboard.  
Documentation of recommendations and scores |
**Step 2**  
Email/ post last 3 case studies to each panel member:  
- Experts engage in separate coding at level 1 (broad level) activity and participation chapters;  
- Experts generate a list of ‘optimal’ recommendations including their rationale.

**Repeat step 2**  
As above.

<table>
<thead>
<tr>
<th>Step</th>
<th>Procedure</th>
<th>Steps taken to minimise bias and confounding</th>
</tr>
</thead>
</table>
|            | recommendation where possible (if it does not conflict with another recommendation), or, majority rule in determining final recommendation and score, with dissention noted in writing;  
NB consensus was reached in all cases via the strategy of including diversity of recommendation. Scoring disparities related to differing inclusion judgements and were resolved consensually. | was emailed to panel members for member checking; any amendments were then emailed to the whole panel for feedback and confirmation. |

**Repeat step 3**  
Convene expert panel for discussion and consensus building re each case.

**As above.**

**Stage 5 - Second Interview**

The task of the second interview was to elicit which of the expert panel’s recommendations the participant elected to take into the hypothetical situation. Second interviews in participants’ homes occurred post-expert panel review, through the period November 2009–January 2010. Exceptions were the participant with Deafblindness who had one interview only, and a rural participant who was interviewed by phone in the second stage. Each participant was provided with verbal feedback about the expert panel’s recommendations, along with product pictures and print outs from the Independent Living Centre (Victoria) database where specific products were recommended. These served as discussion tools to inform participants of the products and what they might offer, and were left with participants for future reference. Additionally, the researcher wrote up accepted recommendations in the form of a letter for several participants, when requested. Discussion of this material afforded the participant and interviewer the opportunity to discuss the rationale for acceptance or refusal of the recommendations, as well as the impacts and
outcomes that the AT solutions were perceived to offer from participant and from expert standpoints.

Having identified which recommendations were accepted, the eFHROM and activity log were readministered, focusing primarily with the eFHROM on previously identified life areas, but re-coded for any envisioned change. Having completed an initial AQoL for the current situation via the survey, participants were provided with a further copy of the AQoL at the second interview and asked to fill this in with the hypothetical optimal situation in mind, and return it by reply-paid post. A $20 or $40 Coles Myer voucher was provided to participants at Interview 2, depending upon the length of second interview (which lasted approximately one to two hours).

**Stage 6: Analyse interview and survey data for ‘The Equipment Study’**

Quantitative data analysis identified the prevalence of AT elements in use, outcomes, issues and characteristics, while thematic analysis of the qualitative data provided valuable information to expand on the quantitative data, in order to understand the lived experience of participants better.

**Initial data set**

The full cohort (i.e. all survey and interview participants) provided ‘survey’ data which was analysed as follows: data was captured in Excel then coded using NVIVO 8 qualitative software. Excel provided statistical counts and correlations, while NVIVO was used to sort, code and recode data into thematic categories. Survey data was analysed according to the category of mediator used and the life domain in which it was used, the category of desired improvements identified, and the effect upon degree of difficulty or time use that changes may offer. These queries represented straight analysis according to the question set.

Demographic data was compared with Australian population and the Victorian Aids and Equipment Program (VAEP) population as the primary government equipment funding source where possible, to gain an indication of the representativeness of the sample. Secondary analysis of all data included a quantitative and qualitative analysis utilising key outcome categories derived from the literature. In particular, data was analysed against the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006),
Victorian Department of Human Services Quality Framework for Disability Services (DHS 2007b), and the National Disability Strategy (Commonwealth of Australia 2011), as well as against social participation and inclusion indices. Emergent themes, such as the differentiation between enabling environments (at home) and environments beyond the doorstep (community and attitudinal environments) were also explored.

**Interview data set**

The initial survey data from eight interview participants were analysed within the above dataset. Three interviewees required the researcher to act as scribe during the survey stage because of their data entry issues, and, for one participant, this became part of the interview process (see Appendix G). Although this caused variation in procedure, it resulted in answers to the survey questions being captured and entered into EXCEL as per other surveys. In addition, one survey participant, who opted out of the VAEP despite significant AT needs, was interviewed separately on this subject; this is reported in the results section. Interview data was summarised into ‘case study’ formats for use by the expert panel. The recommendations of the expert panel and responses to them by participants were analysed as part of the interview series. Interview data was analysed both quantitatively and qualitatively, and included thematic analyses.

**Stage 7 – Collate pre- and post-intervention case studies for the economic study**

The interview and expert panel data was collated and provided to the researchers from Deakin Health Economics who were commissioned to do the economic evaluation. This data was analysed and reported in ‘The Economic Study’ (Colgan et al. 2010).

**Stage 8 – Member check**

As is appropriate for qualitative methods, a member checking process was implemented so participants had an opportunity to check and validate the interpretation of their data, thus building trustworthiness in the research process. Interview participant summaries were written by the author and provided to the participants via email or post, according to their wishes. The opportunity was offered to discuss and amend the summaries and other documentation, to
ensure people felt they were an accurate reflection of the interviews, and to ensure the desired degree of anonymity. Several participants re-drafted sections of their summary, one doing it several times to refine and add to its content. During this member-checking stage, six of the eight participants stated they wished to use their own first names in project publications. As a result, an ethics amendment was submitted seeking approval to enable this. Following ethics approval, all interview participants were contacted again to provide a final opportunity for them to review and confirm or amend material to be published about them.

**Stage 9 – Publication**

‘The Equipment Study’ was published as one of two studies, one authored by the PhD candidate and her supervisor, and the other (‘The Economic Study’) by the economics team. An additional document was co-authored by various members of both teams, outlining the research implications. Taken together, these documents form the *Equipping Inclusion Studies* (Layton et al. 2010).
Appendix F: Survey Tool (Excerpt)

The Equipment Survey:

What difference does assistive technology (aids and equipment) make to life for people with a disability?

Please read the Plain Language Statement for information about this research project.

Principal Researchers: Dr Erin Wilson; Dr Marj Moodie and Prof Rob Carter

Associate Researcher: Natasha Layton

Contact Person: Erin Wilson ph 9244 6158

School of Health and Social Development - Deakin University

221 Burwood Highway, Burwood Victoria 3125 Australia

There are 3 parts to the Equipment Survey

A. Equipment Use in Your Life Survey
B. Australian Quality of Life Measure (2)
C. Demographic questions.

To thank you for your time, we will send you a Coles Myer voucher for $20 when we receive your completed survey.
PART A: Instructions for Equipment Use in Your Life Survey

Please tell us about the things you currently do in life and the equipment devices, home modifications or other items that help you to do these things. Also tell us about other help you get, such as paid or unpaid care that helps you do these things. This includes whether you actually do tasks or activities yourself, or direct others to do them for you. You might use the same things in several or all life areas. It is important that you repeat the information in these sections so researchers know that that things have use in several life areas. *Complete as many of the life areas as are important to you.*

The questions cover eight (8) life areas:

1. **Personal and Family Wellbeing** which includes health and function, happiness, wellbeing, safety, sense of independence and choice
2. **Social Life** which includes friendships and relationships, community involvement and sense of belonging
3. **Recreation and Leisure Life** which includes being involved in recreational or leisure activities at any level. This might be through attending activities, playing an active part or doing what you enjoy.
4. **Economic Life** which includes your finances, employment or business.
5. **Educational Life** This area relates to your education, training, personal or professional development.
6. **Political life** which includes having a say about things that affect you (e.g. in a local service or community group, about your local area, funding etc.).
7. **Cultural life** which includes being involved in cultural activities (e.g. arts, music, theatre, dance at any level). This might be through attending activities or playing an active part. Or through being part of your own cultural group.
8. **Spiritual life** which includes any aspect of your religious or spiritual activities.
Section 1: This section relates to your Personal and Family Wellbeing

1.1 Please list the things that enable you to do activities related to your personal and family wellbeing:

<table>
<thead>
<tr>
<th>Personal and family wellbeing:</th>
<th>Things I use – aids and equipment, modifications and alterations to the environment</th>
<th>Other help I get – paid and unpaid care (how many hours per day)</th>
</tr>
</thead>
<tbody>
<tr>
<td>This is anything that relates to your personal life, health, wellbeing and safety. It might include: looking after yourself (e.g. bathing, toileting, managing your health such as skin care or medications)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Domestic tasks (e.g. meals, laundry, managing household appliances such as changing lightbulbs or charging scooter)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Mobility (eg, getting from chair to bed, getting around inside and outside the home)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Choosing your own lifestyle and supports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Being safe and independent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Having fun and enjoying life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Staying healthy and looking after your health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Communicating</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1.2 Overall, how much difficulty do you have doing activities related to your Personal and Family Wellbeing?

<table>
<thead>
<tr>
<th>No difficulty</th>
<th>Mild difficulty</th>
<th>Moderate difficulty</th>
<th>Moderate to severe difficulty</th>
<th>Severe difficulty</th>
<th>Complete difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Section 1: Personal and Family Wellbeing (continued)

These questions ask what you consider the best equipment solutions are for your Personal and Family Wellbeing, irrespective of costs.

Answer the questions below if you feel improvements could be made to your situation. Otherwise go to the next section.

1. 3 Costs aside, describe any improvements that would meet your Personal Wellbeing needs
    *Tick any relevant boxes and describing the change or solution:*
    - Equipment Changes
    - Changes to your environments (e.g. home modifications, street changes, workplace changes)
    - Changes to carer support
    - Other:

1. 4 What could you do as a result of these changes that you can’t do now?

1. 5 What impact on your time would these changes have?
   (this may be through saved time because of more efficient use of time, or spending extra time on things you want to do)

1. 6 Overall, how much difficulty do you believe you would have if the above changes occurred?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>no difficulty</td>
<td>mild difficulty</td>
<td>moderate difficulty</td>
<td>moderate to severe difficulty</td>
<td>severe difficulty</td>
</tr>
</tbody>
</table>
### Appendix G: Interview Participant Protocols

**Interview Protocols Used: Standard and Amended Protocol**

<table>
<thead>
<tr>
<th>Standard protocol (used with participants 1-7)</th>
<th>Variations from standard protocol used with participant 8 (Deafblind)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Interview with participant and researcher present</td>
<td>Interview with participant, researcher, tactile interpreter and the Victorian expert in AT solutions for dual sensory impairments (AbleLink). Participant and expert led the researcher through the AT suitable for Deafblind, demonstrating each item and explaining the impact of the AT. This served to familiarise researcher with the devices as well as build rapport over concrete discussion – a complex and necessary step with a Deafblind individual given the inability to use expression and meaningful gesture.</td>
</tr>
<tr>
<td>2. Expert Panel consider deidentified case</td>
<td>This small community are all known to each other, and no other expert exists in this specialised area in Australia, hence locating an external independent expert was not possible.</td>
</tr>
<tr>
<td>3. Re-interview participant with findings from expert panel</td>
<td>This step was subsumed into the one-off interview given the limited enabler choices available and the pragmatic considerations with time and interviewer availability. Additionally, document exchange and comment supplemented answers (as identified below).</td>
</tr>
<tr>
<td>4. Member-checking</td>
<td>A lengthy member checking process commenced, significantly longer than with other participants, as the participant waited for the correspondence to be printed in Braille for ease of reading. Despite enthusiasm for the task, this participant took some weeks to be able to respond to member check the case summary. Subsequent to this, participant and expert were asked to member check the costs and benefits for the outcome summary documented by the researcher in the absence of a second interview. Amendments were incorporated and once again circulated for member checking until consensus was reached.</td>
</tr>
<tr>
<td>5. Participant to score and re-score satisfaction and difficulty scales, and complete pre and post activity log</td>
<td>These requirements were modified such that a global satisfaction score was used for current and future (with enablers) scenarios. The activity log format was adapted to capture via interview, the activities in which this participant engages, rather than bring in the extra variable of time which adds a level of complexity to capture in terms of communication.</td>
</tr>
<tr>
<td>6. Participant to complete a second AQoL (this was done without the researcher present and with reply-paid envelope provided)</td>
<td>The AQoL was problematic as several questions contained words not in the Auslan vocabulary (despair) or familiar to participant (family role). Substitute words were provided (e.g. stress, terrible, grief) or examples given (helping your family, being part of the family). All options needed to be held in memory along with the question by the participant when being translated, and the actual translation of the 4 or 5 scale items was, at times, poorly nuanced. While the completion of one AQoL did occur adequately,</td>
</tr>
</tbody>
</table>
participant, expert and interpreter agreed that the added complexity of a hypothetical (what if you had the enablers) would be difficult to manage in translation, and fatigue was a factor by this stage of the interview. Again, the option of the participant completing a second AQoL via Braille or computer access is difficult given the question structure (lists of responses) and the lack of assistance to interpret unfamiliar terms.

| 7. Expert Panel to rate participation extent | Participation was documented by researcher and Expert. Extra advice as to participation for this population was sought from a second expert within ABLE, a speech pathologist who is also a PhD candidate and researching the Deafblind population. This advice confirmed the participation scores. |

**Commentary upon use of eFHROM tool with Deafblind Participant**

Interview tools included the eFHROM data capture tool based on the ICF. All activity and participation chapters of WHO ICF, as expressed in eFHROM tool, were presented to the participant. Any activity and participation sub-chapters with relevance to the participant’s life were rated on the four scales provided (WHO ICF):

- level of difficulty
- need for personal assistance
- extent of participation
- satisfaction with participation

As per AIHW guidelines (Sykes, Oglesby and Carr 2007), the participant’s own rating was used for all scales except extent of participation, which was intended to capture an independent view, in this case that of the associate researcher (occupational therapist). Where a scale did not have relevance to the participant (e.g. help/ supervision when none is used in current situation), this section was not filled in to save time and burden. Scores in relation to these four scales (difficulty, participation etc) were converted to percentages, as allowed in eFHROM protocol. This enabled scores to be viewed in the same numerical context; given the difficulty scale has four increments of change, and all other scales have five increments. This also allowed capacity to generate a percentage change where the participant or clinician identified that the scale increments were insufficiently fine to capture the degree of change.
Appendix H Expert Panel

Protocol for Expert Panel Selection and Implementation

The rationale for the use of expert panels having been covered, the following steps denote the process of appointing and utilizing the Expert Panel for the Equipping Inclusion Studies:

- Step 1: Identify 12 Victorian services and organizations involved in assistive technology service delivery.
- Step 2: Map identified expert services or individuals to ISO, ICF and diagnostic categories to ensure the Expert Panel shortlist provides coverage of broad diagnostic, and AT prescription areas.
- Step 3: Purposefully select candidates from identified services. The outcome was selection of four occupational therapists as follows:
  - Private clinical practice & TAC advisor specialising in AT and multiple /complex clients;
  - VAEP funding co-ordinator;
  - Educator from Independent Living Centre
  - ComTEC (communication technology team).

Careful consideration was given as to a mix of professional groupings in the panel. An environmental scan of prescribers identified the following patterns:

- occupational therapists are main prescribers across breadth of AT;
- physiotherapists prescribe mainly gait aids and mobility equipment (both PT and OT prescribe seating, wheelchairs and pressure care);
- speech pathologists largely prescribe augmentative and alternative communication devices (AAC);
- nurses may prescribe/recommend beds and bed equipment, continence and pressure care equipment;
- rehabilitation engineers, though not generally prescribers, are experts in AT design and equipment failures.

Preliminary discussions were had with speech pathologists, physiotherapists and rehabilitation engineers re the work of the panel. The speech pathologist and rehabilitation engineer indicated that their input may be somewhat limited.
across the breadth of prescription areas involved. The speech pathologist commented that an occupational therapy member of the team would also be able to make recommendations regarding communication, due to the transdisciplinary nature of their work. A physiotherapist was invited to attend however was replaced with an occupational therapist due to staffing issues within the service. The absence of multi-disciplines on the panel is not felt to be a disadvantage, given it represents the most common clinical scenario in terms of who prescribes, especially given the expectation to consider and recommend for the whole individual, rather than a specialty area (communication or mobility). NOTE: an amended protocol was required for participant 8, a Deafblind individual. In this instance, the Expert Panel selected above felt unable to recommend for or rate this individual given the specialist nature of disability, An alternate expert was nominated by this group and is the only individual in Victoria with the skill set to address the AT solution needs of Deafblind individuals.

Case study data was de-identified before being presented for secondary analysis by an Expert Panel of AT specialists. Reimbursement was provided at a clinical pay rate for two of the four panel members whose involvement was dependent on payment; others were supported by their employers to attend. The Panel reviewed cases both separately via email, and together, with seven cases split over two half-day sessions. This face to face session elicited individual recommendations, then used a discussion-based format to generate consensus. In the absence of agreement, the majority decision was documented.

These Consensus sessions together generated an expert panel consensus document including:

1. ‘basic’ AT solutions and the life domains they enable;
2. ‘optimal’ AT solutions and the life domains they enable;
3. consensus scores for all eFHROM areas (level of difficulty, extent of personal care, participation) for both basic and optimal solutions, using averaging to achieve a score when consensus did not exist.
Sample eFHROM Report Format for Expert Panel

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>ICF Activity &amp; Participation Subchapter d430-d449 CARRYING, MOVING AND HANDLING OBJECTS</td>
<td>moderate difficulty - 2</td>
<td>ECU funded to VAEP limits</td>
<td>Environmental Control Unit fully funded Modify kitchen and other cupboards to access beneath and low reach ranges</td>
</tr>
<tr>
<td>always needs help/supervision - 2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderate participation restriction - 2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderate dissatisfaction - 3</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix I: Information Flyer

Equipment Survey Information Flyer

Are you a Victorian adult living with a disability?
Do you use aids and equipment?

A group of researchers at Deakin University, sponsored by the Aids and Equipment Action Alliance, are conducting research on the experiences of people using aids and equipment. The research aims to identify the most effective way for government to provide aids and equipment.

Can you help?
Participation in this project will involve filling in a survey about the equipment you use and the help you get to do everyday things. This will take approximately one hour to complete. The survey also asks whether you would like to take part in an interview. If you are selected for an interview, the researcher will ask you about your equipment, your daily life and your goals and plans in more detail. The interview will take approximately two hours, and the researcher will meet you wherever is convenient, over one or two visits.

To fill in The Equipment Survey on-line, go to http://research.aeaa.org.au. The Equipment Survey does not have to be completed all at once, simply click on ‘Bookmark this page’ to save the survey and return to it later. Alternatively, if you would like us to mail you a paper version of The Equipment Survey, please contact the Associate Researcher below.

Support to participate in this research
Help is available if you require someone assist you to fill it in. We provide a $20 Coles Myer voucher in recognition of your time for survey completion. Reimbursement for attendant care and travel costs is also offered.
Appendix J: Recruitment and Sample

An information and recruitment flyer was widely distributed through the Victorian Aids and Equipment Action Alliance (AEAA) to its members including:

**Distribution channels for flyer**

<table>
<thead>
<tr>
<th>AEAA members</th>
<th>Other organisations/avenues who agreed to distribute</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able Australia</td>
<td>InfoXChange</td>
</tr>
<tr>
<td>Action for Community Living</td>
<td>ZYTEQ</td>
</tr>
<tr>
<td>Association for Children with a Disability</td>
<td>Our Community</td>
</tr>
<tr>
<td>MacKillop Family Services</td>
<td>Vision Impairment Listserv Australasia (to Victorians only):</td>
</tr>
<tr>
<td>CAUS Communication Rights Australia</td>
<td>AFDO</td>
</tr>
<tr>
<td>Care Connect</td>
<td>Health Issues Centre</td>
</tr>
<tr>
<td>Carers Victoria</td>
<td></td>
</tr>
<tr>
<td>Diamond Valley Special Development School</td>
<td></td>
</tr>
<tr>
<td>Bayview Disability Services</td>
<td></td>
</tr>
<tr>
<td>DEAL Communication Centre</td>
<td></td>
</tr>
<tr>
<td>Chronic Illness Society</td>
<td></td>
</tr>
<tr>
<td>Disability Advocacy Resource Unit</td>
<td></td>
</tr>
<tr>
<td>/Victorian Disability Advocacy Network</td>
<td></td>
</tr>
<tr>
<td>Disability Justice Advocacy</td>
<td></td>
</tr>
<tr>
<td>Vision Australia</td>
<td></td>
</tr>
<tr>
<td>Housing Resource and Support Service</td>
<td></td>
</tr>
<tr>
<td>Mobility Plus</td>
<td></td>
</tr>
<tr>
<td>Latrobe Community Health Service</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AEAA members</th>
<th>Other organisations/avenues who agreed to distribute</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent Living Centre</td>
<td>Wesley Neurological Support Services</td>
</tr>
<tr>
<td>ISIS Primary Care</td>
<td>ARATA</td>
</tr>
<tr>
<td>Australian Orthotic Prosthetic Association</td>
<td>Centre for Developmental Disability Victoria</td>
</tr>
<tr>
<td>Melbourne Citymission</td>
<td>Council on the Ageing</td>
</tr>
<tr>
<td>Monashlink Community Health Service</td>
<td>AMIDA disability advocacy group</td>
</tr>
<tr>
<td>MS Australia</td>
<td></td>
</tr>
<tr>
<td>National Disability Services</td>
<td></td>
</tr>
<tr>
<td>Nillumbik Community Health Service</td>
<td></td>
</tr>
<tr>
<td>Office of the Public Advocate</td>
<td></td>
</tr>
<tr>
<td>OT Australia</td>
<td></td>
</tr>
<tr>
<td>ParaQuad Victoria</td>
<td></td>
</tr>
<tr>
<td>Royal Talbot Victorian Spinal Cord Service</td>
<td></td>
</tr>
<tr>
<td>Scope</td>
<td></td>
</tr>
<tr>
<td>VCOSS</td>
<td></td>
</tr>
<tr>
<td>Epilepsy Foundation of Victoria</td>
<td></td>
</tr>
<tr>
<td>Yooralla Society of Victoria</td>
<td></td>
</tr>
<tr>
<td>Youth Disability Advocacy Service</td>
<td></td>
</tr>
</tbody>
</table>
Most respondents heard about the survey through consumer organisations and networks (48%), with a further 16% being recruited via information provided by allied health services, and 13% via case managers.

Table 32: How participants heard about the research project

<table>
<thead>
<tr>
<th>Source of information</th>
<th>Number of participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTAL (respondents for this question)</td>
<td>75</td>
<td>100%</td>
</tr>
<tr>
<td>Consumer organisations (Infoxchange; ARATA; DARU; Metro-access; Carers Victoria; Chronic Illness Alliance; Polio Network; Health Issues Centre; Disabled Motorists Association; AQA)</td>
<td>36</td>
<td>48%</td>
</tr>
<tr>
<td>Allied Health: OT, Speech Pathologist, Social Worker, Physiotherapist)</td>
<td>12</td>
<td>16%</td>
</tr>
<tr>
<td>Case manager/ISP (Disability Linkages; Northern Linkages)</td>
<td>10</td>
<td>13%</td>
</tr>
<tr>
<td>LGA/health and community networks (CRC; Whittlesea Council; Whittlesea Disability Network; Knox City Council; Nillumbik Shire; Royal Talbot Hospital)</td>
<td>8</td>
<td>11%</td>
</tr>
<tr>
<td>Friends/family</td>
<td>6</td>
<td>8%</td>
</tr>
<tr>
<td>Aids and Equipment Program; suppliers (Independence Australia)</td>
<td>3</td>
<td>4%</td>
</tr>
</tbody>
</table>

NB. The question as to how participants heard of the study was placed in the last section of the survey. 25 participants who partially filled in earlier parts of the survey did not complete this question.
Appendix K: Comparison of current VAEP subsidy level with current market cost

Table 33: Victorian Aids and Equipment Program List (DHS February 2010)

<table>
<thead>
<tr>
<th>Categories</th>
<th>Average subsidy gap</th>
<th>Examples of included AT and subsidy amount</th>
<th>Examples of excluded AT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mobility Aids and Equipment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean cost $412</td>
<td>Walking frames</td>
<td>Sticks</td>
<td>Crutches</td>
</tr>
<tr>
<td>(38 in database; 21 priced products)</td>
<td>(Maximum subsidy - $300)</td>
<td>Sports</td>
<td>wheelchairs</td>
</tr>
<tr>
<td>Mean cost $1371</td>
<td>Manual wheelchairs-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(29 in database; 14 products incl 5 price ranges)</td>
<td>basic (Max subsidy - $1000)</td>
<td></td>
<td></td>
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<tr>
<td>Mean cost $2147</td>
<td>Manual wheelchairs-</td>
<td></td>
<td></td>
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<tr>
<td>(13 in database; 7 products incl. 5 price ranges)</td>
<td>lightweight (max subsidy $1250)</td>
<td></td>
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<tr>
<td>Mean cost $6,739 however only 7 of 64 items carried prices: usually POA for customised product therefore costs higher.</td>
<td>Powered wheelchairs</td>
<td></td>
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<tr>
<td>(nb cheap Taiwanese imports – unlikely to be funded but bring mean cost down)</td>
<td>(max subsidy $6000)</td>
<td></td>
<td></td>
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<tr>
<td>Mean cost $3,200</td>
<td>Scooters</td>
<td></td>
<td></td>
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<tr>
<td>($3,004 for 3 wheelers; $3,442 for 4 wheelers)</td>
<td>(max subsidy $4000)</td>
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<tr>
<td>(57 priced of 77 in database incl 3 with price ranges)</td>
<td></td>
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<tr>
<td>(nb cheap Taiwanese imports – unlikely to be funded but bring mean cost down)</td>
<td></td>
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<tr>
<td><strong>Orthoses</strong></td>
<td>Calipers</td>
<td></td>
<td>Jobst garments</td>
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<tr>
<td>Shoes (specialised)</td>
<td>(specialised)</td>
<td></td>
<td>Over the counter splints</td>
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<tr>
<td>Custom moulded orthosis/ build-ups</td>
<td></td>
<td></td>
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<tr>
<td><strong>Personal Aids</strong></td>
<td>Mean cost $2882 (38)</td>
<td>Powered bed</td>
<td></td>
</tr>
<tr>
<td><strong>and Equipment</strong></td>
<td><strong>prices of 73 products in database incl 10 price ranges; exclude programmable turning bed)</strong></td>
<td><strong>(max subsidy $2000)</strong></td>
<td></td>
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<td>------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
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<tr>
<td><strong>Mean cost $220</strong> (2 in database – same cost)</td>
<td><strong>Bedstick (max subsidy $200)</strong></td>
<td></td>
<td></td>
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<tr>
<td><strong>Mean cost $618</strong> (11 priced of 20 in database incl 8 price ranges)</td>
<td><strong>Portable Ramps (max subsidy $400)</strong></td>
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<tr>
<td><strong>Pressure cushions:</strong>&lt;br&gt;Mean cost $551 (11 priced of 40 in database incl 4 ranges; excluded powered alternating cushions)&lt;br&gt;Static pressure mattress: mean cost $1,493 (4 of 51 priced)&lt;br&gt;Dynamic pressure mattress $2,133 (5 of 46 items priced)</td>
<td><strong>Pressure care equipment (max subsidy $1070 per 2 years)</strong></td>
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<tr>
<td><strong>Environmental Control Units</strong></td>
<td><strong>E.g. PROG $4,200</strong></td>
<td><strong>Max subsidy $3000 or $2,300 where ECU included with Electronic Communication Device</strong></td>
<td><strong>Commercially available intercom style systems</strong></td>
</tr>
<tr>
<td><strong>Personal Use Items</strong></td>
<td><strong>Wheeled Commode:</strong>&lt;br&gt;Mean cost $1,038 (8 of 45 items priced)&lt;br&gt;Overhead track hoists $2,881 (6 out of 29 priced)&lt;br&gt;Mobile hoists $3,145 (2 of 27 items priced)</td>
<td><strong>Wheeled commodes (max subsidy $1000)</strong>&lt;br&gt;Shower chairs&lt;br&gt;Hoists (max subsidy $2,600 mobile; $3,300 ceiling plus installation subsidy $300)&lt;br&gt;Specialised seating</td>
<td><strong>Air conditioners</strong>&lt;br&gt;<strong>Computers</strong>&lt;br&gt;<strong>Visual aids</strong>&lt;br&gt;<strong>Bed ladders</strong>&lt;br&gt;<strong>Footstools</strong></td>
</tr>
<tr>
<td><strong>Communication Aids and Equipment</strong></td>
<td><strong>Electronic Voice Aids</strong>&lt;br&gt;<strong>Voice prosthesis</strong>&lt;br&gt;<strong>Electronic communication device</strong></td>
<td><strong>Communication boards</strong></td>
<td></td>
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<tr>
<td><strong>Home Modifications</strong>&lt;br&gt;“personal communication: Environmental Modifications Special Interest**</td>
<td><strong>Ramp to eliminate a 500-600mm rise (3-4steps) costs $8,000 - $10,000</strong>&lt;br&gt;Average bathroom modification costs $17,500 - $23,000*</td>
<td><strong>$4,400 per lifetime subsidy</strong>&lt;br&gt;bathroom, toilet, kitchen, laundry modifications related to disability.&lt;br&gt;hand basins for wheelchair access.</td>
<td><strong>Many aspects of modification are excluded e.g. expenses of making good the bathroom flooring when a stepless</strong></td>
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<tr>
<td>Groups OT Australia Victoria; Archicentre; MS Society 2009/2010</td>
<td>Average kitchen modification/ renovation costs $7,500 - $25,000*</td>
<td>hand rails or grips painting repairs related to modifications. ramps/ step modifications</td>
<td>shower base is installed.</td>
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<tr>
<td>Vehicle Modifications</td>
<td>Figures unavailable</td>
<td>Modified driving controls to enable a person with a disability to drive a vehicle. Conversion of vehicle for wheelchair access. Specialised trailers, lifters and carriers for wheelchairs. Specialised seats. Air conditioning for people with thermo regulatory conditions.</td>
<td>Items generally available for purchase, including mirrors, cruise control, window tinting. The purchase of new or second hand vehicles.</td>
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</tbody>
</table>