



MINISTRY OF
SOCIAL DEVELOPMENT
Te Manatū Whakahiato Ora

Overview Report The Cost of Disability

Prepared by
Joint Steering Committee

**Centre for Social Research and Evaluation
Te Pokapū Rangahau Arotaki Hapori**

25 July 2008

Contents

Executive Summary	1
Background and purpose.....	1
Methodology	1
Key findings.....	1
Conclusion.....	3
Introduction	4
Background	4
Purpose and scope.....	4
Methodology	5
Acknowledgements.....	6
Resources needed to live an ordinary life.....	7
Understanding the need for additional resources	7
Range of additional resources	7
Common resource needs.....	8
Variation in resource needs	10
The cost of living an ordinary life	16
Defining types of costs compared to non-disabled people	16
Overview of the cost to achieve an ordinary life	16
Distribution of resource costs.....	18
Other influences on resource costs	21
Length of time person has had their impairment	21
Life transitions	21
Geographic location.....	22
Personal circumstances.....	22
Ethnicity.....	22
Impairment causation	23
Future considerations.....	24
References.....	25

Executive Summary

Background and purpose

Disabled people, like other New Zealanders, aspire to an ordinary life. However, it is widely acknowledged that disabled people face many barriers and costs to achieving an ordinary life. To date little research has been conducted to identify the additional resources and costs required by disabled people to live an ordinary life.

The Ministry of Social Development (MSD) and the Health Research Council of New Zealand (HRC) commissioned research to inform the Cost of Disability project. The aim of the research was to identify the additional resources and their costs required by disabled people aged 18-64 years to achieve an ordinary standard of living in the community (ie identifying only those resources where there was a difference between disabled and non-disabled people).

Methodology

The research conducted was a collaborative project between disabled people, the Disability Resource Centre Auckland, Inc (DRC Auckland) and the University of Auckland's Centre for Health Services Research and Policy (CHSRP). Consistent with similar research undertaken in the United Kingdom (Smith et al 2004), a budget standards approach was used to integrate a social model of disability with a robust economic approach to identify the additional costs of disability.

A budget standards methodology involves defining the basket of goods, services and activities required for a given household to achieve a certain standard of living. Consensual budget standards were developed through a process of discussion with disabled people whose experience and insight informed and verified the items included in the budgets. Costs were then attached to each item, and budgets achieved by calculating average weekly costs for all items over their lifetime. Final budgets were constructed by comparing the resource use of disabled and non-disabled people.

MSD and HRC acknowledge the research offers an indicative and not definitive qualitative measurement of the additional costs of resources required by disabled people to achieve an ordinary standard of living in the community. This reflects the exclusions of costs mainly covered by the state such as healthcare, the focus on only five impairment types and exclusion of people with multiple impairments and living in different family circumstances.

Key findings

Additional resources required to live an ordinary life

The Cost of Disability Project has confirmed that disabled people with physical, sensory, intellectual and mental health impairments have needs which require additional resources to live an ordinary life similar to non-disabled people. The need for these additional resources arise due to disabled people's unique circumstances, impairment needs (especially limitations of personal energy) as well as the impacts of discrimination (eg environmental and communication barriers and society's attitudes to disability).

Disabled people, based on their individual circumstances and needs may require additional resources to complete their activities of daily living, appropriate food and clothing, access to health and well-being services, housing modifications, specialised

information and communications tools, access to occupation and/or vocation and resources to enable social participation. The type and amount of additional resources required by disabled people to live an ordinary life is reflective of their impairment, level of need, and other personal circumstances.

People with a physical impairment face a number of barriers in their daily living due to inaccessible built environments in both their home and the wider community. Consequently, they need human support, a range of equipment, home modifications and appropriate transport to overcome these barriers to achieve an ordinary standard of living, comparable to non-disabled people.

For people with a visual impairment access to information was identified as the key barrier to an ordinary life. They require therefore specialised information communication technology to efficiently access information. For people with visual impairment, the level of self-defined need to achieve an ordinary life does not necessarily reflect their degree of impairment, (ie someone who is legally blind may perceive they have a relatively low need).

For people with a hearing impairment the design of the built environment and how society perceives them creates barriers to full participation. Unlike people with other impairment types, the resource required by people with moderate hearing impairment is substantially different from those with high needs (ie Deaf people). To live an ordinary life, people with moderate hearing impairment needs require technology to “amplify the world”. For Deaf people, who use New Zealand Sign Language, to engage and communicate with the hearing community requires the use of interpreters.

For people with intellectual impairment resource needs are influenced by their personal living environment. All those who participated in the research lived in some form of supported living environment. To live an ordinary life, people with intellectual impairment require two support roles: one to assist with daily living activities, and the other to facilitate social participation (ie a buddy system). In seeking to live an ordinary life, people with intellectual impairment require more choice about where they live and the daily and recreational activities they undertake.

Mental health impairment is typically intermittent and episodic in nature and a person with this impairment will experience periods of low, moderate and high needs. A person with moderate needs may have long periods where they are able to live an ordinary life similar to non-disabled people. During these times, the additional resources may be minimal, limited to exercises, relaxation and peer support groups important in maintaining a sense of wellness, and for safety and social connectedness reasons 24 hour access to telephone. People experiencing mental illness or taking associated medication take much longer or are unable to accomplish daily living activities. Consequently, they may require a substantial amount of support to live in the community and may move in and out of residential care settings.

The additional costs of disability

Reflecting these needs, disabled people require three types of additional expenditure relative to those required by non-disabled people: 1) unique resources (eg a wheelchair and support from another person(s)); 2) modified forms of a common resource (eg electronic can opener) which may cost more; and 3) greater use of a common resource (eg heating).

Table 1 below overviews the cost range of these additional resources by different impairment types and level of need. Table 1 includes support costs.

Table 1. Total additional weekly costs by impairment type and degree of need

Impairment type	Moderate needs	High needs
Physical impairment	\$640	\$2,311
Vision impairment	\$360	\$720
Hearing impairment	\$195	\$760
Intellectual impairment	\$580	\$2,570
Mental Health impairment	\$720	\$2,415

Table 1 highlights that people with high physical, intellectual and mental health impairment needs require more additional resources than those with a visual or hearing impairment. The correlation between level of need and cost of additional resources is also evident.

Across the impairment types four common resources are consistently mentioned by disabled people regardless of their wider circumstances:

- Human support to undertake activities of daily living and social participation makes up the bulk of the additional resource cost. Human support is critical in enabling disabled people to preserve their time and energy to engage in the breadth of activities constituting an ordinary life
- Overcoming environment and communication barriers through information communication technology
- Accessible and timely transport, as a lack of availability can increase travel time and decrease time available for other, more valuable, activities
- Counselling and life coaching to identify opportunities for personal development which address barriers to a full and meaningful life, and also to facilitate transition periods.

The additional costs for disabled people are not static but evolve over the course of a lifetime and are influenced by other variables (eg geographical location, demographic factors such as age, ethnicity and family status). Further, managing transitions from one state to another – be it a change in impairment, living situation or relationship – tends to have a greater impact on disabled people than on non-disabled people. Such transitions may raise the need for new resources of which the disabled person may not be aware. Support they currently have may no longer be sufficient or appropriate, or may become unavailable.

Conclusion

The Cost of Disability Project demonstrates that disabled people with physical, sensory, intellectual and mental health impairments have needs which require additional resources to live an ordinary life similar to non-disabled people. It is hoped this research will inform future research in the disability sector and provide a basis to facilitate an understanding of what disabled people need to live an ordinary life.

Introduction

Background

Disabled people, like other New Zealanders, aspire to an ordinary life. All people, whatever their level of impairment, have the same fundamental needs and expectations, and should be accorded the 'ordinary' opportunities of access to goods and services, including housing, income, health services, education and community life. (NHC 2003) However, it is widely acknowledged that disabled people face many barriers and costs to achieving an ordinary life.

To date little research has been conducted about the additional costs associated with disability and how these costs vary by individual needs and personal circumstances. To address this research gap, the Ministry of Social Development (MSD) and the Health Research Council of New Zealand (HRC) commissioned the Cost of Disability research to enhance Government's and the disability sector's knowledge in this area.

The research conducted was a collaborative project between disabled people, the Disability Resource Centre Auckland, Inc (DRC Auckland) and the University of Auckland's Centre for Health Services Research and Policy (CHSRP). The research therefore aligned with disability people's rally cry of "*nothing about us without us*" (UN Chronicle Online Edition 2008).

This report presents an overview of the key findings from the Cost of Disability research report (DRC Auckland 2008). Detailed findings of the research can be found in the full report xxx.

Purpose and scope

The aim of the research was to identify the additional resources and their costs required by disabled people aged 18 to 64 years to achieve an ordinary standard of living in the community (ie identifying only those resources where there was a difference between disabled and non-disabled people). The standard of an ordinary life was used, given its familiarity to disabled people (National Health Committee 2003). A metaphor of a car was used to consistently explain an ordinary standard of living to participants (ie a Toyota and not a Rolls Royce nor a broken down old car).

The research included:

- Disabled adults aged 18 to 64 years, living in community settings rather than institutional settings, without dependent children and without multiple impairments
- People with physical, sensory, intellectual and mental health impairments¹.
- Costs of accessing education, employment, health care and community based support services (eg transport and communication support), and excluded costs incurred within those services (eg doctors visits, prescription costs and course fees)
- The household unit to ensure inclusion of informal support costs often transferred onto families or other support people and those aggregated in residential settings.

Care was taken to ensure the research retained its core focus on the additional costs required by disabled people to live an ordinary life. Consequently, the research did not

¹ Note: The decision was made to include a broader range of impairment types, but to balance that by excluding some other population group such as people with multiple impairments.

explore how costs are funded or met, either formally or informally, the prevalence of need in the disabled community, or the resources required by all disabled people.

MSD and HRC acknowledge the research offers an indicative and not definitive qualitative measurement of the additional costs for resources required by disabled people aged 18 to 64 years to achieve an ordinary standard of living in the community. It is hoped this research will inform future research in the disability sector and provide a basis to facilitate an understanding of what disabled people need to live an ordinary life.

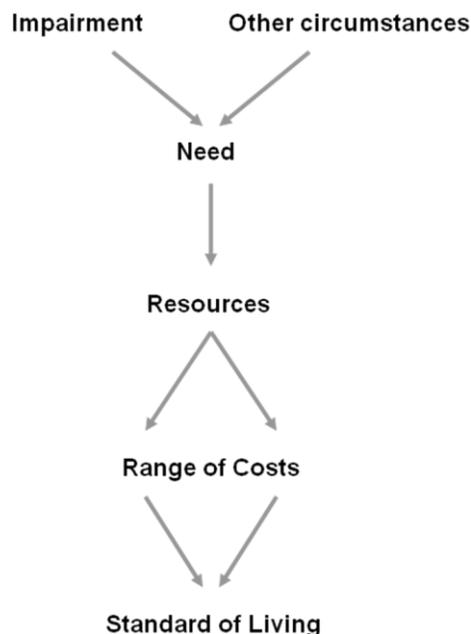
The reference to disabled people in this report refers only to those people with impairment who contributed to the research.

Methodology

Consistent with similar research undertaken in the United Kingdom (Smith et al 2004), a budget standards approach was used to integrate a social model of disability with a robust economic approach to identify the additional costs of disability.

The project team in collaboration with a Reference Group of experts from the disabled community developed a cost model based on the needs of disabled people to achieve an ordinary life. The cost model is shown in Figure 1 below. Individualised costs arise from resources applied to meet a disabled person's needs. Impairment and other personal characteristics combine with surrounding environments and the social context to create needs. Resources are applied to meet each need (often a choice of different services, products or other interventions), which result in a range of costs incurred by different people to achieve a similar standard of living.

Figure 1. Simplified cost model



Consensual budget standards were drafted through structured discussions with disabled people in feedback forums and interviews about the goods, services and activities required by their household to achieve an ordinary life.

Costs were then attached to each item, and budgets achieved by calculating average weekly costs for all items over disabled people's lifetime. Budgets were constructed and validated for moderate and high needs to illustrate the range of potential costs and the factors driving them. The degree of need was determined in association with disabled participants, guided by factors relevant to each impairment type and input from the Reference Group.

The budget standards developed were validated with members of the disabled community. Final budgets were constructed by comparing the resource use of disabled and non-disabled people. Detailed budgets can be found in Appendix C of the main report.

Acknowledgements

MSD and HRC warmly thank the disabled people who contributed their time, energy and insights to inform the research findings. Their contribution has made more visible the challenges faced by disabled people in seeking to live an ordinary life. Special thanks are also extended to the Reference Group, DRC Auckland and the University of Auckland's CHSRP.

Resources needed to live an ordinary life

Understanding the need for additional resources

Similar to non-disabled people, an ordinary life for disabled people encompasses areas of living such as housing, food, clothing, household goods and services, personal care, transport, leisure and access to employment. The need for additional resources beyond that required by non-disabled people reflects a disabled person's own unique circumstances, experiences, needs and strengths. However, disability is not simply an individual experience. It is a complex social process involving society's varied collective and structural response to impairment. To achieve an ordinary life across all areas of living, a disabled person must therefore work around the impacts of discrimination as well as overcome the potential limitations of their impairment.

As identified by forum participants, the key barriers and limitations to achieving an equivalent ordinary life for disabled people are:

- Environmental barriers which arise due to design elements not addressing everyone's need (eg in the built environment the use of stairs instead of lifts, or in communications information being provided in small print).
- General social attitudes to disability and low expectations of and value placed on a disabled person's contribution, particularly in the workplace².
- Disabled people not receiving as prompt and timely a service as that received by non-disabled people resulting in a loss of time.
- Disabled people's restricted levels of energy resulting in the need for additional time and/or resources to accomplish the same tasks as non-disabled people. This is called the opportunity cost of having an impairment. For disabled people requiring significantly more time to perform basic tasks like personal care has a flow on effect of less time being available for other activities such as employment and leisure.
- A disabled person's own adaption to their impairment, particularly if their impairment is newly acquired.

Range of additional resources

The research team in collaboration with disabled people developed a range of additional resources required, to varying degrees by disabled people, to achieve an ordinary life including:

- **Activities of daily living** resources needed each day or week to enable a disabled person to perform the tasks required to live in the community (eg housework, meal preparation, household administration, personal care, shopping).
- **Food and clothing** such as any specialised food or clothing required due to a person's impairment (eg special dietary needs, extra items of clothing or shoes, more laundry).
- **Health and well-being** resources needed to maintain a healthy lifestyle focusing on healthcare visits specifically due to impairment (eg physiotherapy) and the cost of transport to other healthcare services (eg to a medical appointment). Health and well-being excludes the cost of healthcare (eg doctors visits, prescription costs)
- **Housing** modifications needed to make the home accessible and safe.

² Note: overcoming social attitude barriers are not included in the additional cost of resources to achieve an ordinary life.

- **Information** resources such as computers and cell phones to enable disabled people to communicate with their wider community and access information. While these technologies are important resources for non-disabled people, for some disabled people, especially those with visual impairments, they are essential information and communication tools.
- **Occupation** resources needed to access the person's occupation and/or vocation including access to counselling or peer support to identify and maintain a suitable occupation. Occupation excludes modifications to venues or practices to allow the disabled person to perform a specific task.
- **Social participation** resources needed to allow participation in society, including socialising with friends, joining groups or clubs and recreation.

Additional resources required by disabled people to achieve an ordinary life cannot be viewed as hierarchical or prioritised one over the other. Placing emphasis, for example, solely on meeting a disabled person's activities of daily living needs over their needs for occupation and social participation will lessen their opportunity to an ordinary life similar to non-disabled people.

Common resource needs

Disabled people's need for additional resources to achieve an ordinary life is strongly driven by their unique circumstances and impairment type, which is detailed in the next section. However, analysis across the budget standards and themes from the feedback forums highlighted four additional resources which were consistently mentioned by disabled people regardless of impairment type or their wider circumstances, specifically:

- Human support – resource and friend
- Independence through information communication technology
- Accessible and timely transport
- Coaching for an ordinary life.

Human support – resource and friend

Human support is critical for disabled people to achieve an ordinary life. While technology, modifications and aids can help disabled people to independently undertake activities of daily living, human support is important in preserving disabled people's time and energy to engage in the breadth of activities constituting an ordinary life. In this context, the use and amount of human support is wide and varied and includes assistance with personal care, household tasks and social participation through the use of "buddy" systems, interpreters, note takers and trainers.

In seeking to achieve an ordinary life, disabled people strive to balance their desire for independence with their need for human support to create time beyond the activities of daily living for their occupation, leisure and social participation in their community. For disabled people with high physical and intellectual needs, there is less focus on this balance, as their high needs result in more emphasis being placed on resources required to meet their basic survival needs.

To effectively facilitate an ordinary life, disabled people need a voice in who offers them human support and when it occurs. Support seldom, if ever, needs to take over full responsibility from the disabled person, and it is rare for it to extend to 24 hours a day or seven days per week. Ideally, a support person should complement the specific needs

and schedules of the disabled person, including being available in the evenings and weekends. Support people should be chosen by disabled people to ensure their suitability and if undertaking a buddy role matched to the disabled person's preference for gender and age. To ensure continuity in the disabled person's life, back up support people are essential should the main support person become unavailable.

Independence through information communication technology

For all people, information and communication technology is becoming an ever embedded part of daily living. A range of technologies including cell phones, computers and the internet are the common tools used to seek information, to communicate with colleagues and friends, to purchase goods and services and offer a sense of security. For disabled people, information and communication technology have an extended role of enabling them to overcome environment and communication barriers to access information, to communicate and to participate confidently and securely in society.

For some disabled people, information and communication technology is simply ensuring access to standard computers, the internet, email and cell phones. However, others require more specialised hardware and software. A particular challenge for disabled people is the ongoing task of having to keep up with the latest technological developments and upgrades. While the latter may be a challenge for non-disabled people, the effects of not keeping up to date are much more devastating and isolating for disabled people. The latter reflects disabled people's great reliance on alternative modes of communication and interaction, due to barriers facing many disabled people in accessing services and events.

Accessible and timely transport

Transport is another common need across many aspects of an ordinary life. Like non-disabled people who cannot drive or do not have access to a vehicle, there is reliance on either public transport or taxi services. Unlike non-disabled people, disabled people face issues of access to and availability of suitable public transport options. Public transport along well known routes may be an option for those with no physical impairments. However, new and complex routes requiring many transfers can be a barrier for some disabled people, including those with physical, sensory and intellectual impairments.

For disabled people needing a door-to-door service, public transport such as buses is not an option. Consequently, such disabled people tend to rely on taxis. Some people who use manual wheelchairs are able to use any taxi, but those with powered wheelchairs rely on vans equipped with wheelchair hoists. However, users of these mobility taxi services in the Auckland area complained they are unavailable when needed and unreliable. Time spent waiting for suitable transport to arrive increased the travel time for disabled people and decreased time for other activities. Unreliable transport has wider effects through impacts on support person time and reducing the disabled person's control over their schedules.

Coaching for an ordinary life

Like others, disabled people are seeking to create a meaningful and fulfilling life. Disabled people across the four impairment types voiced the need for counselling and life coaching. The role of the life coach extends beyond the traditional role of identifying opportunities for personal development to addressing the persistent external barriers encountered in daily living by disabled people.

The life coach needs therefore to be a competent professional with understanding of the nature of disablement caused by society and knowledge of the existing resource options and how to access them. A particular focus for disabled people is 'meaningful occupation' which may mean working with employers to overcome discrimination in the workplace. Formal employment may not be the right option for some disabled people, and meaningful occupation may focus more on community participation or volunteer work. A life coach is therefore a critical resource for disabled people regardless of their impairment to achieve an ordinary life.

Variation in resource needs

Analysis across the budget standards and themes from the feedback forums highlights individual variation where the amount of additional resources varies for disabled people and is dependent on:

- Impairment type, for example physical, vision, hearing, intellectual or mental health impairment.
- Level of need as self-defined in this research as low to moderate (moderate) and moderate to high (high) need. Caution is needed in correlating the degree of impairment and disabled person's level of need, ie the higher the degree of impairment, the greater the need and vice versa. As demonstrated below, especially for those with a sensory impairment, disabled people can self-define as having a high degree of impairment and self-report a low degree of need.
- The social context of the disabled person and their personal characteristics, circumstances, experiences and preferences (eg disabled people's living situation, support received from family and friends, whether they are at a transition stage in their life, and their preference for independence versus more human support to free up time for other activities).

Described below for each impairment types are the additional resources, identified in the budget standards and the themes from the feedback forums, required by disabled people to live an ordinary life. Also detailed is the rationale for the resources and the variations in resources required between those with moderate and high needs.

Physical impairment

People with a physical impairment face a number of barriers in their daily living due to inaccessible built environments in both their home and the wider community. Consequently, they need human support and a range of equipment and modifications to their home to overcome these barriers to achieve an ordinary standard of living, comparable to non-disabled people. People with physical impairments, in particular, require their environments to be adapted to meet their needs rather than struggling to adapt to an unsuitable environment.

People with physical impairments can be constrained from living an ordinary life as they are entitled to only one funded housing modification in their lifetime. Consequently, as noted by participants with physical impairment, this capped entitlement minimises their ability to move location to maximise their opportunities. Non-disabled people, at a minimum, move about three times in their life time. The ability to change location is further hampered by the limited amount of modified housing stock.

People with physical impairments require access to appropriate and timely transport.

Currently, participation in society is curtailed for people with physical impairment due to a lack of appropriate transport.

Moderate needs

For people with moderate physical impairment needs, an ordinary life can be achieved via modifications to the home environment and slightly modified versions of common household tools, (eg lightweight cookware or an electric can opener), and by modifying the way some activities are carried out. Accessing the community can be achieved via mobility equipment and appropriate and timely transport.

The key resources identified to achieve an ordinary life are:

- Support: Some human support for performing activities of daily living, specifically shopping, meal preparation, housework and social participation
- Equipment: Home modifications such as ramps if mobility equipment is used and an alarm system to ensure safety
- Transport: Mobility taxis and closer to home equipment such as mobility scooter and ultra lightweight wheelchair.

High needs

For people with physical impairment, the amount of resources required to achieve an ordinary life increases with the level of need. Consequently, people with high physical impairment needs require significantly more resources than those who self define as having moderate needs.

- Support: Nearly three times the support person hours than those with moderate needs, particularly in relation to activities of daily living and participation in their community
- Equipment: More extensive home modifications than those with moderate needs, to meet their needs such as widening of doorways and hallways to accommodate a wheelchair, lowering of bench tops, and a bedroom for use by a support person staying overnight
- Transport: Mobility taxis are the main form of transport.

Vision impairment

For people with a visual impairment, the level of self-defined need to achieve an ordinary life does not necessarily reflect their degree of impairment, (ie someone who is legally blind may perceive they have relatively low needs). The level of need appears to correlate with the extent to which a person with visual impairment has learned new skills to reduce the barriers in their everyday living. The latter may reflect the time since the person started losing their sight and their ability to learn new skills.

The process of losing sight is one of the most significant barriers to achieving an ordinary life. Participants with visual impairment noted only limited resources are currently available to aid a person and their family through this transition. As a result, people can lose their sense of independence and become isolated through this transition period. People with vision impairment therefore report the need for more support (eg counselling) during transition periods to assist them in learning new strategies.

Access to information was identified as the key barrier to an ordinary life. People with visual impairment require larger computer monitors, computer screen reading software, broadband internet to efficiently access information, and CCTV to read printed material.

Given the critical role of technology, it is important people with visual impairments remain up-to-date with new technology and software. People with visual impairments also acknowledge the risks and wasted money and time when incompatible equipment or software is purchased.

People with visual impairment can, through practice, learn to use many of their existing household appliances required for daily living (eg washing machine). However, purchasing new household appliances with upgraded or changed features results in vision-impaired people needing assistance to relearn how to use them.

The built environment is not accessible for people with visual impairments due to inaccessible signs, footpaths and markings. A support person is therefore an important resource for activities such as shopping and social participation.

Use of public transport is challenging as buses are not 'end-to-end' and do not provide easily accessible information about the destination. Taxis do overcome these challenges, but extensive forward planning is required if going to a new destination. Consequently, visually impaired people lose the opportunity, enjoyed by non-disabled people, of being spontaneous.

Moderate needs

The key resources identified to achieve an ordinary life are:

- Support: Support person for heavy housework activities and shopping usually provided by trusted family and friends
- Equipment: Technology to access information and for social participation and recreation including screen reading software, computer, broadband internet access. Cell phones with adaptive features offer an important safety net.
- Transport: Use a mix of public transport and taxis for shopping and social participation.

High needs

Additional resources of guide dogs and their associated needs and costs, more support time and greater reliance on taxis are required for those with high needs to live an ordinary life.

The key resources identified to achieve an ordinary life are:

- Support: More support person time required for shopping and social participation.
- Equipment: More specialist technology to access information (eg talking scales, talking timer, monitored alarm)
- Transport: A guide dog to enable greater autonomy and access to the community.

Hearing impairment

People with hearing impairment can, in the main, undertake their daily living activities. It is, therefore, the design of the built environment and how society perceives people with hearing impairments that create barriers to full participation and living an ordinary life. Participants with hearing impairment comment on feeling stigmatised when wearing hearing aids, and having to work hard to overcome the lack of patience with Deaf modes of communications.

People with moderate hearing impairment can become isolated fitting neither into the hearing world nor the Deaf community who use New Zealand Sign Language to communicate. Such people often require considerable support and counselling to transition from one community to the other.

Unlike people with other impairment types, the resource required by people with moderate hearing impairment is substantially different from those with high needs (ie Deaf people).

Moderate needs

To live an ordinary life, people with moderate hearing impairment needs require technology to “amplify the world” and make it more accessible via hearing aids and personal hearing loops. Some human support may also be required with housework for those who have problems with balance.

The key resources identified to achieve an ordinary life are:

- Support: Some support for housework
- Equipment: A personal hearing loop to amplify sound. However, many are not aware such a device exists or about the availability of other support and technology to participate in their community
- Transport: Minimal resource needs as able to use private and public transport.

High needs

Deaf people to a large extent live an ordinary life within the Deaf community. However, for Deaf people, who use New Zealand Sign Language, to engage and communicate with the hearing community requires the use of interpreters. As a result, there is a higher demand on human support as interpreters and note takers in meetings, classes or work.

The key resources identified to achieve an ordinary life are:

- Support: High use of human support as interpreters
- Equipment: Equipment largely consists of technology such as computer software, broadband internet access and printing telephones
- Transport: Same as those with moderate hearing impairment needs.

Intellectual impairment

All participants with intellectual impairment lived in some form of supported living environment either at home with family/caregiver or in a residential living setting (eg group home with 24 hour support or a flatting situation with some home-based support services). Consequently, their resource needs to live an ordinary life are influenced by their personal living environment.

To live an ordinary live, people with intellectual impairment require two support roles. One support role is required to assist with daily living activities, and the other is to support with participation in the community (ie a buddy system). The buddy is a mentor who models the responsibility required to be more independent in the community. The buddy can also ensure safety for people with intellectual impairments when out in the community. Further, if living at home with parents or people much older, the buddy system if matched appropriately offers peer group access.

Support people play a critical role in communicating for and supporting people with intellectual impairment to have an ordinary life. However, high turnover of staff places burden on people with intellectual impairment to develop new relationships and to ensure their support person takes up their role as their key community link.

A common barrier for people with intellectual impairment in living an ordinary life is their lack of choice about where they live and the daily and recreational activities they undertake. Within a residential home, staffing levels can mean everyone has to undertake the same activities regardless of their preference (ie everyone has to go out to the movies even if some would prefer to stay home). People with intellectual impairments believe their degree of control over their lives should match their individual needs rather than one set of rules for everyone.

People with intellectual impairment face significant barriers to paid employment due to society's attitudes towards the perceived risks and value of workers with intellectual impairment. People with intellectual impairment require support and skill training to achieve their employment goals. However, for many people requiring 24 hour support the question of what they want to achieve with their life may never have been asked.

Moderate needs

People with moderate intellectual impairment needs require primarily guidance and mentoring resources to live an ordinary life. The key resources identified to achieve an ordinary life are:

- Support: Assistance with cleaning, cooking and personal care including getting ready in the morning for work, as well as support in choosing appropriate clothes, understanding written language, handling money, understanding technology, health information and taking medication and support to self advocate
- Equipment: Minimal needs including a cell phone for safety
- Transport: Public transport or privately owned vehicle costs for job related or coaching appointments.

High needs

In contrast, people with high intellectual impairment needs require more resources, in particular for activities of daily living and social participation. The key resources are similar to those with moderate needs but they require more of them.

- Support: More support person time is essential in every aspect of daily living
- Equipment: Continence products and other personal hygiene items
- Transport: Taxis to access the community and participate in social activities, as well as for health and well-being appointments and shopping.

Mental health impairment

Mental illness is typically intermittent and episodic in nature. A person will therefore experience periods of low, moderate and high needs associated with their mental health impairment. A person with moderate needs may have long periods where they are able to live an ordinary life similar to non-disabled people. During these times, the resources associated with disability may be minimal, limited to exercises, relaxation and peer support groups important in maintaining a sense of wellness. For safety reasons, 24 hour access to telephone is essential to people with mental health impairment due to the importance of remaining connected to support networks.

When experiencing mental illness, a range of resources are required to live an ordinary life, including human support. People experiencing mental illness or taking associated medication take much longer or are unable to accomplish daily living activities. Consequently, the amount and type of support required is dependent on the individual's level of need and their circumstances. Support tends to come from a range of people including health professionals, and peers who play an important role in maintaining every day routines and connections with the community. Health professional support can include resources such as pharmaceuticals, and psychology or psychiatry services. Accessing these services (including peer support) requires additional time and transport to get to appointments and meetings.

A person with a high level of need may require a substantial amount of support to live in the community and may move in and out of residential care settings. As a result, people experiencing mental illness can lose their accommodation when moved temporarily to a residential care setting, and relationships can be damaged due to disruptive behaviour exhibited during a period of mental illness. The level of formal support may be substantial, particularly in ensuring safety.

People with mental health impairments wish to socialise and participate in their wider community. However, this can be challenging due to a lack of confidence and feelings of isolation. Support people and peer support groups therefore provide an opportunity to socialise, make friends and share information with others with similar experiences.

People experiencing mental illness struggle with sustaining employment due to the intermittent nature of their impairment, social attitudes towards those with mental illness and the time and energy required to maintain a state of wellness. Holistically, people experiencing mental illness need a social worker or coordinator to help them navigate through all the options available to them to achieve an ordinary life.

Moderate needs

For people with moderate needs, the key resource needed to live an ordinary life is support people.

- Support: Support for some daily living and occupation activities.
- Equipment: Cell phone and phone costs for safety and connection to their communities. Gym membership to maintain a sense of well-being
- Transport: Resources to accessing mental health professionals and occupation purposes.

High needs

For people with high needs the level of support resources needed increases substantially. The key resources are

- Support: Substantially more support hours for personal care, activities of daily living, socialising, and in some instances safety.
- Equipment: Household insurance to cover damaged items, a monitored smoke and domestic alarm system, cell phone and phone costs and gym membership
- Transport: Resources to access mental health professionals and occupation.

The cost of living an ordinary life

Defining types of costs compared to non-disabled people

Having identified the range of resources required for disabled people to live an ordinary life consideration is given to the costs of these resources.

Disabled people can require three types of additional expenditure relative to those required by non-disabled people:

- **Unique type of resource** – The disabled person might require a resource that is not required by a non-disabled person. For instance a wheelchair might be required by someone with a physical impairment but would not be required by a non-disabled person. Other examples include:
 - A guide dog for blind people
 - A hearing dog for Deaf people
 - A personal hearing loop system for people with moderate hearing impairment needs
 - Specialised modifications to the home environment for people with physical impairment such as tap turners, ramps, widening doorways
 - Support people for daily living activities, occupation, social participation and specialist impairment related care (eg psychologists for a person experiencing a mental illness).
- **Pay a higher price for a common resource** – The disabled person might have to pay a higher price in order to get a specialised resource to suit their needs. For example, both disabled and non-disabled people might need a can opener in the kitchen, but a disabled person might need an electric can opener which is more expensive. Other examples include people with vision impairments requiring an adaptive cell phone.
- **Pay the same price but use more of a common resource** – The disabled person may require more of a resource also used by non-disabled people. For instance, both disabled and non-disabled people need to heat their homes, but some disabled people might require a warmer home due to their impairment and would have to pay higher utility costs for the resource. Other examples include:
 - Some disabled people requiring specialised food and more clothes due to wear and tear as a result of more frequent laundering.
 - Many disabled people solely relying on taxis or mobility taxis to access their community and services face significantly increased transport costs.
 - Some disabled people need more personal toiletry items.

Overview of the cost to achieve an ordinary life

Table 2 summarises the additional costs for people with moderate to high needs for each impairment type against the identified range of needs. The costs are based on the summary of weekly costs tables detailed in Disability Resource Centre (2008) rounded to the nearest \$5³. The costs were derived through a discussion of impairment and level of need through specific feedback forums with disabled people.

The costs are inclusive of opportunity time (ie the costs acknowledge the time saved or gained by disabled people through the use of support staff for some activities). As a

³ The exception is the \$1 cost for light housework for those with a physical impairment and as it would be misleading to round to \$0 or increase to \$5.

result, there are eight cost ranges where people with high needs have a lower additional resource cost than those with moderate needs, indicated in Table 2 by an asterisk. The latter reflects the time saving for disabled people with high needs due to support people doing many of their activities, thereby freeing up the person's time to do other, more valuable, activities. The exception is people with moderate hearing impairment needs where the higher additional resource cost reflects their unique needs ie assistance with housework due to balance issues, (indicated in Table 2 by two asterisks).

Colour shading is used below to offer a visual analysis of the costs for disabled people to achieve an ordinary life:

- No difference in the costs to achieve an ordinary life from non-disabled people
- Where the highest resource cost in the range is less than \$51
- Where the highest resource cost in the range is more than \$51 and less than \$100
- The most expensive cost items ranging from \$100 to \$2,050 (the most expensive resource for each impairment is circled).

Table 2: Range of total weekly costs by impairment type and degree of need

Needs	Range of total weekly costs by impairment type from moderate to high needs				
	Physical	Vision	Hearing	Intellectual	Mental Health
Light housework	\$80 - \$1*	\$40 - \$40	\$20 - \$0**	\$80 - \$15*	\$120 - \$0*
Heavy housework	\$90 - \$90	\$90 - \$90	\$35 - \$0*	\$85 - \$100	\$85 - \$85
Meal preparation	\$100 - \$110	\$5 - \$5	\$0 - \$0	\$130 - \$10*	\$120 - \$10*
Personal care	\$0 - \$480	\$0 - \$20	\$0 - \$0	\$45 - \$2050	\$120 - \$1960
Household admin.	\$20 - \$20	\$0 - \$20	\$0 - \$0	\$20 - \$20	\$20 - \$20
Shopping	\$120 - \$500	\$70 - \$160	\$0 - \$135	\$85 - \$105	\$80 - \$85
Food and clothing	\$5 - \$30	\$30 - \$30	\$0 - \$0	\$0 - \$40	\$0 - \$0
Health and well-being	\$50 - \$140	\$20 - \$20	\$15 - \$40	\$5 - \$40	\$60 - \$60
Housing	\$30 - \$110	\$5 - \$10	\$10 - \$10	\$0 - \$80	\$0 - \$50
Information	\$10 - \$30	\$50 - \$100	\$90 - \$140	\$10 - \$10	\$10 - \$10
Occupation	\$20 - \$50	\$20 - \$25	\$25 - \$35	\$35 - \$0*	\$20 - \$25
Participation	\$115 - \$750	\$30 - \$200	\$0 - \$400	\$85 - \$100	\$85 - \$110
Total Cost Range	\$640 - \$2311	\$360 - \$720	\$195 - \$760	\$580 - \$2570	\$720 - \$2415

Source: Summary of weekly cost Tables 8-15 detailed in Disability Resource Centre (2008, p50, 52, 64, 66, 73, 75, 87, 89, 102 and 104).

*People with high needs have a lower additional resource cost than those with moderate needs reflecting the time saving for disabled people with high needs due to support people doing many of their activities.

**People with moderate hearing impairment have a higher additional resource cost than those with high needs reflecting their unique need for assistance with housework due to balance issues.

Detailed below are key points from Table 2:

- There is an additional cost for disabled people to live an ordinary life similar to non-disabled people.
- The costs for disabled people vary by impairment type depending on the level of need and the resources required to live an ordinary life. People with a sensory impairment tend to require lower levels of additional resources to achieve an ordinary life than people with high physical, intellectual and mental health impairment needs.
- The cost of additional resources to achieve an ordinary life correlates with a disabled person's level of need (ie the higher the need, the higher the cost to live an ordinary life). With the exception of those with visual impairments, the costs for people with high needs to achieve an ordinary life are around three to four times greater than those with moderate needs.
- Personal care, shopping and social participation resources make up the most costly additional resource needs, reflecting the level of human support required to deliver each of these resources (discussed further below).
- By impairment types, key costs are:
 - For those with physical impairment are support for social participation, shopping and personal care
 - For those with visual impairment are support for social participation, shopping, heavy housework and technology needs for information
 - For those with hearing impairment are support from interpreters for social participation in the hearing community, shopping, and technology needs for information
 - For those with intellectual impairment are support for personal care, social participation, shopping and meal preparation
 - For people experiencing mental illness are support for personal care, housework, meal preparation and social participation.

As discussed, regardless of impairment type, disabled people face a number of barriers to live an ordinary life. The commentary above is therefore not intended to indicate that people with a particular impairment type endure or have greater barriers to overcome to achieve an ordinary life than others. Simply, it demonstrates the differences in resources required by disabled people to achieve an ordinary life. In seeking to enable disabled people to live an ordinary life, focus should be placed on the individual's unique circumstances, needs and preferences.

Distribution of resource costs

Table 2 details the range of additional resources required by disabled people to live an ordinary life. To fully understand the complexity of the additional costs for disabled people to live an ordinary life, a breakdown is needed of the costs by the following resource categories: support; transport; equipment; and time. For example, meal preparation for a high needs person with a physical impairment may require both human support and equipment resources, whereas health and well-being needs may require a

combination of support, transport, equipment and time resources to achieve an ordinary life similar to a non-disabled person.

Table 3 below details the percentage allocation of costs to these four categories defined as:

- **Support** – The sum of human support time allocated across each of the resources (eg various types of support people in the household, support when travelling and interpreters for the hearing impaired).
- **Transport** – The sum of all transport costs including mileage for people using privately owned vehicles or taxi fares for trips, which are assumed to be an average distance of 20 kms (but excluding waiting times for mobility taxis).
- **Equipment** – The sum of all equipment required in daily living including mobility equipment, modifications and guide dogs.
- **Time** – The sum of the additional time it would take a disabled person to undertake the same activity as a non-disabled person. The figures shown are either debits or credits depending on whether the activities are being undertaken by support people. A debit is where the disabled person gains time from having assistance from a support person, and a credit is where the disabled person loses time due to taking longer to do the activity themselves.

Using the physical impairment column as an example, Table 3 is read as follows:

- The range represents moderate to high needs. For those with moderate needs, support makes up 84% of their total resource needs compared to 72% for those with high needs
- Reading down, the column adds to 100%. For those with high needs support makes up 72%, transport 8%, equipment 15% and time 5% of their total resource cost to live an ordinary life.
- Negative values represent the additional time disabled people spend each week compared to non-disabled people. Those with a moderate impairment have a (-24%) value for time. The value is a negative number to indicate that the time is a credit because a person with a moderate needs physical impairment gains time from support workers doing some of their activities of daily living for them.

Table 3: The proportion of additional resources in core categories

Type of resource	Proportion of additional resources from moderate to high needs				
	Physical	Vision	Hearing	Intellectual	Mental Health
Support	84% - 72%	77% - 58%	61% - 60%	125% - 98%	14% - 109%
Transport	22% - 8%	15% - 24%	4% - 1%	1% - 4%	3% - 1%
Equipment	18% - 15%	26% - 34%	50% - 38%	2% - 10%	2% - 3%
Time	(-24%) - 5%	(-18%) - (-16%)	(-15%) - 1%	(-28%) - (-12%)	81% - (-13%)
Total Cost Range	\$640 - \$2311	\$360 - \$720	\$195 - \$760	\$580 - \$2570	\$720 - \$2415

Source: Summary of weekly cost Tables 8-15 detailed in Disability Resource Centre (2008, p50, 52, 64, 66, 73, 75, 87, 89, 102 and 104).

Table 3 shows, that proportionally human support makes up the main additional resource required by disabled people to achieve an ordinary life reflecting assistance received

across a range of activities. For people with hearing and visual impairments proportionally more equipment resources are required than people with other impairments reflecting their need for technology and guide and hearing dogs to communicate and participate in society.

Importantly, Table 3 shows the implications of time in relation to disabled people seeking to live an ordinary life.

- Time gains are achieved by having support people undertaking activities of daily living, and thus time is gained for other activities for people with physical, intellectual, visual and hearing impairment with moderate needs and also the visually impaired with high needs.
- For people with physical impairment and high needs, this gain in time is offset by the amount of hours wasted each week waiting for mobility taxis to take them shopping or to participate in their community.
- Deaf people can undertake many of their activities of daily living without support, and therefore require little support person time.
- For people with intellectual impairment and high needs the time lost through accessing additional health care appointments due to their impairment can be regained through having a support person do most of their cleaning and cooking activities.
- People experiencing mental health illness and with a moderate level of need are able to do many, if not all, of the same activities as a non-disabled person. However, they may take longer to do the same activity to the usual standard, and thus lose time for other activities. In contrast, someone experiencing mental health illness with high needs, gains time, as many activities of daily living are undertaken by a support person thereby freeing the person's time to do more valuable activities.

Other influences on resource costs

The additional weekly cost of resources for a disabled person detailed in the previous section highlighted the variation in costs by impairment type due to barriers in society and limitations of personal energy. However, over the course of a lifetime other variables influence the additional resources needed by a disabled person to achieve an ordinary life. As identified by the disabled people in the feedback forums these include:

- Length of time a person has had their impairment
- Life transitions
- Geographic location
- Personal circumstances
- Ethnicity
- Impairment causation.

Length of time person has had their impairment

The length of time a person has had an impairment can affect disabled people's ability to live an ordinary life. The longer someone has experienced disability, the more resourceful they may have become in successfully negotiating a disabling society and gaining support to meet their changing needs. However, the earlier in their life disability was experienced, the less likely they will have developed the same level of skills, resources, networks and assets as their non-disabled peers. The latter reinforces the need to consider the individual needs of disabled people.

Life transitions

Managing transitions from one state to another – be it a change in impairment, living situation or relationship – tends to have a greater impact on disabled people than on non-disabled people. Transition is demanding for anyone, but the complex interactions of change with impairment and disablement create extra demands. Such transitions may raise the need for new resources of which the disabled person may not be aware. Support they currently have may no longer be sufficient or appropriate, or may become unavailable.

Examples of impairment transitions include:

- People with mental health issues shifting from a state of having no special resource needs to having moderate or high needs at various times. The cyclical nature of their impairment creates particular challenges in identifying and accessing the needed resources, especially when many services are set up assuming stable needs and arrangements.
- For people with visual impairment the transition from moderate to high needs can be particularly daunting, due to a lack of appropriate services and support.
- People with impairments that deteriorate over time, who even if they are resourceful, will need more help over time.

Age specific transitions also have a significant impact on the needs of disabled people and the additional and specific resources required to live an ordinary life.

For a young person aged 18-24 years, support is required to negotiate the major life change of leaving the family home and becoming an adult living independently in the community. Support people are therefore required to explore the available options, to assist in the development of additional life skills, further education or independent living and, in some cases, to develop new social networks.

For people aging with impairment (those aged 45-64 years), the networks of support to which they have grown accustomed may change, posing questions about who will provide support in the future. The answers to these questions may have implications, not only on where and how people live, but also for their vocational and financial security. Spouses or family members who may have provided informal support for a number of years may also be aging and unable to provide the same kind of support they have in the past. Similarly, income from employment or benefit payments may no longer be available, or may lessen with retirement. For those transitioning to retirement, concerns were raised about the inability to save for retirement, particularly for people receiving an Invalid's Benefit.

To successfully navigate these transition periods with the goal of creating or maintaining an ordinary life people may require assistance from a life coach with experience in impairment and disablement and resource knowledge.

Geographic location

For disabled people, geographic location can affect the additional resources required to live an ordinary life in relation to transport and formal and informal support.

Living rurally (and even in some city areas) can limit disabled people's access to public transport. Consequently, a privately owned vehicle may be the only way some disabled people can access services and participate in their community. Further, the built environment in some locations is inaccessible, reducing disabled people's options for moving around their neighbourhood or town centre.

Living in a smaller community where everyone knows everyone else has both its benefits and disadvantages. For some people living in smaller communities, especially those with mental health impairments, concerns were raised about issues of confidentiality and stigma. However, for others the informal support available can enable more access to services and greater participation in the community.

Personal circumstances

A variety of factors in a person's circumstances will interact with impairment and their experience of disability to affect their level of need. Family status (ie: whether a person is married, has a partner, is divorced, has children, grandchildren, or extended family involved or not involved in their daily lives) emerged as a key factor in how successful a disabled person might be in achieving an ordinary standard of living.

Ethnicity

Being Māori brings a different perspective to considerations of disability. Social model concepts can be inconsistent with holistic Māori frameworks for understanding people and their well-being, and there are often no equivalent words in Te Reo. Core concepts like independence and manaakitanga may conflict. Historic trends such as institutionalisation separated some disabled Maori from their whānau and their culture.

For disabled Māori additional time spent planning ahead and negotiating with support people and community leaders was seen as essential to access cultural communities and events in an appropriate manner. However, this research highlighted some examples of access barriers faced by disabled Māori people in seeking to live an ordinary life in their Māori community, specifically:

- The need to replace guide dogs with a support person to access cultural venues
- Entering a Tupuna Whare through a wheelchair-accessible rear or side entrance rather than the outstretched arms of the (inaccessible) front entrance
- The lack of trilingual Sign Language/Te Reo interpreters, and issues with the use of interpreters during some cultural activities.

Further research is needed into the cultural specific barriers and additional resources required by disabled Māori to live an ordinary life in their community. Research is also needed to explore and understand cultural considerations for people from other ethnic groups seeking to live an ordinary life in their community.

Impairment causation

The original cause of impairment whether through birth, accident, illness or aging is one of the most contentious of all the determinants of need and costs. Although funding of needs is beyond the scope of this project, participants raised well-publicised inequities between those who acquired an impairment through accident and were provided support by ACC and those who were born with their impairment or acquired one through illness and were provided support by the Ministries of Health and Social Development. This issue is addressed by the current multi-agency review of long-term disability supports led by the Office for Disability Issues.

While beyond the scope of this project, acknowledgement is also given to the unique and complex needs of those people with multiple impairments. For these disabled people the cost of additional resources to achieve an ordinary life cannot be calculated by simply summing across the impairment type budgets.

Future considerations

In essence, this research is a good starting point in acknowledging and understanding the additional costs for resources required by disabled people to achieve an ordinary life similar to non-disabled people. The research offers a foundation for understanding holistically the breadth of services required and their overlapping and integrated nature. Importantly, it acknowledges the variations across impairment types and level of needs. It also demonstrates resources required are not static but evolve during the life time of the disabled person.

The research also highlights some operational considerations:

- Involving disabled people in the selection of their support people
- Offering flexible support services aligned to the needs and schedules of disabled people
- Balancing support services with disabled people's preference for independence and need to create more time for other activities (ie having support for daily living activities to gain time for occupation, recreation and community participation)
- Having flexible funding mechanisms which recognise the diversity of disabled people and the evolution of their needs especially during transition phases
- Creating awareness of the range of services available
- Checking the effectiveness of services offered for their utility to disabled people.

References

National Health Committee (2003) *To have an 'ordinary' life: community membership for adults with an intellectual disability*. A report to the Minister of Health and the Minister of Disability Issues. Wellington, New Zealand, September 2003.

Disability Resource Centre (2008). *The Cost of Disability Project: Final Report*. A report for the Ministry of Social Development and the Health Research Council. Wellington, New Zealand, June 2003.

Smith N, Middleton S, Ashton-Brooks K, Cox L, Dobson B and Reith L. (2004) *Disabled people's costs of living: More than you would think*. Joseph Rowntree Foundation: York.

UN Chronicle Online Edition. (2008). *'Nothing About Us Without Us' Recognizing the Rights of People with Disabilities*. Retrieved July 22, 2008 from <http://www.un.org/Pubs/chronicle/2004/issue4/0404p10.html>