RESEARCH REPORT

A FRAMEWORK FOR COST-BENEFIT ANALYSIS OF HASI AND RRAP-D VOLUME 2: APPENDICES

Canada

CMHC SCHL
HOME TO CANADIANS

CMHC—HOME TO CANADIANS

Canada Mortgage and Housing Corporation (CMHC) is Canada's national housing agency.

Backed by over half a century of experience, we work with community organizations, the private sector, non-profit agencies and all levels of government to help create innovative solutions to today's housing challenges, anticipate tomorrow's needs, and improve the quality of life for all Canadians.

CMHC assists Canadians in all parts of the country to access a wide range of innovative and affordable financing choices. Through research, we contribute to the well-being of the housing sector. Working with our provincial, territorial, non-governmental partners and the private sector to deliver the federal government's housing agenda, CMHC helps Canadians from all walks of life access quality, affordable homes. At home and abroad, we work in close collaboration with our government partners and the housing industry to enhance Canada's presence in the global marketplace, and share our housing experience and expertise with the world.

In everything we do, we're committed to helping Canadians access a wide choice of quality, affordable homes, while making vibrant, healthy communities and cities a reality across the country.

For more information, visit our website at www.cmhc.ca

You can also reach us by phone at 1 800 668-2642 or by fax at 1 800 245-9274.
Outside Canada call (613) 748-2003 or fax to (613) 748-2016.

Canada Mortgage and Housing Corporation supports the Government of Canada policy on access to information for people with disabilities. If you wish to obtain this publication in alternative formats, call 1 800 668-2642.

A Framework for Cost-Benefit Analysis of HASI and RRAP-D

Final Research Report
Volume 2
Appendices

Prepared

By

Dr. Kenneth Watson
Dr. Anne Perkins
Rideau Strategy Consultants Ltd.

For

Canada Mortgage and Housing Corporation
Project Manager: Luis Rodriguez

December 2005

This study was jointly funded by Canada Mortgage and Housing Corporation (CMHC) and Health Canada. The contents, views and editorial quality of this report are the responsibility of the author s and CMHC and Health Canada accept no responsibility for them or any consequences arising from the reader's use of the information, materials and techniques described herein.

This report is provided for general information purposes only. Any reliance or action taken based on the information provided is the responsibility of the user. Readers are advised to consult appropriate professional resources to determine what is suitable in their particular case. CMHC and Health Canada assume no responsibility for any consequences arising from use of the information provided in the report.

Copyright Notice
© 2005 Canada Mortgage and Housing Corporation.

All rights reserved. No portion of this report may be reproduced, stored in a retrieval system or transmitted in any form or by any means, mechanical, electronic, photocopying, recording or otherwise without the prior written permission of Canada Mortgage and Housing Corporation. Without limiting the generality of the foregoing no portion of this report may be translated from English into other language without the prior written permission of Canada Mortgage and Housing Corporation.

Table of Contents

Volume 2: Appendices

A. Working Paper 1: Literature Review
B. The Questionnaires: Beneficiaries and Caregivers
C. Focus Group
D. Individual Case Study Descriptions: Long Descriptions
E. Survey Responses by Topic
F. Survey Responses, Some Tables
G. An Example of a Costs-Avoided Methodology (HASI, 1994)
H. A Contingent Value Method (RRAP, 2003)
I. Working Paper 2: Contingent Value Analysis of HASI and RRAP-D Benefits
J. Working Paper 3: Measuring RRAP-D/HASI Benefits by Changes in Quality of Life
K. Working Paper 4: Measuring RRAP-D/HASI Benefits by Direct Costs Avoided

Appendix A

Working Paper 1: Literature Review

Cost-Benefit Framework RRAP-D and HASI. Appendix A: Literature Review

October 27, 2004

Rideau Strategy Consultants Ltd.

Introduction

CMHC has commissioned a cost-benefit framework for its programs that support renovations to accommodate aging and disability. The framework is in preparation for the evaluation of the Residential Rehabilitation Assistance Program for Persons with Disabilities (RRAP-D), and Home Adaptations for Seniors Independence Program (HASI). The purpose is twofold:

$ to develop a framework to assess the costs and benefits of combining appropriate home renovations with health and home care services including out-of-pocket expenses and indirect costs to families/informal caregivers in support of independent living, and to compare these with the costs and benefits associated with long-term institutional care; and

$ to test the framework by conducting at least nine case studies of renovations to enable seniors and people with disabilities to remain in their homes.

RRAP-D was established in 1981 in response to the International Year of the Disabled. It provides financial assistance for the repair, improvement or modification of existing housing to better meet the needs of individuals with disabilities.

The Home Adaptations for Senior Independence Program (HASI) provides low income seniors with financial assistance to pay for minor renovations that will allow them to remain in their own homes.

This working paper is a document and literature review which includes published research, CMHC reports, and other evaluations by the federal government in related areas.

It has five sections:

- Disability Definitions, Paradigms and Philosophies
- Disability and Housing Needs
- Literature on Family/Informal Care Giving
- Literature on Formal Care Giving
- Evaluations and Evaluation Frameworks Relevant to Programs for the Elderly and/or Disabled

Bibliographies are attached - cost-benefit methods (Annex 1) and the elderly and disabled, and care giving (Annex 2).

PART 1: Disability Definitions, Paradigms and Philosophies

There is no single accepted definition of disability, internationally or in Canada. Several writers have expressed concern about the lack of policy and program coherence this might imply. *A Common Vision* (2001) and other reports of the Canadian Parliament focused attention on the need for greater coherence across the Government of Canada disability programs and policies. This focus on improving program coherence was seen an alternative to harmonizing definitions of disability across programs.

RRAP-D uses the definition of “disability” promulgated by the World Health Organization (WHO). WHO’s first definition of disability (1980) *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) defined disability as any reduction or lack of ability, caused by impairment, to perform an activity in a way considered normal for a human being. WHO published a revised approach to the definition of disability in May 2001, entitled the *International Classification of Functioning, Disability and Health* (ICF). The ICF shifted from describing disability, impairment and handicap in terms of diminishment to describing body structure, functioning, activities and participation. The general term “functioning” refers to all body functions, activities and participation, while the term “disability,” was understood to encompass the interaction between impairments and externally imposed activity limitations or participation restrictions.[1]

Defining Disability: A Complex Issue, (2003)[2], by Human Resources Development Canada, states that the concept of disability is complex and multi-dimensional, and that there is confusion in regard to definitions, eligibility criteria and objectives of various programs (for example, some programs focus on employability and others on income replacement; some programs determine disability through self identification while others require detailed information from medical specialists).

Part one of the report describes the evolution of medical, functional limitation[3], ecological[4] and social[5] and human rights[6] models of disability. Part two describes Government of Canada laws, programs and tax measures that are relevant to persons with disabilities (antidiscrimination legislation;

activities of daily living and assistance in the home; income, and employment and learning). This review confirms that the Government of Canada does not have a single agreed definition of disability. Part three summarizes issues related to defining disability. Part four proposes action by the Government of Canada to address the issues and bring more coherence to disability-related programs.

Provincial government definitions of disability, and international definitions, are set out in an annex of this report. Their definitions fall into five groups: Disability Policy Definitions of Disability; Human Rights Definitions of Disability; Income Programs Definitions of Disability; Employment Supports Programs Definitions of Disability; Special Education Definitions of Disability.

The World Bank (2004)[7] notes that, during the last 30 years, the conceptualization of disability has changed. At opposite ends of the scale are the medical or individual oriented model and the social or human rights model. The latter is generally preferred by the disability community. Disabled traditionally meant 'handicapped' in the sense of less able. Increasingly a person with a disability is viewed not as inferior but as having different abilities from others, and perhaps as inhibited by society in general from using those abilities to best advantage.

The social model, or human rights model, focuses on the functioning of disabled people within society, and on the social practices and mores that facilitate or inhibit that functioning. The emphasis is on the responsibility of society to remove barriers that unnecessarily inhibit the full functioning and participation of persons with disabilities. These barriers range from prejudice to problems of limited physical access and physical functioning. Disabled people are perceived as active participants in their community whose contribution should be enabled as fully as possible.

The medical model defines disability as a health problem, a disease, to be addressed by doctors and rehabilitation specialists who pursue better treatments and cures for disabling conditions. The focus is on changing disabled people so they can perform more efficiently in a society that has been constructed by and according to non-disabled people. Of course medical intervention to improve functioning, where possible, is essential. However the mind-set it encourages can be problematic. For example, after the polio epidemics, many survivors were encouraged to use crutches and braces to

enable them to continue to walk, even in instances where a wheelchair would have provided better mobility.
Similarly, M.L. Breslin (1998)[8] of the University of California at Berkeley defines four models of disability: moral[9], defect/medical[10], civil rights/independent living[11], and post-modern[12].

Disability Definitions in Europe

The European Council, *Assessing disability in Europe - Similarities and differences* (2002), has stated four approaches to the definition and assessment of disability: barema methods (impairment tables), care needs assessment, functional capacity determination and economic loss estimation. In many European countries, there are general prohibitions against discrimination where disability is mentioned but not defined. The related OECD comparative study of policies to promote work and income security for persons with disabilities in twenty countries, entitled *Transforming Disability into Ability* showed that "many people who subjectively classify themselves as disabled do not receive disability benefits."

The European Commission, *Definitions of Disability in Europe: a Comparative Analysis,* (2002) discusses the definition of disability in four areas: 1) assistance with activities of daily living (ADLs), 2) income replacement, and 3) employment provisions, and 4) antidiscrimination legislation. ADLs include eating, moving and personal hygiene, home help, disability or health-related extraordinary expenses. Two issues are raised (1) to qualify for ADL assistance recipients generally have to pass two types of test in sequence: first a test of inability to work and then a test of limitations in performing ADLs. (2) There is little agreement on what constitutes ADLs. While in many states ADLs mean the ability to sit, lie down and get out of bed, others include incapacity to maintain personal hygiene and to dress and eat, some include "mobility and transportation-related activities and 'social' activities (e.g., housework and household management, communication and aspects of social participation).

In most member states of the European Union, and the United States, work incapacity is the first criterion for establishing eligibility for income replacement benefits. Some states, including the Netherlands, Sweden and Germany have adopted the concept of "partial disability", in recognition of regular part-time work. The European Commission study shows that disability defined on the basis of work incapacity can be assessed in different ways:

through a "procedural approach", probing the reasons a person stopped being part of the labour force; or through a "worker's capacity profile" where the focus is on the cause of work incapacity. The method consists of comparing an applicant's capacity profile with a job requirement. A third approach evaluates disability without explicit reference either to past or potential work, focusing instead on the extent to which a person's functioning is impaired.

Programs concerned with the reintegration of applicants in the labour force tend to evaluate the work inability in which options for medical and/or vocational rehabilitation and other return to work opportunities are explored.

Under the "capacity profile" approaches, some states evaluated disability by taking a 'snapshot' of a person's work capacity at a specified point, for example after the designated sickness benefit period ends. In the UK, the Netherlands and Ireland, assessment tools (e.g., the UK "Personal Capability Assessment" (PCA) and the Irish Medical Review and Assessment) are used to determine "the threshold for work incapacity". In the Netherlands, physicians use a standardized approach for measuring a claimant's functional ability to perform work. The approach defines 28 different types of action required in different occupations, including the basic activities in the PCA but also more specialized work-related activities such as tolerance of environmental conditions (reactions to heat, dryness etc), tolerance of vibration, ability to use special tools on the body (e.g. masks), etc.

The impairment-based approaches for disability assessment are impairment tables or baremas. They include ratings for the damage from disease and internal injuries, sometimes measured using innovative medical technologies.

PART 2: Disability and Housing Needs

Statistics Canada 'Participation and Activity Limitation Survey"

In 2001 Statistics Canada conducted the *Participation and Activity Limitation Survey* (PALS), a post-census survey of adults and children whose everyday activities are limited because of a condition or health problem. The previous major Statistics Canada survey on this topic, in 1991, was entitled the *Health and Activity Limitation Survey.*

The PALS population of disabled people was defined as those who answered "Yes" to the disability filter question(s) in the 2001 Census. A sample of approximately 35,000 adults and 8,000 children living in private, and some collective, households in the ten provinces was selected. Residents of institutions, such as nursing homes, were excluded. The response rate was 82.5%.

PALS used the World Health Organization revised classification of disability, the *International Classification of Functioning, Disability and Health (ICF, 2001).* That is, disability is the interrelationship between body functions, activities and social participation, recognizing the role of barriers and facilitators in the environment.

PALS collected data on difficulties with daily activities. These included moving around, hearing, seeing, communicating and learning. Information was collected on the type and severity of the activity limitation and on specialized equipment and aids used or needed. The survey covered help required to complete everyday activities; impact on employment, education, leisure, accommodation and transportation; information on out-of-pocket expenses related to specialized aids and services, medications, and transportation. It also enquired about insurance coverage and sources of income.

"*… A major difference between HALS and PALS was related to the approach used in the identification of the severity of the activity limitations. In 1991, a severity scale had been developed using the responses to the screening questions. Each respondent received a severity score by adding together the individual's responses to all activity limitation questions. One point was scored for each partial loss of function and two points were scored for each total loss of function. The total score was then divided into three severity levels: mild, moderate and severe. Since some types of disabilities were identified through the use of many questions, they had more weight in the severity scale. As a result, the 1991 HALS severity scale gave more weight to certain disabilities (such as mobility and agility) than to others….*

For the 2001 PALS severity scale, an index measuring the severity of the disability was constructed based on the answers to the survey questions. Points were given according to the intensity and the frequency of the activity limitations reported by the respondent. A single score was computed for each type of disability. Each score was then standardized in order to have a value between 0 and 1. The final score was the average of the scores for each type of

disability. Since the survey questions differed depending on the age of the respondent, a different scale was constructed for adults (15 years and over), for children under 5 and for children aged 5 to 14. Each scale was then divided into different severity levels. The scale for adults and for children aged 5 to 14 was divided into four groups (that is, mild, moderate, severe and very severe), while the scale for children under 5 was divided into two groups (that is, mild to moderate and severe to very severe). The PALS severity scale is therefore equally weighted for all types of disabilities and this results in a different severity profile than in the 1991 HALS."[13]

This approach avoids the issue of whether one type of disability is inherently worse than another. It might, of course, be true that activity limitations from one type of disability are more amenable to improvement by physical modification of the dwelling. Nevertheless, it seems a reasonable assumption that any person with a disability can be helped to some extent by modification of the dwelling.

Statistics Canada *Participation and Activity Limitation Survey: A profile of disability in Canada* (December, 2002) (website[14]) reports that one out of every seven Canadians aged 15 and over (14.6%), about 3.4 million people, reported some level of disability in 2001. Of these, 1.1 million reported mild levels of disability, 855,000 reported moderate levels, and 1.4 million reported severe or very severe levels. The disability rate in the adult population was reported to be 5.0% for mild disabilities, 3.6% for moderate disabilities and 5.9% for severe and very severe disabilities.

Disability rates among 45-64 year olds were 15.9% for males and 17.5% for females. The equivalent rates for 65-74 year olds were 30.2% and 32%, and for persons 75 years of age or more, 52.1% and 54.1%.[15] In general, the disability rate was slightly higher among women.

The most frequent disabilities reported were mobility (71.7%), pain (69.5%), agility (66.6%), hearing (30.4%), seeing (17.4%), psychological (15.3%), learning (13.2%), memory (12.3%), and speech (10.6%).

About 2.5 million people have difficulty walking, climbing stairs, or moving from one room to another. Among seniors aged 65 and over, mobility problems affected an estimated 1.1 million people. In addition, more than 887,000 seniors reported they were disabled because of pain. More than 1 million adults reported hearing difficulties and some 600,000 had a

problem with their vision. More than half-a-million adults reported limitations that were the result of emotional, psychological or psychiatric conditions.

Activity limitations were reported for about 181,000 children (aged 14 and under). Of these, 26,000 were younger than five. Almost 43% of children with disabilities had severe or very severe disabilities. The most widespread disability reported for children related to chronic health conditions that reduced activities, such as asthma.

One-third of adults with disabilities experience severe or very severe activity limitations. The survey distinguished four levels of severity: mild, moderate, severe and very severe. The level of severity assigned by the survey depended not only on the severity of each type of disability, but also on the number of disabilities per individual.

The survey found that one-third of adults with disabilities (1.1 million) had a mild degree of activity limitations, and about 919,000 had severe activity limitations. An additional 480,000 had very severe limitations. Like the number of disabilities, the severity of disabilities appears to increase gradually with age. Men were more likely than women to experience a mild degree of activity limitation, but a greater proportion of women experienced severe limitations. The proportion with very severe disabilities was the same for the two sexes.

Within the working-age population, activity limitations related to pain or discomfort are the most widespread (1.5 million persons aged 15 to 64, 7.5% of all working-age persons) Pain-related disability increases gradually from age 15 to 64, with prevalence within the total population rising from 2.0% for 15-to-24-year-olds to 5.4% for persons 25 to 44 and 13.1% for those aged 45 to 64. Statistics Canada notes that these findings raise questions about supports and adaptations in the workplace and the home to cope with this relatively less visible type of disability.

Mobility problems affect more than 1.1 million persons aged 65 and over (eight persons in ten with disabilities). Nationally, 23.3% of adults aged 65 to 74 reported having mobility problems, and the rate increases to 42.9% for those 75 and over.

Among adults aged 65 and over, 153,000 persons reported being limited by memory problems or periods of confusion (4.3% of Canadian seniors). Among seniors with disabilities, one person in ten reported having limitations in everyday activities related to memory problems. Approximately 364,000

Canadians over 65 years of age have Alzheimer's disease or a related dementia.[16]

The Extent and Nature of Need

The number of Canadians sixty-five years of age or older is expected to double from approximately four million in 2000 to eight million in 2026.

Human Resources Development Canada coordinated the production of the first federal disability report, *Advancing the Inclusion of Persons with Disabilities* (2002). As PALS data had become available updates of sections of the federal disability report have been posted on the Internet.

Publications such as *Bridging the Gap,* and websites such as *Persons with Disabilities Online (www.pwd-online.ca)* also provide summary information on Government of Canada programs and services for persons with disabilities. In addition, the joint federal, provincial and territorial website *Disability Weblinks (www.disabilityweblinks.ca)* provides information on disability-related programs and services offered by the various jurisdictions.

Need Identified in the Evaluation of RRAP

In 2002 CMHC completed an evaluation of its Residential Rehabilitation Assistance Program 1995-2001.[17] This evaluation contains several sections that describe the need for the program.[18]

In 1996 1,826,000 households were in "core housing need" – that is, their housing was inadequate or unsuitable and their income too low to remedy the deficiencies. The main problem was affordability.[19] If they were renters, seniors experienced the lowest level of core need, approximately 4% while 11.8% of families and 6.4% of singles in general were in need.[20]

The report states: "*Off-reserve 480,000 low-income Canadian households occupy housing that is either in need of major repair or is crowded. On-reserve there is a continuing back-log of dwellings in need of repair of at least 14,000 units, 24% of units are over-crowded. In 1996, there were about 38,000 Aboriginal households living off-reserve whose housing was inadequate or unsuitable. Most (75%) were in rental housing*."[21]

The CMHC evaluation of RRAP noted that it had renovated 34,700 resident-owned units and 17,300 rental units during 1996 to 2001. This was approximately 11% of the need identified in 1996.

Need Identified in the Evaluation of HASI

In assessing the rationale for HASI, in 1998, CMHC quoted Statistic Canada's Health and Activity Limitations Survey (1991). Approximately 4.2 million Canadians reported a disability (15.5%). Approximately two in five (42.5%) seniors (65 years and older) reported a disability. The most prevalent types of disability were mobility and agility limitations. "Among adults with disabilities, 59% have limited mobility and 54% limited agility, 30% have hearing disabilities, and 14% have visual disabilities."[22]

The rates of multiple disabilities were higher among seniors with disabilities – 72% limited mobility, 61% limited agility, 41% hearing disabilities and 24% visual disabilities. CMHC estimated that 580,730 adults with disabilities and 252,655 seniors with disabilities were having difficulty using one or more fixtures in their home.[23]

In the HASI evaluation (1998) CMHC noted that a growing number of people with disabilities reported using specialized housing features to help them enter and leave and mover around their home. "*Among adults with disabilities, 164,960use specialized features to enter and leave the home but an additional 72,390 need their features but do not have them. Among seniors with disabilities, 92,655 persons used such features and 41,855 needed them but did not have them. Similarly, 148,375 adults (84,705 seniors) needed specialized features within the home but did not have them. Statistics Canada data suggests that most people with disabilities prefer to live in their own homes as long as possible*."[24]

Statistics Canada data also indicated that adults with disabilities tended to have lower incomes than the average for their age group even among seniors. The average income of senior with a disability in 1990, from all sources, was $16,940 compared with $19,605 for seniors without disability. The income of two in three disabled seniors, and about half of all disabled adults, was below $15,000 per annum. CMHC reported that cost was the main reason why disabled adults did not make modifications to their homes to accommodate their disabilities. CMHC concluded that over 1.5 million adults and about one-half million seniors with disabilities required assistance to modify their

homes. The two main types of assistance needed were financial assistance and advice on modification options.

Trends in the Incidence of Disability

In 2002 the Office of the Chief Actuary published a study of Canada Pension Plan Disability beneficiaries, examining the dynamics of the Canada Pension Plan (CPP) disability program.[25] The paper examines historical data and trends in disability incidence by causes of morbidity are discussed. The paper identifies the main factors that have influenced the costs of the CPP disability program during the 1990s. These were the implementation of new medical adjudication guidelines in 1995 determining medical eligibility and the new eligibility rules that were part of the amendments to the Canada Pension Plan in 1998.

The study noted significant changes in the causes of disability over time. In particular, disabilities related to the circulatory system decreased (from 31% in 1980 to 12% in 2000) and disabilities related to mental disorders increased (from 11% to 23%) relative to other causes. Among younger beneficiaries, mental disorders are the most prominent morbidity.

From 1970 to 2000, the average age of recipients of the disability benefit has greatly decreased. Recipients under age 40 have increased from 5% to 13%, and aged 40-54 from 29% to 45%. The study notes that disability rates per thousand persons increased steadily from 1970 to about 1994, reach a peak for males of approximately 6 per thousand and females 4.5 per thousand, and declined rapidly thereafter.[26]

PART 3: Care Giving to the Disabled

Who are the family/informal caregivers

Informal care givers include family members, friends and neighbours. They are unpaid, often untrained, and provide care either because of love for the individual under care or out of a sense of personal responsibility. Informal care givers may help with transportation, grocery shopping, and house work, managing finances, preparing and giving meals, and arranging services for the recipient. They may help the recipients with the activities of every-day living, They can help them get in and out of beds, chairs; help with dressing, bathing,

toileting; feeding, dealing with incontinence, and so on. They may deliver some services that might otherwise need to be delivered by formal care givers, such as injections, giving transfusions or drug therapy, running dialysis machines, and so on.

The demographics of home care

In Canada, home care is the responsibility of the provinces and territories, and is not covered under the Canada Health Act (CHA) as an insured service. As a consequence, there is significant variation from jurisdiction to jurisdiction with respect to eligibility, availability, accessibility, and which services are paid for publicly or privately (Hirdes, Tjam & Fries, 2001; Canadian Home Care Association, 2003).

Home care is one of the fastest growing components of the Canadian health care system. Home care expenditures have increased by 121% in the past ten years, compared with an increase of 53% in hospital care expenditures for the same period. In 2004-05, Health Canada estimates that 1.6 million Canadians will receive home care, to a total cost of $4.16B or 4.95% of public health care spending. This figure does not include the costs associated with informal care given by family members or friends. It is estimated that 80-90% of the care provided to seniors in their homes is provided by informal caregivers. (Canadian Home Care Association 2003).

The cost-effectiveness of home care is discussed later in this section.

Characteristics of informal care givers

$ According to the most recent census, more than 1.7 million or 16% of Canadian adults, ages 45-64, provide informal care to nearly 2.3 million seniors with long-term disabilities or physical limitations. Of these, 64% are looking after their own parents; 24% are caring for their spouses' parents; and 24% are caring for close friends or neighbours (Stobert & Cranswick, 2004)

$ Canadian data indicates that between 85-94% of seniors over 65 suffering from dementia are cared for by informal care givers: a spouse (36%), daughter (28%), son (9%), and 27% by another relative or friend (Grunfeld, Glossop, McDowell and Danbrook 1997; McDaniel 1994).

$ 4.2 million or 18.2% of Canadians reported that they assisted seniors in the week previous to the 2001 census, and 3.9% or 933,000 are informal care givers according to a 2003 Decima study (Keefe & Legare, March 2004).

$ 51% of those aged 45-64 providing informal care are women, and 49% are men; 59% of informal caregivers over 65 are women, and 41% are men (Stobert & Cranswick, 2004)

$ 77% of caregivers aged 45-64 are married or living common law; the remainder are widowed (3%), divorced (9%), separated (3%) or had never been married (8%). Of those over 65, 68% are married, 21% widowed, 5% divorced and 3% were never married (Stobert & Cranswick, 2004).

$ Women spend two times as much time on caregiving tasks than do men (29.6 hours/month as compared with 16.1 hrs/month). (Stobert & Cranswick, 2004).

Characteristics of care recipients

$ Canadian data (1990) indicates that 31% of seniors 65-79 live alone (of whom more than twice as many are women - 42% are women and 16% men); 67% of women aged 80+ live alone, whereas 68% of men 80+ live with a spouse (Grunfeld, Glossop, McDowell and Danbrook 1997).

$ Nature and locale of recipient residence

S 55% own their own home; 24% live in the care giver's home; 8% live in someone else's home; 13% live in an institution (nursing home, assisted living or retirement home, independent-living group home)

S 33% of recipients' homes are urban, 38% suburban, and 27% rural

S In Canada, 50% of care givers live within 50 km of their parents, and most of those who do not live with their parents reside10 km or less from them (Grunfeld, Glossop, McDowell and Danbrook 1997).[27]

$ The reasons why a recipient needs care include: Alzheimer disease, dementia or mental confusion with other physical problems (25%); "aging" (15%); diabetes, cancer, heart disease & other health/physical

problems (52%); or Alzheimer disease alone (8%). In Canada it is estimated that 8% of seniors over 65 suffer from some type of dementia, half of whom are living in the community (Grunfeld, Glossop, McDowell and Danbrook 1997; Canada Study of Health and Aging Working Group, 1994). The proportion living in the community has been increasing in recent years as the provincial governments close large residential institutions in favour of in-community care of various sorts.

The literature also deals with how different cultures care for their elderly and disabled, and how their choice of mode of care affects informal care givers (e.g., Harwood, et al 2000, John, Hennessy, Dyeson and Garrett 2001, Morimoto 2003, Sansoni, Vellone and Piras 2004, NAC & AARP 2004, Grunfeld, Glossop, McDowell and Danbrook 1997). With respect to seniors, Grunfeld, Glossop, McDowell and Danbrook (1997) point out that culture has no effect on the physical aging process, but is a strong influence on choices of how, where, and under what conditions the elderly are cared for.

Factors affecting the decision to stay at home or go into an institution

Increased emphasis on home care in Canada in the 1990s was fueled by expectations that it would be cheaper in an environment of fiscal restraint in the public sector – there simply were not enough resources to maintain existing institutions or develop new ones to meet the increasing need. Secondly, there was a general belief, which had not yet been proven, that home care was more cost-effective than institutional care (Hollander & Chappell, 2001). The *National Evaluation of the Cost-effectiveness of Home Care* (2001) examined whether and under what conditions home care in Canada might be more cost-effective than care in acute care facilities or long-term institutions.

Fundamental to the choice to stay in one's home is the assumption that family, friends or neighbours will be available *and* willing to provide the needed support. In some instances there may be no suitable family care giver. For example, if the person needing care is single with no offspring or immediate relatives; or if the only available family member is a spouse who is himself or herself too elderly and/or disabled to be a care giver (Carriere, Legare & Keefe, 2004; Grunfeld, Glossop, McDowell and Danbrook 1997). In other cases, there may simply be no one of any capability who is willing to take on the care giving responsibilities (Arundel and Globerman 2001, Grunfeld

Glossop, McDowell and Danbrook 1997, Lubin 1992).

To strengthen the capacity, commitment and effectiveness of informal care givers, Fassbender (2001) suggests that Canadian governments develop policies that encourage the capacity-building and willingness of the family members, friends and neighbours (Keefe & Legare 2004) to provide home care.

The availability of suitable informal supports is clearly one of the key factors that affect the decision to remain at home instead of entering an institution (Alcock, Edwards, Diem and Angus 2001, Philip, et al 1995). Others include:

- Having access to housing that makes accommodation for mobility and access problems (wheelchair accessibility, windows and cupboards of appropriate height/easy opening; kitchen/bathroom accessibility, etc.). [See also, *Canadian Clearinghouse on Disability Issues*, 2004; CMHC, 1996/2004; *Canadian Clearinghouse on Disability Issues*, 2004; Mann, Ottenbacher, Fraas, Tomita and Granger, 1999];

- Availability of reliable and affordable help for home maintenance;

- Community support programs such as meals on wheels, elder watch, day care and respite services , and so on;

- Adequate personal or family finances to be able to undertake renovations when needed (mobility, access), meet home maintenance needs, and get professional services when needed;

- Adequate public funding and staffing for professional services where personal and/or family finances are non-existent or inadequate;

- Family care giver and/or recipient concerns about the lack of continuity in home care workers because lack of continuity may be disruptive, especially to the confused elderly;

- Availability of respite care and day programs which help ensure that the recipient continues to have social interaction with others, and to give informal care giver a break from ongoing care responsibilities (see Warren, Kerr, Smith and Schalm, 2003); and

- Having access to reliable community and public services such as grocery stores that take/deliver grocery orders, para-transport services to attend day programs, medical appointments, and so on.

Alcock, Edwards, Diem and Angus (2001) also identified several reasons for entering or remaining in an institution, including:

- The home environment is unsafe (one/all of functionally, structurally, physically, emotionally).

- The need for transitional convalescent or respite care cannot be met; there is insufficient/ineffective support for care givers (home support, day programs, etc.).

- The individual under care has heavy full-time care needs beyond the capacity of the informal and formal home care givers (medical or physical needs such as incontinence, psychological or behavioral difficulties, etc).

- The client lives alone and has no family willing and/or able to provide informal care.

- Lack of community supports such as appropriate housing, availability of transportation, meals-on-wheels, etc.

- The client (recipient of care/family care giver/family) is unable/unwilling to pay for additional support services that would enable the recipient to remain at home.

- Home care services are insufficient to meet the recipient's needs and/or ineffective; and

- A lack of understanding on the part of the client (recipient of care/family care giver/family) of the cost differences between home care and a long-term care facility (e.g., belief that institutional care is their right and will not cost them anything).

In addition, where a case manager is involved in helping the individual and the informal care giver make decisions about whether to keep the cared for at home or have them enter an institution, the care giver's knowledge of provincial and regional policies related to long-term and home care services is also an important factor (Alcock, Edwards, Diem and Angus 2001). As has

already been noted, the nature of these policies and how they are implemented differ significantly from jurisdiction to jurisdiction in Canada (Grunfeld, Glossop, McDowell and Danbrook 1997; Hollander, Chappell, Havens and McWilliams, 2001, Canadian Home Care Association 2003).

Another study identified several possible impediments to moving a client from acute care into home care (Arundel and Globerman, 2001). One would expect that similar issues may arise for frail seniors or disabled persons:

- Impediments related to the family/care giver/recipient capacities, traits, and/or roles and relationships - such as resistance to change; lack of education about or awareness of the benefits of remaining at home; the lack of an appropriate and willing family care giver with the needed capacity.

- Geographic impediments - e.g., differences in rural and urban access to services, community supports, equipment and supplies; jurisdictional barriers such as service differences between neighboring municipalities, between provinces or territorial jurisdictions, etc.

- Problems related to professional care givers working with each other and with informal care givers, such as the definition and understanding of their respective roles and responsibilities, availability, scheduling and assigning of professional resources, etc.

- Systems management and control issues - especially issues around the adequacy of home care resources, both in terms of financial and other resources, and the types and quality of programs that provide the foundation for effective home care.

Cost-effectiveness of home care

Hollander (*Overview*, 2001) reports that there is relatively little information on the cost-effectiveness of home care in Canada. International literature on the cost-effectiveness of home care in place of acute care and/or long-term care is mixed (Hollander - *Overview* 2001; Leichsenring and Alaszewski, 2002). For example, some U.S. literature concludes that home care is not a cost-effective alternative to institutional long-term care (e.g., Weissert, 1985).

Several of the studies in the *National Evaluation of the Cost-effectiveness of*

Home Care (2001) address this issue from one perspective or another. The following list is a summary of the findings of the most relevant of these studies.

- A study of elderly in continuing care in British Columbia over four fiscal years (1987/88, 1990/91, 1993/4, 1996/7) concluded that (1) home care is less costly for government than residential care at all levels of care, although if the client is in transition from one level of care to another, the savings are less; and that (2) 30-60% of costs for home care clients are for hospital care and that traditional services, such as home nursing account for only about 1/3-1/2 of overall home care costs. (Hollander, *Sub-Study 1*, 2001)

- A study of 5000 home care clients in Edmonton looked at the relationship between the amount of formal care and the amount of informal family support given to clients. The researcher found that overall increases in $1 for family care results in an increase of $1.09 in formal care, whereas $1 in formal care results in an increase of $.30 in family care costs. The researcher also found that increases in family care are associated with significant increases in formal care when higher levels of care are required, although increases in formal care result in modest increases in informal care. The conclusions were: (1) it would appear that increased capacity to provide informal care does not necessarily generate savings in formal care; (2) increases in formal care services may be associated with significant increases in the burden on family care givers; and (3) formal and informal care are complementary, not substitutive. (Fassbender, 2001) This does not necessarily mean that one causes the other, although there may in some cases be such a relationship, but rather that they tend to increase together depending on the severity of the needs of the person cared for.

- Two studies (pilot & main study) looked at the costs and outcomes of care (worse, same, better) for home care clients or for those in institutions. The study measured informal costs of care by identifying the psycho-social and financial burdens shouldered by family members, friends, and volunteers. The researchers found that home care is significantly less costly than residential care when formal costs or both formal and informal care costs are taken into account. Specifically, they found that (1) home care is 40-50% of residential costs in terms of costs to government; and (2) informal costs (client costs and informal

care) contributed about half of the care costs of community care and approximately one third of care costs in facilities. The authors also raised the following policy issues:

- Is it reasonable for government to pay fully for short-term curative care (physicians, hospitals) but not fund clients with ongoing needs?
- If home care is a reasonable (and less costly) substitute for institutional care why are there so few targeted programs to support this choice?
- What is the appropriate allocation of fiscal responsibilities between the family and the state? (Hollander, Chappell, Havens and McWilliams 2001)

- A study of the cost-effectiveness of home care vs acute care in Alberta found that most combinations of hospital care and home care were more expensive than hospital care alone; and that care needs (defined as number of diagnoses) were higher for persons who received home care. It also found that the severity of a case is an important indicator of home care needs assessment, and that single care episodes are usually more costly on average than an equivalent long-term care period because they have a higher degree of intensity. (Jacobs, 2001)

Impacts on family and other informal care givers[28]

There are financial and other costs associated with care giving (see: Anderson and Parent, 1999). These include acute and/or long-term health and emotional problems that may be the result of the stresses and strains associated with care giving. The impact on the care giver's economic well-being - both short- and long-term - must be taken into consideration, as should the impact of his or her general well-being. Care givers may need to pay out-of pocket expenses related to their responsibilities. They may need to retire early, have to miss work or leave work early, and/or decline or become ineligible for promotions. Finally, there may be costs associated with helping the care giver cope with his or her responsibilities effectively (knowledge, skills & techniques).

Virtually all studies report unusually high rates of symptoms of depression among care givers and several report higher rates of clinical depression and anxiety (*Canada Study of Health and Aging Working Group*, 1994; Schulz, R.,

1990; Livingston, 1996; Baumgarten, 1994; Galliccho, Siddiqi, Langenberg and Baumgarten, 2002). The stress and strain of care giving also appears to have an impact on the rate of acute infectious diseases (Grunfeld, Glossop, McDowell and Danbrook 1997). However, it is less clear whether this leads to chronic illness (Grunfeld, Glossop, McDowell and Danbrook 1997; Kiecolt-Glasser et al, 1991).

The NAC-AAPR Report (2004) found that the two best predictors of physical strain on care givers were their own health and the feeling that they had no choice but to be the care giver - so both ability to provide care and the *willingness* to do so seem to be critical. The degree of severity of the recipient's condition is also thought to be another predictor. The most important factors with respect to emotional stress appear to be the degree of severity of the recipient's condition and whether the care giver feels that he or she has a choice or not (Stobert & Cranswick, 2004; Decima, 2002). Grunfeld, Glossop, McDowell and Danbrook (1997) found that family care givers of the elderly often experienced chronic levels of stress at higher levels than those caring for family members with terminal illnesses, sometimes because dementia is an ongoing condition with no predictable end. Other factors which contribute to emotional stress include the state of the care giver's health, whether the care giver lives in the same household, and whether the care giver is female.

Issues that have an impact on the care giver's economic well-being include:

- The impact on work. It is likely that workplace adjustments could have long or short-term financial and/or career implications, or other economically-related lost opportunity costs. For example, there will be a long-term impact on a caregiver's pension plan if he or she has to take time off from work to provide care (Stobert & Cranswick, 2004; Keefe & Legare 2004).

- There may also be physical and/or mental health implications for the care giver's long-term ability to earn a living.

- Family care givers may have an increased financial burden if the recipient needs financial help.

- Finally, there may be direct costs to the care giver. They may need to move into the recipient's home which might involve costs. They may have

to drive some distance back-and-forth on a regular basis, and so on.

In addition to the care giver's financial well-being and the severity of the recipient's condition, other factors which could likely affect an older care giver include: the care giver's age (the older, the more the financial situation is affected adversely), the care giver's own health (usually poorer); and whether the care giver lives with the recipient (NAC-AARP, 2004).

These all point to the need to provide professional and/or other support to care givers if they are to continue to give care over time without significant harm to their own physical and mental well-being and overall quality of life (Fassbender 2001, Donaldson and Burns 1999, National Alliance for Care giving & AARP 2004). Chappell (1992) and others (e.g., Kraal, 1991; NAC-AARP, 2004) point out that informal care givers themselves may need physical, medical and/or emotional support from other informal care givers, and from professionals, if they are not to burn out and/or get ill themselves. Depending on the acuteness and intensive nature of the care giving situation, the stress and emotional needs of family care givers may actually exceed those of the recipient of care (NAC & AARP, 2004; Higginson, 1990).

Homecare care givers may also need specific training in the use of the more sophisticated technologies that increasingly characterize health care (Grunfeld, Glossop, McDowell and Danbrook 1997; *Health Transition Fund Report* # BC 124, 2002). For example, a family care giver may need to operate a home dialysis machine, give medicine intravenously, or other care that, if the patient were in an institution, would ordinarily be done by a medical professional.

Care givers themselves often recognize that they need help with health, emotional, quality-of-life, and recipient care issues. Stobert and Cranswick (report on Canadian Census, 2004) found that 51% of informal caregivers age 45-64 need but are not getting periodic relief from their responsibilities. A significant percentage of these individuals also indicated that they wanted more information (to improve their skills and/or about the nature of long-term illnesses). The need for more flexible work arrangements and/or some level of financial compensation was also high on their list of what would be most useful to them if they were to provide care (Stobert & Cranswick, 2004).

Some studies have also looked at these affects on caregiver stress and strain, and caregiver physical and mental health where the recipient has been institutionalized (Desbiens, Mueller-Rizner, Vimig and Lyn 2001, Yeh,

Johnson and Wang 2002). The *Canadian Study of Health and Aging* (1994), for example, reported that family care givers reported less depression if their loved-one with dementia was in an institution, even if the condition was more severe.

Because the time available for the literature review has been brief, literature on this issue was not reviewed in any depth. However, some studies report that stress appears to be less if the caregiver feels he or she has freely chosen to take on these responsibilities (e.g., Decima Report, 2002; Stobert & Cranswick, 2004).

PART 4: Literature on Formal Care Giving

Formal care givers are paid to render services to the senior or disabled person and, in some situations, the informal care giver. They include paid employees, care from/paid for by private or public agencies, and volunteers (Carriere, Legare & Keefe 2004). Home care services may include nursing and professional services (physiotherapy, occupational therapy, speech therapy, respiratory therapy, nutritional counselling, social work), pharmaceuticals and medical equipment/supplies, and support for essential personal care needs (bathing, dressing, meal preparation, housekeeping, etc).

Home care services may also include case management and assessment. The case manager is responsible for coordinating service providers to meet the special needs of those receiving care. [See discussions of the role of the case manager, and how it may be strengthened and enhanced, in *Health Transition Fund Report* (2002); Alcock, Edwards, Diem and Angus (2001); Hirdes, Tjam and Fries (2001); and Kraal et al, 1990.].

In the context of this study, the literature on formal care giving should address the following two questions:

1. How much formal home care is delivered to the recipient of care and what is the nature of the services provided; and

2. What are the costs related to these services?

To this point, we have not identified literature that deals directly with the first question in a comprehensive way, especially with respect to the target audiences of the RRAP-D and HASI programs. This may need to be the

subject of further research.

Once the nature and type of services provided to these targeted recipients is established, however, determining average remuneration on a per hour or per day basis for each type of service provider should be relatively straightforward, once jurisdictional and geographical factors are taken into account. These would include differences in remuneration between the provinces/territories; between urban, rural and remote areas, and between cities.

PART 5: Evaluations and Evaluation Frameworks Relevant to Programs for the Elderly and/or Disabled

Introduction

This section of the literature review discusses some evaluations and evaluation frameworks that relate to the elderly or disabled. These include the Treasury Board Guide to Cost-Benefit Analysis and Guide to Result-Based Management Accountability Frameworks, evaluations of RRAP-D and HASI, and the other main evaluations of programs for the disabled that have been undertaken by the Government of Canada, specifically the evaluation of the Canada Pension Plan (Disability Component).

Treasury Board Guide to Cost-Benefit Frameworks

The general framework for cost-benefit analysis of all programs of the Government of Canada, including housing programs, is provided by the Treasury Board's *Benefit-Cost Analysis Guide* (1996). The Guide describes how alternatives should be formulated in order to have a fair basis for comparison, how costs and benefits can be identified, quantified and monetized, and what decision rules should be used. It also describes how to use financial simulation techniques (risk analysis) to cope with input data that is uncertain. The Guide states criteria for a good quality cost-benefit analysis.[29]

Other Federal Government Guides to Cost-Benefit Analysis

Other departments and agencies of the Government of Canada have published frameworks for cost-benefit analysis, tailored to their particular types of programs. Examples include Transport Canada (1994) and Industry Canada (1986).

The General Literature of Cost-Benefit Analysis

There is a broad literature of cost-benefit analysis that describes methodologies and applications. (See Bibliography attached) It is worth mentioning that not all scholars believe that cost-benefit analysis is the appropriate tool to assess social programs. See Carter (1972) and Latham and White, Personnel Psychology (47).

CMHC's Cost-Benefit Framework for RRAP

In 2003 CMHC commissioned a working paper on the topic of a cost-benefit framework for the Residential Rehabilitation Assistance Program (Malatest, February 2003). This paper covers RRAP-D as a section of RRAP, but does not deal with it in detail. Nor does the framework deal with HASI.

The framework paper states that it is based on an approach to cost-benefit analysis developed by Amiram Gafni. (Gafni, 1991, 1996, and 1998) and, in particular, methods of "contingent value analysis". The term "contingent" is used to indicate that questions about value are posed directly to the beneficiaries in a "what if" format. For example, a HASI beneficiary might be asked "What would you be willing to pay for the proposed modifications if you were required to pay the whole cost?" Alternatively, the beneficiary might be asked "What amount of money would you be willing to accept instead of having the modifications?" In theory, these two questions should lead to identical monetary valuations of program benefits, although, in practice, because of the inaccuracies typical of self-reporting of intentions and values, the results tend to vary.

Contingent value analysis can work well if certain conditions are fulfilled that make the respondents' self-reports plausible. First, the beneficiary should have a clear quantitative grasp of the benefits they are being asked to value in dollars. Second, they should not be asked to make too great a leap of imagination to state the value in dollars. This means that the beneficiary should have information and experience on which to base a valuation. For example, in another context, people in Ottawa might be asked how much they

would be willing to spend to use a trail in the Gatineau Park in the cross-country ski season. This is a reasonable request since the amount of money is small and the respondent can compare the option of using the park with other recreational opportunities which have market prices.

In contrast, if the money involved is large relative to the beneficiary's resources, or if the benefit is complex and difficult to compare with known prices of similar goods, then "contingent valuations" might be difficult to make and might not be robust when they are made. If conditions are not conducive to good contingent evaluation than the dollar values that result might be inconsistent and inaccurate, and might be poor predictors of actual behavior. That is respondents might say they are willing to pay a certain amount, but their behavior in the event might reveal that the amount they are in fact willing to pay is less or more than their "contingent" estimate.

Although 'contingent value analysis' is the core of the cost-benefit framework described by Malatest, he covers other topics as well. One topic that is important, although it is not, strictly speaking, part of a cost-benefit framework, is "attribution". What effects are truly caused by the program? Malatest refers to the RRAP Evaluation (2003) which used before-and-after-renovation data collection, and also refers to comparisons with persons who applied for funding but did not receive it. The latter he calls a "control group", although it is a fully comparable group and therefore not a control group in the rigorous sense.

Malatest lists six "types of program benefits" (and measures/issues for each), namely: health improvements; safety; economic/productivity impact; extension of dwelling life; reduction in utility/maintenance costs; and reduction in homelessness. He does not construct a causal model or consider which of these factors lead to the beneficiaries remaining in independent housing longer. Also, one would have to be careful of double counting. For example, 'economic impact' depends partly on other impacts that have already been counted.

Malatest also considers what the appropriate sample size would be for a survey, and shows a table[30] of sampling errors for three samples from the Canadian general population (sample sizes 1000, 2000 and 5000). However, the sampling errors quoted in the table depend not only on the relevant population size (which might not be the whole Canadian population) and

sample size, but also on the distribution of values of the variable being estimated (which is not mentioned).

Evaluations of RRAP-D

[1] Evaluation of the Residential Assistance Program (Malatest, 2003)

In 2002 CMHC commissioned an evaluation of RRAP's performance during the period 1995 to 2001. The evaluation included an examination of RRAP-D. It was found that approximately one third of the relevant housing modifications would not have been done in the absence of RRAP-D funding. However 11% of homeowner recipients and 19% of landlords report that they would have done the same renovations even if a subsidy had not been available. About 10% of homeowners would have sold their existing accommodation and changed homes, and 27% would have done fewer modifications or done them later.[31]

The evaluation reported that the participants' satisfaction with accessibility to their home improved significantly.[32] This was especially marked in regard to use of stairs, use of the bathroom, and getting in and out of the home.[33] Sixty-three percent of RRAP-D homeowners reported that their ability to undertake general daily activities had been significantly improved by the modifications.[34] Nevertheless the study found that about half of RRAP-D clients still had significant unmet needs for modifications, mainly in the areas of emergency calling, bath lifts and wheel-in shower, automatic doors and widened doors and hallways.[35] In most cases the reason for not installing these features was cost.

Subsequently, the survey of clients was extended to tenants living in units that were modified under RRAP-D. Also, there more information was collected from homeowner RRAP-D recipients through 126 interviews by occupational therapists (limited to cases where the program was delivered by a federal or provincial agency).[36]

Between 80% and 90% of RRAP-D beneficiaries had mobility disabilities, about one in five had visual disability, and between 10% and 15% had disabilities related to hearing, cognition, or allergies. Approximately 14% of tenants and 18% of homeowner beneficiaries had other disabilities, some related to mental health.[37] About half of the beneficiaries reported significant difficulties using stairs, getting in and out of bed, and using the bathroom. In

each of these cases about another third reported some difficulty. A third of beneficiaries reported significant difficulty approaching the building or dwelling, and an additional 46% reported some difficulty.[38]

The CMHC publication RRAP for Persons with Disabilities – Eligible Modifications (NHA 6810) lists the eligible modifications, fixtures and equipment. The RRAP-D client survey (Malatest, 2002) indicates that by far the greatest number of modifications had to do with bathroom modifications or improved street access.[39] Kitchen modifications were undertaken by only 14% of homeowners and 26% of landlords. Approximately 71% of RRAP-D homeowners and 88% of RRAP-D tenant beneficiaries reported themselves satisfied or very satisfied with the accessibility of their housing after modifications.[40] However only 60% to 63% of beneficiaries reported that their ability to undertake daily activities was significantly improved after the modifications (another 12% of tenants and 29% of homeowners reported "improvement" but not significant improvement).

The interviewers (occupational therapists) judged that 67% of beneficiaries needed still more modifications in their homes. About half these were because the disability had changed since the RRAP-D modifications had been completed. The most common modifications still required after the RRAP-D work related to safety and security[41] and, second, personal care and independence[42].

It is interesting that the same percentage of RRAP-D beneficiaries as others who had not received renovation assistance reported that they intended to move in the next year (3%). However only one third of RRAP-D beneficiaries quoted accessibility problems as their motive for moving, while two thirds of others did.

Only 26% of households received advice from a disability professional on the proposed physical modifications to the dwelling. Occupational therapists judged the modifications that were assessed to be very appropriate (4.8 on a scale 1-5). Whether they were the most appropriate possible, or whether different modifications would have been even more appropriate, is unknown. The study made estimates, from various sources, of the likely costs of modifications still undone. The average cost per dwelling unit for needed additional modifications was estimated to be about $3500.

Evaluation of 'Home Adaptation for Seniors Independence' (HASI)

The National Strategy for the Integration of Persons with Disabilities was a five-year program of the Government of Canada announced in 1991. One component was a pilot program entitled 'Home Adaptation for Seniors Independence' (HASI) with $10 million in funding. At the same time CMHC produced a self-assessment tool which HASI applicants could use to consider the home adaptations that they need in light of their activity limitations.

In 1994, CMHC undertook a survey of HASI beneficiaries and in 1998 published an evaluation entitled *Housing Initiatives under the National Strategy for the Integration of Persons with Disabilities* which drew upon the survey data to evaluate HASI. The mail out survey addressed nearly all persons (1032) who received HASI financial assistance in 1992. Six hundred and thirteen persons completed a questionnaire. The evaluation report states that "*this response rate was high enough to provide an accurate picture of program approach and performance at the national level*". However, of course, this depends on how representative the respondents were of the whole population, and this is unknown. In addition, thirty telephone interviews were conducted in 1995 with persons who had provided detailed responses to the written survey in 1993. At the same time, CMHC Audit and Evaluation Services sent a questionnaire to field staff who delivered the program.

The report considered the continuing relevance of HASI in light of disability rates among seniors.[43] Among HASI beneficiaries it found 80% had age-related mobility disabilities. As with RRAP-D, the most frequent HASI modifications were to the bathroom (approximately 75%) and to the entrance to the home (67%).

The study defined "independence" as, first, the ability to carry out the normal activities of every day life by oneself and, second, the ability to stay in one's current home rather than move in with care givers or move to an institutional residence. The first aspect of independence is measurable on a continuum of comfort, improved safety and security, improved ability to perform everyday activity, and improved quality of life. The second aspect of independence relates to avoiding a threshold of discomfort in any of these aspects of life at which the homeowner or tenant would choose to change residences. "*Overall*

about 55% of HASI clients agreed that without the adaptation, they would have had to move and 30% strongly agreed with this statement." (p.23) Forty percent of beneficiaries strongly agreed, and 17.6% moderately agreed, that they would not have made the adaptations without HASI support. It is unknown whether this was driven by inability to pay or unwillingness to pay without a subsidy (because value did not exceed total price). There were large unexplained variations in the 'incremental effect' percentages by Province.

The part of the study most relevant to a cost-benefit framework is entitled "Cost Effectiveness of the HASI Program".[44] It states "*The key rationale for HASI was to provide seniors with the opportunity to remain in their own homes by facilitating their ability to carry out activities of daily living with minor home adaptations*."[45] The cost-effectiveness analysis considered the costs and benefits of HASI solely in this regard – that is, how long did HASI prolong the beneficiaries' stay their present homes, and with what financial and economic results? Actually, this question was posed only for single-person households because the study team decided that multi-person households were too complex to analyse.

The administrative costs to deliver $8,626,624 in loans were estimated to be $2,129,681.[46] These did not include any costs to clients for their time or expenses in applying to HASI or managing the renovation project. However CMHC estimated that clients expended $553,872 to pay for part of the work, either because some expenses were ineligible under CMHC guidelines or because the total cost exceeded the HASI loan ceiling.

The housing costs of HASI clients who would have moved out of their house without HASI assistance (estimated by the evaluators to be one third of the sample of clients) were estimated to be $11,120 per year. In addition, the costs of in-home care for these persons were estimated. Only the costs that would not be incurred in an institutional setting, or that would be included within the overall fees charged by an institution, were included in the estimate. Responses to the HASI survey indicated that about half the HASI beneficiaries had used in-home services in the previous six months. On the basis of regional data from British Columbia, the average cost of in-home services was assumed to be $2700, and this was doubled (a "guesstimate") to account for informal in-home services by friends and relatives.

Except on an anecdotal basis, the study was not able to ascertain whether the use of in-home services had been significantly reduced by the HASI

renovations. In most cases it appeared to the authors that a reduction in such costs was unlikely.

Set against these costs were the benefits of avoiding institutionalization. The value of this benefit was estimated from Statistics Canada's *Survey of Residential Care Facilities for the Aged*. In 1992-93 the average cost (across all levels of institutional care) was $32,543 per staffed bed per year. The study states that this estimate is probably too high since HASI beneficiaries, if they moved to an institutional setting, would probably require only basic levels of care that is, Type 1 care[47]. On the basis of Hollander (1994) the cost of a Type 1 case was estimated to be $28,312.

The estimate of the incremental impact of HASI was based on the proportion of clients who would have moved out of their homes without HASI (said to be 32%). It was difficult to estimate on a firm basis how long people helped by HASI did in fact remain in their homes since HASI was, at that time, a relatively new program. It would be easier now with a longer history to examine. On the basis of the little that was known at the time, the study concluded that recipients stayed on average for an additional two years in their present homes (guesstimate). A "sensitivity analysis" revealed that HASI was cost-effective if the average additional stay for the 32% of beneficiaries who would otherwise have moved was more than 6 months, on average. The net present value of the program rises rapidly as the additional stay in-home gets longer.

The extra satisfaction (utility) of the HASI beneficiaries who were enabled to stay longer in their homes was mentioned but not quantified or monetized.

Public Consultations

In 2002 CMHC undertook a consultation on housing renovation programs. (Renovation Consultation Report, 2003) In general respondents thought that more money should be available, that there should be less constraint on eligibility (both income and type of housing modification) and that the ceilings on financial contributions should be raised. There was some concern that the programs might encourage recipients to take on more debt than they were able to handle.

Most respondents were of the opinion that income eligibility limits needed to be adjusted to take into account the additional costs incurred by a person

because of disability. The issue of how the caregiver's income should be taken into account was raised.

There was disagreement about the adequacy and reasonableness of the list of eligible modifications, but most respondents stated that they agreed with it.

Other issues were discussed, with respondents taking various views. These issues included whether RRAP-D should be available for new construction, whether "stacking" of program contributions should be allowed, whether the assistance level was adequate, whether conditions on Indian reserves justified special provisions, whether HASI and RRAP-D should be amalgamated, and whether either program was likely to affect homelessness.

Evaluation of the Canada Pension Plan (Disability Component)

Human Resources Development Canada (HRDC) evaluated the Canada Pension Plan Disability Component (CPPD) in 1996. CPPD provides protection against loss of earnings due to disability for claimants whose physical or mental disability is severe and prolonged, who meet certain requirements of past employment. As well, there is a CPP child benefit payable for the children of a disabled beneficiary.

The evaluation included:

- review of the literature relating to public disability insurance;
- review of international PDI programs;
- comparison of CPPD and Quebec PPD clients, based on the 1991 Statistics Canada's Health and Activities Limitation Survey (HALS);
- interviews with CPPD representatives of Workers' Compensation Boards, Provincial Social Assistance Departments, private sector long-term disability insurance providers and advocacy groups;
- statistical analysis of CPPD caseloads and factors that might explain increases in case loads;
- analysis of earnings replacement effects through CPPD; and
- a review of the CPP National Vocational Rehabilitation Project.

Data sources included the 1995 Statistics Canada Survey of CPPD beneficiaries, the HRDC data for tax filers, and the CPPD master benefit computer file data. At the same time the department commissioned related

research, such as the HRDC *Disability Incidence Study,* completed in mid-1995.

The evaluation found that the underlying rationale for the CPPD as a national federal-provincial/territorial program was still relevant; that only a small percentage of persons who have severe activity limitations are actually in receipt of CPPD benefits; that the number of CPPD beneficiaries had increased significantly in contrast with QPPD (the evaluation was unable to determine whether this was a result of "economic grants" – that is, the result of the award of disability pensions to mildly or moderately disabled persons for economic reasons such as increased unemployment, or as a bridge to retirement).

The evaluation found that there were many younger CPPD beneficiaries and that their disability status was not typically reassessed over time and that there were built-in disincentives to returning to the labour force. That is, if an individual returned to work, and became disabled again, he or she would need to re-apply for CPPD benefits whereas if he or she remained out of the work force few questions were asked. Recent changes to CPPD, which continued benefits through a three month trial return-to-work period, and which allowed "fast tracking" of reapplications for CPPD, had made it easier for beneficiaries to try returning to work, without being unreasonably penalized by benefit cut-offs. It was noted that there are additional work incentives could be tried, such as increasing the amount of money which beneficiaries can earn without losing their benefits (to foster re-employment), or supporting more timely and effective rehabilitation.

CPPD has also reviewed the program's administrative decision-making. (*CPP Random Review 1995).* This review made a positive assessment of consistency of administrative procedures, but provided no data on the role of socio-economic factors in adjudication, the severity of disability, or the potential for rehabilitation of applicants or beneficiaries.

The main CPPD evaluation noted that there is not adequate information on the functioning of the application adjudication processes. The key factors in adjudication were not fully known from research. It was thought that data of this sort would be required to accurately measure the existence and extent of economic grants, provide an independent view of decision-making, explicitly measure the severity of applicant disabilities, rehabilitation potential and employability, and provide quality assurance on adjudication.

The evaluators noted that CPPD procedures resulted in about 10% of beneficiaries who, once in receipt of benefits, continue to collect a pension, even though their disabilities may lessen, and even though other factors (e.g. new technology) may make a return to employment possible.

The evaluation noted multiple and duplicative sources of earnings replacement, and that the lack of a coordinated system resulted in a wide variation in the benefits provided to persons with the same or similar disabilities and comparable work histories, but different insurance coverage. These variations resulted from differences in circumstances causing disablement, differences in coverage by different programs and differences between provincial programs.
CPPD was found to be similar to programs operated by Canada's international trading partners, and somewhat less generous. The CPPD caseload was not found to be higher, relative to population, than caseloads in similar programs in other countries.

The CPPD adjudication and appeals system was found to be less efficient than the one operated in Quebec. CPPD medical evidence was usually provided by claimants' own physicians. It was thought that this may place family physicians in a difficult position since their primary responsibility is to their patients rather than the CPPD. Quebec, in contrast, relied extensively on independent medical assessments. As well, CPPD adjudication was found to be less structured than international models which tend to use more exact protocols for grant adjudication.

CPPD recipients were found to draw disability benefits from a number of provincial and private-sector sources, introducing complexities to the earnings-replacement system, and in some cases, resulting in post-disability incomes which are equal to, or higher than, pre-disability incomes.

To improve the overall quality of adjudication, the evaluators recommended that CPPD modify its adjudication procedure and introduce new guidelines/tools, including baseline occupational demands, a structured scoring system to assess claimants' functional limitations to match their residual capacities to specific occupational demands, and independent medical examiners. The evaluation also recommended a comprehensive case review to assess administration of adjudication across regions, and to resolve questions regarding the extent of any economic grants (including their use as a bridge to retirement); and that rehabilitation capacity be reviewed.

CPPD should also consider other key research initiatives, including: (35) a program of *joint research wi*

Evaluation of the National Vocational Rehabilitation Project for People with Disabilities

In conjunction with the evaluation of the Canada Pension Plan (Disability Component), Human Resources Development Canada (SPR Associates, 1996) conducted an evaluation of the National Vocational Rehabilitation Project. The evaluation found that about 60% of participants who successfully completed their rehabilitation found employment, with about two-thirds of those employed were full-time at the time of the evaluation.

Nevertheless the evaluation found systemic barriers to the effective and efficient delivery of rehabilitation services. It recommended that any permanent rehabilitation component of the CPPD should be accompanied by changes designed to make the "rehabilitation mission" integral to the mission of the Canada Pension Plan (Disability). Vocational rehabilitation was found to be extremely uncommon for CPPD beneficiaries. Only 7.3% of CPPD beneficiaries surveyed in 1995 had participated in vocational rehabilitation after they started receiving CPPD benefits.

The evaluation suggested that there is considerable potential for rehabilitation and for return to work among CPP(D) beneficiaries. "*The historic CPPD model appears to have captured many beneficiaries who, once in receipt of benefits continue to collect a pension, even though their capacity may improve, or other factors (e.g. new technology) make a return to substantial gainful employment possible.*" (p.63)

Workforce Participation Effects of Income Support to the Disabled

The Government of Canada has a broad 'disability agenda' and several programs that provide financial support to the disabled, the largest of which is the Canada Pension Plan (Disability) which disburses about $2.7 billion per year. The CPP-D supports the incomes of working-age adults, and, unlike RRAP-D and HASI, restricts the amounts that they can earn without loss of benefits. Therefore there is a risk, whose magnitude is unknown, that some

people who would otherwise work full or part time will not do so, or will do so less. Apart from the economic losses that might result, this outcome would be counter to the modern spirit of enabling people to live full lives with the supports necessary to do in the community.

John Bound and Richard Burkhauser in *The Handbook of Labour Economics*, Chapter 51 "Economic Analysis of Transfer Programs Targeted on People with Disabilities" (Ashenfelter and Carol, 1999)[48] reviews the research on the behavioral effects of income support to the disabled. It suggests that one difficulty in assessing the effects of income support is that at least some of the work that beneficiaries might do is "off the books" – that is, it is in the informal economy.

Gastwirth (1972)[49] suggested that a large percentage of males receiving Social Security Disability Insurance benefits in the United States would work if the income transfers were not available. Swisher (1973)[50] challenged this, comparing beneficiaries only with the severely disabled, and finding that only about 20% of beneficiaries would likely be able to earn enough to keep their families out of poverty. The issue turns on what the appropriate comparison group is. Neither author was able to identify a group of non-beneficiaries whose degree of disability was demonstrably fully comparable with beneficiaries.

Another problem with the comparisons is that many non-beneficiaries receive income support from other programs and from private insurance. Therefore it would be necessary, first, to know what income difference between beneficiaries and non-beneficiaries is created by the disability program. This is particularly true in Canada where the sources of disability income are many and where some other sources of income are off-set against the CPP-D benefits. That is, research would need to establish what the net difference in income is, as well as estimating what effect that net income might have on labour force participation.

Bound (1989)[51] examined the subsequent labour force participation of rejected applicants. He found that about half return to work. However rejected applicants, as such, are clearly not fully comparable with beneficiaries. One must assume that rejected applicants are less disabled. It may be possible to construct a quasi-experiment whereby a sub-group of applicants who are rejected for reasons unrelated to their health is matched with an equivalent group of beneficiaries.

Another approach is to correlate economic conditions with the numbers of applicants for disability financial support. Given a stable program, time series data for both the economy and the program might reveal a relationship. That is, a strong economy with high labour demand might draw some beneficiaries who are able to work back into the work place. Of course it is possible that more persons might have stayed in work if support were not available than are drawn back into the economy later by high labour demand, assuming that re-entry becomes more difficult as time goes by.

A third approach is to examine changes in the proportion of the population over time who report themselves as disabled. If one can assume that the actual percentages of disabled adults is stable over time, then inferences might be drawn about the effects of all such income support programs to the disabled. However, apart from other methodological difficulties, isolating the effect of financial support to the disabled, as such (rather than the joint effects with all income support programs and insurance) would be impossible. Nevertheless Bound and Waidman (1992)[52] attempted such an analysis for the United States. They were able to show that the movement of older men out of the labour force onto disability benefits accounted for a substantial part of the drop in overall work participation rates for older men. However they were not able to isolate what effect more generous disability support had caused, and what was the result of other factors such as lessening of demand for older less skilled workers in poor health.

Other research has attempted to identify the effects of disability benefit levels and screening stringency on labour force participation. (Parsons[53] 1980; Haveman, de Jong and Wolfe[54] 1991). The Canadian data may lend itself to such interrupted-time-series analysis because of the radical changes in the rates of CPP-D applications and approvals in the mid-1990s that may have accompanied more stringent adjudication criteria and procedures. On the other hand, a poor economy in the early 1990s became a very good economy in the mid- and late-1990s, with an exceptionally long period of growth and expansion that has not ended yet. Separating the effects of one from the effects of the other will require a more rigorous research design than simple time series analysis.

Gruber[55] (1996) examined the effects of a change in CPP-D benefit generosity in 1987 on labour force participation using data from 1885 to 1989. He used Quebec, where benefits did not change, as a baseline for his estimates. He estimated the short-run elasticity of non-participation in respect to benefit levels

to be 0.32. In the following year Gruber and Kubik[56] (1997) studied the impact of increased screening stringency on participation rates.
In summary, estimates of the elasticity of labour force non-participation with respect to the level of disability benefits vary from 0.21 to 0.93[57] which shows little consensus on the matter.

Annex 1: Bibliography of Readings on Cost-Benefit Frameworks

Treasury Board Guide

Treasury Board of Canada Secretariat (1996), Principal authors: Kenneth Watson and Charles Mallory, *Benefit-Cost Analysis Guide*, Ottawa, Canada.

General readings

Australia, Department of Finance. Canberra, Australia. 1991. *Handbook of Cost-Benefit Analysis.*. 1992. *Introduction to Cost-Benefit Analysis for Program Managers*. 1993. *Value for Your IT Dollar: Guidelines for Cost-Benefit Analysis of Information Technology Proposals.*
Canada, Treasury Board of Canada Secretariat and Consulting and Audit Canada. 1995. *Benefit-Cost Analysis Guide for Regulatory Programs*, Treasury Board of Canada Secretariat, Ottawa, ON, Canada.
Gramlich, E.M. 1981. *Benefit-Cost Analysis of Government Programs*. Prentice-Hall, Englewood Cliffs, NJ, USA.
Great Britain, Overseas Development Administration. 1988. *Appraisal of Projects in Developing Countries: A Guide for Economists.* HMSO, London, UK.
Harberger, A.C. 1997. *Economic Project Evaluation: Some lessons for the nineties*, Canadian Journal of Program Evaluation, Special Edition.
Jenkins, G., and Harberger, A.C. 1995. *Cost-Benefit Analysis of Investment Decisions.* Harvard Institute for International Development, Harvard University, Cambridge, MA, USA.
Sassone, P.G. 1978. *Cost-Benefit Analysis - A Handbook*. Academic Press, New York, USA.
Siegel, C, Laska, E, & Meisner, M. Statistical methods for cost-effectiveness analyses. *Controlled Clinical Trials* 17(5): 387-406.
Stanbury, R., and Vertinski, I. 1989. *Guide to Regulatory Impact Analysis*. Office of Privatization and Regulatory Affairs, Ottawa, Canada.
Sugden, R., and Williams, A. 1985. *The Principles of Practical Cost-Benefit Analysis*. Oxford University Press, Oxford, UK.
Van Pelt, M., and Timmer, R. 1992. *Cost-Benefit Analysis for Non-Economists*, Netherlands Economic Institute, Amsterdam, Netherlands.
Watson, K. 1997. *Cost-Benefit Analysis in the Nineties*, Canadian Journal of Program Evaluation, Special issue.
World Bank. 1996. *Economic Analysis of Investment Operations.* World Bank, Washington, DC, USA.
World Bank and Economic Development Institute. 1991. *The Economics of Project Analysis: A Practitioner's Guide.* World Bank, Washington, DC, USA.

Defining fair options

Public Works and Government Services Canada. 1995. 2.0 “Real Property Investment Strategies;” and 3.0 “Policies and Practices.” *Real Property Investment Guide*. Public Works and Government Services Canada, Ottawa, Canada.
Transport Canada 1994. 4.0 “Option Identification;” 5.0 “A Common Frame for Comparison.” *Guide to Benefit-Cost Analysis.* Transport Canada, Ottawa, Canada.

Being clear on the point of view

Boardman, Vining, A., and Waters, W.G., 1993, “Cost and Benefits through Bureaucratic Lenses: Example of a Highway Project”, *Journal of Policy Analysis and Management*, 13(3).

Contingent value analysis

Gafni, A., 1991, “Willingness-to-Pay as a Measure of Benefits”, Medical Care, Volume 29, No. 12
Gafni, A., and O’Brien, 1996, “Toward a Conceptual Framework for Contingent Value Studies in Health Care”, Volume 16, No. 3.
Gafni, A. et al, 1998, “Health Care Contingent and Valuation Studies”, *Health Economics*, Volume 7, 313-326.

Inflation adjustments and discounting

Burgess, D.F. 1981. “The Social Discount Rate for Canada: Theory and Evidence.” *Canadian Public Policy,* **7**, Summer, pp. 383-344.
Jenkins, G.P. 1981. “The Public Sector Discount Rate for Canada: Further Implications.” *Canadian Public Policy*, **7**, Summer, pp. 399-407.
Lowenstein, G., and Elster, J., eds. 1992. *Choice over Time*. Russell Sage Foundation.
Pratt, S.P., *Cost of Capital - Estimations and Applications*, John Wiley and Sons Inc., New York, 1998.
Watson, K.F. 1992. “The Social Discount Rate for Canada.” *Canadian Journal of Program Evaluation*, **7**(1).

Decision rules

Bierman, H., and Smidt, S. 1993. *The Capital Budgeting Decision: Economic Analysis of Investment Projects*. Maxwell Macmillan Canada, Toronto, Canada.
Watson, K.F., 1990. “Using the Internal Rate of Return in Public Sector Project Evaluations: A Comment.” *Canadian Journal of Program Evaluation*, **5**(1).

Multipliers

Schwartz, H. 1982. *A Guide to Regional Multiplier Estimation*. Department of Regional Economic Expansion, Ottawa, Canada.
Public Works and Government Services Canada. 1995. *Real Property Investment Guide*. Public Works and Government Services Canada, Ottawa, Canada.

Time savings

Culley, E.K., and Donkor, F. 1993. *Valuation of Passenger Travel Time Savings.* Transport Canada, Ottawa, Canada.

Value of safety, health and life

Cropper, M.L., et al. 1990. “Discounting and the Evaluation of Life Saving Programs,” *Journal of Risk and Uncertainty*. **3**, pp. 369-79.
Keeney, R. 1994. “Decisions about Life-Threatening Risks.” *New England Journal of Medicine,* **331**, pp. 193-196.
Cropper, M.L. 1992. “Rates of Time Preference for Saving Lives.” *American Economic Review,* May.
Lawson, J.J. 1989. *The Valuation of Transportation Safety*. Transport Canada, Ottawa, Canada.
Nathwani, J.S., et al, 1990. “Safety, Social Well-Being and Its Measurement.” Institute for Risk Research, University of Waterloo, Waterloo, Canada. Paper No. 21.
Wildavsky, A. 1980. “Richer Is Safer.” *Public Interest*. **60**, pp. 23-39.

Environment

Pearce D.W., and Markandya, A. 1989. *Environmental Policy Benefits: Monetary Valuation*. Organization for Economic Co-operation and Development, Paris, France.
N. Hanley, N., and Spash, C.L. 1993. *Cost-Benefit Analysis and the Environment.* Edward Elgar Publishing Ltd., Brookfield, VT, USA.

Job creation

Kuo, C.Y. 1997. “Evaluating the Social Cost of Job Creation.” *Canadian Journal of Program Evaluation.*

Foreign exchange

Industry Canada and the Centre for the Study of International Economic Relations, University of Western Ontario. 1986. *The Shadow Price of Foreign Exchange in the Canadian Economy.* Industry Canada, Ottawa, Canada

Approaches to uncertainty

Baird, F.B. 1989. *Managerial Decisions under Uncertainty*. John Wiley & Sons, New York, NY, USA.
Breyer, S. 1993. *Breaking the Vicious Circle - Toward Effective Risk Regulation*. Harvard University Press, Cambridge, MA, USA.
Center for Risk Analysis, Harvard School of Public Health. 1994. *A Historical Perspective on Risk Assessment in the Federal Government*. Harvard University Press, Cambridge, MA, USA.
Dawes, R.M. 1988. *Rational Choice in an Uncertain World*. Harcourt Brace Jovanovich, New York, NY, USA.
Dixit, A.K., and Pindyck, R.S. 1994. *Investment under Uncertainty*. Princeton University Press, Princeton, NJ, USA.
Glickman, T.S., and Gough, M., eds. 1990. *Readings in Risk*. Resources for the Future, Washington, DC, USA.
Morgan, M.G., and Henrion, M. 1993. "*Risk Analysis* and Management." *Scientific American,* July, p. 3241.
Morgan, M.G. 1990. *Uncertainty: A Guide to Dealing with Uncertainty in Quantitative Risk and Policy Analysis*. Cambridge University Press, Cambridge, UK.
Morgan, M.G. et al. 1992. "Communicating Risk to the Public." *Environmental Science and Technology*. **26**(11), pp. 2048-2056.
Society for Risk Analysis. 1997. *Risk Analysis*. Plenum Publishing, New York, NY, USA. (Quarterly.)
Reutlinger, S. 1970. *Techniques for Project Appraisal under Uncertainty*. World Bank, Washington, DC, USA. World Bank Staff Occasion Paper, No. 10.
National Academy of Sciences and National Research Council. 1994. *Science and Judgement in Risk Assessment*. National Research Council, Washington, DC, USA.
Zeckhauser, R.J., and Viscusi, W.K. 1990. "Risk within Reason." *Scientific American,* **248**.

Risk analysis

Anderson, J.R. 1989. "Re-considerations on Risk Deductions in Public Project Appraisal." *Australian Journal of Agricultural Economics*, **33(**2), pp. 136-140.
Arrow, K.J., and Lind, R.C. 1970. "Uncertainty and the Evaluation of Public Investment Decisions." *American Economic Review*, **60**, pp. 364-378.
Carter, E.E. 1972. "What Are the Risks in Risk Analysis?" *Harvard Business Review.* July-August.
Fairley, W., Jacoby, H.D. 1975. "Investment Analysis Using the Probability Distribution of the Internal Rate of Return." *Management Science*, **21**(12), pp. 1428-1437.
Great Britain, Overseas Development Administration, 1990. *Risk Analysis - A Guide to Its Use in Project Appraisal*. Overseas Development Administration, London, UK.
Hertz D.B., and Thomas, H. 1983. *Risk Analysis and Its Applications*, John Wiley & Sons. New York, NY, USA. ---1984. *Practical Risk Analysis: An Approach through Case Histories*

Hull, J.C. 1980. *The Evaluation of Risk in Business Investment.* Pergamon, Oxford, UK.
National Academy of Public Administration. 1995. Chapter 3, Part 1 “Analysing Risks.” and Part 2 “Using Risk Analysis in Regulatory Decisions.” *Setting Priorities, Getting Results: A New Direction for the Environmental Protection Agency*. World Bank, Washington, DC, USA.
Pouliquen, L.Y. 1975. *Risk Analysis in Project Appraisal*. World Bank, Washington, DC, USA. World Bank Staff Occasional Paper, No. 11.
Wiliams, T. 1995. “A Classified Bibliography of Recent Research Relating to Project Risk Management.” *European Journal of Operations Research*. **85**, pp. 18-35.

Sensitivity analysis

Baird, B. 1989. Chapter 11, “Sensitivity Analysis,” *Managerial Decisions under Uncertainty.* John Wiley & Sons, New York, NY, USA. pp. 352-375.
Eschenbach, T.G. 1992. “Quick Sensitivity Analysis for Small Projects and Feasibility Studies.” *AACE Transactions.* **L-6**, pp. 1-8
Rappoport, A. 1967. “Sensitivity Analysis for Decision Making,” *Accounting Review*, July, pp. 441-456.
Watson, K. 1995. “Sensitivity Analysis in Outcome Evaluations: A Research and Practice Note.” *Canadian Journal of Program Evaluation*. **10** (2).

Probabilities

Hampton, J.M., et al. 1973. “Subjective Probability and Its Measurement.” *Journal of the Royal Statistical Society*. **136**, pp. 21-42.
Henley, E.J., and Kamamoto, H. 1992. *Probabilistic Risk Assessment*. IEEE Press, Piscataway, NJ, USA.
Kabus, I. 1976. “You Can Bank on Uncertainty.” *Harvard Business Review,* May-June.
Kachelmeier, S.J., and Shebata, M. “Examining Risk Preferences under High Monetary Incentives.” *American Economic Review*. **82**, pp. 1120-1141.
Keeney, R.L., and von Winterfedlt, D. 1991 “Eliciting Probabilities from Experts in Complex Technical Problems.” *IEEE Transactions in Engineering Management*, **38 (**3), pp. 191-201.
Law, A.M., and Kelton, D. 1991. *Simulation Modeling and Analysis*. McGraw-Hill, New York, NY, USA.
Spetzler, C.S. 1975. “Probability Coding in Decision Analysis.” *Management Science.* **22**, pp. 3
Transport Canada and Consulting and Audit Canada. 1995. *A Guide for Assessing the Benefits of Reducing the Risk of Marine Oil Spills*. Transport Canada, Ottawa, Canada.
Walpole, R.E. and Myers, R.H. 1993. *Probability and Statistics for Engineers and Scientists*. Macmillan, Toronto, Canada.

Income distribution

Australia, Department of Finance. 1991. Chapter 7, "Analysing Distribution Effects." *Handbook of Cost-Benefit Analysis,* Australia, Department of Finance, Canberra, Australia.
Londero, E. 1987. *Benefits and Beneficiaries: An Introduction to Estimating Distributional Effects in Cost-Benefit Analysis*. Inter-American Development Bank, Washington, DC, USA.
Nwaneri, V.C. 1970. "Equity in Cost-Benefit Analysis: A Case Study of the Third London Airport." *Journal of Transport Economics and Policy*.
Weisbrod, B.A. 1968. "Deriving an Implicit Set of Governmental Weights for Income Classes." *In* Chase, S.B. ed. *Problems in Public Expenditure Analysis*. The Brookings Institute.

Multiple objectives

Baird, B.F. 1989. Chapter 13, "The Art of Decision Making with Multiple Criteria," *Managerial Decisions under Uncertainty*. John Wiley & Sons, Toronto, Canada.
Clemen, R.T. 1990. Chapters 15 and 16, "Conflicting Objectives," *Making Hard Decisions.* PWS-Kent Publishing, London, UK.
Finney, C.E. 1990. "A Consultant's Guide for the Economic Ranking of Public Sector Projects." *Project Appraisal*, **5** (1).
Keeney, R., and Raiffa, H. 1976. *Decisions with Multiple Objectives: Preferences and Value Trade-Offs*. John Wiley & Sons, New York, NY, USA.
Kirkwood, C.W. 1992. "Multi-Attribute Evaluation." *Management Science,* **38**, pp. 819-826.
Public Works and Government Services Canada. 1995. Chapter 8, "Analysis of Non-Financial Factors," *Real Property Investment Guide*. Public Works and Government Services Canada, Ottawa, Canada.

Criticisms and limitations of benefit-cost analysis

Carter, E.E. 1972. "What Are the Risks in Risk Analysis?" *Harvard Business Review,* July-August, pp. 72-82.
Downs, G.W., and Larkey, P.D. 1986. *The Search for Government Efficiency: From Hubris to Helplessness*. Temple University Press, Philadelphia, PA, USA.
Gutin, J. 1991. "At Our Peril: The False Promise of Risk Assessment." *Greenpeace*. March-April.
Latham, G.P., and White, G. "The Futility of Utility Analysis." *Personnel Psychology*. **47**, pp. 31-46.
McCloskey, M. 1994. "Problems with Inappropriately Broad Use of Risk Terminology." *Comparative Risk Bulletin*. January.

ANNEX 2: Bibliography: Aging, Disability, Housing and In-Home Care

Alcock, D., Danbrook, C. Walterk D. & Hunt, C. (1998). Home care clients, providers and costs. *Canadian Journal of Public Health*, 89(5), 297-300.

Alcock, D., Edwards, N., Diem, E. & Angus, D. (2001). Decision Making Processes of Assessors/Case Managers, Sub-study #6. *The National Evaluation of the Cost-effectiveness of Home Care*. Victoria, B.C.: Hollander Analytical Services Ltd. and Centre on Aging, University of Victoria.

Anderson, C.S., Lonto, J & Steward-Wynne, E.G. (1995). A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke* May 26(5): 843-9.

Anderson, M. & Parent, K. (1999). *Report on Home Care in Canada*. A study conducted by Queen's health policy research unit for the Canadian Association for the Fifty-Plus, Final Report. Kingston, Ontario: Queen's Health Policy Research Unit.

Arundel, C. & Globerman, S. (2001). An analysis of Blockage to the Effective Transfer of Clients from Acute Care to Home Care. Substudy #15. *The National Evaluation of the Cost-effectiveness of Home Care*. Victoria, B.C.: Hollander Analytical Services Ltd. and Centre on Aging, University of Victoria.

Beach, S.R., Schulz, R., Yee, L. & Jackson, S. (2000). Negative and Positive Health Effects of Caring for a Disabled Spouse: Longitudinal Findings from the Caregiver Health Effects Study. *Psychology of Aging*. June 15(2): 259-71.

Bell, C.M., Araki, S.S. & Neumann, P.J. (2001). The association between caregiver burden and care giver health-related quality of life in Alzheimer disease. *Alzheimer Disease Association Disorders*. Jul-Sep 15(3): 129-36.

Biegel, D.E., Milligan, S.E., Putnam, P.L., and Song, L.Y. (1994). Predictors of Burden among Lower Socio-economic Status of Caregivers with Chronic Mental Illness. *Community Mental Health Journal*, Oct 30(5): 473-94.

Boelzig, H. and Jochen Clasen (February 2002), *A Comparative Analysis and Assessment of the Policy Implications of Alternative Legal definitions of Disability on Policies for People with Disabilities*. National Report Germany.

Browning, J.S. & Schwirian, P.M. (1994). Spousal caregivers' burden: impact of care recipient health problems and mental status. *J. Gerontology Nursing*. Mar 20(3):17-22

Canada, Human Resources Development Canada, Canadian Clearinghouse on Disability Issues, (2004/1984). *Aids to Independent Living*. Ottawa Canada.

Canada, Office of the Chief Actuary, (2002). Canada Pension Plan Experience Study of Disability Beneficiaries: Actuarial Study No. 1.

Canada, Social Development Canada, Office of Disability Issues (2003). *Defining Disability: A Complex Issue*. SDDP-047-10-03E. Ottawa, Canada.

Canada, Human Resources Development Canada, Evaluation and Data Development, Strategic Policy (1996). *Evaluation of the Canada Pension Plan (Disability Component),* SP-AH009E-09-96

Canada, Health Canada, Division of Aging and Seniors (no date). *Best Quality at the Best Price (Continuing Care).* Ottawa, Canada. Available through HC website.

Caap-Ahlgren, M. & Dehlin, O. (2002). Factors of importance to the caregiver burden experienced by family caregivers of Parkinson's disease patients. *Aging Clin Exp Res.* Oct 14(5): 371-7.

Canada Mortgage and Housing (1996/2004). *At Home with Alzheimer's Disease: Useful Adaptations to the Home Environment. Ottawa: CMHC. Available on CMHC website.*

Canadian Association of Independent Living Centres. (June 2004). *A Strategic Investment into the Human and Economic Potential of Canadians with Disabilities*. Ottawa.

Canadian Clearinghouse on Disability Issues. Human Resources Development Canada. (2004). Aids *to Independent Living*. Ottawa: Government of Canada. Available on Government of Canada website.

Canadian Home Care Association (November 2003). *Portraits of Home Care: A Picture of Progress and Innovation*. Available at www.cdnhomecare.on.ca.

Cannuscio, C.C., Jones, C. Kawachi, I, Colditz, G.A. & Rimm, E. (2002). Reverberations of Family Illness: A Longitudinal Assessment of Informal Caregiving and Mental Health Status in the Nurses' Health Study. *American Journal of Public Health*, August 92(8): 1305-11.

Carriere, Y., Legare, J. and Keefe, J. (March 2004). *Protecting the Availability of Informal Support and Its Impact on Chronic Home Care Services*. Available on the Health Canada Website.

Desbiens, N.A., Mueller-Rizner, N., Vimig, B. & Lyn, J. (2001). Stress in Caregivers of hospitalized oldest-old Patients. *Journal Gerontological Association of Biological and Medical Science*. April 56(4): 231-5.

Donaldson, C., Burns, A. (1999). Burden of Alzheimer's Disease: Helping the Patient and Caregiver. *Journal of Geriatric Psychiatric Neurology*. 12(1):21-8.

Emanuel, E.J., Fairclough, D.L., Slutsman, J. & Emanuel, L.L. (2000). Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. Annual of Internal Medicine, Mar. 212, 132(6):451-9.

European Commission. *The Definition of Disability in Europe: A Comparative Analysis.* Final Report (3 Sept. 2002. Funded by the European Commission, Employment and Social Affairs Directorate-General. Brunel University, UK.

Fassbender, K. (2001). Cost Implications of Informal Supports, Sub-study 3. *The National Evaluation of the Cost-effectiveness of Home Care*, Victoria, B.C.: Hollander Analytical Services Ltd. and Centre on Aging, University of Victoria.

Fassbender, K. (1998). *An Economic Evaluation of Home Care Services in Edmonton, Alberta as an Alternative to Nursing Home Care*. Unpublished PhD Dissertation, Edmonton: University of Alberta.

Federal/Provincial/Territorial Committee of Officials (Seniors) for the Ministers Responsible for Seniors (September 2001). *Best Practices Guide for the Prevention of Falls Among Seniors Living in the Community*. Public Works Government Services Canada #H39-591/2001E,

Gallicchio, L., Siddiqi, N., Langenberg, P. & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *Internal Journal Geriatric Psychiatry*. February 17(2): 154-63.

Gitlin, et al. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia, *Gerontologist*, 41: 4-14.

Grunfeld, E., Glossop, R., McDowell, I. and Danbrook, C. (1997). Caring for elderly people at home: the consequences to caregivers. *Canadian Medical Association Journal* 157(8): 1101-1105.

Harwood, D.G., Barker, W.W., Own by, R.L., Bravo, M., Aguero, H. & Duara, R. (2000). Predictors of Positive and Negative Appraisal among Cuban American Caregivers of Alzheimer's disease patients. *International Journal of Geriatric Psychiatry*. June 15(6): 481-7.

Health Canada/Veterans Affairs Canada (2003). *Falls Prevention Initiative: Summaries of Funded Projects, 2000-2004*. Health Canada/Veterans Affairs Canada (2002). *A Guide to Choosing and Using Assistive Devices*. Public Works Government Services Canada # 39-631/2002E.

Health Services Utilization and Research Commission (HSURC). (1996). *The Cost-effectiveness of Home Care: A Rigorous Review of the Literature*. HSURC Background Paper # 2, September 1996.

Health Transition Fund, Health Canada (2002) *Enhanced Case Management Project*. Project BC 124. Ottawa: Government of Canada.

Hebert, R., ed. al. (2001). Resources and costs associated with disabilities of elderly people living at home and in institutions. *Canadian Journal on Aging*, 20(1): 1-22.

Hedrick, S.C. & Inui, T. (1986). The effectiveness and cost of home care: An information synthesis. *Health Services Research*, 20 (6): 851-880.

Hennessy, J.R., Dyeson, C.H., & Garrett, T.B. (2001). Toward the conceptualization and measurement of caregiver burden among Pueblo Indian family caregivers. *Gerontologist* April 41(2): 210-9.

Hirdes, J., Tjam, E.Y. & Fries, B.E. (2001). Eligibility for Community, Hospital and Institutional Services in Canada: A Preliminary Study of Case Mangers in Seven Provinces. Substudy #8. *The National Evaluation of the Cost-effectiveness of Home Care*. Victoria, B.C.: Hollander Analytical Services Ltd. and Centre on Aging, University of Victoria.

Hollander, M. J. (1994). *The costs, and cost-effectiveness, of continuing care services in Canada*. Working Paper No. 94-10. Ottawa: Queen's-University of Ottawa Economic Projects.

Hollander, M.J. (2001). Final Report of the Study on the Comparative Cost Analysis of Home Care and Residential Care Services, Sub-study #1. *The National Evaluation of the Cost-effectiveness of Home Care*. Victoria, B.C.: Hollander Analytical Services Ltd. and Centre on Aging, University of Victoria.

Hollander, M.J. & Chappell, N. (2001). *Overview of the National Evaluation of the Cost-effectiveness of Home Care*. Victoria, B.C.: Hollander Analytical Services Ltd. and Centre on Aging, University of Victoria.
Available at http://www.homecarestudy.com

Hollander, M.J., Chappell, N., Havens, B. & McWilliams, C. (2001). Pilot Study of the Costs and Outcomes of Home Care and Residential Long Term Care Services, Sub-study #4; and Study of the Costs and Outcomes of Home Care and Residential Long Term Care Services, Sub-study #5. *The National Evaluation of the Cost-effectiveness of Home Care*. Victoria, B.C.: Hollander Analytical Services Ltd. and Centre on Aging, University of Victoria.

Joseph Rowntree Foundation (Housing & community care) (1995). Housing needs of people with physical disability. *Findings: Housing Research* #136. York, Great Britain.

Keefe, J. *The Nature of Caregiving by Community Context: A Profile of Informal Caregiving in Canada's Rural and Urban Areas: Final Report* (March 1999).

Available from the author at Department of Gerontology, Mount Saint Vincent University, Halifax Nova Scotia B3M 2J6.

Keefe, J and Fancey, P. ( ). Work and Eldercare: Reciprocity between Older Mothers and their Employed Daughters. *Canadian Journal on Aging.* 21(2):229-241.

Kraal, R.J., et al (1991). *Care for the Elderly: Significant Innovations in Three European Countries*. Vienna: European Centre.

Leichsenring, K, & Alaszewski, A.M., editors (2002). *Providing Integrated Health and Social Care for Older Persons: A European Overview of Issues at Stake*. Vienna: European Centre.

Lubin, S. Palliative care: Could your patient have been managed at home? (1992). *J Palliative Care*. (8)18-22.

Malatest, R.A. (2003) *Cost-Benefit Framework: Rental RRAP, Rooming House RRAP, Conversion RRAP, Homeowner RRAP, RRAP for Persons with Disabilities and the Emergency Repair Program*, Victoria, British Columbia.

Mann, W.C., Ottenbacher, K.J., Fraas, L., Tomita, M. & Granger, C.V. (1999). Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly. A randomized controlled trial. *Archives of Family Medicine*, May-June, 8(3):210-217.

Markowitz, J.S., Gutterman, E.M., Sadik, K. & Papadopoulos, G., (2003). Health-related quality of life for caregivers of patients with Alzheimer disease. *Alzheimer Disease Association Disorders.* Oct-Dec 17(4): 209-14.

Morimoto, T., Schreiner, A.S. & Asano, H. (2003). Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age Ageing*. March 32(2): 218-23

Nagatomo, I., et al. (1999). Gender of demented patients and specific family relationship of caregiver to patients influence mental fatigue and burdens on relatives as caregivers. *Int. J Geriatr Psychiatry*. Aug 14(8): 618-25.

Nagi, S.Z. (1965). “Some conceptual issues in Disability and Rehabilitation”. In M. Sussman (ed.). *Sociology and Rehabilitation*. Washington, DC: American Sociological Association. PP. 100-13.

National Alliance for Caregiving & AARP (2004). *Cargiving inthe U.S.* No City: no publisher.

Nijboer, C., et. al. (1998). Cancer and caregiving: the impact on the caregiver’s health. *Psychooncology*. Jan-Feb 7(1): 3-13.

OECD, (2003). *Ageing, Housing and Urban Development*. No place: OECD.

Phiilip, I, et al (1995). Community care for demented and non-demented elderly people: a comparison study of financial burden, service use, and unmet needs in family supporters. *BMJ* 310: 1503-6.

Sansoni, J., Vellone, E. & Piras, A (2004). Anxiety & Depression in Community-dwelling Italian Alzheimer's disease Caregivers. *Internal Journal of Nursing Pract*. April 10(2): 93-100.

Sewitch, N.J., McCusker,, J., Dendukuri, N. & Yaffe, N.J. (2004). Depression in Frail Elders: Impact on Family Caregivers. *International Journal of Geriartr Psychiatry*. July 10(7): 655-65.

Skellie, A., Favor, F., Tudor, C & Strauss, R. (1984). The Georgia Alternative Health Services Project: Cost-effectiveness depends on population selection. *Home Health Care Service Quarterly*, 4: 49-72.

Slobert, S and Cranswick, K (Autumn, 2004). "Looking After Seniors: Who Does What for Whom." *Canadian Social Trends*. Statistics Canada #11-008: 2-6.

SPR Associates Inc. for Human Resources Development Canada, (1996).
An Evaluation of the National Vocational Rehabilitation Project.

Tobis, D. (2000). Moving from Residential Institutions to Community-Based Services in Central and Eastern Europe and the former Soviet Union.

Vertrees, J.C., Manton, K.G. & Adler, G.S. (1989). Cost effectiveness of home and community-based care. *Health Care Financing Review*, 10(4): 65-78.

Walsh, K.K., Kastner, T.A., & Green, R.G. (2003). Cost comparisons of community and institutional residential settings. *Mental Retardation*, April, 41(2): 103-122.

Warren, S., Kerr J.R., Smith, D & Schalm, C. (2003). The impact of adult day programs on family caregivers of elderly relatives. *J. Community Health Nursing*. Winter 20(4): 209-21.

Weissert, W.G. (1985). Seven reasons why it is so difficult to make community-based long-term care cost-effective. *Health Services Research*, 20(4): 423-433.

Weissert, W.G., Lesnick, T., Musliner, M. & Foley, K.A. (1997). Cost savings from home and community-based services: Arizona's capitated Medicaid long-term care program. *Journal of health Politics, Policy and Law*, 22(6): 1329-1357.

Yeh, Sh., Johnson, M.A. & Wang, S.T. (2002). The Changes in Caregiving Burden Following Nursing Home Placement. *Internal Journal of Nursing Studies*. August 39(6)591-600.

Endnotes:

[1] At least six categories of disabilities have implications for housing - visual, hearing, cognition, mobility, allergy-related and other (e.g. haemophilia, cystic fibrosis) disabilities.

[2] Human Resources Development Canada, Office of Disability Issues, (2003). *Defining Disability*, Ottawa, Canada. Cat. RH37-4/3-200EISBN: 0-662-35368-4

[3] Under the Nagi model (1965) "functional limitations" are a distinct concept. The limitations are tied more to activities associated with social roles (caring for a child, walking a distance) than to accredited, doctor-tested limitations (the ability to carry weight or flex an injured knee). Disability is seen as influenced not only by the characteristics of impairments, such as type and severity, but also by how the individual defines a given situation and reacts to it, and how others define that situation through their reactions and expectations.

[4] HRDC (2003) notes that the ecological perspective arose in the 1970s, but became more prevalent in the mid-1990s in response to criticism of the impairment and functional limitations perspectives. Like the latter perspective, the ecological perspective rests on three distinct disability concepts: pathology (or abnormality), impairment and disability. However, it sees disability as resulting from the interaction of impairment, activity limitations and participation restrictions in a specific social or physical environment such as work, home or school. The Quebec disability production process model *(processus de la production du handicap)* was developed by a team at Université Laval in Quebec, led by social scientist Patrick Fougeyrollas. The Quebec model, which contributed greatly to the review and eventual improvement of the ICIDH, rejects the linear cause-and-effect explanation of disability. This model presents disability as the interaction of three kinds of factors: personal factors (age, sex and cultural identity), environmental factors (the social context in which the person lives) and life habits (the person's daily activities). The Quebec model shifts the focus from a fixed impairment that is part of a person's organic system to other, more changeable factors that affect that person's participation in society. In the Quebec model, disability depends on the environment in which a person lives and carries out daily activities. If the environment is adapted to the person, the disability can change or even disappear.

[5] HRDC notes that there are many variations of the social model, but all portray disability as a social construct created by ability-oriented and ability-dominated environments. The social model rejects the linear causality. According to the social model, even though impairment has an objective reality that is attached to the body or mind, disability has more to do with society's failure to account for the needs of persons with disabilities.

[6] The human rights model is a distinct subgroup of the social model. It understands disability as a social construct. The model is primarily concerned with the individual's inherent dignity as a human being (and sometimes, if at all, with the individual's medical characteristics).

[7] www.worldbank.org/disability

[8] http://guir.berkeley.edu/courses/assistive-tech/spring2002/mlb-paradigms.htm

[9] The Moral Model represents the belief that disability is the result of a sin or punishment for wrongdoing. Under this model, society generally thinks that disabled people suffer from a low spiritual development and that disability is a spiritual punishment that is divinely inflicted. Disability is seen as the result of evil spirits, the devil, witchcraft or God's displeasure. Historically, under this construct the outcome for disabled people has sometimes been isolation, death or banishment.

[10] The Medical Model fosters the idea that disabled people are sick. It defines disability as a physical or mental deficit that results in an inability or restriction of performing everyday activities. In this model, the physician is the authority figure and decision-maker. Historically, the outcome has been to diagnose and treat the person. The key players in this paradigm are doctors, therapists, teachers and counselors. In and of itself this is not a bad thing although some members of the disability community view it as having limited their potential. Under this model, there have been many advances in medicine. This model has been applied in the most legislation on the topic. These definitions were all referring to limitations in daily functions to characteristics of an individual that are otherwise known as "conditions" or "impairments." The indicators for the existence of a problem" include "the observation of impairments in individuals and the confirmation by medical measurement and diagnosis, dependency on assistance, support or other services". The solution for the problem in this paradigm consists of

"the restoration of function (cure) and adaptation to defects" through medical treatment, rehabilitation, special education, counseling, and therapies.

[11] The Independent Living or Civil Rights Model represents the belief that disabled people have a right to choose to live independently and make decisions about their medical care and other important aspects of their life. In brief, it is a philosophy advocating the exercise of as many self-directed, free choices as possible. Among other things this approach has led to the development of architectural standards to foster community integration. The Civil Rights/Independent Living Model defines disability mainly as a problem of the society - its response to people with disabilities, its systems, laws, policies and relationship. The key players in this paradigm are advocates, disability rights activists, lawyers and community organizers. The nature of the problem includes long-standing inequities, discrimination, prejudice, exclusion, and devaluation. To be more specific, there is a deeply ingrained disposition among the non-disabled to associate "human variation" with "human defects".

12 The "post-modern" of disability is still being defined, particularly in areas related to mainstreaming in employment, education, and community access. The emergence of the information age has brought great advances in technology that has helped to level the playing field for people with disabilities. A key challenge is to make the technology accessible to everyone, including people with disabilities. The Post-Modern Model defines disability as the problem of society's economic policies and priorities, which includes uneven distribution of resources, poverty, unemployment, and society's widespread acceptance of the medical model. The key players in this paradigm are people with disabilities, policy makers, lawyers, actors, economists, researchers, etc. The fundamental problem of "disability" is a lack of widespread acceptance of disability as a legitimate cultural experience. Indicators of the problem appear in the form of "uneven distribution of technology, adaptive equipment and supportive assistance based on archaic program eligibility requirements, absence of positive media images, and continued institutionalization. Suggested solutions to the problem include the acknowledgment of disability as an "unemployment" rather than "rehabilitation" issue, recognition of the universality of disability, an increase in access to technology and the removal of work disincentives. Recognizing the contextual aspect of disability, the new paradigm maintains that disability is a product of an interaction between the characteristics of an individual (e.g. conditions, impairments, personal and socioeconomic qualities, etc) and characteristics of the natural, built, cultural, and social environments. The new paradigm is comprehensive and holistic with an emphasis on the whole person functioning in his/her environment.

[13] Statistics Canada, Social Statistics Division, "A New Approach to Disability Data: Changes between the 1991 Health and Activity Limitation Survey (HALS) and the 2001 Participation and Activity Limitation Survey (PALS), Catalogue no. 89-578-XIE.

[14] www.statcan.ca

[15] www.statcan.ca "Participation and Activity Limitation Survey: A profile of disability in Canada, December 3, 2002.

[16] Caledon Institute of Social Policy, Caledon Commentary, May 2004.

[17] CMHC, Residential Rehabilitation Assistance Program Evaluation, Malatest and Associates, May 2003.

[18] These sections include 3.1.1 Extent of Need (health and safety problems from sub-standard housing); 4.1.1 Targeting to Core Need Households; 3.1 Extent of Housing Repair Need On-Reserve.

[19] CMHC Housing in Canada Database quoted in "Evaluation of RRAP", 2002, p.12

[20] CMHC Housing in Canada Database quoted in "Evaluation of RRAP", 2002, Table 3-3, p.15

[21] CMHC Housing in Canada Database quoted in "Evaluation of RRAP", 2002, p.16

[22] CMHC, "Evaluation of Housing Initiatives Under the National Strategy for the Integration of Persons with Disabilities", March 1998, p.13.

[23] CMHC, "Evaluation of Housing Initiatives Under the National Strategy for the Integration of Persons with Disabilities", March 1998, p.13.

[24] CMHC, "Evaluation of Housing Initiatives Under the National Strategy for the Integration of Persons with Disabilities", March 1998, p.15.

[25] Canada Pension Plan Experience Study of Disability Beneficiaries: Advanced Study No. 1. Office of the Chief Actuary. November 2002.

[26] Ibid, Graph 3, p.14

[27] Keefe has done an extensive study comparing informal care giving in rural and urban areas (Keefe, 1999).

[28] See also: Emanuel, Fairclough, Slutsman and Emanuel, 2000; Gitlin et al, 2001; Herbert et al, 2001; Bell, Araki and Neumann, 2001; Caap-Ahlgren and Dehlin, 2002; Cannuscio, Jones Kawachi, Colditz and Rimm, 2002; Livingston, Manela and Katona, 1996; Markowitz, Gutterman, Sadik and Papadopoulos, 2003; Nagatomo et al, 1999; Nijboer et al, 1998; and Sewitch, McCusker, Dendukuri and Yaffe, 2004. Beach, Schulz, Yee and Jackson (2000), and Browning and Schwirian (1994) discuss the health effects on spouses.

[29] Is the problem or opportunity clearly stated? Is there a compelling rationale for the federal government acting in this situation? Are the objectives clear and coherent? Is the analysis set out separately from the point of view of each important actor? Are the alternatives defined in a fair and comparable way? Are the important alternatives analysed? Is this an open and transparent analysis? Is each stage of the analysis set out so that you can follow the reasoning and the numbers? Are the likely incremental effects of the project or program alternatives well analysed? Are the costs and benefits of these effects measured well and set out in detail over the full life of the project? Are likely changes in relative prices taken into account or does the analyst take short cuts? Are inflation adjustments and discounting done separately? Are the price index and discount rate the appropriate ones? Does the analysis take into account uncertainty in the data and risk in the investment? Does the analysis describe who pays and who benefits? Does the analysis make a reasoned recommendation and give a fair showing to the alternatives it does not recommend?

[30] Table B-2

[31] Table 6.1

[32] Table 6-3

[33] Chart 6-1

[34] Table 6-4

[35] Table 6-5

[36] Malatest (2003)*Impacts of Accessibility Modification on RRAP-D Clients*

[37] Table 2

[38] Table 4

[39] Table 5

[40] Table 6

[41] Grab bars in the bathroom; exterior handrails, edge guards or slip resistant surfaces; wall or chair handrails; second entrance accessibility as an emergency exit; exterior ramps for accessibility; wide walkways with slip-resistant surfaces and no abrupt changes in level to provide access to the street, parking, entrances and outside areas for recreation and household chores. See Table 11

[42] Levered taps or hand-held faucets/shower with flexible tubing; grab bars in the bathroom; raised toilet; modify/replace kitchen cabinets, counters or sinks; levered door handles; modify or replace bathroom vanity and/or sink; modify or widen interior doors; wheel-in shower; or relocation of laundry room.

[43] Section 4

[44] Section 8

[45] p.43

[46] Table, p.45

[47] Statistics Canada defines Type 1 care as "that required by a person who is ambulant and/or independently mobile, who has decreased physical and/or mental facilities, and who requires primarily supervision and/or assistance with activities of daily living and provision for meeting psychosocial needs through social and recreational services. The period of time during which care is required is indeterminate and related to the individual condition but is less than 90 minutes in a 24 hour day."

[48] Ashenfelter, O., and Card, D. eds. (1999) *Handbook of Labor Economics*. Ensevier Science: Amsterdam.

[49] Gastwith, J.L. (1972) "On the Decline of Male Labour Force Participation", *Monthly Labor Review* 95 (10). 44-46

[50] Swisher, I., (1973) "The Disabled and the Decline in Men's Labour Force Participation", *Monthly Labor Review*, 96 (11):53

[51] Bound, J. (1989). "The Disincentive Effects of the Social Security Disability Insurance Program", unpublished PhD Dissertation, Harvard University.
[52] Bound, J. and Waidman, T. (1992) "Disability Transfers, Self-Reported Health, and the Labour Force Attachment of Older Men: Evidence from the Historical Record", *Quarterly Journal of Economics*, 107, (4):1393-1419.
[53] Parsons, D. (1980) "The Decline of Male Labour Force Participation", *Journal of Political Economy*. 88:117-134.
[54] Haveman, R.H., de Jong, P.P., and Wolfe, B. (1991) "Disability Transfers and the Work Decisions of Older Men". Quarterly Journal of Economics. 106 (3):939-949
[55] Gruber, J. (1996). "Disability Insurance Benefits and Labor Supply", Working Paper No. 5866, NBER, Cambridge, MA)
[56] Gruber, J. and Kubik, J. (1997) "Disability Insurance Rejection Rates and the Labour Supply of Older Workers", *Journal of Public Economics* 64:1-23
[57] Bound and Burkhauser, op. cit., Table 16, p.3484

Appendix B

The Questionnaires: Beneficiaries and Caregivers

Questions to RRAP-D/HASI Beneficiaries

Context

Personal Details

1. Contact Information

   Name: ____

   Address: ____

   ____
   province postal code

   Telephone ______________________ email ____________________

2. Age: ☐ under 15 ☐ 15-24 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐ 55-64 ☐ 65+

3. Gender: ☐ male ☐ female

4. Beneficiary Income per annum
   ☐ under $10,000
   ☐ $10,000 - $15,000
   ☐ $15,001 - $20,000
   ☐ $20,001 - $25,000
   ☐ $25,001 - $30,000
   ☐ $30,001 - $35,000
   ☐ $35,001 - $40,000
   ☐ $40,001 - $45,000
   ☐ $45,001 - $50,000
   ☐ over $50,000

5. Do you have sources of income other than employment? ☐ yes ☐ no
   If yes, what are they?
   ☐ workmen's compensation ☐ provincial pension or disability plan
   ☐ Canada pension (disability) ☐ other, specify _______________
   ☐ private pension or disability plan

6. Employment Status.
   Do you have a job? ☐ yes ☐ no If so, what? ________________________

7. Is it: ☐ full time? ☐ part time? How many hours/week? _______

8. If you are not now working, did you quit because of your illness/disability?
   ☐ yes ☐ no

9. Will modification/renovation allow you to return to work? ☐ yes ☐ no
   If yes, do you expect to be working: ☐ full time ☐ part time

10. Type of disability or illness (in general)
    - Ì visual
    - Ì mobility
    - Ì hearing
    - Ì allergies
    - Ì cognitive
    - Ì arthritis
    - Ì Other, specify ____

11. Nature of disability or illness, more specifically. ______________________________

    ____

12. Do you use a wheelchair?
    Ì in the home   Ì outside the home   Ì both

13. Do you use any other device to be able to move around / in the home?
    Ì walking aid   Ì cane   Ì other, specify _________________________

14. How often do you use your wheelchair or other mobility aid?
    - Ì all the time
    - Ì only at times certain times or under certain conditions(specify times/conditions)
      Please specify ____

Accommodation

15. Home ownership
    - Ì I own my own home
      - Ì freehold
      - Ì condominium
    - Ì I rent my home
    - Ì I live in special needs housing
      - Ì for seniors
      - Ì for persons with disabilities

16. Type of home:
    - Ì single detached house
    - Ì walk-up apartment
    - Ì semi-detached house
    - Ì an apartment building with an elevator
    - Ì townhouse

17. Number of floors in the home: ______

18. Age of home
    - Ì under 5 years
    - Ì 16 - 20 years
    - Ì 6 - 10 years
    - Ì over 21 years
    - Ì 11 – 15 years

19. Other occupants in home

    Who else lives in the home with you (check all that apply)?
    - Ì no one
    - Ì my parent(s)
    - Ì my spouse
    - Ì another relative, specify ___________
    - Ì my daughter
    - Ì a friend
    - Ì my son
    - Ì another person, specify ____________

20. Total number of persons in the home ________

21. Household Income per annum (self and spouse, only)
    ˆ Under $10,000
    ˆ $10,000 - $20,000
    ˆ $20,001 - $30,000
    ˆ $30,001 - $40,000
    ˆ $40,001 - $50,000
    ˆ over $50,000

22. In addition to you, do any other persons living in the home have disabilities?
    ˆ yes ˆ no. If so, what is the nature of their disability? ____________

23. Do they benefit from the renovation(s) you are going to have done or have already done? ˆ yes ˆ no

24. Do you have a pet? ˆ yes ˆ no. What kind of pet is it (cat, dog, etc)? _____

25. Does your pet have a therapy function? ˆ yes ˆ no. If yes, what support does your pet give you with respect to:
    ˆ your mobility in and outside of the home, specify ____________
    ˆ general physical well-being, specify ____________
    ˆ general emotional well-being, specify ___________

26. Has your pet been formally trained in its therapy function ˆ yes ˆ no
    By what organization, specify? ________________________

27. Will the renovation make your pet's support more effective? ˆ yes ˆ no
    If so, how? ___________________________________

28. Does having a pet affect your choice of accommodation at present?
    ˆ yes ˆ no

Care giving and support services

29. Are support services essential to you to remain in your home?
    ˆ yes ˆ no

30. If yes, do you have access to the types of support services you need?
    ˆ yes ˆ no

31. Do you have a main caregiver? ˆ yes ˆ no
    If yes, indicate who they are:
    ˆ a family member, specify ___________
    ˆ a friend
    ˆ a neighbour
    ˆ other (specify) ___________________
    ˆ someone paid from a home care agency
    ˆ a volunteer from a home care agency

32. Where more than one person is helping you, please indicate the person's affiliation (relative, volunteer, etc.), what each person is doing, and how much time do they spend helping you with that task.

Person one: ____

Person two: ____

Person three: ____

33. How important is the unpaid (other than family and friends) help you receive from others for helping you remain independent?

- not at all important
- not very important
- important
- very important
- help is essential to my independence

34. Have you used or do you expect to use less of these unpaid services since the renovation? yes no
Explain, indicating which services you used less: ___________________

35. If you pay for services/help, what is the total cost/month, overall $___________

36. What is the nature of these services?

- accessing/exiting the home
- moving from one room to another
- preparing meals
- using the toilet
- taking a bath
- going up and down stairs
- general housekeeping
- groceries, meal delivery
- home maintenance
- other, specify _________________

37. How much help time does your main care giver spend helping you during the day?

- 1 hour or less/day
- 2 to 3 hours/day
- 4 to 5 hours/day
- all day long
- at night only
- help is available 24 hours/day

38. Which of the following services do you pay for?

- accessing/exiting the home
- moving from one room to another
- preparing meals
- using the toilet
- taking a bath
- going up and down stairs
- general housekeeping
- groceries, meal delivery
- home maintenance
- other, specify _________________

39. Have you or do you expect that you will use less paid services as a consequence of the renovation? yes no
If yes, which ones? __________________________________

40. Before the renovation: Approximately how much are you / were you paying in dollars for each type of service?
- Ĩ dealing with personal tasks (using toilet, taking a bath, etc.) $________
- Ĩ mobility (moving from one room to another, accessing/exiting home, etc.) $________
- Ĩ meal preparation $______
- Ĩ groceries, meal delivery $______
- Ĩ home maintenance $______
- Ĩ other, specify ____________ $______

41. Do you expect that the costs will be reduced as a consequence of the renovation? Ĩ yes Ĩ no

If yes, which ones and by how much?
- Ĩ dealing with personal tasks (using toilet, taking a bath, etc.) $________
- Ĩ mobility (moving from one room to another, accessing/exiting home, etc.) $________
- Ĩ meal preparation $______
- Ĩ groceries, meal delivery $______
- Ĩ home maintenance $______
- Ĩ other, specify ____________ $______

42. How important is the support your receive from family and friends for helping you remain independent?
- Ĩ not at all important
- Ĩ not very important
- Ĩ important
- Ĩ very important
- Ĩ help is essential to my independence

43. Have you depended less on your family and/or friends since the renovation?

Ĩ yes Ĩ no

Explain, indicating which services you used less: __________________

44. How important is the paid help you receive from others for helping you remain independent?
- Ĩ not at all important
- Ĩ not very important
- Ĩ important
- Ĩ very important
- Ĩ help is essential to my independence

The Modification

CMHC sponsored modifications
The following questions refer to any adaptations or renovations to which CMHC contributed

45. At what stage is (are) your adaptation(s) or renovation(s)?
    - planned to begin by (date) ________
    - just starting
    - nearly complete (date of expected completion) ________
    - just completed
    - completed for a month or more

46. What parts of your home do you plan to modify / have been modified?
    - entry/exit of home
    - the kitchen
    - the laundry
    - the bathroom
    - the bedroom
    - other, specify ________________

47. What types of modifications are you planning / have you done?
    - bars
    - elevator
    - widening entrance or interior doorways
    - call system
    - visual or audio warning devices
    - automatic or easy-to-open doors
    - kitchen modifications, specify ______________________________
    - modified bathrooms (bath lifts, wheel-in shower, other – specify ___________________________________
    - modified laundry facilities
    - ramps/chairlifts/street-level entrance
    - improved lighting (relocation plugs and switches, improved air quality or ventilation, scald protectors, other – specify___________________________
    - other _____________________

48. What are / were the reasons for these modifications? ____________________

Where adaptations have been made:

49. Before the adaptations were made, did you have difficulty in carrying out activities of daily living? yes no
    What was the nature of these difficulties?
    - accessing/exiting the home
    - moving from one room to another
    - preparing meals
    - using the toilet
    - taking a bath
    - going up/down stairs
    - other, specify ______________

50. After the adaptations you made to your home, do you still have difficulty in carrying out the activities of daily living?
   - accessing/exiting the home
   - taking a bath
   - moving from one room to another
   - going up/down stairs
   - preparing meals
   - other, specify _______________
   - using the toilet

51. Did you use an occupational therapist to help you decide on the types of modifications you made? yes no
   If yes, how useful was the advice you received from the occupational therapist?
   - not at all useful
   - not very useful
   - useful
   - very useful
   - exceptionally useful

52. Did the modifications supported by RRAP-D/HASI solve all of your difficulties in your dwelling? _____ If no, what problems are still occurring? _____________

Sources of funding for adapations or renovations

53. Total cost of modifications: estimated: $_______ actual: $_________

54. What was your source of government CMHC funding?
   - HASI
   - RRAP-D
   - both

55. Portion of cost of the modification/s covered by CMHC? _________________

56. In dollars, what part of the total cost of the adaptations or renovations was covered by other sources?
   - self, including additional living costs during modifications $____
   - family/friends, including additional living costs during modifications $ ____
   - other government programs (federal, provincial, local), specify $__________________________________
   - disability organizations, specify $_____
   - other, specify _______________________________ $_______________

57. Did you have any difficulty in having the modifications made? yes no

   If yes, what was the nature of the difficulties, in brief?_______________________

   ____

58. How valuable where the modifications to help you remain independent?
   - not at all valuable
   - not very valuable
   - valuable
   - very valuable
   - essential to my independence

Modifications done without CMHC sponsorship
The following questions refer to any adaptations or renovations made that were not supported through a CMHC program.

59. How much have you spent on renovations in the past three years, in addition to the RRAP-D/HASI modifications? ________________

60. Have you received funding from other programs for modifications to your dwelling or for equipment that made living easier in the dwelling? ˡ yes ˡ no
Explain ____

61. Have you had financial support from family members in terms of these modifications? ˡ yes ˡ no

62. Have family members, friends or neighbours helped with renovations without financial compensation? ˡ yes ˡ no

Quality of Life

63. Has your health/disability changed significantly in the past year? ˡ yes ˡ no

64. Is it presently stable or changing? ˡ yes ˡ no Explain: ______________

65. Do you believe your quality of life was improved as a result of the modification for which CMHC funding was used? ˡ yes ˡ no

66. If so, what was the main improvement in your quality of life that you have noticed since the modification? _______________________

67. Have there been any problems created by the modifications?
ˡ yes ˡ no If yes, what are these problems? _______________________

68. How much have the following improved for you as a result of the modifications for which CMHC funding was used?

- **Mobility into and out of the dwelling.**
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10
  [0=extremely poor to non-existent
  10 = excellent, no problems)

- **Mobility within the dwelling**.
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10
  [0=extremely poor to non-existent
  10 = excellent, no problems)

- **Ability to do usual daily activities**. Such as using the kitchen to cook.
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10

- **Ability to look after oneself**. Such as using the bath and toilet independently.
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10

- **Health**. Physical and mental health.
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10

- **Overall, how do you rate your overall quality of life as a result of the modifications?**
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10

Stability in existing home

69. On a scale of 1 to 10 (where 0 means not important at all and 10 means very important) How important were the modifications to help you to:

    - ❑ maintain your independence
      0 1 2 3 4 5 6 7 8 9 10

    - ❑ stay in your home (as opposed to having to move somewhere else)?
      0 1 2 3 4 5 6 7 8 9 10

70. Have you considered moving to other accommodation? ǐ yes ǐ no
    ǐ before the modifications?
    ǐ after the modifications?

71. If so, what sort of accommodation? ________________________

72. Have you ever lived in temporary housing or shelter? ǐ yes ǐ no

73. Do you have any plans to move? ǐ yes ǐ no
    If yes, why (major reasons)? ____
    If yes, when (in the next six months, 1, 2, 3, 4, 5 years)?

74. Is/was your attitude to moving affected by the modifications to your dwelling?
    ǐ yes ǐ no If so, in what way? _____________________________

75. Would you move/have moved if the RRAP-D/HASI financial support had not been available? ? ǐ yes ǐ no

Financial impact

76. How much time did you spend on applying for the RRAP-D/HASI assistance? (or someone else spent on your behalf)? _____________

77. Did you have out-of-pocket costs to apply? ? ĺ yes ĺ no
    If yes, what were these costs?
    - ĺ hiring a lawyer ĺ telephone costs
    - ĺ hiring an accountant ĺ photocopying
    - ĺ travel costs ĺ mailing costs
    - ĺ other, specify _____________________________

78. Did you hire a contractor to carry out the adaptations? ĺ yes ĺ no

79. How much time did you spend obtaining quotations for the work? ________

80. How much time did you spend dealing with the contractor? _____________

81. Did any problems arise with the contractor? ĺ yes ĺ no
    If yes, what were they and how did this affect you? ____________________
    Do you think the modifications have had an _______ ĺ yes ĺ no

82. Do you think the modifications have had an impact on your home's market value?
    ĺ yes ĺ no If so, was it ĺ positive? or ĺ negative?
    Explain: ____

Willingness to pay

83. Have you spent money on renovations apart from those supported by RRAP D/HASI?
    ĺ yes ĺ no If so, what, when and for how much? _________________

84. If yes, when
    - ĺ before the modifications
    - ĺ at the modifications state
    - ĺ after the modifications?

85. If the program had not been available, would you have paid for the modifications yourself? ĺ yes ĺ no ĺ maybe
    Explain: __________________________________

86. If so, would you have done them: ĺ sooner ĺ later ĺ at the same time?

86. If you had received a cash grant from CMHC without any strings attached would you have spent it on the same modifications to your house? ☐ yes ☐ no
If not, what would you have spent the money on? ______________________________

87. The CMHC contribution was $___________. If I had the choice of KEN

General probes

88. What did you like most about the program? ______________________________

89. What did you like least? ______________________________

90. What did you like most about the modifications?______________________________

91. What did you like least? ______________________________

Appendix B(2) Questions to Care Givers, RRAP-D/HASI

Context

RRAP-D/HASI Case Number: ____________

Care Giver Personal Details

1. Contact Information

   Name: ____

   Address: ____

   ____
   province postal code

   Telephone ______________________ email ____________________

2. Age:
   ☐ under 15
   ☐ 15-24
   ☐ 25-34
   ☐ 35-44
   ☐ 45-54
   ☐ 55-64
   ☐ 65+

3. Gender: ☐ male ☐ female

4. What is your relationship to the beneficiary?
   ☐ spouse
   ☐ daughter
   ☐ son
   ☐ my parent(s)
   ☐ other relative, specify ________
   ☐ a friend
   ☐ a neighbour
   ☐ other, specify _____________

5. Do you live with the beneficiary? ☐ yes ☐ no

6. Were you living with the beneficiary before the modifications? ☐ yes ☐ no

7. If you do not live with the beneficiary, how far away in travel time do you live?

8. Your income per annum
   ☐ under $10,000
   ☐ $10,000 - $15,000
   ☐ $15,001 - $20,000
   ☐ $20,001 - $25,000
   ☐ $25,001 - $30,000
   ☐ $30,001 - $35,000
   ☐ $35,001 - $40,000
   ☐ $40,001 - $45,000
   ☐ $45,001 - $50,000
   ☐ over $50,000

9. Do you have sources of income other than employment? ☐ yes ☐ no
   If yes, what are they?
   ☐ workmen's compensation
   ☐ provincial pension or disability plan
   ☐ Canada pension (disability)
   ☐ other, specify _______________
   ☐ private pension or disability plan

10. Employment Status.
Do you have a job? ☐ yes ☐ no If so, what? ______________________

11. Is it: ☐ full time? ☐ part time? How many hours/week? _______

12. If you are not now working, did you stop work because of your care giving responsibilities?
☐ yes ☐ no

13. Will modification/renovation allow you to return to work? ☐ yes ☐ no
If yes, do you expect to be working: ☐ full time ☐ part time

10. Do you yourself have any disability or illness (in general)
☐ visual
☐ hearing
☐ cognitive
☐ mobility
☐ allergies
☐ arthritis
☐ Other, specify ____________________________________

11. If so have your care giving responsibilities been a contributing factor?
☐ no ☐ yes. If yes, please explain: ___________________________

____

12. Have the modifications/renovation(s) made your care giving easier or more difficult?
☐ easier ☐ more difficult ☐ no change

Please explain: ……………………………………………………………………………

13. What is the nature of your care giving?
☐ accessing/exiting the home
☐ moving from one room to another
☐ preparing meals
☐ using the toilet
☐ taking a bath
☐ going up and down stairs
☐ general housekeeping
☐ groceries, meal delivery
☐ home maintenance
☐ other, specify ________________

14. How much help time, related to the disability, do you spend helping during the day?
☐ 1 hour or less/day
☐ 2 to 3 hours/day
☐ 4 to 5 hours/day
☐ all day long
☐ at night only
☐ help is available 24 hours/day

15. Has this changed because of the renovation/modification to the home?
If so, by how much? ……………………………………………………………
……………………………………………………………………………………
16. Did/do you have out-of-pocket expenses related to your care giving?
☐ No ☐ Yes If so, for what and how much? ……………………..
……………………………………………………………………………

17. Has this changed because of the renovation/modification to the home? If so, by how much? …………………………………………………………
…………………………………………………………………………………

18. How important is your care giving to --------- remaining independent?
 not at all important
 not very important
 important
 very important
 help is essential to my independence

19. Did the modifications supported by RRAP-D/HASI solve all of your difficulties in care giving that relate to the physical home? No Yes If no, what problems are still occurring? _____________

20. Do you believe your own quality of life was improved <u>as a result</u> of the modification for
which CMHC funding was used? yes no

21. If so, what was the main improvement in your quality of life that you have noticed since the modification? _______________________

22. Have there been any problems created by the modifications?
 yes no If yes, what are these problems? _______________________

In your opinion, how much have the following improved for the disabled person as a result of the modifications for which CMHC funding was used?

- **23. Mobility into and out of the dwelling.**
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10
  [0=extremely poor to non-existent
  10 = excellent, no problems)

- **24. Mobility within the dwelling**.
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10
  [0=extremely poor to non-existent
  10 = excellent, no problems)

- **25. Ability to do usual daily activities**. Such as using the kitchen to cook.
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10

- **26. Ability to look after him/herself**. Such as using the bath and toilet independently.
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10

- **27. Health**. Physical and mental health.
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10

- **28. Overall, how do you rate his/her overall quality of life as a result of the modifications?**
  Before: 0 1 2 3 4 5 6 7 8 9 10
  After: 0 1 2 3 4 5 6 7 8 9 10

On a scale of 1 to 10 (where 0 means not important at all and 10 means very important) How important were the modifications, in your opinion, to help him/her to:

(29) maintain his/her independence
0 1 2 3 4 5 6 7 8 9 10

(30) stay in his/her home (as opposed to having to move somewhere else)?
0 1 2 3 4 5 6 7 8 9 10

31. Did you help with the application for the RRAP-D/HASI assistance? ☐ yes ☐ no
If yes, how much time did you spend? _____________

32. Did you have out-of-pocket costs to apply? ? ☐ yes ☐ no
If yes, what were these costs?
☐ hiring a lawyer ☐ telephone costs
☐ hiring an accountant ☐ photocopying
☐ travel costs ☐ mailing costs
☐ other, specify ______________________________

33. Did you hire a contractor to carry out the adaptations? ☐ yes ☐ no

34. How much time did you spend obtaining quotations for the work? ________

35. How much time did you spend dealing with the contractor? _____________

36. Did any problems arise with the contractor? ☐ yes ☐ no
If yes, what were they and how did this affect you? ____________________

37. Do you think the modifications have had an impact on the home's market value?
☐ yes ☐ no If so, was it ☐ positive? or ☐ negative?

Explain: ____

38. What did you like most about the program? ______________________________

39. What did you like least? ____

40. What did you like most about the modifications?_________________________

41. What did you like least? ____

Round 2: Questions to RRAP-D/HASI Beneficiaries and Caregivers (Focus Areas Highlighted)

Context

13. **(a)** What type of disability or illness do you have? (check all that apply)
    1 yes **2** no (each item)
    1 visual
    2 hearing
    3 cognitive
    4 mobility
    5 allergies
    6 arthritis
    7 multiple disabilities
    (b) Other, specify **88** or **99**
    (c) Nature of disability or illness, more specifically. **88** or **99**
    (d) Which of these conditions were/are the direct reasons for you applying for CMHC support? **88** or **99**
    (e) Have there been any changes in your disabilities or illnesses since we last spoke with you on (give date)? **1** yes **2** no
    (f) If yes, please explain in detail: ___________________________

14. **(a)** Do you use a wheelchair?
15. **(a)** Do you use any other device to be able to move around / in the home?
16. **(a)** How often do you use your wheelchair or other mobility aid?
    (b) Has there been any change in your use of mobility devices or aids since we last spoke? **1** yes **2** no
    (c) Explain (questions 14-16)**:** ____

Type of Tenure and Accommodation

17. **(a)** Type of Tenure
    1 freehold
    2 condominium
    3 life lease
    4 lease/rent
    5 foster parents – their freehold home
    (b) Has there been any change with respect to the nature of your home since we last spoke? **1** yes **2** no
    (c) What has changed (questions 17-21): _______________________________

22. 18. I live in special needs housing for: **(a)** seniors **1** yes **2** no **(a)** Other occupants in home. Who else lives in the home with you (check all that apply)? **1** yes **2** no (each item except # 88)

    1 myself only
    2 myself and my spouse only
    3 myself and my daughter only
    4 myself and my son only
    5 myself and a friend, only
    6 myself, my spouse and my son
    7 myself, my spouse and my granddaughter
    8 myself, my son and my granddaughter

9 myself, my foster parents and my sisters
88 other – which see
(b) Has there been any change in home occupancy since we spoke? **1** yes **2** no?
(c) Explain (questions 22-23): ________________________________

23. Total number of persons in the home **1** one; **2** two; **3** three; **4** four; **5** five; **6** six; **7** seven

24. **(a)** Household Income per annum (self and spouse, only)
 Under $10,000 — **3** $30,001 - $40,000
1 $10,000 - $20,000 — **4** $40,001 - $50,000
2 $20,001 - $30,000 — **5** over $50,000
(b) Have there been any change in household income since we last spoke? **1** yes **2** no
(c) What is the current household income: _____________

25. **(a)** In addition to you, do any other persons living in the home have disabilities? **1** yes **2** no.
(b) If so, who are they and what is the nature of their disability? **88** or **99**
(d) Has there been any change in persons with disabilities or in the nature of their disabilities since we last spoke? **1** yes **2** no.
(e) Explain: ____________________________

26. **(a)** If so, do they benefit directly from the renovation(s) you are going to have done/have already done? **1** yes **2** no
(b) If so, how? Sub-question: **88** or **99**
(c) Do they benefit *indirectly* from the renovation(s)? **1** yes **2** no.
(c) If so, how? **88** or **99**
(d) Has there been any change in how they benefit from the renovations since we last spoke? 1 **yes** 2 **no**
(e) Explain: ______________________

Care giving and support services

Primary care giver

32. **(a)** Do you have a main caregiver? **1** yes **2** no
(b) If yes, indicate who that person is - by number
1 a family member - spouse;
2 a family member - son
3 a friend or neighbour
4 a volunteer from a community/home care organization
3 a professional care giver. If so, who? _____________
4 etc…

(c) Has there been any change with respect to having a main caregiver of the services they provide since we last spoke? 1 **yes** 2 **no**
(d) Explain (questions 32-34; 36-41): ________________________________

33. Why do you regard him/her as your main care giver? **88** or **99**

34. What is the nature of the services provided by your main care? **1** yes **2** no or **88** or **99** (each item)

1 virtually everything
2 accessing/exiting the home
3 moving from one room to another
4 preparing meals
5 using the toilet
6 taking a bath
7 going up and down stairs
8 nursing – nurse
9 nursing - practical nurse)
10 physiotherapy services
11 occupational services
12 general housekeeping
13 groceries, meal delivery
14 home maintenance
15 other – specify **88**

35. **(a)** Do other members of your household who have a disability require help with daily living activities? **1** yes **2** no
(b) If yes, how frequently is help needed **88**; **99** (each item)?
1 every day
2 at least once a week
3 less than once a week
(c) Has there been any change in this since we last spoke? **1** yes **2** no
(d) Explain (Ques 36-41) ___________________________

36. **(a)** Is your primary care giver available on a daily basis? **1** yes **2** no
(b) If no, how frequently is he/she available to help?

37. On a average day how much help time does your primary care giver spend helping you number or **99** - each item)?
1 2 to 3 hours/day
2 4 to 5 hours/day
3 all day long
4 available 24 hours/day1 hour or less/day
5 1 hour or less/day
6 at night only

38. How important is the help you receive from your main care giver for maintaining your independence (ability to do everyday activities by yourself)?
ſ not at all important
ſ not very important
1 important
2 very important
3 essential to my independence

39. How important is the help you receive from your main care giver for staying in your home (rather than moving to other housing)?
    ˥ not at all important
    ˥ not very important
    1 important
    2 very important
    3 essential to my independence

40. **(a)** Have you used, or do you expect to use, the services of your main care giver less as a result of the renovation? **1** yes **2** no **3** not sure
    (b) If yes, which services will be affected? **88** or **99**
    (c) How much less time will be involved? **88** or **99**

41. **(a)** Is it easier for your main caregiver's to help you been after the renovations?
    1 yes **2** no
    (b) If yes, how? **88** or **99**

Secondary care giver(s)

42. **(a)** Are you receiving care from others in addition to your main caregiver?
    1 yes **2** no
    (b) If yes, indicate who they are (check all that apply) - (**1** yes **2** no or **88** or **99** – each item):
    1 a family member, specify ___________
    2 a friend or neighbour
    ˥ a volunteer from a community/home care organization
    3 paid help
    4 special support service programs (check all that apply, then proceed to question #38). – **88** or **99**
        A Home Care services program
        ˥ the VAC VIP program (Canadian Veteran)
        other – Ontario Ministry of Community & Social Services
    5 other, specify____

    (c) Has there been any change with respect to having a secondary caregiver of the services they provide since we last spoke? 1 **yes** 2 **no**
    (d) Explain (questions 42-47): ________________________________

43. What is the nature of the special support service programs (by service provider)? **88** or **99**

44. Indicate what each secondary care giver is doing for you, their affiliation (family, friend/neighbour, volunteer, paid help), and how much time/week they spend on the task or tasks they help you with: **88** or **99**

    Person one:
        Affiliation: ____
        Main Tasks: ____
        Time spent per week:____________________________________

Person two:

Affiliation: ____

Main Tasks: ____

Time spent per week:___________________________________

45. How important is / are the secondary care giver(s) for maintaining your independence (ability to do everyday activities by yourself)?
   - ĺ not at all important
   - ĺ not very important
   - **1** important
   - **2** very important
   - **3** help is essential to my independence

46. How important is / are the secondary care giver(s) for staying in your home (rather than moving to other housing)?
   - ĺ not at all important
   - ĺ not very important
   - **1** important
   - **2** very important
   - **3** help is essential to my independence

47. **(a)** Have you used or do you expect to need less help from caregivers as a result of the renovation? **1** yes **2** no **3** not sure
   (b) If yes, which services will be affected? **88** or **99**
   (c) How much less time will be involved? **88** or **99**

Paid services

48. **(a)**If you pay for services/help, what is the total cost/month, overall **88** or **99**

   (b) Has there been any change with respect to having paid help since we last spoke? 1 **yes** 2 **no**
   (c) Explain (questions 48-54): ___________________________________

49. Which of the following services do you pay for (personal care? Professional care? Or care related to living in the home? Please check all that apply)? **88** or **99**

50. **(a)** Have you or do you expect that you will use less paid services as a consequence of the renovation? **1** yes **2** no **3** unsure
   (b) If yes, which ones? **88** or **99**

51. ***Before the renovation***, approximately how much are you / were you paying in dollars for each type of service? **88** or **99**

52. **(a)** Do you expect that the costs will be reduced as a consequence of the renovation? **1** yes **2** no
   (b) If yes, which ones and by how much? **88** or **99**

53. How important is the support your receive from paid assistance to help you remain Independent (ability to do everyday activities by yourself)?

ī not at all important
ī not very important
1 important
2 very important
3 essential to my independence

54. How important is the support you receive from paid assistance for staying in your home (rather than moving to other housing)?
ī not at all important
ī not very important
1 important
2 very important
3 essential to my independence

55. **(a)** Taking into account all the help you received, are you receiving all the help you need with respect to what renovations can do for you ? **1** yes **2** no
(b) If no, what additional renovation-based assistance do you need? **88** or **99**
(c) Has there been any change in your opinion of this since we last spoke? 1 **yes** 2 **no**
(d) Explain: ____

The Modification

CMHC sponsored modifications
The following questions refer to any adaptations or renovations to which CMHC contributed.

56. **(a)** At what stage is (are) your adaptation(s) or renovation(s)?
ī planned to begin by (date) _________
ī just starting
ī nearly complete (date of expected completion) _________
1 just completed
2 completed for a month or more
(b) Date we last spoke with one another is: __________________

57. What parts of your home do you plan to modify / have been modified (check all that apply) - (**1** yes **2** no or **88** or **99** - each item)?

1 entry/exit of home	**4** bathroom
2 the kitchen	**5** the bedroom
3 the laundry	**88** other

58. What types of modifications are you planning / have you done (check all that apply)? **88**

59. What are/ were the main specific reasons for these modifications (**1** yes **2** no or **88** or **99** - each item)?
(a) helps me deal with my disability
(b) building code issues
(c) for specifics

Where adaptations have been made:

60. **(a)** Before the adaptations were made, did you have difficulty in carrying out activities of daily living? **1** yes **2** no
(b) What was the nature of these difficulties (check all that apply)? **88**

61. **(a)** After the adaptations you made to your home, do you still have difficulty in carrying out the activities of daily living (check all that apply)? **1** yes **2** no **3** Too early to tell.
(b) If so, what? **88**
(c) Why so? **88**
(d) Has there been any change with respect to your difficulties in carrying out the activities of daily living since we last spoke? 1 **yes** 2 **no**
(e) Explain: ____

62. **(a)** Did you consult a professional to help you decide on the types of modifications you made? **1** yes **2** no
(b) If you had a professional or specialist help you, what type of professional/ specialist were they? **1** occupational therapist? **2** nurse? **3** MD? **4** equipment specialist? **5** Other
(c) If yes, how useful was the advice you received from this person?
ĺ not at all useful
ĺ not very useful
4 useful
1 very useful
2 exceptionally useful
3 cannot judge.
(d) Did the specialist visit your home? **1** yes **2** no
(e) If no, where do you see him or her? ____________________
(f) Did the specialist (**1** yes **2** no):
- only advise you to consider renovations?
- suggest you apply for RRAP-D or HASI funding?
- suggest what renovations ought to be made?
- do a formal needs assessment?

63. **(a)** Did the modifications supported by RRAP-D/HASI solve all of your difficulties in your dwelling related to your disability? ? **1** yes **2** no.
(b) If no, what problems are still occurring? **88** or **99**
(c) Would you respond to this question differently than you did when we last spoke? **1** yes **2** no
(d) Explain: ____

Quality of Life

74. **(a)** Has your health/disability changed significantly in the past year? **1** yes **2** no
(b) Have there been further changes since we last spoke? **1** yes **2** no
(c) Explain: ____

75. **(a)** Is it presently **(1)** stable or **(2)** changing? **(b)** Explain: **88**
(c) Has your health changed since we last spoke? **1** yes **2** no

(d) Explain: ____

76. **(a)** Do you believe your quality of life will improve or has improved as a result of the modification for which CMHC funding was used? **1** yes **2** no **3** ncertain
(b) Has your opinion about this changed since we last spoke? **1** yes **2** no
(c) Explain (questions 76-77):____

77. If yes, what do you believe will be or has been the main improvement in your quality of life as a consequence of the modification? **88**

78. **(a)** Have there been any problems created by the modifications? **1** yes **2** no
(b) If yes, what are these problems? **88**
(c) Have you noticed any new problems created by the modifications since we last spoke? 1 yes 2 no
(d) Explain ____

Activities of Daily Living

Below is a list of activities that seniors sometimes have difficulty with. Please tell us for each of these, how problematic they were before the renovations and how much the renovations have helped.

	Degree of difficulty		Degree to which renovations helped cope with this problem	
	Minor	Major	Minor	Major
A. Seeing (even when wearing glasses)				
B. Hearing (even when using a hearing aid.)				
C. Going up and down stairs.				
D. Getting on and off the toilet.				
E. Getting into or out of a bed or chair.				
F. Taking a bath or shower.				
G. Doing chores around the house.				
H. Moving around the house.				
I. Moving into or out of the house.				

Do you need help with **cooking**? 1. yes 2. no
If yes, are you receiving help? 1. yes 2. no
If yes, who helps you?
- family

- friend or neighbour
- an agency
- someone else

Did the renovation help you cope better in regard to cooking? 1. yes 2. no
If yes, how much did it help? 1. a little 2. a lot Please describe:

Do you need help with **laundry**? 1. yes 2. no
If yes, are you receiving help? 1. yes 2. no
If yes, who helps you?

- family
- friend or neighbour
- an agency
- someone else

Did the renovation help you cope better in regard to doing laundry? 1. yes 2. no
If yes, how much did it help? 1. a little 2. a lot Please describe:

Do you need help with **taking a bath or shower**? 1. yes 2. no
If yes, are you receiving help? 1. yes 2. no
If yes, who helps you?

- family
- friend or neighbour
- an agency
- someone else

Did the renovation help you cope better in regard to taking a bath or shower? 1. yes 2. no
If yes, how much did it help? 1. a little 2. a lot Please describe:

Do you need help with **nursing care**? 1. yes 2. no
If yes, are you receiving help? 1. yes 2. no
If yes, who helps you?

- family
- friend or neighbour
- an agency
- someone else

Did the renovation help you cope better in regard to nursing care? 1. yes 2. no
If yes, how much did it help? 1. a little 2. a lot Please describe:

How much have the following improved for you as a result of the modifications for which CMHC funding was used? If this interview is pre-renovation, please score only the 'before' scale.
Scoring: [0=extremely poor to non-existent, 10 = excellent, no problems]

Applies to questions 79-84, below:
1 improvement of 1 point
2 improvement of 2 points
3 improvement of 3 points
4 improvement of 4 points
5 improvement of 5 points
6 improvement of 6 points
7 improvement of 7 points

8 no change
88 see note
99 not applicable

79. Mobility into and out of the dwelling.
Before: 0 1 2 3 4 5 6 7 8 9 10
After: 0 1 2 3 4 5 6 7 8 9 10

80. Mobility inside the dwelling.
Before: 0 1 2 3 4 5 6 7 8 9 10
After: 0 1 2 3 4 5 6 7 8 9 10

81. Ability to do usual daily activities. Such as using the kitchen to cook.
Before: 0 1 2 3 4 5 6 7 8 9 10
After: 0 1 2 3 4 5 6 7 8 9 10

82. Ability to look after oneself. Such as using the bath and toilet independently.
Before: 0 1 2 3 4 5 6 7 8 9 10
After: 0 1 2 3 4 5 6 7 8 9 10

83. Health. Physical and mental health.
Before: 0 1 2 3 4 5 6 7 8 9 10
After: 0 1 2 3 4 5 6 7 8 9 10

84. Overall, how do you rate your overall quality of life as a result of the modifications?
Before: 0 1 2 3 4 5 6 7 8 9 10
After: 0 1 2 3 4 5 6 7 8 9 10

Stability in existing home

On a scale of 1 to 10 (where 0 means not important at all and 10 means very important) How important were the modifications to help you to:

Applies to questions 85-86, below:
1 score of 8
2 score of 9
3 score of 10
4 non applicable

85. **(a)** Maintain your independence
0 1 2 3 4 5 6 7 8 9 10
(b) Have you changed your opinion of the importance of the modifications for helping you maintain your independence since we last spoke? **1** yes **2** no
(c) Explain: ______________________________

86. **(a)** Stay in your home (as opposed to having to move somewhere else)
0 1 2 3 4 5 6 7 8 9 10
(b) Have you changed your opinion of the importance of the modifications for helping you stay in your home since we last spoke? **1** yes **2** no

(c) Explain: ______________________________

87. **(a)** Have you considered moving to other accommodation? **1** yes **2** no
(b) When: **1** before the modifications? **2** after the modifications?
(c) If so, what sort of accommodation? **1** nursing home; **2** other house
(d) Have you changed your mind about moving to other accommodation since we last spoke? **1** yes **2** no
(e) Explain (questions 87; 89-91): ______________________________

88. **(a)** Have you ever lived in temporary housing or shelter? **1** yes **2** no
(b) For what period of time? **88** or **99**

89. **(a)** Do you have any plans to move? **1** yes **2** no
(b) If yes, why (major reasons)? **88** or **99**
(c) If yes, when (in the next six months, 1, 2, 3, 4, 5 years)? **88** or **99**

90. **(a)** Is/was your attitude to moving affected by the modifications to your dwelling?
1 yes **2** no **(b)** If so, in what way? **88**

91. Would you move/have moved (earlier) if the RRAP-D/HASI financial support had not been available? **1** yes **2** no **3** not sure

Financial impact

92. How many hours did you spend on applying for the RRAP-D/HASI assistance? (or someone else spent on your behalf)? **88**
93. Did you have out-of-pocket costs? **1** yes **2** no or **88** or **99** - each item
If yes, what were these costs?
ˆ hiring a lawyer
ˆ hiring an accountant
1 travel costs
2 telephone costs
3 photocopying
4 mailing costs
5 other – incorrect estimate
6 other – upgraded fixtures
7 other – electrical box installed
8 other – staying with friends (food)
9 other – running around

94. Did you hire a contractor to carry out the adaptations? **1** yes **2** no

95. How much time did you spend obtaining quotations for the work? **88**

96. How much time did you spend dealing with the contractor? **88**

97. **(a)** Did any problems arise with the contractor? **1** yes **2** no
(b) If yes, what were they? **88**
(c) How did this affect you? **88**
(d) What do you think of the contractor's performance overall? **88**

98. **(a)** Do you think the modifications have had an impact on your home's market value? **1** yes **2** no **3** don't know

(b) If so, was it **1** positive? or **2** negative?
(c) Explain: **88**

Appendix C
Focus Group

Appendix C: Summary of Focus Group Discussion

Focus Group Discussion on the Design of a Cost-Benefit Analysis of CMHC Programs that Contribute Financially to Adaptation of the Home to Accommodate Aging and Disability (Housing Adaptation for Seniors' Independence, HASI, and the Residential Rehabilitation Assistance Program for Persons with Disabilities, RRAP-D).
2 P.M., Monday September 27, 2004, Room B1-100, CMHC National Office, 700 Montreal Rd., Ottawa.

Participants:

Attended

Sandra MacLeod — Health Canada, Primary and Continuing Health Care, Sandra_macleod@hc-sc.gc.ca
Simone Powell — Health Canada, Division of Aging and Seniors, simone_powell@hc-sc.gc.ca
Jennifer Taylor — Health Canada, Program Evaluation Division, jennifer_taylor@hc-sc.gc.ca
Roman Habtu — Social Development Canada
Clarke Wilson — Audit and Evaluation, CMHC, cwilson@cmhc-schl.gc.ca
Brian Ricketts — Assisted Housing, CMHC, brickett@cmhc-schl.gc.ca
Brian Davidson — Housing Policy, CMHC, bdavidso@cmhc-schl.gc.ca
Luis Rodriguez — Housing Research, CMHC, lrodrigu@cmhc-schl.gc.ca
Joe Cottitto — Housing Research, CMHC, jcottitt@cmhc-schl.gc.ca
Faye Porter — Victorian Order of Nurses, porterf@von.ca
Esther Roberts — Cdn. Association of Independent Living Centres, Roberts@cailc.ca
Ken Watson — Consultant ken@rideaugroup.com
Anne Perkins — Consultant anne@rideaugroup.com

Attended by Telephone

Betty Havens — University of Manitoba, havens@ms.umanitoba.ca
Janine Zimmer — Snr. Analyst, Special Projects, CMHC Vancouver, jzimmer@cmhc-schl.gc.ca
Lorna Hillman, — Canadian Caregiver Coalition, lhillman222@telus.net
Kathy Pringle — Occupational Therapist, Accessibility Consultant pringlek@kos.net
Margot McWhirter — Occupational Therapist.
Donna Davis — National Nursing Officer, Veterans Affairs

Could Not Attend but In-put in Writing

Joanne O'Keeffe — COTA, OT okeeffe_j@cotarehab.ca
Teresa Chiu — Manager, Research and Development, COTA Comprehensive Rehabilitation and Mental Health Services, chiu_t@cotarehab.ca

Objectives of the Discussion

The first phase of the design of the cost-benefit study was approaching completion. A draft literature review and a draft 'logic model' (a diagram of how the programs are expected to lead to the desired outcomes) had been prepared and distributed to participants, along with the terms of reference for the study. The next phase of the study design was to prepare data collection instruments and to test them in a small sample of cases (15 cases at three sites, including urban and rural cases).

The Focus Group included people with different areas of expertise. They were asked to consider the following questions, but to speak on what they saw as important to the study – that is, each person was asked not to try to be comprehensive but to make suggestions from his or her particular professional perspective:

[1] Have all of the effects (costs and benefits) that should be taken into account been noted in the Logic Model?

[2] How can information about these effects be gathered?

Who in addition to the direct recipients can give information on particular effects of the renovation? (For example, family and friends, medical support professionals, social support professionals, service providers, and/or other public program personnel). What kinds of information could be obtained from whom? How should these people be approached? What permissions and agreements would be needed to gather such information?

After the Focus Group meeting each participant was given a draft of the points he or she made in discussion, to add to or correct. It is noted below whether each person made an additional response in this second round.

Comments by Participants

Luis Rodrigues opened the meeting with an overview of the project, as managed by him for CMHC and Sandra MacLeod for Health Canada. Dr. Ken Watson, as leader of the consultant team, and Dr. Anne Perkins, reviewed the purpose of the meeting and gave an overview of the Logic Models of the Programs.

The meeting proceeded with a 'round robin' of individual comments and suggestions, each taking turns; and then continued with an open discussion of the issues raised. The summary of participant comments below is organized by participant, and included points made in the individual round and in general discussion.

The following points are arranged alphabetically by name, not in order of speaking.

Summary of Comments

Theresa Chiu, OT/COTA Rehabilitation Toronto – by email

The literature review is very comprehensive and informative. The draft framework captures key components of costs and benefits. As requested, the following is the response to the questions based on my professional perspective. My perspective is a researcher who

specializes in home safety assessment, family care giving, service outcome evaluation, and home-based occupational therapy.

Specific viewpoints to be brought forward:

a) The physical environments one lives in can facilitate or hinder one's ability to participate in everyday living. Occupational therapy has the expertise to evaluate the functional and safety needs of an individual and the impact of the surrounding environments on their ability to remain in their own homes.

b) Impacts of the RRAP-D and HASI are considered as "true" benefits only if they effect on an improved functioning or safety of the residents. This means that other effects will not be considered as true or dominant benefits but as 1) intermediate effects that eventually impact on the resident's ability to function in their own homes (e.g., reduced caregiver burden). 2) Secondary effects if there are other changes as a result of the programs (e.g., changes in the value of the adapted housing unit.)

c) Collecting benefit (service outcome) data is well established at COTA and has been incorporated into daily practice of home-based professional services. We have experience to collect accurate assessment data in practical ways at clients' home.

d) The International Classification of Functioning, Ability and Health (ICF) framework should be better integrated into the cost-benefit analysis framework. Strengthen the concept of Activity and Participation to include other domains such as household management, community program participation, etc., and expand on contextualizing the environment as a facilitator or inhibitor, i.e., a change in the environment cannot be considered as a benefit unless it facilitates the residents' ability to remain at home (Does a modification of the main entrance facilitate or hinder activity and participation?). There are occasions that a change in the environment in fact can reduce the residents' ability to function independently at home. This should be captured too.

e) Caregivers often provide not only physical but also emotional support. Caregivers are often more stressed more by behavioral problems of the person they care by than the physical care they provide. Therefore, caregiver burden is an important construct to measure in addition to hours of care giving.

f) For caregivers who take care of individuals who have both physical and cognitive disabilities, e.g., Alzheimer Disease, stroke, traumatic brain injury, OTs often provide strategies to modify the physical environment to improve the care giving situation. I am very interested to know the impact of physical modification of dwelling on the care giving situation.

g) Not every dwelling modification has the input of rehabilitation professionals, especially occupational therapists. I am interested in finding out whether the presence or absence of OT input in modification requirements would impact on the benefits (and costs).

[1] Have all of the effects (costs and benefits) that should be taken into account been noted in the Logic Model?

Suggested changes	Reasons/comments
1) Add one more main component: Effects	Based on ICF Environmental Context

on the services and systems a) Changes (cost savings) in the health system (long-term care facilities) b) Changes in social support system (meals-on-wheels, day programs, community centres) c) Changes in transportation system (assisted transportation services)	• If programs were successful, less people will need to move into long-term care facilities, and more people will need the support services in b) and c) • The demand for assisted transportation and day programs is an issue. This may have a confounding effort on the benefits of the CMHC programs.
2) Add one more effect under Local Community: a) Changes in public and private building and areas (accessibility)	• An increased number of people with disability living in the local community will increase the demand of changes in the surrounding areas. • This may have a confounding effort on the benefits of the CMHC programs
3) Remove the intermediate effects on the applicants, i.e., “changes to mobility….”, “changes to resident risk….” and “changes to ability to cope”	• See suggestion 4) below
4) Replace effects [6] and [7] with the followings: a) Change in activity and participation (mobility, self-care, household management, interpersonal interaction, work/school, community programs, religious/spiritual activities) b) Change in home safety c) Change in applicant satisfaction	• Quality of life is a construct more difficult to measure compared to activity and participation • The components of the ICF Activity and Participation cover a broad range of everyday tasks that are considered to be very important to people with disability. • A fundamental conceptual change of the ICF from its previous version is the introduction of a positive viewpoint which changes “disability and handicap” to “ability and participation.” Building the framework using a positive viewpoint is therefore desirable.
5) Break [10] into two: “Changes in care giving burden” and “Changes in caregiver safety/health risk”	• Care giving burden, stress and depression is a common construct in care giving literature that measures the demand of both emotional and physical care giving support
6) Modify [13] to “Changes in caregiver services (respite, education and support)	• With modification of the dwelling, caregivers may require more (or less) education about care giving, and support services (e.g., counseling, stress management) in addition to respite
7) Add one more effect under caregiver: “Changes in satisfaction of caregiver”	• Caregiver satisfaction is also important in addition to applicant satisfaction

[2] How can information about these effects be gathered?

Effects	Measures	Administration

		method
Activity and participation	LIFE-H scale, autonomy and participation scale	Self-completed or OT assessment
Home safety	SAFER-HOME	OT assessment
Care giving burden	Burden Scale for Family Care giving	Self-completed
Care giving time	Hours of care giving time per week	Caregiver log
Caregiver support services	Type of services, time taken to receive services per month	Caregiver log
Applicant and caregiver satisfaction	Satisfaction survey	Self-completed

Who in addition to the direct recipients can give information on particular effects of the renovation? What kinds of information could be obtained from whom?

- Family caregivers: information re: caregiver burden, hour of care giving, caregiver satisfaction
- Occupational therapists: information re: home safety of client, participation and ability of client

The availability of OTs to conduct the RRAP-D or HASI projects varies from one pilot site to another. If the SAFER-HOME is selected for use in this study, the study team may consider contracting an OT (or OTs) as an assessor(s) in each site. To improve the reliability of the assessment, it is recommended that the assessor be trained to use the SAFER-HOME.

Joe Cottitto, Housing Research, CMHC [no additional response]

- The issue of self-worth is an important outcome (own home, own garden, own dog, etc.)
- HASI a quick fix. RRAP-D is much more substantial assistance.
- Should family income eligibility limits be increased? Is there enough (or too much) regional flexibility and variation?
- Should the ceiling assistance be increased?

Donna Davis, National Nursing Officer, Veterans Affairs

- What are the assumptions behind these programs? Is it assumed that home care, with renovations, is a panacea? (The Veterans Independence Program has a lot of relevant experience that is worth considering in this study.) (General response from the group: no, this is not assumed.)

- New issues are emerging with older clients – e.g., dealing with frailty, falls and injuries – home care is not for everyone. Some attention needs to be focused on long-term institutional care. Long-term care placement is not a dirty word. Home care can place extreme stress and other burdens on the caregiver - a key issue, especially with respect to dementia (for which home care may not be the appropriate response). (Janice Keefe – National study underway now)

Roman Habtu, Social Development Canada

Will there be a comparison made with a control group?

Betty Havens, University of Manitoba [no additional response]

Logic Chart: esp. items 6-7-8

1) Social isolation seems to be missing from chart (choosing to stay in own home may prove to be more isolating even if the ability to interact has been increased by renovation)

2) Similarly - physical isolation - especially a rural & remote areas issue, which needs more reflection (e.g., propane gas tanks, water tanks; different needs in remote areas – some of which is within municipal responsibilities, sometimes first nations' communities)

US patterns are not going to be the same in Canada. Suggested sources:

- Janice Keefe – the home care sector study (Goss Gilroy – HRDC literature) (Do you have more direct references for these? Thanks.)
- Anderson (Betty, can you clarify this reference, please?)
- Stats Can/Cycle 11 of GSS identifies all the general kinds of caregiving (4 authors); also GSS 17 on care giving and support systems

Lorna Hillman, Canadian Caregiver Coalition

There is information on the total cost of informal care - $5 B is one possible figure. However, Stats Can work on this asks two different questions, which results in two different figures.

[Clarification: Norah Keating estimated the cost of the unpaid work at $5 billion a year.]

Sandra MacLeod, Primary and Continuing Health Care HC

- Home care is not always the best choice, nor is institutionalization the worst. What should be done about long-term clients?
- Not every community will have a spectrum of choices.
- Case studies will be snapshots in time; we will have to get a handle on the longer term
- Logic model – is there too much in the logic model? There are lots of variables – do we need every one of them?

<u>Response</u>: caught her comments well; however, she has sent additional comments on other items:

- Once we develop 'how' we will gather information from family caregivers, perhaps we can think of ways to calculate this? Lost time at work? Early retirement? Because families give so much of their time, we need to find a way to put a price on this.... For example, what if we took the hours provided by a family caregiver and gave it a 'salary' just for costing purposes (ie, salary of a personal care worker)? The other big item is out of pocket expenses.

- Caregivers are individuals who provide care and assistance for their family members and friends who are in need of support because of physical, cognitive or mental health conditions. Caregivers play an integral role in supporting Canadians who require care,

often in the home and community. An estimated three million Canadians are caregivers, spanning the age range from youth to old age.

- References: Janice Keefe, Mount Saint Vincent University, Halifax (Canada Research Chair, Care giving and Aging); Norah Keating, U. of Alberta; Janet Fast, U. of Alberta.

Margot McWhirter, OT/COTA Rehabilitation Toronto (speaking for Theresa Chu)

- Need to have more focus on the applicant/recipient (others are secondary).

  I recommend that the client/applicant be more prominent than some of the other factors in the logic model, given that the primary goal of the RRAP and HASI programs is to maximize the client's/applicant's health, independence, safety and overall well-being.

- The logic model seems to bury the applicant/client in the outside environment.

  The Canadian Model of Occupational Performance (Source Canadian Association of Occupational Therapists, 1997) depicts the dynamic relationship between person, environment and occupation (=activity). In a graphic representation of the model, the person - a physical, cognitive, emotional and spiritual being - is shown at the centre, connecting outwards into the environment - which involves physical, institutional, cultural and social elements - through self-care, productivity and leisure occupations.

  I wasn't meaning to suggest that the logic model buries the client/applicant, but rather that, as the central figure, the client/applicant should be seen as functioning within a multi-dimensional environment. The Canadian Model of Occupational Performance, as well as other person-environment theories such as those of M. Powell Lawton, recognize the person as being influenced by the environment as well as influencing the environment. That is, the person is not a passive, reactive "thing"; the person is an active agent of change within the environment.

- Applicants just don't have physical limitations, but may have cognitive and palliative-related limitations as well.

  My intent was to highlight the fact that people with disabilities include persons with physical, cognitive, visual-perceptual, sensory, emotional, and spiritual disabilities - not to mention those with chronic pain, auto-immune disorders, environmental sensitivities, learning disabilities, temporary disabilities and/or terminal illnesses. RRAP and HASI policy makers need to consider the broader spectrum of people with disabilities and - I would argue - address additional barriers to independence besides stairs in the home, rounded door handles, etc.

- Cost-benefit – what are we comparing it to?

  There is a whole range of options, some relatively new; recipient of care, their family may not know that other options are available. I was getting at the idea that if, for the purposes of this evaluation, you are looking at comparing "people remaining in their homes with modifications funded by the RRAP or HASI programs *versus* people changing residences (in order to receive more care & support)" -- it is important to remember that the latter group has many options. These include supportive housing,

assisted living, and facilities where they receive 24-hour, non-acute health care. This speaks more to the research design than anything else.

I was highlighting the fact that some applicants and their families may not be aware of these alternative housing/care options. I think it was Donna Davis who raised the point that these options are not universally available throughout Canada.

- People do not necessarily recognize the effect of physical modifications.

  I made this comment when someone asked, “How are you going to measure the cost-benefit of RRAP and HASI programs?” They wondered about using a self-report measure. My concern was/is that if you asked clients/applicants about the impact of home modifications on their health, independence, safety and overall well-being, you may not get an especially strong and/or positive result. That is because people tend to change their behaviour (i.e., stop participating in an activity) rather than changing how they do it, or changing the environment to support them do it more easily. Even if/when environmental modifications are made, the person may not attribute their independence, safety, etc to the modifications. This is because most people don't recognise the environment as an enabling or disabling factor in their lives. Thus, I was recommending the use of objective measures of functional status, home safety, etc. rather than self-reporting. Occupational therapists who specialise in home safety assessments and who use reliable and valid outcome measures (i.e., COTA therapists, the SAFER-HOME tool) would be ideal for your research purposes.

Joanne O’Keefe, OT, COTA Rehabilitation and Health Care Services

1) Logic model:

- Effect on local community: in addition to the changes in the renovation trades etc., it also provides local and national employment for administration of the program.
- Effects on professional/commercial services needed. Consider adding: changes in access to service providers and service provision in the home.

2) How can information about these effects be gathered?
Who and what kind of information???

- Effects on applicant and professional services needed (national and provincial OT associations – CAOT, AAROT, OSOT, etc – to advise you of OT subject matter experts

- At CAOT could contact Darene Toal-Sullivan, Director of Professional Practice, tel 613-523-2268 x237).

- Also, Kathy Pringle – OT with extensive experience with home adaptations may have access to OT evidence base, which is known to CMHC.

- Logic model – is there too much in the logic model? There are lots of variables – do we need every one of them?

- Changes to resident risk and safety: - COTA SAFER-HOME outcome measure. COTA Rehabilitation and Mental Health Services – Teresa Chui

- OT and community epidemiology researchers at the key rehabilitation universities – U of T, Western, Queens, U of A, U of Man., Dalhousie, Ottawa U. could be surveyed for current or recent research about the effects of home modifications on the functional abilities and quality of life of residents.

- Changes to resident risk and safety: - COTA SAFER-HOME outcome measure. COTA Rehabilitation and Mental Health Services – Teresa Chui

- Community home care service providers such as Ont. CCAC's and other provincial counterparts may have information about the changes in amount of home care services and recurrent hospital admissions.

- Effects on Caregivers: Alzheimer Society of Canada may have additional information specifically related to the experience of caregivers of those with a diagnosis of dementia. A local contact from the Ottawa Alzheimer Society is: Inika Anderson , 613-523-4004. She may be able to assist you to connect with the most suitable person in their organization.

Faye Porter, Victorian Order of Nurses

- Effects on family caregivers, friends – e.g., stress, quality of life of the care giver, etc. It is very hard to deal with qualitative issues (item 6/logic model). The change in quality of life should show in both the recipient and the care giver.
- Formal/informal – language not good choice. Need to address this up-front. (paid? unpaid?)
- For VON, we have produced a best practice "manual" for providers (on our website at www\\von.ca). In the course of this work and other work on caregiving, we have identified over 4000 references.
- Nora Keeting (University of Alberta) – four projects on burden, costs of care giving (link with this study); also Janice Keefe has done a report on this. Response: I am not sure Nora's work is on "burden" but rather on the hidden costs of care. Janice's project is part of that entire study and would think it may be helpful to clarify how the pieces are linked. Sandra McLeod may know off hand the 4 (or 5) "Theme" areas they are exploring.

Overall response: You have captured my thoughts well - a couple of suggestions. For language alternatives, you will see family/friend in the literature. Caregiver versus provider is ideal but often providers (ie, paid) see themselves as caregivers. Thanks for acknowledging language challenge.

Simone Powell, Division of Aging and Seniors HC [no additional response on this, but a newspaper article indirectly, sent through to Sandra MacLeod]

- What are our assumptions? Are we making a comparison between doing and not doing renovations? What is the baseline? There are other care options, but an appropriate alternative housing choice may not exist.
- What about savings to the health system, and personal costs (logic model item #8)?
- What about prevention of injuries (Key goods: independence, security, safety, comfort)?

Simone Powell sent the following to Sandra who forwarded it to us:

People looking after relatives crave break

ITEM
PUBLICATION The Vancouver Province
DATE Wed 15 Sep 2004
SECTION/CATEGORY News
PAGE NUMBER A26
BYLINE Norma Greenaway

HEADLINE: People looking after relatives crave break
OTTAWA -- Most Canadians caring for elderly family members are not unhappy, but they are begging for a break, says a new Statistics Canada survey. It says 95 per cent of caregivers aged 45 to 64 looking after parents, in-laws and friends with long-term health problems were satisfied with their lives. Only 13 per cent described their lives as very stressful, about the same percentage as those in the same age group who provided no informal care to ailing seniors.

"That's probably the good news in this story," said Susan Stobert, a StatsCan analyst and study co-author. "Their lives don't seem to be made unhappy by doing this work." Stobert said the survey found that most of the caregivers would choose a break from their responsibilities over other options such as payment.

The survey said more than 1.7 million Canadian adults aged 45 to 64 -- about 16 per cent of this age group -- provide informal care to almost 2.3 million seniors with long-term ailments.
C:\eudoraattachments\pic08683.pcxpic08683.pcx

Kathy Pringle, OT Accessibility Consultant [no additional response]

- Sometimes renovations do not turn out well. Depends on inspector, contractor, follow-up with care giver, etc.
- References:
  - "Health Outcomes of Housing Adaptations" (UK study 2004) [Kathy, do you have a more complete reference for this?]
  - [You gave a second reference about interaction between environment and performance – a 2003 peer reviewed article. Can you give me the complete reference? Thanks.]
- There is a great deal of literature from psychology field on performance in changing environments, and on how person adapts to new environment.
- There needs to be a "performance test." Have the activities of those who have received renovations changed? Has how they perform their activities changed?

Brian Ricketts, Assisted Housing CMHC [no additional response]

The issues of social and physical isolation need to be addressed with respect to both applicant and care-giving family.

Esther Roberts, Cdn Assoc of Independent Living Centres [no additional response]

- It is important to keep the focus on people; cost/benefit analysis will be different if the focus is on people.
- Other program supports are key to/in addition to physical modifications.

- Because of home care cutbacks, a recipient cannot get out of his or her home (nor can the care giver) → isolation. This is a pivotal issue.
- There are costs involved for recipients if they have to leave their homes because of deteriorating heath. This is because of the program's payback policy when recipient does not remain in home for certain length of time. And, it is often not their choice to leave. (See comments, Janine Zimmer.)

Luis Rodriguez, Housing Research CMHC

There was a CMHC research report which used a comparison group: "Promotion de l'autonomie des personnes âgées par l'adaptation de leur domicile" by Danielle Maltais (reference number at CMHC's library is Ca1 MH110 93P61). Copy has been sent to Ken.

In addition to Clarke Wilson's comment in his response I suggest that you review the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (see Web link below) and take all necessary steps to ensure compliance with it, including, if necessary, seeking independent counsel.

Link to the 'Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans'. http://www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm

Jennifer Taylor, Program Evaluation HC

- What has happened to the traditional logic model (Treasury Board) → activity, outputs, outcomes? In the meeting, I indicated that for evaluation purposes, it would be useful to have the "traditional TBS" type of logic model, to distinguish between the immediate, intermediate and final outcomes.
- Also, it may be useful to identify differences between the two programs – outcomes, time differences. They have separate authorities. Perhaps, it would also be useful to have two separate logic models, one for each of the programs. While there are many similarities between them, the incremental impacts may be different.

Clarke Wilson, Audit & Evaluation CMHC

There are confounding factors at work that are beyond program. These outcomes are net outcomes. The logic model does not make this explicit (e.g., Item #4 – may contribute, but may not be effective beyond that program) Only those impacts that can be traced back to the program should be looked at, not other sources of the effect.

Clarification/expansion:

I am not a subject matter specialist on disabled living and programs to offer assistance to disabled persons. I am happy with the headings and feel that they can accommodate any detailed benefits that I can think of, but those who work in this area should indicate any major gaps.

The information will come from studies of communities that have some substantial stock of program recipients (#1, 2, 3, 4), program data (#5), disabled occupant surveys (# 6, 7, 8, 9, 14, 15) and surveys of care givers (# 6, 7, 10, 11, 12, 13, 16).

The first group of impacts affect third persons or the community generally. This is why I think there will be, what I call, community studies. These will involve appraisal professionals to advise on the market impact of accessibility modifications (#3), statistical studies of diversity indicators at neighborhood levels (#4, probably using census tract data), labour market studies of unemployment and occupational availability (#2). In trying to imagine indicators and data sources for #1, I came up blank. Does this effect really exist separately from the benefits and costs identified in #6?

Some of the impacts can be traced to individuals, primarily the disabled persons or their care givers. These may be the easiest to measure with interviews or surveys. We would likely require one survey of the occupant and one or more of a key contact. Where this is a family member or friend, they may be easily identified. Where there is no such person, there may be one or several contacts at various institutions or professions (health, legal or financial) that have to be identified and interviewed. That will be difficult.

There is much danger of double counting. With respect to benefits, I have already pointed to #1 and 6. I think all of the benefits noted at #5 are included somewhere in #8, 10, and 11.

Again, with respect to detailed identification of respondents, I am not a good contact.

Regarding privacy and ethics, you should ask Luis for his division's procedures. All CMHC divisions adhere to Access to Information and Privacy guidelines from our ATIP office. We do all kinds of surveys for research, evaluation, marketing and other purposes.

In the evaluation group, our usual procedures are to:

- Indicate in a cover letter or note that participation is purely voluntary and that data will be treated confidentially.
- State what the data will be used for. In this regard, you should ask for agreement (which of course will not be binding on the respondent) to participate in the second phase and perhaps continuing phases of the interviews. If there is any reason that Luis or another researcher may want to contact them later, you would want to ask at the beginning. One reason for a later contact might be to monetize non-monetary costs or benefits after they have been identified.
- Not publish or transmit personal data that could be used to identify individuals. We use identification and personal data (for example account numbers, applicant names or household descriptions) only to manage or to query the data base. We would not, for example, use evaluation responses to check on the status of a repayable loan in a particular account.
- State who will have access to hard copy and electronic data files (generally the consultant and the researcher and for hard copy, perhaps only the consultant).

In evaluation, we destroy hard copy questionnaire and interview files after the report has been published. The primary electronic files are kept indefinitely for CMHC use. After publication we often release data files to the public, stripped of identification data and often grouping or otherwise generalizing personal data.

Janine Zimmer, Special Projects CMHC Vancouver

Re: repayment of loan. If leaving home situation has support of an MD (a note), the loan is

automatically forgiven. However, response may vary from province to province, where the province is delivering the program. If CMHC is delivering the program directly, there is some discretion.

Response

With regards to the repayment of the loan in the situation where the applicant must move into a care facility, we have the ability to automatically forgive the loan when the move is supported by a medical note. I cannot comment on how this policy is applied in other provinces particularly where the province is delivering.
In cases where applicants, for whatever reason, are unable to provide us with information we request, in writing, permission from the applicant to designate a representative who will act on their behalf. In general CMHC does not release particulars on a file to anyone other than the applicant and/or authorized representative. In a lot of cases the representative is a family member or a occupational therapist.

In cases where applicants, for whatever reason, are unable to provide us with information we request in writing, we ask the applicant to designate a representative who will act on their behalf to get permission. In general CMHC does not release particulars on a file to anyone other than the applicant and/or authorized representative. In a lot of cases the representative is a family member or an occupational therapist.

CMHC falls under the Access to Information privacy act and I am not sure as to whether the Access to Information department would have to be involved if information on applicants' files is to be release by CMHC. I do agree that permission from the applicant should be obtained as well.

The Logic Model certainly covers a wide scope of costs/benefits. As the person responsible for the delivery of the programs in B.C., we don't see the effects after the loan is closed out, such as whether the applicant has the necessary support to remain in the home. We do receive numerous thank you notes from applicants and/or family members who are grateful for the assistance. It will be interesting to see the results from the research.

With regards to approaching applicants, on occasion we have done some advertising in the local newspapers and have had the opportunity to ask applicants if they would be willing to be interviewed. For the most, the response was positive.

Appendix D

Individual Case Study Descriptions: Long Descriptions

ANNEX D: INDIVIDUAL CASE DESCRIPTIONS

Beneficiary 01
Care giver 01A

Assistance type:	RRAP-D
Assistance amount:	$10,323
Total cost:	$10,673
Urban/rural:	Rural
Beneficiary sex:	Male
Beneficiary age:	47
Beneficiary disability:	Allergies, asthma and lung cancer
Modifications:	new roof; new flooring (wood instead of carpet)
Modifications completion:	August 2004
Caregiver:	Yes, wife
Interviews:	Round 1: early February; Round 2: early August (6 months)

Overview

The beneficiary (47 yrs) and his wife and 10-year old son live in a 14 year-old high ranch in the country abut 15 minutes out of the nearest small town. He suffers from severe allergies, occupational asthma and lung cancer caused by his work re-painting automobiles, which he did for many years without sufficient protection. By the second round of interviews, the beneficiary's lung cancer had become quite virulent and had spread to his brain. This has had a significant affect on his mobility and ability to see. The summer heat and air quality has also had a deleterious effect.

The beneficiary was very quiet during the first round interview, and generally let his wife answer for him as it is difficult for him to speak. He and his wife are especially proud of their son who, despite the father's serious health issues, has been given an award for 2004 his volunteer work in the community.

His personal income (and household income) ranges between $15,001 - $20,000 a year from workmen's compensation, Ontario disability, and the national child benefit. Because of the nature of his illness, he will never be able to return to work.

During the initial interview, the beneficiary reported that he tries to walk the dog every day he is able, and would not even try to get exercise outside without this incentive. By the time we contacted him during the second round of interviews, his condition would no longer allow him to be outside except for very short periods.

Primary caregiver

The beneficiary's primary caregiver is his wife (aged 49) who, at this time, is the only one available to help him on a day-to-day basis. She helps him move in and out of the house and from room to room, helps him go up and down stairs, and drives him to medical and other appointments. During round two we found that she now has to help him use the toilet and take a bath because of a downturn in his health. She continues to prepare meals, do general housekeeping, and some home maintenance chores. As his health continues to worsen, she will need to give him more and more personal care.

Although she owned her own house cleaning business before her husband was taken ill, she has had to give it up because he needs her home virtually full-time. This is not expected to change, despite the renovations. In addition, her health has suffered. She reports that she is under extreme stress and forever tired. She also has back problems from lifting her husband, and from the heavy cleaning needed to keep the air as clear of dust and allergens as possible. In the round two interview she reported that she had been the hospital for a medically-necessary hysterectomy. Their 10-year old son stayed out of school and became his father's main caregiver with help from neighbours and friends while his mother was recovering.

The renovations have made it easier to clean the house, thus making her care giving somewhat easier. However, because his health is getting progressively worse, they have not lessened the time she needs to care for him.

During the second round of interviews, we learned that, beginning the last week of July, a nurse from the St. Elizabeth Health Care Unit in Kingston (unpaid) has been coming to asses the beneficiary's health on a weekly basis. The intent is to help the family determine what additional help in the home will be needed as the beneficiary's diseases progress, and when he will need to enter institutional care.

The beneficiary believes that the help his wife gives him is important for him to maintain as much independence as possible, and very important for him to remain in the home. She has confirmed this opinion. The new health assessment services noted in the previous paragraph will be very important for providing the basis for determining what additional modifications and personal help may be needed to keep the beneficiary in his home for the longest time possible.

CMHC-funded modifications

The modifications affected the entire house, and included replacing the roof (a code issue) and replacing all the carpeting with laminate flooring (new flooring eases beneficiary's breathing). The new roof cost $6,300, and the flooring $4,373. The RRAP-D Program covered the entire cost except for $350 that was paid by the beneficiary because of a poor cost estimate with respect to the amount of carpeting needed. The renovations were completed in August 2004.

Although the renovations did improve the beneficiary's general mobility and ability to breathe, at least temporarily, it is unlikely that any renovations could improve the beneficiary's health situation significantly. Both he and his wife believe, however, that the modifications have been essential to his independence and ability to remain in the home to this point (score of 9/10). At the same time, they believe that the family would not have considered moving to other accommodations, even if the renovations had not been done.

The beneficiary and his wife did not have expert advice about the renovations from an occupational- or physical therapist, although his doctor did tell them about the CMHC RRAP-D program and suggested that replacing the carpets throughout would help him breathe. Except for the CMHC representative, no one visited to discuss the nature of the renovations and no formal assessment was done with respect to either renovations or the beneficiary's needs if he is to remain in his home prior to end of July when the nursing visits began.

<u>Other renovations</u>

The CMHC representative asked that better railings be put onto the entrance way prior to approving the RRAP-D grants. This was done at no cost with the help of a friend and scrap wood the beneficiary already owned. Aside from this, no other renovations have been made to the home in response to the beneficiary's illnesses.

The home is not air-conditioned. During the second round of interviews, the beneficiary indicated that if the basement could have been dried out and insulated, he could have "moved" there during the heat of the summer where it would have been much easier for him to breathe. However, when the CMHC representative visited prior to the approval for the new flooring and roof, he indicated that no money for this type of renovation would be available.

<u>Quality of Life</u>

The beneficiary and his wife believe that the modifications improved his quality of life in the short term. Because of them, he was able, until recently, to breathe and move around in and outside of the home more easily. During the first round of interviews in February, he had reported that his mobility improved from a score of 3 to 8 for moving in and out of the home, from a 5 to 8 within the home, and from 4 to 7 outside the home. He also reported that his general mental and physical health improved by three points and his overall quality of life by four points. His wife agreed with this assessment.

During the round two interview, we found that these scores have changed significantly because his health has worsened.

- Mobility in/our of the dwelling has dropped by 4 points;
- Ability to do usual daily activities has dropped by 5 points – two points below the score *prior* to the renovations;
- His physical health has dropped from a score of 8 to 2 – three points below the score *prior* to the renovations; and
- His opinion about his overall quality of life <u>as a result of the renovations *only*</u> remains unchanged.

In response to the questions added in the second round, the beneficiary reports that:

- continuous moisture and mold in the basement is a relatively severe risk to his health (4/5),
- he and his wife (primary caregiver) will need more and more outside help as his health worsens, if he is to remain in his home (4/5); and that .
- his access to the bathroom and shower, and to the basement is a safety issue (4/5)

Financial impact and willingness to pay

The beneficiary and his wife estimate that applying for RRAP-D assistance took approximately 1½ hours. Quotations from potential contractors were gotten over a period of two weeks. The beneficiary and his wife decided together which contractor would do the work. The work was very well done, and the contractor did not need ongoing supervision. However, the company that measured for carpeting made an error which, as noted, resulted in the additional unexpected charge of $350 that had to be paid by the beneficiary. This was a hardship as their financial situation is tenuous.

The beneficiary would not have been able to afford the renovations without the CMHC program and, so, would have needed the entire amount to do the renovation. If he could have gotten a cash grant with no strings attached, he would still have spent it on the same renovations.

They believe that the value of the house has increased because of the renovations.

General opinions about Program

The beneficiary and his wife were both very pleased about the speed of the processes involved (application, estimates, renovation work, and payment). Most importantly, the renovations have helped the beneficiary breathe more easily, and the house is cleaner and dryer. Both also thought the CMHC representative was excellent.

As noted, having to pay the additional $350 put significant financial pressure on the family. The disruption during the renovations, although to be expected, was difficult.

Beneficiary 02

Assistance type:	RRAP-D
Assistance amount:	$14,000
Total cost:	$14,000
Urban/rural:	Rural
Beneficiary sex:	male
Beneficiary age:	39
Beneficiary disability:	Arthritis, multiple sclerosis (MS), and severe knee problems
Modifications:	moved bedroom to 1st floor, with accessible bed by height; new bathroom 100% handicapped-accessible; modified laundry facilities and moved to basement (room for new bathroom); grab bars as needed; safety hand rails (all inside stairs, porches and outside decks); windows adjusted on 2nd floor to prevent fall-out
Modifications completion:	October 2004
Caregiver:	none
Interviews:	Round 1: late January; Round 2: early August (6 ½ months)

<u>Overview</u>

The beneficiary lives in a beautiful heritage stone house near the St. Lawrence River between Brockville and Kingston. Because of upcoming surgery and a long recovery in hospital, we were unable to visit him to do the interview.

The beneficiary purchased the home before his illnesses were diagnosed, and had already put considerable money into the upgrades (electricity, plumbing, etc) usually needed to bring a 165 year-old house up to standard. He also had extensive renovation and building experience before he had to stop working because of his disabilities. As a consequence, he has a great deal of knowledge about how things should be done and was able to get the best value for the money invested through the program.

He is a 39 year-old male. He has severe mobility problems (arthritis, Multiple Sclerosis [MS], and severe knee problems). When we first interviewed him, he indicated that he always wears leg braces and uses any one of a manual wheelchair, walker, crutches, or cane as needed. Since the first interview he has gotten a new wheelchair (not electric). He has also had his 11th knee surgery, and was hospitalized until June. He is currently recovering at home, a process that the doctors predict will take up to a year. As a consequence, his mobility has actually decreased – although eventually he should be able to move around the home without his leg braces. He lives alone except for very occasional weekends when his 10-year old son visits. He has no primary caregiver, but receives occupational therapy and physiotherapy from a hospital in Kingston on a regular basis.

His personal income (and household income) ranges between $10,001 - $15,000 a year from workmen's compensation. Because of the nature of his disabilities, he will never be able to return to work as a construction worker.

CMHC-funded modifications

The renovations were done to increase the beneficiary's mobility and safety in the home. Modifications affected entry/exit; laundry room; bathroom; bedroom; all internal stairways, all porches, outside decks, and upstairs windows. The types of modifications included:

- a bedroom moved to the first floor with an accessible bed (height modified);
- a new bathroom which is 100% handicapped-accessible (this renovation and the bedroom have made it much easier for him to live at home during his recovery from the knee operation);
- modified laundry facilities and moved to basement to give room for new bathroom;
- grab bars where ever needed;
- safety hand rails – all inside stairs (basement and 2 inside stairways), porches, outside decks; and
- windows adjusted on the 2nd floor so than no one can fall out.

The CMHC-sponsored renovations cost $14,000, and the program covered the entire amount. The renovations were completed in October 2004.

Prior to the operation, the renovations had improved the beneficiary's general mobility and safety, and resolved these difficulties in the home. Since the operation, however, his mobility (and safety) have temporarily decreased. As well, because he has MS and his overall health can be expected to deteriorate over time, every effort was made to select renovations that will keep him in his home for the longest possible time. The beneficiary believes the modifications have helped him remain independent (very valuable; rating 8/10) and in his own home (essential; rating 9/10). If he had not been able to do the renovations, he believes he might have had to move eventually, something he has no desire to do.

The beneficiary did consult an occupational therapist about the types of modifications to make, and found the advice very useful. Several informal needs assessment have been done over the past few years by different OT officers visiting from the local hospital, and these, in part, provided the basis for the decisions about the renovations.

Other renovations

In the past three years the beneficiary renovated the kitchen at his own expense (does not recall the cost). Altogether, he has spent approximately $85,000 on home renovations over the past several years, some of this prior to becoming so disabled. He has received no other support for renovations, except some general help from his father who is also experienced in construction work.

Quality of Life

The beneficiary believes that the modifications have improved his overall quality of life significantly (from a score of 4 to 9). His mobility has improved both with respect to moving into/out of his home and inside the home (from scores of 6 to 10). He also believes that the renovations have had no effect on his ability to look after himself and his general physical and mental health at this time, but will as his health deteriorates over time. This assessment had not changed when we spoke with him in the second interview in August.

The responses to the questions about his day-to-day activities and quality of life that were added for the second set of interviews did not alter our understanding of his disabilities or the amount of outside help he receives.

Financial impact and willingness to pay

The beneficiary does no know how long the application for support took because the occupational therapist filled it out and submitted it. Quotations from potential contractors were gotten over a period of two weeks. The beneficiary kept a close eye on the contractor, as one might expect, given his work background. He believes the work was very well done, and he had no problems with the contractor. As might be expected, the age of the house caused some difficulties, which were resolved. By choice, he paid for better fixtures for the bathroom than called for in the contract and does not consider these a part of the renovations supported by CMHC.

The beneficiary would have had to pay for the renovations if the CMHC grant had not been available. Because of the cost, they would have had to be done over time. If he could have gotten a cash grant with no strings attached, he would still have spent it on the same renovations, and would want the same level of support as he was given in the program ($14,000).

He believes that some of the modifications (but not all) will have a positive impact on the home's market value. Those that may not have a positive impact are probably those designed specifically for handicapped individuals.

General opinions about Program

The beneficiary was impressed with how quickly he received approval and the go-ahead. He did not particularly like the attitude of the CMHC representative (note, beneficiaries 01 and 04 were very positive about this same person). The modification he liked best was the bathroom – but he was also pleased with the work overall. He disliked the disruption that went with the renovations, but this was to be expected.

Beneficiary 03
Care giver 03A

Assistance type:	RRAP-D
Assistance amount:	$13,750
Total cost:	$13,750
Urban/rural:	urban
Beneficiary sex:	male
Beneficiary age:	over 65
Beneficiary disability:	stroke, paralysis, amputation, circulatory disorder of unknown origin
Modifications:	battery-run stair lift
Modifications completion:	August 2004
Caregiver:	yes, long-term friend who owns house
Interviews:	Round 1: March; Round 2: August (5 months)

Overview

The beneficiary has had several years of health problems. He rents half the house from a friend who is his primary care giver. According to their arrangement, the he pays all household living expenses, and the owner pays the mortgage and property taxes. The house is a 25 year-old 2-storey semi-detached home in a peaceful neighbourhood in an Ottawa-area suburb.

He is over 65 years old, and has severe mobility problems due to stroke and amputation. He is paralyzed on one side. He suffers from a circulatory disorder of unknown origin which, since the first round of interviews, has been beginning to affect his remaining leg. If this has to be amputated, it will be unlikely he will be able to remain in the home without significant nursing help. The stroke has also affected his memory and possibly the hearing in one ear. He uses a motorized wheelchair all the time (in and out), and stair lifts to go up and down stairs.

His personal income in under $25,000 (household income is under $35,000). He stopped working several years ago because of his disabilities, and will not be able to return to work because of age and his ongoing health problems.

Primary care giver

The beneficiary's primary care giver is a long-time friend with whom he lives. The beneficiary has had help from his friend (who is blind) for many years. The care giver is available in the home on a full-time basis. He helps the beneficiary move from room to room (especially from the bedroom to the bathroom), and getting on the stair lift up stairs (see renovation details, below).

Despite his own disability, the caregiver did not need help in the home, and the renovation (a new chair lift) was making it easier to help the beneficiary. However, during the second interview, we found that he has fallen on the home

stairs and broken his hip. He is currently in an Ottawa care facility and will likely have a long recovery time once he returns home at the end of August. The beneficiary's neighbours and friends have filled the gap for the time being. In addition, someone from Orleans Paramedics comes once or twice a week to help with bathing.

The beneficiary believes that the help his friend gives him is essential to both his independence and his ability to remain in the home, and his friend agrees. This will certainly be tested as it is as yet unclear when or even whether the primary caregiver will be able to return to his caregiving role, especially since it sometimes involves lifting the beneficiary.

The beneficiary also has a housekeeper four mornings a week who does some laundry, takes the household cats to vet appointments, and spends some time shopping and in the garden.

<u>CMHC-funded modifications</u>

The program paid for a new battery-run chair lift to run between the first and second floors. The cost for the lift and installation was $13,750, and was fully paid for by the CMHC program. The work was done in August 2004.

The new chair lift has allowed the beneficiary to get onto the lift level with the floor at the downstairs terminal. However, he still has difficulty going downstairs because the mechanism is higher than the floor at the upstairs terminal, and it is necessary to make left turn to get onto the lift. He needs his friend to help him do this. Unfortunately, there is no way to rectify this problem. Before the addition of the new chair lift, the beneficiary had difficulty getting on the lift both upstairs and down. The new lift is also battery- operated, so that it will still work when the power is out.

Both the beneficiary and his care giver believe that the new chair lift is very important to essential if the beneficiary is to continue to be able to undertake everyday activities, and to remain in the home (scores of 8 and 10, respectively). The beneficiary would not have considered moving, even if the renovation had not been done. During the second interview, the beneficiary told us that he has no intention of leaving his home, but that if he loses his other leg and/or his caregiver can no longer help him, be may be forced to move into institutionalized care.

There was no occupational therapist involved in the beneficiary's decision to have a new chair lift installed, and no needs assessment was done. He and his caregiver (the owner of the home) consulted an expert in chair lift mechanics before purchasing and installing the lift. This was very useful.

<u>Other renovations</u>

In the past three years, $17,700 was spent on modifications to the house: $12,000 to redo the bathroom; $3,400 for a less-expensive stair lift to basement; and $2,300 for a back deck as exit from the back of the house. These modifications were paid for by the beneficiary. The chair lift to the basement (CMHC sponsored/04) replaced an older model that was no longer functional.

Quality of Life

The beneficiary had a leg amputated in the last year. At the time of the first round of interviews, he reported that his health was stable. However, during the second round interview in August he told us that he has been having significant circulatory difficulties with his "good leg" and may have to have this amputated. As noted previously, this would severely jeopardize his ability to remain in the home. Despite this, however, he continues to believe that his overall quality of life has improved as a result of the new chair lift, specifically with respect to getting upstairs, and being able to use the upstairs bath and toilet (a 4 point spread from score 3 to 8). His housemate agrees with this assessment.

The additional questions about his day-to-day activities and quality of life did not themselves add significantly to our previous understanding of his disabilities and the care he receives.

Financial impact and willingness to pay

The beneficiary estimates that it took about three hours to apply for assistance, mostly spend on gathering together the required paperwork. Getting quotations took an additional 2-3 hours. And, working with the contract occupied another 2-3 hours. The work was well done and the contractor performed well.

If the beneficiary had been unable to get support through CMHC, he would have had to pay for the new chair lift himself at a later date. If he had been given a cash grant with no strings attached, he would still have spent it on the same renovations. The beneficiary thought that the minimum he would have accepted in cash would have been $8,250 or 60% of the grant he received.

The beneficiary and his care giver do not believe that the home's market value has increased as a result of the addition of the chair lift.

General opinions about Program

The beneficiary was pleased with how easy it was to apply for the program. The new chair lift is much smoother and less bulky than the one it replaced, and because it is battery-powered it will work even if the electricity is out. Unfortunately, nothing can be done about the upstairs entrance to the chair lift

Beneficiary 04
Care giver 04A

Assistance type:	RRAP-D
Assistance amount:	$3,600
Total cost:	$3,600
Urban/rural:	urban
Beneficiary sex:	male
Beneficiary age:	32
Beneficiary disability:	severe mobility and cognitive problems (Cerebral Palsy, epilepsy and cognitive dysfunction)
Modifications:	bath lift, wheel-in shower, toilet reoriented for wheelchair; all areas of house widened and/or reoriented to deal with wheelchair (inside and outside doorways and hallways)
Modifications completion:	September 2004
Caregiver:	yes, foster parents
Interviews:	Round 1: March; Round 2: August (5 months)

Overview

The beneficiary lives with two other foster children, foster parents and two of their own children in a small home about 45 minutes south of Ottawa toward Montreal. The household is a very active one, without a lot of room to maneuver. Nor does there seem to be sufficient land to have an addition that would help alleviate the space problems. Both parents are in the home full-time. The father left his career as a financial advisor to help his wife foster the three children. The mother comes from a family that also fostered children while she was growing up. Mother and father seem to enjoy their roles as foster parents. When we spoke to them in the second round in August, they were preparing to take all the children – their own and the three foster children – to Niagara Falls for the week.

The beneficiary is a 32 year old male. He is disabled foster child with severe mobility and cognitive problems (Cerebral Palsy-CP, epilepsy, and cognitive disjunction). He needs a wheelchair at all times, and his foster parents use ceiling tracks to lift him from the floor.

The beneficiary's income is under $10,000, while the household income is over $50,000. The beneficiary has never worked because of his disabilities. The beneficiary has been living in this house for 3 years. Before that, he lived in special needs housing for the severely disabled.

The home in which he lives is a small one-story single detached house over 21 years old. There are fish tanks and a dog in the house, which the foster parents believe contribute greatly to the emotional well-being of the children and these or similar pets would need to be part of the household for the children's sake.

During the second round interview, the foster parents reported that there have been no changes in the beneficiary's living conditions, house-mates, or health since we first interviewed them at the end of March.

Primary care givers

The beneficiary's primary care givers are his foster parents who have to be available full-time every day. He is virtually helpless, so the parents have to do everything for him. Without them, he (and the other foster children) could not survive. Both parents are full-time foster parents with no other source of income.

Although the renovations have made it easier for the foster parents to work with the beneficiary, the time they need to spend with their foster son has not lessened.

Additional care giving and support

The foster parents receive additional help from the Ontario Ministry of Children and Family Services (unpaid) and from the Community Care Access Centre, for which they pay and are reimbursed, in part or full depending on the usage/month, by the Children's Aid Society (up to $800-$1000/month). The foster parents pay for additional services when they can afford it. Otherwise, they have to depend on friends and family members. The renovations have not reduced the need for these services, although they do make working with the beneficiary easier and safer for the secondary caregivers.

The secondary care givers provide the foster parents help in the following areas:

- getting the beneficiary in and out of the house, helping him move around the house, and helping with outings;
- preparing meals, general housekeeping, and laundry; and
- toileting and bathing.

CMHC-funded modifications

Modifications were made to accommodate the beneficiary's wheelchair. Specific modifications involved the bathroom (bath lift, wheel-in shower, toilet reoriented for wheel chair); and areas of house widened and/or reoriented (entrance to home, entrance to beneficiary's bedroom, and all internal doorways and hallways). The total cost of the renovations was $3600, which was covered completely by the RRAP-D program. The foster parents did have some additional out-of-pocket expenses for long distance phone calls to their CMHC representative in the Ottawa area. Renovations were completed in September 2004. The other foster children also benefit directly from them.

Although the renovations have made it easier and safer for the beneficiary's foster parents to help him and his foster sisters move in and out of the home and within the home, they have not improved his quality of life in any substantial way. As noted, the beneficiary is completely dependent mentally and physically on his foster parents, and has actually surpassed his life expectancy.

In the second round interview, the foster parents identified an additional threat to the beneficiary's safety and that of the others living in the home. Apparently the beneficiary weighs more than 300 lbs in his wheelchair and the joists in the house are too far apart to provide stable support. As a consequence, the flooring is cracking. To prevent the beneficiary from being cut by the edges of the cracks, the foster parents have put down mats when he is on the floor.

The foster parents have thought of moving to another home to increase their living space, but there are no plans to do so in the immediate or mid-term future. The fact that the renovations have been done would not have materially affected this decision.

The beneficiary's foster parents consulted with an occupational therapist (OT) from the Community Care Access Centre about the renovations. They found the help they received from the OT exceptionally useful (she told them about the RRAP-D program, suggested they apply for it, and suggested what renovations should be made). A formal was also done as a normal aspect of the ongoing evaluations of foster parents and their charges.

Other renovations

The foster parents have spent $3400 on a new entry ramp and deck to the building code in the past three years. $2500 of this amount came from the CAS. The CAS has also helped with other things that make the beneficiary's life and that of his foster parents a bit easier.

Quality of life

This is difficult to assess. The beneficiary is almost completely unaware of an increase or decrease in his quality of life because of the nature of his disabilities. From the perspective of the care givers, however, the beneficiary's mobility in/out of the home and inside the home has increased from a score of 3 to one of 10 – a 7 point range. Responses to the questions added to the second set of interviews did not clarify this issue for Beneficiary 04 and his caregivers.

Financial impact and willingness to pay

The foster parents report that it took nearly 6 months from application for the CMHC representative to come to the house to speak with them, and an additional 2 months for approval. Getting quotations from potential contractors took about 4 hours all together. They thought the work was well done; unfortunately, they lost part of their kitchen floor tiles. These were replaced with others that do not match (an aesthetic problem). The spent 2 weeks, full-time, supervising the contractor.

The beneficiary would not have done the renovations if the grant had not been available. If a cash grant with no strings attached had been available, it would have been spent on the same renovations. The foster parents would have accepted $2,800 or 80% of the support they received in cash.

They do not believe the value of the house has increased because of the renovations.

General opinions about Program

Although the foster parents were very grateful for the financial help, they thought that it took a very long time from application to completed renovations. What they liked most about the modifications was the increased mobility and safety for both the beneficiary and care givers. They disliked the mis-matched kitchen tiles, as noted above.

Beneficiary 05

Assistance type:	RRAP-D and HASI
Assistance amount:	$15,000
Total cost:	$19,000
Urban/rural:	rural
Beneficiary sex:	female
Beneficiary age:	over 65
Beneficiary disability:	arthritis, heard & blood pressure problems
Modifications:	2 new doors/screens, re-casing (entrances); lever-action taps, adapted shower (bathroom); lever-action taps (kitchen); handgrips throughout house, new oil furnace and tank; new ductwork, septic field re-done (house overall)
Modifications completion:	September 2004
Caregiver:	none
Interviews:	Round 1: late March; Round 2: August (4 ½ months)

Overview

The beneficiary lives by herself in an older (21+) single detached 2-story home that she owns. She is more than two hours from her daughter who she asked that we interview for this evaluation instead of herself. Her son lives near the mother, but has had legal problems in the recent past and, as a consequence, has been unable to help his mother very much or to organize the CMHC-sponsored renovations. However, he did some of the electrical work that was required in advance of the renovations.

Apparently the house has been in very bad shape for some time. According to the daughter, her father - who died a little more than a year ago - would not let anyone help them bring it up to code, especially if it meant “taking help” from the government.

The beneficiary is over 65 years of age. She has mobility problems, arthritis, and heart and blood pressure problems. She uses a cane and a walker, but – according to her daughter -- not as often as she should. She still drives the 30 miles to get groceries. She has no primary care giver.

Her income is between $15,001 and $20,000 a year from Old Age Security and Canada Pension. She has not worked for several years and will not return to work because of age and her disabilities.

CMHC-funded modifications

Modifications were made to increase the beneficiary‘s mobility, personal safety and ability to care for herself (e.g., to turn on water faucets); and to help her stay in her own home by making sure that it was up to code. Renovations affected:

- the entrance (2 new doors/screens; re-casing);
- the bathroom (all taps lever-action, shower adapted for easier use);
- the kitchen (all taps lever-action); and
- the house overall (handgrips throughout house where needed; new oil furnace and tank; new ductwork; septic field re-done).

The total cost of the renovations was $19,000, $15,000 of which was covered by the CMHC programs, and the balance for an electrical upgrade ($4,000), which was paid by the beneficiary with the help of her family. The electrical upgrade had to be done before the furnace and some other renovations were done. The beneficiary, with the help of her son and daughter, decided that they would do the electrical upgrade so that CHMC funding could be used to redo the septic field. Renovations were completed in September 2004.

As a result of the renovations, she no longer has trouble getting in and out of the house, taking a bath or turning on faucets. It is the daughter's opinion that the modifications to her mother's home have been essential (score of 9/10) to her continued independence and ability to remain in the home.

Before the renovations, the mother thought of moving to a nursing home in the upper Ottawa Valley because the house was unsafe and nearly impossible to heat. She can now stay in her home. And, this was confirmed when we spoke with her daughter five months later during the second round of interviews. The renovations have not, however, resolved all the difficulties with the home. Some wiring needs to be replaced for the house to be completely up to the building code. During the second interview, we were told that the basement stairs are a potential risk to the beneficiary's safety (score 3/5), and the front entranceway will need to be renovated (stairs are dangerous) in the near future (score 3/5).

The beneficiary and her daughter did not speak with an occupational therapist about the renovations. The daughter is an assessor for CCRA and has some knowledge of the CMHC and similar programs in the federal and provincial governments. This is how she and her mother knew about RRAP-D and HASI. They did consult a furnace expert before doing that aspect of the renovations, and they found his advice very useful.

Other renovations

To date, no other renovations have been done on the home.

Quality of life

The beneficiary's health has changed for the worse over the past year. She has had back surgery and stomach surgery, and will need knee surgery in the near future. And, she has had a serious bout of allergies. Despite this, her daughter believes that her quality of life - especially with respect to her mobility and safety - has improved:

- slightly (mobility inside home; ability to do use kitchen)
- somewhat (her physical and mental health)

- significantly (mobility into/out of home; ability to look after oneself, e.g. bathing)

Responses to the other questions that were added to Round Two interviews did not add significantly to our understanding of the beneficiary's disabilities and renovation needs, with the exception of the obstacles to accessibility and potential risks reported in the second-last paragraph of "CMHC-sponsored renovations," above.

Financial impact and willingness to pay

The beneficiary's daughter filled in the application, which took about an hour. Getting quotations from potential contractors took between 5-6 hours altogether. The daughter reports that her mother worked with the contractor, full time, during the three weeks it took to complete the work. She and her daughter thought the work was well done, and there were no problems with the contractor.

If the beneficiary had not received the CMHC grants, she would not have been able to pay for the renovations unless her daughter had borrowed the money to do the work. If a cash grant with no strings attached had been available, it would have been spent on the same renovations, and they would have accepted the same amount ($15,000 or 100%).

The daughter believes that the value of the home has probably increased because, prior to the work, it was significantly below the building code.

General opinions about Program

The program funding helped to resolve lots of mobility, security and safety issues. The daughter believes that the program should be marketed better so that those in need of the help can learn that it exists. She believes that the most important renovation was the furnace because the home was virtually unlivable in the winter under the previous heating arrangements. She found nothing to dislike about either the program or the renovations.

During Round Two and based on her experience as a CCRA assessor, the daughter spoke about couple of instances where the CMHC representative (maybe a third party) did not deal at-all-well with potential recipients who were clearly in great need. This is not the first time such inconsistencies in the application of the programs or treatment of beneficiaries has been reported. She also emphasized that this had not been her or her mother's experience with the programs.

Beneficiary 06

Assistance type:	HASI
Assistance amount:	$3,500.00
Total cost:	$3,502.11
Urban/rural:	rural
Beneficiary sex:	female
Beneficiary age:	over 65
Beneficiary disability:	severe arthritis, hearing problems
Modifications:	bath seat, grab rails, hand-held showers, rails near toilet (bathroom); replaced overhead light (living room); hand rails (outside and entry to home); moved laundry upstairs from basement, changed plumbing/ventilation, new washer and dryer; fire detectors installed, front door replaced, good locks and bolts, new door trim, non-slip surface to basement steps (house overall).
Modifications completion:	January 2005
Caregiver:	none
Interviews:	Round 1: April; Round 2: August (4 months)

Overview

The beneficiary owns her home, which is a 1-story single detached home over 21 years old. She tries very had to maintain the house and her beloved garden, despite her mobility problems. She lives with one daughter who is mentally challenged. They have three cats which are a factor in her wishing to remain in her home. A second daughter also lives fairly close, so is able to help her with cleaning, gardening, and household bookkeeping, when necessary. At the beneficiary's request, the second daughter was present for the interview.

The beneficiary is over 65 years of age. She has severe arthritis. The beneficiary also has hearing problems. She has borrowed a manual wheelchair for use inside and out (weather permitting), and uses a walker when the wheelchair is not adequate. No changes in her living arrangements, overall health or how she deals with her disabilities were reported in the second interview in early August.

Her income is between $10,000 and $15,000 a year from Old Age Security and Canada Pension. She has not worked for several years and will not return to work because of her age. Taking into account the support payments her mentally challenged receives, the household income is just under $20,000.

CMHC-funded modifications

Modifications were made to increase the beneficiary's mobility and personal safety, and to help her stay in her own home by making sure that it was up to the building code. Her mentally challenged daughter has also benefited from some of these modifications (e.g., non-slip surface on basement stairs because daughter is afraid of falling).

Areas of the home that were modified include:

- the bathroom (bath seat, grab rails, hand-held shower, rails near toilet);
- the living room (replaced light overhead);
- the outside and entry of home: installed better hand-rails);
- the laundry (moved upstairs from basement, changed plumbing/ventilation; a new washer and dryer); and
- the house overall (fire detectors installed; front door replaced with good locks and bolts; new door trim; and non-slip surface was applied to basement steps).

The cost of the renovations was $3,502.11 ($2.11 was paid by the beneficiary). They were completed in January 2005.

The beneficiary still has mobility problems, and it is unlikely that any kind of renovation will deal with these completely. Nevertheless, these problems seemed to have been lessened considerably as a result of the work, and the modifications have been essential (score of 9/10) to the beneficiary's continued independence and ability to remain in the home.

Unfortunately, a front closet was lost because of the renovations, although this could not be helped. And, the renovations did not resolve all the difficulties with respect to the building code. These have to do with the exterior of the house; the March of Dimes in Kingston will be helping with these modifications.

Also, there was a problem with one of the contractors that bid for the work. When he was rejected, he continued to telephone the mother and the daughter who lives outside of the home, to ask for the work. They felt harassed.

Before the renovations, the mother wanted to buy a 1-story house so that everything could be on one floor, even though this would not probably have been possible for financial reasons. The beneficiary now wishes to remain in her home because the renovations have made a significant difference.

The beneficiary discussed the renovations with an occupational therapist -- who works for the Senior Assisted Services in the Kingston area. She found her advice very useful.

Other renovations

To date, no other renovations have been done on the home. During the second interview, however, she indicated that repairs are needed on the outside of the house for code and safety reasons (risk scale 3/5).

Quality of life

The beneficiary's health has been stable over the past year. Her quality of life has improved as a result of the renovations, especially with respect to her mobility and ability to care for herself. For example:

- Mobility into/out of home (4 point improvement);
- Mobility inside home (6 point improvement);
- Ability to look after herself (5 point improvement);
- Physical and mental health (6 point improvement); and
- Overall quality of life (5 point improvement)

Based on the second round of interviews, this assessment has remained essentially unchanged since the first round of interviews in April. The questions added in the second round did not provide more information about the beneficiary's condition and her need for help than we had learned in the first round.

Financial impact and willingness to pay

The beneficiary's daughter (the one who does not live with her mother) filled in the application, which took 3-4 hours. Getting quotations from potential contractors took about 5 ½ hours. The beneficiary and the daughters spent very little time with the contractor who they believed was very trustworthy and would do a good job (and he did).

If the beneficiary had not received the HASI grant, she would not have been able to pay for the renovations unless a family member had borrowed the money to do the work. If a cash grant with no strings attached had been available, it would have been spent on the same renovations, and they would have accepted the same amount ($3500 or 100%).

The beneficiary does not know whether there was an impact on the market value of the home as a result of the modifications.

General opinions about Program

Mother and the daughter who helped her get the grant found the CMHC people very helpful (Erin and Sandra). The renovations have made her and her mentally challenged daughter's lives easier and safer. The daughter, who does not live with the beneficiary, finds she is worrying about her mother and sister far less than before. The episode with the rejected contractor was worrisome.

Beneficiary 07

Assistance type:	HASI
Assistance amount:	$3,500
Total cost:	$3,700
Urban/rural:	urban
Beneficiary sex:	male
Beneficiary age:	over 65
Beneficiary disability:	arthritis, losing feeling in lower legs and feet
Modifications:	movement activated light installed; railings into home added; front walk redone to accommodate walker
Modifications completion:	September 2004
Caregiver:	none
Interviews:	Round 1: April; Round 2: August (4 months)

Overview

The beneficiary lives in a 2-storey 21+ year old semi-detached home in a suburb east of Ottawa. He lives alone, but his daughter lives about a block away. The beneficiary's great joy in life is being able to visit his friends and socialize; this has become easier because of the renovations. Unfortunately, he can no longer go ice fishing with his companions, something he mentioned in the interview that he really misses. [The beneficiary asked that we interview him with his daughter present as he is hard of hearing, which we did.]

The beneficiary is over 65 years of age. He has mobility problems due to arthritis, and is losing feeling in his lower legs and feet. He uses a walker except for short distances. He also has access to a cane if he needs it.

His income is between $20,001 and $25,000 a year from Old Age Security, Canada Pension, a private pension, and RSPs. He has not worked for several years and will not return to work because of his age and disability.

CMHC-funded modifications

Modifications were made to increase the beneficiary's mobility coming in and out of the house. A movement-activated light was installed outside near the front door. Railings into the home were added, and the front walk redone to accommodate the walker.

The cost of the renovations was $3,700; the HASI program paid for $3500 of this, and the beneficiary paid the $200 balance. This amount covered the costs associated with living expenses while the renovations were being completed. There were also out-of-pocket expenses (telephone, photocopying, mailing). Work was completed in September 2004.

The beneficiary thought the contractor did a very good job. There was, however, a considerable delay between coming to an agreement with the contractor, and for the work to begin because it was the busy time of year for renovations.

The beneficiary believes that the modifications were essential to his ability to his continued independence and ability to remain in his home (score of 8 and 10, respectively). Because of the changes in the entryway, he is better able to live independently, and get out of the house to see his friends.

Unfortunately, he still has mobility problems in the bathroom (tub, shower) which will need to be addressed. In addition, there was an "unintended consequence" associated with the renovation – the driveway is now below sidewalk grade. During the second round of interviews we learned that the beneficiary is now paying for this to be fixed.

The beneficiary has absolutely no intention of leaving his home – this sentiment had not changed by the time of the second interview in August.

The beneficiary's daughter is an occupational therapist, which was very useful because she knew about the CMHC programs and could do a "quick and dirty" needs assessment to help her father decide what changes should be made.

Other renovations

This beneficiary has done other renovations in the past three years, although he does not recall the costs involved. He paid for replacement windows that are easier to open. Family members helped him put railings on the front stairway; he paid for the materials. He will need to do something about the bathroom to make it more accessible for bathing in the near future, possibly a walk-in shower/tub or other renovation (risk score 4/5, second interview). No other risks or access issues were identified in the second interview.

Quality of life

The beneficiary reports that he has lost physical strength over the past year. He does believe, however, that his quality of life has improved as a result of the renovations. For example:

- Mobility into/out of home (6 point improvement);
- Physical and mental health (4 point improvement); and
- Overall quality of life (7point improvement)

His assessment about this did not change from the first to the second interview. No more information was gained about his overall situation from the questions about his day-to-day activities that were added to the second round of interview questions, although he reiterated the need to deal with the bathroom-related issues for reasons of access and safety.

Financial impact and willingness to pay

The beneficiary's daughter filled in the application, which took 5-6 hours. Getting quotations from potential contractors took about 3 hours. He estimates he spent about 4 hours with the contractor when he was doing the work.

If the beneficiary had not received the HASI grant, he would have had the work done and paid for it himself, over time. If a cash grant with no strings attached had been available, it would have been spent on the same renovations, and they would have accepted the same amount ($3500 or 100%).

The beneficiary does not know whether the renovations have had an impact on the market value of the home.

General opinions about Program

The beneficiary found that the HASI program was very helpful and efficient. Unfortunately, it did not cover the whole amount that will be needed to bring the driveway to the same level as the sidewalk. What he liked most was his increased ability to get in and out of the house by himself.

Beneficiary A8

Assistance type:	HASI
Assistance amount:	$3500
Total cost:	$3500
Urban/rural:	Urban
Beneficiary sex:	Female
Beneficiary age:	83
Beneficiary disability:	Sight, hearing, some mobility limitations
Modifications:	Kitchen and bathroom fixtures
Modifications completion:	Mid-February 2005
Caregiver:	None
Interviews:	Round 1: May; Round 2: August (3 months)

Overview:

The beneficiary lives alone in a small immaculately kept bungalow in an inner suburb. She is strongly attached to her house, partly because she nursed her husband there. He died in 1989 with Alzheimer's disease. The HASI contribution covered minor modifications to fixtures in kitchen and bathroom. Her main problem, however, was cold from inadequate doors, windows and insulation. She enquired about a RRAP-D contribution to fix this problem and was told that she would have to wait for up to two years. Therefore she borrowed from her bank to do the most urgent components of the winterizing needed. The loan requires that she pay $500 per month, which is a hardship, as it is a substantial part of her pension.

The beneficiary is 83 years of age. She has mobility difficulties due to arthritis and a worsening heart condition. She also has some hearing difficulties and severe eyesight problems. The beneficiary uses a walker most of the time. Nevertheless we observed that she is alert and very competent in keeping her house in good condition.

Her personal income (and household income) is between $10,001 - $15,000 a year from Canada Pension and Old Age Security. Because of age, she will not return to work.

CMHC-funded modifications

The modifications affected the exit/entry into the home (a peephole; intercom); the kitchen (lever taps, cupboard and shelves lowered); the bathroom (lever taps; hand-held shower); the bedroom (new handle on window); and the house overall (fire extinguisher). The renovations cost $3,500; all of which was paid for by the HASI grant. The renovations were completed in mid-February 2005. Although the beneficiary's general mobility has improved, she is still having some mobility problems which may be exacerbated because of her vision difficulties. Her security issues were, in the main, resolved; however, she would like to have a

safety calling service – something that had not yet been rectified when we spoke with her in the second round of interviews at the beginning of August.

She believes that the modifications have been essential to her independence and ability to remain in the home (score of 10/10). At the same time, she would not have considered moving to other accommodations, even if the renovations had not been done (this continues to be the case, Round Two). Her attachment to her home is very strong. The beneficiary had advice from her physician who told her about the CMHC programs and made some general suggestions as to the types of renovations that might be suitable. She found this very useful. No formal needs assessment was done, however.

Quality of Life

The beneficiary believes that the modifications have improved her quality of life. She reports that her mobility has improved from a score of 2 to 5 for moving in and out of the home and within the home. She is better able to look after herself (improvement of 5 points), and do daily activities (improvement of 4 points). She also believes that, as a consequence of the renovations, her general mental and physical health has improved by 4 points, and her overall quality of life by 4 points. During the second round of interview, she indicated that she was still quite thrilled with the renovations and that her earlier assessment of improvements to her quality of life remains essentially the same.

With the possible exception that her sight difficulties may be exacerbating her mobility problems, we gained no additional information about the beneficiary's health or needs from the questions that were added to the second round of interviews.

Financial impact and willingness to pay

The beneficiary estimates that applying for HASI assistance was done over a period of 2 days. Quotations from more than one potential contractor were not sought because the beneficiary's daughter had previously had a good experience with a particular contractor, who was used by the beneficiary. The work done was excellent and within budget. The beneficiary would not have been able to afford the renovations without the CMHC program and, so, would have needed the entire amount to do the renovation. If she could have gotten a cash grant with no strings attached, she would still have spent it on the same renovations. The beneficiary believes that the modifications have had no impact on the home's market value.

General opinions about Program

The beneficiary is pleased that the HASI program is available. Her favourite renovation was the bathroom. She found nothing negative about the program or the modifications.

Beneficiary A-9
Care giver A-9a

Assistance type:	HASI
Assistance amount:	$3500
Total cost:	About $4700 (including over-run not yet paid)
Urban/rural:	Rural
Beneficiary sex:	Male
Beneficiary age:	65+
Beneficiary disability:	Kidney and heart problems affecting mobility
Modifications:	Railings, rubber steps, door to bedroom balcony
Modifications completion:	August-Sept. 2004
Caregiver:	Yes (spouse)
Interviews:	Round 1: May; Round 2: August

Overview:

The beneficiary lives with his wife and granddaughter in two-story + basement house a small rural town. Open steps to the front door and to the second floor inside the house were a safety hazard to him, given his mobility and balance problems. The replacement of sliding doors to the main bedroom balcony has greatly improved what was a very cold room.

However the renovation has not been an entirely happy experience. He found it impossible to get three quotations for the work because of the remoteness of his location. The contractor was inexperienced, took a long time to do the work and went substantially over budget. Some aspects of the work are observably sub-standard. The beneficiary has paid the contractor up to the HASI grant amount and is worried whether to pay more or not.

His personal income ranges between $20,001 and $25,000 a year, and the household income is between $30,000 and $35,000 per year. His income comes from various pensions. He is unable to return to work because of his age and his disability.

Primary caregiver

The beneficiary's primary care giver is his wife, who needs to help him dress on days that he is retaining a large amount of water because of kidney problems. His wife also benefits from the CMHC-supported renovations because of mobility problems due to an injured arm.

During the second round interview, we found that there have been no substantive changes in the beneficiary's living situation since May. His wife still provides ongoing support at the same type and level as reported in the first interview. Unfortunately, he has yet to be called up for a kidney transplant which could go a long way to relieving his health problems if his

heart and circulation have not been damaged too much by the progressive kidney failure.

CMHC-funded modifications

The renovations were done to increase the beneficiary's mobility and safety in the home. Modifications affected the entry/exit (railings and rubber on the front steps to prevent sliding); inside stairways (railings), and a second entry (replaced sliding door to prevent freeze-up).

The renovations improved the beneficiary's general mobility and safety, but he expects to continue to have mobility and safety issues because of his heart and kidney conditions. The beneficiary believes that the modifications have helped him remain independent (absolutely essential; rating 10/10) and in his own home (essential; rating 9/10). If he had not been able to do the renovations, he believes he might have had to move to a single story home, something he had no desire to do. We observed that the steep steps to the front door and to the upstairs are likely to become an obstacle to his mobility in the near future, and he did note this in the second interview. Railings have made the stairs safer but will not solve the medium-term problem of decreasing mobility.

The beneficiary did not consult any professional or specialist about the required modifications.

Other renovations

In the past three years the beneficiary has had no other renovations done.

Quality of Life

The beneficiary believes that the modifications have improved his overall quality of life significantly (from a score of 3 to 8). His mobility has improved slightly, both with respect to moving into/out of his home and inside the home (from scores of 3 to 5). He also believes that the renovations have increased his ability to do daily activities and look after himself (4 point improvement). He also believes that his general physical and mental health and overall quality of life have improved by 5 points.

The beneficiary identified the need to deal with the steps going outside and within the home as a source of risk to his safety in the second round of interviews (score 4/5). Otherwise, we did not gain additional insights into his condition and his need for help from the responses to the questions added to the second round questionnaire.

Financial impact and willingness to pay

The beneficiary believes the application for support took between 4 and 5 hours to complete. Quotations from potential contractors were sought over a period of three months. The beneficiary kept a close eye on the contractor; he had extensive building experience when he was younger. In addition to the

considerable over-run, the beneficiary had some out-of-pocket expenses (travel costs, photocopying, mailing). The beneficiary would have had to pay for the renovations if the CMHC grant had not been available. Because of the cost, they would have had to be done over time. If he could have gotten a cash grant with no strings attached, he would still have spent it on the same renovations. He believes that some of the modifications will have a positive impact on the home's market value.

General opinions about Program

The beneficiary was pleased that the program is available, and that it gave him the freedom to choose the renovations that he needed most. He liked the replaced door and railings, and thought that they were aesthetically nice. He could think of nothing negative about either the program or the renovations.

Beneficiary A-10

Assistance type:	RRAP-D
Assistance amount:	$29,000
Total cost:	$34,000
Urban/rural:	Urban
Beneficiary sex:	Female
Beneficiary age:	45-54
Beneficiary disability:	Arthritis, sight and hearing difficulties, mobility
Modifications:	Extensive renovations to meet safety/health code
Modifications completion:	October 2004
Caregiver:	None
Interviews:	Round 1: April; Round 2: August (4 months)

Overview:

The beneficiary has mobility problems due to severe arthritis. She is a participant in a long-term study into arthritis at the medical school in a local university. She also has sight and hearing difficulties that are not directly affected by the renovations. She uses a cane and a walker every day, but not all day. Her personal income (and household income) ranges between $15,001 and $20,000 a year. Her income comes from the provincial disability pension. She is unable to return to work because of her disability.

From the second round interview, we learned that she has recently had a treatment for one knee that was expected to make her more mobile – which it did. However, the physician giving her the treatment made an error by not freezing the knee before inserting the needle and, as a consequence, has done nerve damage. The beneficiary is now reluctant to have the other knee treated for fear of the same thing happening. As a consequence, she is under constant pain in the affected leg.

The beneficiary owns a semi-detached single story home (with basement) which is over 21 years old. She has no caregiver, and her son and granddaughter live with her. Both of them are disabled as well. Her son is schizophrenic and her 7-year old granddaughter has ADHD. She is her granddaughter's legal guardian. Both son and granddaughter benefit from the CMHC-supported renovations which have made the home more livable, safer, and more organized.

CMHC-funded modifications

The renovations were done to deal with code issues, make the home better functionally, and to increase the beneficiary's mobility and safety in the home. Modifications affected:

- the entry/exit (all exterior doors replaced, screen doors and locks added);
- the bathroom (raised toilet; replaced tub with stand-in shower);

- the kitchen (all kitchen-related stuff in one space; slide out drawers; counters & cupboards lowered for easier reach);
- created office out of hall closet with easy-access storage; and
- and the house overall (replaced all floors which were buckling, including base floors; replaced all windows; replaced part of wall which was rotten to support replacement window)

However, since her condition is a progressive one, she does not expect that renovations of any kind can completely deal with the difficulties she has in her home. The beneficiary believes that the modifications have helped her remain independent and in her home (absolutely essential: rating 10/10). She would not have moved, even it she had not been able to do the renovations (this has not changed – Round 2). The beneficiary spoke to an occupational therapist about the possibility of having renovations, but the initiative came from the beneficiary who asked the OT what she thought of her plans. No formal needs assessment was done.

Other renovations

In the past three years the beneficiary has spent approximately $5500 on her home. The renovations included: a replaced furnace, a fence, sidewalk replacement/widening and leveling; installation of window well; putting a third bedroom in the basement; and replacing a built-in stove top. The beneficiary paid for these renovations from savings, with no help of any sort from friends or relatives.

As noted in the first interview, the beneficiary would like to install a new front porch to replace a steep and dangerous set of steps. She reiterated this and added that the back entrance also needs work for the same reason in round two (level of risk; access difficulties - 4/5).

Quality of Life

The beneficiary believes that the modifications have improved her overall quality of life significantly (5 point improvement). Her mobility in/out of the home has improved by 4 points, and her mobility inside the home by 6 points. Ability to do daily activities and to look after herself have improved by 6 points because of the renovations. Finally, her overall health has improved slightly because of the renovations (mental, 1 point; physical 2 points improvement). Her assessment remained essentially the same for the second round interview – despite the problems with her physician which have caused her ongoing pain (see above).

The questions added to the second round questionnaire did not add information about her disabilities and other help she may need.

Financial impact and willingness to pay

The beneficiary believes the application for support took an hour to complete. Quotations from potential contractors were obtained over several weeks. The beneficiary spent a lot of time with the contractors prior to the start of the renovations to make sure that they understood exactly what was expected of

them. She also checked on progress at least once a day. She found that the renovations were well done. She spent time coordinating the different contractors and resolving problems between them (e.g., one contractor plastered over areas the electrical contractor had to get access to). She also had some small out-of-pocket expenses (travel costs, photocopying, mailing, and food for staying with friends during bathroom and kitchen renovations).

The beneficiary could not have paid for the renovations herself. If she could have gotten a cash grant with no strings attached, she would have spent it on the same renovations. Given the option she would not have chosen a smaller cash grant. She believes that some of the modifications will have a positive impact on the home's market value.

General opinions about Program

The beneficiary liked most the difference the renovations made for her, her son and granddaughter in living in the home. She reports that it greatly improved the quality of life for all of them. She did find it difficult to gather all the information required for the submission to CMHC, but this was a result of lack of organization of her files, a problem that has been rectified by the creation of an office (covered by the CMHC contribution). She did not like the disruption caused by the renovations but believes it was unavoidable.

Beneficiary A-11

Assistance type:	RRAP-D
Assistance amount:	$28,000
Total cost:	$38,000
Urban/rural:	Rural
Beneficiary sex:	Female
Beneficiary age:	55-64
Beneficiary disability:	Arthritis. Husband uses wheelchair full time.
Modifications:	Ramp, extensive bathroom, doors, windows, etc.
Modifications completion:	September 2004
Caregiver:	None
Interviews:	Round 1: May; Round 2: August (3 months)

Overview

The beneficiary lives in a bungalow in a rural area. The work on the bungalow was extensive, including a large well-built ramp to the front door and replacement of doors (widening) and windows. The renovations are a major benefit to the beneficiary and her husband. However they took unreasonably long to do (the couple lived in a trailer/camper for three months while the work proceeded) and there was a lot of roughness left at the end of the work, particularly in regard to stucco siding that was damaged by replacing exterior doors and windows. Screen doors were not replaced. The couple now feel that the work had not been carefully enough specified in writing as the basis of quotes from the contractor; and that the contractor did not provide the government good value for money ("taken for a ride").

If anything, this feeling has increased between the first set of interviews and the second round in August. After seeing the results of the renovations, the CMHC representative has recommended that they send a complaint to the contractor with a list of deficiencies. Whether the representative can do anything to help rectify the situation is unclear.

In the second interview, the beneficiary reported that her overall health has not changed, although she feels that she has slowed down much more than she expected in a short time. She and husband still intend to remain in their home, despite these difficulties.

Her personal income is under $10,000, and the household income is between $10,000 - $20,000. Her income comes from a provincial disability program. She is unable to return to work because of her disability.

The beneficiary and her husband own a split-level home (with basement) which is over 21 years old. She has no caregiver. Both she and her husband are disabled. Her husband has less mobility than her. He has rheumatoid arthritis and lupus, and uses a wheelchair full time. He has benefited from the renovations because they have increased his mobility. Both also

benefited from the resolution of health and safety problems (housing code issues).

CMHC-funded modifications

The renovations were done to deal with code issues, and to increase the beneficiary's mobility and general comfort in the home. Modifications affected:

- the entry/exit (outdoor ramp; entry railings; new front & back doors; entry widened);
- the bathroom (walk-in shower; raised toilet; grab bars);
- the kitchen (safety plugs; bars at entry to kitchen);
- bedroom (moved onto main floor from 2nd ½ of split level); and
- and the house overall (internal doors widened; replaced house siding; new furnace; new plumbing; electric to code; safety plugs throughout; dealt with water problem in basement – not sure how)

The CMHC-sponsored renovations cost $38,000. The program covered $28,000 of the amount, and the beneficiary's children paid the balance of $10,000. She and her husband had out-of pocket telephone costs which were not insignificant ($800) and which her children also helped them pay. This was primarily due to the fact that they had to use a cell phone to speak with doctors and keep contact with their family when they were living in the trailer.

Prior to the renovations, the beneficiary had difficulties entering and exiting the home, moving from one room to another, using the bathroom (toilet and bath), and going up and down stairs. Although she is still having the same problems, she believes that the renovations have made these activities far less difficult, and have resolved her problems with the house, at least for now (confirmed in second interview).

The beneficiary discussed the renovations with an occupational therapist who told her about the CMHC programs and helped her decide what should be done. She found this very useful. No needs assessment was done.

Other renovations

The beneficiary and her husband have done no other renovations in the past three years. They have had financial help and non-financial help from their children (who covered the $10,000 difference between CMHC funding and the total costs of the renovations).

In the second interview in August, the beneficiary reported that she believes that the mildew caused by the poor quality of the renovations is a risk to her health and safety (risk score 4/5).

Quality of Life

The beneficiary believes that the modifications have improved her overall quality of life significantly (4 point improvement). Her mobility in/out of the home has improved by 7 points, and her mobility inside the home by 2 points. Ability to do

daily activities has not changed, and her ability to look after herself has improved by 4 points. She also reports that the renovations were very important for helping her maintain her independence and remain in her home (8/10). Finally, she believes that her overall physical and mental health has not changed because of the renovations.

During the second interview in August, we found that she now believes that her ability to look after herself has increased by another 2 points (from 1 to 5, to 7 in August). Overall, her quality of life has dropped from 5 (first interview) to 4 (second interview). No more information about the beneficiary's disabilities or need for help was gained from the questions added to the second round questionnaire.

Financial impact and willingness to pay

The beneficiary believes the application for support took 2-3 hours to complete. Quotations from potential contractors were gotten over 3-month period. The beneficiary spent full time with the contractors during the renovations.

The beneficiary would not have paid for the renovations if the CMHC contribution had not been available for financial reasons. If she could have gotten a cash grant with no strings attached, she would still have spent it on the same renovations, and would want the same level of support as she was given in the program ($28,000).

She believes that the modifications will have a positive impact on the home's market value, although given the roughness of some of the work, the impact may be less than expected.

General opinions about Program

The beneficiary appreciated the program support. Her favorite renovations were the bathroom and the entry ramp. She found the disruption and the need to move to their trailer difficult to deal with, and found that not all renovation damage was repaired.

Beneficiary A-12

Assistance type:	RRAP-D
Assistance amount:	$5600
Total cost:	$5600
Urban/rural:	Urban
Beneficiary sex:	Female
Beneficiary age:	55-64
Beneficiary disability:	Heat sensitivity, mobility limitations
Modifications:	Install two air conditioners
Modifications completion:	November 2004
Caregiver:	None
Interviews:	Round 1; May; Round 2: Mid-August (3 ½ months) Note, this beneficiary was difficult to contact (several telephone calls were needed); they were visiting friends during the early part of the round two interview period

<u>Overview</u>

The beneficiary lives in a pleasant and well-maintained mobile home park in an inner suburb. She is happy with the air conditioners (although the compressor had to be moved once to the opposite side of the home because of noise rules in the mobile home park). However she complains that the roof of her mobile home leaks and CMHC has not agreed to contribute to major roof repairs. (An attached room has settled somewhat opening a crack in the roof abutments.)

The beneficiary is a female between 55-64 years old. She has mobility problems due to poor joints (knees, ankles), and is prone to sun/heat stroke (which is the reason for the current renovations. Because of her mobility problems, she has been using a wheelchair as she recovers from a recent surgery. She has no caregiver, although her husband would fulfil the role if needed (as she would for him).

Her personal income is between $10,000 and $15,000, and the household income is between $20,000 - $30,000. Her income comes from a CPP-disability, and a local authority pension. She is unable to return to work because of her disability.

The beneficiary and her husband have two birds, and would not want to have to live somewhere where they couldn't have them.

<u>CMHC-funded modifications</u>

The renovations were done to deal with the beneficiary's problems with heat. The CMHC-sponsored renovations cost $5600, and were paid for by the program. She and her husband had no out-of-pocket expenses.

Prior to the renovations, the beneficiary had difficulties dealing with summer heat, which resulted in heat/sun stroke. During the round two interview, she reported that she has been able to function much better in her home, sleep better and be more mentally alert and physically capable in the heat since the air conditioner has been working.

The current renovations have not resolved all the beneficiary's difficulties with the home. Their roof leaks and skylights suffer from condensation.

The beneficiary consulted her physician in his office. She found very useful. However, no needs assessment was done and no one else visited to give advice.

The beneficiary reports that the work was well done, and that the air conditioning will be a big factor in her being able to remain independent and in her home.

Other renovations

The beneficiary and her husband have done no other renovations than those noted above in the past three years. They have had no financial help from friends or family members; friends and family will help with minor renovations, however.

Quality of Life

The beneficiary reports that her health has changed significantly during the past year because of surgeries; she is now much better and her health is stable. When we first spoke with her, the air conditioners had not yet been tested in a mid-summer. At that time, she indicated an overall score of

- 2 with respect to doing usual daily activities;
- 3 - mental ad physical health;
- 3 overall quality of life a score of 3.

In the second round interview, the Beneficiary reported that her overall quality of life has improved significantly with the air conditioning (from 3 to 9), and that she is now able to do daily activities with much more energy (from 2 to 8). She rates the importance of the air conditioning for helping her maintain her independence and remain in the home as very high (9/10).

Financial impact and willingness to pay

The beneficiary believes the application for support took 7-8 hours over a few days to complete. Quotations from potential contractors were obtained over a 7 month period because they had to get two separate sets of quotations (one set for central air – the original plan, which they learned would not work in a mobile home; and the second set for the window units). The beneficiary spent full time with the contractors during the renovations.

The beneficiary would not have paid for the renovations if the CMHC grant had not been available for financial reasons. If she could have gotten a cash grant with no strings attached, she would still have spent it on the same renovations, and would not have accepted a smaller cash grant instead.

She believes that the modifications will have a positive impact on the home's market value.

General opinions about Program

The beneficiary was pleased that they have been accepted to receive help from the program. However, she and her husband do not like the fact they had to get two different sets of estimates and say that they were given poor advice by program representatives. They also are still upset that their roof was not repaired at the same time, as the damage water is causing is getting progressively worse. (We do not know what was actually discussed with CMHC in regard to the leaks problem.)

Beneficiary A-13
Care giver A-13a

Assistance type:	RRAP-D and HASI
Assistance amount:	$25,000
Total cost:	$25,000
Urban/rural:	Urban
Beneficiary sex:	Female
Beneficiary age:	65+ (Son 48)
Beneficiary disability:	Multiple, including amputation of both legs
Modifications:	Extensive renovations to all parts of house
Modifications completion:	November 2004
Caregiver:	Yes. Son.
Interviews:	Round 1: May; Round 2: August (4 months)

Overview:

The beneficiary is a female over 65 years of age, who lives with her unemployed son who is her care giver and who is also disabled (heart problems). The house, even after extensive renovation, gives a strong impression of being in poor condition. Both respondents tended to complain about the various government and social agencies assisting them.

The beneficiary has mobility difficulties due to arthritis, the amputation of both her legs, and open sores on her hips. She also has had a colonoscopy, so does not use a toilet (not related to CMHC funding). She uses a wheel chair all the time, both inside and out. Her personal income ranges between $20,001-$25,000 from Canada pension, OAS, and provincial government pension. The son earns under $10,000 through a provincial disability fund. Household income is $25,000-$35,000.

The beneficiary has a dog and a cat, she would not want to lose her animals by having to move.

There had no changes in the health or living status or opinions of this beneficiary when we spoke with her in the second round of interviews.

Primary care giver

As noted, the son (age 48) lives with the beneficiary and is her primary care giver. He helps her get around, get into bed, get dressed, prepare meals, and with general housekeeping and yard work. He is available every day and helps her on the average of 2-3 hours/day. Both mother and son judge his help to be important for helping her maintain her independence and stay in her own home, although they do not believe that the need for his help has lessened after the renovations.

The son has himself benefited from the renovations in terms of increased mobility, and says that they have enabled him to help his mother better. Nevertheless, both mother and son report that they do not expect the renovations to result in an improvement in their conditions.

No changes in caregiver status were reported in the second round interview in August.

Secondary care givers

The beneficiary also receives help from the Edmonton Home Care Services, which consists of nursing (3 times/week), and homemaker services (2 times/week - bathing). This is a free service which she judges is important for maintaining her independence, and essential for remaining in her own home. She does not believe that the renovations will affect the nature or frequency of their help (first round), a belief that was confirmed in the second round interview.

CMHC-funded modifications

The renovations were done to improve the beneficiary's mobility, safety and security, and to deal with housing code issues (the dwelling was in very poor condition). Modifications affected:

- the entry/exit (ramp repaired);
- the bathroom and kitchen (counters and sinks lowered);
- and the house overall (new plumbing, new hot water tank, new furnace, new roof, house rewired and additional plugs throughout, all windows replaced except basement where break-away frames were added).

The beneficiary believes that the renovations have resolved most problems that renovations could resolve (mobility, safety, and security, code issues), but that her health and general situation is such that nothing can really help. Her responses were not fully consistent, since she also stated that the renovations have been essential to her independence and ability to remain in the home (score of 10/10). At the same time, she would not have considered moving to other accommodations, even if the renovations had not been done. She has not changed her opinion about moving (round two).

The beneficiary had advice from her physician about what changes should be made in the home. She found his help valuable. No needs assessment was

done and no one other than a CMHC representative came to the home to confirm that the renovations were needed.

Other renovations

The beneficiary has had no other renovations done on the house. Family members have not helped the beneficiary financially, but are available to help on a volunteer basis.

Quality of Life

The beneficiary's health has not changed in the past year and is currently stable. She also believes her quality of life has improved as a consequence of the CMHC funding she has received. However, lowering the sinks in the bathroom and kitchen did not really solve her problems with being able to reach the sinks – and believes that nothing can be done to deal with her inability to reach the faucets in her wheelchair. Also, she states that the new window in her bedroom is actually worse than the one it replaced because she is unable to open it.

The beneficiary reports that there have been no improvements in her mobility, ability to do daily activities, look after herself, her mental and physical health, or her overall quality of life resulting from the renovations. This seems to contradict other opinions that she voiced in the interview. It appears that she was answering questions 79-84 in a poor frame of mind because of the severity and progression of her disabilities and her feelings that her overall quality of life is really quite poor – irrespective of any possible renovations. With the exception of identifying an obstacle to accessibility (reaching into fridge, other high placed; 3/5), we gained no additional information in the second interview about her condition, the help she receives from her caregivers (primary, secondary), or about what help she might need in the future.

Financial impact and willingness to pay

The beneficiary judged that the application for funding took about a month, and getting estimates took over 2 months. She spent full time with the contractors. She reports that she had no out-of-pocket costs.

She reports problems with two contractors. She believes that the electrical contractor was incompetent, rude and reluctant to do the work requested; and the roofers destroyed the soffits and refused to replace them. She and her son do not appear even now to understand that roof shinglers do not normally do soffit, facia and gutter work, unless specifically provided for in the contract.

The beneficiary would not have been able to afford the renovations without the CMHC program. If she could have gotten a cash grant with no strings attached, she states that she would have spent it on the same renovations, so long as there was not a health emergency at the same time.

The beneficiary believes the home's value has increased with the renovations.

General opinions about Program

The beneficiary was pleased that the program is there. She found it difficult getting estimates. She liked the new roof, hot water tank, and furnace the best. However, she disliked the mess and disruptions caused by the renovation process.

Beneficiary A-14

Assistance type:	RRAP-D and HASI
Assistance amount:	$21,000
Total cost:	$21,000
Urban/rural:	urban
Beneficiary sex:	Female
Beneficiary age:	88
Beneficiary disability:	Some mobility, sight and hearing limitations
Modifications:	Bars, bath lift, laundry to main floor, windows
Modifications completion:	October 2004
Caregiver:	none
Interviews:	Round 1: May; Round 3: mid-August (3 ½ months) Note: this beneficiary was difficult to contact for the second round of interviews (about 10 tries). Their phone had been out-of-order, on and off, apparently because of moisture in the lines.

Overview

The beneficiary is a female, 88 years of age. She has mobility difficulties due to hip and back problems. She walks using a cane or walker as needed, but very bent. Her house is a suburban bungalow.

Her personal income (and household income) ranges between $15,001 - $20,000 a year from Canada pension and Old Age Security. She does not work because of her age.

The beneficiary has a dog; she would not want to lose him by having to move.

CMHC-funded modifications

The renovations were done to improve the conditions for the beneficiary's mobility, safety and security, and to deal with housing safety (code) issues. Modifications affected:

- the entry/exit (sidewalk repaired; all exterior doors replaced, screen doors and locks added; outdoor railings);
- the laundry (moved to the bedroom, including related plumbing, so beneficiary does not have to go up and down basement stairs);
- and the house overall (replaced all windows with proper locks; moved freezer from basement; electrical upgrade)

The beneficiary believes that the renovations have resolved the mobility, safety and code problems identified in her home. She believes the renovations have been essential to her independence and to her ability to remain in the home (score of 10/10). At the same time, she would not have considered moving to other accommodations, even if the renovations had not been done. Her family

had tried to convince her to move into a senior's complex prior to the renovations; they now believe that she can safely remain in her own home.

The beneficiary did not have out-of-family expert advice about the renovations. Her daughter used to own a renovations company that did work for the City of Calgary similar to that done for the beneficiary. Consequently, the daughter had knowledge of what would be required and had contacts in the building industry. [At the request of the beneficiary, her daughter was present during the interview and was knowledgeable about the renovations; her opinions are indicated in this interview summary.]

Other renovations

The beneficiary also had work done during the previous three years, to a total of approximately $6,000 supported totally by an Alberta program for seniors. Renovations included work on the bathroom and a new washer and dryer. Family members have not helped the beneficiary financially, but have been available to help with small changes on a volunteer basis.

Quality of Life

The beneficiary's health has not changed in the past year and is currently stable. She also believes her quality of life has improved as a consequence of the CMHC funding she has received. She is especially pleased that she no longer has to go up and down the basement stairs because the laundry and freezer have been moved to the main floor. She reports that her mobility in and out of the home has improved by 6 points, and 4 points for mobility inside the home. There has been no change with respect to her ability to do usual daily activities, although her ability to look after herself has improved by 4 points. Her general mental and physical health and overall quality of life have improved by 5 points. She reports no problems with the renovations.

In the second interview in August, the beneficiary reported no changes in the status of her health or her need for help (additional questions, Round 2).

Financial impact and willingness to pay

The beneficiary's daughter prepared the application for funding (about 20 hours with research into various programs), and obtained the estimates from contractors (over 3 months). The daughter and/or the beneficiary spent full time with the contractors when they were on site. The beneficiary believes the work was well done.

The beneficiary would not have been able to afford the renovations without the CMHC program. If she could have gotten a cash grant with no strings attached, she would still have spent it on the same renovations.

The daughter believes that the value of the house has increased because of the renovations. Her opinion is likely accurate, given her experience as former owner of a renovation company.

General opinions about Program

The daughter believes the best part of the program is the great people who work for it. She and her mother did not like the upheaval created during the renovations, but agree that this cannot be helped. The beneficiary liked everything about the modifications, and could identify nothing she liked least.

Beneficiary A-15

Assistance type:	RRAP-D
Assistance amount:	$6,810
Total cost:	$6,810
Urban/rural:	urban
Beneficiary sex:	female
Beneficiary age:	over 65
Beneficiary disability:	mobility issues due to poor hips and back
Modifications:	conversion of tub to walk-in shower, grab bars, raised toilet and bathroom re-tiles
Modifications completion:	March 2005
Caregiver:	none
Interviews:	Round 1: May; Round 2: August (4 months)

Overview

The beneficiary is a woman who lives in a suburban seniors' community of well-kept single-floor attached condominium units that is 11-15 years old. She has (relatively) minor mobility problems, hips and back, and found it increasingly difficult to use a normal bath tub. She uses a cane outside in the winter, but otherwise gets around the house without a mobility-related device. The renovation replaced he bath tub with a walk-in shower, including the necessary re-tiling, installed a new higher toilet, and installed grab bars near both.

She has no caregiver. Her personal income (and household income) ranges between $20,001 - $25,000 a year from Canada pension, Old Age Security, and a CP Railroad pension. She has retired.

Based on the results from the second interview in August, there have been no changes in the beneficiary's living conditions or health since the first interview.

CMHC-funded modifications

The renovations were done to improve the beneficiary's mobility and safety in the bathroom. The renovations cost $6,810, all of which was covered by the RRAP-D program. She did not have any out-of-pocket expenses.

The beneficiary believes that the renovations have resolved her mobility and safety issues with respect to the bathroom, and that there are no other renovations needed, at least for the present. She believes that the renovations have been valuable with respect to helping her remain independent and in her own home (score of 10/10 – which indicates that they are essential). However she reports that she would not have considered moving to other accommodations, even if the renovations had not been done.

The beneficiary's physician helped her decide on the types of renovations she would need, and she found this help useful. No formal needs assessment was done.

Other renovations

The beneficiary has had no other renovations done in her home.

Quality of Life

The beneficiary's health has not changed in the past year and is currently stable. She also believes her quality of life has improved (by 4 points) as a consequence of the CMHC funding she has received, especially with respect to her mobility and safety. She reports that her mobility in the bathroom has improved by 6 points and out of the home has improved by 6 points, and her mental and physical health by 3 points due to the relief of feeling more safe in using the bathroom. She reports no problems with the renovations.

During the second interview, the beneficiary indicated that she is having difficulty using the vacuum cleaner, but that this has not relationship to the renovations sponsored by CMHC (bathroom). She also indicated that getting into the basement is a problem (site of furnace and hot water heater, possible storage – score of 2/5). Her grandson who lives nearby goes to the basement for her.

Financial impact and willingness to pay

The beneficiary reports that it took her 5-6 hours to complete the application for the RRAP-D program, including gathering together the information requested. Obtaining estimates from contractors was done over a period of 8 months. She reports that she spent full time with the contractor when on site until the renovations were completed. Finally, she believes that the renovations have had a positive impact on her home's market value.

If the RRAP-D Program had not been available, the beneficiary would have paid for the modifications herself, but it would have been much later – in 2 or 3 years because of financial issues. If she had received a cash grant, she would have spent it on the same modifications, and would not have accepted a lesser cash payment without strings.

General opinions about Program

The beneficiary thought the people she dealt with from CMHC were wonderful. She reports that she likes everything about the program. She liked most that she could choose what she wanted done, and could find nothing to dislike about the modifications.

Appendix E
Survey Responses by Topic

Annex E: Survey Responses, by Topic

Personal Details and Housing (questions 1 – 31)

1. Income and Employment Status

Employment Issues

None of the beneficiaries currently work, nor do they plan on returning to work as a result of the renovations. Seven (01, 02, 03, 05, A10, A11, A12) quit work because of their disability. One quit because of the combination of age and disability (A13). One has never worked because of the nature of his mental and physical disabilities (04). And, six left work primarily because of age (06, 07, A8, A9, A14, A15).

Five reported that they would not be able to return to work, despite the renovations, because of their disability (01, 02, A10, A11, A12). In one case (01), the beneficiary has terminal health problems in the short term. In another case, the beneficiary reported that his disabilities are expected to get progressively worse (A10). Three reported that they could not return to work primarily because of their age, although their disabilities could also be a factor (03, 05, 06, 07, A8, A9, A13, A14, A15). And, one (04) will never be able to work because of the nature of his disabilities. [It should be noted that nearly all of the beneficiaries can expect that some or all of their disabilities will get worse over time, although only the two (01, A10) said this explicitly.]

Sources of Income

All but one beneficiary (03) reported his or her sources of income, which were as follows, in order of most to least common:

- Regular CP (8 beneficiaries – 05, 06, 07, A8, A9, A13, A14, A15)
- Old Age Security (8 beneficiaries– 05,06,07,A8,A9,A13,A14,A15)
- Provincial pension/disability plan (5 beneficiaries-01,04,A10,A11,A13)
- Work/private pension or disability of plan (3 beneficiaries-07, A9, A15)
- National Child Benefit (1 beneficiary – 01)
- Workman's Compensation (1 beneficiary – 02)
- CPP-Disability (1 beneficiary – A12)
- RIFs (1 beneficiary – 07)
- Local government pension (1 beneficiary – A12)

2. The Beneficiary's Disabilities

All of the beneficiaries (HASI and RRAP-D) have at least one disability related to the need for the renovations supported by the HASI or RRAP-D programs. In addition to the disabilities listed in the questionnaire, beneficiaries reported other disabilities, some of which were the reasons for the renovations, at least in part. These are listed in the following table by disability:

Hip/knee/joint damage/issues	02, A12, A14, A15	Heat/sun stroke	A12
Multiple Sclerosis (MS)	02	Severe disabilities	04
Amputation	03, A13	Cerebral palsy (CP)	04
Bad back	A11, A14	Epilepsy	04
Occupational disease	01	Loss of feeling in limbs	07
Cancer	01	Stroke	03
Paralysis	03	Vacinitis	03
Heart problems	A9	Open sores	A13
Heart & blood pressure issues	05	Coordination difficulties	A11
Kidney problems	A9	Colonostomy	A13

Seven beneficiaries made additional comments on the nature of their disabilities, as follows:

- Have occupational asthma and lung cancer (01)
- Have long-term knee damage and MS (02)
- Has had stroke and also suffers from vacinitis (a circulatory disorder of unknown origin); is paralyzed on left side and has had right leg amputated. Also having problems with circulation in left leg; could result in amputation. Stroke has also caused cognitive difficulties (03)
- Severely disabled: cerebral palsy, epilepsy; foster parents must do everything for the individual (04)
- Have mobility problems are due to heart and kidney problems (A9)
- Have general mobility issues, and hips/back problems (A14)
- Have mobility issues, including poor hips, syatica, stiff joints (A15)

In most cases, the beneficiaries' reasons for the CMHC-supported renovations corresponded to the disabilities they listed. Seven beneficiaries listed additional disabilities that they did not link explicitly to the need for the renovations:

- cognitive difficulties due to stroke (03)
- circulatory problems (03)
- hearing difficulties (06, 07, A8, A10)
- vision difficulties (A8, A10)
- knee & ankle surgeries (A12)
- open soars (A13
- colonostomy (A13)

The health and/or disabilities of six of the beneficiaries had changed between the first and second round of interviews (01, 02, 03, A9, A10, A11):

- Beneficiary 01: lung cancer has become quite virulent and has spread to his brain; summer heat and humidity has caused him significant breathing difficulties
- Beneficiary 02 has had his 11th knee operation, has spent several months in the hospital, and has returned home to recuperate; it is estimated that he will need a full year to regain the use of his knees
- Beneficiary 03 is having more circulatory problems which could result in the loss of his remaining leg
- Beneficiary A9 has yet to be called up for a kidney transplant and, as a result, is getting progressively worse

- Beneficiary A10 had a treatment on one knee that was to have helped her walk better. However, the physician neglected to freeze the area and touched a nerve; she is in constant pain because of this and is reluctant to submit the other knee to the same treatment.
- Beneficiary A11's overall health has not changed, but she feels as if she is slowing down more than expected.

3. Accommodation and Others in the Home

Eight beneficiaries indicated that someone else in the home has disabilities and benefits directly or indirectly from the renovations supported by RRAP-D or HASI. This information is summarized in the following table:

Beneficiary	Who else/disabilities?	How benefit?
03	Friend (who owns home)	Indirectly – easier to help me
04	2 foster sisters	Directly – have similar disabilities to mine
06	daughter	Directly – afraid of stairs; because of renovations, do not need to use stairs
A9	spouse	Directly – mobility and safety increased
A10	Son and granddaughter	Directly – code issues resolved, and better functioning of home decreases stress on both
A11	spouse	Directly – benefits same way as beneficiary (code, mobility, arthritis)
A12	spouse	Indirectly easier (air conditioner) – helps him breathe, but does not deal directly with his own disabilities
A13	son	Directly – he has mobility issues also, which are helped by renovation. Also indirectly as it makes it easier for him to help beneficiary

There were no changes in the nature of the Beneficiaries' occupancy or those who live with them.

4. Importance of Pets in Home

Nine beneficiaries (01. 03, 04, 06, A10, A11, A12, A13, A14) reported that they have pets in the home and all of them indicated that they believe that the pet(s) are having a positive physical or emotional impact on their lives. Two beneficiaries indicated that the pet is not a factor in his decision to remain in the home (one thought bird would be able to be retained in an institution, the other simply did not consider it an issue).

Caregiving and Support Services (questions 32 – 55)

1. Primary Caregivers

One-third or five beneficiaries indicated that they have a primary caregiver (01, 03, 04, A9, and A13). The reasons why they consider the individual their primary caregiver are as follows:

- Spouse (wife): she is the only one I can turn to for help with everyday living (01)

- Friend and housemate: he has been helping me for many years on a regular basis (03)
- Foster parents: foster son is virtually helpless (04)
- Spouse (wife): beneficiary needs help dressing sometimes – especially when kidneys cause water retention (A9)
- Son: he helps beneficiary move around, dress, and prepare meals. (A13)

Three of these beneficiaries reported that their caregivers provided services not included in the list in the questionnaire:

- Transportation to and from doctors, hospitals, other appointments (01)
- Getting onto the lift at top of stairs - renovation created this problem while resolving the same problem at the bottom of the stairs; 'cannot be helped' (03)
- Help with dressing (A9)

When asked whether the renovations have made it easier for their caregivers to help them, four beneficiaries indicated that it does:

- Easier to keep house clean (01)
- I can now get upstairs without his help (03)
- Getting in and out of doors is easier, and causes less stress and strain on foster parents (04)
- It is easier for my son to help me (A13)

By the second round (early August) there had been changes in the status, nature or responsibilities of the primary caregiver in two cases:

- Caregiver 01a had entered hospital for a hysterectomy. As a result, their 10 year old son stayed out of school and became his father's caregiver for a couple of weeks while his mother recovered. In addition, Caregiver 01a now gives her husband more personal care because his illnesses have progressed significantly (e.g., bathing, dressing, etc.)
- Caregiver 03a is currently unable to help Beneficiary 03 as he has broken his hip and is not expected to return home until the end of the summer. Friends, neighbours, and a staff member from Orleans Paramedics (bathing) have tried to fill in. Moreover, it is unclear when – or whether – he will be able to take on his responsibilities again, as they involve heavy lifting. The impact this accident will have on the Beneficiary's living situation is not yet clear.

-

2. Secondary Caregivers

In the first round of interviews, two beneficiaries reported that they have 'secondary' caregivers (04, A13). In the second round, we found that beneficiary 01 now has a secondary caregiver. The current situation is as follows:

- Since the last week of July, a nurse (unpaid) from the local health care unit is visiting Beneficiary 01 to assess his health. The purpose is to help the family

determine what additional help they will need to keep the beneficiary at home, and when he should enter institutional care.

- Foster parents to Beneficiary 04 receive help from the local Ontario Children's Aid Society (CAS, unpaid), and from the Community Care Access Centre (CCAC), for which they pay and are later reimbursed by CAS, in part or full, depending on the usage/month (up to $8001,000/month). If they need more help, they must pay for it themselves. They also depend on friends and family for additional help. The organizations support them with general housekeeping, laundry and general housekeeping; with diapering, bathing, and toileting the foster children; and with mobility issues (getting foster children in/out of home, moving them from room to room and up/down stairs, and taking them on outings). The use and nature of these services has not been affected by the renovations.

- Beneficiary A13 receives nursing services (personal care and bathing) 3 times/week and homemaker services (house cleaning) 2 times/week from the City of Edmonton Home Care Services Program. According to the beneficiary, the services have not been affected by the renovations. Because service is usually given by a different person each time, and the beneficiary was unwilling to give us permission to speak with her case worker, we were unable to interview the service providers to confirm whether the renovations have had an impact on their work. There has been no change in this caregiver-beneficiary relationship since we spoke to Beneficiary A13 in the first round of interviews.

3. Paid Caregivers

Beneficiary 04's foster parents receive services from a Home Care Services organization for which they pay, and for which they are later reimbursed by the Ontario Children's Aid Society to a maximum of $8001000/week. See "Secondary Caregivers" for details.

Modifications (questions 56 – 73)

CMHC-sponsored modifications.

1. Nature of the modifications

The following table summarizes the modifications made to each home by category, with the beneficiary or beneficiaries indicated for each modification.

Parts of home modified		Modification
exit/entry	9	railings added (02, A09, A11) entrance widened (04, A11) new doors, screens, re-casing (05, A11) hand rails, replaced front and/or back door, new locks & bolts, re-casing (06, A14) entrance and sidewalk altered to accommodate walker, light added (07) non-slip surface on steps (A09) peephole/intercom (A08) front and/or back screened door(s) (A14) repaired ramp (A13) or new ramp (A11) sidewalk repaired (A14)
kitchen	5	lever-action taps (05, A08) lowered cupboards (A08, A10) safety plugs, grab bars at entry (A11) lowered sink, counter, put in more sockets (A13) lowered counters; slide-out drawers (A10) moved all kitchen-related into 1 space (A10)
laundry	2	moved to basement (02) moved upstairs from basement, new ventilation, new W&D (06)
bathroom	10	converted to 100%accessable (02) wheel-in shower, bath lifts, re-orient entry (04, A10) lever-action taps, shower head adaptation (05, A08) lowered sink and counters (A13) roll-in shower (A10) bath seat, grab bars, hand-held shower (06) walk-in shower, raised toilet, grab bars (A11, A15))
bedroom	5	moved to ground floor (02, A11); bed height fixed (02) window air conditioner (A12) reoriented entry to bedroom (04) new handle for window (A08)
other	13	
- whole house	11	new roof (01, A13) new flooring replacing carpet (01) safety rails for all internal & external stairways (02, A09) widening all internal doorways (04, A11) hand grips throughout house, new oil furnace & tank, new duct work, new septic (05) installed new fire detectors (06) installed fire extinguishers (A07) upgraded electricity or rewiring (A11, A13, A14) replaced all windows (A10, A13, A14) & part of 1 rotten wall (A10) replaced floor and sub-floor (A10) new hot water tank (A13) new gas furnace (A11, A13) dealt with water in basement/not clear how (A11) safety plugs throughout (A11) all new plumbing (A11) burglar bars added in basement windows (A13) replaced house siding (A11)

- chairlift	1	chairlift 1st to 2nd floor (03)
- upstairs windows	1	windows adjusted so he can't fall out (02)
- all porches/decks	1	railings (02)
- living room	1	replaced overhead light (06)
	1	window air conditioner for rest of home and condenser for both units (A12)
- additional exit	1	replaced sliding door to avoid freeze-up (A09)
- laundry	1	moved out of basement – to bedroom (A14)
		moved freezer from basement to 1st floor (A14)
- basement	1	put non-slip surface on stairs (06)
- office	1	converted closet to office for storage (A10)

2. Main reasons for the modifications

Beneficiaries indicated the main reasons for the modifications supported by the RRAP-D or HASI programs as follows:

Reasons for Modifications		
eases breathing	1	01
building code issues	7	01, 05, 06, A10, A11, A13, A14
increased mobility	14	01, 02, 03, 04, 05, 06, 07, A8, A9, A10, A11, A13, A14, A15
increased safety	11	02, 03, 05, 06, 07, A8, A9, A10, A13, A14, A15
increased security	6	06, A8, A10, A13, A14, A15
general function/comfort in home	2	A10, A11
heat / sun stroke	1	A12

3. Nature of beneficiaries' difficulties, before and after renovations.

All beneficiaries reported that they had difficulties carrying out the activities of daily living prior to having the renovations done. Although the renovations did help, eleven reported that they still have difficulties with these activities, and one reported that it was too early to tell if the renovation had made a difference.

These are summarized in the following table:

	Difficulties before	Improvement?
01	Going room to room Going up/down stairs General mobility issues because of breathing	Yes, still problems, but easier Beneficiary is terminally ill
02	Moving around home and in/out of home	Yes, but still essentially same problems All issues that renovations could solve were solved
03	Going up and down stairs (bottom to top)	Yes, problem down stairs resolved; but now problem upstairs
04	Moving inside home and in/out of home Using toilet	Yes, makes it easier Beneficiary is severely handicapped and will not get better, no matter what
05	Moving around home, and in/out of home Taking baths; turning on faucets	Yes, all issues identified for renovations have been resolved Additional issue: wiring needs replacing
06	Moving around home; in/out of home Bathing and using toilet	Yes, helped, but still have problems Lots of external issues need to be resolved Problems on exterior of home need resolving
07	In/out of home; taking bath	Yes, dealt with entryway But mobility in bathroom still an issue Also, grade difference between side-walk and driveway
A8	Moving around home, and in/out of home Bathing Security issues	Yes, security issues resolved; mobility has improved, but still have problems Still need changes in home in future
A9	Moving around home; and in/out of home	Yes, has improved greatly – but will never be totally resolved
A10	Moving around home, and in/out of home Preparing meals Bathing and using toilet Need for storage and work area	Yes, all just great. However, will have to deal with access/entry to home
A11	Moving around home; in/out of home Bathing and using toilet Code issues*	Yes, still have some difficulties but fewer Nothing will completely resolve my difficulties; everything has been done that can be for now
A12	Breathing problems, headaches	Second round: reported that the air conditioning units made a very significant difference to her ability to breathe and reduced the incidents of headaches a great deal. Did not resolve all home issues (leaking roof, eg.)
A13	Moving around home; in/out of home bathing preparing meals safety and security issues	Yes, BUT -- still have difficulties in kitchen and bathroom – this cannot be resolved (beneficiary tended to be negative and not emphasize what was improved, like most safety and security issues)
A14	Moving around home; in/out of home	Yes, resolved all difficulties at this time
A15	Bathing and using toilet	Yes, all resolved

*Code issues were common, but noted here only if the beneficiary referred to them.

4. Additional information about activities of daily living, the effect of the renovations, and Quality of Life (Round 2)

During the second round of interviews, we asked the beneficiaries and their caregivers a few additional questions about the quality of their day-to-day living and how this has been affected by the CMHC-supported renovations. The nature of the responses to these questions changed in five cases:

- For beneficiaries 01, 02 and A 10 changes in their health status affected the relationship between their degree of difficulty in doing daily activities and the degree to which the renovations have helped their situation (for A10, the change in status was precipitated by difficulties with her medical care);
- Beneficiary 03 reported that daily activities have been affected adversely by his caregiver's own health difficulties; and
- Beneficiary A11 reported that she has slowed down somewhat since the first interview, but that this has had a minor effect, only, on the relationship between the difficulties she faces doing daily activities and the renovations sponsored RRAP-D.

The following tables summarize the results of these discussions.

Difficulties with Certain Activities I

Type of difficulty	Degree of difficulty (currently – 2nd round)	Degree to which renovations have helped the situation (2nd round)	Explanation
Seeing, even with glasses	Minor – A13, A 14, A15 Mid-degree - A10 Major – 04, A8, A11 No difficulty - 01, 02, 03, 05, 06, 07, A9, A12	Changed from major to minor degree of difficulty – A8, A11 No effect - 04, A10, A12, A13, A14, A15	Beneficiaries A8 and A11believe the renovations had no effect (both rounds), but sight problems may have exacerbated problems with mobility.
Hearing, even with hearing aid	Minor – 03, A14, A13 Mid-degree – 06, A10 Major – 04, A8, A11 No difficulty – 01, 02, 05, A9, A11, A12, A15	Changed from major to minor degree of difficulty – A8 No effect - 03, 04, 06, 07, A10, A12, A13, A14	Beneficiary A8 believes renovation has no effect, but there may be to a minor degree with respect to safety.
Going up/down stairs (inside)	Minor- A8, A13, A15 Mid-degree – 01, 07, A11, A12 Major – 02, 03, 04, 05, 06, A9, A10, A14	Initially improved only – 01 Changed slightly within minor category – A15 Changed from major to mid-degree of difficulty – 02, 03, 05, 06, A9 Changed from major to minor degree of difficulty – A14 Difficulty has gotten worse – A8 Changed slightly within major category – A10 No effect - 04, 07, A11, A12, A13	Initially improved, but no longer due to change in health (01) Laundry moved so became minor problem – A14 Nothing to do with renovation (air conditioning) – A12

Getting on/off toilet	Minor – 05, A9, A12, A14 Mid-degree – 07 Major – 01, 02, 03, 04, 06, A8, A10, A11, A15 No difficulty – A13	Changed from major to minor degree of difficulty - 02, 06, A10, A11, A15 Changed from major to mid-degree of difficulty – A8 No effect - 01, 03, 04, 05, 07, A9, A12, A14	Nothing to do with renovation – A12
Getting in/out of bed or chair	Minor – 05, 06, A8, A9, A13, A14 Mid-degree – 01, 03, A10, A12 Major – 02, 04, A11 No difficulty – 07, A14, A15	Changed from major to mid-degree of difficulty – 02 Changed slightly within major category – A11 Changed slightly within mid-degree category – A12 No effect - 01, 03, 04, 05, 06, 07, A8, A9, A10, A12, A13	
Taking bath or shower	Minor - A9, A14 mid-degree – 03, 05, A12 Major – 01, 02, 04, 06, 07, A8, A10, A11, A13, A15	Changed from mid-degree to minor degree of difficulty – 05, Changed from major to minor degree of difficulty – 02, 06, A10, A11, A13, A15 No effect – 01, 03, 04, 07, A8, A9, A12, A14	Renovations dealt with this issue – A8
Doing chores around home	Minor – 06, A8, A10, A12, A15 Mid-degree – 02, A9, A11, A14 Major – 01, 04, A13 No difficulty – 03, 05, 07	Improved to slight degree within minor category – A15 Changed from major to a relatively minor degree of difficulty – A12 No effect - 01, 02, 04, 06, A8, A9, A10, A11, A13, A14	Air conditioning helps her get things done – A12
Moving around home	Minor – 03, A8, A14, A15 Mid-degree – 06, 07, A9, A11, A13 Major – 01, 02, A10 No difficulty – 04, 05	Improved to slight degree within minor category – A8 Changed from mid-degree to minor degree of difficulty – 06, A11 Changed from major degree to mid-degree of difficulty – 02, A10 Changed from major to a relatively minor degree of difficulty – A12 No effect - 01, 03,07, A9, A13, A14, A15	Air conditioning helps her get things done – A12
Moving into/out of home	Minor – A8, A13, A14, A15 Mid-degree – 03, 05, 06, 07, A9, A11, A12 Major – 01, 02, 04, A10	Changed from mid-degree to minor degree of difficulty – 05, 06, 07, A9 Changed from major degree to mid-degree of difficulty - 02 No effect - 01, 03, 04, A8, A10, A11, A12, A13, A14, A15	

Difficulties with Certain Activities – Table II

In the second round of interviews, a few beneficiaries reported difficulties with cooking, laundry, taking a bath or shower, or had a need for nursing care. Whether they receive the help they need, whether they receive the help, and whether the renovations had an impact on responding to this need are summarized in the following table:

	Need help?	Are you receiving it? from whom?	Did renovations effect this? Comments
Cooking	Yes – 04, A13 No – remaining beneficiaries	Yes: 04 – foster parents A13 - son	Three beneficiaries reported that they have never done their own cooking (01, 07, A9) The remaining beneficiaries reported that the renovations have made no difference in cooking since the first round of interviews – although the renovations did initially have a positive effect for some of them (e.g., A10)
Laundry	Yes – 02, 03, 04, A10, A13 No – remaining beneficiaries	Yes: 02 – friends, neighbours 03 – paid cleaning woman 04 – foster parents A10 – son and granddaughter A13 - homemaker	Beneficiaries 01, 07, A9 have never done their own laundry The remaining beneficiaries reported that the renovations have made no difference in doing laundry – although the renovations did initially have a positive effect for some of them (e.g., 06, A14)
Taking bath/shower	Yes – 01, 03, 04, 07, A9, A13 No – remaining beneficiaries	Yes: Spouse – 01, A9 Caregiver – 03 Local paramedics – 03 Foster parents – 04 Municipal home care – A13 No - 07	Renovations dealt completely with this issue – 02, 05, 06, A8, A10, A15 Situation has changed since first interview because of caregiver's health; will again become caregiver role when caregiver's health allows this - 03 Renovations had no effect: 07
Nursing	Yes – 01, A13 No – remaining beneficiaries	Yes: Spouse – 01 Service agency – 01 Municipal home care – A13	Renovations had no effect on nursing care – 01, A13

Difficulties with Certain Activities - Risks and Obstacles III

In the second round we also asked whether beneficiaries have identified any remaining risks or obstacles to their health and/or safety in their homes that have not been dealt with by the CMHC-sponsored renovations. The following table identifies these risks/obstacles, and their significance.

Remaining in home		What risks or obstacles? How significant (1 to 5, 5=severe)
Risks to health	Yes – 01, 02, 07, A9 Unsure – A8 No – remaining beneficiaries	- Continuing mold in basement – 01 (4/5) - Possibility of losing significant feeling in legs; losing legs in future – 07 (4/5) - Continuing worsening health – 02, A9 (4/5) - Mildew as result of renovations – A11 (4/5)
Risks to safety	Yes – 01, 04, 05, 06, 07, A8, A9, A10, A11 No – remaining beneficiaries	Difficulty with bath/shower - 01, 07 (4/5) Joists not close enough to carry weight – 04 (4/5) Basement stairs - 05 (3/5) Need wiring work – 05 (3/5) Outside repairs needed for code and safety - 06 (3/5) Need for safety calling service - A8 (3/5) Continuing worsening health - A9 (4/5) Unsafe stairs going outdoors, front and back - A10 (4/5) Mildew around cracks as result of renovations - A11 (4/5)
Obstacles to accessibility	Yes - 01, 02, 03, 05, A10, A13, A15 No – remaining beneficiaries	Bathroom – 01 (3/5) Basement - 01, 02, 03 (3/5); A15 (2/5) Access to/within house – entrance stairs - 02, 05 (3/5); A10 (4/5); , and inside stairs – 05 (3/5) Inability to reach in fridge, other places - A13 (3/5)
Obstacles - staying in home	Yes – 01, 03 No – remaining beneficiaries	Must have caregiver help – 01 (3/5) If I lose my other leg - 03 (5/5)

5. Sources of funding?

The following table summarizes the amount of funding received, whether the beneficiary needed additional monies, by whom they were provided, and why they were needed.

Total cost	CMHC	Other	Source	Reason not all covered by CMHC
$10,650	$10,323	$350	self	cost over estimate (01)
$14,000	In-full			(02)
$13,750	In-full			(03)
$3,600	In-full			(04)
$19,000	$15,000	$4,000	self	Electrical box upgrade (05)
$3,502.11	$3,500	$2.11	self	Cost over estimate (06)
$3,700	$3,500	$200	self	Cost over estimate (07)
$3,500	$3,500			(A08)
$7,900	$3,600	4,300	self	Significant cost over estimate (A09)
$34,000	$29,000	$5,000	self	Costs expected to be higher (A10)
$38,000	$28,000	$10,000	children	More $ needed than CMHC made available (A11)
$5,600	In-full			(A12)
$25,000	In-full			(A13)
$21,000	In-full			(A14)
$6,810	In-full			(A15)

6. Difficulties having modifications made

Seven beneficiaries (02, 04, 06, 07, A11, A12, A13) reported difficulties with having the modifications made. The difficulties were as follows:

- Problems doing some of the work due to the age of the home (02).
- Disruption of their normal lives caused by the work (04, A13).
- The need to move out of the home while work was being done (A11).
- Contractor was backlogged and could not do the work right away; this was due to the time of year, the amount of work the contractor was committed to doing, and/or the distance from a larger centre where competition for work would be greater (07, A11).
- Incorrect work plan, incorrect materials and costs all stalled the process – wrong air conditioning unit/compressor for mobile home (A12); we found that the air conditioning units are working very well in the second round of interviews
- Having to deal with a rejected contractor who harassed them (06).

This list is probably not complete, as beneficiaries also mentioned other problems that occurred. A few had to find money to pay for unexpected expenses, but reported it at another point in the interview (for example: 01, A9).

7. Modifications made without CMHC support

Six beneficiaries reported that they have had renovations to their homes in the past three years that were not supported by RRAP-D or HASI:

- Beneficiary 02: kitchen (not sure of amount)
- Beneficiary 03: miscellaneous renovations for $17,700
- Beneficiary 04: new ramp and deck for $3,400
- Beneficiary 07: replacement windows (not sure of amount)
- Beneficiary A10: replaced furnace; fence; replaced part of sidewalk, widened it and leveled it; put 3rd bedroom in basement; window wells; new cooking stove

Quality of Life (questions 74 – 84)

1. State of beneficiary's health

The following beneficiaries indicated that their health had changed over the past year and/or expect it to change over time:

- Beneficiary 02 reported that his knees should get better in the short-term as a result of another knee surgery (January/February 05), but that his MS will increase the severity of his disability over the longer term. This has occurred. During the second round of interviews, he told us that the operation has been a success, although he will be recuperating for at least a year.

- Beneficiaries 01 and A10 indicated that their conditions are getting progressively worse in the first set of interviews. By the time of the second round of interviews, Beneficiary 01 was much worse (asthma – difficulty breathing because of weather; lung cancer more virulent and had spread to his brain). Beneficiary A10's knee has improved, but she is

in constant pain because of the procedure used to help make it function better.

- Beneficiary 03 reported that he has been stable over the past year; however, by the time of the second round of interviews in early August, he was having worrisome circulation problems in his good leg.

- Beneficiary 04 is already well-beyond his life expectancy, given his disabilities, according to his foster parents.

- Beneficiary 05 has indicated that she has recently had major problems with allergies. She has also had back and stomach surgeries in the past year or so. Her doctor has also told her that she will need knee surgery in the near future.

- Beneficiary 06 reported that he finds he has less strength in his arms and legs than in the past.

- Beneficiary A08 has developed heart and eye problems, and may have to undergo stomach surgery in the near future.

- Beneficiary A9 reports that his kidneys are continuing to deteriorate. This will be life-threatening unless he is able to get a kidney transplant.

- Beneficiary A11 feels that his physical health has worsened. However, she feels better emotionally because of the renovations.

2. Main improvements in Quality-of-Life

Beneficiaries indicated many areas of improvement. The improvements each beneficiary thought <u>most</u> important are indicated below:

- Breathing easier (01)
- Increased or easier mobility in general or in particular situations or parts of home (01, 02, 03, 06, A8, A9, A14)
- Increased safety (05, A8, A15)
- Increased independence (05, 07)
- Able to get out socially (07)
- Energy level up; increase in productivity; sleeping better; increased mental/emotional well-being (A12)
- Material improvement in overall quality of life due to renovations, eg., furnace, new roof, etc (A10, A13)
- No improvement reported (04, A11)

With the exception of Beneficiary 01 whose quality of life is getting progressively worse, even to the point of being worse than prior to the renovations, the beneficiaries gave the same or almost the same scores to the improvements made because of the renovations.

3. Problems created by renovations

Five beneficiaries reported that they had problems with the modifications supported by the RRAP-D or HASI programs:

- Beneficiary 03: the chairlift is now in line with the floor at the bottom of the stairs; however, it is out of line upstairs. Nothing can be done to rectify this, as it is a technological problem for which, to date, there is no solution.
- The foster parents of beneficiary 04 point to the fact that kitchen tiles had to be replaced by tiles that do not match the rest of the floor as their only problem.
- Beneficiary 06 lost her front closet as a consequence of the renovations, but this was unavoidable.
- Beneficiary 07 reports that, as a result of the renovation, he now has a gradient difference between the sidewalk and the driveway – something he will fix over the next few months.
- Beneficiary A13 indicated that she cannot open the new window in her bedroom but that, otherwise, the renovations have been very helpful.

No new problems were identified in the second round of interviews.

Stability in Home (questions 85 – 91)

None of the beneficiaries now expects to leave his or her home. In the second round of interviews, we found that this had not changed. However, six beneficiaries had thought they might have to move, or were encouraged by their families to move, prior to the renovations:

- One beneficiary (02) indicated that he might have had to move if he could not renovate because the home was unsafe for him because of his disabilities.
- The foster parents caring for Beneficiary 04 believe they will eventually need a larger home, but will remain where they are for now. The renovations have made remaining there easier.
- Beneficiary 05 believes she would have had to move into a local nursing home because the house was unsafe and unlivable before the CMHC-supported renovations were done.
- Beneficiary 06 originally thought of changing houses to have everything on one floor prior to the renovations, but could not have done so because of lack of financial capability.
- Similarly, Beneficiary A9 might have had to move to get everything on the same floor if he had not been able to do the renovations.

- Beneficiary A14 had no intention of moving, but family members were pushing her to live elsewhere prior to the renovations being done. They now seem satisfied that she is safe and secure in her existing home as a consequence of the renovations.

Financial Impact (questions 92 – 98)

1. Time on applying for assistance, getting quotations, and dealing with contractor
Time used to apply to CMHC, get quotations, and deal with the contractor were as follows:

Beneficiary	Time applying	Time getting quotes	Time dealing with contractor
01	Apx 1.5 hours	Over 2 weeks	Not much
02	Don't know	Over 2 weeks	Full time, every day
03	3 hours	2-3 hours	2-3 hours
04	6 months from filling-in to someone showing up 2 months more to approval	4 hours	2 weeks full-time
05	1 hour	5-6 hours	3 weeks full-time
06	3-4 hours	4-5 hours	Very little
07	5-6 hours	3 hours	4 hours
A8	2 days	none	Full time
A9	4-5 hours	Over 3 months	Full time
A10	Apx 1 hour	Over several weeks	Lots of time making sure all understood what was to be done (number of different contractors), then at least 1 x a day during renos
A11	2-3 hours	Over 3 months	Full time
A12	7-8 hours	Over 7 months (had to do twice because of poor advice	Full time
A13	Over a month	Over 2 months	Full time
A14	20 hours with research	Over 3 months	Full time
A15	5-6 hours	Over 8 months	Full time

2. Problems with contractors

Six beneficiaries made comments about problems with contractors or other suppliers, two of which did or might have had serious consequences (01, A9, A10, A13). They are as follows:

- Beneficiary 01 did not report problems with contractors, but had to pay an additional $350 because of a poor estimate by supplier.
- Beneficiary 07 reported that there was a significant delay starting the work because possible contractors were busy.
- Beneficiary A9 has a cost over-run of $4,300.
- Beneficiary A10 had problems getting the contractors to work together and respect each other's needs. This was a product of having several contractors with different sets of responsibilities working on the renovations.

- Beneficiary A11 reported that the contractor was slow.
- Beneficiary A13 reported that the electrical contractor did not do the work agreed-to and was unpleasant to work with. She also had problems with the roofers who 'destroyed' the sophits and refused to replace them (not usually thought to be a roofer's responsibility).

3. Impact on home's market value

Only three beneficiaries had an opinion about the possible impact of the renovations on the market value of their home:

- Beneficiaries 02 and 03 thought the market value might be increased if purchased by someone with similar needs.
- Beneficiary 05 believes the home's market value has increased because it had been well-below the building code prior to the renovations.

Willingness to Pay (questions 99 – 104)

1. Money spent on renovations independently of CMHC support

Seven beneficiaries provided information on money spend on home renovations prior to receiving approval from the CMHC programs (01, 02, 03, 04, 07, A10, A14).

The information on such expenditure is as follows:

- Beneficiary 01 spent no money on renovations prior to receiving support from CMHC. However, he was asked to improve the railings at the main entrance by the CMHC agent as a condition for receiving the program monies. This was done at no cost to the beneficiary by friends.
- Beneficiary 02 had spent around $85,000 on his heritage home prior to receiving program support (much of it before he was disabled). He did not describe the nature of these renovations.
- Beneficiary 03 spent approximately $17,500 on renovations prior to receiving CMHC support (bathroom re-done, installed basement stair-lift, replaced back deck)
- Beneficiary 04's foster parents reported that they have spent money prior to receiving CMHC support, but do not know exactly how much. They knew they had spent about $3,400 on a new entry ramp, and another $2,500 on bringing their rear deck up to code (the latter was paid for by the Childrens' Aid Society).
- Beneficiary 07 reported that he spent money on replacement windows prior to receiving support from CMHC, but was unclear about how much that cost.

- Beneficiary A9 spent $5,500 on renovations prior to receiving funding from CMHC, but was vague about what the expenditure was for.

- Beneficiary A14 received $6,000 from the Alberta Provincial government for renovations prior to getting support from CMHC.

2. Would the beneficiary pay for renovations if support were not available?

   Eight (01, 05, 06, A10, A11, A12, A13, A14) beneficiaries made a comment about why they would not be able to pay for the renovations if RRAP-D and HASI were not available – i.e., they do not have the financial resources. Two of them said their children (daughters in both cases) would have to pay for the renovations and arrange for financing (05, 06).

3. Desirability of a Cash Grant

   Only one beneficiary (A13) commented on the desirability of receiving a “no strings attached” cash grant (“yes this would be acceptable and I would want to spend it on the same renovations *unless an emergency required that I spend it elsewhere*.”)

4. Acceptable level of cash grant in dollars.

   Thirteen beneficiaries indicated that they would accept no less than 100% of the funding, had it been available as a cash grant. Two beneficiaries would have accepted less: Beneficiary 03 would have accepted 60% or $8,250 of the $13,750 needed, and Beneficiary 04 would have accepted 80% or $2,800 of the $3,500 needed.

   This is summarized in the following table:

beneficiary	percentage	$ amount	beneficiary	percentage	$ amount
01	100%	$10,323	A8	100%	$3,500
02	100%	$14,000	A9	100%	$3,600
03	60%	$8,250 of $13,750	A10	100%	$29,000
04	80%	$2,800 of $3,500	A11	100%	$28,000
05	100%	$15,000	A12	100%	$5,600
06	100%	$3,500	A13	100%	$25,000
07	100%	$3,500	A14	100%	$21,000
			A15	100%	$6,800

General Probes

Questions 105 – 108 asked beneficiaries what they liked and disliked about the program and the renovations they had done with CMHC support. Although they were asked to identify the "most" or "least" – few were willing to emphasize one single thing that they particularly liked or disliked. With one exception, responses to this set of questions did not change in Round two (exception was comment by daughter of Beneficiary 05, whom we had been asked by the Beneficiary to interview in her stead.

What did you like best about the CMHC Program?

Responses to this question fell into distinct categories:

- The application and approval process: The speed, ease of the application and approval processes (01, 02, 03, 07)
- Complements about the people with whom the beneficiary had to deal. CMHC people were excellent, very helpful and efficient (01, 06, 07, A13, A14, A15)
- Sentiment that they are grateful the program exists: Grateful that the program exists (03, A11, A13); Getting the help; that the help is available (04, A8, A9, A12)
- That the program(s) could resolve some important general or specific issues for the beneficiary: Solved lots of issues (05); Increased my security and well-being (05); The difference it made for living in the home (A10)
- Other: Freedom to choose what is really needed (A9); Everything (A15)

What did you like least about the CMHC Program?

The majority of respondents could identify nothing they disliked about the program (03, A8, A9, A11, A15). The other responses had to do with the application process; the need for the beneficiary or his/her family to put in some of the funding; the attitude of the CMHC representative, and the lack of marketing to those in need of the program on the part of the CMHC.

The comments were as follows:

- The application process, timing/amount of time and related issues: Deadlines for application could be difficult to respect and the type of information asked for might scare some people; or might be difficult to get or a burden (06, A10). The time it took from application to completion (04, A14). Having to get estimates (A13). Did not like the attitude of the CMHC representative (02 – note that this was the same representative that 01 thought was so good). The program does not always cover the full amount needed (01, 07). The program is not marketed well enough, so cannot be used by more people (05). Having to re-apply for the air conditioning; having to get three sets of quotations (A12)

- Contractor or supplier-related issues: Having to find extra money because of a poor supplier or contractor estimate (01, 07). Having to deal with a troublesome contractor whose bid was rejected (06)

- Unfair or inconsistent treatment of possible beneficiaries? During the round two interview in early August, the daughter of Beneficiary 05 told us about a couple of instances where the CMHC representative (maybe a third party) did not deal at-all-well with potential recipients who were clearly in great need. She was aware of this because of her work as a CCRA assessor who needs to be knowledgeable about the CMHC and similar programs in the federal and provincial governments. She also emphasized that this had not been her or her mother's experience with the programs. Nevertheless, this is not the first time such inconsistencies in the application of the programs or treatment of beneficiaries has been reported in these interviews.

What did you like best about the CMHC-sponsored renovations?

Responses to this question fell mainly into two categories:

- Specific renovations: The bathroom (02, A11); The chair going up-and-down stairs is more reliable, smoother and less bulky than the one it replaced (03); The furnace (05); The shower (A8); Door replaced and stair railings (A9); The roof, hot water tank and furnace (A13)

- General Quality of Life: The house is cleaner and I can breathe easier (01). My increased mobility and safety; easier life (04, 06). Being able to get in and out of the house by myself (07). Renovations were aesthetically nice (A9). Greatly improved the QL for the whole household (A10). Air conditioning has made a very big difference during the hot summer (A12 – second round of interviews).

- Other: I got everything I wanted/had a choice of what I wanted done (02/A15). Everything (A14)

What did you like least about the CMHC-sponsored renovations?

Seven beneficiaries could think of nothing they disliked about the CMHC-sponsored renovations (05, 06, 07, A8, A9, A14, A15). After these, the most common response to this question had to do with the disruptions that occurred during the renovations (01, 02, A10, A11, A13) – and they all admitted that this could not have been helped. Two beneficiaries reported that they had to move away from their home while all or part of the renovations were being done, one for four months (A10, A11).

The remaining negative comments from beneficiaries were: Chairlift difficulties were simply transferred to the upper floor, a problem that cannot be resolved for technical reasons (03). Because the tiles removed during the renovation could not be duplicated, the kitchen floor looks bad (an aesthetics issue) (04) It took too long to get the compressor installed (A12) Electricians were pretty rough on the house (A11)

Caregiver Responses

Questions 44 – 47 of the caregiver questionnaire covered the same ground. Four of the five caregivers (01a, 04a, A9, A13) responded to the questions, and one (03a) indicated that he had no opinion. The similarities between caregiver responses and those of their respective beneficiaries are clear in these questions. As already noted, caregivers sat in on the beneficiary interviews, and the beneficiaries were present during discussions with caregivers, so this is not surprising. Beneficiary and caregivers 04 are a special case, in that the real beneficiaries of the CMHC RRAP-D program are the beneficiary's caregivers, his foster parents. They were the ones that responded to both questionnaires because of his severe disabilities. As well, Caregiver 01a had to respond for Beneficiary 01 because of his poor condition on the day of the interviews.

What did you like most about the program?

The speed with which we got underway (01a). Getting the help/that it exists and will do what is needed (04a/A13a). No opinion (A9a)

What did you like least about the program?

It took too much time from application to finishing the job (04a). Having to find the additional $350 (01a). Nothing (A9a, A13-a)

What did you like most about the modifications?

A cleaner house; no leaking roof (01a). Mobility, safety for us and the beneficiary (04a) The railings (A9a). The renovations which covered building code issues (A13a)

What did you like least about the modifications?

The disruption during the renovations (01a). The mismatched tiles (04a). Problems with the contractor (A12a). Nothing (A9a)

Appendix F
Survey Responses, Some Tables

Personal Details

Ques 1-16

Program Table 1				
	RRAP-D/urban	5	HASI/rural	1
	RRAP-D/rural	4	both/urban	2
	HASI/urban	2	both/rural	1

Table 3:	Gender
male	6
female	9

Age Table 2 Ques 4				
	<15		45-54	2
	15-24		55-64	2
	25-34	1	65+	9
	35-44	1		

Table 4: Beneficiary Income		Ques 6	
<10,000	2	$25,001 - 30K	
$10 - 15K	4	$30,001 - 35K	
$15,001 - 20K	4	$35,001 - 40K	
$20,001 - 25K	5		

Table 6: Sources of income	
work's comp	1
private pens/dis'ty	3
provincial pens/dis	5
other	5
regular CP	9
CPP-Dis	1
Local gvt pension	1
OAS	9
National Child Bene	1
RIFs	1
CPRail Pension	1

Table 5: Employment		Ques 7-11		
working	0	why left?	disability	5
not-working	15		age	9
			never worked	1
will return to work	0			
will not return to work	15			

Table 7: Disability - basic information Ques 12-16		
	have disability	15
	do not have disability	0
	disability - cause reno	15

Table 8: Type of disability					
		Other			
visual	3	occupat'l disease	1	severe mental/pysical	1
hearing	5	cancer	1	epilepsy	1
cognitive	3	MS	2	heart/BP problems	1
mobility	15	hip/knee/joint damage	3	loss of feeling in limbs	1
allergies	1	paralysis	1	stroke	1
arthrisis	9	amputation	2	vacinitis	1
multiple	12	heart problems	1	open sores	1
single	3	kidney problems	1	coordination difficulties	1
		bad back	2		
		heat stroke	1		

Table 9: Mobility device			
none	1	crutches	1
multiple	4	leg brace	1
wheel chr	6	Ceil'gTrk	1
walker	9	stair lift	1
cane	6		

Table 10: Frequence of use	
N/A	1
rarely	2
inside only	1
outdoor only	1
as needed	3
most times	2
always	5

Housing

Ques 17-31

Nature of Housing

Table 11: Tenure/ownership	
freehold	12
lease/rent	1
spec'l needs - foster	1
condominium	1

Table 12: Type of home	
single detached	10
duplex/semi-detached	3
mobile home	1
condominium	1

Table 13: Number of floors	
high ranch or bungalo	2
1 1/2 + basement	1
2-story + basement	6
1-story + basement	3
1-story/no basement	2
1-storey/crawlspace	1

Table 14: Age/Home	
11 - 15 yrs	2
16 - 20 yrs	
over 21 yrs	13

Table 15: Special housing?	
yes*	2
no	13

* (1) foster home; (1) senior complex condominium

Occupancy and related

Table 16: Household occupants					
who lives in home?		Total # in home		Do any others have disabilities?	
- only beneficiary	6	one	6	yes	8
- plus spouse	4	two	5	no	1
- plus daughter	1	three	2		
- plus son	3	four	1	Do they benefit from renovation(s)	
- plus parents	1			yes	8
- plus grandchild	2	seven	1	no	1
- plus friend	1				

Table 17: How do they benefit?		
blind	1	easier to help beneficiary, only
foster sisters have same disability	1	benefit directly (mobility)
mentally challenged daughter	1	benefit directly (mobility)
spouse	1	mobility problems - rt. Arm
son (schizophrenia) & granddaughter (ADHD)	1	safety, code issues, better function
son has poor heart; spouse has arthritus, lupus; in wheelchair;		
spouse in wheelch (reno not affect this, but general well-being)	3	mobility issues as well

Table 18: Household income	
under $10,000	
$10,000-$20,000	8
$20,001-$30,000	4
$30,001-$40,000	2
$40,001-$50,000	
over $50,000	1

Table 19: Household Pets		Ques 27-31	
Have pet(s)		Therapy function?	
- yes	8	- yes	8
- no	6	- no	
		not trained?	8
		reno no help	8

Table 20: Reasons for Pets	
makes me more active	1
comforting	6
mentally stimulating	1
protection	3
makes us happy/laugh	1

Type of pet		benefit	
- dog	5		
- cat(s)	3	- phyysical	4
- fish	1	- emotional	7
- bird	1		
Does having pet affect your choice of housing?		Yes	6
		No	3

Table 19: Household Pets			Ques 27-31
Have pet(s)		Therapy function?	
- yes	8	- yes	8
- no	6	- no	
		not trained?	8
		reno no help	8
Type of pet		benefit	
- dog	5		
- cat(s)	3	- phyysical	4
- fish	1	- emotional	7
- bird	1		
Does having pet affect your choice of housing?		Yes	6
		No	3

Table 20: Reasons for Pets	
makes me more active	1
comforting	6
mentally stimulating	1
protection	3
makes us happy/laugh	1

Caregiving

Ques 32-41

Primary Caregivers

Table 21: Primary caregiver				Why?	
yes	5	**Who?**		only one available	1
no	10	spouse	2	I am helpless	1
		foster parents	1	has helped for years	1
(O1; O3; O4; A-09; A-13)		housemate	1	kidney pblms cause mobility pblms	1
		son	1	need to move around, dress, etc	1

Table 22: Nature of help provided	
virtually everything	1
accessing/exiting home	2
moving from one room to another	3
preparign meals	2
using toilet	1
taking bath	
going p/down stairs	3
nursing	
physiotherapy services	
occupational services	
groceries, meal delivery	1
general housekeeping	2
home maintenance	2
other	
- to/from appointments	1
- dressing help	2

Table 23: Caregivers in home who need help?		
yes	3	
no	2	
frequency	3	every day

Table 24: Availability of Primary Caregiver	
daily	5
other	
Time:	
1 hr or less	
2-3 hrs/day	1
4-5 hrs/day	
all day	4
nights only	

Table 25: Importance of help			
maintaining independence		**staying in home**	
not at all		not at all	
not very		not very	
important	1	important	
v. important	1	v. important	2
essential	3	essential	3

Table 26	
less help?	
yes	
no	5
Easier on caregiver?	
yes	1
no	4

Secondary & Paid Caregivers

Ques 42-55

Table 27: Secondary Caregiver(s)		Who/what: special support service
yes	2	Home Care services program (paid) &
no	13	Ont. Min of Community & Soc'l Services (#04)
		Edmonton Home Care Services (#A13)

Will need less help/renovation?	
yes	
no	2

Table 28: Nature of help	
laundry	1
diapering	1
accessing/exiting home	1
moving in home	1
preparing meals	1
using toilet	1
bathing	1
up/down stairs	1
gen'l housekeeping	1
help with outings	1
nursing	1
home-making	1

Table 29: Importance of help			
maintaining independence		staying in home	
not at all		not at all	
not very		not very	
important		important	
v. important	1	v. important	
essential	1	essential	2

Table 30: Have paid caregiver	
yes	1
no	14

Will need less help/renovation?	
yes	
no	1

Who/what/$: special support servic (#04)	
Home Care Services Program	$800-$1,000
(They pay and are re-imbursed by CAS.)	

Table 31: Nature of help	
laundry	1
diapering	1
accessing/exiting home	1
moving in home	1
preparing meals	1
using toilet	1
bathing	1
up/down stairs	1
gen'l housekeeping	1
help with outings	1

Table 32: Importance of help			
maintaining independence		staying in home	
not at all		not at all	
not very		not very	
important		important	
v. important		v. important	
essential	1	essential	1

Table 33: Additional needs not covered yet?	
yes	
no	1
Explanation	(04) need more house space, esp another bathroom

The Modifications (1)

Ques 56-59

Table 34: Stage of renovations?		Date completed	
planned		2004-Aug	2
just starting		2004-Sept	4
nearly complete		2004-Oct	3
just completed	1	2004-Nov	1
completed month +	14	2005-Jan	2
		2005-Feb	1
		2005-Mar	1
		2005-May	1

Table 35: Reasons for Modificat's	
eases breathing	1
code issues	7
increased mobility	14
increased safety	9
increased security	4
gen'l function/comfort	0
in home	2
sun stroke	1

Table 36: parts of home modified		Modification
exit/entry	11	railings added (02, A09, A11) entrance widened (04, A11) new doors, screens, recasing (05, A11) hand rails, replaced front and/or back door, new locks & bolts, recasing (06, A14) entrance and sidewalk altered to accommodae walker, light added (07) non-slip surface on steps (A09) peephole/intercom (A08) front and/or back screened door(s) (A14) repaired ramp (A13) or new ramp (A11) sidewalk repaired (A14)
kitchen	5	lever-action taps (05, A08) lowered cupboards (A08, A10) safety plugs, grab bars at entry (A11) lowered sink, counter, put in more sockets (A13) lowered counters; slide-out drawers (A10) moved all kitchen-related into 1 space (A10)
laundry	2	moved to basement (02) moved upstairs from basement, new ventilation, new W&D (06)
bathroom	9	converted to 100%accessable (02) wheel-in shower, bath lifts, re-orient entry (04, A10) lever-action taps, shower head adaptation (05, A08) lowered sink and counters (A13) roll-in shower (A10) bath seat, grab bars, hand-held shower (06) walk-in shower, raised toilet, grab bars (A11, A15))
bedroom	5	moved to ground floor (02, A11); bed height fixed (02) window air conditioner (A12) reoriented entry to bedroom (04) new handle for window (A08)

other	13	
- whole house	11	new roof (01, A13) new flooring replacing carpet (01) safety rails for all internal & external stairways (02, A09) widening all internal doorways (04, A11) hand grips throughout house, new oil furnace & tank, new duct work, new septic bed (05) installed new fire detectors (06) installed fire extinguishers (A07) upgraded electricity or rewiring (A11, A13, A14) replaced all windows (A10, A13, A14) & part of 1 rotten wall (A10) replaced floor and sub-floor (A10) new hot water tank (A13) new gas furnace (A11, A13) dealt with water in basement/not clear how (A11) safety plugs throughout (A11) all new plumbing (A11) burgular bars added in basement windows (A13) replaced house siding (A11)
- chairlift	1	chairlift 1st to 2nd floor (03)
- upstairs windows	1	windows adjusted so he can't fall out (02)
- all porches & decks	1	railings (02)
- living room	1	replaced overhead light (06)
	1	window air conditioner for rest of home and condenser for both ACs(A12)
- additional exit	1	replaced sliding door to avoid freeze-up (A09)
- laundry	1	moved out of basement - to bedroom (A14) moved freezer from basement to 1st floor (A14)
- basement	1	put non-slip surface on stairs (06)
- office	1	converted closet to office for storage (A10)

The Modifications (2)

Ques 60-63

Table 37: Before adaptations - difficulty carrying out adcivities of daily living	
yes	15
no	

Table 38: Nature of difficulties	
virtually everything	1
accessing/exiting home	10
moving around home	6
preparign meals	2
using toilet	3
taking bath	8
going p/down stairs	10
other	7
- dealign with heat	1
- general mobility	3
- turning on faucets	1
- security	3
- storage of legal papers	1
- reaching (cupboards, shelves, etc)	1

Table 38: Consulting Professionals		
yes	13	
no	2	
Type Professional		
O Th	6	
Other	5	
physician	5	
Elev Exp	1	
Furnace Exp	1	
Helpful?		
useful	2	(1- O Th)
v. useful	9	(3- O Th)
except. Useful	2	(2- O Th)

#A14 - daughter was in contracting business for City of Calgary for similar renos for seniors

Table 39: After adaptations - still have difficulty carrying out acivities of daily living		
yes	11	
no	3	
too early to tell	1	
Nature of difficulties		
virtually everything	1	
accessing/exiting home	5	
moving around home	5	1-expected
preparign meals	1	
using toilet	2	
taking bath	5	
going p/down stairs	6	
other	2	
- general mobility	3	1-expected
- dealing with heat	1	1-expected

Why???

mobility still difficult, but less so (02, 06, A09)
problem transferred to 2nd floor (03)
nothing will resolve my problems (01, 04, A11, A13)
have difficulties with mobility in bathroom, shower, tub (07)
security resolved; mobility issues helped (A08)
need better front/back door steps (A10)
things are better, but still same issues (A11)

Table 40: Renovations solve all problems with home related to disability?	
yes*	3
no	12

* 2 - "all problems solved for now"

Table 41: What problems still occurring?	
No renos can resolve my problems	5
wiring problems	1
still have some external issues to deal witht	1
grade differences issues still exist	2
still other issues inside & outside	1
front/back steps	1
sinks in kitch & bath access stil issue	1
still need to fix leaking roof from previous CMHC reno, which is significantly damaging other parts of home; request made but denied at this time, even though need judged as "urgent" by CMHC (A12)	1

The Modifications (3)

Ques 64-69

Sources of Funding

Table 42				
Total cost	**CMHC**	**Other**	**Source**	(Ques 64-66)
$10,650	$10,323	$350	self	cost over estimate (01)
$14,000				(#02)
$13,750				(#03)
$3,600				(#04)
$19,000	$15,000	$4,000	self	electrical box upgrade (05)
$3,502.11	$3,500	$2.11	self	cost over estimate (06)
$3,700	$3,500	$200	self	cost over estimate (07)
$3,500	$3,500			(#A08)
$7,900	$3,600	4,300	self	significant cost over estimate (#A09)
$34,000	$29,000	$5,000	self	costs expected to be higher (#A10)
$38,000	$28,000	$10,000	children	more $ needed than CMHC made avaible (#A11)
$5,600				(#A12)
$25,000				(#A13)
$21,000				(#A14)
$6,810				(#A15)

Table 43: Difficulty having modifications made? (Ques67)		
yes	6	
no	8	
too soon to tell	1	(#A12)
Explanations		
related age of home (02)	1	
the disruption (04, A13)	2	
rejected contractor harassed them (06)	1	
contractor backlog/time of year (07, A11)	2	
had to live away from home for long period (A11)	1	
too soon to tell - see if compressor can circulate air	1	

Table 44: Value of modifications?					
maintaining independence			**staying in home**		
not at all			not at all		
not very			not very		
important	1		important	1	
v. import	4		v. import	3	
essential	9		essential	10	
N/A	1	(#04)	N/A	1	(#04)

N/A = severely mentally & physically disabled foster child

The Modifications (4)

Done without CMHC sponsorship **Ques 70-73**

Table 45: Amount spent on renovations in past 3 years/not CMHC funded	
nothing	9
yes	6
amount	**nature**
?	kitchen (02)
$17,700	miscel. (03)
$3,400	new ramp & deck (04)
?	replacement windows for easier opening (07)
$5,500	replaced furnace; fence; replac'd part sidewalk/ widened/leveled; 3rd bedrm in basemt;window wells; stove (A10)
$6,000	bathroom work and new washer & dryer (A14)

Table 46: Received funding from other programs?		Amount and Nature
yes	2	CAS (04); provincial program (A14)
no	13	

Table 47: Help - family or neighbours?			
financial		**non-financ'l**	
yes	1	yes	10
no	14	no	5

Quality of Life (1)

Ques 74-84

Table 48: State of Beneficiary's health			
Changed significantly in the last year?		Present state of health?	
yes	9	stable	7
no	6	changing	8

Explanations / comments	
knees should get better/MS will take over	(#02)
getting progressively worse	(#01, A10)
health could go any time, but now stable	(#03)
already beyond life expectancy	(#04)
major allergies, back & stomach surgery; will need knee surgery	(#05)
less strength	(#07)
heart and eye problems have developed; possible stomach surgery in future	(#A08)
Kidneys are getting worse	(#A09)
Body is worse, but general feeling of well-being is much better (unsure)	(#A11)

Table 49: Any problems with modifications?		
yes	5	
no	10	
Explanations / comments		
Downstairs problem fix'd/ caused upstairs to be out of line - can't fix	(#03)	
Tiles removed fr kitchen replaced w mis-match	(#04)	
Lost front closet/could not help this	(#06)	
Different grade btwn sidewalk and driveway	(#07)	
cannot open new bed-room window	(#A13)	

Table 50: Has your QL life improved as result of CMHC-funded reno? (Ques 76-78)	
yes	13
no*	1
not sure	1
* no = 04	

Table 51: What is main improvement?	
breathing easier	2
increased/easier mobility	8
increased safety	5
increased independence	2
able to get out socially	1
better access to parts of house	2
energy level up; increase in productivity; sleep better; mental well-bng	1
up/down stairs easier	1
not going up/down stairs	1
genl feeling well-being	1
no: past life expectancy	1
lowered br & k sinks	1

Quality of Life (2)

Ques 79-84

Table 52: Degree of improvement				
Mobility in/out of home		Improved by:		
1 pt		5 pts	1	
2 pts	1	6 pts	3	
3 pts	2	7 pts	2	
4 pts	3	no change	1	
		n/a	2	
Mobility inside home		Improved by:		
1 pt	1	5 pts		
2 pts	2	6 pts	3	
3 pts	1	7 pts	1	
4 pts	3	no change	1	
		n/a	3	
Ability to do usual daily activities		Improved by:		
1 pt		6 pts	1	
2 pts	1	7 pts		
3 pts	1	no change	4	
4 pts	3	n/a	4	
5 pts		before only*	1	(score - 2)
Ability to look after oneself		Improved by:		
1 pt		6 pts	1	
2 pts		7 pts		
3 pts		no change	1	
4 pts	4	n/a	5	
5 pts	4			
Physical & mental health		Improved by:		
1 pt	1	6 pts	1	
2 pts		7 pts		
3 pts	2	no change	2	
4 pts	3	n/a	3	
5 pts	2	before only	1	(score - 3)
Overall QL		improved by:		
1 pt		6 pts		
2 pts		7 pts	1	
3 pts	2	no change	1	
4 pts	5	n/a		
5 pts	5	before only	1	(score - 3)

* Beneficiary A12; work just completed

Stability in existing home

Ques 85-92

Table 53: How important were modifications for helping you maintain your independence			
score 1-3		score 9	4
score 4-6		score 10	6
score 7		n/a	1
score 8	4		

Table 54: Ability to stay in own home			
score 1-3		score 9	7
score 4-6		score 10	7
score 7		n/a	1
score 8			

Table 55: Considered moving to other accommodat'n?	
yes	4
no	11
When in relation to modifications	
before	4
after	
What sort of accommodation?	
nurs'g home	2
other house	2

Table 56

Ever lived in temporary housing/shelter?	
yes	
no	15

Table 57

Do you have plans to move? (Ques 90)	
yes	
no	15

Table 58

Has your attitude re moving been affected by modifications?	
yes	4
no	11

Table 59

Would you move/have moved if CMHC financial support not avail?	
yes	1
no	10
not sure	4

Table 60: Explanations/comments	
home unsafe	1
home unlivable	1
get everything on one floor	1
family wanted beneficiary to move into senior complex, but she refused*	1
beneficiary was not sure whether she and spouse should move (A11)	1

* she is a "no" with respect to ever moving.

Financial Impact

Ques 93-99

Table 61: Time spent on applying	
1 hr or less	2
1.5 hrs	1
2-3 or 3 hrs	2
3-4 hrs	1
4-5 hrs	1
5-6 hrs	2
7-8 hrs	1
20 hrs with research	1
over 2 days	1
over month	1
don't know	2

Table 62: Hire contractor?	
yes	15
no	

Table 63: Time getting quotes	
2-3 hrs	1
3 hrs	1
4 hrs	1
4-5 hrs	1
5-6 hrs	1
over period of 2 weeks	2
over 2 months	1
over 3 mos	3
over 7 mos	1
over 8 mos	1
over several weeks	1
no time	1

Table 64: Time with contractor?	
2-3 hrs	1
4 hrs	1
full-time	10
lots ahead of work + at least 1xday	1
not much	2

Table 65: Problems w/contractor?	
yes	5
no	10

Nature of problems
delay starting due to time of year (x2); work slow (x1)
work was way over estimate
co-ord several contractors; referee
rude electrical contractor; didn't do job requested
roofers broke sophets and refused to fix

Table 66: Out-of-pocket costs	
yes	11
no	4

What costs	
hiring lawyer	
hiring account'	
travel costs	2
telephone costs*	4
photocopying	4
mailing	4
other	4
incorrect estimate	3
upgraded fixtures	1
electrical box installed	1
staying w friends (food)	1

* one not insignificant (A11 - $800)

Table 67: Impact on home's market value?	
yes	10
no	3
don't know	2
positive?	10
negative?	

Willingness to Pay

Ques 100-105

Table 68: Renovations not support by CMHC

Spent money on renos apart from those supported by CMHC?	
yes	6
no	9

(Ques 100)

Nature of renovations		cost
various things over years	1	don't know
bathroom redone - plus--->		
chairlift to basement - plus --->		
back deck on house/2nd exit	1	$17,700
ramp on back of house	1	don't know
replacement windows	1	don't know
3rd bedroom; window wells; re-placed stovetop; fence; replaced furnace; replaced part side-walk/widened/leveled	1	5,500
bathroom work; new washer/dryer	1	6,000

(Ques 101)

When were other renos done?	
before CMHC mods	5
at same time	1
after CMHC mods	

Table 69: If money not available

IF CMHC $ not available would you have paid?		when	
yes	5	sooner	
no	10	later	3
maybe		same time	1
don't know		over time	1

Explanation/comments (Ques 102-103)	
financial situation would not allow	10

Table 70: If cash grant?

If cash grant without strings attached?	
yes	15
no	
not sure	

Percentage would accept?		
20%		
40%		
60%	1	$13,750/$8,250
80%	2	$3,500/$2,800
100%	12	

General Probes

Ques 106-109

Table 71: CMHC Program		(Ques 106-107)	
what like best?		**what like least?**	
speed of CMHC process	2	having to pay extra $	
CMHC people are excellent,		because of poor estimate	2
very helpful and efficient	4	CMHC not paying all bill	1
easy application	1	attitude of CHMC representative	1
getting the help	1	took 8 months from application	
solved lots of issues	1	to work to be done	1
increased security & well-being	1	program not marketed well enough	1
program availability	4	contractor who harrassed beneficiary	1
freedome to select what		nothing	4
actually needed	2	the upheaval & wait to get work done	1
difference made in living	1	difficult with deadlines & type of	
that they acceped us	1	information needed	2
		having to get the estimates	1
		having to redo estimates because	
		could not use or central air (A12)	1

Table 72: CMHC- sponsored renovation(s)		(Ques 108-109)	
what like best?		**what like least?**	
cleaner home	1	the disruption	4
more able to breathe	1	having to do windows upstairs -	
got everything wanted	1	requested by CMHC	1
chairlift more reliable/battery-run	1	aesthetics (mis-matched tiles)	1
increased safety/mobillity	3	nothing	8
new furnace	2	having to move out during renos	1
my life is easier	1	dealing with electration difficult	1
shower	1	time needed to get compressor up and	
stair railings & door replacement	1	running	1
aesthetically nice, well done	1		
overall increase in QL	1		
everything	2		
new roof	1		
hot water tank	1		
bathroom and ramp	1		
too early to tell (finished May 05)	1		

Appendix G

An Example of a Costs-Avoided Methodology (HASI, 1994)

Appendix G: An Example of Costs-Avoided Methodology (HASI, 1994)

In 1994, CMHC undertook a survey of HASI beneficiaries and in 1998 published an evaluation entitled *Housing Initiatives under the National Strategy for the Integration of Persons with Disabilities,* which drew upon the survey data. The mail out survey addressed nearly all persons (1032) who received HASI financial assistance in 1992.[1] As with RRAP-D, the most frequent HASI modifications were to the bathroom (approximately 75%) and to the entrance to the home (67%).

The study defined "independence" as, first, the ability to carry out the normal activities of every day life by oneself and, second, the ability to stay in one's current home rather than move in with care givers or move to an institutional residence.[2]

The part of the study most relevant to a cost-benefit framework was entitled "Cost Effectiveness of the HASI Program".[3] It stated "*The key rationale for HASI was to provide seniors with the opportunity to remain in their own homes by facilitating their ability to carry out activities of daily living with minor home adaptations*."[4] The cost-effectiveness analysis considered the costs and benefits of HASI solely in this regard – that is, how long did HASI prolong the beneficiaries' stay their present homes, and with what financial and economic results?[5]

The administrative costs to deliver $8,626,624 in loans were estimated to be $2,129,681.[6] These did not include any costs to clients for their time or expenses in applying to HASI or managing the renovation project. However CMHC estimated that clients expended $553,872 to pay for part of the work, either because some expenses were ineligible under CMHC guidelines or because the total cost exceeded the HASI loan ceiling.

The housing costs of HASI clients who would have moved out of their house without HASI assistance (estimated by the evaluators to be about one third of the sample of clients) were approximately $11,120 per year. In addition, the costs of in-home care[7] for these persons were estimated. Only the costs that would not be incurred in an institutional setting, or that would be included within the overall fees charged by an institution, were included in the estimate. On the basis of regional data from British Columbia, the average cost of in-home services was assumed to be $2700, and this was doubled (a "guesstimate") to account for informal in-home services by friends and relatives.

Except on an anecdotal basis, the study was not able to ascertain whether the use of in-home services had been significantly reduced by the HASI renovations. In most cases it appeared to the authors that a reduction in such costs was unlikely.

Set against these costs were the benefits of avoiding institutionalization. The value of this benefit was estimated from Statistics Canada's *Survey of Residential Care Facilities for the Aged*. In 1992-93 the average cost (across all levels of institutional care) was $32,543 per staffed bed per year. The study states that this estimate is probably too high since HASI beneficiaries, if they moved to an institutional setting, would probably require only basic levels of care that is, Type 1 care[8]. On the basis of Hollander (1994) the cost of a Type 1 case was estimated to be $28,312.

The estimate of the incremental impact of HASI was based on the proportion of clients who would have moved out of their homes without HASI (said to be 32%). It was difficult to estimate on a firm basis how long people helped by HASI did in fact remain in their homes since HASI was, at that time, a relatively new program. It would be easier now with a longer history to examine. On the basis of the little that was known at the time, the study concluded that recipients stayed on average for an additional two years in their present homes (guesstimate). A “sensitivity analysis” revealed that HASI was cost-effective if the average additional stay for the 32% of beneficiaries who would otherwise have moved was more than 6 months, on average. The net present value of the program rises rapidly as the additional stay in-home gets longer. The extra satisfaction (utility) of the HASI beneficiaries who were enabled to stay longer in their homes was mentioned but not quantified or monetized.

Limitations of the Costs-Avoided Methodology

The methodology has the following limitations. First, the assumption that without HASI the recipients would have moved to institutional care was unproven. Second, effects on quality of life during tenure in the present dwelling were unmeasured. Third, the evaluators did not measure how much longer HASI recipients actually remained in their homes than they would otherwise have done. The evaluators estimated the incremental costs of institutionalization, but not the incremental benefits. There may also have been a ‘signaling’ problem in the survey. The evaluator signals the desired response when he or she asks program beneficiaries a question like “Would you have changed dwellings if you had not received the grant to modify this one?”

Endnotes:

[1] Six hundred and thirteen persons completed a questionnaire. The evaluation report states that "this response rate was high enough to provide an accurate picture of program approach and performance at the national level". However, of course, this depends on how representative the respondents were of the whole population, and this is unknown. In addition, thirty telephone interviews were conducted in 1995 with persons who had provided detailed responses to the written survey in 1993. At the same time, CMHC Audit and Evaluation Services sent a questionnaire to field staff who delivered the program. The report considered the continuing relevance of HASI in light of disability rates among seniors. Among HASI beneficiaries it found 80% had age-related mobility disabilities.

[2] The first aspect of independence is measurable on a continuum of comfort, improved safety and security, improved ability to perform everyday activity, and improved quality of life. The second aspect of independence relates to avoiding a threshold of discomfort in any of these aspects of life at which the homeowner or tenant would choose to change residences. "Overall about 55% of HASI clients agreed that without the adaptation, they would have had to move and 30% strongly agreed with this statement." (p.23) Forty percent of beneficiaries strongly agreed, and 17.6% moderately agreed, that they would not have made the adaptations without HASI support. It is unknown whether this was driven by inability to pay or unwillingness to pay without a subsidy (because value did not exceed total price). There were large unexplained variations in the 'incremental effect' percentages, by province.

[3] Section 8

[4] p.43

[5] Actually, this question was posed only for single-person households because the study team decided that multi-person households were too complex to analyse.

[6] Table, p.45

[7] Responses to the HASI survey indicated that about half the HASI beneficiaries had used in-home services in the previous six months.

[8] Statistics Canada defines Type 1 care as "that required by a person who is ambulant and/or independently mobile, who has decreased physical and/or mental facilities, and who requires primarily supervision and/or assistance with activities of daily living and provision for meeting psychosocial needs through social and recreational services. The period of time during which care is required is indeterminate and related to the individual condition but is less than 90 minutes in a 24 hour day."

Appendix H

A Contingent Value Method (RRAP, 2003)

Appendix H: A Contingent Value Method (RRAP, 2003)

A version of 'contingent value' approach was recommended to CMHC by the consultants who produced a *Cost-benefit Framework*[1] *for the Residential Rehabilitation Assistance Program* in 2003.[2] This Framework was presented as a working paper towards the end of a two-phase evaluation study of RRAP[3].

The evaluation of RRAP during the period 1995 to 2001 found that many beneficiaries were not, in fact, willing to pay 100% of the renovation costs, some because they were financially not able to do so. Only eleven percent of homeowner RRAP recipients and 19% of landlords reported that they would have done the same renovations even if no subsidy had been available. The evaluation of RRAP's performance indicated that approximately one third of the relevant housing modifications would not have been done in the absence of CMHC funding. About 10% of homeowners would have sold their existing accommodation and changed homes, and 27% would have done fewer modifications or done them later.[4]

The '03 Framework suggested that the willingness-to-pay question be asked of the population at large. This was an unusual choice. When the benefits accrue almost entirely to a small number of beneficiaries, their specific willingness to pay is normally the best measure of value. Researchers normally ask broad populations about their willingness to pay only when the impact of the intervention is widely spread in the community. For example, a proposal to set aside parkland, which in principle all could visit and enjoy, might be valued by the willingness to pay by the whole population. Similarly an oil spill that fouls beaches can be monetized by aggregating the community's willingness to pay for clean up.

Such situations are quite different from HASI and RRAP-D. There are some benefits to the general community but they are likely minor compared with the benefits to the beneficiary household (See Figure 4.1, *Logic Model of RRAP-D and HASI Effects*). Not only are the community benefits minor compared with the specific benefits to individuals, but the general population is largely unaware of the program because few communities have a significant number of HASI and RRAP-D renovations that are visible.

The '03 Framework states: "The proposed evaluation method primarily examines the benefits that society as a whole attribute to the program impacts. It is possible to add to this evaluation the actual net benefits that accrue to program beneficiaries (i.e. RRAP assisted landlords, homeowners and occupants in RRAP-assisted projects) in the form of better health (reduction in health costs), higher productivity, and reduction in maintenance/utility costs, reduced accidents and fire, etc. Hence the total value of the program benefits could include both the societal estimate of program benefits as well as the economic/financial impact among the actual program beneficiaries."[5]

A problem with this statement is that the '03 Framework does not identify what exactly these "societal benefits" are, over and above the benefits to the particular landlords, homeowners and occupants; nor how they would be distinguished from the individual benefits to the recipient households. In our opinion, RRAP does not

seem to be an instance where one would normally ask the population in general what the program benefits are worth.

---

[1] Malatest and Associates, Feb 2003, "RRAP and the Emergency Repair Program: Cost Benefit '03 Framework",

[2] Although 'contingent value analysis' is the core of the cost-benefit '03 Framework described by Malatest, he covers other topics as well. One topic that is important, although it is not, strictly speaking, part of a cost-benefit '03 Framework, is "attribution" - that is, the determination of what effects are truly caused by the program. Malatest refers to the RRAP Evaluation (2003), which used before-and-after-renovation data collection, and also refers to comparisons with persons who applied for funding but did not receive it. This may be a comparable group, but it is not a control group in the rigorous sense. Malatest lists six "types of program benefits" (and measures/issues for each), namely: health improvements; safety; economic/productivity impact; extension of dwelling life; reduction in utility/maintenance costs; and reduction in homelessness. He does not construct a causal model or consider which of these factors lead to the beneficiaries remaining in independent housing longer. Also, one would have to be careful of double counting. For example, 'economic impact' depends partly on other impacts that have already been counted.

[3] Phase 1 by Malatest Associates and Auguste Solutions and Associates, "Residential Rehabilitation Assistance Program Evaluation", May 2003; and Phase 2 "Working Paper on Impacts of Accessibility Modifications on the Clients of RRAP Disability", March 2003.

[4] Table 6.1

[5] Malatest, '03 Framework, February 2003, p.5

Appendix I

Working Paper 2: Contingent Value Analysis of HASI and RRAP-D Benefits

Working Paper 2: Contingent Value Analysis of HASI and RRAP-D Benefits

In 2003 CMHC commissioned a cost-benefit framework[1] for the Residential Rehabilitation Assistance Program (RRAP). This Framework was presented as a working paper towards the end of a two-phase evaluation study of RRAP[2]. The impetus for preparing a framework was the inability of the evaluation team to sum up the effectiveness of RRAP on the basis of the evidence generated by the study methods used in Phase 1 and Phase 2.

The main purpose of the Framework was to describe how to obtain a monetary valuation of the benefits of RRAP housing modifications. The reason why this was difficult was that beneficiaries do not pay for the modifications. Therefore the market mechanism, which normally signals the money value and the beneficiaries' true willingness to pay for the benefits of the dwelling modifications, does not operate. The underlying assumption is that the value of HASI and RRAP-D is what the benefits are worth, not what they cost. Therefore some non-market mechanism is needed to value the benefits.

We know that beneficiaries were not willing to pay 100% of the renovation costs, for whatever reason. Only eleven percent of homeowner RRAP recipients and 19% of landlords reported that they would have done the same renovations even if no subsidy had been available. The evaluation of RRAP's performance during the period 1995 to 2001 indicated that approximately one third of the relevant housing modifications would not have been done in the absence of RRAP-D funding. About 10% of homeowners would have sold their existing accommodation and changed homes, and 27% would have done fewer modifications or done them later.[3]

To cope with this difficult valuation problem, the Framework suggests 'contingent valuation' methods. The term "contingent" means that questions about value are posed in a "what if" format. If it were necessary to pay, how much would you be willing to pay? This question could be asked of the direct beneficiaries, interested parties and indirect beneficiaries such as caregivers, or the population at large.

The Framework suggests that the question be asked of the population at large. This is an unusual choice. When the benefits accrue almost entirely to a small number of beneficiaries, their specific willingness to pay is normally the best measure of value. Broad populations are generally asked about their

willingness to pay only when the benefits are widely spread in the community and the costs are covered by taxes. For example, a proposal to set aside parkland, which in principle all could visit and enjoy, might be valued by a survey of the willingness to pay by the whole population. This is quite different from HASI and RRAP-D, except in regard to effects on the local community (See Figure 1, RRAP-D and HASI Effects). Even in this case, the general population would probably be the appropriate group of people to ask about the value of HASI/RRAP-D in their community only in communities were there had been a significant number of cases over time.

The Framework states:

"The proposed evaluation method primarily examines the benefits that society as a whole attribute to the program impacts. It is possible to add to this evaluation the actual net benefits that accrue to program beneficiaries (i.e. RRAP assisted landlords, homeowners and occupants in RRAP-assisted projects) in the form of better health (reduction in health costs), higher productivity, and reduction in maintenance/utility costs, reduced accidents and fire, etc. Hence the total value of the program benefits could include both the societal estimate of program benefits as well as the economic/financial impact among the actual program beneficiaries."[4]

A problem with this statement is that the Framework does not identify what societal benefits there are over and above the benefits to the particular landlords, homeowners and occupants. Undoubtedly there are some additional societal benefits (as described in Figure 1 of our report) but they are probably small relative to the benefits that accrue specifically to those persons awarded assistance.

Indeed, RRAP does not seem to be an instance where one would normally ask the population in general what the program benefits are worth. Therefore we find the discussion in the Framework of the appropriate sample size as it relates to the whole population of Canada somewhat beside the point. Actually we do not agree with the characterization of sampling error in this case. Malatest considers what the appropriate sample size would be for a survey, and shows a table[5] of sampling errors for three samples from the Canadian general population (sample sizes 1000, 2000 and 5000). However, the sampling errors quoted in the table depend not only on the relevant population size and sample size, but also on the distribution of values of the variable being estimated (which is not mentioned).

The Willingness-to-Pay of Direct Beneficiaries

RRAP-D and HASI beneficiaries could be asked what they would be willing to pay for the modifications if they had to pay; or how much money they would be willing to accept instead of having the modifications. The actual questions might be:

> *"What would you be willing to pay for the proposed modifications if you were required to pay the whole cost?" or*
>
> *"What amount of money would you be willing to accept instead of having the modifications?"*

In theory, these two questions should lead to identical monetary valuations of program benefits, although, in practice, because of the inaccuracies typical of self-reporting of intentions and values, the results may vary. In the case of HASI or RRAP-D, the first formulation of the question (what would you be willing to pay) appears to be impractical.

The beneficiaries are low-income people. Asking them what they would be willing to pay for the modifications if they had the money is to ask them to make a complex leap of imagination. If they were sufficiently wealthy to afford the modifications, what would they be willing to pay for them? Well, first, this obviously depends how wealthy they were. The marginal utility of income declines as wealth increases. To put it another way, if they were more wealthy they would be willing to pay more to improve their quality of life through modifications to their dwelling. If they were less wealthy, and therefore had other competing priorities that they could not afford in addition to the housing modifications, they would generally be willing to pay less. The specifications of 'wealth scenarios' could get quite complex. It seems unlikely that beneficiaries, including elderly and disabled people, could reasonably be expected to make these hypothetical mental calculations.

The alternative formulation of the question appears to be more appropriate to the HASI and RRAP-D clientele. What payment would the beneficiary accept in lieu of the HASI or RRAP-D award? This is still hypothetical, of course, but it is a question that a beneficiary could plausibly be asked to address. It could be asked before and\or after the renovations. Asked before the renovation, the question could be: "What would you say if you were offered a

no-strings-attached cash payment of $ ----- instead of the (HASI, RRAP-D) assistance with the renovation?"

Obviously one could not simply ask how little the applicant would be willing to accept in cash instead of the renovation assistance with any hope of getting useable answers. If CMHC policy were to accept any cash payment less than 100% of the renovation assistance, then the appropriate strategic response by applicants would be to say they would accept 99% in cash. Why would they say less?

This choice (cash or program assistance) could be made more real for applicants in various ways. CMHC could, for instance, actually offer the choice to all persons at the time they were awarded HASI or RRAP-D assistance, and after bids had been received for the work, so the cost of the work was known. People could be offered sums that varied between say 10% of the HASI/RRAP-D assistance and 100%. Who got offered what amount would be determined by a random-number generator.

To illustrate, consider the situation where the applicant was offered 60% of the expected cost of the renovation in cash, instead of the HASI/RRAP-D assistance. If he or she accepted the cash, then one can safely assume that the renovations were not worth more, in the eyes of the beneficiary (and CMHC would have saved some money). If the beneficiary rejected the cash, in favour of the renovation assistance, then one can assume that the renovation assistance was worth more than the 60%, in the eyes of the beneficiary. If a beneficiary rejected a 70% cash payment, then we know that the perceived value is between 71% and 100%. Similarly, if a beneficiary rejected a 10% offer, then we know that the perceived value lies between 11% and 100%.

The cash-or-program assistance decisions by the applicant do not pinpoint exactly how much each renovation is worth in the eyes of the beneficiary. However they do indicate bands of value. Given a large number of cases, one could do a statistical analysis of the results that would identify the band of value on average. For instance, we might find that, on average, the beneficiaries value the renovation assistance as equal to a cash grant of between 55% and 68% of the potential cost of the renovation.

This cash-or-program experiment could be carried on continuously, or for a limited period of time, say one year. Also, the offer could be made to all recipients or only to a sample. Probably the most acceptable design would be

to make the offer to applicants, and to conduct the experiment for a limited period of time. If it were explained to applicants that the point of the exercise was research that CMHC had underway, then it would probably be acceptable. Some applicants might be annoyed to be offered, say, 10% in cash relative to the expected cost of the renovation, especially if they knew that another applicant had been offered 75%, say. However in a real sense they would have been treated equally (equal probabilities of being offered one percentage or another in cash value), and, of course, they have the option of refusing the cash offer and taking the renovation assistance. There would be no legitimate complaint, but CMHC might be taking some risk of being perceived to be unfair.

Alternatively, the question could be asked hypothetically after the renovations, phrased: "Knowing what you now know about how useful the renovations are to you, what would you have said if you had been asked to choose between having the renovations or, instead, receiving a cash payment of $ ---." At this stage the beneficiary has nothing to lose financially, whatever his or her response. They have the renovations complete and paid for by HASI/RRAP-D. Nevertheless they might be embarrassed to say to a representative of the program that, say, they would have accepted 10% in cash, even if they knew that were the case. And, of course, they might not be sure. Estimating what payment one would have accepted and actually facing the choice are two different things.

In another type of program, one could ask what cash payment would be accepted to compensate for discontinuing the benefit. For example, consider an elderly person receiving a daily meal-on-wheels. The question of a cash pay payment (lump sum or daily sum) in lieu of the meals might make sense. However it would not make sense to ask a HASI/RRAP-D beneficiary what cash payment would be acceptable in return for having the renovations torn out and the dwelling returned to its original state.

In the case of HASI/RRAP-D there is an additional complexity. Some of the costs of the inadequate dwelling unit may be borne by caregivers rather than by the elderly or disabled direct beneficiary. Would they be asked as well how much they would be willing to accept in cash in lieu of the renovations? In some cases this might be feasible (where there was just one caregiver, perhaps), but in others not. There is also the issue of the degree to which the primary beneficiary might take the wellbeing of caregivers into account in thinking about the cash or renovations choice. A research design could

encourage the primary program beneficiary to consult with caregivers before making the cash or renovations choice, but could not insist on it.

Quantitative and Qualitative Effects of the Dwelling Modification

Before the beneficiary could make a reasoned choice between cash and the renovations, he or she would need to have a clear and comprehensive picture of the benefits of the renovation to them and to their caregivers. This is asking a lot. The benefits, in this case, are improvements in the quality of life of the beneficiary and/or reductions in the costs of maintaining an acceptable quality of life. This is a complex matter because HASI and RRAP-D can have multiple impacts. Modifications can improve the beneficiary's in-home mobility (home access, ability to move around in the dwelling, and ability to get out of bed or chairs). They can also improve the beneficiary's ability to use facilities and systems in the home (bathroom, kitchen, storage, electrical and heating systems). Is the beneficiary likely to have a clear grasp of the value of improvements in all these areas?

An alternative would be to ask the primary caregiver to make the 'cash or renovations' decision (where there was a primary caregiver). Or perhaps one could reasonably assume that the primary caregiver would in fact make the decision in those cases where the elderly or disabled person's necessary reliance on the caregiver was high.

Potential Measurement Problems

Although the contingent valuation method has been widely used for the past two decades, there is considerable controversy over whether it is a reliable methodology. Researchers have noted several issues.

Strategic valuations

As discussed above, care would have to be taken to avoid providing the respondents with an incentive to inflate or deflate their true willingness to pay for the HASI/RRAP-D benefits.

Phase II of the evaluation of RRAP-D showed that the dwellings in question needed considerably more modification than was completed with RRAP-D assistance. In this situation, the recipient of assistance might exaggerate his or her hypothetical willingness to pay in hopes of receiving additional assistance.

Scale of Assistance

Second, they should not be asked to make too great a leap of imagination in order to be able to state the value in dollars. This means that the beneficiary should have information and experience on which to base a valuation. For example, in another context, people in Ottawa might be asked how much they would be willing to spend to use a trail in the Gatineau Park in the cross-country ski season. This is a reasonable request since the amount of money is small and the respondent can compare the option of using the park with other recreational opportunities which have market prices.

In contrast, if the money involved is large relative to the beneficiary's resources, or if the benefit is complex and difficult to compare with known prices of similar goods, then "contingent valuations" might be difficult to make and might not be robust when they are made. If conditions are not conducive to good contingent evaluation then the dollar values that result might be inconsistent and inaccurate, and might be poor predictors of actual behavior. That is respondents might say they are willing to pay a certain amount, but their behavior in the event might reveal that the amount they are in fact willing to pay is less or more than their "contingent" estimate.

Although 'contingent value analysis' is the core of the cost-benefit framework described by Malatest, he covers other topics as well. One topic that is important, although it is not, strictly speaking, part of a cost-benefit framework, is "attribution". What effects are truly caused by the program? Malatest refers to the RRAP Evaluation (2003) which used before-and-after-renovation data collection, and also refers to comparisons with persons who applied for funding but did not receive it. The latter he calls a "control group", although it is a fully comparable group and therefore not a control group in the rigorous sense.

Malatest lists six "types of program benefits" (and measures/issues for each), namely: health improvements; safety; economic/productivity impact; extension of dwelling life; reduction in utility/maintenance costs; and reduction in homelessness. He does not construct a causal model or consider which of these factors lead to the beneficiaries remaining in independent housing longer. Also, one would have to be careful of double counting. For example, 'economic impact' depends partly on other impacts that have already been counted.

Warm glow effect

When a program provides 'socially approved' goods or services, respondents may express a positive willingness to pay because they feel good about the social good (referred to as the "warm glow" effect). This may be particularly true when the population in general is asked about its (hypothetical) willingness to pay a small amount to subsidize a good cause such as improving the housing of the elderly and disabled. This is important since small dollar increments to 'willingness to pay', extrapolated over a whole population, can add up to large sums. Of course there are literally thousands of good causes and the population is not in fact willing to pay the total amount for all of them as it seems willing to do when asked about them one by one.

Asking HASI/RRAP-D beneficiaries, and family and friends, how much they would be willing to pay for the dwelling modifications, or accept as compensation for not having them, might also raise issues of social approval.

Positive and Negative Associations

Respondents may state a positive willingness to pay in order to signal that they place importance on helping the elderly and disabled in general. Alternatively, some respondents may value the good, but state that they are not willing to pay for it, because they are protesting some aspect of the scenario, such as increased taxes or government involvement in housing. That is, respondents may base their expressed willingness to pay on associations that the researcher did not intend. For example, if asked for willingness to pay for improved mobility in and out of the dwelling, the respondent may actually answer based on the risks that he or she associates, rightly or wrongly, with moving about in a particular neighbourhood.

The Irresponsibility Effect

Some researchers argue that there is a fundamental difference in the way that people make hypothetical decisions relative to the way they make actual decisions. Respondents may fail to take valuation questions seriously because they will not actually be required to pay the amount they say they are willing to pay.

Willingness to Pay/Willingness to Accept Compensation - Disjunction

The valuation question can either be phrased as 'What are you willing to pay (WTP) to receive this good or service?', or 'What are you willing to accept (WTA) in compensation for giving up this good or service?' In theory, the amounts should be identical or at least very close. However, in actually cases

when the two questions have been asked of the same respondents at the same time, the WTA has often substantially exceeded WTP. From an economic point of view this is obviously irrational. Some critics have claimed that this result shows that true valuations are unlikely when the willingness to pay is hypothetical.

Others, however, have pointed out that actual consumers may act in the same manner. That is, 'buyers' will resist paying more than the minimum necessary, and 'sellers' will try to obtain the maximum compensation possible. Therefore if a respondent is switched from one role to another (buyer to seller or vice versa) then his or her expressed valuation of the good or service is bound to change as well. It is only in the interaction between reluctant payers (buyers) and eager gainers (sellers) that a true value is established. That is, value is established not by people deciding in the abstract what they would be willing to pay, but by the interactions between buyers and sellers in a market, where there are many substitutes, complements and competing goods and services. This is not quite true in economic theory. In some cases the equilibrium market value will be an average of all consumers' willingness to pay, but in other cases not. It all depends on the shape of the supply and demand curves.

The Embedding Effect

It has been shown that people are not good at disaggregating their preferences. If they are asked about their willingness to pay for one part of an improvement (say, kitchen improvements), and then asked to value a wider asset in which that improvement is embedded (say, kitchen improvements plus widening the access to the kitchen), then the expressed willingness to pay may be similar. This is the "embedding effect." In some cases it may arise when people answer according to what they think they could afford rather than what they think the good or service is worth in the abstract. If they have a certain budget in mind for home modifications then the budget might influence what they are 'willing to pay'. The idea of 'willingness to pay' in the abstract, divorced from considerations of ability to pay, is an odd notion and a difficult one for many people to deal with.

The Ordering Problem

In some cases, people's expressed willingness to pay for something has been found to depend on where it is placed on a list of things being valued. This is referred to as the "ordering problem." For example, items at the end of a list may be subject to some accumulated resistance to saying that one is willing to

pay still more. Alternatively, an item listed among expensive items might be 'pulled up' in perceived value, or if the difference in value is stark, the item might be deprecated. Context can be influential on what people are willing to pay, sometimes in ways that do not reflect true utility. For example, a person who has just purchased a new automobile may be vulnerable to being sold an expensive extended warranty plan that in another context he or she would not consider worth the money.

Mode of Payment Effects

Respondents may express different willingness to pay, depending on the mode of payment. For example, taxes might elicit protest responses from people who do not want increased taxes in general. Other modes of payment, such as a contribution or donation, may lead people to answer in terms of how much they think their "fair share" contribution is, rather than expressing their opinion of the actual value for the good.

Starting Bid Effects

Some researchers using contingent valuation methods have prompted respondents by suggesting a starting 'bid' (willingness to pay) and then increased or decreased the bid based upon whether the respondent agreed or refused to pay a such sum. In many cases this made the respondent more comfortable. However, it has been shown that the choice of starting bid can have a strong effect on respondents' expressed willingness to pay. To some degree this phenomenon may exist in actual markets. A seller might place a high reserve at an auction, or price a house high to affect buyers' perceptions of value. However the psychology of 'leading' the value perceptions of the respondent may operate more strongly when the valuation is entirely hypothetical.

Information Bias

Information bias may arise when respondents are asked to value attributes with which they have little or no experience. For example, a respondent asked about willingness to pay for a bath lift might respond differently depending on his or her degree of knowledge and experience. In such cases, the amount and type of information presented to respondents may affect their answers.

Non-Response Bias

Non-response bias is potentially a serious concern in any research. It may be particularly problematic in research on willingness to pay if it is systematically linked with factors like wealth, location or availability to answer questionnaires.

Endnotes:

[1] Malatest and Associates, Feb 2003, "RRAP and the Emergency Repair Program: Cost Benefit Framework",

[2] Phase 1 by Malatest Associates and Auguste Solutions and Associates, "Residential Rehabilitation Assistance Program Evaluation", May 2003; and Phase 2 "Working Paper on Impacts of Accessibility Modifications on the Clients of RRAP Disability", March 2003.

[3] Table 6.1

[4] Malatest, Framework, February 2003, p.5

[5] Table B-2

Appendix J

Working Paper 3: Measuring RRAP-D/HASI Benefits by Changes in Quality of LIFE

Measuring RRAP-D/HASI Benefits by Changes in Quality of Life

Introduction

Modifications to the dwelling supported by RRAP-D and HASI are expected to have the following effects on grant recipients:

1. Improvement in the beneficiary's quality of life
2. Reduction in the cost to maintain the same quality of life

The costs that may be reduced include costs of formal service providers and costs to care givers (family and friends). These costs may have a 'quality of life' aspect, as well, for formal service providers and care givers. That is, the risk, difficulty or unpleasantness (apart from out-of-pocket costs) of service or care giving may be reduced.

We expect that 'improvements in the beneficiary's quality of life' are likely to be the major first-order effect of RRAP-D and HASI. These improvements may then have second-order effects, including reducing demands on service providers and care givers, and/or reducing pressure on the beneficiary to change dwellings, either to another autonomous dwelling or to a managed-care institution.

The question addressed in this paper is whether one can measure the value of that first-order effect on beneficiaries – the improvement in their quality of life.

Counting Improvements in the Quality of Life

In the past decade a considerable literature has been devoted to measuring the relative cost effectiveness of different interventions (mostly health interventions) that improve the length and quality of life. This research was driven by the need a standard unit of value in cost-effectiveness analysis. If the value of an intervention can be assessed in terms of a 'cost per X' (where 'X' is a standard unit of quality of life) then one would know which interventions are more cost-effective.

Defining a standard unit of outcome, 'X', however, is not easy. At first, researchers tried to work with the concept of life extension (one year of extra life would be the standard unit of benefit). However this is not a satisfactory metric by itself because no one regards a year of healthy life as

equal to a year afflicted with disease and pain. Therefore an effort has been made to combine considerations of life extension with considerations of quality of life, in order to define a standard unit of benefit.

A standard unit of benefit thus defined is the HALY, or `Health Adjusted Life Year.' This is a generic term that covers two more specific concepts - the QALY or `Quality Adjusted Life Year' and the DALY or `Disability Adjusted Life Year'.

In the case of RRAP-D and HASI we do not expect the interventions to make a significant difference to length of life, except in a few cases perhaps. Therefore what interests us most in this methodology is effects on quality of life, which can be measured in QALYs (with length of life held constant).

The QALY combines life expectancy with a quality of life measure, from 0 (dead) to 1 (perfect health). For example, say a person is 25, with a life expectancy if male of 50.6 years, and, if female, 55.5. If a medical intervention saves this person’s life returning him or her to perfect health. What is the outcome gain? 50.6 or 55.5 QALYs? No. Although the person may have good health now, one can predict a period of reduced quality of life before death, so the gain would be less, say 42.6 or 47.5 QALY. If the intervention were only partially successful, and the person becomes permanently disabled, and their quality of life falls from 1.0 to 0.6, then the outcome gain would be only 25.5 or 28.5 QALYs.

These preference scores have been documented for various populations, mainly in the United States. In one catalogue of preference scores, for example, under ICD-9 Category “Mental Disorders”, the preference score for a caregiver after six months of standard care for a demented patient is said to be 0.53, and with a caregiver support program, 0.64.

HASI and RRAP-D, in most instances, probably do not influence life expectancy significantly. The time period during which the changes in quality of life will be enjoyed by the beneficiary is the time likely to be spent in this dwelling (t_b). It is difficult to estimate this time period because it is influenced by many factors.

Self-Reported Quality of Life Measures

This ‘quality of life’ (sometimes called ‘utility’ or ‘preference weight’) is difficult to measure. The method generally used has been tried is to ask

patients or the public to estimate a number for the quality of life of a given condition, or to rank a number of different conditions in order of their quality of life.

Another self-reporting approach to measuring quality of life is through a questionnaire that presents ‘standard gamble' or ‘time trade off' questions. In the ‘standard gamble', the respondent is asked to imagine a hypothetical situation in which he or she has a certain chronic disease and is offered a medical treatment that has some chance of curing and some chance of killing. Does he or she take the treatment? If the person accepts the gamble at 50:50 he or she is thereby valuing their quality of life (hypothetically) at 0.5. This is a ‘preference score’. Some of the states scored resemble disabilities that are common in RRAP-D; but they are fairly crude measures. I haven’t found any that a sufficiently fine to discriminate between having a disability in an unsuitable dwelling and having the same disability in a more suitable dwelling. However, conceptually the measurement problem is not different.

Professional Assessment of Quality of Life

It is also possible to assess a change in the quality of life in two steps. First, one might assess factors underlying the quality of life on the basis of objective criteria. For example, a RRAP-D/HASI beneficiary’s condition might be assessed on a scale of 1-3 in 5 different areas - mobility, pain, ability to perform usual daily activities, ability to look after oneself, and depression. Ideally, this would be done by occupational therapists, but, with less precision, it might be done by the beneficiaries themselves.

Once these ratings are available, they could be converted to QALYs either be asking the beneficiaries for rankings (self-reports), or by asking professionals (doctors, occupational therapists) to rank the changes in quality of life against other conditions whose preference scores are already established by prior research.

Calculation of Cost-Effectiveness

Once one has a preference score for the health state (quality of life), and knows the relevant life expectancy, then a cost-effectiveness ratio can be calculated. This is done by taking the cost of a treatment and dividing by the health gain. The result is a `cost-utility ratio' or $/QALY. This lower the

ratio the more cost-effective is the treatment. Values that have been calculated range from less than $200/QALY to more than $2million/QALY.[i]

DALY

Another similar metric is the DALY or Disability Adjusted Life Year. The DALY scale is from 0.0 for perfect health to 1.0 for dead, and it is estimated for particular diseases, instead of a health state. An even more important difference is that in this measure, the value of a healthy person's life depends on age. The DALY function has the form $C.age^{(-age/25)}$ which is low at low or high age, and peaks at age = 25. The constant C (0.16243) makes the average DALY over your life expectancy equal to one.

DALYs have typically been discounted.at 3% (QALYs are not normally discounted). The further in the future the benefit is, the less it is worth now. For example, a treatment that extends a person's lifespan from 75 to 85 is more cost-effective if done to a 75-year old than to a 25-year old who sees no benefit for 50 years.

In both QALYs and DALYs, the elderly and the disabled are treated differently because their quality of life is less than a healthy person in the prime of life. Therefore the increments that are possible from an intervention may be less than those available to the fully healthy young person.

DALY seems more strongly advantageous to young adults. Does this mean they should be treated in preference to their parents and in preference to their children? The advocates of DALYs have a rejoinder that although it is true that DALYs discriminate by age, in another sense everyone is treated the same, assuming that we all move through all of the age groups over our lifetime.

Summary

Quality of life can be approached through self-reporting by beneficiaries or through professional assessment.

Professional assessment is likely to be more consistent and accurate. It would involve two steps:

1. Assessment of the change in the life situation (condition) of the beneficiaries consequent to RRAP-D/HASI, on the basis of criteria

such as mobility, pain, ability to perform usual daily activities, ability to look after oneself, and depression

2. Assessment of the value of the changes in each case by comparison with ranges of preference scores arrived at in previous research

These procedures would require significant amounts of professional time, but might be possible for a small random sample of beneficiaries.

It would also be possible, in theory, to ask beneficiaries to self-assess in regard to the change in their condition and/or to rank the value of those changes against benchmarks. However that is asking a lot of an elderly and disabled clientele.

Glossary: Cost Effectiveness Terms

Cost-effectiveness analysis:

A technique by which two or more alternatives are ranked according to their incremental cost per unit of benefit. For example, an alternative that costs $12 per unit of benefit ranks above one that costs $15 per unit of benefit.

Cost-benefit analysis:

A technique by which the net value of an intervention is calculated, in dollars, taking all costs and benefits into account. The net value is normally expressed as a 'net present value' and alternatives may be ranked in order of their net present values.

Cost-effectiveness ratio:

Cost per unit of benefit (such as dollars per life-year gained) or the number of units of benefit per unit cost (such as life-years gained per $million of investment).

Cost-utility analysis:

A type of cost-effectiveness analysis that uses a 'quality-adjusted life year' (QALY) as the unit of benefit.

Cost-utility ratio:

The incremental cost per quality adjusted life year (dollars per QALY).

Discounting:

The calculation of the present value of future events (the future events might be, for example, expenditures, or income, or health outcomes such as incremental QALYs). Discounting allows items that occur at different times to be directly compared, where otherwise the time variability would obscure any comparison of their relative values.

Effectiveness:

The extent to which an intervention achieves desirable outcomes, which in a health context may be such things as cases of disease prevented, years of life saved, or quality-adjusted life years saved.

Health state:

The condition of an individual's health, including any disease or disability and functional status.

Incremental cost (benefit):

The difference between costs (or benefits), given an intervention, and costs (or benefits) without the intervention.

League table:

A table ranking interventions by their cost-effectiveness ratios.

Net costs:

The total cost of an intervention, taking into account any savings in medical resources that the intervention may produce (for example, a drug therapy that decreases hospitalization would have a net cost that included the price of the drug, minus the savings in hospitalization).

Panel on Cost-Effectiveness in Health and Medicine:

The Panel was convened by the U.S. Public Health Service in 1993, and was chaired by Louise B. Russell and Milton C. Weinstein. The Panel developed a set of recommendations to standardize the methods used in conducting cost-effectiveness analyses in order to enhance the comparability of cost-effectiveness studies across interventions and conditions.

Preference weights:

The numerical score associated with the value attached to a given health state. A commons scale of preference weights uses scores 1.0 (perfect health) and 0.0 (dead). Some studies have used values less than 0 for health states considered worse than dead.

Quality-adjusted life years (QALYs):

A quality-adjusted life year is the product of a time period and a score (preference weight) for the quality of life during that period. If a life is saved by an intervention, then the number of QALYs gained equals the person's incremental life-expectancy (which will vary according to the person's age when saved), with each incremental year weighted by a preference weight that expresses the expected quality of life at each age. For example, if an eighty-five year old person gained three additional years of life that would be fewer QALYs than would be normally gained by a twenty-year old in similar circumstances. Of course, this depends on their states of health during the incremental three years.

Quality rating scale:

A method of ranking health states by preferences, using a graphic scale (typically a line or a depiction of a thermometer) with one end representing the

best health state and one end representing the worst. The respondent is asked to evaluate a given health state by placing it on the scale between these anchors.

Sensitivity analysis:

Analyses of how 'sensitive' an outcome is to change in a particular variable. That is, for example, by what percentage does the outcome change if the input variable changes by 10%?

Standard gamble:

The 'standard gamble' is a method of assessing how people value certain states of health (that is, assessing their perceived quality of life in each health state). The respondent is asked to indicate whether he/she would accept a treatment that would lead to one of two outcomes with known probabilities. The two outcomes are usually (1) a full cure leading to one incremental year in perfect health, and (2) and immediate painless death. The hypothetical probabilities are varied systematically to find that probability at which the respondent is indifferent between undertaking the treatment or not. For example, if the respondent is indifferent between the two options when the probability of a cure is 20%, then the preference score is 0.8 (on a scale of 0.0 dead to 1.0 perfect health). One assumes that the higher the probability the respondent will accept of death associated with treatment, the worse the quality of life without intervention.

Time trade-off:

Another method for assessing quality of life (preferences for a given health state), in which the respondent is asked how much time he or she would be willing to trade from a given lifespan in the health state, to have the remaining lifespan in perfect health. For example, a respondent might have a 40 year life expectancy in a given health state, and might be willing to trade 10 years in order to have a 30 year life expectancy in perfect health.

Utility:

The preference of an individual for a particular health state or treatment outcome measured using the standard gamble technique. Utilities for a given health state have been measured by different researchers using different populations, including a representative sample of the general public, patients who have experienced the disease state or outcome, or clinicians, or other surrogate respondents.

References:

Gold, M.R., et al, "HALYS and QALYS and DALYS, Oh My: Similarities and Differences in Summary Measures of Population Health", Annual Review of Public Health, Vol. 23: 115-134. May 2002.

Shapiro, I., "Life, At What Price?" Walrus Magazine, November 2004.

Review Studies (Listed chronologically)

Horsman, John, William Furlong, David Feeny, and George Torrance, "The Health Utilities Index (HUI(r)): Concepts, Measurement Properties and Applications." Health and Quality of Life Outcomes (electronic journal) (Vol. 1: 54, October 16, 2003), at http://www.hqlo.com/content/1/1/54

Torrance GW, Furlong W, Feeny D. "Health utility estimation." *Expert Review of Pharmacoeconomics and Outcomes Research*, Vol. 2(2), 2002, pp 99-108. [Constructs and Inter-Instrument Comparisons]

Eiser, Christine, Rachel Morse, "The Measurement of Quality of Life in Children: Past and Future Perspectives." *Developmental and Behavioral Pediatrics*, Vol. 22, No. 4, 2001, pp 248-256. [Measurement Properties, Inter-Instrument Comparisons]

Furlong, William J., David H. Feeny, George W. Torrance, Ronald D. Barr, "The Health Utilities Index (HUI[R]) system for assessing health-related quality of life in clinical studies." *Annals of Medicine*, Vol. 33, No. 5, July, 2001, pp 375-384. [Description of Systems; Reliability; Scoring; Validity][Canada]

Feeny, David H., George W. Torrance, and William J. Furlong, "Health Utilities Index," Chapter 26 In Bert Spilker, ed. *Quality of Life and Pharmacoeconomics in Clinical Trials.* Second Edition. Philadelphia: Lippincott-Raven Press, 1996, pp 239-252. [Description of Systems; Reliability; Scoring; Validity][Canada, Pediatric ALL]

Methodological Studies [Cross-Cultural Validation; Description; Development of Systems; Interpretability; Reliability; Responsiveness; Scoring; Theory; Validity] (Listed alphabetically by 1st author)

Barr, Ronald D., David Feeny, and William Furlong, "Economic Evaluation of Treatments for Cancer in Childhood." *European Journal of Cancer*, Vol. 40, No. 9, June, 2004, pp 1335-1344. [HUI2; HUI3][childhood cancer]

Barr RD, Saleh M, Furlong W, Horsman J, Sek J, Pai M, Walker I. "Health status and health-related quality of life associated with hemophilia." *Am J*

Hematology,Vol. 71, 2002, pp 152-160. [HUI2, HUI3, Construct Validity; Responsiveness][Canada, Hemophilia]

Barr, Ronald D., Claire Petrie, William Furlong, Marilyn Rothney, and David Feeny, "Health-Related Quality of Life during Post-Induction Chemotherapy in Children with Acute Lymphoblastic Leukemia in Remission: An Influence of Corticosteroid Therapy." *International Journal of Oncology,* Vol. 11, 1997, pp 333-339. [Construct Validity; Responsiveness][Canada, Pediatric ALL]

Blanchard, Chris, David Feeny, Jeffrey L. Mahon, Robert Bourne, Cecil Rorabeck, Larry Stitt, and Susan Webster-Bogaert, "Is the Health Utilities Index Valid in Total Hip Arthroplasty Patients?," *Quality of Life Research*, Vol. 13, No. 2, March, 2004, pp 339-348. [HUI2; HUI3; Construct validity] [Canada, hip disease]

Blanchard, Chris, Isabelle C, and David Feeny, "Comparing Short Form and RAND Physical and Mental Health Summary Scores: Results from Total Hip Arthroplasty and High-Risk Primary-Care Patients," *International Journal of Technology Assessment in Health Care*, Vol. 19, No. 4, 2003, pp 1-7. [HUI3; Construct Validity][Canada, clinical, hip disease, osteoarthritis, total hip arthroplasty]

Blanchard, Chris, David Feeny, Jeffrey L. Mahon, Robert Bourne, Cecil Rorabeck, Larry Stitt, and Susan Webster-Bogaert, "Is the Health Utilities Index Valid in Total Hip Arthroplasty Patients?," *Quality of Life Research* (2003), in press. [HUI2; HUI3; Construct Validity][Canada, osteoarthritis, total hip arthroplasty]

Blanchard, Chris, David Feeny, Jeffrey L. Mahon, Robert Bourne, Cecil Rorabeck, Larry Stitt, and Susan Webster-Bogaert, "Is the Health Utilities Index Responsive in Total Hip Arthroplasty Patients,?" *Journal of Clinical Epidemiology*, Vol. 56, No. 11, November 2003, pp 1046-1054. [HUI2; HUI3; Construct Validity; Responsiveness][Canada, clinical, hip disease, osteoarthritis, total hip arthroplasty]

Bosch, Johanna L., Elkan f. Halpern, and G. Scott Gazelle, "Comparison of Preference-Based Utilities of the Short-Form 36 Health Survey and Health Utilities Index Before and After Treatment of Patients with Intermittent Claudication." *Medical Decision Making*, Vol. 22, No. 5, September-October 2002, pp 403-409. [HUI2, HUI3, Construct Validity; Responsiveness] [Netherlands, Intermittent Claudication]

Bosch, Johanna L., James K. Hammitt, Milton C. Weinstein, and Maria G. Hunink, "Estimating General-population Utilities Using One Binary-gamble Question per Respondent." *Medical Decision Making,* Vol. 18, No. 4, October-December, 1998, pp 381-390. [Scoring][USA]

Boyle Michael H, and George W. Torrance, "Developing Multi-attribute Health Indexes." *Medical Care,* Vol. 22, No.11, November, 1984, pp 1045-1057. [Development of Systems]

Boyle, Michael H., William Furlong, David Feeny, George Torrance, and Jeff Hatcher, "Reliability of the Health Utilities Index - Mark III Used in the 1991 Cycle 6 General Social Survey Health Questionnaire." *Quality of Life Research,* Vol. 4, No 3, June, 1995, pp 249-257. [Reliability][Canada]

Brazier, John, Jennifer Roberts, Aki Tsuchiya, and Jan Busschbach, "A Comparison of the EQ-5D and SF-6D Across Seven Patient Groups." *Health Economics*, Vol. 13, No. 9, September, 2004, pp 873-884. [HUI3; Construct Validity; Responsiveness]

Buron, Catherine, Catherine Le Galès, Nathalie Costet, et al. "Développement d'un Système de Classification Générique d'états de santé pondéré par les Utilités: le Health Utility Index." *Communication Présentée au XIXème Séminaire des Économistes de la Santé.* Lyon, October 16-17, 1997. [Cultural Adaptation][France]

Cadman, David, and Charles Goldsmith, "Construction of Social Value or Utility-Based Health Indices: The Usefulness of Factorial Experimental Design Plans." *Journal of Chronic Disease,* Vol. 39, No. 8, 1986, pp 643-651. [Development of Systems; Scoring]

Cadman, David, Charles C. Goldsmith, and P. Bashim, "Values, preferences, and decisions in the care of children with developmental disabilities." *Developmental and Behaviourial Pediatrics,* Vol. 5, 1984, pp 60-64. [Development of Systems; Scoring]

Cadman, David, Charles Goldsmith, George W. Torrance, et al., "Development of a Health Status Index for Ontario Children," *Final Report to the Ontario Ministry of Health on Research Grant DM648 (00633)*. Hamilton, Ontario: McMaster University, 1986. [Development of Systems; Scoring]

Conner-Spady, Barbara, and Maria E. Suarez-Almazor, "Variation in the Estimation of Quality- Adjusted Life-Years by Different Preference-based Instruments." *Medical Care*, Vol. 41, No. 7, July, 2003, pp 791-801. [HUI3; Construct Validity; Responsiveness][Canada, musculoskeletal disease]

Costet, Nathalie, Catherine Le Galès, Catherine Buron, Françoise Kinkor, Mounir Mesbah, Judith Chwalow, Clinical and Economic Working Groups, and Gérard Slama, "French Cross-Cultural Adaptation of the Health Utilities Index Mark 2 (HUI2) and 3 (HUI3) Classification Systems." *Quality of Life Research,* Vol. 7, No. 3, April, 1998, pp 245-256. [Cross-Cultural Validation][France]

Côté, Isabelle, Karen Farris, and David Feeny, "Is Adherence to Drug Treatment Correlated with Health-Related Quality of Life?" Quality of Life Research, Vol. 12, No. 6, September, 2003, pp 621-633. [HUI2; HUI3; Construct Validity][Canada]

de Vries, Sybolt O., Wietze D. Kuipers, Maria G. M. Hunink, "Intermittent Claudication: Symptom Severity Versus Health Values." *Journal of Vascular Surgery,* Vol. 27, 1998, 422-430. [Construct Validity][Netherlands, Peripheral Artery Disease]

Drummond, Michael, "Introducing Economic and Quality of Life Measurements into Clinical Studies." *Annals of Medicine*, Vol. 33, No. 5, July, 2001, pp 344-349.[Review]

Drummond, Michael F., Greg L. Stoddart, and George W. Torrance, Methods for the Economic Evaluation of Health Care Programmes. Oxford: Oxford University Press, 1987. [Description of Systems and Scoring; Theory]

Drummond, Michael F., Bernie O'Brien, Greg Stoddart, and George W. Torrance, Methods for the Economic Evaluation of Health Care Programmes. Second Edition. Oxford: Oxford University Press, 1997. [Description of Systems and Scoring; Theory]

Eiser, Christine, Rachel Morse, "The Measurement of Quality of Life in Children: Past and Future Perspectives." *Developmental and Behavioral Pediatrics*, Vol. 22, No. 4, 2001, pp 248-256. [Measurement Properties, Inter-Instrument Comparisons]

Feeny, David, Lieling Wu, and Ken Eng, "Comparing Short Form 6D, Standard Gamble, and Health Utilities Index Mark 2 and Mark 3 Utility Scores: Results from Total Hip Arthroplasty Patients." *Quality of Life Research*, in press. [HUI2; HUI3; Scoring][Orthopedic surgery]

Feeny, David, Chris Blanchard, Jeffrey L. Mahon, Robert Bourne, Cecil Rorabeck, Larry Stitt, and Susan Webster-Bogaert, "Comparing Community-Preference Based and Direct Standard Gamble Utility Scores: Evidence from Elective Total Hip Arthroplasty." *International Journal of Technology Assessment in Health Care*, Vol. 19, No. 2, Spring, 2003, pp 362-372. [HUI2; HUI3; Scoring][Canada, osteoarthritis, total hip arthroplasty]

Feeny, David, William Furlong, Saroj Saigal, and Jian Sun,"Comparing Directly Measured Standard Gamble Scores to HUI2 and HUI3 Utility Scores: Group and Individual-Level Comparisons." *Social Science & Medicine*, Vlo 58 No. 4, 2003, pp 799-809. [HUI2; HUI3; Scoring][Canada, Extremely low birthweight, pediatrics]

Feeny, David, "A Utility Approach to Assessing Health-Related Quality of Life." *Medical Care*, Vol. 38, No. 9, Supplement II, September, 2000, pp II-151 - II-154. [Theory]

Feeny, David and George W. Torrance, "Incorporating Utility-Based Quality-of-Life Assessments in Clinical Trials: Two Examples." *Medical Care,* Vol. 27, No. 3, Supplement, March, 1989, pp S190-S204. [Theory]

Feeny, David, William Furlong, Ronald D. Barr, George W. Torrance, Peter Rosenbaum, and Sheila Weitzman, "A Comprehensive Multiattribute System for Classifying the Health Status of Survivors of Childhood Cancer." *Journal of Clinical Oncology,* Vol. 10, No. 6, June, 1992, pp 923-928. [Description; Construct Validity][Canada, ALL, Wilms Tumour, Neuroblastoma]

Feeny, David, William Furlong, Michael Boyle, and George W. Torrance, "Multi-Attribute Health Status Classification Systems: Health Utilities Index." *PharmacoEconomics,* Vol 7, No 6, June, 1995, pp 490-502. [Description; Development of Systems]

Feeny, David, William Furlong, George W. Torrance, Charles H. Goldsmith, Zenlong Zhu, Sonja DePauw, Margaret Denton, and Michael Boyle, "Multi-Attribute and Single-Attribute Utility Functions for the Health Utilities Index Mark 3 System." *Medical Care*, Vol. 40, No. 2, February, 2002, pp 113-128. [Scoring HUI3]

Feeny, David H., George W. Torrance, and William J. Furlong, "Health Utilities Index," Chapter 26 In Bert Spilker, ed. *Quality of Life and Pharmacoeconomics in Clinical Trials.* Second Edition. Philadelphia: Lippincott-Raven Press, 1996, pp 239-252. [Description of Systems; Reliability; Scoring; Validity][Canada, Pediatric ALL]

Feeny, David H., George W. Torrance, and Roberta Labelle, "Integrating Economic Evaluations and Quality of Life Assessments," In Bert Spilker, ed. *Quality of Life and Pharmacoeconomics in Clinical Trials.* Second Edition. Philadelphia: Lippincott-Raven Press, 1996, pp 85-95. [Description of Systems and Scoring]

Feeny, David, William Furlong, and Ronald D. Barr, "Multiattribute Approach to the Assessment of Health-Related Quality of Life: Health Utilities Index." *Medical and Pediatric Oncology,* Vol. 31, Supplement 1, 1998, pp 54-59. [Construct Validity; Responsiveness][[Canada, Pediatric ALL]

Felder-Puig, Rosemarie, E. Frey, G. Sonnleithner, David Feeny, H. Gadner, Ronald D. Barr, William Furlong, and Reinhard Topf, "German Cross-Cultural Adapation of the Health Utilities Index and Its Application to a Sample of

Childhood Cancer Survivors." *European Journal of Pediatrics*, Vol. 159, No. 4, April, 2000, pp 283-288. [Cross-Cultural validation; Construct Validity; Reliability/Agreement][German/Austria; Childhood Cancer]

Fisher, Gregory W., "Utility Models for Multiple Objective Decisions: Do They Accurately Represent Human Preferences." *Decision Sciences,* Vol. 10, 1979, pp 451-479. [Theory]

Franks, Peter, Erica L. Lubetkin, Marthe R. Gold, and Daniel J. Tancredi, "Mapping SF-12 to Preference-Based Instruments: Convergent Validity in a Low-Income, Minority Population." Medical Care. Vol. 41, No. 11, November, 2003, pp 1277-1283. [HUI3; scoring][USA]

Furlong, William J., David H. Feeny, George W. Torrance, Ronald D. Barr, "The Health Utilities Index (HUI[R]) system for assessing health-related quality of life in clinical studies." *Annals of Medicine*, Vol. 33, No. 5, July, 2001, pp 375-384. [HUI2; HUI3; Description of Systems; Reliability; Scoring; Validity][Canada]

Furlong, William, George W. Torrance, and David Feeny, "Properties of Health Utilities Index: Preliminary Evidence." *Quality of Life Newsletter,* Numbers 13-14, June, 1995 - January, 1996, pages 3, 4, and 10. [Construct Validity; Reliability]

Furlong, William, David Feeny, George W. Torrance, Charles Goldsmith, Sonja DePauw, Michael Boyle, Margaret Denton, and Zenglong Zhu, "Multiplicative Multi-Attribute Utility Function for the Health Utilities Index Mark 3 (HUI3) System: A Technical Report," McMaster University, *Centre for Health Economics and Policy Analysis Working Paper No. 98-11.*[Scoring][Canada]

To see the abstract for WP98-11 click here or on the **CHEPA 98-11** navigation button on the left. Information on ordering CHEPA Working Papers may be obtained from:
Centre for Health Economics and Policy Analysis,
McMaster University,
1200 Main Street West,
Hamilton, ON L8N 3Z5 Canada;
(905) 525-9140, ext. 22135;
FAX: (905) 546-5211;
E-mail: chepa@mcmaster.ca or on the WWW at
http://chepa.mcmaster.ca/ceb/

Gabriel, Sherine E., Terry S. Kneeland, L. Joseph Melton, III, Megan M. Moncur, Bruce Ettinger, and Anna N. A. Tosteson, "Health-Related Quality of Life in Economic Evaluations for Osteoporosis: Whose Values Should We Use?" *Medical Decision Making,* Vol. 19, No. 2, April-June, 1999, pp 141-148. [Scoring][USA, Osteoporosis]

Garratt, Andrew, Louise Schmidt, Anne Mackintosh, Ray Fitzpatrick, "Quality of life measurement: bibliographic study of patient assessed health outcome measures." *BMJ*, Vol. 324, No. 7351, 15 June 2002, pp 1417-1421. [Review]

Gemke, Reinoud J. B. J., and Gouke J. Bonsel, "Reliability and Validity of a Comprehensive Health Status Measure in a Heterogeneous Population of Children Admitted to Intensive Care." *Journal of Clinical Epidemiology,* Vol 49, No 3, March, 1996, 327-333. [Construct Validity; Reliability][Netherlands, Pediatric Intensive Care]

Glick, Henry A., Daniel Polsky, Richard J. Willke, and Kevin A. Schulman, "A Comparison of Preference Assessment Instruments Used in a Clinical Trial: Responses to the Visual Analog Scale from the EuroQol EQ-5D and the Health Utilities Index." *Medical Decision Making,* Vol. 19, No. 3, July-September, 1999, pp 265-275. [Construct Validity; Scoring][USA, Subarachnoid Haemorrhage, Adult]

Gold, Marthe R., Donald L. Patrick, George W. Torrance, Dennis G. Fryback, David C. Hadorn, Mark S. Kamlet, Norman Daniels, and Milton C. Weinstein, "Identifying and Valuing Outcomes," Chapter 4 in Marthe R. Gold, Joanna E. Siegel, Louise B. Russell, and Milton C. Weinstein, eds., *Cost-Effectiveness in Health and Medicine.* New York: Oxford University Press, 1996, pp 82-134. [Description of Systems; Theory]

Grima, Daniel T., George W. Torrance, G. Francis, G. Rice, A.J. Rosner and L. LaFortune, "Cost and Health Related Quality of Life Consequences of Multiple Sclerosis." *Multiple Sclerosis*, Vol. 6, No. 2, April, 2000, pp 91-98. [Construct Validity][Canada; Multiple Sclerosis]

Grootendorst, Paul, David Feeny, and William Furlong, "Does It Matter Whom and How You Ask? An Investigation into Inter- and Intra-rater Agreement in the 1990 Ontario Health Survey." *Journal of Clinical Epidemiology,* Vol. 50, No. 2, February, 1997, pp 127-135. [Reliability][Canada, Population Health]

Grootendorst, Paul, David Feeny, and William Furlong, "Health Utilities Index Mark 3: Evidence of Construct Validity for Stroke and Arthritis in a Population Health Survey." McMaster University, *Centre for Health Economics and Policy Analysis Working Paper No. 99-06,* June, 1999. [Construct Validity][Canada, Stroke]

Grootendorst, Paul, David Feeny, and William Furlong, "Health Utilities Index Mark 3: Evidence of Construct Validity for Stroke and Arthritis in a Population Health Survey." *Medical Care,* Vol. 38(3), March, 2000, pp 290-299. [Construct Validity][Canada, Stroke]

Harsanyi, John C., "Cardinal Welfare, Individualistic Ethics, and Interpersonal Comparisons of Utility." *Journal of Political Economy,* Vol. 63, 1955, pp 309-321. [Scoring; Theory]

Hatoum, Hind T., John E. Brazier, and Kasem S. Akhras, "Comparison of the HUI3 with the SF- 36 Preference Based SF-6D in a Clinical Trial Setting." *Value and Health*, Vol. 7, No. 5, September, 2004, pp 602-609. [HUI3; Construct Validity; Responsiveness]][Canada and USA, cardiovascular]

Hawthorne, Graeme, Jeff Richardson, "Measuring the Value of Program Outcomes: A Review of Multiattribute Utility Measures." *Expert Reviews in Pharmacoeconomics Research*, Vol. 1, No. 2, 2001, pp 215-228. [HUI3; Review Paper; Construct Validity]

Hawthorne, Graeme, Jeff Richardson, and Neil Atherton Day, "A Comparison of the Assessment of Quality of Life (AQoL) with four other Generic Utility Instruments." *Annals of Medicine*, Vol. 33, No. 5, July, 2001, pp 358-370. [HUI3; Review Paper; Construct Validity][Australia]

Houle, Christian, and Jean-Marie Berthelot, "A Head-to-Head Comparison of the Health Utilities Mark 3 and the EQ-5D for the Population Living in Private Households in Canada", *Quality of Life Newsletter*, No. 24, January-June 2000, pp 5-6. [Construct Validity][Canada]

Keeney, Ralph L., "A Group Preference Axiomatization with Cardinal Utility." *Management Science,* Vol. 22, No. 2, October, 1976, pp 140-145. [Scoring; Theory]

Keeney, Ralph L., "Building Models of Values." *European Journal of Operational Research,* Vol. 37, 1988, pp 149-157. [Scoring; Theory]

Keeney, Ralph L., and Howard Raiffa. Decisions with Multiple Objectives: Preferences and Value Tradeoffs. New York: Cambridge University Press, 1993. First Edition: John Wiley & Sons, 1976. [Scoring; Theory]

Kopec, Jacek A., and Kevin D. Willison, "A Comparative Review of Four Preference-Weighted Measures of Health-Related Quality of Life." *Journal of Clinical Epidemiology*, Vol. 56, No. 4,April, 2003, pp 317-325. [HUI3; Review Article]

Lee, Todd A., William Hollingworth, and Sean D. Sullivan, "Comparison of Directly Elicited Preferences Derived from the SF-36 in Adults with Asthma." *Medical Decision Making*, Vol. 23, No. 4, July-August, 2003, pp 323-334. [HUI2; Scoring][USA, asthma]

Keren, Ron, Susmita Pati, and Chris Feudtner, "The Generation Gap: Differences Between Children and Adults Pertinent to Economic Evaluation of Health Interventions." *Pharmacoeconomics*, Vol. 22, No. 2, 2004, pp 71-81. [HUI2, HUI3]

Le Galès, Catherine, Catherine Buron, Nathalie Coster, Françoise Kinkor, David Feeny, William Furlong, Judy Chwalow, and Pr. Gérard Slama, "Assessment of the Multi-Attribute Preference Function for Health Utilities Index 3 in France: Preliminary Results." *Quality of Life Research,* Vol. 6, No. 7/8, October/December, 1997, p 678 (Abstract). [Cross-Cultural Validation; Scoring][France]

Le Galès Catherine, Catherine Buron, Nathalie Costet, Sophia Rosman, Pr. Gérard Slama, "Developpement d'un index d'etats de sante pondere par les utilites en population francaise: le Health Utilities Index." *Economie et Prevision* (in Press). [Cross-Cultural Validation; Scoring][France]

Le Galès Catherine, Catherine Buron, Nathalie Costet, Sophia Rosman, and Pr. Gérard Slama, "Development of a Preference-Weighted Health Status Classification System in France: the Health Utilities Index." *Health Care and Management Science,* Vol 5(1), 2002, pp 41-52. [HUI3; Cross-Cultural Validation; Scoring][France]

Luce, R. Duncan, and Howard Raiffa, Games and Decisions: Introduction and Critical Survey. New York, John Wiley & Sons, Inc., 1957. [Theory]

Lubetkin, Erica I., and Marthe R. Gold, "Areas of Decrement in Health-Related Quality of Life (HRQL): Comparing the SF-12, EQ-5D, and HUI3." Quality of Life Research, Vol. 12, No. 8, December, 2003, pp 1059-1067. [HUI3; Construct Validity][USA]

Lutetkin, Erica I., and Marthe R. Gold, "Comprehensibility of Measures of Health-Related Quality of Life in Minority and Low-Income Patients." *Journal of the National Medical Association*, Vol. 94, No. 5, May 2002, pp 327-335. [HUI3, Construct Validity, Routine Use][USA]

Maddigan, Sheri L., David H. Feeny, and Jeffrey A. Johnson, "Construct Validity of the RAND- 12 and Health Utilities Index Mark 2 and 3 in Type 2 Diabetes." *Quality of Life Research*, Vol. 23, No. 2, March, 2004, pp 435-448. [HUI2; HUI3; Construct validity][Canada, diabetes]

Maddigan, Sheri L., Sumit R. Majumdar, Ellen L. Toth, David H. Feeny, and Jeffrey A. Johnson, "Health-Related Quality of Life Deficits Associated with Varying Degrees of Disease Severity in Type 2 Diabetes." *Health and Quality of*

Life Outcomes (electronic journal) (Vol 1: 78, December 15, 2003), www.hqlo.com/content/1/1/78 [HUI3; Construct Validity][Canada, diabetes]

Maddigan, Sheri L., David H. Feeny, and Jeffrey A. Johnson, "A Comparison of the Health Utilities Indices Mark 2 and Mark 3 in Type 2 Diabetes." Medical Decision Making, Vol. 23, No. 6, November-December, 2003, pp 489-501. [HUI2; HUI3; Construct Validity][Canada, diabetes]

Mathias, Susan D., Molly M. Bates, David J. Pasta, Miriam G. Cisternas, David Feeny, and Donald L. Patrick, "Use of the Health Utilities Index with Stroke Patients and their Caregivers." *Stroke,* Vol. 28, No. 10, October, 1997, pp 1888-1894. [Construct Validity; Reliability][USA, Alzheimer]

Moy, Marilyn L., Anne L. Fuhlbrigge, Karen Blumenschein, Richard H. Chapman, Alan J. Zillich, Karen M. Kuntz, A. David Paltiel, Barrett T. Kitch, Scott T. Weiss, and Peter J. Neumann, "Association Between Preference-based Health-Related Quality of Life and Asthma Severity." *Annals of Allergy, Asthma, and Immunology*, Vol. 92, No. 9, March, 2004, pp 329- 334. [HUI3; asthma; construct validity][USA, asthma]

Mrus, Joseph M., Michael S. Yi, Kenneth A. Freedberg, Albert W. Wu, Robert Zachin, Heather Gorski, and Joel Tsevat, "Utilities Derived from Visual Analog Scale Scores in Patients with HIV/AIDS." Medical Decision Making, Vol. 23, No. 5, September-October, 2003, pp 414-421. [HUI2; Construct Validity]

Nathan, Paul C., William Furlong, and Ronald D. Barr, "Challenges to the Measurement of Health-Related Quality of Life in Children Receiving Cancer Therapy." *Pediatric Blood and Cancer*, Vol. 43, No. 3, September, 2004, pp 215-223. [Clinical][Canada, pediatric oncology]

Nathan, Paul C., William Furlong, John Horsman, Charmaine van Schaik, M. Rolland, Sheila Weitzman, David Feeny, and Ronald D. Barr, "Inter-Observer Agreement of a Comprehensive Health Status Classification System for Pre-School Children among Patients with Wilms' Tumor or Advanced Neuroblastoma." *Quality of Life Research*, 2004, in press. [Reliability; Construct Validity][Canada, Pediatric Oncology]

Neumann, Peter J., Karen M. Kuntz, Joel Leon, Sally S. Araki, Richard C. Hermann, Ming Ann Hsu, and Milton C. Weinstein, "Health Utilities and Health Status in Alzheimer's Disease: A Cross-Sectional Study of Subjects and Caregivers." *Medical Care,* Vol. 37, No. 1, January, 1999, pp 27-32. [Construct Validity]

Neumann, Peter J., Eileen A. Sandberg, Sally S. Araki, Karen M. Kuntz, David Feeny, and Milton C. Weinstein, "A Comparison of HUI2 and HUI3 Utility Scores

in Alzheimer's Disease", *Medical Decision Making*, Vol. 20, No. 4, October-December, 2000, pp 413-422. [Construct Validity; Scoring][USA; Alzheimer Disease]

Nichol, Michael B., Nishan Sengupta, and Denise R. Globe, "Evaluating Quality-Adjusted Life Years: Estimation of the Health Utility Index (HUI) from the SF-36." *Medical Decision Making*, Vol. 21, No. 2, March-April, 2001, pp 105-112. [HUI2; Construct Validity; Scoring][USA; Primary Care]

O'Brien, Bernie J., Marian Spath, Gordon Blackhouse, J. L. Severens, Paul Dorian, and John Brazier, "A View from the Bridge: Agreement Between the SF-6D Utility Algorithm and the Health Utilities Index." Health Economics, Vol. 12, No. 11, November, 2003, pp 975-981. [HUI3; scoring]

Oostenbrink, Rianne, Henriette A. Moll, and Marie-Louise Essink-Bot, "The EQ-5D and the Health Utilities Index for Permanent Sequelae after Meningitis: A Head-to-Head Comparison." *Journal of Clinical Epidemiology*, Vol. 55, No. 8, August, 2002, pp 791-799. [HUI2; HUI3; Construct Validity][The Netherlands, meningitis, pediatrics]

Patrick, Donald L., and Pennifer Erickson, Health Status and Health Policy: Quality of Life in Health Care Evaluation and Resource Allocation. New York: Oxford University Press, 1993. [Description of Systems]

Petrou,Stavros,"Methodological Issues Raised by Preference-Based Approaches to Measuring the Health Status of Children." Health Economics, Vol. 12, No. 8, August, 2003, pp 697-702. [HUI2; Construct Validitiy]

Pickard, A. Simon, Jeffrey A. Johnson, and David H. Feeny, "Responsiveness of Generic Health- Related Quality of Life Measures in Stroke."Quality of Life Research, 2004, in press. [HUI2; HUI3; Construct Validity; Responsiveness]

Pickard, A. Simon, Jeffrey A. Johnson, David H. Feeny, Ashfaq Shuaib, K. C. Carriere, and Abdul M. Nasser, "Agreement Between Patient and Proxy Assessments of Health-Related Quality of Life after Stroke using the EQ-5D and Health Utilities Index." *Stroke*, Vol. 35, No. 2, February 2004, pp 607-612. [HUI2; HUI3; Inter-rater Reliability][Canada, stroke]

Polsky, D., Keating, N.L., Weeks, J.C., and Schulman, K.A. "Patient choice of breast cancer treatment: impact on health state preferences." *Medical Care*, Vol. 40, No. 11, 2002, pp 1068-1079. [HUI3, breast cancer]

Raat, Hein, Gouke J. Bonsel, Marie-Louise Essik-Bot, Jeanne M. Landgraf, and Reinoud J. B. J. Gemke, "Reliability and Validity of Comprehensive Health Status Measures in Children: The Child Health Questionnaire in Relation to the Health

Utilities Index." *Journal of Clinical Epidemiology*, Vol. 55, No. 1, January, 2002, pp 67-76. [HUI2, Reliability, Construct Validity]

Raat, Hein, Gouke Bonsel, Reinoud Gemke, Erik Verrips, Paul Krabbe, and Marie-Louise Essink-Bot, "Feasibility and Reliability of a Mailed Questionnaire to Obtain Visual Analogue Scale Valuations for Health States Defined by the Health Utilities Index Mark 3." *Medical Care*, Vol. 42, No. 1, January, 2004, pp 13-18. [HUI3, Generalizability, Scoring][Netherlands, pediatrics]

Raina, Parminder, Brenda Bonnett, David Waltner-Toews, Christel Woodward, and Tom Abernathy, "How Reliable are Selected Scales from Population-based Health Surveys? An Analysis Among Seniors." *Canadian Journal of Public Health,* Vol. 90, No. 1, January-February, 1999, pp 60-64. [Reliability of selected HUI3 items]

Rizzo, John A., Steven Pashko, Rebecca Friedkin, John Mullahy, and Jody L. Sindelar, "Linking the Health Utilities Index to National Medical Expenditure Survey Data." *PharmacoEconomics,* Vol. 13, No. 5, Part 1, May, 1998, pp 531-541. [Construct Validity]

Rizzo, John A. and Jody L. Sindelar, "Linking Health-Related Quality-of-Life Indicators to Large National Data Sets." *PharmacoEconomics,* Vol. 16, No. 5, Part 1, November, 1999, pp 473-482. [Construct Validity]

Robertson CMT, Watt JM, Joffe AR, Murphy DB, Nagy JM, McLean DE, Pain KS, Saunders LD. "Childhood morbidity after severe traumatic brain injury: Increased detection with the Multiattribute Health Status Classification." *Pediatr Crit Care Med*, Vol. 2, No. 2, April, 2001, pp 145-150. [HUI2, Content Validity, Inter-rater Agreement] [Canada, Pediatrics, Brain Injury]

Ruiz, Miguel, Javier Rejas, Javier Soto, Antonio Pardo, and Irene Rebollo, "Adaptación y validación del Health Utilities Index Mark 3 al castellano y baremos de corrección en la población española." *Medicina clinica (Barcelona)*, Vol. 120, No. 3, 2003, pp 89-96. [HUI3; Scoring; Generalizability][Spain]

Saigal, Saroj, Peter Rosenbaum, Barbara Stoskopf, Lorraine Hoult, William Furlong, David Feeny, and Ronald Hagan, "Development, Reliability and Validity of New Measure of Overall Health for Pre-School Children." *Quality of Life Research*, forthcoming.[pediatrics]

Samsa, Greg, David Edelman, Margaret Rothman, G. Rhys Williams, Joseph Lipscomb, and David Matchar, "Determining Clinically Important Differences in Health Status Measures: A General Approach with Illustration Using the Health Utilities Index Mark II." *PharmacoEconomics,* Vol. 15, No. 2, February 15, 1999, pp 141-155. [Interpretability][USA, Stroke]

Sengupta, Nishan, Michael B. Nichol, Joanne Wu, and Denise Globe, "Mapping the SF-12 to the HUI3 and VAS in Managed Care Population." Medical Care, Vol. 42, No. 9, September, 2004, pp 927-937. [HUI3; Scoring]

Silberfeld, Michael, Sergio Rueda, Murray Krahn, and Gary Naglie, "Content Validity for Dementia of Three Generic Preference Based Health Related Quality of Life Instruments." *Quality of Life Research*, Vol. 11, No. 1, February, 2002, pp 71-79. [HUI2; HUI3; Content Validity][Canada; Dementia]

Speechley, Kathy Nixon, Elizabeth Maunsell, Marie Desmeules, Dena Schanzer, Jeanne Landgraf, David H. Feeny, and Maru E. Barrera, "Mutual Concurrent Validity of the Child Health Questionnaire and the Health Utilities Index: An Exploratory Analysis Using Survivors of Childhood Cancer." *International Journal of Cancer,* Supplement 12, December, 1999, pp 95-105. [Construct Validity][Canada, Childhood Cancers]

Torrance, George W., William Furlong, and David Feeny, "Health Utility Estimation." *Expert Reviews in Pharmacoeconomics Outcomes Research*, Vol. 2, No. 2, 2002, pp 99-108. [Review Paper]

Torrance, George W., "Multiattribute Utility Theory as a Method of Measuring Social Preferences for Health States in Long-Term Care," in Robert L. Kane and Rosalie A. Kane, eds., Values and Long-Term Care. Lexington, MA: Lexington Books Division of D. C. Health, 1982, pp 127-156. [Description of Systems; Scoring; Theory]

Torrance, George W., Michael H. Boyle, Sargent P. Horwood, "Application of Multi-Attribute Utility Theory to Measure Social Preferences for Health States." *Operations Research,* Vol. 30, No. 6, November-December, 1982, pp 1042-1069. [Scoring; Theory][Canada]

Torrance, George W., William Furlong, David Feeny, and Michael Boyle, "Multi-Attribute Preference Functions: Health Utilities Index." *PharmacoEconomics,* Vol. 7, No. 6, June, 1995, pp 503-520. [Scoring; Theory][Canada]

Torrance, George W., Yueming Zhang, David Feeny, William Furlong, and Ronald Barr, "Multi-Attribute Preference Functions for A Comprehensive Health Status Classification System". McMaster University, *Centre for Health Economics and Policy Analysis Working Paper No. 92-18,* 1992. [Scoring; Theory][Canada]

Torrance, George W., David H. Feeny, William J. Furlong, Ronald D. Barr, Yueming Zhang, and Qinan Wang, "Multi-Attribute Preference Functions for A Comprehensive Health Status Classification System: Health Utilities Index Mark

2." *Medical Care,* Vol. 34, No. 7, July 1996, pp 702-722. [Scoring; Theory][Canada]

Torrance, George W., "Measurement of Health State Utilities for Economic Appraisal - A Review." *Journal of Health Economics,* Vol. 5, No. 1, 1986, pp 1-30. [Description of Systems; Scoring; Theory]

Torrance, George W., and David Feeny, "Utilities and Quality-Adjusted Life Years." *International Journal of Technology Assessment in Health Care,* Vol. 5, No. 4, 1989, pp 559-575. [Theory]

Verrips, G.H.W., M.C. Stuifbergen, A. L den Ouden, G.J. Bonsel, R.J.B.J. Gemke, N. Paneth, and S.P. Verloove-Vanhorick, "Measuring Health Status Using the Health Utilities Index: Agreement Between Raters and Between Modalities of Administration." *Journal of clinical Epidemiology*, Vol. 54, No. 5, May, 2001, pp 475-481. [HUI3; Inter-rater Reliability; Inter-mode Reliability; Child Health][Netherlands]

von Neumann, John, and Oskar Morgenstern, Theory of Games and Economic Behavior. Princeton: Princeton University Press, 1944. [Theory]

Wang Q, Furlong W, Feeny D, Torrance G, Barr R. "How robust is the Health Utilities Index Mark 2 utility function?" *Medical Decision Making*, Vol. 22, No. 4, July/August, 2002, pp 350-358. [Reliability, Generalizability, Scoring].

Wiebe, Samuel, Suzan Matijevic, Michael Eliasziw, and P. A. Derry, "Clinically Important Change in Quality of Life in Epilepsy." *Journal of Neurology, Neurosurgery, and Psychiatry*, Vol. 73, No. 2, August, 2002, pp 116-120. [HUI3; Interpretation; Responsiveness][Canada, epilepsy]

Wiebe, Samuel, Michael Eliasziw, and Suzan Matijevic, "Changes in Quality of Life in Epilepsy: How Large Must They Be to be Real?" *Epilepsia*, Vol. 42, No. 1, January, 2001, pp 113-118. [HUI3; Interpretation; Reliability; Responsiveness][Canada, epilepsy]

Wodchis, Walter P., John P. Hirdes, and David H. Feeny, "A Health-Related Quality of Life Measure Based on the Minimum Data Set." *International Journal of Technology Assessment in Health Care*, forthcoming. [HUI2, Construct Validity] [Canada, Long-term Care]
Return to top of page.

Clinical and Evaluative Studies Using HUI [Clinical; Evaluative; Reliability; Responsiveness; Validity] (Listed alphabetically by 1st author)

Albertsen, Peter C., Robert F. Nease, and Arnold L. Potosky, "Assessment of Patient Preferences among Men with Prostate Cancer." *Journal of Urology,* Vol. 159, No. 1, January, 1998, pp 158-163. [Clinical][USA, Prostate Cancer]

Avorn, Jerry, Josh Benner, Ian Ford, David A. Ganz, Allan Gaw, Robert J. Glynn, Joseph Jackson, A. Margot Lagaay, SebastianSchneeweiss, Thomas Walley, and Philip S. Wang, "Measuring the Cost-Effectiveness of Lipid-lowering Drugs in the Elderly: The Outcomes Research and Economic Analysis Components of the PROSPER Trial." *Controlled Clinical Trials*, Vol. 23, No. 6, December, 2002, pp 757-773. [HUI3][USA, Scotland, Ireland, heart disease]

Baladi, Jean-Francois, Devidas Menon, and Nicholas Otten, "An Economic Evaluation of Finasteride for Treatment of Benign Prostatic Hyperplasia." *PharmacoEconomics,* Vol. 9, No. 5, May, 1996, pp 443-454. [Evaluative][Canada]

Barr, Ronald D., David Feeny, and William Furlong, "Economic Evaluation of Treatments for Cancer in Childhood." *European Journal of Cancer*, Vol. 40, No. 9, June, 2004, pp 1335-1344. [HUI2; HUI3][childhood cancer]

Barr, Ronald D., Julia Sek, John Horsman, William Furlong,, Mahassen Saleh, Mohan Pai, and Irwin Walker, "Health Status and Health-Related Quality of Life Associated with van Willebrand Disease." *American Journal of Hematology*, Vol. 73, No. 2, June 2003, pp 108-114. [HUI2; HUI3; Clinical; Construct Validity][Canada, von Willebrand disease]

Barr RD, Saleh M, Furlong W, Horsman J, Sek J, Pai M, Walker I. "Health status and health-related quality of life associated with hemophilia." *Am J Hematology*,Vol. 71, 2002, pp 152-160. [HUI2, HUI3, Construct Validity; Responsiveness][Canada, Hemophilia]

Barr, Ronald. D., A.Gonzalez, M. Longchong, W. Furlong, M. P. Vizcaino, J. Horsman, L. Fu, and L. Castillo, "Health Status and Health-Related Quality of Life in Survivors of Cancer in Childhood in Latin America: A MISPHO Feasibility Study." *International Journal of Oncology*, Vol. 19, No. 2, August, 2001, pp 413-421. [HUI2; HUI3; Clinical; Construct Validity]

Barr, Ronald D., Dawn Chalmers, Sonja DePauw, William Furlong, Sheila Weitzman, and David Feeny, "Health-Related Quality of Life in Survivors of Wilms' Tumor and Advanced Neuroblastoma: A Cross-Sectional Study." *Journal of Clinical Oncology*, Vol. 18, No. 18, September 15, 2000, pp 3280-3287. [HUI2; HUI3; Clinical; Construct-Validity][Canada; Wilms Tumor; Neuroblastoma]

Barr, Ronald D., William Furlong, Susan Dawson, Anthony C. Whitton, Ingrid Strautmanis, Mohan Pai, David Feeny, and George W. Torrance, "An Assessment of Global Health Status in Survivors of Acute Lymphoblastic Leukemia in

Childhood." *American Journal of Pediatric Hematology/Oncology,* Vol. 15, No. 4, 1993, pp 284-290. [Clinical; Construct Validity][Canada, ALL]

Barr, Ronald D., William Furlong, Jennifer Henwood, David Feeny, John Wegener, Irwin Walker, and Michael Brain, "Economic Evaluation of Allogenic Bone Marrow Transplantation ? A Rudimentary Model to Generate Estimates for the Timely Formulation of Clinical Policy." *Journal of Clinical Oncology,* Vol. 14, No. 5, May, 1996, pp 1413-1420. [Clinical; Evaluative][Canada]

Barr, Ronald D., David Feeny, William Furlong, Sheila Weitzman, and George W. Torrance, "A Preference-Based Approach to Health-Related Quality of Life in Children with Cancer." *International Journal of Pediatric Hematology/Oncology,* Vol. 2, 1995, pp 305-315. [Clinical; Construct Validity][Canada]

Barr, Ronald D., Mohan K. R. Pai, Sheila Weitzman, David Feeny, William Furlong, Peter Rosenbaum, and George W. Torrance, " A Multi-Attribute Approach to Health Status Measurement and Clinical Management - Illustrated by an Application to Brain Tumors in Childhood." *International Journal of Oncology,* Vol. 4, 1994, pp 639-648. [Clinical; Construct Validity; Reliability][Canada, Pediatric, Brain Tumour]

Barr, Ronald D., Claire Petrie, William Furlong, Marilyn Rothney, and David Feeny, "Health-Related Quality of Life during Post-Induction Chemotherapy in Children with Acute Lymphoblastic Leukemia in Remission: An Influence of Corticosteroid Therapy." *International Journal of Oncology,* Vol. 11, 1997, pp 333-339. [Clinical; Construct Validity; Responsivness][Canada, Pediatric, ALL]

Barr, Ronald D., Toni Simpson, Anthony Whitton, Bonnie Rush, William Furlong, and David H. Feeny, "Health-Related Quality of Life in Survivors of Tumours of the Central Nervous System in Childhood - A Preference-Based Approach to Measurement in a Cross-Sectional Study." *European Journal of Cancer,* Vol. 35, No. 2, 1999, pp 248-255. [Clinical; Construct Validity; Cross-Cultural Validation][Canada, Pediatric, Brain Tumour]

Bayoumi, Ahmed M., and Donald A. Redelmeir, "Economic Methods for Measuring the Quality of Life Associated with HIV Infection." *Quality of Life Research,* Vol. 8, No. 6, September, 1999, pp 471-480. [Clinical; Construct Validity][Canada, AIDS]

Beaton, Dorcas E., Sheilah Hogg-Johnson, and Claire Bombardier, "Evaluating Changes in Health Status: Reliability and Responsiveness of Five Generic Health Status Measures in Workers with Musculoskeletal Disorder." *Journal of Clinical Epidemiology,* Vol. 50, No. 1, 1997, pp 79-93. [Clinical; Reliability; Responsiveness]

Bell, Chaim, Sally S. Araki, and Peter J. Neumann, "The Association Between Caregiver Burden and Carregiver Health-Related Quality of Life in Alzheimer Disease." *Alzheimer Disease and Associated Disorders*, Vol. 15, No. 3, July-September, 2001, pp 129-136. [HUI2; Construct Validity][USA, Alzheimer's disease]

Bennett, Kathryn J., George W. Torrance, Lea-Anne Moran, Frank Smith, and Charlie H. Goldsmith, "Health State Utilities in Knee Replacement Surgery: The Development and Evaluation of McKnee." *Journal of Rheumatology,* Vol. 24, No. 9, 1997, pp 1796-1805. [Clinical][USA, Total Knee Replacement]

Bichey, Bradford G., Jon M Hoversland, Michael K. Wynne, and Richard T. Miyamoto, "Changes in Quality of Life and the Cost-Utility Associated with Cochlear Implantation in Patients with Large Vestibular Aqueduct Syndrome." *Otology & Neurotology*, Vol. 23, May, 2002, pp 323-327. [HUI3; Construct Validity][USA, hearing]

Billson, Amanda L. and David A. Walker. "Assessment of Health Status in Survivors of Cancer." *Archives of Disease in Childhood,* Vol. 70, No. 3 March 1994, pp 200-204. [Clinical; Construct Validity][United Kingdom, Pediatirc, Cancers]

Blanchard, Chris, David Feeny, Jeffrey L. Mahon, robert Bourne, Cecil Rorabeck, Larry Stitt, and susan Webster-Bogaert, "Is the Health Utilities Index Valid in Total Hip Arthroplasty Patients?," *Quality of Life Research*, Vol. 13, No. 2, March, 2004, pp 339-348. [HUI2; HUI3; Construct validity] [Canada, hip disease]

Blanchard, Chris, Isabelle C, and David Feeny, "Comparing Short Form and RAND Physical and Mental Health Summary Scores: Results from Total Hip Arthroplasty and High-Risk Primary-Care Patients," *International Journal of Technology Assessment in Health Care*, Vol. 19, No. 4, 2003, pp 1-7. [HUI3; Construct Validity][Canada, clinical, hip disease, osteoarthritis, total hip arthroplasty]

Blanchard, Chris, David Feeny, Jeffrey L. Mahon, Robert Bourne, Cecil Rorabeck, Larry Stitt, and Susan Webster-Bogaert, "Is the Health Utilities Index Valid in Total Hip Arthroplasty Patients?," *Quality of Life Research* (2003), in press. [HUI2; HUI3; Construct Validity][Canada, osteoarthritis, total hip arthroplasty]

Blanchard, Chris, David Feeny, Jeffrey L. Mahon, Robert Bourne, Cecil Rorabeck, Larry Stitt, and Susan Webster-Bogaert, "Is the Health Utilities Index Responsive in Total Hip Arthroplasty Patients,?" *Journal of Clinical Epidemiology*, Vol. 56, No. 11, November 2003, pp 1046-1054. [HUI2; HUI3; Construct Validity; Responsiveness][Canada, clinical, hip disease, osteoarthritis, total hip arthroplasty]

Bosch, Johanna L., Elkan f. Halpern, and G. Scott Gazelle, "Comparison of Preference-Based Utilities of the Short-Form 36 Health Survey and Health Utilities Index Before and After Treatment of Patients with Intermittent Claudication." *Medical Decision Making*, Vol. 22, No. 5, September-October 2002, pp 403-409. [HUI2, HUI3, Construct Validity; Responsiveness][Netherlands, Intermittent Claudication]

Bosch, Johanna L., Maria G. M. Hunink, "The Relationship Between Descriptive and Valuation Quality-of-Life Measures in Patients with Intermittent Claudication." *Medical Decision Making,* Vol. 16, No. 3, July-September, 1996, pp 217-225. [Clinical; Construct Validity][Netherlands, Peripheral Artery Disease]

Bosch, Johanna L. and M. G. Myriam Hunink, "Comparison of the Health Utilities Index Mark 3 (HUI3) and the EuroQol EQ-5D in Patients Treated for Intermittent Claudication." *Quality of Life Research*, Vol. 9, No. 6, 2001, pp 591-601. [Clinical; Construct Validity; Responsiveness] [The Netherlands][Peripheral vascular disease]

Bosch, Johanna L., Eric Tetteroo, Willem P. T. M. Mali, Maria G. M. Hunink, for the Dutch Iliac Stent Trial Group, "Iliac Arterial Occlusive Disease: Cost-Effectiveness Analysis of Stent Placement versus Percutaneous Transluminal Angioplasty." *Radiology,* Vol. 208, No. 3, September, 1988, pp 641-648. [Clinical; Construct Validity][Netherlands, Peripheral Artery Disease]

Bosch, Johanna L., Yolanda van der Graaf, Maria G. M. Hunink, for the Dutch Iliac Stent Trial Group, "Health-Related Quality of Life after Angioplasty and Stent Placement in Patients with Iliac Artery Occlusive Disease: Results from a Randomized Controlled Clinical Trial." *Circulation,* Vol. 99, No. 24, June 22, 1999, pp 3155-3160. [Clinical; Construct Validity][Netherlands, Peripheral Artery Disease]

Bosch, J. L., E. E. E. van Wijck, P. L. Baum, M. C. Donaldson, J. J. A. M. van den Dungen, and M. G. M. Hunink, "The McMaster Health Utility Index (II) and the EuroQol 5D Assessed in Patients with Peripheral Arterial Disease in the United States and the Netherlands." *Medical Decision Making,* Vol. 16, No. 4, October-December, 1996, p 450 (Abstract). [Clinical; Construct Validity][Netherlands, USA, Preipheral Artery Disease]
Boyle, Michael H., George W. Torrance, John C. Sinclair, and Sargent P.

Horwood, "Economic Evaluation of Neonatal Intensive Care of Very-Low-Birth-Weight Infants." *New England Journal of Medicine,* Vol. 308, 1983, pp 1330-1337. [Clinical; Evaluative][Canada, Neonatal Intensive Care]
Brady, Bruce, Laura McAuley, and vijay K. Shukla, "Economic Evaluation of Zanamiriv for the Treatment of Influenza," Ottawa: *Canadian Coordinating Office*

for Health Technology Assessment Technology, Report No. 13, January, 2001. [HUI3, Clinical][Canada, Influenza]

Brazier, John, Jennifer Roberts, Aki Tsuchiya, and Jan Busschbach, "A Comparison of the EQ-5D and SF-6D Across Seven Patient Groups." *Health Economics*, Vol. 13, No. 9, September, 2004, pp 873-884. [HUI3; Construct Validity; Responsiveness]

Brunner, H. I., D. Maker, B. Grundland, N. L. Young, V. Blanchette, A-M Stain, and B. M. Feldman, "Preference-Based Measurement of Health-Related of Life (HRQL) in Children with Chronic Musculoskeletal Disorders (MSKDs)." *Medical Decision Making*, Vol. 23, No. 4, July-August, 2003, pp 314-322. [HUI3; Clinical; Construct Validity][Canada, children, musculoskeletal disorders]

Cheng, André K., Haya R. Rubin, Neil R. Powe, Nancy K. Mellon, Howard W. Francis, and John K. Niparko, "Cost-Utility Analysis of the Coclear Implant in Children." *Journal of the American Medical Association*, Vol. 284. No. 7, August 16, 2000, pp 850-856. [HUI3, Clincal, Evaluative][USA, Children, Hearing]

Cheng, André K., and John K. Niparko, "Cost-Utility Analysis of the Coclear Implant in Adults." *Archives of Otolaryngology--Head and Neck Surgery*, Vol. 125. No. 11, November, 1999, pp 1214-1218-856. [HUI3, Clincal, Evaluative][USA, Adults, Hearing]

Ching, Shim, Achilles Thoma, Randi E. McCabe, and Martin M. Antony, "Measuring Outcomes in Aesthetic Surgery: A Comprehensive Review of the Literature." *Plastic and Reconstructive Surgery*, Vol. 111, January, 2003, pp 469-480. [HUI; Clinical][surgery]

Chong, Christopher A. K. Y., Anar gulamhussein, E. Jenny Heathcote, Les Lilly, Morris Sherman, Gary Naglie, and Murray Krahn, "Health-State Utilities and Quality of Life in Hepatitis C Patients." *American Journal of Gastroenterlogy*, Vol. 98, No. 3, March, 2003, pp630-638. [HUI3; Construct Validity][Canada, hepatitis]

Conner-Spady, Barbara, and Maria E. Suarez-Almazor, "Variation in the Estimation of Quality- Adjusted Life-Years by Different Preference-based Instruments." *Medical Care*, Vol. 41, No. 7, July, 2003, pp 791-801. [HUI3; Construct Validity; Responsiveness][Canada, musculoskeletal disease]

de Keizer, N. F., G. J. Bonsel, and R. J. B. M. Gemke, "Health Status Prediction in Critically Ill Children: A Pilot Study Introducing Standardized Health Ratios." *Quality of Life Research,* Vol. 6, No. 2, March, 1997, 192-199. [Clinical; Predictive Validity][Netherlands, Pediatric]

Feeny, David, Chris Blanchard, Jeffrey L. Mahon, Robert Bourne, Cecil Rorabeck, Larry Stitt, and Susan Webster-Bogaert, "Comparing Community-Preference Based and Direct Standard Gamble Utility Scores: Evidence from Elective Total Hip Arthroplasty." *International Journal of Technology Assessment in Health Care*, Vol. 19, No. 2, Spring, 2003, pp 362-372. [HUI2; HUI3; Scoring][Canada, osteoarthritis, total hip arthroplasty]

Feeny, David H., Alison Leiper, Ronald D. Barr, William Furlong, George W. Torrance, Peter Rosenbaum, and Sheila Weitzman, "The Comprehensive Assessment of Health Status in Survivors of Childhood Cancer: Application to High-Risk Acute Lymphoblastic Leukaemia." *British Journal of Cancer,* Vol. 67, 1993, pp 1047-1052. [Clinical; Construct Validity][United Kingdom, Pediatric, ALL]

Feeny, David, William Furlong, Ronald D. Barr, George W. Torrance, Peter Rosenbaum, and Sheila Weitzman, "A Comprehensive Multiattribute System for Classifying the Health Status of Survivors of Childhood Cancer." *Journal of Clinical Oncology,* Vol. 10, No. 6, June, 1992, pp 923-928. [Clinical; Construct Validity][Canada, Pediatric, ALL, Wilms Tumour, Neuroblastoma]

Feeny, David, Lieling Wu, and Ken Eng, "Comparing Short Form 6D, Standard Gamble, and Health Utilities Index Mark 2 and Mark 3 Utility Scores: Results from Total Hip Arthroplasty Patients." *Quality of Life Research*, in press. [HUI2; HUI3; Scoring][Orthopedic surgery]

Felder-Puig, Rosemarie, E. Frey, G. Sonnleithner, David Feeny, H. Gadner, Ronald D. Barr, William Furlong, and Reinhard Topf, "German Cross-Cultural Adapation of the Health Utilities Index and Its Application to a Sample of Childhood Cancer Survivors." *European Journal of Pediatrics*, Vol. 159, No. 4, April, 2000, pp 283-288. [Clinical; Cross-Cultural validation; Construct Validity; Reliability/Agreement][German/Austria; Childhood Cancer]

Fontana, Robert J., Cheryl A. Moyer, Seema Sonnad, Anna S. F. Lok, Naomi Sneed-Pee, John Walsh, Steven Klein, and Steven Webster, "Comorbidities and Quality of Life in Patients with Interferon-Refractory Chronic Hepatitis C." *American Journal of Gastroenterology*, Vol. 96, No. 1, January, 2001, pp 170-178. [HUI3; Clinical; Construct Validity]
Foreman, Nicholas K., Paul M. Faestel, Joanne Pearson, Jennifer Disabato, Marty

Poole, Greta Wilkening, Edward B. Arenson, Brian Greffe, and Robert Thorne, "Health Status in 52 Long-Term Survivors of Pediatric Brain Tumors." *Journal of Neuro-Oncology,* Vol. 41, No. 1, January, 1999, pp 47-53. [Clinical; Construct Validity][USA, Pediatric, Brain Tumour]

Francis, Howard W., Nelson Chee, Jennifer Yeagle, Andre Cheng, and John K. Niparko, "Impact of Cochlear Implants on the Functional Health Status of Older Adults." *The Laryngoscope*, Vol.112, No. 8, Part 1, August, 2002, pp 1482-1488. [HUI3; Construct Validity; Responsiveness][USA, hearing]

Frey, E., R. Felder-Puig, G. Sonnleithner, R. Topf, and H. Gadner, "The Assessment of Health-Related Quality of Life in Survivors of Childhood Cancer: Our Experience with the Health Utilities Index Mark 2 + 3 (HUI2/3) in the After-Care Clinic," *International Journal of Pediatric Hematology/Oncology,* Vol. 6, No. 3, 1999, pp 214-216 (Abstract). [Clinical; Cross-Cultural Validation; Reliability/Agreement][Austria, Pediatric, Cancers]

Gabriel, Sherine E., Terry S. Kneeland, L. Joseph Melton, III, Megan M. Moncur, Bruce Ettinger, and Anna N. A. Tosteson, "Health-Related Quality of Life in Economic Evaluations for Osteoporosis: Whose Values Should We Use?" *Medical Decision Making,* Vol. 19, No. 2, April-June, 1999, pp 141-148. [Clinical][USA, Adult, Osteoporosis]

Gemke, Reinoud J. B. J., and Gouke J. Bonsel, "Reliability and Validity of a Comprehensive Health Status Measure in a Heterogeneous Population of Children Admitted to Intensive Care." *Journal of Clinical Epidemiology,* Vol. 49, No. 3, March, 1996, pp 327-333. [Clinical; Construct Validity; Reliabilty][Netherlands, Pediatric, Intensive Care]

Gemke, Reinoud J. B. J., Gouke J. Bonsel, and A. Johannes van Vught, "Long Term Survival and State of Health after Paediatric Intensive Care." *Archives of Disease in Childhood,* Vol. 73, September, 1995, pp 196-201. [Clinical; Construct Validity][Netherlands, Pediatric, Intensive Care]

Glaser, Adam, Colin R. Kennedy, Jonathan Punt, and David Walker, "Standardized Quantitative Assessment of Brain Tumor Survivors Treated within Clinical Trials in Childhood." *International Journal of Cancer,* Supplement 12, December, 1999, pp 77-82. [Clinical; Construct Validity; Reliability][United Kingdom, Pediatric, Brain Tumour]

Glaser AW, N. F. Nik Abdul Rashid, U. Chin Lyn, and D. A. Walker, "School behaviour and health status after central nervous system tumours in childhood." *British Journal of Cancer,* Vol. 76, No. 5, 1997, pp 643-650. [Clinical; Construct Validity; Cross-Cultural Validation][United Kingdom, Pediatric, Brain Tumour]

Glaser AW, K. Davies, D. Walker, D. Brazier, "Influence of proxy respondents and mode of administration on health status assessment following central nervous system tumours in childhood." *Quality of Life Research,* Vol. 6, No. 1, January, 1997, pp. 43-53. [Clinical; Construct Validity; Cross-Cultural Validation; Reliability][United Kingdom, Pediatric, Brain Tumour]

Glaser, Adam W., William Furlong, David A. Walker, Katherine Fielding, K. Davies, David H. Feeny, and Ronald D. Barr, "Applicability of the Health Utilities Index to a Population of Childhood Cancer Survivors of Central Nervous System Tumours in the United Kingdom." *European Journal of Cancer,* Vol. 35, No. 2, 1999, pp. 256-261. [Clinical; Construct Validity; Cross-Cultural Validation; Reliability][United Kingdom, Pediatric, Brain Tumour]

Glick, Henry A., Daniel Polsky, Richard J. Willke, and Kevin A. Schulman, "A Comparison of Preference Assessment Instruments Used in a Clinical Trial: Responses to the Visual Analog Scale from the EuroQol EQ-5D and the Health Utilities Index." *Medical Decision Making,* Vol. 19, No. 3, July-September 1999, pp 265-275. [Clinical; Construct Validity][USA]

Gortner, Susan R., Adelheid A. Jaeger, Judith Harr, and Terry Miller, "Elders' Expected and Realized Benefits from Cardiac Surgery." *Cardiovascular Nursing,* Vol. 30, No. 2, March/April 1994, pp 9-14. [Clinical; Evaluative][USA, Adult, Cardiac Surgery]

Grima, Daniel T., George W. Torrance, G. Francis, G. Rice, A.J. Rosner and L. LaFortune, "Cost and Health Related Quality of Life Consequences of Multiple Sclerosis." *Multiple Sclerosis*, Vol. 6, No. 2, April, 2000, pp 91-98. [Clinical; Construct Validity][Canada; Multiple Sclerosis]

Grossman, R., J. Mukherjee, D. Vaughan, C. Eastwood, R. Cook, J. LaForge, and N. Lampron, "A One-Year Community-Based Health Economic Study of Ciprofloxacin versus Usual Antibiotic Treatment in Acute Exacerbations of Chronic Bronchities." *Chest,* Vol. 113, 1998, pp 131-141. [Clinical; Evaluative][Canada, Bronchitis]

Hatoum, Hind T., John E. Brazier, and Kasem S. Akhras, "Comparison of the HUI3 with the SF- 36 Preference Based SF-6D in a Clinical Trial Setting." *Value and Health*, Vol. 7, No. 5, September, 2004, pp 602-609. [HUI3; Construct Validity; Responsiveness][Canada and USA, cardiovascular]

Heidenheim, A. Paul, Norman Muirhead, Louise Moist, and Robert M. Lindsay, "Patient Quality of Life on Quotidian Hemodialysis." *American Journal of Kidney Disease*, Vol. 42, No. 1 (Supplement), July, 2003, pp S36-S41. [HUI3; Responsivness][Canada, end-stage renal disease]

Hinds, Pamela S., J. S. Gattuso, A. Fletcher, E. Baker, B. Coleman, T. Jackson, A. Jacobs- Levine, D. June, S. N. Rai, S.Lensing, and C.-H. Pui, "Quality of Life as Conveyed by Pediatric Patients with Cancer." *Quality of Life Research*, Vol. 13, No. 4, May, 2004, pp 761-772. [HUI2; HUI3; Content Validity][USA, pediatric oncology]

Hux, M., N. Milkovich, G. Torrance, and G. Sibbald, "Health-related quality of life related to chronic foot ulcers in diabetics." *Quality of Life Research,* 8, 1999 PP 655. (Abstract)[Clinical][Canada, Diabetes]
Juniper, Elizabeth F., Gordon H. Guyatt, David H. Feeny, Lauren E. Griffith, and Penelope J. Ferrie, "Minimum Skills Required by Children to Complete Health-Related Quality of Life Instruments for Asthma: Comparison of Measurement Properties." *European Respiratory Journal,* Vol. 10, 1997, pp 2285-2294. [Clinical; Reliability; Responsiveness][Pediatric, Asthma]

Kamlet, M.S., Nancy Paul, Joel Greenhouse, David Kupfer, Ellen Frank, and Martcia Wade, "Cost utility analysis of maintenance treatment for recurrent depression." *Controlled Clinical Trials*, Vol. 16,1, 1995, pp 17-40. [HUI1, depression, cost utility]

Kanabar, D. J., S. Attard-Montalto, V. Saha, J. E. Kingston, J. E. Malpas, and O. B. Eden, "Quality of Life in Survivors of Childhood Cancer After Megatherapy with Autologous Bone Marrow Rescue." *Pediatric Hematology and Oncology,* Vol. 12, 1995, pp 29-36. [Construct Validity][United Kingdom, Pediatric, Bone Marrow Transplant]

Kennedy, Colin R., and Kathleen Leyland, "Comparison of Screening Instruments for Disability and Emotional/Behavioral Disorders with a Generic Measure of Health-Related Quality of Life in Survivors of Childhood Brain Tumors." *International Journal of Cancer,* Supplement 12, December, 1999, pp 106-111. [Clinical; Construct Validity; Discriminative Validity][United Kingdom, Pediatric, Brain Tumour]

Kennes, Janneke, Peter Rosenbaum, Steven E. Hanna, Stephen Walter, Dianne Russell, Parminder Raina, Doreen Bartlett, and Barbara Galuppi, "Health Status of School-Aged Children with Cerebral Palsy: Information from a Population-Based Sample." *Developmental Medicine & Child Neurology*, Vol. 44, No. 4, April, 2002, pp 240-247. [HUI3; Construct Validity][Canada, cerebral palsy]

Kiltie, Anne E., and H. Rao Gattamaneni, "Survival and Quality of Life of Paediatric Intracranial Germ Cell Tumour Patients Treated at the Christie Hospital, 1972-1993." *Medical and Pediatric Oncology,* Vol. 25, 1995, pp 450-456. [Construct Validity][United Kingdom, Pediatric, Brain Tumour]

Klassen, Anne F., Shoo K. Lee, Perminder Raina, Herbert W. P. Chan, Derek Matthew, and David Brabyn, "Health Status and Health-Related Quality of Life in a Population-Based Sample of Neonatal Intensive Care Graduates." *Pediatrics*, Vol. 113, No. 3, March, 2004, pp 594-600. [HSCS-PS; construct validity][child health, neonatal intensive care]

Lee, Todd A., William Hollingworth, and Sean D. Sullivan, "Comparison of Directly Elicited Preferences Derived from the SF-36 in Adults with Asthma." *Medical Decision Making*, Vol. 23, No. 4, July-August, 2003, pp 323-334. [HUI2; Scoring][USA, asthma]

Le Galès, Catherine, Nathalie Costet, Jean-Claude Gentet, Chantal Kalifa, Didier Frappaz, Christine Edan, Eric Sariban, Dominique Plantaz, and François Doz, "Cross-Cultural Adaptation of a Health Status Classification System in Children with Cancer. First Results of the French Adaptation of the Health Utilities Index Marks 2 and 3." *International Journal of Cancer,* Supplement 12, December, 1999, pp 112-118. [Clinical; Construct Validity; Cultural Adaptation; Reliability][France, Pediatric, Cancer]

Leidy, N.K., and C. Coughlin, "Psychometric Performance of the Asthma Quality of Life Questionnaire in a U.S. Sample." *Quality of Life Research,* Vol. 7, No. 2., February, 1998, pp 127-134. [Construct Validity][USA, Asthma]

Leidy, N.K., KS Chan, and C. Coughlin, "Is the Asthma Quality of Life Questionnaire a Useful Measure for Low-Income Asthmatics." *American Journal of Respiratory and Critical Care Medicine,* Vol. 158, No. 4, October, 1998, pp 1082-1090. [Construct Validity][USA, Asthma]

Lubeck, Deborah P., "Patient-Reported Outcomes and Their Role in the Assessment of Rheumatoid Arthritis." *Pharmacoeconomics*, Vol. 22, Supplement 1, 2004, pp 27-38. [HUI3][rheumatoid arthritis]

Lubetkin, Erica I., and Marthe R. Gold, "Areas of Decrement in Health-Related Quality of Life (HRQL): Comparing the SF-12, EQ-5D, and HUI3." Quality of Life Research, Vol. 12, No. 8, December, 2003, pp 1059-1067. [HUI3; Construct Validity][USA]

Lutetkin, Erica I., and Marthe R. Gold, "Comprehensibility of Measures of Health-Related Quality of Life in Minority and Low-Income Patients." *Journal of the National Medical Association*, Vol. 94, No. 5, May 2002, pp 327-335. [HUI3, Construct Validity, Routine Use][USA]

Macran, Susan, Helen Weatherly, and Paul Kind, "Measuring Population Health: A Comparison of Three Generic Health Status Measures." *Medical Care*, Vol. 41, No. 2, February, 2003, pp 218-231. [modified non-standard version of HUI3; Construct Validity; Primary Care; Routine Use][UK]

Maddigan, Sheri L., David H. Feeny, and Jeffrey A. Johnson, "Construct Validity of the RAND- 12 and Health Utilities Index Mark 2 and 3 in Type 2 Diabetes." *Quality of Life Research*, Vol. 23, No. 2, March, 2004, pp 435-448. [HUI2; HUI3; Construct validity][Canada, diabetes]

Maddigan, Sheri L., Sumit R. Majumdar, Ellen L. Toth, David H. Feeny, and Jeffrey A. Johnson, "Health-Related Quality of Life Deficits Associated with Varying Degrees of Disease Severity in Type 2 Diabetes." *Health and Quality of Life Outcomes (electronic journal)* (Vol 1: 78, December 15, 2003), www.hqlo.com/content/1/1/78 [HUI3; Construct Validity][Canada, diabetes]

Maddigan, Sheri L., David H. Feeny, and Jeffrey A. Johnson, "A Comparison of the Health Utilities Indices Mark 2 and Mark 3 in Type 2 Diabetes." Medical Decision Making, Vol. 23, No. 6, November-December, 2003, pp 489-501. [HUI2; HUI3; Construct Validity][Canada, diabetes]
Mahon, Jeffrey L., Robert B. Bourne, Cecil H. Rorabeck, David H. Feeny, Larry Stitt, and Susan Webster-Bogaert, "Health-Related Quality of Life and Mobility in Patients Awaiting Elective Total Hip Arthroplasty: A Prospective Study." *Canadian Medical Association Journal*, Vol. 167, No. 10, November 12, 2002, pp 1115-1121. [HUI3; Construct Validity; Responsivness][Canada, Total Hip Arthroplasty, orthopedic surgery]

Malthaner, Richard A., and John D. Miller, "Lung Volume Reduction Surgery: Results from a Canadian Pilot Study." *Canadian Journal of Surgery*, Vol. 43, No. 5, October, 2000. [HUI3;Responsiveness][Canada, Surgery]

Mathias, Susan D., Molly M. Bates, David J. Pasta, Miriam G. Cisternas, David Feeny, and Donald L. Patrick, "Use of the Health Utilities Index with Stroke Patients and their Caregivers." *Stroke,* Vol. 28, No. 10, October, 1997, pp 1888-1894. [Clinical; Construct Validity; Reliabiltty][USA, Stroke]

McMahon, Pamela M., Sally S. Araki, Eileen A. Sandberg, Peter J. Neumann, and G. Scott Gazelle, "Cost-Effectiveness of PET in the Diagnosis of Alzheimer Disease." *Radiology*, Vol.228, No. 2, August, 2003, 515-522. [HUI2; HUI3; Construct Validity][USA. Alzheimer Disease]

McMahon, Pamela M., Sally S. Araki, Peter J. Neumann, Gordon J. Harris, and G. Scott Gazelle, "Cost-Effectiveness of Functional Imaging Tests in the Diagnosis of Alzheimer Disease." *Radiology*, Vol. 217, No. 1, October, 2000, pp 58-68. [HUI2; Clinical][USA, Alzheimer's disease]

Midgley, Deborah E., Tatum A. Bradlee, Christopher Donohoe, Kevin P. Kent, and Estella M. Alonso, "Health-Related Quality of Life in Long-Term Survivors of Pediatric Liver Transplantation." *Liver Transplantation*, Vol. 6, No. 3, May, 2000, pp 333-339. [HUI2, Clincal, Construct Validity][USA, Liver Transplantation, HUI2]

Mills, J. Michael, Estella M. Alonso, James B. Piper, David S. Bruce, Kenneth A. Newell, E. Steve Woodie, Alfred L. Baker, Peter F. Whitington, and J. Richard

Thistlewaite, "Liver Transplantation at the University of Chicago," in J.M. Cecka and Paul I. Terasaki, eds., Clinical Transplants (Los Angeles, UCLA Tissue Typing Laboratory, 1995), 187-197. [Clinical][USA, Liver Transplant]

Moore, Andrew D., Ann E. Clarke, Deborah S. Danoff, Lawrence Joseph, Patrick Bélisle, Carolyn Neville, and Paul R. Fortin, "Can Health Utility Measures Be Used in Lupus Research? A Comparative Validation and Reliability Study of 4 Utility Indices." *Journal of Rheumatology*, Vol. 26, No. 6, June, 1999, pp 1285-1290. [Clinical; Construct Validity; Reliability] [Canada] [Lupus]

Moy, Marilyn L., Anne L. Fuhlbrigge, Karen Blumenschein, Richard H. Chapman, Alan J. Zillich, Karen M. Kuntz, A. David Paltiel, Barrett T. Kitch, Scott T. Weiss, and Peter J. Neumann, "Association Between Preference-based Health-Related Quality of Life and Asthma Severity." *Annals of Allergy, Asthma, and Immunology*, Vol. 92, No. 9, March, 2004, pp 329- 334. [HUI3; asthma; construct validity][USA, asthma]

Mulhern, Raymond K., "Correlation of the Health Utilities Index Mark 2 Cognition Scale and Neuropsychological Functioning among Survivors of Childhood Medulloblastoma." *International Journal of Cancer,* Supplement 12, December, 1999, pp 91-94. [Clinical; Construct Validity; Discriminative Validity][USA, Pediatric, Cancer]

Nathan, Paul C., William Furlong, John Horsman, Charmaine van Schaik, M. Rolland, Sheila Weitzman, David Feeny, and Ronald D. Barr, "Inter-Observer Agreement of a Comprehensive Health Status Classification System for Pre-School Children among Patients with Wilms' Tumor or Advanced Neuroblastoma." *Quality of Life Research*, 2004, in press. [Reliability; Construct Validity][Canada, Pediatric Oncology]

Nathan, Paul C., William Furlong, and Ronald D. Barr, "Challenges to the Measurement of Health-Related Quality of Life in Children Receiving Cancer Therapy." *Pediatric Blood and Cancer*, Vol. 43, No. 3, September, 2004, pp 215-223. [Clinical][Canada, pediatric oncology]

Neumann, Peter J., Eileen A. Sandberg, Sally S. Araki, Karen M. Kuntz, David Feeny, and Milton C. Weinstein, "A Comparison of HUI2 and HUI3 Utility Scores in Alzheimer's Disease", *Medical Decision Making*, forthcoming. [Clinical; Construct Validity][USA; Alzheimer Disease]

Neumann, Peter J., Karen M. Kuntz, Joel Leon, Sally S. Araki, Richard C. Hermann, Ming Ann Hsu, and Milton C. Weinstein, "Health Utilities and Health Status in Alzheimer's Disease: A Cross-Sectional Study of Subjects and Caregivers." *Medical Care,* Vol. 37, No. 1, January, 1999, pp 27-32. [Clinical; Construct Validity][USA, Alzheimer Disease]

Neumann, P. J., R. C. Hermann, K. M. Kuntz, S. S. Araki, S. B. Duff, Leon J. Berenbaum, P. A. Goldman, L. W. Williams, and M. C. Weinstein, "Cost-Effectiveness of Donepezil in Treatment of Mild or Moderate Alzheimer's Disease." *Neurology,* Vol. 52, No. 6, April 12, 1999, 1138-1145. [Clinical; Evaluative][USA, Alzeimer Disease]

Nichol, Michael B., Nishan Sengupta, and Denise R. Globe, "Evaluating Quality-Adjusted Life Years: Estimation of the Health Utility Index (HUI) from the SF-36." *Medical Decision Making*, Vol. 21, No. 2, March-April, 2001, pp 105-112. [HUI2; Construct Validity; Scoring][USA; Primary Care]

Nichol, Graham, I. G. Stiell, P. Hebert, G. Wells, K. Vandemheen, and A. Laupacis, "What is the Quality of Life for Survivors of Cardiac Arrest? A Prospective Study." *Academic Emergency Medicine,* Vol. 6, No. 2, February, 1999, 95-102. [Clinical; Construct Validity; Evaluative][Canada, Cardiac Disease]

Oostenbrink, Rianne, Henriette A. Moll, and Marie-Louise Essink-Bot, "The EQ-5D and the Health Utilities Index for Permanent Sequelae after Meningitis: A Head-to-Head Comparison." *Journal of Clinical Epidemiology*, Vol. 55, No. 8, August, 2002, pp 791-799. [HUI2; HUI3; Construct Validity][The Netherlands, meningitis, pediatrics]

Oostenbrink, Rianne, Jan B. Oostenbrink, Karel G. Moons, Gerarad Derksen-Lubsen, Marie- Louise Essink-Bot, Diederick E. Grobbee, W. Ken Redekip, and Henriette A. Moll, "Cost- Utility Analysis of Patient Care in Children with Meningeal Signs." *International Journal of Technology Assessment in Health Care*, Vol. 18, No. 3, Summer, 2002, 485-496. [HUI3; Construct Validity][The Netherlands, meningitis, pediatrics]

Palmer, Cynthia S., John K. Niparko, Robert Wyatt, Margaret Rothman, and Gregory de Lissovoy, "A Prospective Study of the Cost-Utility of the Multichannel Cochlear Implant." *Archives of Otolaryngology--Head and Neck Surgery*, Vol. 125, No. 11, November, 1999, pp 1221-1228. [HUI2, Clinical, Evaluative][USA, Adults, Hearing]

Pickard, A. Simon, Jeffrey A. Johnson, and David H. Feeny, "Responsiveness of Generic Health- Related Quality of Life Measures in Stroke."Quality of Life Research, 2004, in press. [HUI2; HUI3; Construct Validity; Responsiveness]

Pickard, A. Simon, Jeffrey A. Johnson, David H. Feeny, Ashfaq Shuaib, K. C. Carriere, and Abdul M. Nasser, "Agreement Between Patient and Proxy Assessments of Health-Related Quality of Life after Stroke using the EQ-5D and Health Utilities Index." *Stroke*, Vol. 35, No. 2, February 2004, pp 607-612. [HUI2; HUI3; Inter-rater Reliability][Canada, stroke]

Polsky, D., Keating, N.L., Weeks, J.C., and Schulman, K.A. "Patient choice of breast cancer treatment: impact on health state preferences." *Medical Care*, Vol. 40, No. 11, 2002, pp 1068-1079. [HUI3, Clinical, Construct Validity, Responsiveness][USA, breast cancer]

Post, Piet N., Anne M. Stiggelbout, and Peter P. Wakker, "The Utiity of Health States after Stroke: A Systematic Review of the Literature." *Stroke*, Vol. 32, No. 6, June, 2001, pp 1425-1429. [HUI2; HUI3; Construct Validity; Review Article]

Raat, Hein, Gouke J. Bonsel, Marie-Louise Essik-Bot, Jeanne M. Landgraf, and Reinoud J. B. J. Gemke, "Reliability and Validity of Comprehensive Health Status Measures in Children: The Child Health Questionnaire in Relation to the Health Utilities Index." *Journal of Clinical Epidemiology*, Vol. 55, No. 1, January, 2002, pp 67-76. [HUI2, Reliability, Construct Validity][Netherlands, pediatrics]

Raat, Hein, Gouke Bonsel, Reinoud Gemke, Erik Verrips, Paul Krabbe, and Marie-Louise Essink-Bot, "Feasibility and Reliability of a Mailed Questionnaire to Obtain Visual Analogue Scale Valuations for Health States Defined by the Health Utilities Index Mark 3." *Medical Care*, Vol. 42, No. 1, January, 2004, pp 13-18. [HUI3, Generalizability, Scoring][Netherlands, pediatrics]

Ramsey, Scott D., M. Robyn Andersen, Ruth Etzioni, Carol Moinpour, Sue Peacock, Arnold Potosky, and Nicole Urban, "Quality of Life in Survivors of Colorectal Carcinoma." *Cancer*, Vol. 88, No. 6, March 15, 2000, pp 1294-1303. [HUI3; Clinical; Construct Validity; Predictive Validity]

Raynauld, JP, GW Torrance, PA Band, CH Goldsmith, P Tugwell, V Walker, M Schultz, and N Bellamy, "A Prospective Randomized, Pragmatic, Health Outcomes Trial Evaluating the Incorporation of Hyland G-F 20 into the Treatment Paradigm for Patients with Knee Osteoarthritis (Part 1 of 2): Clinical Results." *Osteoarthritis and Cartilage*, Vol. 10, No. 7, 2002, pp 506-517. [HUI3, Construct Validity, Responsiveness][Canada, Knee Osteoarthritis][see Torrance et al below for Part 2 of 2 Economic Results]

Revicki, Dennis A., N. K. Leidy, F. Brennan-Diemer, C. Thompson, and A. Togias, "Development and Preliminary Validation of the Multiattribute Rhinitis Symptom Utility Index." *Quality of Life Research,* Vol. 7, No. 8, December, 1998, 693-702. [Construct Validity][USA]

Revicki, Dennis A., K. N. Simpson, Albert W. Wu, and R. L. LaVallee, "Evaluating the Quality of Life Associated with Rifabutin Prophylaxis for Mycobacterium avium Complex in Persons with AIDS: Combining Q-Twist and Multiattribute Utility Techniques." *Quality of Life Research,* Vol. 4, No. 4, August, 1995, pp 309-318. [Clinical; Construct Validity; Evaluative][USA, AIDS]

Robertson CMT, Watt JM, Joffe AR, Murphy DB, Nagy JM, McLean DE, Pain KS, Saunders LD. "Childhood morbidity after severe traumatic brain injury: Increased detection with the Multiattribute Health Status Classification." *Pediatr Crit Care Med*, Vol. 2, No. 2, April, 2001, pp 145-150. [HUI2, Content Validity, Inter-rater Agreement] [Canada, Pediatrics, Brain Injury]

Rosner, Andrew J., Daniel T. Grima, George W. Torrance, Cathy Bradley, Jonathan D. Adachi, Rolf J. Sebaldt, and Donald J. Willison, "Cost Effectiveness of Multi-Therapy Treatment Strategies in the Prevention of Vertebral Fractures in Postmenopausal Women with Osteoporosis." *PharmacoEconmics,* Vol. 14, No. 5, November, 1998, pp 559-573. [Clinical; Evaluative][Canada, Adult, Osteoporosis]

Saigal, Saroj, Peter Rosenbaum, Barbara Stoskopf, Lorraine Hoult, William Furlong, David Feeny, and Ronald Hagan, "Development, Reliability and Validity of New Measure of Overall Health for Pre-School Children." *Quality of Life Research*, forthcoming.[pediatrics]

Saigal, Saroj, David Feeny, Peter Rosenbaum, William Furlong, Elizabeth Burrows, Barbara Stoskopf, and Lorraine Hoult, "Self-Perceived Health Status and Health-Related Quality of Life of Extremely Low Birthweight Infants at Adolescence." *Journal of the American Medical Association,* Vol. 276, No. 6, August 14, 1996, pp 453-459. [Clinical; Construct Validity][Canada, Neo-natal Intensive Care]

Saigal, Saroj, Peter L. Rosenbaum, David Feeny, Elizabeth Burrows, William Furlong, Barbara L. Stoskopf, and Lorraine Hoult, "Parental Perspectives of the Health Status and Health-Related Quality of Life of Teen-Aged Children Who Were Extremely Low Birth Weight and Term Controls." *Pediatrics,* Vol. 105, No. 3, March, 2000, pp 569-574. [Clinical; Construct Validity]

Saigal, Saroj, Peter Rosenbaum, Barbara Stoskopf, Lorraine Hoult, William Furlong, David Feeny, Elizabeth Burrows, and George Torrance, "Comprehensive Assessment of the Health Status of Extremely Low Birthweight Children at Eight Years of Age: Comparison with a Reference Group." *Journal of Pediatrics,* Vol. 125, No. 3, September, 1994, pp 411-417. [Clinical; Construct Validity][Canada, Neo-natal Intensive Care]

Saigal, Saroj, David Feeny, William Furlong, Peter Rosenbaum, Elizabeth Burrows, and George Torrance, "Comparison of the Health-Related Quality of Life of Extremely Low Birthweight Children and a Reference Group of Children at Age Eight Years." *Journal of Pediatrics,* Vol. 125, No. 3, September, 1994, pp 418-425. [Clinical; Construct Validity][Canada, Neo-natal Intensive Care]

Siderowf, Andrew, Bernard Ravina, and Henry A. Glick, "Preference-Based Quality-of-Life in Patients with Parkinson's Disease." *Neurology*, Vol. 59, No. 1, July, 2002, pp 103-108. [HUI2; Construct Validity][USA, Parkinson Disease]

Speechley, Kathy Nixon, Elizabeth Maunsell, Marie Desmeules, Dena Schanzer, Jeanne Landgraf, David H. Feeny, and Maru E. Barrera, "Mutual Concurrent Validity of the Child Health Questionnaire and the Health Utilities Index: An Exploratory Analysis Using Survivors of Childhood Cancer." *International Journal of Cancer,* Supplement 12, December, 1999, pp 95-105. [Clinical; Construct Validity][Canada, Pediatric, Cancer]

Stiell, Ian, Graham Nichol, George Wells, Valerie De Maio, Lisa Nesbitt, Jos,e Blackburn, and Daniel Spaite, "Health-Related Quality of Life Is Better for Cardiac Arrest Survivors Who Received Citizen Cardiopulmonary Resuscitation." *Circulation*, Vol. 108, No. 16, October 21, 2003, pp 1939-1944. [HUI3; Construct Validity][USA and Canada, cardiac care]

Stiell, Ian G., George A. Wells, Brian Field, Daniel W. Spaite, Lisa P. Nesbitt, Valerie J. De Maio, Graham Nichol, Donna Cousineau, Jos,e Blackburn, Doug Munkley, Lorraine Luinstra- Toohey, Tony Campeau, Eugene Dagnone, and Marion Lyver, "Advanced Cardiac Life Support in Out-of-Hospital Cardiac Arrest." New England Journal of Medicine, Vol. 351, No. 7, August 12, 2004, pp 647-656. [HUI3; Clinical][Canada, cardiac care]

Stolk, E. A., and J. J. V. Busschbach, "A Comparison of the EuroQol and the Health Utilities Index in Patients Treated for Congenital Anomalies." *European Journal of Health Economics: Health Economics in Prevention and Care*, Vol. 2, No. 2, 2001, pp 54-59. [HUI3; Clinical; Construct Validity][Netherlands]

Suarez-Almazor, Maria E., Chris Kendall, Jeffrey A. Johnson, K. Skeith, and D. Vincent, "Use of Health Status Measures in Patients with Low Back Pain in Clinical Settings. Comparison of Specific, Generic, and Preference-Based Instruments. *Rheumatology*, Vol. 39, No. 7, July, 2000, pp 783-790. [HUI2; Clinical; Construct Validity; Reliability; Responsiveness][Canada; Low Back Pain]

Summerfield, A. Quentin, David H. Marshall, Garry R. Barton, and Karen E. Bloor, "A Cost-Utility Scenario Analysis of Bilateral Cochlear Implantation." *Archives of Otolaryngology - Head and Neck Surgery*, Vol. 128, No. 11, November, 2002, pp 1255-1262. [HUI2; Clinical; Construct Validity][United Kingdom, hearing, cochlear implants]

Sung, Lillian, Mark L. Greenberg, J. J. Doyle, Nancy L. Young, S. Ingber, J. Rubenstein, J. Wong, T. Samanta, M. McLimont, and B. M. Feldman, "Construct Validation of the Health Utilities Index and the Child Health Questionnaire in

Children Undergoing Cancer Chemotherapy." *British Journal of Cancer*, Vol. 88, No. 8, April, 2003, pp 1185-1190. [HUI2; HUI3; Construct Validity][Canada, childhood cancer]

Szecket, Nicolas, Gabriela Medin, William J. Furlong, David H. Feeny, and Ronald D. Barr, "Preliminary Translation and Cultural Adaptation of Health Utilities Index Questionnaires for Application in Argentina." *International Journal of Cancer,* Supplement 12, December, 1999, pp 119-124. [Clinical; Construct Validity; Cultural Adapation][Argentina, Pediatric, Cancer]
Torrance GW, Tugwell P, Amorosi S, Chartash E, Sengupta N. "Improvement in health utility among patients with rheumatoid arthritis treated with adalimumab (a human anti-TNF monoclonal antibody) plus methotrexate." *Rheumatology Advance Access* published March 23, 2004, DOI 10.1093/rheumatology/keh153. On-line access here... http://rheumatology.oupjournals.org/cgi/content/abstract/keh153?ijkey=05yC79TX45kYA&keytype=ref [HUI3, construct validity, responsiveness][Canada, USA, rheumatoid arthritis]. See also ... Torrance et al, *Rheumatology*, 2004, in press.

Torrance GW, Tugwell P, Amorosi S, Chartash E, Sengupta N. "Improvement in health utility among patients with rheumatoid arthritis treated with adalimumab (a human anti-TNF monoclonal antibody) plus methotrexate." *Rheumatology*, 2004, in press. [HUI3, construct validity, responsiveness][Canada, USA, rheumatoid arthritis]

Torrance GW, Raynauld JP, Walker V, Goldsmith CH, Bellamy N, Band PA, Schultz M, Tugwell P. "A Prospective, Randomized, Pragmatic Health Outcomes Trial Evaluating the Incorporation of Hylan G-F 20 into the Treatment Paradigm for Patients with Knee Osteoarthritis (Part 2 of 2): Economic Results." *Osteoarthritis and Cartilage*, Vol. 10, No. 7, 2002, pp 518-527. [HUI3, Construct Validity, Responsiveness][Canada, Knee Osteoarthritis][see Raynauld et al above for Part 1 of 2: Clinical Results]

Torrance, George W., Valery Walker, Ronald Grossman, Jayanit Mukherjee, David Vaughan, Jacque LaForge, and Noel Lampron, "Economic Evaluation of Ciprofloxacin Compared with Usual Antibacterial Care for the Treatment of Acute Exacerbations of Chronic Bronchitis in Patients Followed for 1 Year." *PharmacoEconomics,* Vol. 16, No. 5, Part 1, November, 1999, pp 499-520. [Clinical; Construct Validity][Canada, Bronchitis]

Trudel, J. G., M. Rivard, P.L. Dobkin, J.-M. Leclerc and P. Robaey, "Psychometric Properties of the Health Utilities Index Mark 2 System in Paediatric Oncology Patients." *Quality of Life Research,* Vol. 7, No. 5, July, 1998, pp 421-432. [Clinical][Canada, Pediatric, Cancer]

van Schaik, Charmaine S., Ronald D. Barr, Sonja De Pauw, William Furlong, and David Feeny, "Assessment of Health Status and Health-Related Quality of Life in Survivors of Hodgkin Disease in Childhood." *International Journal of Cancer,* Supplement 12, December, 1999, pp 32-38. [Clinical; Construct Validity][Canada, Pediatric, Hodgkins Disease]

Wiebe, Samuel, Suzan Matijevic, Michael Eliasziw, and P. A. Derry, "Clinically Important Change in Quality of Life in Epilepsy." *Journal of Neurology, Neurosurgery, and Psychiatry*, Vol. 73, No. 2, August, 2002, pp 116-120. [HUI3; Interpretation; Responsiveness][Canada, epilepsy]

Wiebe, Samuel, Michael Eliasziw, and Suzan Matijevic, "Changes in Quality of Life in Epilepsy: How Large Must They Be to be Real?" *Epilepsia*, Vol. 42, No. 1, January, 2001, pp 113-118. [HUI3; Interpretation; Reliability; Responsiveness][Canada, epilepsy]

Whitton, Anthony C., Helen Rhydderch, William Furlong, David Feeny, and Ronald D. Barr, "Self-Reported Comprehensive Health Status of Adult Brain Tumor Patients Using the Health Utilities Index." *Cancer,* Vol. 80, No. 2, July 15, 1997, pp 258-265. [Clinical; Construct Validity][Canada, Adult, Brain Tumour]

Wodchis, Walter P., John P. Hirdes, and David H. Feeny, "A Health-Related Quality of Life Measure Based on the Minimum Data Set." *International Journal of Technology Assessment in Health Care*, forthcoming. [HUI2, Construct Validity] [Canada, Long-term Care]

Wright, Marilyn J., Victoria Galea, and Ronald D. Barr, "Self-Perceptions of Physical Activity in Survivors of Acute Lymphoblastic Leukemia in Childhood." *Pediatric Exercise Science*, Vol. 15, No. 2, May, 2003, pp 191-201. [HUI2; HUI3; Construct Validity][Canada, childhood acute lympoblastic leukemia]

Wyatt, JR, J. K. Niparko, M. Rothman, and G. de Lissovoy, "Cost Utility of the Multichannel Cochlear Implant in 258 Profoundly Deaf Individuals." *Laryngoscope,* Vol. 106, July, 1996, pp 816-821. [Clinical; Evaluative][USA, Cochlear Implant]

Yaris, Nilgun, Melek Nur Yavuz, A. Aydin Yavuz, and Aysenur Okten, "Assessment of Quality of Life in Pediatric Cancer Patients at Diagnosis and During Therapy." *Turkish Journal of Cancer*, Vol. 31, No. 4, 2001, pp 139-149.[HUI2; Clinical; Construct Validity; Responsiveness][Turkey]

Yi, Michael S., Maria T. Britto, Robert W. Wilmott, Uma R. Kotagal, Mark H. Eckman, Dennis W. Nielson, Vikki L. Kociela, and Joel Tsevat, "Health Values of Adolescents with Cystic Fibrosis." *Journal of Pediatrics*, Vol. 142, No. 2, February, 2003, pp 133-140. [HUI2; Construct Validity][USA cystic fibrosis]

Younossi, Zobair, Navdeep Boparai, Marilyn McCormick, Lori Lynn Price, and Gordon Guyatt, "Assessment of Utilities and Health-related Quality of Life in Patients with Chronic Liver Disease." *American Journal of Gastroenterology,* Vol. 96, No. 2, February, 2001, pp 579-583. [HUI2; Clinical; Construct Validity][United States, Liver Disease]
Return to top of page.

Population Health Applications of HUI [Cross-Cultural Validation; Description; Reliability; Scoring; Theory; Validity]

Austin, Peter C., "A Comparison of Methods for Analyzing Health-Related Quality-of-Life Measures." *Value in Health*, Vol. 5, No. 4, July-August, 2002, pp 329-337. [HUI3][Canada]

Austin, Peter C., "Bayesian Extensions for the Tobit Model for Analyzing Measures of Health Status." *Medical Decision Making*, Vol. 22, No. 2, March-April, 2002, pp 152-162. [HUI3; Construct Validity][Canada]

Beland, Yves, "Canadian Community Health Survey - Methodological Overview." *Health Reports*, Vol, 13, No. 3, March, 2002, pp 9-14. [HUI3][Canada]

Berthelot, Jean-Marie, Roger Roberge, and Michael Wolfson, "The Calculation of Health-Adjusted Life Expectancy for a Canadian province using a Multi-Attribute Utility Function: A First Attempt." in J. M. Robine, C. D. Mathers, M. R. Bone, and I. Romieu, Calculation of Health Expectancies: Harmonization, Consensus Achieved and Future Perspectives. Montrouge, France: Colloque INSERM/John Libbey Eurotext Ltd., Vol. 226, 1993, pp 161-172. [Construct Validity][Canada, Population Health]

Boyle, Michael H., William Furlong, David Feeny, George Torrance, and Jeff Hatcher, "Reliability of the Health Utilities Index - Mark III Used in the 1991 Cycle 6 General Social Survey Health Questionnaire." *Quality of Life Research,* Vol. 4, No 3, June, 1995, pp 249-257. [Reliability][Canada, Population Health]
Curtis, Lori J., Martin D. Dooley, Ellen L. Lipman, and David H. Feeny, "The Role of Permanent Income and Family Structure in the Determination of Child Health in Canada". *Health Economics*, Vol. 10, No. 4, June, 2001, pp 287-302. [HUI3; Construct Validity]

Denton, Margaret, and Vivienne Walters, "Gender Differences in Structural and Behavioral Determinants of Health: An Analysis of the Social Production of Health." *Social Science & Medicine*, Vol. 48, No. 9, May, 1999, pp 1221-1235. [HUI3; Construct Validity][Canada]

DesMeules, Marie, Douglas Manuel, and Robert Cho, "Mortality: Life and Health Expectancy of Canadian Women." *BMC Women's Health*, Vol. 4, Supplement 1, S9 (http://www.biomedcentral.com/1472-6874/S1/S9 [HUI3][Canada, Population health]

Erickson, Pennifer, "Modeling Health-Related Quality of Life: The Bridge Between Psychometrics and Utility-Based Measures." *Journal of the National Cancer Institute Monographs*, No. 20, 1966, pp 17-22. [HUI1; Construct Validity][Pop'ln Health, USA]

Feeny, David H., George W. Torrance, Charles H. Goldsmith, William Furlong, and Michael Boyle. 1993. "A Multi-attribute Approach to Population Health Status." Proceedings of the 153rd Annual Meeting of the American Statistical Association (Alexandria, VA: American Statistical Association, 1994), pp 161-166; modestly revised version available as McMaster University Centre for Health Economics and Policy Analysis Working Paper 94-05, February, 1994. [Scoring; Theory]

Goel, Vivek, Karey Iron, and J. Ivan Williams, "Indicators of Health Determinants and Health Status." Chapter 2 in Vivek Goel, J. Ivan Williams, Geoffrey M. Anderson, Paula Blackstien-Hirsch, Cathy Fooks, and C. David Naylor, eds., *Patterns of Health Care in Ontario. The ICES Practice Atlas,* 2nd Edition. Toronto, Institute for Clinical Evaluative Sciences, 1996, pp 5-26. (This report is available at: http://www.ices.on.ca/index.asp) [HUI3; Description]

Gold, Marthe, Peter Franks, and Pennifer Erickson. "Assessing the Health of the Nation: The Predictive Validity of a Preference-Based Measure and Self-Rated Health." *Medical Care,* Vol. 34, No. 2, February, 1996, pp 163-177. [Predictive Validity][USA, Population Health]

Grootendorst, Paul, "Results on an Investigation into the Integrity of the Ontario Health Survey." McMaster University, *Centre for Health Economics and Policy Analysis Working Paper No 93-11,* December, 1993. [Reliability][Canada, Population Health]

Grootendorst, Paul, David Feeny, and William Furlong, "Does It Matter Whom and How You Ask? An Investigation into Inter- and Intra-rater Agreement in the 1990 Ontario Health Survey." *Journal of Clinical Epidemiology,* Vol. 50, No 2, February, 1997, pp 127-135. [Reliability][Canada, Population Health]

Grootendorst, Paul, David Feeny, and William Furlong, "Health Utilities Index Mark 3: Evidence of Construct Validity for Stroke and Arthritis in a Population Health Survey." McMaster University, *Centre for Health Economics and Policy Analysis Working Paper No. 99-06,* June, 1999. [Construct Validity][Canada, Population Health]

Grootendorst, Paul, David Feeny, and William Furlong, "Health Utilities Index Mark 3: Evidence of Construct Validity for Stroke and Arthritis in a Population Health Survey." *Medical Care,* Vol. 38(3), March, 2000, pp 290-299. [Construct Validity][Canada, Population Health]
Holmes, Ann M., "A QALY-Based Societal Health Statistic for Canada, 1985." Social Science, *Medicine,* Vol. 41, No. 10, 1995, pp 1417-1427. [Scoring][Canada, Population Health]

Hood, Sheila C., Marie P. Beaudet, and Gary Catlin, "A Healthy Outlook." Health Reports, Vol. 7, No 4, Spring, 1996, pp 25-32. [Construct Validity][Canada, Population Health]

Kaplan, Robert M., and Pennifer Erickson, "Gender Differences in Quality-Adjusted Survival Using a Health Utilities Index." *American Journal of Preventive Medicine*, Vol. 18, No. 1, January, 2000, pp 77-82. [Construct Validity]

Kopec, Jacek A., J. Ivan Williams, Teresa To, and Peter C. Austin, "Measuring Population Health: Correlates of the Health Utilities Index among English and French Canadians." *Canadian Journal of Public Health,* Vol. 91, No. 6, November-December, 2000, pp 465-470. [HUI3; Construct Validity][Canada]

Macran, Susan, Helen Weatherly, and Paul Kind, "Measuring Population Health: A Comparison of Three Generic Health Status Measures." *Medical Care*, Vol. 41, No. 2, February, 2003, pp 218-231. [modified non-standard version of HUI3; Construct Validity; Primary Care; Routine Use][UK]

Manuel, Douglas G., Vivek Goel, J. Ivan Williams, and Paul Corey, "Health-Adjusted Life Expectancy at the Local Level in Ontario." *Chronic Diseases in Canada*, Vol. 21, No. 2, 2000, pp 73-80. [HUI3; Construct Validity][Canada, population health]

Manuel, Douglas G., Susan E. Schultz, and Jacek A. Kopec, "Measuring the Health Burden of Chronic Disease and Injury using Health-Adjusted Life Expectancy and the Health Utilities Index." *Journal of Epidemiology and Community Health*, Vol 56, No. 11, November 2002, pp 843-850. [HUI3; Construct Validity][Canada, population health]

Manuel, Douglas G., and Susan E. Schultz, "Adding Years to Life and Life to Years: Life and Health Expectancy in Ontario," Report 1, *Institute for Clinical Evaluative Sciences Atlas Report: The Health of Ontarians.* Toronto, Institute for Clinical Evaluative Sciences, 2001. (This report is available at: http://www.ices.on.ca/index.asp) [HUI3; Description]

Manuel, Douglas G., and Susan E. Schultz, "Adding Years to Life and Life to Years: Life and Health Expectancy in Ontario - Technical Supplement," Report TS-1, *Institute for Clinical Evaluative Sciences Atlas Report: The Health of Ontarians.* Toronto, Institute for Clinical Evaluative Sciences, 2001. (This report is available at: http://www.ices.on.ca/index.asp) [HUI3; Description]

Manuel, Douglas G., Wei Luo, Anne-Marie Ugnat, Yang Mao, "Cause-deleted health-adjusted life expectancy of Canadians with selected chronic conditions." *Chronic Diseases in Canada*, Vol. 24, No. 4, 2003, pp 108-115.[HUI3][Canada, Population Health]

Manuel, Douglas G., Susan E. Schultz, "Diabetes - Health Status and Risk Factors." *Diabetes in Ontario-Practice Atlas*, Chapt. 4, 2002, pp 77-94.
Manuel, Douglas G., Susan E. Schultz, "Using Linked Data to Calculate Summary Measures of Population Health: Health-adjusted Life Expectancy of People with Diabetes Mellitus." *Population Health Metrics*, Vol. 2, No. 1, 2004, 4; http://www.pophealthmetrics.com/content/2/1/4 [HUI3][Canada, Population Health]

Manuel, Douglas C., Mark Leung, Kathy Nguyen, Peter Tanuseputro, and Helen Johansen, "Burden of Cardiovascular Disease in Canada." *Canadian Journal of Cardiology*, Vol. 19, No. 9, August, 2003, pp 997-1004. [HUI3][Canada, Population Health]

Manuel, Douglas G., and Susan E. Schultz, "Health-Related Quality of Life and Health-Adjusted Life Expectancy of People with Diabetes in Ontario, Canada, 1996-1997." *Diabetes Care*, Vol. 27, No. 2, February, 2004, pp 407-414. [HUI3][Canada, Population Health]

Mittmann, Nicole, Kostas Trakas, Nancy Risebrough, and Barbara A. Liu, "Utility Scores for Chronic Conditions in a Community-Dwelling Population." *Pharmacoeconomics,* Vol. 15, No. 4, April, 1999, pp 369-376. [Scoring][Canada, Population Health]

Nault, F., Roger Roberge, and Jean-Marie Berthelot, "Espérance de vie et espérance de vie en santé selon le sexe, l'état matrimonial et le statut socio-économique au Canada." *Cahiers québécois de démographie,* Vol. 25, No. 2, 1996, 241-259 (In French). [HUI3; Construct Validity]

Raina, Parminder, Brenda Bonnett, David Waltner-Toews, Christel Woodward, and Tom Abernathy, "How Reliable are Selected Scales from Population-based Health Surveys? An Analysis Among Seniors." *Canadian Journal of Public Health,* Vol. 90, No. 1, January-February, 1999, pp 60-64. [Reliability of selected HUI3 items]

Rizzo, John A., Steven Pahko, Rebecca Friedkin, John Mullahy, and Jody L. Sindelar, "Linking the Health Utilities Index to National Medical Expenditure Survey Data.", *PharmacoEconomics*, Vol. 13, No.5, Part 1, May, 1998, pp 531-541.[Construct Validity] [USA, Population Health]

Rizzo, John A. and Jody L. Sindelar, "Linking Health-Related Quality-of-Life Indicators to Large National Data Sets." *PharmacoEconomics,* Vol. 16, No. 5, Part 1, November, 1999, pp 473-482. [Construct Validity][USA, Population Health]

Roberge, Roger, Jean-Marie Berthelot, and K. Cranswick, "Adjusting Life Expectancy to Account for Disability in a Population: A Comparison of Three Techniques." *Social Indicators Research*, Vol. 48, 1999, pp 217-243. [HUI3; Scoring][Canada, Population Health]

Roberge, Roger, Jean-Marie Berthelot, and Michael Wolfson, "Health and Socio-economic Inequalities." *Canadian Social Trends,* No. 37, Summer, 1995, pp 15-19 (also available in French). [Construct Validity][Canada, Population Health]

Roberge, Roger, Jean-Marie Berthelot, and Michael Wolfson, "The Health Utility Index: Measuring Health Differences in Ontario by Socioeconomic Status." *Health Reports,* Vol. 7, No. 2, November, 1995, pp 25-32 (also available in French). [Construct Validity][Canada, Population Health]

Roberge, Roger, Jean-Marie Berthelot, and K. Cranswick, "Linking Disability-Adjusted Life Expectancy with Health Adjusted Life Expectancy: Calculations for Canada," Presented at the 9th meeting of the Health Expectancy Network (REVES 9), Rome, Italy, December 1996. [Construct Validity][Canada, Population Health]

Roberge, Roger, Jean-Marie Berthelot, and Michael C. Wolfson, "Adjusting Life Expectancy to Account for Morbidity in a National Population." *Quality of Life Newsletter,* No. 17, March, 1997 - August, 1997, pp 12-13. [Scoring]

Ross, Nancy A., Stephane Tremblay, and Katie Graham, "Neighbourhood Influences on Health in Montreal, Canada." *Social Science & Medicine*, Vol. 59, No. 7, October, 2004, pp 1485-1494. [HUI3; Construct Validity, Canada]

Schultz, Susan E., and Jacek A. Kopec, "Impact of Chronic Conditions." *Health Reports*, Vol. 14, No. 4, August, 2003, pp 41-53. [HUI3; Construct Validity][Canada]

Statistics Canada, September 2000 and on-going, Canadian Community Health Survey.
In the first year of each two-year cycle, the survey covers approximately 130,000 Canadians and is designed to provide valid information for each of 136 health regions. In the second year of the cycle, provincial-level surveys are undertaken

(n=~30,000). The survey covers household residents 12 years of age and over. HUI3 is included in the survey. The first output is scheduled for release in 2002. Additional information can be obtained from the official Statistics Canada website at http://www.statcan.ca/english/concepts/health/ccshinfo.htm.
Statistics Canada, Statistical Report on the Health of Canadians. Ottawa: Statistics Canada, Catologue 82-570-X1E, September, 1999. Available from http://www.hc-sc.gc.ca/hppb/phdd/report/eng/report.html

Statistics Canada, The 1991 General Social Survey - Cycle 6: Health - Public Use Microdata File Documentation and User's Guide. Ottawa: Statistics Canada, June, 1992. [Description][Canada, Population Health]
Statistics Canada, Health Status of Canadians: Report of the 1991 General Social Survey. Ottawa: Statistics Canada, Catologue 11-612E, No. 8, March, 1994.[Canada, Population Health]

Tambay, Jean-Louis and Gary Catlin, "Sample Design of the National Population Health Sruvey". *Health Reports*, Nov. 7, No. 1, 1995, pp 29-38. [HUI3; Survey Design][Canada]

Thomas, Vince Salazar, Sultan Darvesh, Chris MacKnight, and Kenneth Rockwood, "Estimating the Prevalence of Dementia in Elderly People: A Comparison of the Canadian Study of Health and Aging and National Population Health Survey Approaches." *International Psychogeriatrics*, Vol. 13, Supplement 1, 2001, pp 169-175. [HUI3; Construct Validity]

Trakas, Kostas, Kate Lawrence, and Neil H. Shear, "Utilization of Health Care Resources by Obese Canadians." *Canadian Medical Association Journal,* Vol. 160, No. 10, May 18, 1999, pp 1457-1462. [Construct Validity][Canada, Population Health]

Trottier Helen, Laurent Martel, Christian Houle, Jean-Marie Berthelot, and J. Légaré, "Living at Home or in an Institution: What Makes the Difference for Seniors." *Health Reports*, Vol. 11, No. 4, Spring 2000, pp 49-61; Statistics Canada Catalog # 82-003-XPB. [Construct Validity][Canada]

Tully, P. and C. Mohl, "Older Residents of Health Care Institutions." Health Reports, Vol. 7, No. 3, 1995, pp 27-30. [Description][Canada, Population Health]
van Doorslaer, Eddy, and Andrew M. Jones, "Inequalities in Self-Reported Health: Validation of a New Approach to Measurement." *Journal of Health Economics*, Vol 22, No. 1, January, 2003, pp 61-87. [HUI3; Construct Validity]

Verrips, G.H.W., M.C. Stuifbergen, A. L den Ouden, G.J. Bonsel, R.J.B.J. Gemke, N. Paneth, and S.P. Verloove-Vanhorick, "Measuring Health Status Using the Health Utilities Index: Agreement Between Raters and Between Modalities of Administration." *Journal of clinical Epidemiology*, Vol. 54, No. 5, May, 2001, pp

475-481. [HUI3; Inter-rater Reliability; Inter-mode Reliability; Child Health][Netherlands]

Wagstaff, Adam, and Eddy van Doorslaer, "Overall versus Socioeconomic Health Inequality: A Measurement Framework and Two Empirical Illustrations." *Health Economics*, Vol. 13, No. 3, March, 2004, pp 297-301. [HUI3]

Wang, Qinan, and Geraldine Chen, "The Health Status of the Singaporean Population As Measured by the Health Utilities Index Mark III System." *Singapore Medical Journal,* 1999, forthcoming. [Cross-Cultural Validation; Description][Singapore, Population Health]

Wolfson, Michael C., "Health-Adjusted Life Expectancy." *Health Reports,* Vol. 6, No. 1, Summer, 1996, pp 41-46. [Construct Validity][Canada, Population Health]
Return to top of page.

Use of HUI3 in Canadian Population Health Surveys

The HUI Mark 3 System was devised for the 1990 Ontario Health Survey and has been incorporated in every major subsequent population health survey in Canada. To date the list of surveys includes:

Ontario Ministry of Health, Ontario Health Survey I, 1990; survey of 35,349 dwellings and 61,239 persons.

Ontario Ministry of Health and Statistics Canada national Population Health Survey, Ontario Health Survey II (1996/97); augmented Ontario sample in the 1996/97 NPHS, 36,892 respondents sampled through random digit dialing.

Statistics Canada, 1991 Sixth Cycle Canadian General Social Survey; survey of health status of 11,760 persons.

Statistics Canada, 1994 and future Canadian National Population Health Survey. 1994-95 survey covers 19,600 households. Longitudinal component to be repeated every two years.

Statistics Canada, 1994 and future National Longitudinal Survey of Children and Youth. 1994-1995 survey covers 22,831 children; coverage newborns to 11 years of age; parental report on children < 10 years of age; self report of child for ? 10 years of age; complete HUI3 data for ages 6 and up; considerable HUI3 data for children ages 4 and 5; public-use data files released in 1998. Longitudinal component to be repeated every two years.

Vozoris, Nicholas T., and Valerie S. Tarasuk, "The Health of Canadians on Welfare." *Canadian Journal of Public Health*, Vol. 95, No. 2, March-April, 2004, pp 115-120. [HUI3; Construct Validity][Canada, population health]

Wall, Ron, and Robyn Foster, "Using Canada's Health Data: Beyond Life Expectancy." *Health Policy Research Bulletin*, Vol. 1, Issue 3, March, 2002, pp 32-33; 39. [HUI3; Descriptive]

Endnotes:

---

[i] There have been attempts, notably in Oregon, to use the $/QALY rankings to determine the cut-off point for free health care. The idea is that the government pays only for those treatments that have low $/QALY, and stops at the point in the list of treatments where the actuaries calculate that the public health budget will be exhausted. Economists have assigned a value of a statistical life by, among other things, comparing the wages of those in high-risk occupations (e.g. mining) with the wages of those in relatively safe occupations. Results have generally been about $5 million to $6 million, for a high school graduate in 2000, or assuming a mean HALE of 50 years, a $/QALY threshold of about $100,000. A regulation against cell-phone use while driving has been costed, for example, at $360,000/QALY, which would make it a relatively expensive intervention.

Appendix K

Working Paper 4: Measuring RRAP-D/HASI Benefits by Direct Costs Avoided

Measuring RRAP-D/HASI Benefits by Direct Costs Avoided

Introduction

In addition to improving the beneficiary's quality of life while he or she remains in the modified dwelling, RRAP-D and HASI are expected to have the following effects:

1. Savings in the financial costs of formal services and/or care giving
2. Savings that come from postponing a change of residence

Baseline Scenario

The 'baseline', without the modifications to the dwelling, is that the disabled and/or elderly person(s) would remain in their dwelling for a period of time (t_0 to t_1), at a certain quality of life (Q_1) that may deteriorate because of advancing age or disability to (Q_2). This period may be terminated at t_1 by death or the persons may move to another dwelling at a different quality of life (Q3). In general one would expect that $Q_3>Q_2$ unless, of course, the move is dictated by necessity rather than a desire to live in a more appropriate dwelling at a higher quality of life. We may assume that the person(s) die at t_4.

The persons' accommodation costs from t_0 to t_1 will be $X per month. From t2 to t3, they will be $Y per month. Therefore total costs in the baseline scenario will be $[(t_1-t_2)*X] + [(t_2-t_4)*Y]$

The Assistance Scenario

The effect of the RRAP-D/HASI contribution is to improve the quality of life of the persons in their existing dwelling and thereby enable them to stay in that dwelling for longer (to t_2). Their quality of life immediately after the modifications to their dwelling will be Q_1+. This will deteriorate over time till it reaches Q2 at which time they will move to a different dwelling just as they did in the baseline scenario. This will happen at t_3.

The persons' accommodation costs from t_0 to t_3 will be $X per month. From t_2 to t_3, they will be $Y per month. Therefore total costs in the assistance scenario will be $[(t_1-t_3)*X] + [(t_3-t_4)*Y]$

Calculating the Direct Financial Benefit of RRAP-D/HASI

In order to calculate the direct financial benefit of RRAP-D/HASI we need to know two things:

1. How much longer do the persons stay in their initial dwelling? That is, what is the time period t_2 to t_3?

2. What is the difference between their present cost of accommodation and the cost after their eventual move? That is, what is $Y - $X.

Of course actual situations are seldom this simple. The picture would be more accurately portrayed by two sets of curves – downward trending quality of life curves for both the baseline and the assistance scenarios; and upward trending accommodation cost curves.

Evaluation of 'Home Adaptation for Seniors Independence' (HASI)

In 1994, CMHC undertook a survey of HASI beneficiaries and in 1998 published an evaluation entitled *Housing Initiatives under the National Strategy for the Integration of Persons with Disabilities* which drew upon the survey data to evaluate HASI. The mail out survey addressed nearly all persons (1032) who received HASI financial assistance in 1992.[1] As with RRAP-D, the most frequent HASI modifications were to the bathroom (approximately 75%) and to the entrance to the home (67%).

The study defined "independence" as, first, the ability to carry out the normal activities of every day life by oneself and, second, the ability to stay in one's current home rather than move in with care givers or move to an institutional residence. The first aspect of independence is measurable on a continuum of comfort, improved safety and security, improved ability to perform everyday activity, and improved quality of life. The second aspect of independence relates to avoiding a threshold of discomfort in any of these aspects of life at which the homeowner or tenant would choose to change residences. "*Overall about 55% of HASI clients agreed that without the adaptation, they would have had to move and 30% strongly agreed with this statement.*" (p.23) Forty percent of beneficiaries strongly agreed, and 17.6% moderately agreed, that they would not have made the adaptations without HASI support. It is unknown whether this was driven by inability to pay or unwillingness to pay without a subsidy (because value did not exceed total

price). There were large unexplained variations in the 'incremental effect' percentages by Province.

The part of the study most relevant to a cost-benefit framework is entitled "Cost Effectiveness of the HASI Program".[2] It states "*The key rationale for HASI was to provide seniors with the opportunity to remain in their own homes by facilitating their ability to carry out activities of daily living with minor home adaptations*."[3] The cost-effectiveness analysis considered the costs and benefits of HASI solely in this regard – that is, how long did HASI prolong the beneficiaries' stay their present homes, and with what financial and economic results? Actually, this question was posed only for single-person households because the study team decided that multi-person households were too complex to analyse.

The administrative costs to deliver $8,626,624 in loans were estimated to be $2,129,681.[4] These did not include any costs to clients for their time or expenses in applying to HASI or managing the renovation project. However CMHC estimated that clients expended $553,872 to pay for part of the work, either because some expenses were ineligible under CMHC guidelines or because the total cost exceeded the HASI loan ceiling.

The housing costs of HASI clients who would have moved out of their house without HASI assistance (estimated by the evaluators to be one third of the sample of clients) were estimated to be $11,120 per year. In addition, the costs of in-home care for these persons were estimated. Only the costs that would not be incurred in an institutional setting, or that would be included within the overall fees charged by an institution, were included in the estimate. Responses to the HASI survey indicated that about half the HASI beneficiaries had used in-home services in the previous six months. On the basis of regional data from British Columbia, the average cost of in-home services was assumed to be $2700, and this was doubled (a "guesstimate") to account for informal in-home services by friends and relatives.

Except on an anecdotal basis, the study was not able to ascertain whether the use of in-home services had been significantly reduced by the HASI renovations. In most cases it appeared to the authors that a reduction in such costs was unlikely.

Set against these costs were the benefits of avoiding institutionalization. The value of this benefit was estimated from Statistics Canada's *Survey of*

Residential Care Facilities for the Aged. In 1992-93 the average cost (across all levels of institutional care) was $32,543 per staffed bed per year. The study states that this estimate is probably too high since HASI beneficiaries, if they moved to an institutional setting, would probably require only basic levels of care that is, Type 1 care[5]. On the basis of Hollander (1994) the cost of a Type 1 case was estimated to be $28,312.

The estimate of the incremental impact of HASI was based on the proportion of clients who would have moved out of their homes without HASI (said to be 32%). It was difficult to estimate on a firm basis how long people helped by HASI did in fact remain in their homes since HASI was, at that time, a relatively new program. It would be easier now with a longer history to examine. On the basis of the little that was known at the time, the study concluded that recipients stayed on average for an additional two years in their present homes (guesstimate). A "sensitivity analysis" revealed that HASI was cost-effective if the average additional stay for the 32% of beneficiaries who would otherwise have moved was more than 6 months, on average. The net present value of the program rises rapidly as the additional stay in-home gets longer.

The extra satisfaction (utility) of the HASI beneficiaries who were enabled to stay longer in their homes was mentioned but not quantified or monetized.

Limitations of the Methodology

The methodology has the following limitations.

Hypothetical

The evaluators did not actually measure how much longer HASI recipients remained in their homes. The conclusion was hypothetical - that the program was cost effective if they had stayed a certain time. However measurements could be made on a quasi-experimental basis (comparing recipients to non-recipients) and extended to RRAP-D.

Important Benefits Ignored

The evaluators estimated the incremental costs of institutionalization, but not the incremental benefits. Since the persons freely choose to move and

also bear considerable transition costs, they clearly see major benefit in changing dwellings.

Signalling

The evaluator is signalling the desired response when he or she asks program beneficiaries a question like "Would you have changed dwellings if you had not received the grant to modify this one?" One can make one's own judgement about the inherent plausibility of a small HASI contribution resulting in a third of beneficiaries staying in their home rather than moving.

Summary

The 'costs avoided' methodology has the attraction of being relatively straightforward to measure. However, it would require it would require a rigorous comparative analysis (with a control group) of just how much longer recipients stayed in their existing dwelling, and it would require taking the benefits of a move into account as well as the costs.

Endnotes:

[1] Six hundred and thirteen persons completed a questionnaire. The evaluation report states that "*this response rate was high enough to provide an accurate picture of program approach and performance at the national level*". However, of course, this depends on how representative the respondents were of the whole population, and this is unknown. In addition, thirty telephone interviews were conducted in 1995 with persons who had provided detailed responses to the written survey in 1993. At the same time, CMHC Audit and Evaluation Services sent a questionnaire to field staff who delivered the program.The report considered the continuing relevance of HASI in light of disability rates among seniors. Among HASI beneficiaries it found 80% had age-related mobility disabilities.

[2] Section 8

[3] p.43

[4] Table, p.45

[5] Statistics Canada defines Type 1 care as "that required by a person who is ambulant and/or independently mobile, who has decreased physical and/or mental facilities, and who requires primarily supervision and/or assistance with activities of daily living and provision for meeting psychosocial needs through social and recreational services. The period of time during which care is required is indeterminate and related to the individual condition but is less than 90 minutes in a 24 hour day."

Visit our home page at www.cmhc.ca