

---

# **ISSUES OF AGEING AND DISABILITY:** International Perspectives



NGO COMMITTEE ON AGEING/NY

---





# ***ISSUES OF AGEING AND DISABILITY: INTERNATIONAL PERSPECTIVES***

**Edited by  
Mary J. Mayer and Dr. Florence L. Denmark**

**December, 2010**

**NGO COMMITTEE ON AGEING/NY  
[www.nycoa-ny.org](http://www.nycoa-ny.org)**

## DEDICATION

Ruth A. Begun was an inspiration to us all not only because of her “I can do anything” attitude but because of her intellect and support to others.

Ruth contracted polio when she was 27, during her pregnancy with her second child. She was married to Frank Begun for 42 years and had two children, Frank and Barbara Begun. She also had 4 grandchildren

She worked at Equitable Life Assurance Society of the United States 1970 to 1990. As a colleague, Rami Rabby wrote, “Ruth Begun was a pioneer, one of the earliest advocates for equal treatment of people with disabilities, and probably the first to break down the doors of big business for the disabled; and all that was accomplished by Ruth, a near-generation before the ADA ever came into being.”

Her NGO UN experience was rich. She was an active member of the Committee on Ageing and the Committee on the Status of Women. She was a staunch member of the Sub Committee on Older Women (SCOW) and was part of the group who wrote many of the position papers. She was involved in the meetings that produced the Convention on Disabilities.

She was one of the 12 honorees by the NGO CSW and SCOW in the special program in June of 2009 called “Honoring our Own,” which recognized women who had made an impact on equality issues.



**Ruth A. Begun • December 18, 1927 - February 9, 2008**

Ruth was an avid advocate through the Gray Panthers and Disabilities in Action (DIA) in New York, demonstrating and attending rallies.

Lyn Voss from Ruth’s NGO wrote, “Ruth was a person who never gave up throughout the many years we knew her .... She was a person who always strived to do more for people, especially those with disabilities for she herself had been paralyzed for many years with the effects of polio. Ruth did us proud during the years she represented the National Women’s Conference Committee, and we are eternally grateful to her for her many accomplishments while at the UN.”

This publication is a testament to her accomplishments.

## FOREWORD

The NGO Committee on Ageing is pleased to present this publication on “Issues of Ageing and Disability” in memory of Ruth Begun, a former member of the NGO Committee on Ageing – New York, and a life-long advocate for persons with disabilities. She led our initiatives in promoting equality and dignity for persons ageing with disabilities.

Population ageing is one of humanity’s greatest triumphs. It is also one of our greatest challenges and places increasing economic and social demands on all countries. For the first time in history older persons will exceed the number of children by the year 2050.

The General Assembly resolved to hold the Second World Assembly in 2002 which adopted the Madrid Plan of Action on Ageing. The adoption of the International Plan of Action aims to ensure that persons everywhere are able to age with security and dignity and to continue to participate in their societies as citizens with full rights. The Madrid Plan lays out an important objective in order to promote the maximum functional capacity throughout the life course and promotion of the full participation of older persons with disabilities. (Issue 6: Older persons and disabilities).

Older men and women have the same rights as everyone else: we are all born equal and this does not change as we grow older. Even so, older people’s rights are mostly invisible. Older persons and persons with disabilities have the right to freedom from discrimination. Older men and women are often denied access to services, jobs or treated without respect because of their age and other factors such as disability. Older people and persons with disabilities are assets to society and can contribute significantly to the development process if given the opportunity. As such, they need to be empowered and their participation ensured.

Those who participated in the production of the publication deserve significant recognition, in particular the co-editors, Mary J. Mayer and Florence L. Denmark.

Acknowledgement is also extended to Fred Doulton and Akiko Ito of the Secretariat for the Convention on the Rights of Disabled Persons and Rosemary Lane of the United Nations for the Programme on Ageing for their guidance and contribution to this project. Much appreciation is expressed to those who played an important role in ensuring high quality papers that represent all six United Nation regions in the world and thus present a global perspective on the issues of ageing and disability.

**Jessica Frank López**  
**Chair, NGO Committee on Ageing – New York**



## TABLE OF CONTENTS

	Page
<b>Dedication</b>	<b>i</b>
<b>Foreword</b>	<b>ii</b>
<b>Table of Contents</b>	<b>1</b>
<b>Statement of the UN Focal Point on Ageing</b>	<b>2</b>
<b>Statement of the UN Focal Point on Disability</b>	<b>3</b>
<b>Introduction</b>	<b>4</b>
<b>Aging, Long-Term Disability and Disasters</b> <i>Elaine Congress, DSW, Michael Cronin, PhD, and Marcia Wallace, MSSA</i>	<b>5</b>
<b>Social Well-Being of Disabled Older Persons: Evidence of Unequal Ageing in Europe</b> <i>Katrin Gasior, Mag.rer.soc.oec. and Ashgar Zaidi, PhD</i>	<b>13</b>
<b>Care Concerns, Enabling Environmental Challenges and Policy Responses in Asia, with Special Reference To India</b> <i>Mala Kapur Shankardass, PhD.</i>	<b>24</b>
<b>The Experience of Acquiring a Disability as a Senior Citizen</b> <i>Alessandra Marques Sohn, BSci, Michele Santos Cruz, BSci, Michele Schultz Ramos Andrade, PhD</i>	<b>29</b>
<b>The Effect of Age and Age of Onset on Involuntary Retirement For People with Disabilities in Canada</b> <i>Margaret Denton, PhD, Jennifer Millen Plenderleith, MSc, and James Chowan, M.A.</i>	<b>38</b>
<b>Access to Assistance and Services for Disabled People in Developing Countries</b> <i>Bheki Jele, Secretariat of the African Decade of Persons with Disability</i>	<b>46</b>
<b>Implications of Visual Impairment for Functioning and Mobility Of Older Persons: A Global Health Perspective</b> <i>Moon Choi, PhD and Briana Mezuk, PhD</i>	<b>49</b>
<b>Older People and Hearing Disability</b> <i>Ghassan Sharour, MD</i>	<b>56</b>
<b>Cognitive Impairment: The Need to Recognize It as a Form Of Disability</b> <i>Ravi Samuel, MPhil, PGCARM, Udaya Mahadevan, PhD and Vivian Isaac, MSc, MPhil</i>	<b>62</b>
<b>Ageing Impaired Persons Suffering from an Amputation – An Investigation of Their Requirements and Wishes for a Vehicle</b> <i>Doris Kortus-Schultes, Prof Dr., Angelika Engel, MBA and Max Feierabend, B.A.</i>	<b>70</b>



The United Nations programme on ageing welcomes the issuance of this timely publication on age and disability for a number of reasons.

For the United Nations and traditional data gathering reasons, older persons are classified as those 60 years and above, but we have to acknowledge that the majority of older persons are not disabled. However, as both the number of older persons increases in all regions of the world and life expectancies continue to grow, there are an increasing number of the “oldest old”, namely those age 80 years and above, who bear a disproportionate level of disability in old age. Added to this, since women live longer than men more older women spend a greater proportion of their older years in poor health and with disabilities. The fast growing number of older persons living with Alzheimer’s due to increased longevity is also becoming a major disabling condition worldwide.

We cannot ignore the link between poverty, poor health and disability as we age. In low income countries in particular, impairments that should be easy to address such as the provision of cataract surgery, lead to blindness for many as they age. The provision of assistive devices such as eyeglasses, hearing and walking aides can prevent impairments from becoming disabling. In fact, low levels of gerontological training for health care workers worldwide leads to an increasing number of older persons with disabilities from a growth in non-communicable diseases such as diabetes, and cardio vascular problems, which would most likely be preventable. Thereafter, in a circular fashion, the double burden of being both old and disabled leads to low levels of wellbeing and a greater probability of living in poverty.

For many years, for various reasons, there has been a disconnect between issues of disability and ageing. The Convention on the Rights of Persons with Disabilities has shown that there is in fact much common ground; in particular with issues of accessibility.

We hope that this publication will stimulate some thinking about these connections and show how simple preventative and assistive measures can be taken as people age, and to both lessen the number and address the issues of older persons living with disabilities.

**Rosemary Lane**  
**Focal Point on Ageing**  
**United Nations Department of Economic and Social Affairs**





In the United Nations Charter and the Universal Declaration of Human Rights (1948), the foundational documents of modern human rights law, the international community sought a peaceful and prosperous world created by economic and social progress based on universal human rights. Through the end of the last century, the United Nations adopted a total of seven core human rights conventions. Each of these core conventions contain legal obligations that can be applied to persons with disabilities; however, these conventions did not address specific barriers that persons with disabilities face in realizing their human rights.

Prior to the Convention on the Rights of Persons with Disabilities, several instruments and policy guidelines relating to disability and persons with disabilities had been adopted by the United Nations General Assembly. These include the World Programme of Action concerning Disabled Persons (1982) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993).

The Convention on the Rights of Persons with Disabilities which was adopted by the General Assembly in 2006 and came into force in 2008, set out the legal obligations of States to promote and protect the rights of persons with disabilities in, society and development. It contains a number of articles which highlight the cross-sectionalities of ageing and disability. For instance article 9 [accessibility], article 19 [living independently and being included in the community], article 20 [personal mobility] and article 25 [health] are just a few examples of how the Convention provides a concrete framework for action which may be of particular interest to the discussions on disability and ageing.

Currently, it is estimated that 1 in every 10 people worldwide or some 650 million individuals live with one or more disabling conditions. Looking ahead, the global trends in population ageing is likely to lead to further increases in the population affected by disability. Available data indicate a close association between population ageing and increased incidence of impairment. The current trends in demographic shifts suggest a rapid and unprecedented increase in older persons in the twenty-first century. Persons aged 60 and above are projected to increase from 675 million in 2005 to 1.9 billion by the year 2050.

As we all know, even today persons with disabilities face a number of obstacles including attitudinal, environmental and institutional barriers preventing their full and equal participation in all aspect of life. Often girls and women with disabilities and older persons with disabilities remain the most adversely affected. Therefore any discourse on ageing and disability need to ensure the inclusion of such excluded groups.

Furthermore as life expectancy in general increases, persons with disabilities who survive in to old age can also be expected to contribute to the overall growth in the population of older persons with disabilities.

This highlights the need for countries to take a longer-term approach to investment in the planning, design and construction of their community to ensure environmental inclusiveness and accessibility in moving towards the goal of creating a society which meets the needs and capacities of all users. It demonstrates a clear need to start articulating policies and programmes with regard to ageing which takes in to consideration the cross-sectionalities between ageing and disability and how the society can ensure programmes and facilities designed to meet the needs of an ageing population are also successful in meeting the needs of older persons with disabilities. In doing so, there is an opportunity to review and further explore the complementarities between the discourses on disability and on ageing.

**Akiko Ito, Chief  
Secretariat for the Convention on the Rights of Persons with Disabilities  
United Nations Department of Economic and Social Affairs**

## INTRODUCTION

This publication on “Issues of Ageing and Disability: International Perspectives” honors the memory of Ruth Begun, a long-time member of the NGO Committee on Ageing as well as the NGO Committee on Disability. The publication, launched in December 2010, also calls attention to the month in which the United Nations formally recognizes disability through the International Day of Disabled Persons.

In planning for the publication, the NGO Committee on Ageing issued a Call for Papers that was sent through many international channels. The ten papers on various aspects of ageing and disability included in this volume were selected from among those received through peer review based on their research and/or good practice. The papers come from many parts of the world including Brazil, Canada, Germany, India, Syria, South Africa and the United States. All are original and not previously published. Some address specific disabilities, such as vision and audition, while others are more general covering such topics as access to services, involuntary retirement caused by disability and experiencing disability as an older person.

The NGO Committee on Ageing recognizes that the subject of ageing and disability encompasses topics other than those addressed in this publication. Also readers may note that the word “ageing” is spelled “aging” in some papers, reflecting the usage in the country from which the paper emanated. Similarly, the references cited in each paper may vary. The form of referencing each author used was not changed because different fields of study have their own reference styles.

Hopefully you will find these articles an informative and valuable addition to your knowledge of ageing and disability.

**Mary J. Mayer, International Federation on Ageing, [mjmayer\\_128@hotmail.com](mailto:mjmayer_128@hotmail.com)**

**and**

**Florence L. Denmark Ph.D., Main Representative, International Council of Psychologists; Former Chair, NGO Committee on Ageing – New York, [fdenmark@pace.edu](mailto:fdenmark@pace.edu)**

**Editors**

# Ageing, Long-Term Disability, and Disasters

Elaine Congress, DSW

Professor and Associate Dean, Fordham University Graduate School of Social Service  
International Federation of Social Workers representative, New York, New York, United States  
congress@fordham.edu

Michael Cronin, PhD

Monmouth School of Social Work  
International Federation of Social Workers, Main representative, New Jersey, United States  
mcronin@monmouth.edu

Marcia Wallace, MSW

Retired Social Worker, New York, NY  
International Federation of Social Workers, representative  
mtswal@optonline.net

## INTRODUCTION

The “graying” of the world has been well documented as the number of older people is rapidly increasing in all countries. Unfortunately, the number and intensity of natural disasters such as earthquakes, hurricanes, typhoons, and subsequent flooding and drought is also on the increase. While older people are particularly vulnerable in times of disasters, (Lamb, O’Brien, & Fenza, 2008), those with a long-standing disability are especially at risk when there is a natural disaster. This paper will examine the multiple factors related to this growing population, human rights documents that support the need to provide assistance, as well as community interventions that can help disabled people during a disaster.

## INCIDENCE

It is well known that many older people experience disabilities such as visual and auditory deficits, as well as increased mobility problems when they age. This paper, however, will address a population that receives infrequent attention:

older people with long-term disabilities.

While there is much literature on ageing as well as disability, few have attempted to focus on ageing with a long-term disability. A notable exception is Putnam’s article in *The Gerontologist* that attempts to link theories on disability with those on ageing. Incorporating social models of disability that focus on the strong impact of environment in the lives of disabled people with individual theories on ageing such as activity theory, disengagement theory, and continuity theory can help to better understand the experiences of the older person with life-long disabilities (Putnam, 2002). Existing theories on older people as well as disability stress the importance of environment. Yet in times of disasters the environment as the older disabled person has known it may no longer exist.

## DISASTERS

Despite efforts to reduce, deflect or prevent them, disasters will continue to confront humankind. Webster defines disaster as “a calamitous event especially one occurring suddenly and causing

great loss of life, damage or hardship... adverse happenings often occurring suddenly and unexpectedly and causing great affliction.”

Disasters occur from natural causes such as hurricanes, tsunamis, floods, earthquakes, tornados, droughts, cyclones and from acts of man such as catastrophic accidents, explosions, fire and war. The calamitous effect on human life and particularly on those who are elderly and disabled is of critical significance. Despite anticipated efforts to mitigate climate-related disasters these, unfortunately, will continue to occur. And despite the world communities’ efforts to prevent accidents and to limit warfare (which is the premise of the founding of the United Nations), wars, too, will continue. So, the realization of these factors and preparation for the effects of disasters are imperatives.

## AGEING/ ELDERLY

The world’s population is ageing at a rapid rate. The projection is that by year 2050, 2 billion persons, making up 22% of the total population, will be aged 60 years or older. Within that group the proportion

of people over 80 years old will increase significantly. There are currently 6.6 million people aged over 80 worldwide. In 2025 the number of people aged over 80 is projected to increase by almost 50% (Robinson, Novelli, Pearson, & Norris, 2007). In 2050 this over-80 group will make up an increasingly greater proportion of the total population in most areas of the world (United Nations, 2007).

This is of considerable significance because the prevalence of disabling conditions (sensory, mobility, brain function etc.) is highest in this age group. According to Sheets (2005), "Gains in life expectancy have made disability an increasingly common experience in later life." Yet older adults are rarely regarded as "disabled" in the same way that younger adults with similar impairments would be" (p. 38). This population, those who have become disabled late in life as a result of the ageing process is not a major focus of this paper. It is noted, however, that this group adds significantly to the elderly and disabled in need of disaster response.

## **DISABILITIES**

The number of disabled worldwide has been estimated at over 650 million. It is not possible to have an accurate counting of people with disabilities given the range of infirmities, the lack of uniformity of identification, and the history of long-term exclusion from society and abandonment. There is no formal definition of disability within the World Health Organization International Classification of Functioning, Disability, and Health. Nor is there a definition

found in the United Nations Convention on the Rights of Persons with Disabilities, other than that in Article 1, which states, "Persons with disabilities are those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." Older people with early-onset disabilities are said to "age with disability" (Robinson, Novelli, Pearson, & Norris, 2007). Because individuals with severe impairments are now living longer they are now entering the ranks of the elderly. The increase in longevity among the disabled population has brought more challenges in that many experience unanticipated health problems. The secondary health conditions related to the effects of ageing are superimposed on the primary disability (Sheets, 2005). The fragility and vulnerability of this ageing with disability cohort is thereby greatly increased. They are in double jeopardy

Literature has focused on specific issues for the older person with life-long disabilities. Strategies to work effectively with older people with developmental disorders have been proposed in Ireland and Australia (McCarron & Lawlor, 2003; Bigley, 2008). Cultural differences in the way that older people with developmental disorders receive care from their families have been identified (McCallion, Janicki, & Grant-Griffin, 1997)

Little is known about how older disabled people fare in times of disasters but those who have mobility as well as sensory disabilities seem ill equipped to survive natural disasters either by staying in place or migrating.

Ardalan et al. (2010) outlines some of the factors that increase older people's vulnerability in times of disaster, including chronic illnesses that may require regular treatment not available during a natural disaster, diminished sensory and organ capacities, difficulties in adjusting to extreme weather changes, and slower reaction times. Psychosocial factors that may detrimentally affect older people in times of disasters are low income, reactions to loss and change, the need to take care of grandchildren whose parents are missing, and greater reluctance to seek assistance.

A common misconception is that many older people are in institutions that provide some measure of protection for their residents during periods of natural disasters. Although the expectation is that institutions have protocols and procedures for dealing with emergency crisis events, we discovered following the Katrina hurricane that many institutions are ill-prepared to help their residents survive natural disasters. Furthermore, the majority of older people do not live in institutions. According to a profile of older Americans compiled by the U.S. Department of Health and Human Services (2009), it is estimated that 95% of older people live in the community, either independently or with a spouse.

## **REASONS FOR GREATER VULNERABILITY**

Multiple physical, psychological, and social factors detrimentally affect older people with disability capacity in coping with natural disasters. First, increased mobility difficulties make it difficult for older

disabled people in an emergency situation to survive. For example, an older person who is in a wheelchair following a recent stroke or because of childhood polio cannot easily move to higher ground when there is a devastating flood. Family members and community caretakers who once were available to help may not be during a natural disaster as they are occupied with their own and their children's survival. Second, older disabled people often experience chronic illnesses that require regular treatment. For example, an older person with diabetes may need to take medication and monitor blood sugar on a daily basis. This is possible for older people during non disaster times especially in developed countries. What happens, however, when there is a natural disaster and medications as well as food are not available on a regular basis? Third, older people with disabilities often have difficulties coping with extreme temperature changes that are often associated with natural disasters. Food shortages may also be extremely difficult for older people. Those with pulmonary and cardiac disabilities may be challenged by atmospheric changes that affect their breathing capacity. One response worldwide to climate changes and natural disasters has been increased migration. It is estimated that there are 191,000,000 migrants around the world and by 2010 at least 50 million have migrated because of severe environmental changes (United Nations University, 2005). While older people do migrate, they are less likely to move than younger people. Both physical and psychological factors may

contribute to their decisions to stay in their homes after a natural disaster.

Psychosocial factors contribute to older disabled people's vulnerability after a natural disaster. First, those who have lower economic status with limited resources often fare worse during a natural disaster. One example of this was during the Katrina hurricane in which wealthier people were able to leave New Orleans before the hurricane struck using their own cars or public transportation, while poorer residents were forced to stay. Although not all older people are poor, there is some evidence that older people around the world are of lower social economic status than other age cohorts. They also may have fewer resources to draw upon. Second, older people may be reluctant or unable to ask for assistance during times of natural disasters and may not be aware of resources that they could use. As many have had a lifetime of handling crises independently, they may not easily think about reaching out for help during a natural disaster. Third, specialized assistance to older people with disabilities may not be readily available following a natural disaster. More emphasis may be given to helping children who have been orphaned rather than older people. Finally, older people are often caretakers of grandchildren. This is on the increase globally as children in developing countries have often been orphaned due to the increase in AIDS, while in developed countries, substance abuse among parents may result in grandparents caring for their grandchildren. Often older people with disabilities are less

likely to seek disaster relief for them.

## **SOCIAL JUSTICE ISSUES**

Older people with lifelong disabilities may be doubly stigmatized both for their age as well as disability. This may lead to prejudice, discrimination and difficulties in accessing needed health care and social services (Sheets, 2005). They also may be at increased risk for elder abuse (Ansello and O'Neill, 2010). Some factors that increase their risk of abuse include invisibility to the community and learned behaviors such as low self-esteem (Ansello and O'Neill, 2010).

## **HUMAN RIGHTS INSTRUMENTS**

Human rights documents support the rights of older people with lifelong disabilities. The human rights imperative for disaster response to persons ageing with disabilities is documented in a number of human rights instruments.

1948: The Universal Declaration of Human Rights Article 3 states "Everyone has the right to life, liberty and security of person".

1991: The United Nations Principles for Older Persons is an intergovernmental initiative to recognize the importance of focusing attention on the situation of older persons. It encourages governments to address the "independence, participation, care, self fulfillment and dignity of older persons."

1998: The International Plan of Action on Ageing establishes UN principles for older persons and identifies "the promotion of

the activities, safety and well being of the elderly” as an essential part of development. Among the principles, Principle 11(m) states “Government, nongovernmental organizations and all concerned have special responsibility to the most vulnerable among the elderly...” It further recommends in 111 A 3 (b) Rec.22 “special attention should be paid to environmental problems...”

2001: The United Nations High Commission for Refugees (UNHCR) developed a policy on older refugees.

2002: The Madrid International Plan of Action on Ageing (MIPAA) is an international agreement, signed by 192 member states, linking ageing to social development, economic development, and human rights. Social protection specifically identifies “disaster prevention and management” as a component. The MIPAA calls for special attention to safeguard the rights of frail older persons from abuse and neglect as they are vulnerable and defenseless.

2006: The World Health Organization Inter Agency Standing Committee (IASC) is the primary mechanism for coordination between UN and non UN humanitarian organizations. The guidelines mention older people among those whose physical security may be most at risk during displacement and notes discrimination against older people in disasters.

2006: The Convention on the Rights of Persons with Disabilities (CRPWD) details the rights that all persons with disabilities should enjoy and the

obligations of states and others to ensure they are respected. Amongst the antecedents to the CRPWD is the 1975 UN Declaration on the Rights of Disabled Persons, the 1982 World Programme of Action concerning Disabled Persons, which promotes the full social participation of disabled people, and the 1991 Principles for Protection of Persons with Mental Illness. The CRPWD specifically protects life, liberty and security for persons with disabilities. Article 11 specifies situations of risk and humanitarian emergencies, stating, “States parties shall take ... all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrences of natural disasters.”

2008: In addition to the UN documents the International Federation of Social Workers (IFSW) Policy Paper on Ageing and Older Adults calls for “support, protection, and strengthening of human rights for older adults, including elimination of physical, emotional, and sexual abuse, financial and material exploitation, and neglect and abandonment ...” It also calls for “specialized attention to the needs and contributions of older adults in emergencies such as natural disasters and humanitarian crises.”

### **SPECIAL CHALLENGES FOR OLDER PEOPLE WITH BIRTH OR EARLY-ONSET DISABILITIES**

In a manmade or natural disaster people with lifelong

disabilities face special physical, social, and psychological crises. Some people with serious disabilities are in institutions that often have policies and procedures to help them cope with disasters. Although not always successful, as events during the recent Hurricane Katrina indicated, institutionalized disabled adults do have some support in coping with disasters. However, the majority of disabled people live in the community and are taken care of by their families. Ansello and O’Neill (2010) identify the following risks for older disabled people: physical dependence, emotional dependence, lack of financial resources, isolation, low self-esteem, poor social judgment, and lack of knowledge about community resources. These issues place older disabled people at greater risk during times of great crisis. Families who may have taken care of the disabled person may not be able to provide physical care or emotional support. Caretakers themselves may have been killed or severely injured during a disaster. More attention may be given to caring for vulnerable children rather than elderly disabled people. The very nature of their long-term disability may make it difficult for them to cope with independent living. Those who suffer from visual and auditory disabilities may not be able to find their way when forced to leave environments with which they are accustomed. Others who have motor disabilities may not be able to navigate in wheelchairs or with canes when displaced from homes and communities they knew. Finally those with intellectual or emotional disabilities may have major difficulties adjusting to a

different environment (Thorpe, Davidson, & Janicki, 2000).

The following needs of older disabled people during a disaster may not be met:

### **Physical**

An older disabled person may not be able to obtain basic needs such as food and water. In times of natural disasters caregivers who have experienced their own losses may not be available to provide food, especially on a regular basis, for older disabled people. Because of physical infirmities, older disabled people may not be able to survive on the same level of food/water deprivation that a younger person without disabilities could handle. Older disabled people may need to take regular medications for chronic health conditions that may not be available during natural disasters. Health facilities that provided ongoing care may have been destroyed or only able to handle those requiring emergency care.

### **Shelter**

Home surroundings that are familiar to the older disabled person may not exist anymore. For example, a legally blind older person may have been able to live relatively independently in a familiar home environment where the locations of sleeping quarters, bathrooms, and kitchens are known. In the case of a natural or manmade disaster, however, the older person may have been forced to leave this environment to move to an unfamiliar living situation they are not able to navigate. An older person with lifelong mobility problems may not easily be able to relocate to a new home environment that may not be accessible. Also,

family members who may have helped with transfers may have been separated from the older disabled person during the disaster.

### **Psychological & Social**

Older disabled people often demonstrate much strength and resiliency in coping with a lifelong disability. A natural disaster certainly increases their stress and they may experience major difficulty in coping. Those who previously provided emotional support for the older person may now be absent. In addition, during a natural disaster older people with long-term disabilities may lose many of the social supports that have helped them live relatively independent lives, despite their disabilities. They may have become separated from family members who previously provided both physical and psychological support for them. Community supports may no longer be available when community residents are preoccupied with helping their own families cope with the disaster.

### **CASE EXAMPLES**

These short case examples illustrate some of the dilemmas that older people with long-term disabilities face around the world in natural and manmade disasters. The disasters and traumatic events include natural disasters such as monsoons, climate change, earthquakes, and illnesses, as well as manmade disasters such as war and forced migration.

As is evident, chronic disabilities may be aggravated with ageing. The importance of disaster-preparedness is especially significant in meeting the needs of disabled older

people in the wake of a disaster.

Ji Seon Wong is a 78-year-old widow who lives alone in rural China. Her husband died last year and her only child died about 10 years ago. For the last several years she has helped take care of children while their parents were working and in exchange neighboring families have given her a place to sleep and food to eat. Ji Seon has been blind in one eye and with limited vision in the other eye since birth, but now has lost vision in her "good" eye. Because of her visual loss she is having difficulty caring for children. Recently one of the very young children disappeared when she was taking care of them and was not found until the next day. Every year there is a major monsoon and she is fearful what will happen if her town is flooded and she has to leave.

65-year-old Ayanni Yetu lives in a refugee camp in Nairobi. She emigrated there from the Congo after warring tribes burnt houses in her small village. Ayanni takes care of her three grandchildren aged 3, 6, and 9 who were orphaned when their parents both died last year of AIDS. Her youngest grandchild is very sickly and she fears that she may also have the "slim disease." From childhood Ayanni has had difficulty walking and twenty years ago suffered a stroke that left her unable to use her left arm. She has never been to a doctor. Recently she heard that people in her neighborhood have died very suddenly of the "bleeding disease." She is fearful for the health of her grandchildren.

75-year-old Manuel Gonzalez lives on the streets of Los Angeles. Much of his life has been spent in and out of

hospitals because of alcoholism and mental illness. About 10 years ago he survived an earthquake while homeless, although he incurred an injury when debris from a building fell on him. He recently lost his leg to diabetes which has made it increasingly difficult for him to survive on the streets. He is very paranoid and does not want to go into an institution.

80-year-old Ivanova Sidorav lives with her married daughter and family in London. Both her daughter and her husband work in a distant part of the city. The family emigrated from Russia after the breakup of the Soviet Union. She attended school for two years in Russia but left because she could not learn to read and write. In London she remains homebound and has never learned English. Recently she has become more confused and forgetful. While her children are out of the house for most of the day, she sometimes forgets to eat. Also her daughter discovered that she had drunk some olive oil thinking that it was the apple cider she made when she lived on a farm in Russia. Ivanova is very anxious when her daughter leaves for work in the morning. Her fears have accelerated recently after a subway bombing on the line that her daughter takes to work. 83-year-old Natasha Querales is an indigenous woman who lives with her adult son in a distant mountain town in the Peruvian Andes. She has never left her small village and speaks only Quechua. She has always had severe asthma but in recent years her condition has worsened. Much of the time, especially when she walks around the hills in her small village, she becomes extremely short of breath. Because of climate change and increasingly

cold winters her son cannot work in agriculture as he once did and wants to move to Lima where he has an offer of a job.

## **DISASTER PREPAREDNESS AND RESPONSE**

Preparing for impending natural disasters requires advanced planning and preparation, which is especially crucial to the survival; safe evacuation and shelter of older adults, particularly those with disabilities or severe limitations. In the event of a disaster, older adults, especially those that have difficulty walking and those who require medical equipment, are among the most vulnerable groups (Saliba et al. 2004). The most vulnerable older adults are those who are housebound and frail either through illness or disability and who might require assistance to evacuate (Fernandez et al, 2002; Morrow, 1999). A variety of recommendations for addressing the specific needs of older disabled persons during times of disaster will be offered. Mobility is one of the most important activities of daily living. While it is not absolutely necessary in routine daily life, the ability to walk becomes highly important before, during, and after a disaster. Anyone who is immobile, or becomes so because of disaster, will have tremendous difficulty evacuating, seeking appropriate shelter, and gaining access to needed relief supplies, personnel, or services.

Keeping older people mobile should be a high priority in the response, mitigation, and recovery phases of any disaster. Mobility assessment should be a routine part of any disaster assessment for an older disabled person. Does the

person use a walker, a cane or wheelchair? If so, can these devices be evacuated with the person, or provided at the place of shelter? Mobility aids should be considered lifesaving equipment for vulnerable persons and should be stockpiled alongside medications and other emergency supplies. People that cannot get up without assistance may require a special-needs shelter. Expecting them to walk across a crowded shelter or wait in line for food or services is unrealistic. Alternatives to standard shelter cots may be needed for those that cannot get up and down from them safely and effectively. Additional changes to the environment that may be necessary include removal of physical hazards that could cause tripping or falling on the floors or walkways (Rothman & Brown, 2007).

People with cognitive impairments or dementia are at high risk for isolation, suffering, and even death during disasters (Huus, 2005). While such people may have adapted to their home environments, some may become confused in new environments after being evacuated. They may not always be able to express their needs. The disruption of routine that often accompanies disaster response can exacerbate such difficulties.

For geographical areas that are at risk of a natural disaster, having baseline data on the number of community-dwelling older adults with a disability and those who require the use of special equipment should assist planners in preparing for potential evacuation and equipping members of this vulnerable population with canes, walkers, wheelchairs



and other special equipment (McGuire, Ford, & Okoro, 2007). The increased vulnerability of older disabled persons in disasters underscores the need for adequate planning. By identifying issues that address these special needs before, during, and after a disaster, communities can go a long way toward minimizing poor outcomes. An emphasis on planning is critical and needs to be flexible to be useful and effective (Fernandez et al., 2002).

Specific needs for assistance may be quite diverse and may be considered in the following priority categories:

1. Helping older persons with disabilities locate and settle into appropriate housing (temporary or permanent)
2. Re-establishing public benefits and services
3. Securing long-term health and mental health services as needed

4. Accessing other services as necessary to resume life, including basic necessities
5. Obtaining transportation to address all needs and potentially to relocate to reunite with family or re-establish permanent residence (BCM/AMA, 2006, 18).

Planning must be accompanied by coordination among ageing and disability service network providers. Clarification of organizational roles at the local, regional, national and international levels must be undertaken in the absence of a crisis and updated routinely.

Older disabled persons are a diverse group who require extra support in any disaster situation but who may also be of tremendous assistance to others. The key to preparing for and implementing disaster activities to support this population is the recognition of their reduced ability to maintain physical and cognitive functioning and the high need

for medicine and sustaining treatments. Disaster workers and planners must be prepared for the possibility of higher death tolls, and leaders should be trained in making difficult decisions if resources are not adequate (Hall, 2010).

In contrast, this population may be more resilient in dealing with the emotional stress of disasters. Planners and managers of disaster-relief programs should include this resource whenever possible in their plans and activities.

## REFERENCES

- Ansello, E., & O'Neill, P. (2010). Abuse, neglect, and exploitation: Considerations in aging with lifelong disabilities. *Journal of Elder Abuse and Neglect*, 22, 105-130.
- Ardalan, A., Mazaheri, M., Naieni, K., Rezaie, M., Teimoori, F., & Pourmalek, F. (2010). Older people's needs following major disasters: A qualitative study of Iranian elder's experiences of the Bam earthquake. *Ageing and Society*, 30(1), 11-23.
- Baylor College of Medicine and American Medical Association. (BCA/AMA). (2006). Recommendations for best practices in the management of elderly disaster victims, 18. <http://www.bcm.edu/pdf/bestpractices.pdf> Retrieved 9/30/10.
- Bigley, C. (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 33(1), 76-86.
- Fernandez, L.S., Byard, D., Lin, C.C., Benson, S., & Barbera, J.A. (2002). Frail elderly as disaster victims: Emergency management strategies. *Prehospital and Disaster Medicine*, 17(2), 67-74.
- Hall, N. (2010). Older persons in disasters and emergencies: The overlapping mental and physical issues. In J. A. Toner (Ed.), *Geriatric mental health disaster and emergency preparedness*. New York: Springer.
- Huus, K. (2005, November 4). Lost in the shuffle: Katrina leaves elderly evacuees displaced, disconnected. *Msnbc.com*. Retrieved from <http://www.msnbc.msn.com/id/10180296/>
- International Federation of Red Cross and Red Crescent Societies. (2007). *World Disaster Report 2007*. Satigny/Vernier, Switzerland: IFRCRC.

- International Federation of Social Workers. (2008). IFSW International Policy on Ageing and Older Adults. Berne, Switzerland: IFSW.
- Lamb, K., O'Brien, C., & Fenza, P.J. (2008). Elders at risk during disasters. *Home Healthcare Nurse*, 26(1), 30-38.
- McCallion, P., Janicki, M., & Grant-Griffin, L. (1997). Exploring the impact of culture and acculturation on older families' caregiving for persons with developmental disabilities. *Family Relations*, 46, 347-357.
- McCarron, M., & Lawlor, B.A. (2003). Responding to the challenges of ageing and dementia in intellectual disability in Ireland. *Ageing and Mental Health*, 7(6), 413-417.
- McGuire, L.C., Ford, E.S., & Okoro, C.A. (2007). Natural disasters and older US adults with disabilities: Implications for evacuation. *Disasters*, 31(1), 49-56.
- Medora, H., & Hassiotis, A. (2007). Policies and practices affecting health and longevity of people with disabilities: Lessons from the United Kingdom. In M. Robinson, W. Novelli, C. Pearson, & L. Norris (Eds.), *Global Health and Global Aging* (300-312). San Francisco, CA: Jossey-Bass.
- Morrow, B.H. (1999). Identifying and mapping community vulnerability. *Disasters*, 23(1), 1-18.
- Perls, T. (2009). Health and disease in people over 85: Despite disease, disability is low. *BMJ*, 339, 59-60.
- Putnam, M. (2002). Linking aging theory and disability models: Increasing the potential to explore aging with physical impairment. *The Gerontologist* 42(6), 799-806.
- Rothman, M., & Brown, L.M. (2007). The vulnerable geriatric casualty: Medical needs of frail older adults during disaster. *Generations*, 31(4), 16-20.
- Saliba, D., Buchanan, J., & Kingston, R.S. (2004). Function and response of nursing facilities during community disaster. *American Journal of Public Health*, 94(8), 1436-1441.
- Sheets, D.J. (2005). Aging with disabilities: Ageism & more. *Generations*, 29(3), 37-41.
- Thorpe, L., Davidson, P., & Janicki, M.P. (2000) *Healthy Ageing – Adults with Intellectual Disabilities: Biobehavioral Issues*. Geneva, Switzerland: World Health Organization.
- United Nations (2006). *Convention on the rights of persons with disabilities*. New York: United Nations.
- United Nations (2008). *Guide to the national implementation of the madrid international plan of action on ageing*. New York: United Nations.
- United Nations High Commissioner for Refugees (2006). *Global refugee trends*. New York: United Nations.
- United Nations (1998). *International plan of action on ageing and United Nations principles for older persons*. New York: United Nations.
- United Nations (2007). *Major developments and trends in population ageing*. New York: United Nations.
- United Nations (2002). *Political declaration & Madrid international plan of action on ageing*. New York: United Nations.
- United Nations (1991). *Principles for older persons*. New York: United Nations.
- United Nations (1948). *Universal declaration of human rights*. New York: United Nations.
- United Nations University (2005). *Environmental Refugees*. Retrieved from <http://www.ehs.unu.edu/index.php/article:130?menu=44>
- U.S. Department of Health and Human Services (2009). *A profile of older Americans*.
- Webster's New Universal Unabridged Dictionary (1996). New York: Barnes & Noble.
- Weinberger, M.B. (2007). Population aging: A global overview. In M. Robinson, W. Novelli, C. Pearson, & L. Norris (Eds.), *Global Health and Global Aging* (15-30). San Francisco, CA: Jossey-Bass.
- World Health Organization Inter Agency Standing Committee (2006). *Protecting persons affected by natural disasters: IASC Operational guidelines on human rights & natural disasters*. Washington, DC: Brookings-Bern Project on Internal Displacement.

# Social Well-being of Disabled Older Persons

## An Evidence of Unequal Ageing in Europe

Katrin Gasior, Research Assistant and Asghar Zaidi, Director Research, European Centre for Social Welfare Policy and Research

Berggasse 17, 1090 Vienna, Austria [www.euro.centre.org](http://www.euro.centre.org) [zaidi@euro.centre.org](mailto:zaidi@euro.centre.org) +43-1-319 45 05 26

### 1. Introduction

One of the most apparent consequences of an ever rising life expectancy observed in the European countries is that older persons now constitute a higher-than-ever fraction of European societies. Since years gained in life are not matched equally by longer working lives, older people are also enjoying a longer phase of life post retirement. The longevity gains offer the opportunity for new social and economic experiences for older people and many go on to enjoy this time in good economic and health conditions.

One other rather obvious phenomenon is that older people are far from being a homogenous group, and they differ *inter alia* with respect to social, economic and health status. Moreover, advances in medicine and rehabilitation methods have made the expectation of living to late life fairly reasonable, even for persons with a significant disability. In fact, disability can be viewed as one of the most important factor determining the individual experience of ageing. For instance, many older people are restricted in their aspirations towards active ageing, due mainly to limitations linked with their ill-health and physical frailty. In the absence of a decent retirement income and a supporting environment, the disabled older people run a higher risk of being socially excluded from the society in which they live.

Important research questions are therefore what are the perceptions, feelings and experiences of the disabled older persons? Are these persons also enjoying and benefiting from a longer phase of old age life? How to best capture these unequal experiences of ageing of older people? Whether institutional differences across European countries play in mitigating the perverse effects of disability during old age? The paper examines this phenomenon of unequal ageing of older people in European countries by looking into how disability alone has an influence on the well-being of disabled older persons, covering several different domains of social well-being.

The disadvantages of disabled persons are often discussed in relation to their labour market disadvantage (See for example OECD 2009), lacking equality in education or other provisions in childhood (See e.g. Burchardt and Zaidi (2008)). Also, in measuring disadvantages, many studies focus on the economic aspects alone, such as the fact that disabled persons face a relatively higher risk of financial poverty (see e.g. Zaidi and Burchardt 2009).

Although it is important to show the economic disadvantage of disabled older persons, the other forms of disadvantages, not directly linked with financial matters, are also of high relevance when studying individual experiences of ageing. For instance, linked with the concept of substantive

freedom within the capability approach (Sen 1985), there are measures of social disadvantages that provide insights into these differential ageing experiences (see e.g. Pedace et al. 2010 and Zaidi 2011). This paper focuses on such related measures of social welfare of older disabled persons. It uses quantitative multivariate analyses, so as to disentangle the affect of disability on the wider social measures of well-being for European older persons.

The remainder of the paper is organised as follows. Section 2 provides a brief description of the research methodology and introduces the population under study. Section 3 reports the descriptive results as well as those based on multivariate modelling techniques. The final section provides the synthesizing discussion. Annex A includes auxiliary statistical tables.

### 2. Research methodology

#### 2.1 Data come from the 2006 European Social Survey

The data are extracted from the European Social Survey (ESS), Round 3, carried out in 2006. The ESS is a representative of people living in private households across 25 European countries. The countries covered in the ESS are: Austria, Belgium, Bulgaria, Cyprus, Denmark, Estonia, Finland, France, Germany, Hungary, Ireland, Latvia, the Netherlands, Norway, Poland, Portugal, Romania, the Russian

Federation, Slovakia, Slovenia, Spain, Sweden, Switzerland, Ukraine and the United Kingdom. Adults living in private households (aged 15 and older) are asked questions about various kinds of socio-political topics, such as media.

and social trust, politics, subjective well-being or national and ethnic identity. Round 3 is of special interest to this study because it also includes a special module on personal and social well-being. Results reported here make use of the pooled data of all ESS countries, except the Russian Federation and Ukraine.

## ***2.2 Multivariate models are estimated in disentangling the impact of disability***

Descriptive statistics – simple two-way tables – are used to show the differences in social well-being between disabled and non-disabled older persons. These descriptive results display the impact of multitude of factors, including disability. However, advance multivariate modelling methods are used in this paper so as to disentangle the impact of disability alone. By including in the model other socio-demographic factors, we also obtain insights on the relative importance of these different factors that affect social well-being of older persons. But, the sole purpose of the empirical work in this paper is to show that the disability alone has an impact, when we control for other factors such as the level of education and income.

Instead of the simpler method of the ordered logistic regression (ologit), the advanced generalized ordered logit regressions (Gologit2 is a user-written program by Richard Williams to be used to calculate

generalized ordered logit models in Stata (a Data Analysis and Statistical Software). The “2” refers to another user-written program called gologit by Vincent Fu which is the precursor of gologit2 (Williams 2006)). are used to overcome the violation of the parallel regression assumption, which is often present in ologit type regressions. In fact, the simple ordered logistic regression is a special case of the generalized ordered logit model, in which the slope coefficients are assumed to be the same across response categories (Williams 2006). Thus, interpretations of results are quite similar, although the results are obtained using a technically superior technique. By taking into account that some of the independent variables affect outcome values differently, the generalized ordered logit model predicts variations in social well-being better than the simple ordinal logistic regression.

## ***2.3 Two groups of social well-being measures are used: life outlook and social ties***

The concept of well-being is strongly connected to the notion of quality of life, which already in its hour of birth was meant to cover and connect multiple dimensions (Schäfers 2008). In line with the research objective of this paper, the focus here is on various dimensions of social well-being. Two groups of measures are selected for this purpose, classified under the life outlook domains and the social ties domains. They are highlighted in Figure 1 (page 15).

The “life outlook” domains cover direct questions about older people’s present situation, about their life as a whole, about satisfaction with their

standard of living, and about their future optimism. The “social tie” domains cover questions on whether they feel treated with respect, whether they get the recognition deserved, whether there are people who care about them, whether local help is available, whether they participate in events as often as others of same age, and whether social contacts are made.

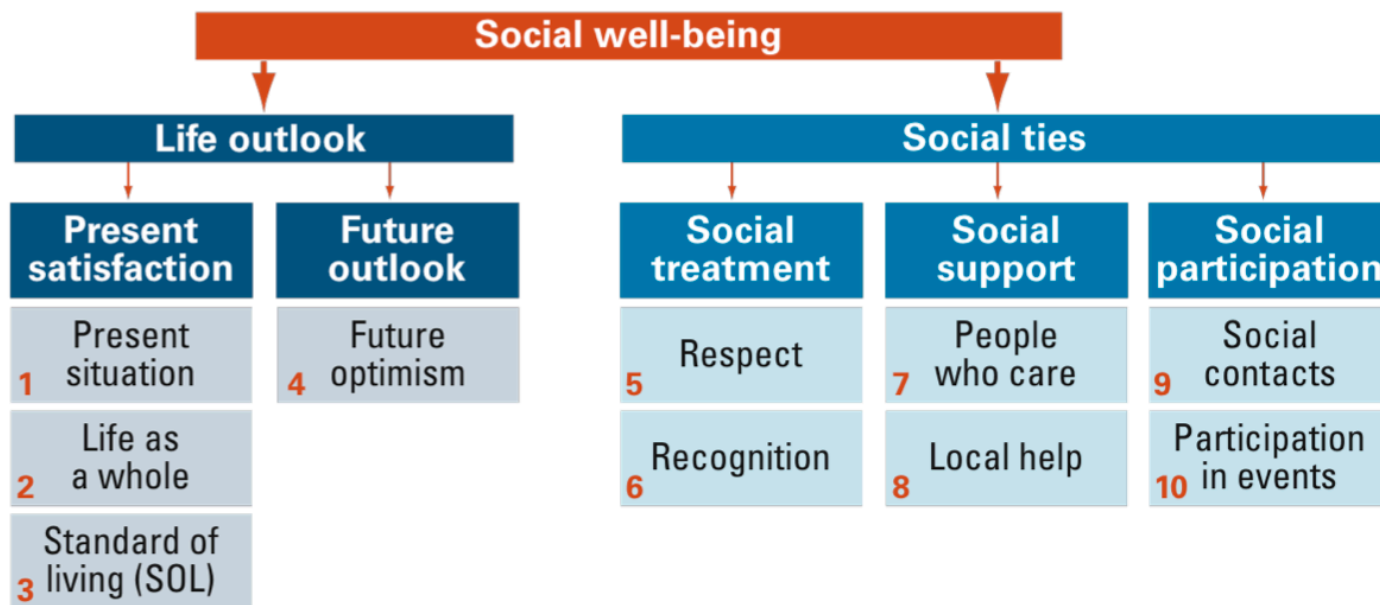
John Donne once wrote the well known phrase: “No man is an island”, meaning that human beings do not live isolated from each other. Thus, the life outlook measures used here do not just show how someone evaluates his/her life but how someone evaluates his/her life in the context of a very specific social environment in which he/she lives.

While the first set of measures covers general questions about one’s current life and future outlook, the second part of the analyses refers to more specific and personal questions on social ties. It investigates the social structure and status of disabled persons in contrast to persons without disability.

## ***2.4 What do we mean by disability?***

Disability is undoubtedly a multi-dimensional concept, not just related to a personal impairment but also to societal shortcomings in adapting to the needs of disabled persons. (for a discussion, see Burchardt 2003, Schädler et al. 2008). The 2006 ESS does not include a direct question on disability, but there is a global health question that can be conveniently adopted as a proxy for disability. The disability indicator is derived from the following question:

**Figure 1: Multiple dimensions of well-being, from the data available in Round 3 of European Social Survey, 2006**



Are you hampered in your daily activities in any way by any longstanding illness, or disability, infirmity or mental health problem?

In our analyses, respondents are characterised as having a disability when they report they are hampered ‘a lot’ or ‘to some extent’. Due to the rather small sample size (at the country level) it is not useful to distinguish between persons who are just to some extent hampered and those who are hampered a lot, although such information about the severity of disability is often very helpful in the type of analysis aimed at in this paper. Thus, it can be presumed that the definition of disability used here is very broad.

Furthermore, it should be underlined that the disability variable in our case is based on a subjective response, and it is different from institutional variables such as persons who receive disability benefits. Here, we are not able to fully control for unobservable “cultural

differences” across countries and that these differences may also play some role in what we are observing in responses to the social well-being questions. As such, the focus in this study is solely on the differences in social well-being between disabled and non-disabled older persons. Thus, the social well-being questions presented are less likely to be affected by culturally biased responses, especially to questions on satisfaction (see for example Suh et al., 1998).

Another caveat may be that the scope of these analyses is restricted since people living in institutional homes are not covered. People with mental illnesses, such as dementia and Alzheimer, are in principle included but they are likely to be underrepresented since they are more likely to be resident in institutional homes.

**2.5 Controlling for other socio-demographic variables is also required**

Gender, age groups, education and income level, marital

status, and country-specific control variables are also required as control variables, so as to disentangle the independent impact of disability on the social well-being of older persons. Additional interaction terms, such as the interaction between disability and gender, disability and age, disability and educational level as well as between disability and marital status, are tested, but they resulted in very little changes in the coefficient for the disability variable. Thus, no interaction terms are included into the regression models whose results are reported here.

**2.6 The population under study is persons aged 60+**

The study population covered in the empirical results consists of 10,952 persons aged 60 and older. Thereof, 4,956 persons are hampered in their daily activities in any way by any longstanding illness, disability, infirmity or mental health problem and are in consequence defined as disabled older persons. The

**Table 1: Social well-being measures for people aged 60+, descriptive results**

		<b>no disabi lity</b> (%)	<b>disability</b> (%)	<b>difference</b> (p.p.)
<b>1. Present situation</b>	dissatisfied	11.1	24.8	13.7
	neither	16.6	22.4	5.8
	satisfied	72.3	52.8	-19.5
<b>2. Life as a whole</b>	dissatisfied	3.8	10.4	6.6
	neither	22.0	31.6	9.6
	satisfied	74.2	58.0	-16.2
<b>3. Standard of living</b>	dissatisfied	7.0	16.6	9.6
	neither	24.5	30.1	5.6
	satisfied	68.5	53.3	-15.2
<b>4. Future optimism</b>	not optimistic	9.8	20.9	11.1
	neither	19.7	26.0	6.3
	optimistic	70.6	53.2	-17.4
<b>5. Feel treated with respect</b>	no	4.0	6.0	2.0
	neither	9.0	12.0	3.0
	yes	87.0	82.0	-5.0
<b>6. Gets recognition he/she deserves</b>	no	7.0	13.0	6.0
	neither	17.0	22.0	5.0
	yes	76.0	65.0	-11.0
<b>7. People who care</b>	no	3.0	4.0	1.0
	neither	4.0	7.0	3.0
	yes	93.0	89.0	-4.0
<b>8. Local help</b>	no	20.0	24.0	4.0
	neither	20.0	21.0	1.0
	yes	60.0	55.0	-5.0
<b>9. Participation in events as often as others of same age</b>	less	34.6	51.0	16.4
	about the same	44.3	34.4	-9.9
	more	21.0	14.6	-6.4
<b>10. Social contacts</b>	less than once a month / never	9.2	17.3	8.1
	at least once a month	29.4	27.3	-2.0
	at least once a week	46.6	39.9	-6.7
	every day	14.9	15.5	0.7

**Source:** Calculations are based on the pooled data of the 2006 European Social Survey.

**Notes:** Weighted results are reported here.

majority of the persons aged 60 and older in the survey is a women (55%), between 60 to 69 years old (50%), married (63%) and already retired (73%). For an overview of the study population please see Table A.1 in Annex A (page 22).

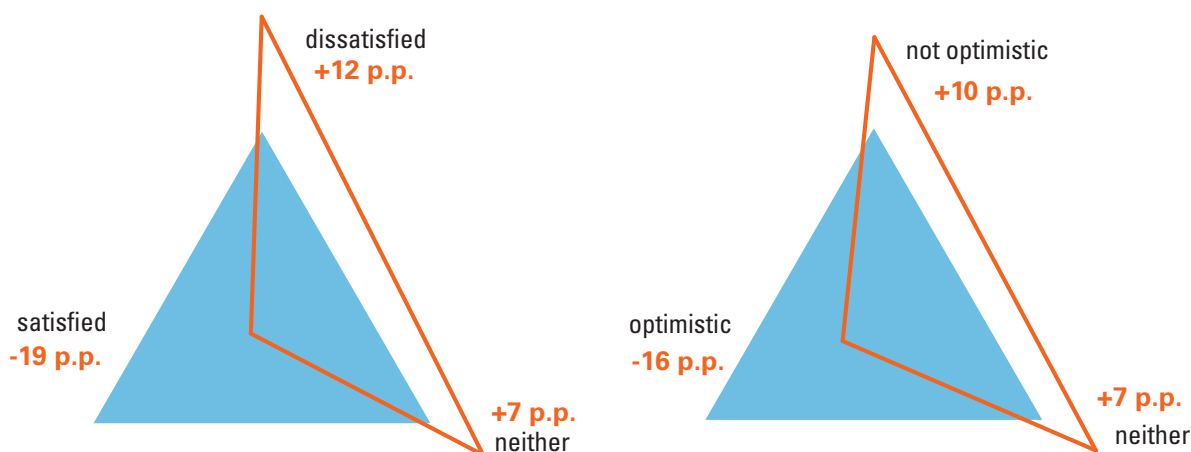
### **3. Key empirical findings**

#### ***3.1 Descriptive results show social disadvantages of disabled older persons***

The purpose of the empirical work reported here is to investigate whether disability has an independent impact on

various domains of social well-being of older people. Starting with an analysis of the descriptive results, the differences between disabled and non-disabled older persons are significant across the ten social well-being measures (results are reported in Table 1 above; social well-being

**Figure 2: Life outlook: Present vs. future situation.**  
Present situation                      Future situation



**Source:** Calculations are based on the pooled data of the 2006 European Social Survey, with the help of gologit regression models.

**Note:** Differences in predicted probabilities between disabled and non-disabled older persons are used, controlling for other factors. Recoded 3-category variables are used.

dimensions are displayed in Figure 1).

The differences are higher in the first set of measures: the life outlook domains. Disabled older persons are 13.7 p.p. less satisfied with their present situation, 6.6 p.p. less satisfied with their life as a whole, 9.6 p.p. less satisfied with their standard of living, and 11.1 p.p. less optimistic about their future. In comparison, differences observed in the second set of measures (for the social tie domains) are relatively small but still significant ( $p < 0.01$ ). Differences in social treatment and social support measures range between 1 to 5 p.p. in the negative category and from 4 to 10 p.p. in the positive category. Comparatively high are the differences in social participation where disabled older persons are 8.1 p.p. more likely to have very few social contacts and 16.4 p.p. more likely to think that they participate less in social events than others of their age. Although descriptive results show the social disadvantage of disabled older persons at first glance, they do not control for

other possible impacts such as gender, age and marital status, and level of education or financial situation. Thus, multivariate models are used to analyse whether disability alone has an impact after controlling for other socio-demographic factors. Detailed results of the advanced generalized ordered logit regression models for all measures are included in Table A.2 in Annex A (page 23). Below, in sub-sections 3.2 to 3.4, some of the key findings for a selection of social well-being measures are explained with the help of triangle charts (see Figure 2 to Figure 4).

### ***3.2 Disabled older persons' life outlook is significantly worse!***

Within the first life-outlook measures, the differences between older disabled persons and non-disabled older persons are compared with respect to the present and the future situations. In general, many disabled older persons have not managed to adapt to their situation and thus evaluate their life outlook significantly worse

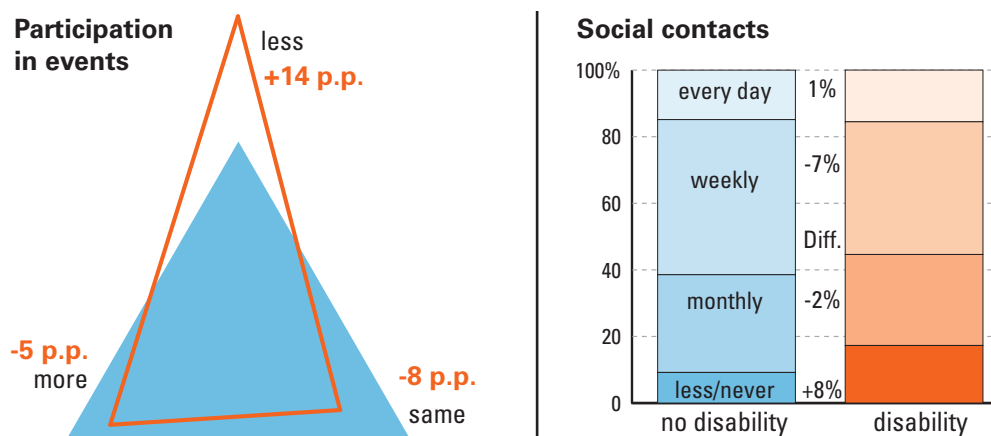
than non-disabled older persons.

Respondents were asked to estimate if on the whole their life is close to how they would like it to be. Satisfaction with the present situation is therefore measured as the discrepancy between expectations and evaluation of the current situation. Regression results show that disability has the strongest impact on the evaluation of respondents about how life meets their expectations, holding other socio-demographic characteristics constant.

Similar to the present situation, disability also has a strong affect on future optimism. How respondents think about their future seems to be strongly correlated with the evaluation of their own health status. Thus, disability does not only affect the current state of well-being but has a very strong negative influence on the future perspective as well.

Figure 2 presents the differences in predicted probabilities between disabled and non-disabled older persons, with a focus on

**Figure 3: Social participation: own perception vs. actual frequency**



**Source:** Calculations are based on the pooled data of the 2006 European Social Survey, with the help of gologit regression models.

**Note:** Differences in predicted probabilities between disabled and non-disabled older persons, controlling for other factors. Recoded 3-category variables are used.

measures of life outlook with respect to the present and the future situations. The shaded triangles present how the outcome would look like in a social utopia – a world without any differences in social well-being due to disability alone. Each side of the triangle presents the differential in the value of three possible outcomes of the well-being measure: whether ‘satisfied’, ‘dissatisfied’ or ‘neither’. In contrast, the non-shaded triangles present the actual outcomes (as estimated using the ESS data and the gologit multivariate modelling technique). The differences between the two triangles show how the reality is different from the perfect world of a social utopia.

Figure 2 shows that disabled older persons are 12 percentage points more likely to be dissatisfied with their present situation and 19 percentage points less likely to be satisfied. In the same way, the non-shaded triangle showing differences in the future optimism has also moved to right, indicating that disabled older

persons are 16 percent-age points less likely to be optimistic about their future; also, they are 10 percentage points more likely to be not optimistic about their future as well.

In effect, as is often argued in the literature, disabled individuals are able to adapt to their new situations, implying that persons experiencing a worsening health status may be able to cope and adapt their expectations according to their new situation. Coming from this perspective, our results show that many older persons have difficulties in everyday life, despite some extent of adaptation that may have happened. Thus, the experience of a longstanding illness, disability, infirmity or mental health problem is incisive to many of them and furthermore affects their social well-being.

### ***3.3 Differentials in the social participation measures are equally high***

Although differentials between disabled and non-disabled older persons also exist in the social

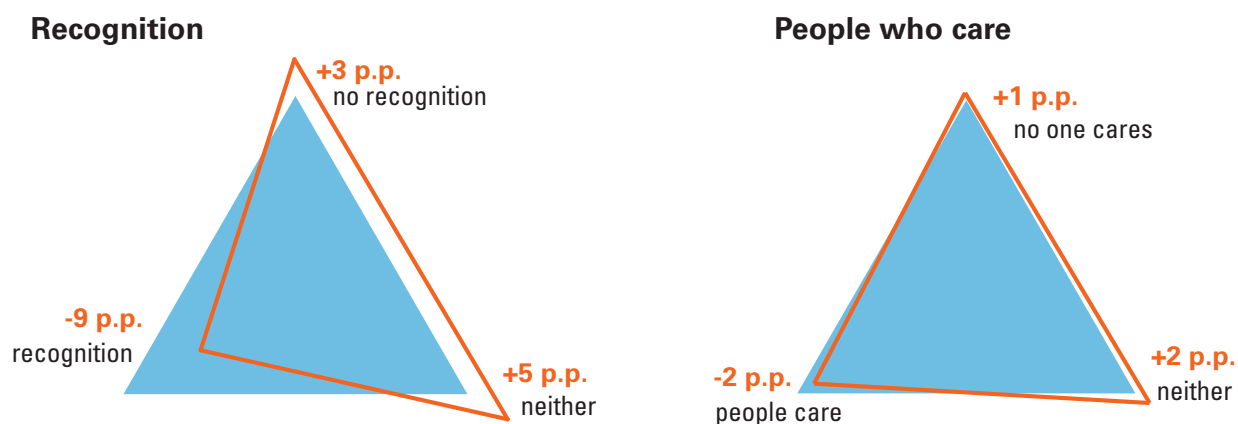
tie measures, they are in general smaller than the life outlook self-perception measures. An important exception is for the social participation measures within the social tie domains: (9). Social contacts and (10). Participation in events.

The left hand side of Figure 3 shows that disabled older persons are much more likely to think that they take less part in social activities (14 p.p.) compared to others of same age. Thus, the fact of feeling hampered in daily activities strongly influences older persons’ social participation with others within the age group of 60 or older. Comparing this result of the multivariate analysis with the descriptive results of the social contact indicator (see right hand side of Figure 3) shows that older persons with disability in fact participate less but the perceived difference is higher than the difference in the actual frequency of social contacts.

The results and differences in these two measurements of



**Figure 4: Minor impact of disability on social treatment and social support**



**Source:** Calculations are based on the pooled data of the 2006 European Social Survey, with the help of gologit regression models.

**Note:** Differences in predicted probabilities between disabled and non-disabled older persons, controlling for other factors. Recoded 3-category variables are used.

social participation can be interpreted in two ways.

- Firstly, the difference could point to the fact that the two questions measure different social contexts by one asking for meetings in general and the other for social activities in particular. Nevertheless, both indicators measure meetings by choice rather than for reasons of work or duty. The used definition of social activities in the European Social Survey is furthermore very broad including not only social events but encounters in general. Therefore, it could be argued that both these indicators measure to a broad extent the same sort of social participation.

- The second way of interpreting differences in the two indicators points to the fact that respondents in the question about social activities have been asked to evaluate their social participation in comparison to others of the same age-group. In that case, disabled older persons are more likely to feel socially isolated than non-disabled older persons. It

seems like struggles in carrying out daily activities are often followed up by the perception that one is also unable to participate in social activities as often as others do of the same age.

### **3.4 Impact of disability on social support and social treatment measures is minor**

Compared to the life outlook and social participation indicators, the impact of disability on questions about social support and social treatment is minor. Figure 4 shows the output of the multivariate analysis for “recognition” (under social treatment; see Figure 1), the indicator with the most impact of disability within these groups of social tie indicators and the output for “people who care” (under social support), where the impact is still significant although almost not existent.

Results show that disabled older persons are 9 p.p. less likely to think they get the recognition they deserve for what they do and are 3 p.p. more likely to think they do not get the deserved acknowledgment. Differences also exist in the question if older persons

feel that there are people in their life who care about them. Nevertheless, disabled older persons are just 2 p.p. less likely to think that people care and are, simultaneously, just 1 p.p. more likely to think that no one cares, compared to older non-disabled persons.

Our results suggest (counter-intuitively) that disabled older persons live in an almost “perfect” world in terms of supportive environments and social handling, since the status of disabled older persons within society is just slightly different from their non-disabled fellows. Further analysis shows that the effect of other factors, such as gender, age, marital status, education or income is also minor across social support and social treatment indicators. Thus, it seems like socio-demographic factors in general fail to explain variation of these indicators.

This paradoxical non-finding implies that other attributes (whether observed or latent) have an effect on these domains of well-being, and they need to be investigated. One possible reason for the different results between life outlook and social support/treatment

measures could be related to the type of questions asked. Life outlook issues focus mostly on very general questions such as satisfaction with how life is. In contrast, questions on the social environment and support structure highlight very specific and personal social facts. These differences in the ESS questions will be explored further in our future research.

#### **4. Synthesizing discussion**

The research question addressed at the outset is how disability influenced social well-being of older persons in Europe. The empirical results presented showed the significant negative impact of disability on various aspects of the social well-being of older persons. Therefore, it is safe to conclude that disabled older persons face disadvantages that go beyond financial matters which are of great relevance to their life quality. That said, it is important to note that there is no single impact pattern, as the disability impact varies depending upon the social well-being domain in question. The life outlook domains address the issue of satisfaction and can be defined as an evaluation of one's present situation (including retrospective questions) and future optimism. The social tie domains, on the other hand, refer to more specific and personal questions on the social structure and status of disabled persons in contrast to persons without disability. Although our analyses show the significant impact of disability across all social well-being domains, even after controlling for other factors, the "life outlook" domains are more affected by disability than the "social tie" domains.

Empirical results highlight the discrepancy between actual support/treatment and the evaluation of social participation and life in general. While the difference between disabled and non-disabled older persons in the more specific and personal questions on social support and treatment are minor, disabled older persons tend to be less likely to evaluate their life as satisfying and their social participation as active than older persons without disability. The exception is noticed in the social participation measures.

These analyses provide additional insights about the heterogeneity of older population in general, but particularly the fact that the experience of ageing will be strongly influenced by disability factors. The strategies to improve social well-being of older persons have a lot to do with their feelings of belonging to the community. Equally, it is about educating communities in raising their understanding that older people are valuable members of the society, and they all share the responsibility to promote positive attitudes in the society, and provide disabled older people opportunities to participate in the society in which they live.

## References

- Burchardt, T. (2003): Being and becoming. Social exclusion and the onset of disability. CASEREport 21.
- Burchardt, T. / A. Zaidi (2008) "Disabled Children, Poverty and Extra Costs", in Sterlitz and Lister (Eds.), Why Money Matters: Family Income, Poverty and Children's Lives, Save the Children, UK, 2008 (with Tania Burchardt).
- OECD (2009). "Sickness, Disability and Work: Keeping on Track in the Economic Downturn" Background Paper Directorate for Employment, Labour and Social Affairs. High-Level Forum, Stockholm, 14-15 May 2009.
- Pedace, L. / M. Pisani / A. Zaidi (2010) "Employing the capability approach to compare pensioners' well-being across UK", Her Majesty's Treasury Economic Working Papers, London.
- Schädler, J./ Rohrmann, A/ Schür, S. (2008): The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs. Report of a European Study. Volume 2: Research and Analysis. European Commission.
- Schäfers, M. (2008): Lebensqualität aus Nutzersicht. Wie Menschen mit geistiger Behinderung ihre Lebenssituation beurteilen. VS Verlag für Sozialwissenschaften. Wiesbaden.
- Sen, A. (1985): Commodities and Capabilities. Oxford. North Holland.
- Suh, E./ Diener, E./ Oishi, S./ Triandis, H.C. (1998): The shifting basis of life satisfaction judgements across cultures. Emotions versus norms. Journal of Personality and Social Psychology 74(2): p. 482-493.
- Williams, R. (2006): Generalized Ordered Logit/ Partial Proportional Odds Models for Ordinal Dependent Variables. In: The Stata Journal 6(1): p. 58-82.
- Zaidi, A. / Burchardt, T. (2009): Estimating the extra costs of living for disabled people in the EU. Draft paper for the Joint OECD/University of Maryland International Conference on Measuring Poverty, Income Inequality, and Social Exclusion – Lessons from Europe. Paris, 16- 17 March 2Annex A: Additional tables
- Zaidi, A. (2011): "Exclusion from Material Resources: Poverty and Social Exclusion among Older People in EU Countries", forthcoming in: Scharf, T. / Keating, N. (eds.), From Exclusion to Inclusion in Old Age: A Global Challenge, Bristol, the UK: The Policy Press.

## Annex A: Additional Tables

**Table A.1: Socio-demographic overview of the study population (%), for persons aged 60+**

<b>Disability</b>	Disability	45.3
	No disability	54.7
<b>Gender</b>	Men	44.8
	Women	55.2
<b>Age groups</b>	60-69	50.0
	70-79	35.2
	80 plus	14.8
<b>Highest level of education</b>	Primary education, or less	31.9
	Secondary education	45.7
	Post secondary, non-tertiary	7.4
	Tertiary education	15.0
<b>Marital status</b>	Married/civil partnership	62.7
	Separated (still married/in civil partnership)	0.8
	Divorced/dissolved	6.1
	Widowed	25.2
	Never married/civil partnership	5.2
<b>Main activity</b>	Paid work	12.2
	Permanently sick or disabled	2.4
	Retired	73.3
	Others	12.2
<b>Household income</b>	less than 1,000	37.9
	1,000 > 2,000	27.9
	2,000 > 3,000	17.8
	3,000 > 5,000	10.3
	5,000 plus	6.0

**Sources:** Calculations are based on the pooled data of the 2006 European Social Survey. N=10,952 persons aged 60+

**Table A.2: Social well-being indicators, using gologit regression, for persons aged 60+**

	Life outlook				Social contacts					
	Present satisfaction			Future	Social treatment		Social support		Social participation	
	1	2	3	4	5	6	7	8	9	10
Disability	-1.13***	-1.06***	-1.08***	-1.27***	-0.31***	-0.86***	-0.39***	-0.31***	-0.88***	-0.73***
	-0.96***	-1.06***	-0.99***	-0.87***		-0.62***		-0.32***	-0.53***	-0.56***
	-0.82***	-0.73***	-0.65***	-0.70***		-0.45***		-0.19***	-0.34***	-0.37***
	-0.52***	-0.51***	-0.50***	-0.43***		-0.42***		-0.15***	-0.15***	-0.30***
					-0.28***		-0.08*	-0.15***		
					-0.24***		0.03	0.12**		
Women	-0.11***	-0.06	-0.32***	-0.17***	0.08	0.08**	0.52***	-0.15	0.19***	0.03
			-0.26***					-0.11*		
			-0.09**					0.01		
			0.06					0.06		
							0.13***			
							0.110*			
Age 60-69										
Age 70-79	0.10**	0.16***	0.09**	-0.02	0.13**	-0.27*	0.08	-0.11	-0.56***	-0.09**
						-0.13		-0.01	-0.22***	
						0.14*		0.11*	-0.15***	
						0.04		0.15***	-0.05	
						0.04		0.15***	-0.04	
						0.23***		0.30***	-0.14**	
Age 80+	0.41***	-0.08	0.21	-0.23	0.32***	-0.40**	-0.28**	-0.33***	-0.91***	-0.45***
		0.29**	0.165*	0.023		-0.22	0.07	-0.18**	-0.51***	-0.29***
		0.51***	0.46***	0.00		-0.03		-0.03	-0.44***	-0.13
		0.59***	0.44***	0.16**		-0.02		0.08	-0.25***	0.13
					0.09		0.17***	-0.26***		
					0.257***		0.435***	-0.143*		
Married/cp										
	-1.10***	-1.22***	-0.95***	-0.66***	-0.48***	-0.69***	-1.01***	-0.69***	-0.53**	-0.36***
	-0.84***	-1.24***	-0.92***	-0.44***		-0.51***		-0.68***	-0.11	-0.24***
	-0.70***	-0.87***	-0.65***	-0.24***		-0.55***		-0.51***	0.13	0.15*
	-0.25**	-0.71***	-0.70***	0.10		-0.31***		-0.30***	0.27***	0.27
					-0.19**		-0.40***	0.33***		
					-0.21**		-0.11	0.23**		
Widowed or partner died	-0.76***	-0.62***	-0.41***	-0.18***	-0.07	-0.15***	-0.77***	-0.08*	-0.34**	-0.30***
	-0.60***							0.06	-0.10*	
	-0.61***							0.215***	0.13*	
	-0.32***							0.31***	0.37***	
								0.34***		
								0.25***		
Never married or in civil partnership	-0.61***	-0.63***	-0.44***	-0.24***	-0.37***	-0.36***	-1.57***	-0.05	-0.54**	-0.69***
								-0.15	-0.39***	
								0.016	-0.21*	
								0.082	-0.20	
								0.231**		
								0.351***		
N	10,544	10,589	10,587	10,535	10,457	10,100	10,527	10,328	10,600	10,354
Pseudo R2	0.08	0.10	0.14	0.06	0.055	0.034	0.095	0.023	0.070	0.051

Source: Calculations are based on the pooled data of the 2006 European Social Survey, with the help of gologit regression models.

Note: The equations include controls for income, highest level of education and country fixed effects. "Past satisfaction" and "Satisfied SOL" are recoded into 5 categories. "Respect" and "people who care" recoded into 3 categories. \*\*\* significance at 0.1%, \*\* significance at 1%, \* significance at 5%.

For the name of the indicators 1-10, see Figure 1 and Table 2.

# Care Concerns, Enabling Environment Challenges and Policy Responses in Asia, with Special Reference to India

Dr. Mala Kapur Shankardass\*

In most countries of Asia, the 20th century, particularly the second half, is marked with increases in the number of people with disabilities due to population growth, ageing, emergence of chronic diseases and medical advances that preserve and prolong life. In Asian and other countries undergoing socioeconomic, demographic and epidemiological transition, as per the forthcoming WHO report on disability in association with the World Bank, in making since 2006, the most common causes of impairment and disability include chronic diseases such as diabetes, cardiovascular diseases and cancer; injuries, such as those due to accidents at home, at the workplace, on the road; conflicts; falls; mental impairments, birth defects, AIDS, malnutrition and other causes often related to poverty, communicable diseases and environmental degradation (WHO, 2010). These trends leading to people acquiring disabilities and impairments in adult and later years along with the fact that people with disabilities from birth and those acquired at younger ages are living longer, are creating an overwhelming demand for health care provisions, including rehabilitation services, long term care and social care facilities.

Some countries in Asia, especially those with fast growing proportion of older people in the total population and of people with disabilities are beginning to respond by identifying the interface between policy issues relating to ageing and disability. India, which is the second country in the world with the largest population of older people, China being the first, for instance, as part of the current exercise of revising the National Policy on Older Persons formulated in 1999 to make it more concurrent with the growing emergent needs is bringing focus on disability and ageing issues, especially from a gender perspective (1). It is observed that older women bear more disabling illnesses, for example osteoporosis and dementia since they are now living longer than men. National Sample Survey Organization (NSSO) data of the 52nd Round conducted in 1995-96 based on functional impairments that count as disabilities among the population over age of 60 years indicated prevalence higher in females than males in both rural and urban areas. For the older population in general, disability was seen to be higher in rural areas probably because of poor access to health care facilities. Variations based on nature and extent of disabilities interfaced with ageing, are noticeable

among the different States. Functional impairments in the data is seen in terms of decline in functional capacity due to visual impairment, hearing loss, locomotors problems, arthritis, speech problem, amnesia/senility, dementia, Alzheimer's disease and other kinds of severe disabilities. NSSO data revealed that 27 per cent of older persons in rural areas suffer from visual impairment in contrast to 24 per cent in urban areas. 15 per cent and 12 per cent of older persons suffer from hearing disability in rural and urban areas respectively. In terms of locomotors disability the statistics for older persons were 11 per cent in rural areas and 9 per cent in urban areas. Last Census which was conducted in 2001 identified visual, hearing, speech, locomotor and mental disabilities across the ages in the total population.

Many of the Asian countries, to name some, for instance, China, India, Indonesia, Malaysia, Singapore, Sri Lanka, Thailand are becoming conscious of the need for training of professionals in disability and ageing issues and disability equality issues, community-based rehabilitation, disability in emergencies and assistive technologies among other issues. These countries along with others in the Region

\*Dr. Mala Kapur Shankardass is a Sociologist with specialization in health, gerontology and development studies. She works as Associate Professor of Sociology at Maitreyi College, University of Delhi, South Campus, New Delhi, India. She holds the Chair for Asia and India of the International Network for Prevention of Elder Abuse (INPEA). She is Managing Trustee: Development, Welfare and Research Foundation, an Indian voluntary organization involved with programs and advocacy for improving quality of life of people as they age. Contact: malakapurshankardass@hotmail.com

are signatory to the Declaration on the Full Participation and Equality of People with Disabilities in the Asia Pacific Region and as Member countries of ESCAP had also adopted the Agenda for Action for the Asian and Pacific Decade of Disabled Persons, 1993-2002. The Declaration and the Agenda proclaimed that the lives of people with disabilities must improve through the impetus of the Decade in villages, towns, cities and the myriad communities of the Region. These countries along with others on the conclusion of the Decade of Disabled Persons are also signatories to the Biwako Millennium Framework for Action, which is a commitment towards an inclusive, barrier free and rights based society in Asia and Pacific in the decade from 2003 to 2012. This regional framework for action identifies seven areas for priority action in the new decade. Each priority area contains critical issues, targets and the action required specifically in relation to self-help organizations of persons with disabilities and related family and parent associations; Women with disabilities; Early detection, early intervention and education; Training and employment, including self-employment; Access to built environments and public transport; Access to information and communications, and assistive technologies; Poverty alleviation through capacity-building, social security and sustainable livelihood programs.

Despite these initiatives, among the general public and policy makers in most countries in Asia, there is scarce attention

paid to age related disabilities and frailties and limited awareness of ageing of people living with disabilities and impairments, the challenges they face in participating fully in their societies and their difficulty in accessing healthcare and rehabilitation services. Also the interplay between social prejudice and natural deficiency continues in relation to the legal capacity of persons with disabilities. Often persons with disabilities are socially stereotyped as incompetent and incapable of managing their own affairs. Stigma and discrimination are among the underlying factors thwarting the inclusion and full participation of people with disabilities in their societies. Furthermore, the lives of people with disabilities are made more difficult by the way society interprets and reacts to disability, which requires environmental and attitudinal changes. In India research conducted in 2008 by HelpAge in Delhi as part of the project initiated by WHO Ageing and Life Course Program to identify and understand the positive features and barriers for older persons in the built environment in 33 cities in 22 countries of the world revealed that there was consensus in all groups, including older persons, care givers and service providers that the built environment in the city was unmindful and at times unfriendly to older persons especially those with disability. The gradual weakening of human element in the entire setup was acknowledged by all, who wanted changes in the environment that would encourage independence of older persons and also development of formal structures for care of older persons, especially those with

disabilities, frailties and exposed to various vulnerabilities in lieu of declining support from informal care givers.

In the Region, in general, there is lacuna of scientific evidence on the nature and magnitude of the issues to promote policy response for inclusion of support and protection to people with disabilities across the life span. In case of dementia, a major social and health care challenge connected with older people in the region, it is observed particularly in China, which alone has 40 per cent of the demented population of the world (Wimo and others, 2003), institutionalization of the people affected by dementia is not the best option, in spite of the fact that it is a condition that often requires institutionalization. Research has indicated that earlier the institutionalization from the onset, the shorter the survival time for the person (McClendon, Smyth and Neundorfer, 2006). Societal response to deal with the growing problem has its limitations as care in the community of people affected with dementia is very demanding and also availability of trained care givers is a big hindrance. In many other countries, such as India, Nepal, Sri Lanka where incidence and prevalence of dementia is seen to be increasing, adequate provisions for institutionalization are lacking, thus adversely affecting quality of life of people impacted with this disabling condition (Shankardass, 2007 [a]).

In fact, the future of long term care is undoubtedly the biggest challenge in health and social

care for older persons in Asia. Most of the development initiatives in the region ignore the needs of people with disabilities, in particular those connected with ageing and also poverty limits the access to health and rehabilitation services. It is crucial to realize the grey areas in services for ageing people with a disability. While there are similarities between the current disability and aged care service systems in broad service philosophies and policy directions, the two systems differ in their program focus, service types, main target groups and trained personnel. Provision for both, disability and aged care services are under the nodal Ministry of Social Justice and Empowerment in India, but under different sections. In particular aged care services are geared to the needs of older people including the frail and those with a disability, while disability services generally focus on people aged below 65 years. Aged care services focus more on social needs, broad personal care and self-maintenance, while disability support services emphasize health and social needs and address a broader range of life domains, including employment. People ageing with a disability may encounter 'grey areas' in service provision in the border territory between the disability and aged care service systems, which need to be overcome. There are three categories of people with special needs who approach potential service 'grey areas'. These categories are not necessarily mutually exclusive but may be of use in identifying particular issues for service planning. People ageing with an early onset disability often have

fewer basic living skills and so need higher levels of assistance in some areas. The services they require may be different from those needed by their younger counterparts. People ageing with a disability acquired during adulthood usually have basic living skills. Their need for assistance generally arises from increasing physical frailty and diminishing levels of functional skills, thus the requirement for long term care givers. Some people ageing with an intellectual disability may acquire dementia relatively early in life, at around age 50. They may become frail and need health and medical care along help with other activities. These people require to be more appropriately assisted by aged care services, because of their early ageing and deteriorating health. Clearly, people living with disabilities and ageing are not a homogenous group. Recognition of their needs for different service programs based on individual assessments is pertinent for most countries in the Region and new policy initiatives must take into account the condition and needs of the disabled who are likely to survive to old age and also take cognizance of the increased health care needs of older persons due to disability and consequent loss of autonomy.

Despite recommendations put by the World Report on Disability and Rehabilitation for countries to draft disability legislations to bring paradigm shift from 'medical model' to 'social model' of disability and for approval of new International Classification of Functioning Disability and Health (ICF) as suggested by

the 58th World Health Assembly in 2005, many countries have still to put these in place. Though, some countries in the Region have ratified the UN Convention on the Rights of Persons with Disabilities and thus are obliged to create more accessible societies for people with disabilities and those ageing and contribute towards improving their quality of life. India ratified the UN Convention on 1st October, 2008 and proposes in the next census in 2011 to move from traditional approach of asking one about disability to one based on a functional approach consistent with the International Classification of Functioning.

In Asian countries as elsewhere too, 'ageing in place' is becoming the core of a solution for policy makers to enable independent living in a supportive environment for older people and those with disabilities. The concept aims at supporting older people in their homes and communities for as long as possible. Policy critics however point the need to view ageing in place as a matter of choice for the well being of older people (United Nations, 2008). It is important that in encouraging older persons to live at home, even those with some degree of frailty and disabilities, policy and societal directives must foster family oriented culture and care giving, given the fact that in many countries there is growing trend towards nuclearization of families and many family members are increasingly feeling constraints in care giving for older people. In China, Hong Kong, for instance, ageing in place has become an explicit policy along with care in community directives. In India, with trends indicating increases



in women's participation in the work force, and yet being the primary care givers, quality and quantity of home care for older people, especially for those affected by disabilities and frailties, is becoming a concern requiring urgent policy response.

Unlike some of the other countries in the Region, India has not built conducive environment for ageing in place, which is more specific to adequate housing and a safe and enabling environment. Most buildings, except the very recent ones do not have lifts, ramps, proper stair cases, hand rails and modern toilets and those specially marked for the disabled. Besides strategies for enhancing family and community care of older persons, it is essential that various other services and programs are developed which can support ageing in place. Provisions for discounts on commodities, medications, better transportation facilities and mobility, barrier free housing, availability of suitable appliances, assistive technologies and adaptations in the home, in other words, provisions for age friendly and age supportive environments is an emerging need to address concerns of care for people interfaced with disability and ageing. The town planners, municipal authorities, public transport managers, architects, builders, all need to be sensitized to enabling environments and required legislations and bye laws put in place for the implementation of age friendly designs and construction materials. Special focus is required to meet the needs of older people residing in rural areas. In India almost

75 per cent of older people are living in rural areas where not only services and facilities to meet the needs of older people are scarce but also where accessibility to limited available services and provisions is a question.

As signatories to MIPAA, many Asian countries are party to the objectives and recommendations around health and supportive and enabling environments. These include measures to reduce the cumulative effects of factors that increase the risk of disease and dependence in old age, development of policies to prevent ill-health in older persons, ensuring access to food and adequate nutrition, the creation of an enabling environment supportive of older people with disabilities with emphasis on their full participation in all aspects of society. For Asia, as people continue to live longer, the challenge for public health is to increase the number of years a person lives free of disability, primarily by ensuring access to high quality, affordable and sustainable health and care services. In many countries in the region trained health personnel, especially in geriatric medicine are in short supply. Adequate provision for health care calls for integrating, preventive, curative and rehabilitation measures within a continuum of care and by enhancing training and support for care givers. Further, self help groups which are integral part of community based rehabilitation can address the issues concerning ageing and disability.

To conclude, disability issues in all countries are now gaining

importance as they cut across all sectors and thematic areas of community development. Yet, older persons with disabilities are invisible in design of projects or programs to address disability concerns. With ageing of the populations, a stark reality of the 21st century for most of Asia, interface between ageing and disability must be given adequate attention. Article 1, 4, 8, 9, 16, 19, 20, 23, 25, 26, 27 and 28 of the UN Convention on the Rights of Persons with Disabilities are particularly sensitive to age related concerns and therefore provide opportunities for mainstreaming ageing into disability discourse (Shankardass, 2007 [b]). Countries should give priority to developing normative tools including guidelines and a national plan of action to strengthen medical care and rehabilitation services and integrate it into overall primary health care system. To improve quality of life of people with disabilities across all ages, specialized rehabilitation centers linked with community-based rehabilitation need to be strengthened. Finally, disabled old and old disabled must be empowered to be full participants in the society and be knowledgeable about their own condition and support and protect their rights and dignity.

## References

- HelpAge India, 2008: Age Friendly Cities Report Delhi, Research Project under the technical guidance of World Health Organization, New Delhi.
- McClendon, M.J; K. A. Smyth and M. M. Neundorfer, 2006: Long term care and placement and survival of persons with Alzheimer's disease. *Journal of Gerontology: Psychological Sciences*, Vol. 61B, No. 4, pp 220-227.
- Shankardass, Mala Kapur, 2007 [a], Ageing in South Asia with Special Reference to Bangladesh, India, Nepal and Sri Lanka, Monograph for UNFPA CST, Nepal.
- Shankardass, Mala Kapur, 2007 [b], Paper 'Ageing and Disability: Need for Public Discourse' Presented at the World Bank and Ministry of Social justice and Empowerment Seminar on People with Disabilities in India: Status, Challenges and Prospects, November 21-22, New Delhi.
- UNESCAP, 1993: Agenda for Action for the Asian and Pacific Decade of Disabled Persons, 1993-2002
- UNESCAP, 2002: Biwako Millennium Framework (BMF),  
<http://www.unescap.org/esid/psis/disability/bmf/bmf.html>
- United Nations, 2006: Convention on the Rights of Persons with Disabilities.
- United Nations, 2008: Regional Dimensions of the Ageing Situation, Department of Economic and Social Affairs, New York.
- WHO, forthcoming 2010 World Disability Report [http://www.who.int/disabilities/world\\_report/en/index.html](http://www.who.int/disabilities/world_report/en/index.html) and [http://www.who.int/disabilities/publications/dar\\_world\\_report\\_concept\\_note.pdf](http://www.who.int/disabilities/publications/dar_world_report_concept_note.pdf)
- Wimo, A.; and others, 2003: The magnitude of dementia occurrence in the world. *Alzheimer's Disease and Associated Disorders*, Vol. 17; No.2, pp 63-67.

# The Experience of Acquiring a Disability as a Senior Citizen

Alessandra Marques Sohn, Michele Santos Cruz e Michele Schultz Ramos Andrade. School of Arts, Sciences and Humanities, University of São Paulo.

Corresponding author: Michele Schultz Ramos de Andrade E-mail: mschultz@usp.br Address: Rua Arlindo Bettio, 1000 room 237 Zip code: 03828-000 São Paulo-SP, Brazil Phone: +55 11 30918830

## INTRODUCTION

In the last few years, Brazil has presented a new demographic profile characterized by a profound transformation in its age structure composition, with a significant increase in the elderly population. This aging of the population could be related to incentives given to the public health system, National Health Service, urban infrastructure and work regulations in the main provinces of the country since the 1930s. These factors contributed to advancements in the chemical and pharmaceutical industry which led to the control and reduction of many illnesses, specifically contagious and pulmonary diseases, which at that time had high incidence and were the cause of many deaths (IBGE, 2009). In this context, there has been an increase in the general life span of the Brazilian people. This scenario necessitated the creation of more public policies facilitating the elderly who have specific demands related to health because they are more vulnerable to diseases and accidents that lead to disability. Although increasing age is a risk factor in the development of certain diseases and disabilities in the elderly, this does not mean that a person should lose their functional capacity, defined as the capacity to maintain the physical and mental abilities necessary for an independent life (Gordilho et al. apud Freitas, 2006). However, some of these physical limitations can deter-

mine if an elderly person will be in a situation of social, physical and economic dependence, as has been observed in many elderly persons with disability. Data from the last two demographic censuses (1991 and 2000) collected by the IBGE (Brazilian Institute of Geography and Statistics), show a considerable increase in the number of its senior citizens. In 1991, there were just over 10 million people over the age of 60 and in 2000 this number had already reached 14 million. As the years pass by, there is an indication that the number of senior citizens tends to increase even more. This suggests that there is a pressing need to investment in public policies that guarantee the quality of life and well being of senior citizens, who represented 7.3% and 8.6% of the total population in the years 1991 and 2000, respectively. According to a projection done by IBGE, the number of senior citizens over the age of 60 by the year 2050 will represent 22.71% of the Brazilian population. This projection also indicates that the elderly population would represent 19 million people by 2010, while in 2050 that number would reach 64 million. This again reinforces the necessity of public intervention so that this population group can maintain themselves within a society in fair form and ensure their rights. It is therefore vital to address collective health, social security, housing, and other rights so

that senior citizens have their quality of life guaranteed. Data from the IBGE also indicates that in Sao Paulo (Brazilian city with the highest social and economic projections) 12.3% of its senior citizens between the ages of 60 and 69 are physically disabled; 21.5%, between 70 and 79, and 38.4% of people over the age of 80.

In the Americas, there are 60 million men, woman and children with some kind of disability (50 million concentrated in the Latin and Central Americas). The numbers indicate that for every 10 people at least one of them knows someone with a disability (Vasquez, 2008a). In relation to senior citizens, the projection is that this number will double by 2025 corresponding to approximately 14% of the total population of the Latin and Central Americas (Vasquez, 2008b).

The risk of incapacity associated with senior citizens is high. Not because this group is considered frail, but because there are higher incidence of falls (Delbaere et al., 2010), encephalic vascular accidents (Lim and Kwon, 2010), diabetes and its systemic complications (Volpato et al., 2010), and others. These conditions represent strong risk factors in the development of disabilities and/or reduction of mobility. Falls, for example, have a prolonged effect as they can be associated with post-traumas such as the fear of falling again, which in turn, could generate a lack of confidence and a self-

imposed reduction in mobility activities (Filho and Netto, 2006).

According to the International Classification of Functioning, Disability and Health of the World Health Organization (WHO, 1980), disability means the loss or abnormality of anatomic structures and biological systems and can be characterized by two aspects: disability, functional restriction of exercise activities, handicap or incapacity that limits the whole expression of the persons as individuals (Barbotte et al., 2001). Morris (2001) and Maciel (2008) add that a disability is a characteristic or lasting attribute and presents an incapacity as a disadvantage or restriction of physical activity caused by a society that makes small or no provisions for those with disabilities and, in this way, exclude them from these activities.

Considering this reality, we believe in the importance of studies that focus on the perception of senior citizens in relation to their own experience of becoming disabled, their difficulties and necessities, and their relationships with families and communities, making it possible to discuss the development of efficient public policies for this particular population group.

## **OBJECTIVE**

This work intends to study the conflicts and necessities related to the moment that a senior citizen becomes physically disabled and other factors that surround their return to everyday life after having acquired some sort of physical disability. We also intend to investigate how the elderly citizen faces the impact of

mobility loss and then identify the adaptation mechanisms used in dealing with the disability and the elderly years.

## **METHOD**

This research was based on a qualitative delineation that used a semi-structured interview approach with audio recording. In order to access the person's experience with the disability acquired, the interview was done with little direction of the interviewer, making it possible to create an inter-subjective relationship between the interviewer and the interviewee and, consequently, allowing a better comprehension of the meanings of their values and opinions in relation to their social situation and life experiences (Fraser and Gondim, 2004). The Ethical Research Committee of the Institute of Psychology of the University of Sao Paulo approved this experimental protocol.

The guiding questions of the interviews were: "How was the moment in which you became disabled? How was the process from the moment you became disabled until now? How is your relationship with the community?" These questions were used in this exact order to direct the interview so the objective of this study could be reached. However, the interviewer did not strictly use these exact words forming the questions above.

Inclusion criteria regarding subject selection were: subjects at least 60 years of age; having acquired the physical disability for a minimum of a year via accident or illness; to present reduced mobility; to feel comfortable talking about their experience of becoming

disabled; to be able to express themselves clearly through speech. Exclusion criteria: subjects less than 60 years of age; having acquired the disability less than a year before the interview; having being less than 60 years of age at the time of the disability incident; unable to talk comprehensively about their experience.

First contact with the disabled senior citizens was done in person, the objective of this research was explained and data protection was guaranteed. A term of free consent form was read and explained to them. After this procedure and agreeing to participate in this research, the subjects then formalized their interest in participating in this study.

### **Interviewees' profile**

Subject 1: 69-year-old male. He has been paraplegic for approximately three years after suffering a spinal cord lesion as sequel to vascular surgery. He uses a wheelchair.

Subject 2: 63-year-old male. He has hemiparesis on the left side of his body as a result of a encephalic vascular accident that happened approximately a year before the interview. He uses a simple walking stick when goes out.

Subject 3: 69-year-old-male. He has difficulties with mobility because of a shortened right leg after being run over approximately five years ago. He uses crutches.

Subject 4: 65-year-old male. Hemiparetic on the left side of his body as a result of a encephalic vascular accident approximately three years ago. He does not use anything to assist locomotion, although he does have difficulties walking.

Subject 5: 71-year-old female. She has difficulties with mobility because of a shortened left leg after a fall, which happened approximately 23 years ago. This subject was excluded from the results because the accident, which provoked the loss of mobility, happened during adulthood.

Subject 6: 64-year-old female. She has difficulties with mobility because of a fall, which happened approximately six years ago. She uses a walking and reports that she is unable to firm the leg while walking because she feels pain in her hips. This subject was excluded from the results because the accident, which provoked the loss of mobility, happened before the age of 60.

Subject 7: 84-year-old female. She has difficulties with mobility as a result of a fall approximately six years ago. She uses a walking stick. She reports feeling pain in her right knee, being unable to firm that leg while walking.

## RESULTS

In analyzing the interviews, we were able to highlight a number of themes, which were separated in order to understand the speech better, however, during the reports they appeared in fluid form. With the intention of elucidating these topics, we articulated them aiming to discuss each theme more thoroughly. Therefore, these topics are not isolate or in temporal order.

### Dependence

The dependence on another was a relevant point highlighted by the interviewees as it affects their relationship with the carer and their own well-being.

*"If someone falls, it is difficult to get up, right? If I fall, I don't get*

*up. If I fall on the street, I have to find a pole, right? A tree to pull myself and get up, right?"* (Subject 4)

Even though the interviewees are able to independently exercise self-care and domestic activities, such as going to the toilet, eating, walking around their homes, this seems to be insufficient to fulfill their sense of well-being. In order to do certain things, many times it is necessary the help of others.

*"I have to be taken to the toilet because the shower chair doesn't rotate, but if it is loose in I do it myself."* (Subject 1)

On the other hand, in some reports we could detect the feeling of total capacity to perform some actions independently.

*"For me it is easy to get in the car here. I put the chair there and soon quickly get in."* (Subject 1)

Dependence on a carer means that often the carer is required to permanently assist the senior citizen. Thus, a context in which the carer is directly responsible for the senior citizen is generated, what provokes in the dependent person a feeling of incapacity, being unable to perform activities that they used to do themselves before acquiring the disability. This scenario could make both the carer and the disabled senior citizen feel uncomfortable.

*"Then my daughter wants to work and I say: no! You are not going! Because how can I stay here at night by myself? (...) I am taking her time to live, ain't I? Her time to go out, it is like that, isn't it? I have my life, she has hers, right? She can't go to work, why... poor thing!"* (Subject 7)

Family support was considered an important mechanism in coming to terms with the

difficulties met after acquiring the disability.

*"Anna (wife's fictional name), supported us. It was primordial. You know if it wasn't for her, I wouldn't have survived all this..."* (Subject 1)

Many of the subjects' actions, including every day activities and leisure, are linked to this family support, which in turn motivate actions, such as going out. It seems that the families had two different types of approaches. The analysis of the reports shows that sometimes the family would encourage the senior citizen to perform activities themselves, and other times, they would address the senior citizen's needs and directly perform the activities for them.

The familiar bond seemed to be very relevant in the senior citizens' feeling of security, as this proximity was shown to be strongly linked to the trust that the senior citizens have towards the members of the family.

*"Look, I'm happy! I'm very happy! I have no money, I have my pension, but with the little I have I'm happy. You know, if I say to my son: 'Son, I need this', he helps me!"* (Subject 7)

Factors such as limited mobility interfere with their presence in family events, such as birthday parties. Due to the extreme importance that these familiar relationships present the elderly, their absence or distance from their families brings about an uncomfortable feeling.

*"... the worse think in the world is to have problem like this in the leg... Look, I do not go to a party for two years. I do not go to a wedding or birthday party because I can't."* (Subject 7)

## Community

The social life of the senior citizens with disabilities usually revolves around family members and close neighbors only. This also was considered a constant and available support.

*"Look, here all the neighbors like me, I like everyone. We have our intimacy, each of us in our own space (...) But here, if I get sick and call someone, anyone comes."* (Subject 7)

Mobility also is considered an important factor in maintaining wider social relationships.

*"I am afraid of going somewhere far, it is difficult to come back afterwards... but here close to me I go (...) Then I walk like that, stop here and there to talk to friends... Friends that I bump into on the street, they pass by and say: 'I'll walk you home'."* (Subject 4)

Environmental conditions, such as access to buses, were shown as factors that contribute to the isolation of the disabled elderly persons.

*"Because I can't walk. Taking the bus is very difficult, right? (...) By bus, I don't go. Because to get in is difficult to get out is even more... It is a fight. The bus driver doesn't wait for you to climb up properly and it is the same when going down out of the bus. That is why I'm afraid. (...) On the street is easy, you just trip. Then you trip, loose balance, go to the floor. (...) You're going to get in the bus... Many people respect, right? Offer you a seat. Others look at you as if you weren't there. When you want to go out the bus, it's a challenge, right? 'Get out, uncle' and pushes you, right? A herd of cattle and you in the middle of them."* (Subject 4)

The family as a resource was constantly mentioned. Being

able to assist in mobility and offer companionship.

*"...my wife, my daughter can give me transport, I take a taxi, sometimes I go, sometimes I don't, because it is not everyday that we have... I take a taxi when I have money, when I don't have, I don't go."* (Subject 2)

The absence of a job, vehicle of social interaction, brought up a feeling of suffering in the interviewees.

*"... a person who always worked, always walked, and suddenly finds themselves in a wheelchair, not even in a chair I could stay, (...) it is very difficult for you who worked all your life to find yourself completely dependent on someone, right? It is not easy!"* (Subject 1)

Work not only represents a formal obligation but also a social bond that develops between the subject and employer. The inability of exercising this bond seems to bring about a feeling of futility.

*"Look, to me it was an abrupt change because I used to work, all my life I worked and suddenly I was unusable at home."* (Subject 2)

Regarding social relationships, the existence of prejudice was noticed. However, this was not always relevant in the interviewee's experience.

*"Once, I was coming down, and fell. I saw a few women. Instead of helping they said: 'Oh! At this hour and already drunk.'" (Subject 4)*

Some of the interviewees seemed not too worried about prejudice. Some reports show that the interviewees experienced prejudice attitudes, but they try to ignore such behavior. *"I don't think about prejudice. I do what I like and want to do. I don't even notice or care about anyone. Each to*

*his own. If you are bias, it is your problem, not mine."* (Subject 3)

## Hope for life

Hope, desperation and even anxiety in the absence of a definite and clear future surrounded all the reports. As all the interviewees characterized this experience with many impossibilities (i.e. the impossibility of walking or cleaning the house), there is a tendency to perceive that in the future the situation will improve. There are many mediators of this expectancy, like the figure of the health carers that seems to shape the hope of the subject in relation to improvement possibilities or healing.

*"The movement is back, especially on my left leg. This is small, but they (the doctors) said that to walk one kilometer we need to take the first step, right?"* (Subject 1)

On the other hand, desperation can be stimulated by the convincing information given by health professionals that the possibility of recovery does not exist.

*"... one doctor says that I will be good and the other says that is quite difficult, right? And then I am fighting, right? Let see where it will go (...). But, I am conformed."* (Subject 7)

Faith in "God" also influences this expectancy, creating a security based on the faith that God can deal with the difficulty. It seems, however, that this builds a situation in which hope lives together with conformism, considering that the person may have hope that things can get better but they themselves are not the agent of this improvement. When asked about what could change in the community, the answer was:

*"Darling, I just wanted... I don't even know now. Because*

*everything, the changes that happen to us is God. God is the boss, right? God is the one who gives things when we least expect it. We receive that wonderful thing, we get so happy. We don't even know where it came from.*" (Subject 7)

There is a situation, when hope is present that improvement is not expected. Just the mere fact of being alive already represents something positive to the interviewee.

*"Because this stroke... when it doesn't kill it cripples, doesn't it? I thought when I was told that it was something to do with the brain : 'I'm fucked! Either crippled or dead. But it just bent. Crippled, didn't it? But one doctor says that I will get well the other one says it is a bit difficult. And I'm fighting, right? I'm fighting. Lets see where it gets us. (...) But I got over it. Lets see what happens from now on."* (Subject 4)

For others, hope is strongly linked to a desire for change, for improvement.

*"I want to change! One thing that is very important! I want to get better! I want to get better, not having anything wrong with my leg! I want the day to rise up and I say: 'It is today!' I wish that so much..."* (Subject 7)

## **DISCUSSION**

The fact that the words "disability" and "elderly" are socially linked to frailty does not mean that all senior citizens feel that way. On the contrary, some elderly persons with disabilities are able to perform activities in an independent way, which indicates that the presence of a disability may not necessarily affect their self-esteem and independence (Buscaglia, 2006). These aspects can vary according to the person's perception of health, economic

disposition, how much the deficiency limits them and how their family deals with this new situation (Diogo, 1997). Difficulties associated with the deficiencies, especially regarding functional mobility, do not always result in the inability of accomplishing certain actions. Mobility has strong relations with the socio-economic situation in which senior citizens find themselves. For example, many senior citizens use their own vehicles as means of transport while others, who possibly do not have vehicles, are often limited to their own homes. A possible alternative, improving access, would be the construction and adaptation of public pavements and improvement of public transport, adapting it to the needs of people with disabilities and increasing the number of adapted vehicles on the streets. It is the numerous so-called impossibilities, generated by socioeconomic conditions that contribute to the isolation of senior citizens. As it is difficult to move from place to place, some

senior citizens limit themselves to their homes or circulate in places very close to their homes. The Citizen Pavement Booklet (Gabrilli, 2010) proposes that public pavements in the city of Sao Paulo be renovated in such a way as to facilitate the mobility and locomotion of disabled and/or physically impaired people. Thinking about the democratization of the city and the freedom of movement of all its citizens, it had been created norms so that the public pavement can faithfully exercise its function: making people's transit possible, whether they have a disability, reduced

mobility or not. Council laws such as no 14.675 of the city of Sao Paulo are important in the reestablishment of this right to move adequately around the city, being disabled or not. Following this law, an "Emergency Plan to Replenish Public Pavements" was established, with the objective of promoting the necessary roadworks to refurbish or build pavements that are not in accordance with the law.

The fear of going out alone was a common theme in the subjects' speeches. It seems that the difficulties reported above create a sense of insecurity when subjects found themselves outside their comfort zone, their homes. One of the subjects even mentioned that this fear is responsible for a slower physical recovery, once social life is limited to a restricted environment. Young people seldom think twice about going down dangerous steps, but an elderly person does not take that risk because of a fear of the serious consequences a fall may bring upon them. Biological factors such as a less acute sense of balance that an elderly person may experience can affirm that this feeling of insecurity is the result of a sum of events. Old age coupled with a deficiency can intensify fear and insecurities, and in this way, limit mobility.

Going out by oneself is not a possibility for most of the subjects, although there is the desire to do so. One of the subjects suggested a resource that would be very useful: an available vehicle, such as an ambulance, that could pick the person up from their home, take them to the required practice or hospital where they could have their exams and appointments done and then take them back

home again. They reinforce that this would eliminate this inconvenience for their families. The subjects showed that several resources are able to improve their comfort and well-being. Not only public transport and adequate pavement, but family as a resource was mentioned many times regarding the mediation of locomotion and companionship. Facing a disability, the subject may need a carer to assist with daily activities. If a relationship of dependence develops between the senior citizen and the carer, the carer can be seen as a person who makes it possible for the elderly person to perform certain activities. Thus, the carer's actions allow the elderly person to perform some essential daily activities independently, such as bathing and using the toilet alone, however needing the carer to get them to the bathroom.

Excessive dependence, noticed in some interviews, seems to provoke a uncomfortable sensation of incapacity. Perhaps this sensation is related to the fact that the elderly person wants to be present and active, and not limited to the spacial restrictions imposed by the carer in fulfilling the elderly person needs.

Family support was considered an important mechanism in overcoming difficulties. It is important to encourage this relationship and maintain the family core (Buscaglia, 2006), although in some situations members of the family excessively assist the senior citizen not allowing them to exercise of their abilities (Diogo, 1997). Having a close and present family generates a sensation of security, as they feel comforted by the support of people close to them and the

fact that the family will not abandon them. The family can be a mechanism of defense or a barrier against complete collapse, disintegration, despair, and guilty experienced when a person finds themselves in an 'abnormal' situation (Loureiro et al., 1997; Laing apud Rojas, 2001). Another aspect reported during the interviews is work. Being unable to work and reduced mobility, amongst other factors, build an environment in which the disabled elderly person's social life is restricted to their own families and close neighbors only. This reality compromises the maintenance of wider relationships, considering that mobility and work makes it more possible for the senior citizen to get to know new people and create new friendships. That is why the creation of public policies which minimize mobility problems are imperative (i.e. adequate public transport and the development of programs that meet the disabled senior citizen's physical, social and psychological necessities, promoting higher interaction with the community). It was possible to detect from the reports analyzed that the subjects suffer because of the absence of work. What make them upset is not necessarily the financial implications of not working, but the nonexistence of a work that could be done by the senior citizen in the community, something that could be fully developed before acquiring the disability. In this way, one can say that work does not exclusively represent a formal obligation, but a social bond in which the person has with the person they work for and, if the work could be done, this could give them satisfaction for being

an active part of society (Loureiro et al., 1997).

The lack of work available for this section of the population can result in forced retirement, considering that which takes them to this situation is most of the time impossibilities generated by the dependence and/or lack of resources to promote mobility. For Freitas (2006) retirement asks for a mental and social state that most people do not have, and that happens because the end a professional life constitutes the exclusion of the productive world, which is the base of modern society. This same condition is a recurring theme in the analyzed interviews, once they showed dissatisfaction with the inability to perform their work function in the society.

Dependence and absence of work can generate a sense of futility, what can develop more frustration, depression, anxiety and frailty, possibly aggravating health issues (Pont, 2003). For this author it is necessary to look for gratifying and motivating activities, which would occupy at least a part of their day, helping these senior citizens overcome soulless times, and depression. Activities that could make them feel useful and active, and that, on the other hand, become a social reference point, to be considered a bond of union between the participants and a way of integrating themselves in a social group. Working could be a way to help this section of the population identify themselves as an active part of society, minimizing their sense of incapacity to do certain tasks.

Another point presented in the interviews was the prejudice linked to the lack of information about the possibilities related to a senior citizen's behavior



towards the deficiency, being taken as a negative judgment of their actions. On the other hand, some subjects seemed not to care about prejudice, perhaps as a self-defense mechanism.

Within the interviews there was a strong feeling present: the hope of getting better. For some, this expectancy represents a strong desire that, many times, does not necessarily implicate a real perspective of physical improvement. For others, the improvement of their health state is not necessarily expected, but a change that does not make them too anxious. The fact that some health professionals make negative comments about their improvement or affirm the instability of their health state can contribute to the appearance of a sense of despair.

External factors such as religious faith, information provided by health professionals, family support and the perspective of improvement seemed to shape the hope or despair of the subjects. For Buscaglia (2006) some medical information bring discouragement for the patients and their families. The Pan American Health Organization (Vasquez, 2008a,b) highlights the importance of the health professionals when affirming that nurses and other health professionals should be familiar with the persons with disabilities rights and be conscious that they may represent the last line of physical, psychological and moral defense for the persons with disability.

The United Nations (UN) has studied the problems of the persons with disability and produced a document emphasizing the main needs of this

group and setting standards for their rights. Brazil ratified this document, the Rights of the Persons with Disability Convention in March 2007. On July 9th 2008, through Legislative Decree 186 and Executive Power Decree no 6.949 (August 25th 2009), the principles of the Convention were changed into a Constitutional amendment. All the fundamental human rights are reaffirmed in relation to the person with a disability. Areas in which adaptations for people with disability to effectively exercise their rights were identified.

Thus, as a signatory and for having ratified the Convention, Brazil promised to make it possible for people with disabilities to live life independently and fully participate of all aspects of life, to assure people with disabilities access, to equal opportunities with others people, to the physical environment, to transport, information and communication, including systems and information and communication technology, also other services (Legislative Decree no 186, of July 9th 2008). Despite being the signatory and having ratified this Convention, the rights of the senior citizens with disability are far from being completely exercised. The results presented in this study show reports of extreme difficulties in using public transport, difficulties in accessing adequate health and rehabilitation services, amongst others.

IBGE's population projections for 2050 has shown growth in number of elderly citizens, indicating that the aging process of the population in Brazil will demand new priorities

relating to public policies that should be aimed at specific population groups. As example of these priorities, we highlight the urgent allocation of human resources for geriatric and gerontological care, as well as changes to be made to social security, which should be adequate for this new demographic configuration (IBGE, 2008).

It is important to attend to the necessities of the elderly persons and also to determine how these necessities are presented to guarantee the access to the rights established by the Convention. For instance, the condition of a dependence on a carer was shown as a complex issue because of many reasons, such as carer limitations, the possibility or impossibility of exercising their activities and the senior citizen's feelings of discomfort.

We believe that knowing the way a disabled elderly person feels towards their own "incapacity" in performing certain tasks makes it possible to contemplate adequate and sensible strategies. Also, knowing how a family bond is related to support, rehabilitation, adaptation and the well-being of the senior citizen with a disability is fundamental so that proposals to the family can be included.

A proposal that could place the senior citizen as a worker or someone who is performing an important service for others seemed to be essential to their quality of life.

The deficiency, as already defined by WHO, is a physical characteristic of anatomic structures and physiological functions. Taking this into consideration, one can say that it is a personal characteristic.

Many political and social factors, however, can be viewed as incapacity and disadvantage generators, such as a lack of adequate public transport and prejudice. The resources used by citizens as to facilitate their social context are factors that require more studies: family bonds, dependence on the other, relationships within the community and work.

Finally, dependence and autonomy refer to different every day life conditions affecting elderly people with disabilities. Many of the people interviewed affirmed having autonomy despite their limited ability in performing tasks independently. An issue that remains to be discussed in the future is the relationship between autonomy and

dependence and how it affects the quality of life and well-being of the people.

### **Acknowledgments**

We would like to thank Mark Godfrey and Vanessa Schultz for English revision.

### **REFERENCES**

- André, MEDA. *Texto, Contexto e Significados: Algumas questões na análise de dados qualitativos*. Cad. Pesq., São Paulo, 1983; 45:66-71.
- Barbotte E, Guillemin F, Chau N & the Lorhandicap Group. *Prevalence of impairments, disabilities, handicaps and quality of life in the general population: a review of recent literature*. Bulletin of the World Health Organization. 2001; 79 (11).
- Buscaglia, LF. *Os deficientes e seus pais*. Tradução de Raquel Mendes. 5th ed. Rio de Janeiro. Record, 2006.
- Constituição Federal Brasileira. *Decreto Legislativo no 186, de 09 de Julho, 2008*.
- Cox-white, B, Boxal, SF. *Redefining Disability: Maleficent, Unjust and Inconsistent*. Journal of Medicine and Philosophy, 2008; 0:1–19.
- Delbaere K, Close JC, Heim J, Sachdev PS et al. *A Multifactorial Approach to Understanding Fall Risk in Older People*. J Am Geriatr Soc. 2010; 58(9):1679-1685.
- Diogo, MJD'E. *A dinâmica dependência/autonomia em idosos submetidos à amputação de membros inferiores*. Rev. Latino-am.enfermagem, Ribeirão Preto, 1997; 5(1): 59-64.
- Farias, N, Buchalla, CM. *A Classificação Internacional de Funcionalidade, Incapacidade e Saúde da Organização Mundial da Saúde: Conceitos, Usos e Perspectivas*. Rev. Bras Epidemiologia. 2005; 8(2): 187-193.
- Filho, ETC, Netto, MP. *Geriatrics: Fundamentos, clínica e terapêutica*. 2nd Ed. Atheneu: São Paulo, 2006.
- Fraser, MTD, Gondim, SMG. *Da fala do Outro ao Texto Negociado*. Rev Paidéia, 2004; 14(28): 139 -152.
- Freitas, EV. *Tratado de geriatria e gerontologia*. 2nd. Ed. Guanabara Koogan: Rio de Janeiro, 2006.
- Gabrilili, M. *Cartilha da calçada cidadã*. AME Jardins: São Paulo, 2010.
- Harris, J. *Is there a coherent social conception of disability?* J. Med. Ethics 2000; 26:95-100.
- Instituto Brasileiro de Geografia e Estatística (IBGE). *Projeção da população do Brasil por sexo e idade 1980-2050. Revisão 2008*. Rio de Janeiro, 2008.
- Jones, RB. *Impairment, disability and handicap - old fashioned concepts?* J. Med. Ethics 2001; 27: 377-379.
- Lei 14. 645 [http://ww2.prefeitura.sp.gov.br/passeiolivre/pdf/lei\\_14675.pdf](http://ww2.prefeitura.sp.gov.br/passeiolivre/pdf/lei_14675.pdf). Accessed in 9/19/2010.
- Lim JS, Kwon HM. *Risk of "silent stroke" in patients older than 60 years: risk assessment and clinical perspectives*. Clin Interv Aging. 2010; 7(5): 239-51.
- Loureiro SCC, Faro ACM, Chaves EC. *Qualidade de vida sob a ótica de pessoas que apresentam lesão medular*. Rev. Esc. Enf. USP, 1997; 31(3): 347-67.
- Maciel, CT. *A modernidade e o mito da deficiência*. Rev. Eletrônica dos Pós-Graduandos em Sociologia Política da UFSCar, 2008; 5(1): 38 – 48.
- Morris, J. *Impairment and Disability: Constructing and Ethics of Care that Promotes Human Rights*. Hypatia, 2001; 16(4).

- Pont, GP. *Atividade física e saúde na terceira idade: teoria e prática*. 5th Ed. Porto Alegre: Artmed, 2003.
- Resende, MC. *Ajustamento Psicológico, Perspectiva de Envelhecimento Pessoal e Satisfação com a Vida em Adultos e Idosos com Deficiência Física*. Faculdade de Educação, Universidade Estadual de Campinas, Campinas, 2006.
- Resende, MC. *Atitudes em relação ao idoso, à velhice pessoal e ao portador de deficiência física em adultos com deficiência física*. Faculdade de Educação, Universidade Estadual de Campinas, Campinas, 2001.
- Rojas, MF. *Família e deficiência: O significado de conviver e crescer junto a uma pessoa portadora de deficiência mental na idade adulta*. Universidade Estadual de Campinas, Campinas, 2001.
- Segalla JISF, Silva CR, Pedroso, GS. *O idoso e a deficiência – um novo olhar à questão da inclusão social do idoso*. XVII Congresso Nacional do CONPEDI, Brasília, 2009.
- Vasquez, J. Pan American Health Organization (PAHO). *Human Rights & Health persons with disabilities*. 2008a.
- Vasquez, J. Pan American Health Organization (PAHO), *Human Rights & Health older persons*, 2008b.
- Volpato S, Maraldi C, Fellin R. *Type 2 diabetes and risk for functional decline and disability in older persons*. *Curr Diabetes Rev*, 2010; 6(3):134-43.

# The Effect of Age and Age of Onset on Involuntary Retirement for People with Disabilities in Canada

Margaret Denton, Ph.D.

Director, Gilbrea Centre for Studies in Aging

Professor, Department of Health, Aging and Society & Department of Sociology

McMaster University, Ontario, Canada

(905-525-9140, ext 23923; mdenton@mcmaster.ca)

Jennifer Millen Plenderleith, M.Sc.

Research Coordinator

Gilbrea Centre for Studies in Aging

McMaster University, Ontario, Canada

&

James Chowhan, M.A.

Ph.D Candidate

DeGroote School of Business

McMaster University, Ontario, Canada

## Introduction

Research has shown that the three main reasons workers retire from the labour market in Canada are health, wealth and labour market redundancy (Myles, 2002). While some retirement is welcomed and on-time, other retirements are involuntary or forced due to: the loss of a job (Osberg, 1988), an early retirement incentive (Frenken, 1991), a health problem, mandatory retirement (Schellenberg, 1994), a lack of control with too many job strains (Trucotte & Schellenberg, 2005), or a need to provide care to a family member (McDonald et al., 2000b). Poor health is one of the most frequently reported reasons for early retirement (Morissette, Schellenberg & Silver 2004; Pyper, 2006). An analysis of the Canadian 2002 General Social Survey (GSS) reveals that 27% of retirees retired involuntarily (Schellenberg & Silver, 2004). Illness

or disability is the number one reason for involuntary retirement in Canada (Statistics Canada, 1997).

The purpose of this paper is to examine age and age of onset as key factors that influence the retirement decisions of people with disabilities. For a more detailed analysis of factors associated with involuntary retirement for persons with disabilities in Canada see Denton, Plenderleith & Chowhan (2010).

## Brief Literature Review

A review of the Canadian and international literature on the impact of disability on labour market outcomes revealed that most of the literature focused on labour force participation and wage discrimination. Study after study has demonstrated a consistent negative employment effect of health/disability on labour force participation and wage

discrimination. Further, the literature review showed labour force participation rates for persons with disabilities varies by socio-demographic, socio-economic and health status (for a review of studies see Baldwin & Johnson, 2001; Jones, 2008; and Statistics Canada, 2008). Further, the type of disability, the severity of the disability, and the age of onset are all important determinants of labour force participation (Jenkins & Rigg, 2003; Zwerling et al., 2002; Galarneau & Radulescu, 2009).

The literature on retirement for health reasons is much more limited in scope. There is a small body of international literature that demonstrates that poor health or a change in health status is a risk or a pathway to early retirement (Disney, Emerson, & Wakefield, 2004; Mein et al., 2000, Schuring et al., 2009). Bound and colleagues (1999)

*This research was funded through a grant from Human Resources and Skills Development Canada.*

found that it is not just poor health but “health shocks” or declines in health that help explain early retirement behaviour. A recent Canadian study shows that one-third of recent retirees left for health reasons (Morissette et al., 2004). In an analysis of the 2003 Canadian Community Health Survey, Pyper (2006) reveals that while retirement was the reason given most often by Canadians, aged 50-69 as their reason for not working, nearly half a million Canadians aged 50-69 were not working for health-related reasons. The proportion not working for health related reasons decreased with age from 41% for those 50-54 to 6% for age 65-69.

There is very little research on involuntary retirement per se. Our review of the literature revealed three studies that focused on involuntary retirement (Szinovacz & Davey, 2005; Shultz, Morton, & Weckerle, 1998; McDonald et al., 2000b). While they did find that involuntary retirement is structured by socio-demographic, socio-economic and health factors, they did not consider age of onset as a determinant of involuntary retirement. The purpose of this paper is to consider age and age of onset as key factors that influence the retirement decisions of people with disabilities while also controlling for differences in socio-demographic, socio-economic, geographical factors and health status.

### **Methodology and Findings**

The sample selected for analysis was from the 2006 Canadian Participation and Activity Limitations Survey

(PALS). The PALS used the 2006 Canadian Census of Population as a sampling frame to identify its target population. The PALS data allows an investigation of how disability and the experience of barriers affect the decision to retire. The sample used for analysis includes persons with disabilities, aged 15-74, who had retired either voluntarily or involuntarily from the labour force during the period 2001 to 2006. The retirement questions were only asked to people aged 15-74 who had retired within this time frame.

The selection of variables for analysis was guided by the economic model of retirement (Shultz et al., 1998) and the life course perspective (Moen, 1996; Szinovacz & Davey, 2005). These perspectives provide a set of lens to aid in the understanding of involuntary retirement.

The profile of Canadians with disabilities who had retired from the labour force is very heterogeneous across socio-demographic, geographic and socio-economic characteristics. The data show that during the period 2001 to 2006, 39% of people with a disability retired involuntarily from the labour force. Results reported elsewhere indicate that some groups of people with a disability, however, were clearly at higher risk of involuntary retirement than others. For example, those who have lower levels of education, and those who were classified as having economic family or unattached individual household incomes below the low income cut off point after taxes had significantly higher rates of involuntary retirement (See

Denton et al., 2010). We did not find significant associations with the retirement decision and the following characteristics gender, marital status, employment status prior to retirement, and type of employment compensation.

Table 1 shows persons with disabilities aged 54 and under were much more likely than their older counterparts to experience involuntary retirement. The results also point to the importance of considering age of onset as a precursor to involuntary retirement. Employed Canadians who were born with or acquired a disability before the age of 35 were least likely to report involuntary retirement, whereas those most likely to report involuntary retirement were age 35-44. Poor health at the time of retirement, and severe or very severe disabilities, increase the likelihood of involuntary retirement. Those who retired due to their condition, either completely or partially, were much more likely to report involuntary retirement.

Researchers suggest that there may be socio-demographic and productivity differences between disabled and non-disabled workers that may magnify the “health effects” on employment outcomes (Smith & Twomey, 2002; Baldwin & Johnson, 2001). They find that when these differences are controlled, about half of the differences in labour market outcomes are explained (Blackaby et al., 1999; Madden, 2001). Further, we speculate that age differences may be due to cohort differences in these socio-demographic and socio-economic characteristics. The tabular analysis does not allow

us to examine the relationship between the type of retirement and health while controlling for or taking into account differences in socio-demographic and socio-economic characteristics. Nor does it allow us to disentangle differences in retirement decisions that may be due to age cohort effects. Therefore, we conducted a multivariate logistic analyses to show the relationship of each of the possible determinants of involuntary retirements when other determinants are controlled or held constant.

Table 2 illustrates that age of onset mattered, even after controlling for socio-demographic, socio-economic and geographical determinants. People who acquired their disability after age 35 were much more likely to retire involuntarily. These results differed from the tabular analysis that showed persons with the age of onset of disability at 35-44 to have the highest proportion of involuntary retirement of any age group (Table 1). In the multivariate analysis, people who acquired their disability, between ages 55-64, were the most likely to experience involuntary retirement. This group was over 5 times more likely to experience involuntary retirement than those whose age of onset was 0-34 (Table 2). Acquiring a disability between the ages of 55-64 may be a key factor contributing to involuntary retirement for this age group (Table 2).

Persons with disabilities who had to permanently retire because of their condition were 7 times more likely to retire involuntarily than those who did not have to retire because of

their condition. Those who partially retired due to their condition were almost 3 times more likely to have faced involuntary retirement than those who were not made to do so (Table 2). Finally, age, health at retirement, and the degree of severity of the condition appear to not be significantly associated with involuntary retirement once other factors are controlled for in the model.

## **Discussion and Conclusion**

Twenty-seven percent of Canadians retire involuntarily (Schellenberg & Silver, 2004) and illness or disability is the number one reason for involuntary retirement in Canada (Statistics Canada, 1997). The analysis of the 2006 PALS has shown that persons with a disability have a much higher rate of involuntary retirement than the general population. Of those who retired during the period 2001 to 2006, 39% of persons with a disability retired involuntarily from the labour force. Their higher rate of involuntary retirement means that many persons with disabilities are excluded from the labour market.

This paper seeks to investigate whether age and age of onset are key factors that influence the retirement decisions of people with disabilities. We find differences by age in the decision to retire involuntarily. The likelihood of involuntary retirement decreases with increases in age. That is younger persons with disabilities are more likely to retire involuntarily from the labour force than their older counterparts. There are also other groups who are at risk of involuntary retirement and they

include immigrants and non-permanent residents, those with lower levels of education and those with low incomes.

As discussed in the literature review differences in socio-demographic characteristics (i.e., gender, age, marital status), human capital characteristics (i.e., education, work experience), economic incentives (i.e., wages), and regional effects may magnify the “health effects” on employment outcomes of the disabled. The multivariate analysis of the PALS data clearly revealed that the effects of disability on the decision to retire are very real. Involuntary retirement occurs when people with disabilities are no longer able to work as a result of their disability rather than due to differences in socio-economic and other characteristics.

These findings suggest that involuntary retirement is often due to a “health shock” - the sudden onset of a disability or a dramatic change in a disabling condition that prevents people from continuing in the workforce. It is important to distinguish the age of onset when investigating the labour market outcomes of the persons with disabilities because those who are disabled during childhood and those who are disabled later in life (after entering work) have different labour market experiences (Baldwin & Johnson, 2001). This study contributes to the literature in the consideration of the age of onset as a determinant of the retirement decision. The onset of disability in mid life is a trigger to an involuntary retirement. Employed persons born with a disability or who acquire it early in life are more likely to have a long career and

retire voluntarily from the labour force. This may be because they have been more likely to have benefited from workplace accommodations and the use of technology.

### **Implications**

Policy analysts are concerned that with the retiring of the baby boom generation and the tendency for early retirement, there will be labour shortages in the very near future (Scherer, 2002; Statistics Canada, 2003; Human Resources and Social Development Canada, 2005). A recent analysis of the 2006 PALS has shown that the labour force participation rates are much lower for the disabled population (56%) as compared to those for all Canadians aged 15 to 64 (80%) (Statistics Canada, 2008) The analysis of the PALS data presented here show that three-quarters of persons with disabilities who retired from the labour force between 2001 and 2006 did so before the age of 65. In particular, persons who acquire a disability between the ages of 55 to 64 had the highest risk of involuntary retirement. Given that the gap between their expected retirement date and the onset of their disability is shorter than that for younger age groups, the onset of a disability may be the trigger that forces earlier than expected retirement. Some employers may be less willing to provide incentives or accommodation to their continued employment or the workers themselves may be less willing to continue working with a disability. Future research could focus more specifically on the retirement decision when the onset of disability occurs after the age of 55.

Studies have shown that about half of all Canadian retirees

would prefer to work full- or part-time jobs if they were available (Morissette et al., 2004). Given the interest of some older Canadians to continue to participate in the labour force and the benefit of their continued employment to the economy, future research could address issues that would remove impediments and provide incentives for persons with disabilities to extend their working lives including: the use of technology; the acceptance by employers and unions of greater flexibility of work days, work weeks and work years; changes in attitudes towards disabled people and their productive capabilities; and the need to provide work-place accommodation to persons with disabilities. Burkhauser, Butler, & Kim (1995) found that in the U.S. the receipt of accommodations could prolong employment. Most recently, Campolieti (2009) uses the 2001 PALS to consider labour market variations in accommodations provided and desired (such as modified duties, modified hours, human support, technical aids, specialized computer, communication aids and other accommodations). Desires for accommodations were much higher for persons who had to change jobs or leave the workforce than those who did not have to change jobs, suggesting that accommodation to the workplace would decrease the likelihood of involuntary retirement. Further, women had a greater desire for accommodations that involve reduced hours than men. There is a need for research on strategies for improving the ability of persons with disabilities to remain in the workforce or to return to the

workforce through workplace accommodation.

**Table 1. Voluntary and Involuntary Retirement by Age and Disability Characteristics of Persons with Disabilities, Age 15-74.**

	<b>Voluntary Retirement (%)</b>	<b>Involuntary Retirement (%)</b>	<b>F-Statistic</b>
<b>Total</b>	60.6	39.4	
<b>Age*</b>			
15-44	31.1	68.9	F(2.55, 2548.44)=10.00, p=0.00
45-54	38.9	61.1	
55-64	63.9	36.1	
65-74	75.5	24.5	
<b>Condition Onset (Age of Onset)</b>			
0-34	71.0	29.0	F(2.98, 2973.21)=2.51, p=0.057
35-44	46.6	53.4	
45-54	60.9	39.1	
55-64	60.5	39.5	
<b>Health at Retirement*</b>			
Excellent/Very Good	74.0	26.0	F(2.95, 2950.40)=10.34, p=0.00
Good	72.8	27.2	
Fair	71.2	28.8	
Poor	39.2	60.8	
<b>Degree of Severity*</b>			
Mild	82.8	17.2	F(2.91, 2904.88)=19.18, p=0.00
Moderate	64.8	35.2	
Severe	47.5	52.5	
Very Severe	25.8	74.2	
<b>Does condition prevent you from working*</b>			
Yes	43.7	56.3	F(1, 999)=55.95, p=0.00
No	85.6	14.4	
<b>Permanently retired due to condition*</b>			
No	87.1	12.9	F(1.99, 1990.61)=37.76, p=0.00
Yes, partially	71.7	28.3	
Yes, completely	34.1	65.9	

**Note:** Due to missing data some cells do not add up to the total sample size listed.

\* Significant difference found between voluntary and involuntary groups.



**Table 2. Multivariate Logistic Regression and Involuntary Retirement by Age and Disability Characteristics of Persons with Disabilities, Age 15-74<sup>i</sup>.**

Variables	Odds Ratio	BRR Std. Err.	t	P> t
<b>Age</b>				
15-44 (ref.)				
45-54	1.08	0.85	0.10	0.92
55-64	0.54	0.38	-0.87	0.39
65-74	0.43	0.35	-1.03	0.31
<b>Age of Onset</b>				
0-34 (ref.)				
35-44	4.16	2.72	2.18	0.03
45-54	3.78	2.13	2.36	0.02
55-64	5.36	3.24	2.78	0.01
<b>Health at Retirement</b>				
Excellent/Very Good (ref.)				
Good	0.89	0.58	-0.17	0.86
Fair	0.80	0.49	-0.37	0.71
Poor	1.39	0.80	0.58	0.56
<b>Degree of Severity</b>				
Mild (ref.)				
Moderate	1.40	0.75	0.62	0.53
Severe	1.30	0.82	0.42	0.67
Very Severe	2.55	2.28	1.05	0.29
<b>Permanently Retired Due to Condition</b>				
No (ref.)				
Yes, Partially	3.14	1.77	2.03	0.04
Yes, Completely	7.50	4.56	3.31	0.00

<sup>i</sup> Other characteristics that were controlled include: gender, marital status, education, immigration, region, size of urban residence, home ownership, employment status prior to retirement, employment compensation, low income status, does the condition prevent you from working, and various types of limitations.

## References

- Baldwin M., & Johnson W. G. (2001). Dispelling the myths about work disability, Paper prepared for the 1998 IRRA Research Volume, New Approaches to Disability in the Workplace.
- Blackaby D., Clark K., Drinkwater S., Leslie D., Murphy P., & O'Leary N. (1999). Earnings and Employment Opportunities of Disabled People, Department for Education and Employment, Research Report No.133, Nottingham.
- Bound, J., Schoenbaum, M., Stinebrickner, T. R., & Waidmann, T. (1999). The dynamic effects of health on the labour force transitions of the older worker. *Labour Economics*, 6, 179-202.
- Burkhauser, R., Butler, J. & Kim, Y. (1995). The importance of job accommodation on the job duration of workers with disabilities: A hazard model approach. *Labour Economics*, 2, 109-130.
- Campolieti, M. (2009). Worker adaptation and the desire for accommodations after the onset of a disability. *Industrial Relations*, 48(2), 329-349.
- Denton, M., Plenderleith, J., & Chowhan, J. (2010). Retirement Decisions of People with Disabilities: Voluntary or Involuntary. SEDAP Research Paper No. 271.
- Disney, R., Emmerson, C. & Wakefield, M. (2004). Ill health and retirement in Britain: A panel data based analysis. IFS Working Paper No 03/02.
- Frenken, H. (1991). The Pension Carrot: Incentives to Early Retirement. *Perspectives*. (Autumn): p. 19-27.
- Galarneau, D., & Radulescu, R. (2009). Employment among the disabled. *Perspectives on Labour and Income Dynamics* (Statistics Canada, catalogue no 75-001-X) May:5-15.
- Human Resources and Social Development Canada. (2005). The future needs of the Canadian Labour market: 10 things you might not know but should: HRSDC presentation made at the December 2004 PRI Conference on new approaches to social policy, as quoted by Canada, Policy Research Initiative, in PRI Conference on new approaches to social policy. Encouraging choice in work and retirement project report.
- Jenkins, S., & Rigg, J. (2003) Disability and disadvantage: selection, onset and duration effects, ISER Working Paper No 2003-18.
- Jones, M. K. (2008). Disability and the labour market: A review of the empirical evidence. *Journal of Economic Studies*, 35(5), 405-424.
- McDonald, L. & Donahue, P. (2000a). Poor Health and Retirement Income: The Canadian Case. *Ageing and Society*. 20(5): p. 493-522.
- McDonald, L., Donahue, P., & Marshall, V.W. (2000b). The Economic Consequences of Unexpected Early Retirement, in *Independence and Economic Security in Old Age*, B. Spencer and F. Denton, Editors, UBC Press. p. 267-292.
- Mein, G., Martikainen, P. A., Stansfeld, S. A., Brunner, E. J., Fuhrer, R. & Marmot, M. G. (2000). Predictors of early retirement in British civil servants. *Age and Ageing*, 29(6), 529.
- Moen, P. (1996). A life course perspective on retirement, gender, and well-being. *Journal of Occupational Health Psychology*, 1(2), 131.
- Morissette, R., Schellenberg, G., & Silver, C. (2004). Retaining Older Workers. *Perspectives*. Winter: p. 33-39.
- Myles, J. (2002). Editorial: Back to Bismarck? The Public Policy Implications of Living Longer. *Canadian Journal on Aging*. 21(3): p. 325-329.
- Osberg, L. (1988). Is It Retirement or Unemployment? The Constrained Labour Supply of Older Canadians. Health and Welfare Canada: Ottawa, ON.
- Pyper, W. (2006). Aging, health and work. *Perspectives on Labour and Income* (Statistics Canada, catalogue no 75-001-XIE) February: 5-15.
- Schellenberg, G. (1994). The Road to Retirement: Demographic and Economic Changes in the 90s. Canadian Council on Social Development: Ottawa, ON.
- Schellenberg, G. & Silver, S. (2004). You Can't Always Get What You Want: Retirement Preferences and Experiences. *Canadian Social Trends*. Winter: p. 2-7.

- Scherer, P. (2002). Age of Withdrawal from the Labour Force in Oecd Countries. Organizations for Economic Cooperation and Development, Paris: www.oecd.org. November 5.
- Schuring, M., Burdorf, L., Kunst, A., & Mackenbach, J. (2009). The effects of ill health on entering and maintaining paid employment; evidence in European countries, *Journal of Epidemiology Community Health*: 61:597-604.
- Shultz, K. S., Morton, K. R., & Weckerle, J. B. (1998). The influence of push and pull factors on voluntary and involuntary early retirees' retirement decision and adjustment. Orlando, Fla.: Academic Press.
- Smith, A., & Twomey, B. (2002). Labour Market Experience of People with Disabilities, *Labour Market Trends*, August, 415-27.
- Statistics Canada. (1997). A Portrait of Seniors in Canada (2nd Edition). Ministry of Industry: Ottawa.
- Statistics Canada. (2003). Perspectives on Labour and Income. 4, 9, 1-6. Statistics Canada: Ottawa
- Statistics Canada. (2008). Participation and Activity Limitation Survey 2006: Tables (Part III). Social and Aboriginal Statistics Division (Statistics Canada-Catalogue No. 89-628-X—No 008).
- Szinovacz, M. E., & Davey, A. (2005). Predictors of perceptions of involuntary retirement. *The Gerontologist*, 45(1), 36-47.
- Trucotte, M. & Schellenberg, G. (2005). Job Strain and Retirement. *Perspectives*. July: p. 13-17.
- Zwerling, C., Whitten, P. S., Sprince, N. L., Davis, C. S., Wallace, R. B., Blanck, P. D. & Heeringa, S.G. (2002). Workforce participation by persons with disabilities: The national health interview survey disability supplement, 1994 to 1995. *Journal of Occupational and Environmental Medicine*, 44(4), 358.

# Access to Assistance and Services for Disabled People in Developing Countries

Bhekile Jele, Secretariat of the African Decade of Persons with Disability, [bheki@africandecade.co.za](mailto:bheki@africandecade.co.za)

## WHY ACCESS?

Improving access to the physical environment results in greater social equity: it enables disabled people to participate in social, economic and religious activities on the same level as non-disabled people, resulting in a more inclusive society. Dismantling barriers reduces disabled people's vulnerability and dependence on others.

On the other hand, older persons, particularly those suffering from physical or mental impairments in Africa, are most at risk and exposed to current infections, confusional states and imposed dependency. Such impairments are generally considered as age-related limitations, but most development and relief agencies do not recognize these groups of people in their agenda. Good sense dictates that old age is a stage of human life which demands not only accompanying basic material provisions, but also abundance of care. There has been a growing realization that society frequently falls foul of meeting the required expectations of older persons and even violates their basic rights at times, perhaps unknowingly. For this reason national and international institutions, including the Focal Point on the

Rights of Older Persons in Africa of the African Charter on Human and Peoples' Rights (ACHPR) have been established to set up the standards and to address the problem of older persons.

It is of no argument that the two groups have similar challenges at a particular time. The older one gets, he / she is bound to face the challenges also faced by people with disabilities in society due to the societal environment.

## ACCESS FOR ALL

A common misconception is that adapting or building accessible environments is a costly exercise. Conventional design is aimed at non-disabled people and accordingly fails to provide for many potential users' needs. Universal design principles, by contrast, aim to accommodate as wide a range of potential users as possible, including, but not exclusively, people with disabilities. North Carolina State University in the USA defines universal design as the design of products, communications and environments which can be used by everyone, to the greatest extent possible, without the need for adaptation or specialized design<sup>1</sup>. Dave Maunder and Jo Sentinella highlight results from their

research on disabled access to transportation services, in which they found this principle to be an essential aspect of successful projects<sup>2</sup>.

Similarly, research in Uganda by the Water, Engineering and Development Centre and in Sri Lanka by the Intermediate Technology Development Group (ITDG), on building accessible toilets demonstrates that designs based on universal principles need not be costly and can be adopted and constructed by local communities, with little or no outside assistance. Hazel Jones and Bob Reed<sup>3</sup>, looking at water and sanitation infrastructure for poor people in Cambodia, Uganda and Bangladesh, point out that services designed for disabled users are beneficial for other members of society, including elderly and sick people, and mothers with young children.

## ENSURING ACCESS

It is important to note, however, that solutions are about more than just design and building codes. First and foremost, approaches should be centered on what disabled people themselves say they need and how best to achieve it. Enabling environments that encourage the involvement of users and

<sup>1</sup> Centre for Universal Design (1997). The Principles of Universal Design, Version 2.0, Raleigh, NC: North Carolina State University." by Bettye Rose Connell, Mike Jones, Ron Mace, Jim Mueller, Abir Mullick, Elaine Ostroff, Jon Sanford, Ed Steinfeld, Molly Story, and Gregg Vanderheiden.

<sup>2</sup> Breaking barriers: building access for disabled people – Dave Maunder and Jo Sentinella.

<sup>3</sup> Water and sanitation for disabled people and other vulnerable groups 2006 – Hazel Jones & Bob Reed, Water, Engineering and Development Centre Loughborough University Leicestershire.

ensure their views are heard are therefore a primary consideration.

Disability is becoming recognised as a development area requiring inclusive strategies or remedies. Numerous disability-focused movements are gaining visibility. However, the way forward needs to be carefully thought out. Considering that most disabled people in developing countries are the very poorest, planners must also ask: access to what and for whom? Rebecca Yeo provides a cautionary tale from post-Tsunami Sri Lanka, where, despite the rhetoric of disabled access, the reality might mean that not only disabled people but other poor people as well, may be cut off from their former livelihoods as reconstruction favours business interests<sup>4</sup>.

The term 'disability' masks a wide range of types and experiences: disabled children, women and the elderly are doubly or even triply disadvantaged. The case study on disabled women's experiences based on research by Hazel Jones and Bob Reed emphasises that any consideration of disabled access must examine the particular needs of different groups.

## **BUILDING ACCESSIBLE ENVIRONMENTS**

The opportunities for and constraints to improving access to both new and existing infrastructure will depend on the context in which improvements are undertaken, including availability of resources

(human, physical, financial), culture, attitudes and laws regarding disabled people's rights. There are likely to be significant differences in needs and therefore approaches among and within countries, between rural and urban areas, and between formal and informal developments. Anybody working with disabled people to achieve barrier-free environments should also remember that:

- ✓ Professionals should be ready to involve disabled people, who are in the best position to identify their own needs and concerns, in decision making.
- ✓ Physical and technical interventions are only one part of a bigger picture that also requires paying attention to human rights and equal opportunities.
- ✓ Systematic reviews of the performance of projects, programmes and policies are necessary to ensure that good and bad practices are identified. It is as important to learn from mistakes as from successes and to share learning.
- ✓ International frameworks such as ICF and universal standards can be useful tools for implementation and research.

## **AVAILABLE POLICIES AND STRATEGIES**

The principle of non-discrimination and equality before the law was never meant to be

interpreted so as to render more difficult the life of older persons, or persons with physical disabilities. Rather, it requires that States adopt special measures to protect the disadvantaged and vulnerable groups of their societies. In this regard, every individual has a role to play in protecting the rights of these groups of people. This protection should not only be narrowed to the basic rights of older persons with age-related limitations, but also to older persons with physical disabilities who are also often the object of discrimination and maltreatment.

### **a) The African Charter on Human and Peoples' Rights (the African Charter)**

- ✓ Article 18(4) of "the African Charter" provides that the aged and the disabled shall, "...have the right to special measures of protection in keeping with their physical and moral needs."

### **b) Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa**

- ✓ The protocol is a result of Article 66 of the African Charter on Human and Peoples' Rights which provides for special protocols or agreements, if necessary, to supplement the provisions of the African Charter. The following article provides for the rights of people with

<sup>4</sup> Disability in Conflict and Emergency Situations: Focus on Tsunami-affected Areas Maria Kett, Sue Stubbs and Rebecca Yeo - Disability Knowledge and Research

disabilities and old aged people;

- ✓ Article 23 - Special Protection of Women with Disabilities states that States Parties undertake to ensure the protection of women with disabilities and take specific measures commensurate with their physical, economic and social needs to facilitate their access to employment, professional and vocational training as well as their participation in decision-making and further to ensure their right to freedom from violence, including sexual abuse, discrimination based on disability and the right to be treated with dignity.

c) **UN Principles of Older Persons**

- ✓ The UN Principles for Older Persons identified five key elements which are needed to create a just society for older persons. These are: independence, participation, care, self-fulfillment and dignity.

d) **UN Convention on the Rights of Persons with Disability (CRPD)**

- ✓ Internationally, the Convention on the Rights of Persons with Disabilities (CRPD) has established that the rights of persons with disabilities are inalienable, interdependent and indivisible. The most progressive current international norms, best practices and standards have been set by this human rights instrument. As of October 2010, 26<sup>5</sup> African Union Member States that have ratified CRPD and 12 AU Member States have ratified the Optional Protocol<sup>6</sup>. This reflects that 50% of all African Member States have signed the Convention while 20% have ratified the Optional Protocol. 13 other African countries have signed but not ratified the CRPD or Optional Protocol. Thus 39<sup>7</sup> African countries show commitment to and

cognizance of disability rights within this international framework.

**Conclusion:**

There is nowhere in Africa where people with disabilities are fighting for special privileges. All people with disabilities on the continent are fighting for basic human rights and necessities which include but are not limited to access to water, sanitation, housing, food and clothing. There is therefore a need to ensure that government in Africa put available policies into action by ensuring access to the above basic needs by people with disabilities. Development partners (funding agencies) should also play a part in providing access to financial support to non-governmental organizations and development project organizations to lobby governments for implementation of international treaties, policies and legislations applicable to the needs of disabled elderly.

<sup>5</sup> Algeria, Burkina Faso, Egypt, Ethiopia, Gabon, Guinea, Kenya, Laos, Lesotho, Malawi, Maldives, Mali, Mauritius, Namibia, Niger, Nigeria, Rwanda, Tunisia, Senegal, Seychelles, Sierra Leone, South Africa, Sudan, Zambia, Uganda, Tanzania and Morocco.

<sup>6</sup> Burkina Faso, Guinea, Mali, Namibia, Niger, Nigeria, Rwanda, Uganda, South Africa, Sudan, Tanzania and Tunisia

<sup>7</sup> Angola, Botswana, Djibouti, Eritrea, Gambia, Guinea Bissau, Mauritania, Republic Saharawi, Sa Tome and Principe, Somalia, Chad, Zimbabwe, Equatorial Guinea and DRC have as of yet not signed.

**References:**

‘Breaking barriers: building access for disabled people’, May 2005, id21 insights #55

Activity Report of Commissioner Yeung Kam John Yeung Sik Yuen Inter-Session period, May 2008-November 2008.

UN Convention on the Rights for People with Disabilities

African Charter on Human and Peoples’ Rights.

Protocol and African Charter on Human and Peoples’ Rights.

# Implications of Visual Impairment for Functioning and Mobility of Older Persons: A Global Health Perspective

Moon Choi, PhD and Briana Mezuk, PhD Department of Epidemiology and Community Health Virginia Commonwealth University School of Medicine, Richmond, Virginia

Corresponding Author:

Moon Choi, PhD Postdoctoral Fellow Virginia Commonwealth University School of Medicine Department of Epidemiology and Community Health 830 E. Main Street, Suite 5053 PO Box 980212 Richmond, VA 23298 Phone: (216) 536-2126 Fax: (804) 828-9773 Email: moonchoi365@gmail.com

## Population Ageing and ‘Healthy’ Life Expectancy

Over the past 50 years, increasing life expectancy has changed our conceptualizations of the developmental life course. At the global level, average life expectancy rose from 47 years in 1950 – 1955 to 65 years in 2000 – 2005 and is expected to reach 75 years by 2050 (United Nations, 2007). This dramatic shift has required gerontologists to coin and apply new terminology to understand and explain developmental stages in old age. For example, “the Third Age” refers to the developmental period in which people, who are healthy and free from the responsibilities of work and childcare, can begin to realize a greater degree of self-fulfillment (Laslett, 1991). Thus, age at retirement is very critical for the length of the Third Age (Laslett, 1991). On the other hand, “the Fourth Age” refers to the period of final dependence, dysfunction, and resulting death (Smith, 2001). Many developed countries have identified the political, societal, and economic benefit of not just increasing life expectancy overall, but rather on promoting health across the life span by increasing the longevity of the Third Age while simultaneously decreasing years spent in the

Fourth Age. However, this concept of the Third Age is not applicable to many developing countries, wherein citizens do not have socially titled retirement due to lack of adequate pension.

The World Health Organization (WHO) defines “healthy life expectancy” as the average number of years that a person can expect to live in “full health” (that is, total life expectancy minus years lived in less than full health due to disease and/or injury) (World Health Organization). Increased life expectancy is generally considered to be a favorable outcome of social and economic development, but the important issue related to this increased life expectancy is how healthy people will live for the added years of life (United Nations, 2007). In this regard, the index of healthy life expectancy is a useful tool for both public health practitioners and policy makers because it incorporates concepts of functioning and quality of life. It also explicitly acknowledges that longevity, per say, is not the goal of public health; rather, that nations should develop and implement programs that promote well-being in later life. Besides helping individual

nations understand their public health needs, this index can be applied to the global population as a means of understanding cross-national differences in wellbeing in later life. It also helps in identifying the programs and policies that promote healthy life expectancy in different settings around the world.

Ageing is often associated with the acquisition of impairments in vision, functioning, and cognition, which can result in either chronic or acute disability in later life. For example, in the United States 38% of adults aged 65 and older have disabilities as compared to 5% of children ages 5 to 17 have (U.S. Census Bureau, 2010). These acquired disabilities in later years challenge older persons’ everyday life and are associated with negative consequences regarding mobility, access to food and health care, finance, social networks and so on (Albert & Freedman, 2010). Women, minorities, and persons of low socioeconomic status are especially vulnerable to acquire age-related disabilities and disproportionately experience negative consequences of these impairments (Ostchega, Harris, Hirsch, Parsons, &

Kington, 2000). The trends in global ageing are projected to continue for several decades, and thus it is critical that nations proactively address issues regarding acquired disability in old age. In this article we focus on one of the most common acquired disabilities in later life – visual impairment.

### **Significance of Visual Impairment for Global Healthy Ageing**

Worldwide, approximately 314 million people have some sort of visual impairment, including 45 million persons with vision loss (World Health Organization, 2009b). Age-related cataracts are the leading cause of blindness, accounting for nearly 40% of all cases worldwide (World Health Organization, 2009a). Data based on the 2002 world population reported a reduction in the incidence of visual impairment due to infectious disease (World Health Organization). However, the number of people with visual impairment mainly due to noncommunicable chronic diseases and longevity has increased (World Health Organization). Over 85% of visually impaired people live in low- and middle-income countries, and up to 80% of all blindness in adults is preventable or treatable (World Health Organization, 2009a). In the sections below we review the epidemiology and etiology of visual impairment in later life and provide recommendations for promoting global vision health.

### **Definition of Visual Impairment**

Visual impairment refers to eyesight that cannot be

corrected to a normal level using glasses or contact lenses (Centers for Disease Control and Prevention, 2004) and includes both blindness and low vision (World Health Organization, 2005). Visual impairment may be caused by a *loss of visual acuity*, in which the eye does not see objects as clearly as usual (i.e., blurriness), or by a *loss of visual field*, in which the eye cannot see as wide an area as usual without moving the eyes or turning the head (Centers for Disease Control and Prevention, 2004). For example, 20/20 vision is considered normal in the U.S. and indicates that a person can see clearly as 20 feet (American Optometric Association). 20/100 vision indicates that a person must be as close as 20 feet to see what a person with normal vision can see at 100 feet (American Optometric Association). The WHO defines low vision as visual acuity less than 6/18 (20/60) but equal to or better than 3/60 (20/400), with best possible correction in the better eye, which is equivalent to visual impairment categories 1 and 2 in the International Statistical Classification of Diseases (ICD-10) (World Health Organization, 2005). Blindness is defined as a visual acuity of less than 3/60 (20/400) with best possible correction, or a visual field no greater than 10° around central fixation (World Health Organization, 2005). The definition of low vision or blindness varies from nation to nation, and this variability has pragmatic implications for eligibility of social services and government assistance. For example, in Australia, visual blindness was defined as a visual acuity of

less than 6/60 (20/200) in the better eye (Landers, Henderson, & Craig, 2010), which is higher than the standard of WHO. The U.S. also has the same definition of legal blindness with Australia – those with a visual acuity of less than 20/200 in terms of social security title (U.S. Social Security Administration, 2010).

### **Epidemiology of Visual Impairment**

A majority of persons (approximately 82%) with visual impairment are age 50 and older, and females are more likely to have visual impairment than their counterparts regardless of age and region (World Health Organization, 2009b). Globally, the four major eye conditions account for blindness, in order of frequency – cataracts, uncorrected refractive errors, glaucoma, and age-related macular degeneration (World Health Organization, 2009b). Conspicuously, cataracts accounts for 48% of cases of blindness worldwide (World Health Organization, 2005) and is the fourth leading cause of blindness in the United States (Hooyman & Kiyak, 2005). With normal ageing, the lens becomes more opaque, and less light passes through (especially shorter wave lengths of light); however, some older persons experience a more severe opacification (clouding of the lens) to the point that the lens prevents light from entering, which is called a cataract (Hooyman & Kiyak, 2005). Refractive error refers to an optical defect of the eye which prevents effective focus of images (World Health Organization, 2005). People with Refractive error have near-sightedness or far-sightedness.



Glaucoma refers to a group of conditions characterized by an optic neuropathy (nerve damage) due to structural abnormalities and functional deficit (World Health Organization, 2005). Late-stage glaucoma may result in tunnel vision, a gradual narrowing of an individual's field of vision in which the individual can focus only on the center of their visual field (Hooyman & Kiyak, 2005). Macular degeneration, which generally onsets after age 60, is a progressive condition in which the central part of the retina is damaged, blurring the center of the field of vision and making it hard to read or recognize faces (The American Foundation for the Blind, 2010).

### **Implications of Visual Impairment on Functioning of Older Persons**

Visual impairment is a significant predictor of functional limitations in performing everyday tasks. Older persons with visual impairment are more likely to have difficulty with daily activities such as going to the grocery store, accessing health care, and visiting friends. Previous studies have reported that visual impairment is strongly associated with functional dependence among older persons (Rubin, Roche, Prasada-Rao, & Fried, 1994). Turano and colleagues reported that walking speed decreased, and the number of bumps into obstacles increased, with decreases in the visual field among older persons. Interestingly, Vu and colleagues (2005) investigated whether unilateral vision loss reduced any aspects of quality of life in comparison with normal vision and to compare its impact with that of bilateral vision loss. They

found that non-correctable unilateral vision loss was associated with issues of safety and independent living while non-correctable bilateral vision loss was associated with nursing home placement, emotional wellbeing, use of community services, and activities of daily living in Australian older persons (Vu, Keeffe, McCarty, & Taylor, 2005).

Older persons with visual impairment are more likely to experience restricted mobility. Rubin and colleagues reported that reduced acuity and contrast sensitivity were significant risk factors for self-reported disability. Specifically, acuity was associated with difficulty in tasks requiring good resolution and adaption to changing light conditions, whereas contrast sensitivity was associated with difficulty in tasks requiring distance judgments, night driving, and mobility. The loss in visual field which occurs with ageing has been reported to be associated with a decline in mobility performance (Turano et al., 2004). In addition, visual impairment has been reported as a major risk factor for driving cessation in the U.S. (Campbell, Bush, & Hale, 1993; Forrest, Bunker, Songer, Cohen, & Cauley, 1997; R. Marottoli et al., 1993). Driving is necessary for mobility in the U.S. with the exception of a handful of metropolitan areas (Dickerson et al., 2007). In this context, driving ability can be comparable to the ability to use public transportation in many other countries. Previous studies have reported that driving cessation is associated with decreased out-of-home activity levels (R. A. Marottoli et al., 2000), a smaller network of

friends (Mezuk & Rebok, 2008), accelerated decline in general health (Edwards, Lunsman, Perkins, Rebok, & Roth, 2009), and increases in depressive symptoms (Fonda et al., 2001; Fonda, Wallace, & Herzog, 2001; R. A. Marottoli, Mendes, Glass, & Williams, 1997). These findings provide the impact implications of restricted mobility, a consequence of visual impairment, on the quality of life among older persons around the world.

Supporting this, previous studies have reported negative health outcomes resulting from visual impairment. Depressive symptoms have been reported to be both prevalent and persistent among older persons with visual impairment (Brody et al., 2001; Rovner, Zisselman, & Shmueli-Dulitzki, 1996). Furthermore, visual impairment is strongly associated with risk of falls and hip fracture (Ivers, Cumming, Mitchell, Simpson, & Peduto, 2003) and increased mortality (McCarty, Nanjan, & Taylor, 2001).

The associations between vision, functioning, and health extend beyond the burden to the individual, and are associated with substantial financial costs to society, both directly in terms of healthcare and social services utilization, and indirectly in terms of lost productivity of both the individual and their caregiver (Roberts et al., 2010). For examples, visual impairment affected more than 1.64 million people in Japan and cost their economy nearly ¥8785.4 billion (US \$72.8 billion), equivalent to 1.7% of Japan's gross domestic product in 2007 (Roberts et al., 2010). In addition, older persons with visual impairment

are more likely to use healthcare services (Chiang, Javitt, & Metrick, 1994; Orr, Barron, Schein, Rubin, & West, 1999) and regular social support services provided by the municipality (Wang, Mitchell, Smith, Cumming, & Attebo, 1999).

### **Recommendations to Promote the Wellbeing of Older Persons with Visual Impairment**

Despite the demonstrated relationship between visual impairment and declines in function and health, there are several cost-effective and readily available programs and policies that communities can adopt to promote the wellbeing of older persons with visual impairment.

#### ***Aids and adaptations in the home environment***

A disabled older person's ability to carry out everyday activities can often be improved with appropriate aids, equipment and adaptations (HelpAge International, 2004). Family and friends can help older persons with visual impairment at minimal cost, by moving low tables and footstools outside the traffic flow or putting large-print labels on prescription bottles and cooking supplies (Hooyman & Kiyak, 2005). Increasing the number of light sources or placing contrasting color strips on stairs can be helpful to prevent falls of older persons with low vision (Hooyman & Kiyak, 2005). Older persons with low vision also benefit from and the use of aids such as magnifiers, telescopes, glare control devices, bold line pens and paper, writing guides, magnifying mirrors, and needle-threaders (World Health

Organization, 2005). Recently, electronic devices (e.g., Quicklook, a light weight video magnifier); however these devices are not yet widely available in all settings because of costs.

#### ***Multifaceted vision care***

Older persons with visual impairment could benefit from multifaceted vision care in the form of visual stimulation and training, mobility instruction, and education. Older persons with vision loss also benefit from psychological counseling, which can help them cope with their condition and learn how to plan and effectively adjust (HelpAge International, 2004). Monitoring of vision via regular clinic visits can reduce the risk of advanced disease by providing clinicians a more complete picture of disease progression so they can be proactive about treatment decisions.

#### ***Social Inclusion***

Older persons with visual impairment are often marginalized by society, especially in terms of employment and social engagement. The concept of disability is composed of the interaction between physical abilities and social systems; this suggests that many conditions are only disabling (or are particularly disabling) insofar as social and political barriers exist. Alternate approaches to integrating persons with disabilities into society exist. The Haitian Society for the Blind (SHAA), for example, runs a "Credit Scheme" to help blind people set up their own business such as home-based trading or farming activities (HelpAge International, 2004). This Credit Scheme includes

training in business management and personal development, to build up blind older people's self-confidence and equip them for working in a difficult business environment (HelpAge International, 2004). This program is a good example of providing opportunities to older persons with visual impairment, who can be easily socially excluded. Older persons with visual impairment should be able to access social resources and have opportunities to engage in their communities. To maintain person-environment congruence and psychological well-being, an ageing person with visual impairment should be encouraged to maintain social contacts, even if new activities must be substituted for old (Hooyman & Kiyak, 2005).

### **Prevent Visual Impairment in Later Life**

#### ***Preventive Eye Care***

A majority (about 87%) of persons with visual impairment live in developing countries (World Health Organization, 2009b). Nonetheless, available health care resources for older persons are limited in developing regions as compared to the developed world (United Nations, 2007). For example, only 0.1 physicians were available per 1,000 residents in African countries, compared with 2.7 in developed countries, based on the data for the most recent available year in the period 1997-2004 (United Nations, 2007).

Prevalence of disability is influenced by both environment and personal factors (Albert & Freedman, 2010; World Health Organization, 2001). The lack of

preventive eye care may account for prevalence of visual impairment caused by age-related chronic illnesses in older persons living in developing regions. Particularly in low-income countries, the priority of existing health systems is to provide care for acute episodic conditions rather than for chronic illnesses, which many older persons suffer from (United Nations, 2007).

Building health care systems providing preventive health care is critical to reduce the prevalence of visual impairment among older persons. Notably, many developing countries have a shortage of eye care personnel. Adequately trained human resources are a core requirement for the prevention, treatment, and rehabilitation of avoidable blindness (World Health Organization, 2005). Therefore, institutional capacity needs to be built for enhancing training of ophthalmologists, ophthalmic nurses, and allied health personnel for eye health.

### ***Raising awareness of prevention***

The main causes of blindness are cataract, glaucoma, trachoma, and injuries, combined with “lack of information about basic eye care” (HelpAge International, 2004). Policy makers and health professionals, particularly in public health, should acknowledge the impact of visual impairment on older persons at both the individual and societal levels and raise the public’s awareness of the preventability of age-related eye diseases.

### **Summary**

This paper discusses the implications of visual

impairment for functioning and mobility among older persons from the global perspective. Vision problems are one of the most commonly experienced challenges in later life. However, if detected early and regularly monitored, visual impairment can be delayed or prevented. Efforts to promote vision health are particularly difficult in developing regions due to a lack of availability of adequate eye care for older persons. As a result, many of these nations face a high prevalence of visual impairment in the older population.

Acquired visual impairment in later life profoundly affects older persons and their families. These persons often must cope with limitations in mobility and functioning, including social engagement, finding employment, and receiving regular healthcare. Disability in later life is a major determinant of falling into poverty, and as the first UN Millennium Development Goal (MDG) is to end poverty and hunger, this suggests that UN advocates and policymakers should incorporate efforts to promote visual health to achieve their overarching development goals. Understanding the implications of population ageing and other demographic transitions, which are embedded in the disablement process, will facilitate the achievement of the MDG. UN bodies work separately, but the populations which are at the greatest need of assistance often overlap across agencies (e.g., women, older persons, and the disabled). The WHO provides the concept of “healthy life expectancy,” a construct that speaks to common goals across the WHO and UN

Secretariat, and is useful for promoting inter-organization partnerships. Finally, December 3, 2010 is the International Day of Persons with Disabilities, and we hope that this paper will help UN policy makers, advocates, and health personnel understand global epidemiology of visual impairment, particularly among older persons in their areas.

## References

- Albert, S. M., & Freedman, V. A. (2010). *Public health and aging: Maximizing function and well-being* (2nd ed.). New York: Springer Publishing Company.
- American Optometric Association. *Visual acuity: What is 20/20 vision?* Retrieved 09/2010, 2010, from <http://www.aoa.org/x4695.xml>
- Brody, B. L., Gamst, A. C., Williams, R. A., Smith, A. R., Lau, P. W., Dolnak, D., Rapaport, M. H., Kaplan, R. M., & Brown, S. I. (2001). Depression, visual acuity, comorbidity, and disability associated with age-related macular degeneration. *Ophthalmology*, *108*(10), 1893- 900; discussion 1900-1.
- Campbell, M. K., Bush, T. L., & Hale, W. E. (1993). Medical conditions associated with driving cessation in community-dwelling, ambulatory elders. *Journal of Gerontology: Social Sciences*, *48*(4), S230-S234.
- Centers for Disease Control and Prevention. (2004). *Vision impairment*. Retrieved 09.2010, 2010, from <http://www.cdc.gov/ncbddd/dd/vision2.htm>
- Chiang, Y. P., Javitt, J., & Metrick, S. (1994). Health insurance coverage and medical care utilization among working-age Americans with visual impairment. *Ophthalmic Epidemiology*, *1*(1), 41-52.
- Dickerson, A. E., Molnar, L. J., Eby, D. W., Adler, G., Bedard, M., Berg-Weger, M., Classen, S., Foley, D., Horowitz, A., Kerschner, H., Page, O., Silverstein, N. M., Staplin, L., & Trujillo, L. (2007). Transportation and aging: A research agenda for advancing safe mobility. *The Gerontologist*, *47*(5), 578.
- Edwards, J. D., Lunsman, M., Perkins, M., Rebok, G. W., & Roth, D. L. (2009). Driving cessation and health trajectories in older adults. *Journal of Gerontology: Medical Sciences*, *64*(12), 1290-1295.
- Fonda, S. J., Wallace, R. B., & Herzog, A. R. (2001). Changes in driving patterns and worsening depressive symptoms among older adults. *Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, *56*(6), S343-S351.
- Forrest, K., Bunker, C., Songer, T., Cohen, J., & Cauley, J. A. (1997). Driving patterns and medical conditions in older women. *Journal of the American Geriatrics Society*, *45*(10), 1214-1218.
- HelpAge International. (2004). Ageing and disability. *AgeWays*, (64) Hooyman, N. R., & Kiyak, H. A. (2005). The social consequences of physical aging. In *Social gerontology: A multidisciplinary perspective* (7th ed., pp. 68-108). Boston: Pearson.
- Ivers, R. Q., Cumming, R. G., Mitchell, P., Simpson, J. M., & Peduto, A. J. (2003). Visual risk factors for hip fracture in older people. *Journal of the American Geriatrics Society*, *51*(3), 356-363.
- Landers, J., Henderson, T., & Craig, J. (2010). The prevalence and causes of visual impairment in indigenous Australians within central Australia: The central Australian ocular health study. *The British Journal of Ophthalmology*, *94*(9), 1140-1144.
- Laslett, P. (1991). *A fresh map of life : The emergence of the third age*. Cambridge, MA: Harvard University Press.
- Marottoli, R., Ostfeld, A., Merrill, S., Perlman, G., Foley, D., & Cooney, L. (1993). Driving cessation and changes in mileage driven among elderly individuals. *Journal of Gerontology: Social Sciences*, *48*(5), 255-260.
- Marottoli, R. A., Mendes, d. L., Glass, T. A., & Williams, C. S. (1997). Driving cessation and increased depressive symptoms: Prospective evidence from the new haven EPESE. *Journal of the American Geriatrics Society*, *45*(2), 202-206.
- Marottoli, R. A., Mendes, d. L., Glass, T. A., Williams, C. S., Cooney, L., & Berkman, L. F. (2000). Consequences of driving cessation: Decreased out-of-home activity levels. *Journal of Gerontology: Social Sciences*, *55B*(6), S334.
- McCarty, C. A., Nanjan, M. B., & Taylor, H. R. (2001). Vision impairment predicts 5 year mortality. *The British Journal of Ophthalmology*, *85*(3), 322-326.
- Mezuk, B., & Rebok, G. W. (2008). Social integration and social support among older adults following driving cessation. *Journal of Gerontology: Social Sciences*, *63B*(5), S298-S303.
- Orr, P., Barron, Y., Schein, O. D., Rubin, G. S., & West, S. K. (1999). Eye care utilization by older Americans: The SEE project. Salisbury eye evaluation. *Ophthalmology*, *106*(5), 904- 909.
- Ostchega, Y., Harris, T. B., Hirsch, R., Parsons, V. L., & Kington, R. (2000). The prevalence of functional limitations and disability in older persons in the US: Data from the national health and nutrition examination survey III. *Journal of the American Geriatrics Society*, *48*(9), 1132-1135.

- Roberts, C. B., Hiratsuka, Y., Yamada, M., Pezzullo, M. L., Yates, K., Takano, S., Miyake, K., & Taylor, H. R. (2010). Economic cost of visual impairment in Japan. *Archives of Ophthalmology*, 128(6), 766-771.
- Rovner, B. W., Zisselman, P. M., & Shmueli-Dulitzki, Y. (1996). Depression and disability in older people with impaired vision: A follow-up study. *Journal of the American Geriatrics Society*, 44(2), 181-184.
- Rubin, G. S., Roche, K. B., Prasada-Rao, P., & Fried, L. P. (1994). Visual impairment and disability in older adults. *Optometry and Vision Science: Official Publication of the American Academy of Optometry*, 71(12), 750-760.
- The American Foundation for the Blind. (2010). *Understanding vision loss*. Retrieved 09/2010, 2010, from <http://www.afb.org/seniorsite.asp?SectionID=63>
- Turano, K. A., Broman, A. T., Bandeen-Roche, K., Munoz, B., Rubin, G. S., West, S., & SEE Project Team. (2004). Association of visual field loss and mobility performance in older adults: Salisbury eye evaluation study. *Optometry and Vision Science: Official Publication of the American Academy of Optometry*, 81(5), 298-307.
- U.S. Census Bureau. (2010). Facts for features 20th anniversary of Americans with Disabilities Act: July 26 No. CB10-FF.13). Washington D.C.: U. S. Census Bureau.
- U.S. Social Security Administration. (2010). *Meaning of terms: Aged, blind, or disabled individual*. Retrieved 09/2010, 2010, from [http://www.ssa.gov/OP\\_Home/ssact/title16b/1614.htm](http://www.ssa.gov/OP_Home/ssact/title16b/1614.htm)
- United Nations. (2007). World economic and social survey 2007: Development in an ageing world - 60th anniversary edition, 1948-2007. New York: United Nations.
- Vu, H. T., Keefe, J. E., McCarty, C. A., & Taylor, H. R. (2005). Impact of unilateral and bilateral vision loss on quality of life. *The British Journal of Ophthalmology*, 89(3), 360-363.
- Wang, J. J., Mitchell, P., Smith, W., Cumming, R. G., & Attebo, K. (1999). Impact of visual impairment on use of community support services by elderly persons: The Blue Mountains eye study. *Investigative Ophthalmology & Visual Science*, 40(1), 12-19.
- World Health Organization. (a). *Healthy life expectancy (HALE) at birth (years)*. Retrieved 09/2010, 2010, from <http://www.who.int/whosis/indicators/2007HALE0/en/>
- World Health Organization. (b). *Prevention of blindness and visual impairment*. Retrieved 09/2010, 2010, from <http://www.who.int/blindness/en/>
- World Health Organization. (2001). International classification of functioning, disability and health No. A54/VR/9). Geneva, Switzerland: World Health Organization.
- World Health Organization. (2005). State of the world's sight, vision 2020: The right to sight, 1999-2005. Geneva, Switzerland: World Health Organization Press.
- World Health Organization. (2009a). *10 facts about blindness and visual impairment*. Retrieved 09/21/2010, 2010, from <http://www.who.int/features/factfiles/blindness/en/index.html>
- World Health Organization. (2009b). *Visual impairment and blindness*. Retrieved 09/2010, 2010, from <http://www.who.int/mediacentre/factsheets/fs282/en/>

# Older Persons and Hearing Disability

Ghassan Shahrour, MD, Otolaryngologist, Coordinator of Alyarmouk Society, Damascus Syria  
Ghassan.dr@gmail.com

## I- Introduction and Basic Facts:

The gradual loss of hearing is a part of the general aging process. However, the loss of hearing, and its associated difficulties in understanding speech, pose social, psychological and emotional problems for the older persons and for their families.

Unfortunately, as people age, people's hearing worsens. Age-related hearing loss, is one of the most common disabilities in the older people. This growing disability ranks third among chronic conditions affecting the elderly, only behind arthritis and hypertension. It is estimated that one in three adults over age 60 experiences some degree of hearing loss. The condition is less prevalent among women and results from a combination of both environmental and genetic factors. In some parts of the world, 60% of people over the age of 65 and up to 90% of people aged 80 and over have some degree of hearing disability.

It is well known that a healthy ear processes sound frequencies ranging from 20 Hz to 20,000 Hz. Sound frequencies between 500 and 4000 Hz include the frequencies most important for speech. An older person with hearing disability will have greater problems hearing sharp tone sounds (high frequency sound) than deep sounds (low frequency sound). He or she may hear the speech, but be unable to understand it well and this difficulty increases in a noisy

environment such as public streets and shopping centers.

Approximately, 8% of the population have a hearing loss; about 90% of them have Sensorineural hearing loss type. The rest have conductive hearing loss type, the second most common form of hearing loss, in which sound is not transmitted into the inner ear. An example of conductive hearing loss is plugging up of the ear by ear wax. Other things that cause conductive hearing losses are fluid in the middle ear, and disorders of the small bones (ossicles) in the middle ear. All forms of conductive hearing loss can be restored well.

In modern societies, older people with hearing disability face further problems as greater use is made of telephones for example, because the constant face to face communication where older persons can see expressions etc, is reduced.

## II- Causes and Factors:

No medicines can cure or prevent this sensorineural hearing loss from worsening. Some hearing loss is part of the normal ageing process, due to the changes and impairment of the small parts of the inner ear. The affected parts include the hearing organs and the hearing fibers of the ear, the nerves and the brain. The normal ageing process may also affect parts of the middle ear. These changes may mean that the movement and vibration of the small bones of the middle ear become very limited. Other factors may lead to hearing loss including:

1. Chronic noise injury: The hearing loss that results from long term exposure to noise (workers in industry or the military for example).
2. Certain medicines: Some medicines used to treat high blood pressure (hypertension), as well as certain pain killers and antibiotics can lead to hearing loss. In this respect, other factors are important including the amount of the medicine and duration of its usage as well as the individual readiness and reactions of some persons to develop drug-induced hearing loss.
3. Inflammatory diseases: Chronic infections or inflammations of the ear such as chronic middle ear infections and its complications. Some viral infections may affect hearing nerve fibers.
4. Other Systemic diseases- Such as diabetes, some diseases of the kidney and high blood fat in addition to smoking, help deterioration of hearing. These diseases and their complications affect many organs of the body including the hearing organs.
5. Hereditary hearing loss- If others in a family have lost their hearing it is likely that their sons and daughters will also gradually lose their hearing too. Many genes have been found that affect of progressive hearing loss.

### **III- Psycho-Social Consequences of Hearing Loss:**

Older people tend to wait many years from the onset of hearing loss before seeking medical assistance. In many cases, the hearing loss is so gradual as to be unnoticed. Therefore, it is often undetected and often interferes with the older person's relationship with family and friends. It also interferes with the physical and mental wellbeing of the individual.

As mentioned before, older people with hearing loss fail to understand well what is being said and face many difficult situations affecting their behavior. This can lead to frustration, depression and withdrawal from the family as well as the rest of society. This difficulty in understanding speech usually acts as an obstacle to successful health treatment; it strains family relations and minimizes previously enjoyed activities which have a negative affect on daily living, contact with family/friends, communication with a doctor or health worker and a number of solitary activities such as the radio and telephone. It is widely agreed that hearing loss as well as other chronic health conditions have important implications on elderly people quality of life.

Being hearing impaired is also a very significant health problem and puts the impaired person at a competitive disadvantage. Hearing impaired people have more trouble getting jobs, are paid less, and can't communicate or enjoy music to the same extent as the rest of the population.

### **IV- Early Intervention of Hearing Loss:**

In order to help older people, hearing loss should be detected as early as possible. Any well trained health worker or doctor can help to detect the hearing loss and refer the older person to medical as well as psycho-social assistance. If there is a hearing loss, the first step is to get an audiogram. The audiogram is the graph of hearing.

There is simple equipment which can help in screening and detecting hearing loss at the community level, so the early detection can be backed and coupled with early intervention. The management of the hearing loss depends on a number of community factors as well as personal ones such as life style, previous job and experiences.

It seems to be that the personal understanding and acceptance of the difficulty in communication is the most important factor in this respect. This is why counseling services are so vital in all stages of rehabilitation.

Some older people with hearing disability can benefit from hearing aids to restore some of their hearing. However, these can be expensive and will not suit everyone. Elderly people who use hearing aids should understand that hearing aids are not perfect instruments that solve their problems, and unlike spectacles which can greatly help to improve sight, hearing aids will not perfectly restore the hearing loss. It should also be noted that hearing aids may not be effective in certain situations, such as a large auditorium, theatres and other noisy environments. In such places, microphones and amplifiers can help to improve the understanding of speech.

It is worth-mentioning that the Convention on the Rights of Persons with Disabilities, (CRPD), that was opened for signature on 30 March 2007 and entered into force in May 3, 2008, included a commitment in article 25, (b), that states parties shall provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including children and older persons. It is crucial for all who are responsible for policy and support for older people to change this commitment into action on the ground especially in developing countries.

Integration of health care services and early detection and intervention on disability in the mainstream of primary health care programs is of utmost importance in developing countries. This successful integration will help and enable older people with hearing loss to be ready to deal with the loss, rather than deny it.

### **V- Rehabilitation**

A rehabilitation program should be tailored to individual needs. The goal of a rehabilitation program, we should not forget, is to minimize the handicapping effects of hearing loss on both the individual and the family . It consists of:

- Hearing aid orientation to those who benefit from hearing devices in order to make the most of their hearing aids.
- Re-listening training sessions because hearing aids do not perfectly compensate for hearing loss. Older people who use hearing aids need to

attend training sessions of listening run by a trained specialist. These sessions of listening make the most of the benefits gained from the hearing aid and can help the person to communicate better.

- Hearing/sight communication training to reduce the perceived handicap associated with hearing loss and to increase the person's ability to communicate. It may take several weeks to get better results.
- Counseling the person with hearing loss and training their families on methods to help them. It is important to note that the family or the caregiver has an active role in the rehabilitation and integration of the older person with hearing disability into society.

Many older people with hearing disability receive no health, psycho-social or eye care services that add to the burden on the general wellbeing of older people with hearing disabilities. Also, the cost of hearing aids that need maintenance and change in addition to regular medical services and counseling are not affordable in many developing countries.

Since cognition and memory often also show declines with age, their relationship to hearing loss is an important issue for audiologists and other rehabilitation workers to explore in the decision to provide hearing aids and aural rehabilitation.

Unfortunately, It is found that among the most important factors determining the success or failure of hearing aids are those unrelated to audiometric findings or results. Specifically, we must take into consideration all of the following: (1) the age and general physical and

mental health of the patient; (2) the patient's, as opposed to only the family's, attitude and interaction; (3) income; (4) cosmetic considerations especially for women; and (5) communication needs.

As professionals, our objective is to provide people with hearing disability, (PHD), with better tools for hearing and listening. Although hearing aids are typically the vehicle for such an objective, other forms of aural rehabilitation, either in lieu of or in association with hearing aids, may be necessary. Just as physical therapy is provided to patients receiving artificial limbs, aural rehabilitation is important for hearing-impaired persons for whom central processing abilities have been compromised as a result of neural plasticity, cognitive changes, and aging processes. Adapting to hearing aid use takes time and should not be expected to occur automatically without instructions on how to adapt the hearing environment, supplement an impaired auditory system with visual cues, and enhance listening skills with compensatory strategies. These abilities can be supported through individual or group aural rehabilitation sessions. In addition, people with hearing disability and their families should expect to receive simple and easy publications from their rehabilitation workers that address these issues. Because it may be difficult for some patients to return for frequent aural rehabilitation sessions, recent programs, such as Listening and Communication Enhancement, (LACE) have been introduced to enable PHD to obtain rehabilitation in their own homes. For example, LACE is a computerized, adaptive training program

designed to assist patients' listening skills in degraded speech environments, as well as to strengthen cognitive skills (speed of processing and auditory memory), and to teach communication strategies.

On the other hand, the Convention on the Rights of Persons with Disabilities (CRPD), Article 26 on Habilitation and Rehabilitation called on states to take appropriate measures to enable persons with disabilities to attain and maintain independence... and fully inclusion and participation in all aspects of life. To that end states shall organize...and extend comprehensive habilitation and rehabilitation services and programmes to:

- Begin at the earliest possible stage, and is based on the multidisciplinary assessment of individual needs and strengths;
- Support participation and inclusion of PHD in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
- States ... shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Also in Article 30, CRPD calls upon states to take all appropriate measures to ensure that persons with disabilities:

- Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;



- Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

There has been much discussion regarding the benefit of hearing aids. However, It is found that hearing aids do indeed provide substantial benefit and reduce communication problems. Data indicate that individuals with untreated hearing loss were more likely to report depression, anxiety, and paranoia, and less likely to participate in organized social activities compared to those who wear hearing aids. Other studies have indicated that hearing aid use is associated with significant improvements in the social, psychological, emotional, and physical aspects of the lives of PHD with all degrees of hearing loss.

In this respect, it is important to elaborate on some aspects of hearing aids and other rehabilitation services including: Candidacy for hearing aid, Degree of hearing loss and hearing aids, Word Recognition (Speech Discrimination), Main Challenges, Number of Devices Required, Processing Types of Hearing Aid, as well as Assistive Listening Devices:

### **V-I: Candidacy for Hearing Aid:**

Candidacy for amplification should be based on the patient's subjective needs rather than strictly on the basis of the audiogram.

In the past, it was believed that the use of hearing aids was limited to individuals with conductive hearing impairment

and would not be helpful for individuals with a sensorineural hearing loss. Patients were informed that hearing aids could make sounds louder, but would not make them clearer. Nowadays, technological improvements and innovations in hearing aids offer improvement to most individuals with hearing disability, including most individuals with a sensorineural hearing disability.

### **• Degree of Hearing Loss**

Depending on the audiogram:

1. **MILD HEARING LOSS (20-40 dB):** Hearing aid use may be helpful depending on the patient's communicative needs. Some may prefer to use amplification only on a part-time basis.
2. **MODERATE HEARING LOSS (45-65 dB):** Amplification is needed and is usually successful if proper fitting strategies are used.
3. **SEVERE HEARING LOSS (70-85 dB):** Amplification is necessary if the patient wishes to use the auditory channel as the primary receptive mode. Cochlear implants may be considered if hearing aids are unsuccessful.
4. **PROFOUND HEARING LOSS (> 85 dB):** At a minimum, amplification is useful as a warning device; at a maximum, it allows the patient auditory use and likely enhances speech reading capabilities. Its effectiveness may depend on the age at which amplification is first used.

Individuals with a profound hearing loss may be strong candidates for cochlear implantation.

With the versatility available in digital hearing aids, audiometric configuration is much less of an issue in determining candidacy.

### **• Word Recognition (Speech Discrimination)**

Word recognition ability becomes diminished because of four main factors: (1) reduced audibility, (2) cochlear distortions producing reduced frequency and temporal selectivity and resolution, (3) abnormal central auditory processing, and (4) diminished cognitive function. Modern hearing aid technology allows the audiologist the ability to correct reduced audibility. The other three factors, however, may not be subject to correction by amplification; they can, in fact, render a poor prognosis for success with amplification. Furthermore, word recognition testing is typically performed in a quiet environment. It is well known that individuals with a sensorineural hearing loss have considerably more difficulty understanding speech in a noisy environment. This difficulty is often a function of both peripheral and central disorders and may be particularly emphasized in elderly populations.

PHD presenting bilaterally asymmetrical word recognition scores often prefer monaural amplification for the better-hearing ear. There are many exceptions, however, so unless there are other contraindications (eg, extremely poor speech discrimination ability, an extremely limited dynamic range, or medical

contraindications), low discrimination scores should not, by themselves, preclude a trial with amplification.

- **Challenges:**

Despite need, many patients resist trying hearing aids. There is an unfortunate, yet undeniable social stigma attached to wearing hearing aids. The issue of cosmetic vanity is being addressed, in part, by the continuing trend toward miniaturization of hearing devices and the increased use of open coupler devices described later. However, not all hearing-impaired listeners are candidates for these hearing aids. It is regrettable that hearing aids are often dispensed to patients who lack motivation for amplification. A poorly motivated patient is a poor candidate for amplification regardless of the degree of hearing loss and should not be forced into trying hearing aids. It is difficult to undo the damage that may be done if a candidate prematurely tries and fails with amplification. For these patients, it may be advisable to wait a year so that they may clearly perceive the need. However, encouraging patients to put forth the effort toward a trial period, with the understanding that it is possible they may be pleasantly surprised, is certainly worthwhile.

Occupational and social demands vary greatly among individuals. A consultant or community leader who has a mild hearing loss may desperately need amplification, whereas a retired elderly patient, with the same degree of hearing loss, living alone may not. Patients must ask themselves if the ability to hear,

albeit not understand, is acceptable and adequate for their needs. They must unselfishly examine whether they are becoming a burden to others, even if they do not personally recognize difficulty hearing. The critical variable is whether the patient experiences difficulty hearing or increased stress and fatigue in daily function. Amplification may simply relieve the strain of hearing, as opposed to improving word recognition or making sounds louder. This alone, however, can be a significant benefit.

- **Number of Devices Required**

Over 80% of hearing aid fittings in the United States are binaural. A number of factors are likely contribute to binaural superiority. Eliminating or minimizing the head shadow (the reduction in signal intensity from the side of the head opposite the signal) is important for listeners with a high-frequency hearing loss, which is common in older people with hearing disability. Improved localization and the better balance of sounds result from hearing sounds from both sides. Other factors to consider in choosing binaural versus monaural amplification include the possibility of tinnitus reduction regardless of a perceived dominant side because of increased stimulation to a more cortical neural substrate, and the legal implications of the potential deprivation of an unaided ear. The general rule should be that unless there is a significant asymmetry in sensitivity, tolerance to loudness, or word recognition ability, or unless a medical condition exists

contraindicating the insertion of anything into the external auditory canal, the standard should be at least to try binaural amplification. For these patients, a wired or wireless contralateral routing of signal (CROS) aid or transcranial CROS (placing a hearing aid in the "dead" ear, producing bone conduction stimulation of the "good" ear) may be tried. It should be noted that CROS devices should be applied only if the better ear has normal or near-normal hearing, and the transcranial CROS should be used only if the poorer ear has no residual hearing that might produce recruitment or other distortion factors. If the "good" ear is in need of amplification, a BICROS (bilateral contralateral routing of signal), in which microphones are located on both ears but the signal is routed only to the "good" ear, can be tried. In cases of unilateral impairment, candidacy should be based on the individual's communicative needs. It is also possible to try a bone-anchored hearing aid (BAHA) if the impaired ear is unaidable.

- **Processing Types of Hearing Aids**

- A. Conventional Hearing Aids**

Less than 20% of hearing aids dispensed today fall into the conventional category. These devices are analog instruments that amplify, filter, and limit the maximum power via on-instrument screw-set controls, switches, or rotary wheels. They do not have the flexibility found in programmable or digital hearing aids. They typically use linear processing or contain relatively simple compression strategies. Many, though not all, have variable screw

potentiometers that can be used to obtain a balance between low-frequency and high-frequency gain. In addition, most utilize user-operated volume controls.

## **B. Programmable Hearing Aids**

Digitally programmable hearing aids are hybrid instruments that process sound signals with analog components, but are programmed using a computer. Digitally programmable instruments are being phased out as fully digital instruments gain in popularity and are reduced in cost.

## **C. Digital Hearing Aids**

Digital hearing aids are computer-controlled devices that use digital technology. Digitization means that incoming sounds are converted to numbers, which are then analyzed and manipulated via a set of rules (algorithms) programmed into the chip controlling the hearing aid. Digital signal processing (DSP) allows instruments to attempt a differentiation of noise from speech, not only on the basis of spectral composition, but also on the basis of temporal characteristics. Noise and speech have quite distinct temporal patterns. DSP hearing instruments assess the modulation pattern (rate and depth) of the input signal to predict whether or not that signal is primarily speech. If it is, full amplification is provided. If not, gain is attenuated within that frequency band. Studies have consistently shown subjective preferences for digital hearing aids, but, similar to binaural amplification, this perceived benefit may not always be reflected by word recognition scores.

## **V-II- Assistive Listening**

### **Devices:**

Unfortunately, background noise often surrounds the listener, so although the intensity of the speech decreases with distance, the intensity of the noise may not as it is everywhere. This situation interferes with the work of the hearing aids. Assistive Listening Devices (ALDs) amplify and deliver the desired sounds directly to the user bypassing the noise of the environment. So, ALDs complement hearing aids by amplifying only the desired sound, and not the background noise. For some people who have a hearing loss but don't wear hearing aids, ALDs alone are sometimes sufficient. The ADA requires that ALDs be placed and accessible in public places such as schools, theaters and cinema.

ALDs use different kinds of technologies, but all pick up the sound from the source and deliver it directly to the user, who wears a receiver (headphones, earbuds, neck loops). Some kinds of hearing aids have a telecoil inside them so that they can receive ALD transmissions through the hearing aid, without using a special receiver.

The different kinds of ALD technologies include FM systems where sound is transmitted from the speaker's microphone directly to users who are wearing FM headsets. Receivers can be attached directly to the hearing aid. If the hearing aid has a telecoil, a loop can be attached. FM systems are reliable and the sound quality is excellent. When wearing an FM system, one can sit anywhere in the room. FM's also cut out a substantial amount of

background sound. The same is true for Infra Red Systems and Induction Loops.

Other Assistive Listening Devices include the doorbell that can be connected to the house lights so the lights flash when the doorbell rings, and special 'shake-awake' alarm clocks.

For the telephone, widely used everywhere, there is a volume control for incoming speech (for use with or without a hearing aid); systems that enable the use of both ears with a telephone, often improving word clarity, and a ringer volume control; a ringer pitch control, a light on the phone that flashes when it rings. Also, for those who cannot use voice telephones, visual telephones allow users to type conversations.

## **VI- Conclusion:**

Hearing disability is among the most common and growing disability in both developed and developing countries. In order to minimize its psychosocial consequences, early detection of hearing disability must be coupled with early intervention including the provision of rehabilitation services at the community level and based on a multidisciplinary approach and assessment. This needs to be considered among the public health priorities.

It is vital for all organizations involved in support of older people, including the elderly themselves, to make use of CRPD as well as other related human rights conventions and current proposals in order to promote plans and actions that address hearing disability to enable older people to achieve their basic rights of self fulfillment, independence and dignity.

# Cognitive Impairment: The Need to Recognize It as a Form of Disability?

Samuel, M. Udaya, Department of Social Work, Loyola College and Vision Age India, NGO for Aged, Chennai, Tamil Nadu, India

I.Vivian, Honorary Research Associate, Institute of Psychiatry, King's College, London and Vision Age India, NGO for Aged, Chennai, Tamil Nadu, India

e-mail: rsam\_67@yahoo.co.uk

## Introduction:

The medical advancement over the past twenty years in India has increased longevity, but has not prevented diseases and disabilities in aged persons. The prevalence of physical disabilities in the year 2002, in the Indian population in the age group above 60 years was 25.7 percent in urban areas according to National Sample Survey Organisation (NSSO). (1)

Similar to physical disabilities, elderly can suffer from mild to severe cognitive impairment: which might range from benign memory loss, mild cognitive impairment to dementia. The prevalence of cognitive impairment in the Indian aged population has been found to be between 14 to 16 percent (2,3) Cognitive impairment is known to cause malnutrition in the elderly, which will further affect their health status and that in turn make them vulnerable towards developing a disability. (4, 5) Similarly, physical activities are important to enhance physiological functioning for reducing oxidative stress and inflammation biomarkers which will mitigate chronic medical conditions. (6) Those affected by physical disability and cognitive disability would not be able to engage in physical activities, and this would make them vulnerable towards further morbidity and disability.

In India many of the studies on disability and the NSSO while enumerating disability prevalence in the population, do not assess the cognitive profile of the elderly. This study aims to measure the extent of physical and cognitive disabilities among the elderly population and demonstrates the adverse effect of cognitive impairment on the aged.

## Methods:

Sample: The city of Chennai is divided into ten zones: each zone contains 15 to 20 wards. Four wards were chosen through stratified simple random method and then in the selected wards, through survey method 226 elderly persons were screened for disability. The data was collected in the residence of the elderly by trained research assistants after carrying out reliability exercises.

## Instruments:

Measure of Disability: The 12 items brief population screening WHO Disability Assessment Schedule (WHODAS) was utilized to measure disability. The instrument measures the individual's ability to: Understanding and Communicating, Mobility, Self Care, Socializing, Household and Work Activities and Participation in Society. The reliability of the instrument is 0.94 and validity exercises shows unidimensionality of domains average loading >0.7,

among different population groups in different countries.

## Results:

The sample size was 226, and women constituted 61 percent. The mean age of the sample was 71 (6.4) years. The care givers of these elderly were mostly women: daughter or daughter-in-law (82.7%). Only 27 percent of the subjects received a regular income; among them barely 8% received more than USD 60 a month. The mean disability score measured using the WHODAS was 12.4 (19.9) for the sample. High disability (tertile split) was seen in 38% of the subjects with a score of > 31.

## Sample characteristics and disability profile:

The specific prevalence of disability were: Cognition was 36.84, Getting around was 45.61, self care was 20.18, 'getting along with people' was 14.91, life activities was 30.7 and community participation was 32.46. Increasing age was associated with greater disability: 44 percent of the subjects aged between 70 -79 years and 44 percent aged above 80 years were highly disabled compared to 30 percent for age 60 -69 years (Chi-square=6.4, p=0.04). Similar effects were seen for various domains of disability, with aged above 80 years showed higher disability than

subjects aged 60-69 years (fig 1). The prevalence of disability (>80 Vs 60-69) years were: cognitive (understanding and communication) (48% Vs 28.2%), getting around (55% Vs 37.9), self-care (27.6% Vs 8.6), getting along with people (27.6% Vs 6.8), life activities (37.9% Vs 21.4) and community participation (37.9% Vs 28.2). There was a significant gender difference in disability; women were likely to be more affected than men (44.8% Vs 28.3%, Chi-square=6.6, p=0.03). Significant gender difference was seen in getting around (53% Vs 35%), self-care (27.2% Vs 9.8%), and life-activities (38.2% Vs 19.6%)

### **Common health problems and disability profile:**

Common health problems reported by older persons in the present sample were eye problems (51.3%), arthritis (50%), blood pressure (24.3%), breathing difficulty (18.2%), and hearing impairment (14.3%). These health ailments significantly disabled the aged (all p<0.05) and affected various disability domains (table 2). Sensory impairments affected their cognitive aspects (55%) as much it affected their ability to get around (60%). (fig 2a). Similarly, medical ailments also affected individual's cognitive functions as revealed by high prevalence of cognitive disability in these ailments (all >40%) (Fig 2b) We also see accumulation of these ailments were significantly associated with higher disability scores (r=0.48, p<0.001), and the association is stronger for women, suggesting a profound effect of health problems on disability in women.

### **Being active and disability:**

In this study 19 percent reported that they were active, while 12.3 percent reported that they were not active and the remaining 68.7 percent considered themselves fairly active. Nearly 90 percent of the subjects who reported to be not active were disabled, whereas only 11 percent of the subjects who reported to be active were disabled. Being physically active significantly altered the impact of health problems also on disability. Persons who reported they were active were not disabled with increasing health problems (r=0.27, p=0.07), whereas persons who were not active had significant disability with increasing health problems (r=0.63, p<0.001) (fig 3).

We also tested the hypothesis if cognitive disability contributed to people being active. We found a significant association between cognitive impairment and ability to be active, even after controlling for age, gender, medical ailments and self-care disability (table 3).

### **Discussion:**

As cognitive impairment will affect the person's ability to perceive his environment and participate in activities, it affects their overall functioning, even if they are not physically disabled. In India though benign memory loss, mild cognitive impairment and dementia are well recognized conditions, cognitive impairments are not yet recognized as a form of disability in the Persons with Disabilities Act 1995 and Multiple Disabilities Act 1999; so is the case with many developing nations. (7) The disability prevalence in this study reveals that following

difficulty in mobility (45.61%) 36 percent of the aged people were affected by cognitive disability. So, while enumerating disabled people in the nation, not including cognitive impairment would considerably reduce the number of disabled people in the country. The strength of the numbers to bring about policies, intervention programmes and services for the disabled people would be lost. Many of the cognitive disabilities could be due to reversible cause like depression, infection, vitamin deficiencies, negligence of health and inactive life style. Providing rehabilitation could facilitate reversing cognitive impairment, thereby enabling them to have a better quality of life. (8)

Disability is related to disease, injury or aging. While injury could be avoided and diseases, if adequately medically managed, can minimize the disability, the disabilities occurring in older persons seem inevitable. Even aged people with chronic medical problems did not visit a doctor for more than a three month period due to problems in finance, finding assistance, transport and mobility difficulties. (9) Since aged people with a disability will have numerous physical limitations to go to a hospital, it is very essential to develop mobile medical care units, which can provide medical assistance for the aged people in their residence. Accessibility to health services lead to better utilization as was found in an old age home as doctors were visiting the home.

The WHODAS measures cognitive functioning by assessing concentration and

new task learning ability. The diagnostic criteria for Mild Cognitive Impairment (MCI) are classified into amnesic— involving memory difficulties and nonamnesic single or multiple cognitive impairments —not involving the memory. Thus, not including memory related cognitive impairment would exclude total subtype of MCI. (10) The measure of disability among different nations show different results: United States of America 19.4, United Kingdom 12.2, Bangladesh 0.8, Kenya 0.7, India 2.1, and Mexico 2.3 demonstrate that the nations having good health care facilities have higher levels of disability whereas the developing nations have lesser rates of disability. (11) This

would reflect the methodology with which disability data is obtained; as the questions are subject to how the person interprets and understands. The initiative to measure disability among different nations with a single instrument (WHODAS) was carried out by the United Nations Washington Group of Disability Statistics as outlined by the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization. The results clearly show that the different disability rates and differences in each domain. (11) These differences could be subject to certain cultural factors: the way they understand a question in the context of their life style. (11) Since answering the question

depends entirely on the cognitive functioning as they have to interpret and understand a question, given the high prevalence of cognitive impairment among the elderly, it would pose very serious methodological problems in ascertaining disability information from the elderly people. One way to overcome this problem would be to check their performance instead of asking for their opinion: WHODAS question 'Concentrating on doing something for ten minutes' instead can assess their ability to concentrate with calculation or spelling 'World' backward as found in Mini Mental Status Examination. (12)

#### References:

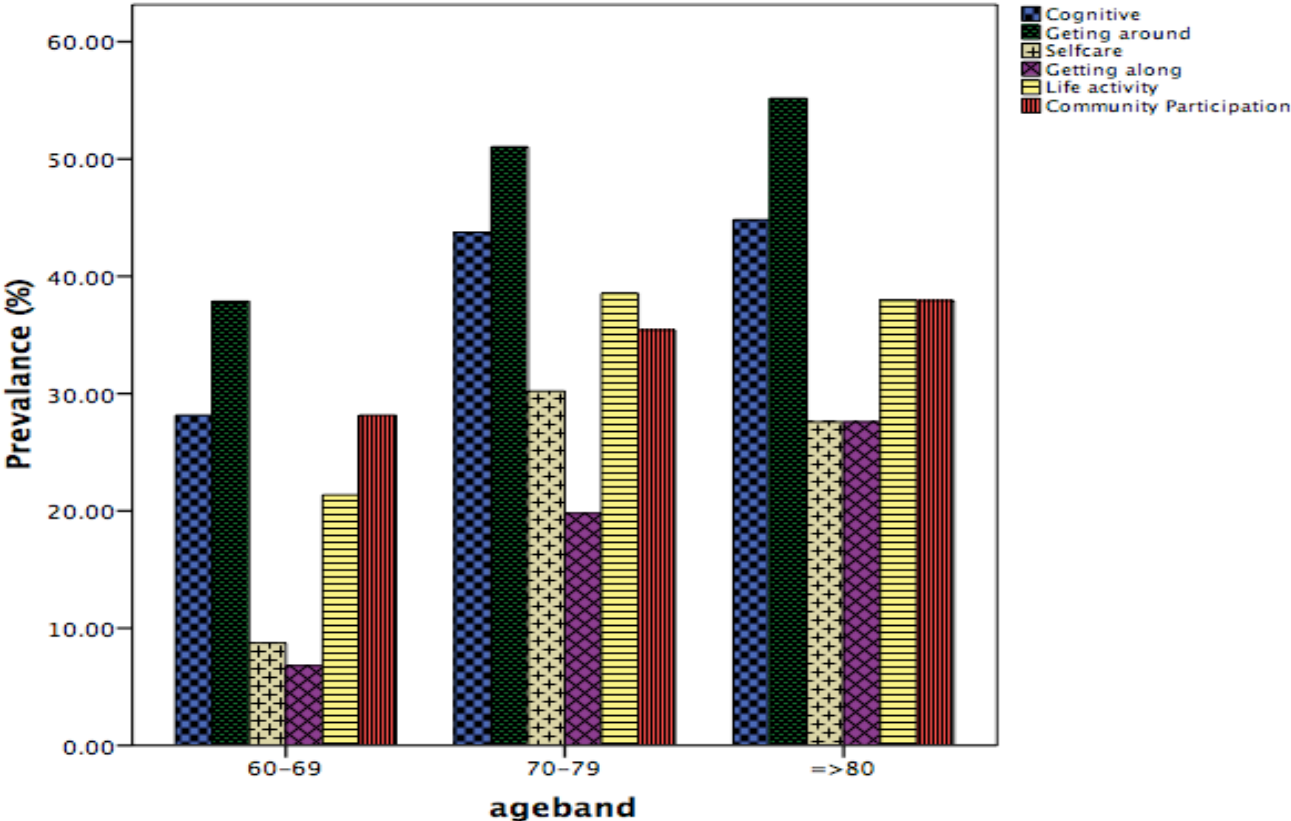
1. A Report of Disabled Persons, 58<sup>th</sup> Round 2002, National Sample Survey Organisation. 2002.
2. Das, S, K, Bose, P, Biswas, et al. An epidemiologic study of Mild Cognitive Impairment in Kolkata, India. *Neurology* 2007; 68:2019 – 2026
3. J. E. Graham, K, Rockwood, B. L. Beattie et al. Prevalence and severity of cognitive impairment with and without dementia in an elderly population. *The Lancet*. 1997;21: 1793 – 1796 (1997)
4. C. M. Callahan, H C. Hendrie and W M. Tierney. Documentation and Evaluation of Cognitive Impairment in Elderly Primary Care Patients. *Annals of Internal Medicine*. 1995; 122, 6:422 – 427
5. C. Nina, Franklin and A. Charlotte. Tate. Lifestyle and Successful Aging: An Overview. *American Journal of Lifestyle Medicine* 2009;6:6 – 11
6. D. Balzi, F. Lauretani, A. Barchielli and L. Ferriucci. Risk Factors for disability in older persons over 3-year follow up. *Age and Ageing* 2010; 39:92-98
7. P. J. Indira 'Aging, Disability, and Disabled Older People in India' *Journal of Aging & Social Policy* 2003;15, 2:85 – 108
8. R. Samuel. A Comparative Study on Health Services Utilization and Cost: Male Elderly in Community and Institution. *Indian Journal of Gerontology* 2005;19: 457- 462
9. R. Samuel. Cognitive rehabilitation for reversible and progressive brain injury. *Indian Journal of Psychiatry* 2008; 50:282-284
10. P. B. Rosenberg, D. Johnston, C. G. Lyketsos. A Clinical Approach to Mild Cognitive Impairment. *The American Journal of Psychiatry* 2006: 163:1884 – 1890
11. M. Daniel. Measuring Disability Prevalence. World Bank S. P. Discussion Paper (NO:0706) 2007:6-22
12. M. F. Folstein, S. E. Folstein, P. R. McHugh. 'Mini Mental State': a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975;12:189-198.

**Table 1: Sample characteristics and WHODAS II**

	<i>WHODAS II</i>			
	n	High tertile (%)	OR (95% CI)	<i>p</i>
Patient Age				
60-69	102	30.4	1.0	0.05
70-79	95	44.2	1.8 (1.01-3.2)	
>80	29	44.8	1.9 (0.8-4.3)	
Patient Gender				
Female	134	44.8	1.0	0.01
Male	92	28.3	0.5 (0.3-0.8)	
Informant Relation				
Spouse	59	39.0	1.0	-
Child	61	39.3	1.0 (0.5-2.1)	0.96
S/D In-law	78	35.9	0.9 (0.4-1.8)	0.71
Other relations	27	40.7	1.1 (0.4-2.7)	0.87
Income				
No	164	40.2	1.0	0.29
Yes	62	32.3	0.7 (0.4-1.3)	
Income				
Nil	180	39.4	1.0	0.49
<INR 2500	26	30.8	0.7 (0.3-1.6)	
>INR 2500	20	35.0	0.8 (0.3-2.1)	

Note: OR –Odds Ratio; CI- Confidence Interval; INR- Indian Rupees; S/D-Son or Daughter

Figure 1: Prevalence of various domains of disability, stratified by age





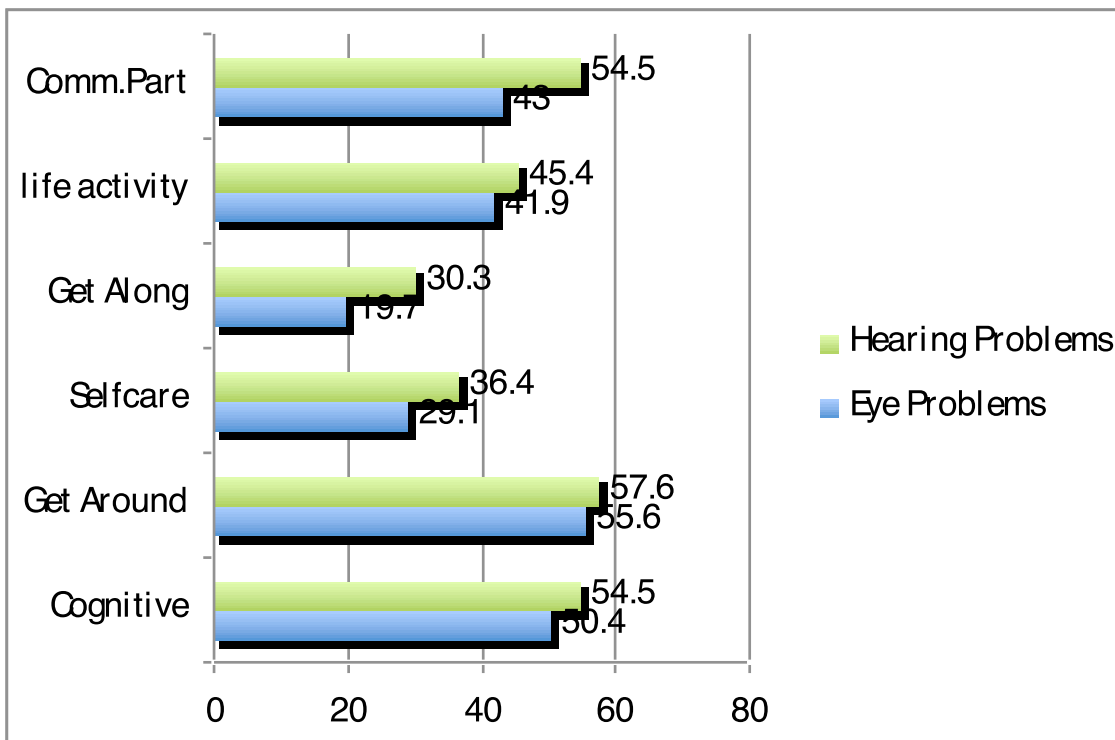
**Table 2: Common health problems in old age (in the order of prevalence) and their association with WHODAS II**

	n	High tertile (%)	OR (95% CI)	p
Eye Impairment				
No	110	22.7	1.0	<b>&lt;0.001</b>
Yes	116	52.6	3.8 (2.1-6.7)	
Arthritis				
No	113	27.4	1.0	<b>0.002</b>
Yes	113	48.7	2.5 (1.4-4.3)	
Blood Pressure				
No	170	32.9	1.0	<b>0.007</b>
Yes	56	53.6	2.3 (1.3-4.3)	
Breathing Difficulty				
No	184	35.3	1.0	0.06
Yes	42	50.0	1,8 (0.9-3.6)	
Head Injury				
No	187	36.4	1.0	0.27
Yes	39	46.2	1.5 (0.7-3.0)	
Hearing Impairment				
No	193	34.2	1.0	<b>0.006</b>
Yes	33	60.6	3.0 (1.4-6.3)	
Cough				
No	198	36.9	1.0	0.40
Yes	28	46.4	1.5 (0.7-3.3)	
Fainting				
No	198	34.8	1.0	<b>0.01</b>
Yes	28	60.7	2.8 (1.3-6.5)	
Diabetes				
No	199	36.2	1.0	0.14
Yes	27	51.9	1.9 (0.8-4.2)	
Heart Problem				
No	208	36.1	1.0	0.04
Yes	18	61.1	2.7 (1.03-7.4)	
Limb				
No	210	35.2	1.0	<b>0.002</b>
Yes	16	75.0	5.5 (1.7-17.2)	
Gastrointestinal				
No	213	36.6	1.0	0.08
Yes	13	61.5	2.7 (0.9-8.6)	
TIA*				
No	220	36.4	-	<b>0.003</b>
Yes	6	100		
CVA*				
No	222	36.9	-	<b>0.02</b>
Yes	4	100		

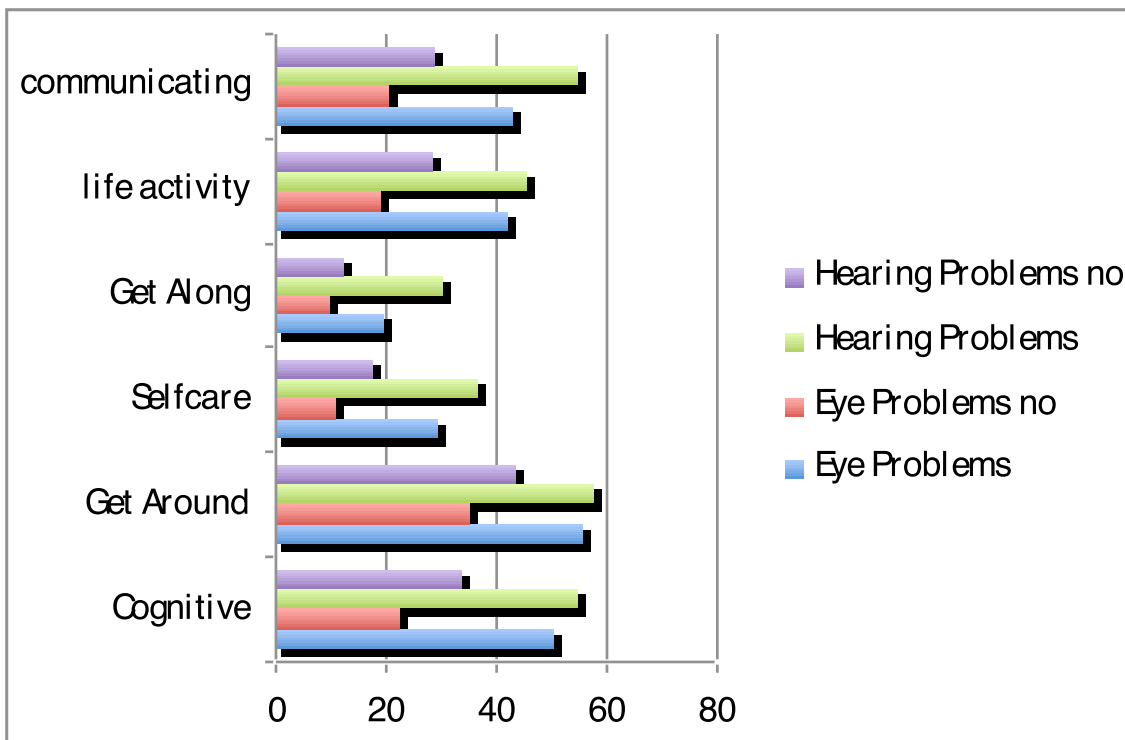
\* Odds ratios were not computed

**Fig 2: Common health problems and domains of disability affected**

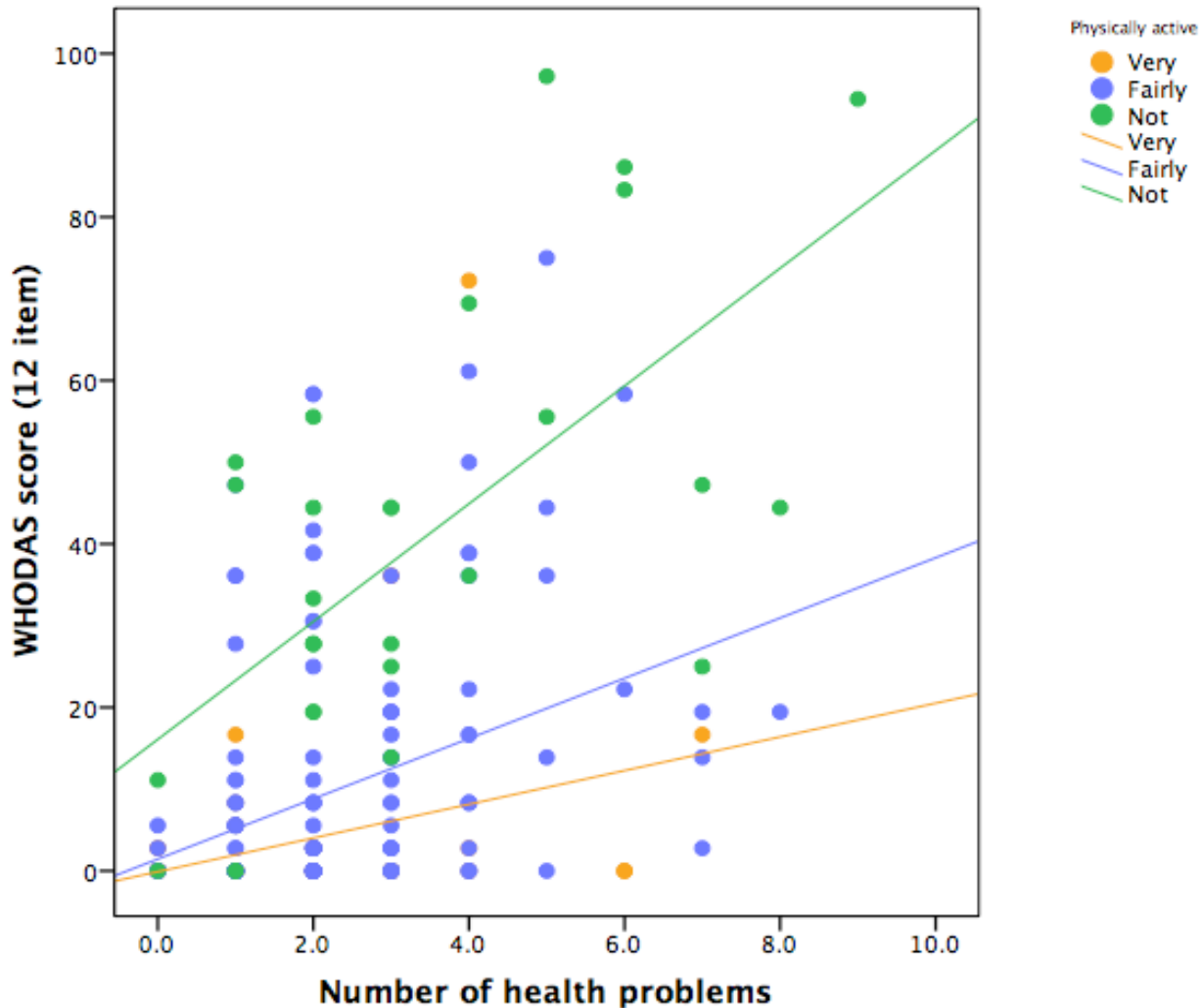
a) Sensory impairment and disability domains



b) Medical ailments and disability domains



**Figure 3: Self-perceived activeness, health problems and WHODAS**



**Table 3: Association between cognitive disability and self-perceived activeness controlling for physical disability**

Cognitive Disability	Physical Inactivity		
	B	SE	P
Model 1	0.48	0.07	<0.001
Model 2	0.45	0.08	<0.001
Model 3	0.33	0.07	<0.001

*Model 1 shows unadjusted association*

*Model 2 was adjusted for age, gender and medical ailments*

*Model 3 was further adjusted for self-care*

# Ageing: Impaired Persons Suffering from an Amputation of the Left Arm - Investigation of their Specific Requirements and Wishes towards a Vehicle

Prof. Dr. Doris Kortus-schultes, Niederrhein University of Applied Sciences; www.frau-und-auto.hsnr.de  
 Angelika Engel, MBA, Ergonomics Attribute Specialist at Ford Development Centre, Cologne, Germany  
 Max Feierabend, B.A. (Ford Motor Company, AG)

**Tab 1: Severely Disabled Persons by Gender and Age (by Dec. 31, 2009); source: German Statistical Office (DeStatis); Sep. 14, 2010**

Gender / Age	Total	
	Number	Per 1,000 Inhabitants
<b>Total</b>		
Male.....	3,658 107	91
Female .....	3,443 575	83
<b>Total ...</b>	<b>7,101 682</b>	<b>87</b>
<b>By Age</b>		
less than 4 .....	14 275	5
4 - 15 .....	109 044	13
15 - 25 .....	160 405	17
25 - 35 .....	210 081	22
35 - 45 .....	417 603	34
45 - 55 .....	874 509	67
55 - 65 .....	1, 452 236	149
65 And more .....	3, 863 529	229

In Germany as in most other European countries as well as in the US people are getting older, thus contributing to an increasing number of persons suffering of any kind of physical disability. Until end of 2009 7.1 million of severely disabled persons were living in Germany – totalling up to 183.510 persons or 2.9% more than in 2009. This means that every 12th inhabitant in Germany (8.6 %) is severely disabled. Severely disabled is a definition by the German pension offices grants, starting with a degree of impairment of 50 % or more. Gender distribution reveals that of all persons with impairments 51.5 % are male and 48.5 % female. This is an indication that older men are more often physically impaired than women of the same age. By end of 2009 more than half of all disabled persons in Germany (54.4 %) were aged 65 years and older; one fifth (20.4 %) were aged 55 and less than 65 years. This states that about 75 % of all disabled persons in Germany are aged 55 years and older. Most of the disabilities have been caused by an illness (82%). By end of 2009, 64% of the impaired persons in Germany were suffering from any kind of a physical impairment, another 14 % with difficulties to use their arms or legs, 12 % having problems with their back and/or body, 5 % were blind or partially sighted, 4 % suffered from defective hearing, vertigo or speech disorder.

When studying German and European data on impaired persons the authors noticed that there are significant differences in the numbers of disabled persons in different European countries. For example data in Great Britain show much higher percentages of persons with impairments.

One explanation for these differences in official data on persons with disabilities could be that there is a better reporting history on the issue in Great Britain. Also the German distinction between 50 % and 100 % impairment didn't support the aim of this study.

Persons with an amputation of their left arm have been chosen as target group because there are strong synergies in their special requirements when driving with persons who are suffering from arthritis or rheumatism, diseases that usually limit mobility of extremities.

The investigation presented here was carried out in summer 2010 focussing on the decision making processes and influences during a vehicle purchase process by people

with impairments of their left arm or an amputation of it. A focus group interview with 11 participants (10 participants aged between 50 and 75 and one person aged 40 years) was performed to collect and classify influences and decision factors of the target customers. Useful hints how to guide the discussion and how to structure qualitative as well as quantitative data collected were provided by members of Ford Development Centre, Cologne.

The business challenge of the investigation was to search for priorities in technical improvements enhancing

vehicle usage by people with disabilities – with a main emphasis on improvements of standard respectively mass production vehicles. Screening disabilities usually going along with a left arm amputation enlarges the total target group of the evaluated adoptions by transferring the insights to the enlarged group of persons with similar functional problems, like paresis or spastics as well as older persons suffering from rheumatism or gout.

With the possibility of driving a vehicle disabled citizens gain a vast variety of personal mobility and so much higher participation in social and day-to-day life. In Germany altogether 963.000 persons with disabilities are reported as owners of a vehicle – this sums up to 2.5 % of all private car owners (37.6 Mil).

Applying the classical model of buying decisions, the results of the focus groups showed the following procedural behaviour in the early phases of 'searching for information' and 'assessment of alternatives':

1. Opinions out Of The private/ personal area of the decision maker, i.e. family members, friends or relatives, show strongest influence on the decision making process of impaired persons. When preparing a vehicle purchase persons with disabilities pose strongest emphasis on the expertise and opinions of persons close to them. Their suggestions and recommendations are more trusted than any information from company marketing sources or from sales persons in the outlet. Impaired persons put more

trust in correctness and validity of persons' recommendations they judge to know their individual requirements by their daily experiences and so to be well acquainted with the consequences of the specific disability.

2. As important, second factor of influence during the decision making process members of the focus group mentioned previously gathered experiences with sales and use of special vehicles were stated by THE MEMBERS Of the Focus Group.

Nevertheless, participants in the focus group discussion criticised sales persons' missing knowledge about useful information. They stated, however, that compared to this ignorance in individual recommendations, OEMs would put increasingly more emphasis on providing vehicles that can be made useful to people with disabilities. Participants also stated that most useful information had been given by the so-called converters – workshops doing the adaptation work on the vehicle.

These companies are normally specialising on one brand or model thus reducing the possibilities of choice, unfortunately.

Assessment of the buying decision phase showed once more that important influence arises from friends and family member's recommendations.

In the phase after the purchase, additional service like breakdown service, driver service to the regular inspections and a good repair service have been stressed to

be of high importance for customer satisfaction with a car and its dealership. Some participants pointed out being explicitly frustrated and unsatisfied by bad service they had experienced after vehicle purchase. Being deeply disappointed they tended to rank bad service to the target group of impaired persons as something to be accepted as a matter of fact. On the other hand, however, they pointed out that there had been some positive experiences, too. These experiences and OEMs resp. dealerships involved have been very positively remembered and recalled. This also indicates that word of mouth receives very high attention in this target group. Brands with reputation of delivering good service to the target group have been discussed by the group and received strong attention.

It was stated that the increasing use of electronics and other technologies provides more possibilities to adaptation than in previous times. Already available features such as sliding doors on the driver and the passenger sides have been positively assessed.

In summary, the following attributes and features in the car have been highlighted as being very important to impaired drivers:

- Easy ingress and low load over height.
- Improvements in seat adjustments like
  - Easy height adjustment – most current seats can only be adjusted diagonally and not VERTICALLY. It was requested to have it vertically, too.
  - Longer seat rails – to enlarge space behind the seats to accommodate a wheelchair
  - Longer seat cushions
  - Better steering wheel adjustment ranges. The request on the option for a removable steering wheel was discussed – nearly half of the participants stated, they usually grasped the steering wheel as help to get easier into the seat
- More generic proposals point to a more intuitive and simple use of the cockpit and interior equipment.

There was a split attitude towards computerisation and innovation. This can be attributed to the age average in the group.

- Another wish of the participants was standardised kits provided for various kinds of disabilities thus reducing the cost of adaptation.

It was stated that the current generation of vehicles is more comfortable and much safer than 10 years ago, but they are more difficult to adapt to specific use – as an example the participants stated that individual handles were easier to build in than it is today.

Despite the criticisms expressed, it was looked upon being a very positive improvement and change of paradigms that an increasing number of OEMs offer information about specific vehicle adaptation in their homepages. The internet also helps to improve the interest groups' organisation. The development of prosthetic aids have made significant progress during the last years and hope was expressed that they may enable drivers to conduct a vehicle without much adaption in the near future.

A last but not the least subject is the styling of vehicles. Exterior styling ranks in this group as an important criterion – persons with disabilities wish to demonstrate social equality and wish to express being a part of society.

Finally it is important to note that most of the identified requirements are identical with those of older drivers and many findings apply to short statured persons as well.

## **ACKNOWLEDGMENTS**

For their valuable assistance in the development of this publication the NGO Committee on Ageing/NY thanks:

**Dr. Martha Bial, Ph.D.**

**Dr. Patricia Brownell, Ph.D.**

**Dr. Judith Gordon, Ph.D.**

**Judy Lear, MPA**

**Dr. Rosita Perla Resnick, Ph.D., DSW**

**Dr. Norma Simon, Ed.D.**

