ABSTRACT

DECISION-MAKERS’ PERCEPTIONS AND KNOWLEDGE ABOUT LONG-TERM CARE IN NEPAL: AN EXPLORATORY STUDY

by Kelina Basnyat

Understanding issues related to long-term care (LTC) is more prominent in western countries than in developing countries. Many developing countries including Nepal are passing through a process of modernization which is replacing traditional social structures and value systems. For example in Nepal, even though long-term care is sometimes provided by a very limited number of government funded old age homes and non-profit organizations, the family remains the sole care-taker for most elderly. Research has demonstrated that the modern ideology of individualism along with the growing number of nuclear families is placing vulnerable populations such as the elderly in a difficult predicament. It is thus safe to argue that if decision-makers of Nepal lack basic knowledge of needs related to aging, disability, and LTC, this will impact all policies concerning these issues. This paper, therefore, explores the perception and knowledge pertaining to aging, disability and LTC among key decision-makers (bureaucrats and politicians) of Nepal. This exploratory study was conducted in Kathmandu and involved face-to-face in-depth interviews with 18 decision makers. The findings reveal that decision-makers have limited knowledge about aging, disability in aging and LTC needs. This paper maintains that the formulation and implementation of any new policies regarding aging and LTC needs could be problematic due to the unstable Nepali political climate.
DECISION MAKERS’ PERCEPTIONS AND KNOWLEDGE ABOUT
LONG-TERM CARE IN NEPAL: AN EXPLORATORY STUDY

A Thesis

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# Table of Contents

<table>
<thead>
<tr>
<th>Chapter One</th>
<th>1-5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Background</td>
<td>1</td>
</tr>
<tr>
<td>Purpose</td>
<td>4</td>
</tr>
<tr>
<td>Outline of the Study</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter Two</th>
<th>5-11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>5</td>
</tr>
<tr>
<td>Geographical Background</td>
<td>5</td>
</tr>
<tr>
<td>Politics and Political History</td>
<td>6</td>
</tr>
<tr>
<td>Economy</td>
<td>7</td>
</tr>
<tr>
<td>Education</td>
<td>8</td>
</tr>
<tr>
<td>Health and Healthcare System</td>
<td>8</td>
</tr>
<tr>
<td>Overview of Disability in Nepal</td>
<td>9</td>
</tr>
<tr>
<td>Table 1: Distribution of disabled persons by types and age groups</td>
<td>10</td>
</tr>
<tr>
<td>Social Welfare System</td>
<td>11</td>
</tr>
<tr>
<td>Government Old Age Home</td>
<td>11</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter Three</th>
<th>12-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample Selection</td>
<td>12</td>
</tr>
<tr>
<td>Data Collection</td>
<td>13</td>
</tr>
<tr>
<td>Research Question</td>
<td>13</td>
</tr>
<tr>
<td>Demographic Characteristics of the participants’</td>
<td>13</td>
</tr>
<tr>
<td>Table 2: Demographics Characteristics of the Participants</td>
<td>14</td>
</tr>
<tr>
<td>Informed Consent</td>
<td>15</td>
</tr>
<tr>
<td>Data Analysis Procedure</td>
<td>15</td>
</tr>
<tr>
<td>Chapter Four</td>
<td>15-26</td>
</tr>
<tr>
<td>-------------</td>
<td>-------</td>
</tr>
<tr>
<td>Findings</td>
<td>15</td>
</tr>
<tr>
<td>Section 1: Demographic Changes and Aging Issues</td>
<td>15</td>
</tr>
<tr>
<td>Section 2: Disability Issues</td>
<td>22</td>
</tr>
<tr>
<td>Section 3: Long-Term Care Issues</td>
<td>16</td>
</tr>
<tr>
<td>Chapter Five</td>
<td>29-37</td>
</tr>
<tr>
<td>Are Aging, Disability and Long-term care important issues?</td>
<td>29</td>
</tr>
<tr>
<td>Discussion</td>
<td>31</td>
</tr>
<tr>
<td>Conclusion</td>
<td>32</td>
</tr>
<tr>
<td>Reference</td>
<td>34</td>
</tr>
<tr>
<td>Appendix</td>
<td>37</td>
</tr>
</tbody>
</table>
I dedicate this work to all the older citizens of Nepal
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Chapter One

Introduction

Long-term care is designed to assist individuals who need help with activities of daily living (ADL) and instrumental activities of daily living (IADL). Individuals who need such care might be older adults with chronic illness, adults with physical or mental disabilities, or children. For developing countries, the concept of long-term care is relatively new phenomenon. In Nepal, long-term care has traditionally been provided by family members, rather than governmental and non-governmental agencies. Institutional care is almost unheard of by most of the population. There are few old age homes in the country, where services are provided for those who don’t have families. The purpose of the critical inquiry paper is to identify the issues surrounding long-term care in Nepal.

In general, issues of long-term care are usually associated with developed countries due to the advancement of technology, healthcare system, disability, and aging of the population. However, it is a growing concern in developing countries as well. According to the World Health Organization (2002), developing countries are experiencing notable increases in long-term care needs. Demographic and epidemiological transitions have resulted in dramatic changes in the health needs of the population of the world. These trends reflect two interrelated processes: (1) growth in factors that increase the prevalence of long-term disability in a population, and (2) the changes in capacity of the informal support system to address these needs. Thus, as a result of increases in disability and global aging, there is a steep increase in the need for formal/institutional facilities providing long-term care services and public policies to address the consequences of these changes. Unfortunately, the information about long-term care needs in developing countries is still very limited.

Background

Recently, the WHO conducted in-depth studies in ten developing countries that have initiated some type of long-term care program: China and South Korea (East Asia), Sri Lanka
(South-Central Asia), Indonesia and Thailand (South East Asia), Lebanon (Middle East), Lithuania and Ukraine (Eastern European), Mexico and Costa Rica (Latin America). The countries represent different stages of demographic and epidemiological transitions and different levels of economic development (Brodsky et al. WHO 2003). The study examines three critical areas (1) general health care system, social policies and the organizational/service structures that have major implications for long-term care, (2) informal care, culture and values, role of the family, migration pattern and (3) mechanism to support the family, issues of coordination among various long-term care services (health and social systems) and human resources strategies for providing effective long-term care.

Broadly, long-term care can be divided in two parts (1) long term care in institutional settings, and (2) home based care. Many developing countries have been passing through a process of westernization and modernization. Ripple effects of such processes tend to affect the traditional value system of the society. Historically, both the population with disability and the aging population’s needs were met by their families. However, some have suggested that traditional value systems are being replaced by modern ideology of individualism, which places this vulnerable population in a more difficult predicament (Beall & Goldstein, 1983; Cowgill, 1972). WHO (2003) suggests that most of these countries do not have institutionalized (formal) long-term care. However, different countries have initiated different strategies to tackle the problems of disability and aging. For example, Indonesia has not yet taken any formal initiatives for the provision of care and service delivery depends on the mobilization of volunteers by the family. Sri Lanka also relies mainly on such volunteers; however, some forms of community care are beginning to develop in response to increases in the number of individuals with disability. Similarly, the unusually high rates of population aging in the Chinese cities of Shanghai and Beijing have contributed to the development of home health services provision. A number of other countries such as Costa Rica, Lebanon, Mexico, and Thailand have also prioritized the development of home health care services. In Lithuania and Ukraine, the aging of the population has created a great incentive to prioritize the provision of services and to develop a range of services for individuals with low incomes. The Republic of Korea has a smaller proportion of older people today as compared with Lithuania and Ukraine, but a much higher level of resources and more highly developed range of services. The WHO (2003) study suggests
that several developing countries are initiating important policy changes that can serve as a foundation to identify the ingredients that could be a model for further success.

Two decades ago, World Health Organization noted a distinction in prominent causes of disability between developed and developing countries. In industrialized, developed countries, disability resulted from the chronic diseases as well as accidents and the consequences of drug and alcohol abuse. In the latter, disability stemmed primarily from malnutrition, communicable diseases, accidents and congenital conditions. As economies in developing countries expand along with and the demographic and epidemiologic shifts, changes in the nature and prevalence of various disabilities may be expected (Kinsella and Velkoff, 2001).

The prevalence rates of the disability in The United States and Canada for older adults is 19.4% and 18.5% (WHO, 2003). However, developing countries often report very low rates of disability. For example, in Kenya and Bangladesh the reported rates of disability are under 1%. According to WHO, there are various reasons why the reported disability rates in the developing countries appear lower. There are differing definitions of disability, different measurement methodologies, and variance in the quality of data collected. The United Nations tried to create a strategy to uniformly measure the prevalence of disability so that it could be comparable internationally. They endorse an approach that uses the national census and attempts to measure the portion of the population that has a limitation in a basic core activity of daily living, such as walking. This functional approach has been tested and implemented in many countries, and generates a narrower range of prevalence estimates; for example, Brazil 14.5%, Zambia 13.1%, Nicaragua 10.3%. However, data from most of the developing countries are not yet available to make a definitive estimate. It is extremely important, however, to keep in mind that disabilities range from severe to moderate to mild. It is much more useful to present information on the range of disabilities instead of reporting a single prevalence rate. For example, the overall disability rate in Ecuador was measured at about 12%, but the rate of severe disabilities was about 4%.

Overall, a worldwide estimate of about a 10-12% rate of disability for all ages seems reasonable (WHO, 2003). Further, disability and poverty are intricately related to each other because disability causes poverty and poverty exacerbates disability. Therefore, people with disabilities are among the poorest and most vulnerable segment of the population in the world.
and lack basic support such as access to social services, education, health services, employment and long-term services and supports (Elwan, 1999). It is therefore safe to argue that the overall incidence of disability for all ages in developing societies may be increasing due to long-term political and civil unrest, disasters, malnutrition, HIV/AIDS pandemic and aging. However, in such countries, disability issues are given low priority or are excluded from official statistics; and information about the rates for disability in general and for older adults (disability in aging) is limited.

Research indicates that politicians and policy makers of most developing countries still think that caring for disabled and older adults is the responsibility of their children (filial piety) and families (Goldstein & Beall, 1983 and Subedi, B. 1996). Unfortunately, they have failed to realize the problems related to disability, older people and need for long-term care. For example, Kunkel and Subedi, J. (1996) report that senior health and planning officials of Nepal expressed in interviews that issues related to aging were not a problem in Nepal and they were not ready to accept it as a problem just because some American academics believed this was the case. Given the fact that most developing countries have not yet recognized issues related to disability and old age, it is not surprising that they have generally failed to devise any initiatives or policies to address such issues. Hence, it is crucial to understand the attitudes and beliefs of key decision makers regarding disability, old age, retirement system, and long-term care. It is also important to understand their beliefs and opinion since they themselves are part of the ageing population in a country where they reside.

This study will focus on the developing country of Nepal which is one of the poorest countries in the world. Like other developing countries, Nepal’s population is rapidly increasing and the issues of aging, disability in aging, and long-term care have not been fully recognized. Most of the available literature focuses on the demographic changes in Nepal, and there is complete absence of research and publications regarding disability and long-term care issues.

**Purpose of the study**

The purpose of this exploratory study then is to examine the attitudes, opinions and beliefs about aging, disability and long-term care issues among some key political and bureaucratic officials of Nepal who are in influential positions of decision-making, and will be thus referred to as decision-makers throughout. It is important to understand and explore
perceptions, beliefs, attitudes and knowledge of these decision-makers regarding issues surrounding both young and old people with disability. It is argued that if the decision makers of a nation lack basic knowledge of issues related to long-term care, policy formulation will not happen or will not be successful.

**Overview of Thesis/ Critical Inquiry Paper**

Chapter 1 provides background information highlighting the importance of understanding issues pertaining to aging, disability, and the provision of long-term care services in a developing country such as Nepal. In doing so, it states the purpose of this study.

Chapter 2 describes the overall Nepali context within which disabled and older people reside. The chapter also discusses why Nepal decision makers tend to ignore the issue of disability, aging and long-term care.

Chapter 3 discusses the study design and method. Specifically, site and sample selection procedures, nature and construction of the questionnaire, data collection methods and the methodology to be used for analyses are described in detail.

Chapter 4 focuses on the findings/results from the data analysis. Finally Chapter 5 discusses policy of the findings make recommendations.

**Chapter Two: An Overview of Nepal**

**Introduction**

In order to understand the aging, disability and long term care issues faced by Nepal, it is important to understand the geographical, economical, political, healthcare system, socio-cultural and structural system of the country. This section will provide an overview of Nepal and the available resources for the people with disability and for the older adults.

**Geographical background**

Nepal is a small country, located between India and China. It is a landlocked country, rectangular in shape of 142,000 square kilometers. In the past, the name “Nepal” by common usage referred to the valley in which the present capital city “Kathmandu” is located. Geographically, the country is divided in three regions; Mountain, Hill and Terai (plain) constituting 23% 35%, and 42% respectively of the total land area. There are five development
regions and 75 administrative districts. These 75 districts are further divided into smaller units known as Village Development Committees (Shrestha, 2007).

The current population of Nepal is approximately 29 million. The nation is composed of seventy-five ethnic groups of Indian and Tibetan origin. Thirty different Indo-Aryan and Tibeto-Burman languages are spoken in the country, but Nepali is the national language and spoken by the largest number of people. Geographically, the majority of the population resides first in the Terai region (49%), secondly in Hill region (41%) and then least in Mountain region (8%). Apart from this geographical distribution of the population, most of the younger working age population resides in Kathmandu valley. Overall, 80% of the total population lives in the rural areas (CBS, 2007).

According to CBS (2003), life expectancy at birth has been increasing for both males and females in Nepal. It has increased from 42 years for males and 40 years for females in 1971 to 61 years for males and 61 years for females in 2003. The total population 65 years and over is about five millions and approximately 83% of the older population reside with their children in rural areas (Pienta, Barber, & Axinn 2000).

**Politics and Political History**

The political system of Nepal can be divided into five parts. These are (1) Unification of Nepal (1769), (2) Autocracy of Rana Ruler (1846), (3) Multiparty system of 1950, (4) Panchayat system (1960) and (5) Multi-party democratic system after 1990 which includes the emergence of Maoist movement in Nepal (Thapa, 1999).

Prior to the unification of Nepal as an independent country, Nepal was divided into 40 different principalities. The first King of Nepal, who belonged to Shah Dynasty, unified all the principalities and declares himself as the monarch. This dynasty ruled for over 100 years. In 1850, because of the family rivalry and conflict a young man name Jung B. Rana was successfully able to lead a coup and declared himself as a prime minister of Nepal. Even though the King was head of the state, the prime minister accumulated executive, legislative and judicial power. In Nepal when the King dies his elder son inherits the throne. Similarly, after the coup, the Rana Prime-minister made the same rule for the Prime-Ministership. That is after his death, his son or brother will inherit the Prime-Ministership. This Rana clan ruled the country over 104 years. In 1950 under the leadership of King Tribhuvan there was a revolt against Rana regime.
This revolution brought a major political change in Nepali history. They instituted a Multi-party Democratic System and the King as a constitutional monarch. However, because of the institutionalized corruption and lawlessness, in 1961, the son of King Tribhuvan, Mahendra decided to lead a coup and instituted a new political system called the Partyless Panchayat Political System. In this system the King had absolute power and oppositional political party system is banned. Some of the political leaders of this time were put in the prison and some took asylum in India. This system continued until 1989, when there was a popular revolution led by the exiled politicians. The success of this revolution once again led to the institutionalization of Multi-party Democracy and the King became the constitutional monarch (Thapa 1999).

In 1990, there was the first open election and members of 35 different parties participated. However, the three main participating parties were the Nepali Congress, Communist (United Marxist Leninist), and the National Democratic Party. In the first election, the Nepali Congress (oldest party) got the majority and consequently they formed the government. During 90’s just like in 1950s, corruption was widespread. The king could not do anything because of constitutional limits and international support for the democratic government. In 1995 a group of communists who called themselves Maoists had major conflict with the government as well as with all other political parties. They decided to revolt against and declare a “Peoples War,” as it was called war against the existing political system. This so-called war has gone on for the past 10 years and more than ten thousand people have been killed from both the government and Maoist sides and still the problem has not been solved as yet (Thapa, 1999).

**Economy**

Nepal is among the poorest and least developed countries in the world with almost one-third of its population living below the poverty line. Agriculture is the mainstay of the economy, providing a livelihood for three-fourths of the population and accounting for 38% of GDP. According to the Ministry of Finance (2007), Nepal’s economic growth remained below 5% in the last six years because of the country’s unstable economic circumstances. Industrial activity mainly involves the processing of agricultural produce including jute, sugarcane, tobacco, and grain. Security concerns relating to the Maoist conflict have led to a decrease in tourism, a key source of foreign exchange. Nepal has considerable scope for exploiting its potential in
hydropower and tourism, areas of recent foreign investment interest. Prospects for foreign trade or investment in other sectors will remain poor, however, because of the small size of the economy, its technological backwardness, its remoteness, its landlocked geographic location, its civil strife, and its susceptibility to natural disaster.

**Education**

Prior to 1950 during the Rana regime, the general population of Nepal was actively discouraged from access to general education. In 1950 there were less than 10,000 children attending school; less than 100 students completed secondary school, and the literacy rate was less than 2 percent. The present education system was developed under the new education plan of 1971 and has been a priority ever since. Nepal has made significant progress in education at all levels during the past three decades. According to CBS, in 2007 the overall literacy rate was 49% for the total population.

**Health and Healthcare System in Nepal**

All attempts of modernization including the implementation of the biomedical or modern health care system in Nepal are relatively new. Historically, the modern healthcare system was introduced in Nepal by a number of Christian missionaries, foundations and trusts. Further, countries such as the United States, India, former Soviet Union, China and organizations such as the World Health Organization (WHO) were primary contributors for implementing and funding this system (Subedi, J. 1989, Subedi and Subedi, 1995). The government of Nepal initiated the first five year plan in 1956-61. Since then, the modern healthcare system of Nepal has become the dominant medical system. However, research indicates that irrespective of the value of modern health care system, the way it has been implemented and is practiced in Nepal has led to access to for only a limited number of urban population (Subedi and Subedi, 1995, Subedi and Subedi 1993).

The Ministry of Health (MOH) plays a leading role in improving the health of the people. The Ministry is also responsible for formulating policies for the effective delivery of curative services, disease prevention, health promotion activities, and the establishment of a primary health care system.

In 1991 Nepal adopted a national health policy to improve health conditions. Since then the focus has been on (1) preventive health services (2) promotive health services (3) curative
health services (4) basic primary health services with one health post each in the entire 205 electoral constituencies to be converted into primary health care centre (5) ayurvedic and other traditional health services (6) community participation (7) human resources for health development (8) resource mobilization (9) decentralization and regionalization (10) drug supply, and (11) health research (MOH, 2002). It is interesting to note that the Ministry of Health is focusing on the improvement of health status of the most vulnerable groups, particularly those whose health needs often are not met. These include women and children, the rural population, the poor, and the underprivileged; but health improvement of older adults has not received much political attention thus far.

**Overview of Disability in Nepal**

Disability consists basically of two types namely physical and mental. The Sample Survey of Disabled Persons 1980 collected information on types of disability by these two broad classifications. According to Nepali census data of 2001, 44% of children age 0-14 years suffered from physical disability, and 32% of disabled at age 50+ years reported this disability. On the other hand, percent of Blindness which was 13% for aged 0-14 years, increased to 30% for 50+ years aged disabled persons.

Over the past decades the definition of disability has changed. In Nepali constitution a person with disability is defined as an individual who is incompetent to lead a normal life both physically as well as mentally. This term includes individuals whose mobility is impaired, and those visually and hearing impaired, or unable to speak, etc. (JICA, 2002). Other studies have defined disability classification in different ways: (1) the 1971 census defined the disabled as the “economically inactive population” due to physical disability. Based on this definition the rate of disability in 1971 was 1.50 percent, (2) the 1980 sample survey of disabled persons in Nepal defined persons with disabilities as those with physical and/or mental disabilities incapable of living independent (personal or social) life, or engaging in gainful employment, or acquiring normal education consistent with his or her age and sex. It also had sub-categories describing physical disabilities, (3) the 1995 Disabled People of Nepal Survey conducted by four not-profit organizations defined disability using five categories which were hearing, visual, physical, mental and intellectual disabilities. This survey, reported that the prevalence of disability was 4.55 percent, (4) in 1998 a study conducted by Agricultural Projects Services Center (APROC)
classified disabilities into six categories which included multiple disabilities along with epilepsy (developmental delay) and speech problems, and (5) study conducted by New Era (1999) defined persons with disabilities as individuals who could not perform the activities of daily living, who required special care, support, and rehabilitations services. The study also reported that services and organizations for people with disabilities are concentrated in urban the accessible areas of the country (JICA, 2002).

Table 1 shows the distribution of disabled persons by ages and types as reported in the Nepal census of 2001 is shown.

Table 1: Distribution of disabled persons by types and by age groups, census 2001

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Physical Blindness</th>
<th>Deafness</th>
<th>Mentally Retarded</th>
<th>Multiple Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-49 (44.22)</td>
<td>13.47</td>
<td>23.02</td>
<td>11.24</td>
<td>8.05</td>
</tr>
<tr>
<td>50+ (37.72)</td>
<td>10.89</td>
<td>26.26</td>
<td>17.39</td>
<td>7.74</td>
</tr>
<tr>
<td>Total (39.32)</td>
<td>15.92</td>
<td>24.61</td>
<td>12.69</td>
<td>7.33</td>
</tr>
</tbody>
</table>


Singh (2002) reported that the census data does not provide information about the causes of disability. The overall disability prevalence rate in Nepal is higher for males than females. The majority of those with disability (64.3 percent) are in the working age group (15-59 years of age). A survey conducted in 2001 showed that 57.6 percent of the head of households with disabled members had no education. Among the disabled, 22 percent of economically active people were working in the agriculture sector. According to Sarlahi survey (2003), the causes of disability among aged 60 years and above were 16 percent due to communicable diseases, 14 percent due to non-communicable diseases, 14 percent from birth, 16 percent due to accidents and 25 percent due to aging.

Overall, research on disabilities associated with aging is still limited and governmental health policies only focus largely on physical disabilities alone.
Social Welfare System in Nepal

The Ministry of Women, Children and Social Welfare (MWCSW) was established in September 1995 and is the central ministry for policy, planning, programming, and overall development and coordination of all activities related to women and children, senior citizens, orphans, and disabled or handicapped persons. It has two divisions: Policy, Planning, and Administration; and Women, Social Welfare, and Child Development.

The Social Welfare Council is an umbrella organization of the Ministry of Women, Children and Social Welfare and has more than 160 staff. The MWCSW and the Social Welfare Council are responsible for the welfare of disabled and older citizens, but currently their main priority is on issues related to women such as problems of trafficking women and children and their commercial sexual exploitation.

Government Old Age Home

The term “Briddha Ashram” refers to an old age home in Nepal. There are several Briddha Ashrams but “Pasupati Briddha Ashram” is one of the oldest. It is fully funded by the Government of Nepal. This Briddha Ashram is situated near the famous temple called Pasupatinath Temple. In Nepal it is a religious and cultural belief that once a person gets old, it is better to be near the god or goddess. Given the fact that Pashupati temple is considered a major holy shrine among the Nepalis, and after the death, cremation near this temple assures heaven. Hence, similar to the temple, this old age home is equally well known. However, this is not a nursing home, but a shelter home for the old and destitute older population of Nepali society.

In the capital city of Nepal, Kathmandu, the Pasupati Briddha Ashram (shelter or old age home) is funded by the government. Interestingly, the capacity of this shelter home is 150 individuals; however, about 200 older people reside in this setting.

Recently, several shelter homes for older adults have opened in Nepal. The Nisaya Sewa Sadan (shelter home for helpless) is partially funded by the government with 56 residents. It also receives contribution from the residents and/or their families and some funds were provided by the other sources, such as voluntary contributions by various individuals; and (3) Siddhi memorial old age home, a private non-profit organization funded by the family, friends and an international non-profit organization (Germany). Interestingly, this institution targets those older adults who are economically well off, however, in actuality, this is more of a daycare center
rather than a home for the older adults. At present, they have a total of six residents living in this facility.

Thus, there is no basic income maintenance program for older adults except for individuals who are in the work force such as military, police and civil servants. Some private company employees participated in the governments’ provident fund programs, but the numbers are very small. The vast majority of older adults have to rely on the old age allowance which is not reliable due to the instability of the government.

Chapter Three: Methodology

This qualitative, exploratory study was conducted in Kathmandu, capital city of Nepal in the summer of 2007. Decision-makers of Nepal are persons in powerful positions from various governmental departments include prime-ministers cabinets and ministers who happened to be members of the parliament, legislators who represented various political parties, and member of the planning commission appointed by the cabinet members who are responsible for planning and policy activities for Nepal. These officials bring their own background, experience, values, attitudes, beliefs, and knowledge which shape or influence planning and policy for the country. Decision makers’ knowledge about their familiarity with the demographic transition of the country, old and young disabled populations knowledge of issues related to long-term care, and aging policy. Perceptions regarding old age, disability, old age homes, and their expectation of care in old age will be explored. Eighteen interviews with decision makers were completed; eleven of these interviews were conducted in the participants’ home, and seven interviews were conducted in the participants’ offices.

Sample Selection (N=18):

The sample population included 18 key decision makers holding various positions in the government. As stated earlier, participants included bureaucrats from various government agencies (N=4), members of the cabinet (prime-minister and ministers) who are also members of the parliament and legislators who represent various political parties (N=13), and a planning commission member appointed by a cabinet minister (N=1). The goal of this study was to interview a total of 25 decision-makers, but 18 decision makers agreed to be interviewed. The list of names were identified from the government and political party’s telephone directory.
Then, the names were selected for those individuals from ministries/government agencies directly or indirectly involved in aging and disability related issues.

**Data Collection:**

The data were collected through face to face interviews using 12 semi-structured, open-ended questions (Refer to appendix for questionnaire). The interviews were conducted in the Nepali language, tape-recorded, transcribed in Nepali language and later translated into English. Telephone calls were made to the secretary of the respected decision-maker, and interviews were scheduled. During each initial call, I briefly introduced the project to the secretary, explained that about half an hour to 45 minutes of time was needed, and that only the interviewer and interviewee would be present. All interviews lasted approximately 35 to 45 minutes each.

**Research Question:**

The central research question this study explores is “What do decision-makers of Nepal think about aging, disability and long-term care issues?”

**Demographics Characteristics of the Participants:**

Below table 2 describes the demographic characteristics of the participants (key decision-makers) and their political parties or bureaucratic affiliation. The age of the participants ranged from 38 to 82 and the level of education ranged from high school to doctorate (PhD) level. Even though, the caste system has been officially abolished, however, it is prevalent in the social hierarchy of Nepali social structure. Therefore, the caste system is embedded in the social stratification system of Nepal. It is thus important to identify the caste of each decision-maker in order to see whether these decision makers came from all the different castes. Interestingly, of the 18 participants 9 were Brahmins, 4 were Kshatriyas, 4 were Vaishaya and 1 was from the Sudra caste (Detailed explanations about caste system see: Rossi des, 1997). Regarding gender, of the 18 participants fourteen were males and four were females. Political affiliation was categorized. Those who belonged to various democratic parties and held democratic ideology were lumped together as “democrats”, whereas those who belong to various communist parties and communist ideologies were labeled as “communists”. It appeared that 8 decision-makers’ were democrats’, 5 were communists, and remaining 5 were bureaucrats. It may be interesting to note that one of the participants was the Prime Minister of Nepal four times in the past; two of the participants are Prime Minister and Deputy Prime Minister (at present), three participants
were Ministers multiple times in the past with various portfolios, whereas seven decision-makers were Cabinet Ministers, and one decision-maker/participant was the Deputy Speaker of the Parliament during the time of these interviews.

Table 2: Demographics Characteristics of the Participants

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<tr>
<th>Participants</th>
<th>Age</th>
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<th>Caste</th>
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</table>

* They belong to an ethnic group of Kathmandu valley called “Newar”. Newars are either belongs to Hinduism or Buddhism. They have their own caste hierarchy which is similar to Hindu Caste Hierarchy. However, Brahminic Hindu Caste Hierarchy tends to put Newar in Vaishaya Category of Hindu caste system.

** For bureaucrats party affiliation is not applicable*
Informed Consent:

Prior to the interview, each participant was told about the nature of the study, and verbal permission/consent to have the interview to be recorded was taken.

Qualitative Data Analysis Procedure:

All the participants’ were identified by ID numbers to assure confidentiality. The obtained data were transcribed into Nepali and then translated to English. The total time for transcribing and translating each interview took approximately six to seven hours. From the raw data, themes and the patterns were identified and recorded. These themes focused on three broad categories (1) aging: five questions exploring the perceptions and knowledge of familiarity with the demographic changes in the country, old age homes, challenges associated with aging, and expectation of care in old age; (2) disability: four questions regarding knowledge, familiarity, and perceptions of disability. This section also explored the importance and the policy issues surrounding both young and old people with disabilities; and (3) long-term care and the policy issues: three questions explored in this section in which two questions were regarding knowledge, perceptions about long-term care. The last question was the role of government in initiating programs related to aging, disability and long-term care.

Chapter Four: Results

In this section the themes and patterns of responses that emerged from the semi-structured interviews conducted with the 18 key decision-makers of Nepal are presented. The first section contains the perception and knowledge about aging issues, encompassing the demographic changes in the country, and their understanding of policy issues. The second section examines the perception and knowledge about disability issues, such as the importance of age and disability, knowledge about where and how the older individual with disability goes for help and the role of the government to meet the challenges of people with disability. Finally, the third section describes the participant’s knowledge of long-term care and the role of the government.

Findings:

Section (1): Demographic Changes and Aging Issues:

In this section, five questions were asked: Are you familiar with the demographic changes of the country? If so, explain. Would you explain what does it mean to be old? What
kinds of challenges are associated with the aging population of Nepal? Have you ever been to Briddha Ashram? And what do you think about Briddha Ashram? Who will look after you once you and your spouse get old and need help?

The overall findings suggested that the most of the participants’ have a general understanding that the population of Nepal is increasing. However, the participants have a lack of understanding about the demographic reality of the country. Depending on their official position and their life and work experiences, the participants were able to understand some limited aspects of demographic changes. Nevertheless, responses seem to indicate population increment, migration pattern, changes in family structure, and the impact of Maoist insurgency as the cause for demographic changes. However, these participants were less clear in their understanding about the consequences of these demographic changes. For example, out of 18 participants 16 participants specifically said that the changes in the family structure were the key factor for the demographic changes in the country. Whereas, all the seventeen participants said that changes in family structure were the consequences of having a nuclear family, people were migrating to the urban areas as well as abroad. At the same time the overall life expectancy has increased consequently, the older population is destined to be alone in their later life. Further, 13 participants reported that both internal and external migration was the key for the demographic changes in Nepal. Further, fifteen participants also suggested that the Maoist insurgency has also played a dramatic role for this unnatural migration pattern. In the words of one participant:

“Um…Nepal has more rural areas than urban an area…it is made up of many villages…I feel that the Nepal has changes demographically for example Nepali people are seeking opportunities to go to the urban areas for the jobs or for the higher educations. If Nepali people get more opportunities, they tried to go to abroad for the same reasons especially for the jobs…this is the trend I have seen in our nation. We also have witnessed that in the village, we hardly see younger generation…these young people tend to leave their old parents and the children for the services in the urban areas and as well as the other countries…those who have high school degrees (I.A.), they tend to go to Gulf countries and South Korea for the job…and also there is a Maoist problem…who would want to stay in this country, when you have better opportunity in other places…um… Well this is what I have seen in terms of demographic changes in the country.”
Only one participant demonstrated the understanding of demographic changes of the country. He suggested that the reason the overall population of the nation has increased due to the overall development of the society. According to him,

“This is a process of society’s development….um…like economic development…um …society’s democratic change…this is the process of world’s development…it’s a common thing…you know. This is what is happening in Nepal…um…in that process of development…number of old and young population is increasing and the number of people especially younger generation will increase more. This is what I see.”

The participants were also asked the meaning of old age to capture the essence of getting old, i.e., would you explain what does it mean to be old? This is a broad question which is applicable to decision-makers’ own life course and meaning of the old age in the cultural context of the Nepali society.

What kind of knowledge did participants have regarding old age? Some of the participants responded with “I” in a personal way rather than in an impersonal manner. The patterns of responses identified by the participants were physical symptoms, economic burden & mental state.

Four main response patterns and themes were identified, those are: physical symptoms, economic burden, mental and psychological burden, and old age dependency. All 18 respondents described old age as being associated with physical symptoms. For example, the participant #2 described that:

“Um…if somebody says I’m old…um….that the person is not physically well, due to the age, you know once you cross certain age…if the person is inactive in his/her life…that’s what I think.”

Further, response of the participant # 11 is another example which divulges that the old age associated with the physical symptoms and the dependency on others. For example,

“…as the person gets old, the person will show the physical symptoms such as physically weakness, age-related symptoms-changes in the body and the person will be dependent on others.”

Moreover, of the 18 participants, 16 participants also described that the meaning of old age entails economic burden for the older adults, because the older person will be inactive or incapacitated in old age and the sources of income will be very limited, consequently, they have to depend on their family for their economic need. Since the family structure has changed over
time with many younger people migrating to the urban areas and/or abroad, the older people will be left alone in their dwelling with tremendous economic vulnerability.

Of the 18 participants, 13 participants also identified that old age was associated with deteriorating psychological and mental process that one needs to deal with it. One participant identified the meaning of old age in more personal term. For example the participants#5 said that:

“Um…physically inactive, depended on others…um….I need somebody to take care of me…I can’t do anything….I need help from my son and daughter-in-law….when I become ill, I need somebody to take care of me and my medication and same with the foods, washing clothes…I think these kinds of feelings will come when people will get old…people will dependent on others that’s that.”

The overall findings suggest that the participants associate “old age” with physical and mental weakness or with health related issues. Further, sixteen participants suggested that older adults will be unproductive in the later years, if these older adults don’t have savings in their lives then, it will be a economic burden to sustain their later lives. Further, fifteen participants said that older people have to depend on others such as family members or the relatives or somewhere else for the help. Of the 18 participants, thirteen participants said that the meaning of old age can be associated with the mental and psychological burden. The participants further mentioned about the feeling of loneliness, or they will be ignored by the family members.

In response to the challenges of old age (third question) all 18 participants’ reported that older adults would face economic challenges in their old age. These economic challenges could be due to retirement form the government jobs, or income decreases from the agricultural job, or inconsistent income due to various reasons and some of older adults survived in very limited resources. The second theme emerging from this question was family. Of the 18 participant nine participants said that due to the modernization, civil war and internal/ external migration family started to disintegrate and in urban areas people started to live in nuclear family which had major impact in older adults. As result older adults were left alone in the villages, psychologically challenged, become emotionally weak and lonely. Of the 18 participants sixteen participants’ reported about the challenges associated with older people health as well as healthcare in the country. The sixteen participant described that older adult will have some form of chronic diseases such as physical weakness, joint pain etc. Three participants mentioned the lack
geriatric health care in the country. Two participants said that it is not the time to think about the challenges associated with old age, because it was not in the country’s priority list. They emphasized stabilizing the country first then only think about other issues in the country.

Regarding the fourth question, of the 18 participants, fifteen had visited Pasupati Briddha Ashram (Old Age Home); four participants had also visited old age/nursing homes abroad as in England, Japan and Malta; three participants also said that they had visited other Briddha Ashrams along with the Pasupati Briddha Ashram. Two of the participants had visited Briddha Ashram outside Kathmandu while one respondent had not visited any Briddha Ashram but was scheduled to do so.

The participants were asked whether the visit was personal or official visit. Eight participants said that it was part of their official work, while six participants went there for personal reasons, such as giving food to older adults during the anniversary of their dead parents. One participant went to visit Briddha Ashram officially as well as unofficially. For example the participant #6 said that

“I went to Pasupati Briddha Ashram twice…um…one time officially …there was some kind of function at the ashram…I was the chief guest…I had to distribute all kinds of goods like food and clothes to the older people. The second one was something more personal…in the memory of my father…you know we did “shraddha” every year in the memory of the people who are deceased…after we finished the rituals at home, we went to Pasupati Briddha Ashram and distribute food and some money to those old people. This we do occasionally.”

Two participants visited Pasupati Briddha Ashram for the research purposes. For example participant # 7 said that:

“um…when our late queen was head of department, she inquiry about the old people in Pasupati Briddha Ashram…she told us that the people who lived there was in despair and asked us to visit and come up with the solution….like writing proposal etc….Her Majesty told my boss…that was in 2035 B.S or 2036 B.S.(1978 or 1979AD)…well…my boss told me to visit there and I met volunteer name Cristina from Germany…she was taking care of the older people who are burned…burned case… I was very young at that time, just finished my studies and working…I was very glad to that I met Cristina…she gave me the idea of research methodology and learned from her…I wrote a proposal…also found that those days there were only 12 or 13 INGOs or NGOs….they were not at all not interested in old people…at that time nobody took any interest in aging population…neither the government nor the NGOs….whatever the benefits the old people in Pasupati Briddha Ashram are getting…it is still there…that’s the contribution from the government.”

19
Then the participants were asked about their view of the Pashupati Briddha Ashram that all of them had visited. Fifteen participants said that the situation of Pasupati Briddha Ashram was in a pathetic state. One of the participants said that Briddha Ashram was neglected and so were the older adults of Briddha Ashram. For example participant #15 said that:

“Talking about the overall environment…um…I don’t think you have been to that Briddha Ashram…it’s totally a strange environment…have its own world and you can see a large number of old people from various background. There are very limited good services for the old people, physical environment…um…I don’t know what to say. But if you talk with the individuals, you can hear the sad stories of their lives…um…I was surprised…you know…the children are not taking care of their parent/parents and they end up there. Those old individuals are neglected, dehumanized by their own children…their last resort was that ashram…some of them are depressed, morally down…the only support and hope is Briddha ashram….you know they can get free food, shelter and its near to the temple…well this is a unique place where you can see and feel the pain of the older and rejected people.”

Four participants’ said that they had visited nursing home for older adults in the western countries. When asked about the difference between Nepal’s Briddha Ashram and the nursing homes, three participants said that Nepal should learn from the western world. Further, two participants said that old age home was a new concept but it seemed to be emerging in the context of Nepal. One of the participant also said that it was a sign of modernization of society. For example participant #7 states:

“In terms of England, we can’t compare but in Bhaktapur, we had seminar… that’s why I went there and was happy that the concept of old age home is finally there, kind of modernity…”

The overall findings suggested that the participants are aware of old age home in Nepal, particularly, Pasupati Briddha Ashram. The participants reported that the old age home especially Pasupati Briddha Ashram is in dismal state. Even though, this Briddha Ashram was fully funded by the government, some of the participants reported that it is one of the neglected areas in the country. They also reported that there were inadequate staff members which allowed the older people with disabilities (both physically and mentally) to roam around without supervision. One of the participants reported that the individuals who came to Briddha Ashram were from abusive families or included individuals who did not have family at all. The participants who visited officially often reported that they were in the ashram for specific functions and they really did not spend enough time in the shelter. However, the participant who
went to Briddha Ashram for personal/religious purposes had some time to spend with the older adults. One participant admitted that he never wanted to visit again because he could not stand to see the pain that older adults were suffering.

The four participants who visited nursing homes in foreign countries were amazed by the system, the treatment of the older adults and the facilities. These four participants, however, did not know the difference between old age homes and nursing homes. However, they admitted that Nepal needed to learn from the western countries to enhance the life of older adults who are in need by constructing the proper care facilities. These participants also believed that these issues needed to address.

The final question (expectation of care) in this section tried to capture the individual perception and knowledge about their old age life. The question was “who will look after you once you and your spouse get old and need help?” Of the 18 participants, 15 said that their family will take care them and of their spouse. Further, the participants also said that they did not want to be dependent or burden on their children. Among the same fifteen participants, three of the participants’ also said that the God’s Will will take care of them. For example participant #5 laughed and said:

“…God…God will take care of me…I’m fifty and over…very religious person …my eldest daughter got married and settled in U.S. Who will take care of me and my wife…it’s in God’s hand.”

Among these fifteen participants two also said that they had realized the importance of long-term care and they would hire somebody to look after them if they got disabled in old age. For example participant # 16 said that:

“Of Course my children…but you mentioned about this long term care…now I have to think…you made me think…what we will do in our old age…”

The participants #6 said that:

“Um…I’m hoping that my children will take care of us…every parents will hope that one day their children will look after them. But I’m determined…um…in my old days whether I will be healthy or disabled, I’m making some plans that I don’t have to rely on anybody. That’s that.”
Further one added that:

“Um…if that happens…then I’m hoping that my children will take care of me, if not my children will hire somebody to look after me. Um…I don’t think, I want to think about this…laughs…well, that’s not what you think…being disable…having someone to take of you….well… um… question is already in the table…now I have to think…well…in terms of support…have to find more about nursing care…and those type of people I can hire, I guess…you know…I have to try my best…any how I have to survive in a good way.”

Only 2 of the 18 participants said that their own political party would take of them in their old age. These two participants also said that they had sacrificed their life to build their political party and they were hoping that their political party would support them. One participant also said that the Nepali citizens would take care of his/her old age.

“Well…I gave my whole life to the society…we don’t have any property or wealth….I am here for the people of Nepal…sacrifice my whole life….I think people of Nepal should look after me.”

The overall findings suggested that family is the integral part of old age. Most of the participants wanted their sons or daughters to take care of them. This shows that traditional values still dominate. Expectations of help from their own children were much higher than from relatives or other sources. It is also interesting to note that participants who had expectations from their children were from all the political spectrums. These participants were also torn between the impact of modernization/political conflict in the country and the traditional value system. Due to modernization and political conflict most of their children were either abroad or were planning to move. The participants admitted that their children might not come back to Nepal. Additionally, the participants acknowledged that they had never thought about their old age in this context and this question had made them aware of their own future.

**Section (2) Disability Issues:**

This section examined the perception and knowledge about disability issues among the decision makers of Nepal. In order to do so, four questions were asked: is disability is a major problem in Nepal? Do you think is disability in younger adults or older adults is a major problem? Where do older people with disability get help? And what do you think this nation should do to meet the needs of disabled population?
The findings indicate that the participants had different perceptions about disability in Nepal. The responses for the first question varied from “have no idea… to disability is a recognized population.” The overall pattern emerging from this question suggests that most of the participants did not think disability was a major problem in the country. Two participants also reported that they did not know anything about disability in the country. For example participant #3 said that:

“How do I know…disability is a huge problem or not? I don’t know the number of people with disability live in the country?”

Of the 18 participants, four reported that “disability” in general was not an issue at all. Similarly, the remaining participants suggested that they had very limited knowledge on issues related to disability.

Those participants who have some working experience in related fields reported to have some knowledge on disability issues. For example, the two participants who are bureaucrats highlighted the lack of census data on disability in Nepal.

Furthermore, these participants could not agree or disagree about the issue of disability in Nepal. These participants said that they have no idea whether disability was a huge problem or not. The reason behind their skepticism was related to census of Nepal conducted in 1991 and 2001. They stated that even the 2001 census was not able to provide concrete statistics on rates of disability. In fact, they suggested that the 2001 Census did not even include any questions regarding disability.

For example, in the words of participant #7:

“Yes, I think disability is a problem in the country, in terms of the number of disabled population, there is always a dispute…the disabled association always maintained that 10% of the total population are disabled….I know a man who himself is disabled …um…his name is S. Shah, went to the census office and asked them to put the questionnaire but it was already too late…I believe that was in 1991…I’m not sure in 1991 census had the disabled questions or not. Due to S. Shah, census office gave the responsibility to New Era to conduct the survey…um…to find out the disabled population. After that for the 2001 census, with the help from the UNICEF…I guess…introduced the questions about the disability…well we don’t know exactly, how many people are disabled in the country…um…we also need to include those people who got disabled during this people’s war...”
One participant maintained that disabled individuals were a recognized segment of the population but unfortunately they were victims of stigmatization. Further, this participant stressed that something needed to be done urgently. Overall, participants had limited knowledge on disability issues and stated that in general disability was not a major issue in Nepal.

When the questions “Do you think disability in younger adults or older adults is a major problem?” was asked, of the 18 participants seven expressed that disability in both young and old was equally important; however, one should not compare the two segments of the population. The most important point was to recognize that both were disabled and had different problems, hence different needs. Upon asking the question about disability needs in old age, participants reported having minimum knowledge. Most responses were that old age disability was a family issue and the family needed to tackle it. The participants had also stereotypical points of view of disability in old age. For example, participants had the idea that all older adults had arthritis or some form of chronic disease. Some participants suggested that older adults tended to be senile. Participants implied that family support was more important. One of the participant felt that disability in old age was mainly due to chronic diseases.

Moreover, two participants suggested that disability in old age was a cultural issue.

“When we talk about older adults separately, then I think it a problem but if we talk about the people with disability…um…then it is minor compare to younger people with disability. But one thing, we have to remember that these older adults have contributed their lives for the country, the government and their family cannot ignore these older people. If we ignore the older population then we have to face social, moral and cultural consequences…negative impact for the children, younger generations and for the society as a whole.”

They further stated that charitable organizations need to pay attention to older population with disability.

Interestingly, two participants adamantly maintained that old age disability was not even an issue or if it was an issue, it was a minor. To them disability in old age was a fact of life. We all get old and disabled somehow, somewhat suffer, and die. However, four participants felt that disability in younger population was a serious issue. They recommended that as a society we should prioritize the younger population with disability. The reason is that the younger populations have a long period of time to live with disability. They need to be productive citizens and live with dignity. Older people have already lived their life for a long time, and since they
are not going to live for that much longer, society should not spend valued resources for this segment of the population. Interestingly, all seventeen participants admitted that the awareness about disability in both the young and old population is due to the “people’s war, i.e., Maoist insurgency.” In one sense, all the participants consciously or unconsciously try to blame Maoist movement for creating more disabled people in Nepal.

For the question about where do older people with disability get help, all participants stated that older people with disability get help from their family. Participants stated that it was the responsibility of the family to provide for whatever the older person needed. All of the participants were quite adamant, forceful, and a bit emotional when they suggested that the role of the family was to provide unconditional support to older population with disability. For example, participant # 7 suggests that “Most of the help they get from the family…and some from the government.”

Of the 18 participants, three referred to existing old age homes and some NGOs as places of help for older people with disability. For example participant # 11 reported that

“Um…I told you before…again I’m telling you that old home concept is not a bad idea…well…I think they get help from the family, if not I think from the existing old home that is available in Kathmandu and other parts of Nepal.

Three participants expressed their frustrations and stated that government should provide help to this segment of the population but had not initiated any program at the present time. Overall, all participants felt that family support played the most vital role regarding disability in old age. If the older adults with disability did not have any family, then they should seek help from old ages home or non-profit organizations.

Finally, when the question “What do you think this nation should do to meet the needs of the disabled population” was asked 13 of the 18 participants suggested that the government of Nepal needed to define its role regarding the disabled population. They suggested that as a nation, we could not continue to ignore this segment of vulnerable population who needed help. Participants suggested that the government needed to create various comprehensive programs to tackle the needs of the disabled population. Families of the disabled population should also be involved in providing care but comprehensive healthcare facilities need to be expanded. They further stated that Nepal was a poor nation and that the government could not take total
responsibility; hence family and community should be involved. Three participants did not mention the government and its role, but mentioned their own political parties. Basically they suggested that their political parties have their own disabled association designed for take care of the disabled members:

“In terms of disabled population, to tell you the truth, our own political party has disabled association. Those disabled population who are in our organization are physically disabled, we don’t have people with mentally disabled or ideologically disabled. We are trying to tackle these issues…um…related to disabled population… I think in terms of mentally disabled population…politicians are mentally disabled…they don’t know what they are doing…these politicians”

Interestingly one participant was dumbfounded and could not answer the question. This participant said that “there is no need for further discussion regarding this issue I never thought about it, and therefore, I need to think about it.”

Overall, the findings reveal that most of the participants feel that the government of Nepal should take action and take some responsibility for the disabled population. However, they view younger populations with disability as more important than older populations with disability. All maintain the beliefs that care for the older population with disability is the responsibility of the family.

Section (3): Long-term care Issues

This section examined the perception and knowledge about long term care issues among the key decision makers. Three main questions were asked to the participants: have you heard about LTC? whose responsibility is it to provide LTC for older individuals with disability? and do you think Nepal needs to initiate a policy related to aging, disability and long-term care?

In response to the first question, all 18 participants said that they had not heard of long term care. Therefore, for five to ten minutes depending on the participant’s interest, I explained the meaning of long-term care. After general understanding of long-term care, all 18 participants admitted that Nepal did not have any programs regarding long-term care for the aging disabled populations. As participant #3 states:

“I think INGO and NGO have started that kind of program, I really don’t know… but the government doesn’t have this kind of program and we have not planned anything regarding long-term care. I think most people even don’t know what long-term care is all about…this is new…”
The next question was “Whose responsibility is it to provide long-term care for older adults with disability?” The patterns emerging were (1) nation, (2) nation and the non-profit organization and (3) government, community and the family. Of the 18 participants, 13 almost immediately said that it was the government or society’s responsibility to provide long-term care for the older disabled individuals. Participant #5 stated that in Nepal there were some organizations to look after older individuals with disability. Participant #5 also mentioned about one of the oldest non-profit organizations in the country serving people with disability especially who were infected with leprosy. This participant maintained that the nation or the government should play the major role providing long-term care:

“Immediate family…um…have you heard about Khagendra Navajeewan…the disabled individuals go there to live…they have a very good program…some people stay home and are taken care by their family and some go to this not for profit organization ….we have small numbers of places for mentally or physically disabled people eventually the government should take the initiative and provide the long-term care.”

Three of the 18 participants said that there should be collaboration between the government and the community. For example participants’ #7 said that:

“It has to be the collaboration between the government and the community…the government can’t alone do anything…the community should be aware and organized…um…taking care of the older population with disability…and voice or lobby for these people then only government will do something…then only can sustain for the long run.”

Similarly, participant #14 reported that the government should be involved in supporting the social organizations. Therefore there will be fewer burdens for the government and society. For example, Participant#14 suggests that:

“I think it is the responsibility of the society in which they live in…um…the government also has to support them. But the government also can’t take all the responsibility…it will be the burden; therefore, with the government support other social organizations should also take the responsibility. Well this is what I think.”

Overall, findings indicate that all seventeen participants had not heard or had knowledge about long-term care. Some participants felt that long-term care was a western concept which may or may not be applicable to Nepal. However, they were enthusiastic about long-term care, when the interviewer explained the meaning. The responsibility for older adults with disability
then should fall on the government mainly. This section will describe the participant’s perception about the role of the government to initiate the comprehensive program regarding long-term care. In order to do so, participants were asked whether Nepal needs to initiate a policy related to aging, disability and long-term care.

Finally, participants’ were asked whether Nepal needed to initiate a policy related to aging, disability and long-term care. The themes emerging from this question were (1) Social challenges, (2) Cultural barriers, (3) Political barriers, (4) Political ideology barriers (4) Government’s role, and (5) Creation of new program for aging, disability and long-term care. All participants reported that this was a huge challenge in society due to the impact of modernization.

As far as the role of government in initiating programs related to aging, disability and long-term care, two participants reported that it was already late and if related officials did not realize the need to act promptly then there will be a huge problem in the future. These two participants said that it was a shame that Nepal did not recognize these issues as problem. Other participants suggested that the country was not advanced in terms of these issues because of the cultural value system of filial piety and reciprocity. In other words, it is the family’s responsibility first. Furthermore, the political instability in the country has also played a very negative role in creating such a situation. Political situation has been identified throughout the interviews as a “political barrier.” Most of the participants indicated that the main priority of the nation was to stabilize the political system through a democratic government. However, due to differences in ideology, political stabilization was difficult. As such policies concerning long-term care were not priority.

The next theme that emerged from this question was the political barrier which was raised by Maoist/Communist participants. These participants believe that until and unless the elitist ideology is eradicated, there would not be fair opportunities for the majority of the people and that such elitist ideology would continue to have negative impact on the lives of the general population.

Participants however contradicted the above statement by suggesting that there should be some kind of programs related to long-term care for the older adults and people with disability and that the government should be responsible for taking care of these needy people. Some of the
participants suggested that the government should be the only one responsible to create and implement aging, disability and LTC programs. But others responded that government should also involve family members in planning. Participants felt that government, non-profit organizations, and family members should all be involved for the betterment of aging and disabled older adults. One participant suggested that the program should include a free health clinic.

One of the participants raised an interesting question concerning current government priorities. This participant said that there was an ethical dilemma in terms of priorities of the government. He asked whether the government should focus on infectious diseases to save younger children/population or protect older adults from chronic diseases and disability and initiate long-term care program. Thus, overall participants admitted that Nepal as a nation is way behind in terms of initiating programs to take care of older populations with disabilities. However, they all admitted that nothing can be done due to the unstable political climate of the nation.

The next chapter will discuss the role of the decision-makers in the policy making process, policy implication, and recommendations.

**Chapter V: Summary, Discussion and Policy Implications**

In any society a range of actors play an important role in formulating and implementing policy. Institutional actors are the political decision-makers and non-institutional actors are the interest groups, advocates, media, and political consultants for aging and disabled populations. The institutional players are the most powerful in the policy making process, whereas the non-institutional players tend to influence the decision-making processes (Theodoulou, 1995a). It is important here to note that this research is focused on the institutional players only. The question in the context of Nepal is what role do these decision-makers (institutional players) play regarding the issues of the aging of the population, older people with disability and long-term care? Do these decision-makers perceive these issues as “problems”?

**Are Aging, Disability and Long-term care important issues?**

This study has attempted to explore the decision-makers’ knowledge and perception about these issues. As indicated in chapter-3, decision-makers have very limited knowledge regarding the issues of aging and disability. Interestingly even government officials in Nepal
have almost no data regarding the incidence and prevalence of disability. Throughout the history of the census, the government has never included any questions pertaining to disability and aging. Therefore, it is not surprising to discover that the decision-makers lack real understanding regarding issues related to aging and disability, and thus they do not foresee these issues problems.

It appears that decision-makers have a very traditional understanding of aging. They believe that disability in old age is inevitable; it’s a fact of life. In their mind, the quality of life in old age and living with dignity is for the privileged class. It is important to note that these decision-makers themselves are middle aged and/or older; however their knowledge and perception failed to recognize problems associated with disability and old age among the vast majority of the older population. Therefore, they feel that the younger disabled segment of the population should be the priority and not the older segment.

The key decision-makers also strongly believe that it is a responsibility of the individual family to take care of the older person with disability and not the government. However, they do admit that those older people with disabilities who do not have family to support them should be cared for by some sort of institution like the famous Pashupati Briddha Ashram. But, the participants were not sure how to fund such care.

It appears that decision-makers’ education and political ideology also played a crucial role in the perceptions and the knowledge about these issues. For example, the decision-makers who had higher education tended to have more knowledge on aging issues than those who had less education. Similarly, decision-makers who held communist ideology tended to focus on the younger population of the country compared to older people and people with disabilities; were more focused on power (aiming for the higher government official rank) and how to change the country; and repeatedly suggested that aging services is not in the country’s priority right now.

Regarding long term care the findings of this research suggested that all 18 participants had not heard or /had no knowledge about it. Further, some of the participants suggested that it is the western concept which may or may not be applicable to the country. However, they were enthusiastic about long-term care, when the interviewer explained the meaning. The responsibility for older adults with disability then, the participants said should fall under the government. This indicates that if the key decision-makers of Nepal understand the issues
involved in provision of long term care several steps can be taken to strengthen the existing programs and to create a better program for the older adults and adults with disabilities.

Discussion

The aging population of Nepal is continuously increasing. An increase in the number of older people will likely result in a higher number of individuals with a disability therefore, the older adults of Nepal could face massive challenges to sustain their lives. Hence, the government of Nepal urgently needs to initiate/take certain actions: (a) Scientific research to accurately understand the overall disability rate in the country, (b) data on the rate of disability among the older population, and (c) the types of disability. Findings of such scientific study should be used to (a) prioritize the country’s resources, (b) formulate policy and (c) identify the services needed.

Similarly, Brodsky and Hirschfeld (2003), suggest that “a key resource in formulating a long term care policy for developing countries should be in their own existing experience which needs to reflect each country’s unique conditions (depth and complexity.) These countries should also learn from the industrialized countries to identify the successful, as well as unsuccessful policies, to have the range of options for the respective countries.” They also indentify five key issues concerning long-term care. These are (1) the role of family and the informal care and mechanisms to support the family, (2) issues of coordination among various long-term care services and of LTC with the health and social services, (3) human resources strategies in delivering LTC, (4) approaching to evaluating LTC systems and (5) approaches to defining overall LTC strategies. These five above mentioned areas are very important for Nepal; however, in the context of Nepal, the main focus immediately should be on awareness/education and research regarding these issues.

Education and research are integral to policy formulation. Thus, the government of Nepal and decision-makers should strive to become aware and be educated about the county’s situation. There are several steps that can be taken in order to create policies for aging and older disabled population. First, there should be comprehensive research on the aging and disabled population. This can be performed in collaboration with the Planning Commission of Nepal, Central Bureau of Statistics, Ministry of Women and Social Welfare Council, Ministry of Finance, Ministry of Health. If Nepal is not in the position to do so, the government should seek outside help from
such organizations as the United Nations, and other International non-profit/aid organizations. Further, it is not enough to involve these organizations only; academic researchers can also be encouraged to conduct research and contribute to the formulation of policy making and identifying the social, environmental, and biological aspect of these issues.

Secondly, after comprehensive research, the government with the help of experts in the field should create programs that can be effective. Examples from various countries and policy guidelines can be taken from the ten case studies conducted by the World Health Organization. Nepal also can take the example of Sri Lanka and Indonesia for preliminary guidelines for the long-term care policy. Both countries have similar backgrounds; particularly Sri Lanka has had continuous civil war in their country.

Thirdly, given the cultural context of Nepal and the traditional value system, the government needs to encourage and provide incentives to families. In other words, the government needs to clearly define informal care and create mechanisms to support family members as stated by Brodsky and Hirschfeld (2003). For those older individuals without family support, decision-makers needs to pay more attention and cannot afford to make assumption that “Pasupati Briddha Ashram” will take care of such individuals. The government should achieve collaborating with social service agencies and volunteers from the community.

Fourth, health care financing is also an integral part in creating a long term care policy. With the coordination between the Ministry of Social Welfare, Ministry of Finance and Ministry of Health, and international donor countries and agencies, the government can create some firm policies to benefit older people with disabilities.

Also during annual budget hearings, the government of Nepal can set some budget aside for older adults and those with disabilities in older adults.

**Conclusion**

At present, the political system of Nepal is not stable. The old constitutional monarchy, multiparty democratic system has been replaced by federal system. Within the new federal system, the monarchy has been replaced by presidential system in which prime minister has absolute executive authority. This arrangement has been made through an interim constitution. Furthermore, based on the new interim constitution, the election of constitution assembly has taken place and a new government was formed under the leadership of United Marxist/Leninist-
Maoist Party. The purpose of this government led by Maoist was to form a new constitution. Unfortunately, due to political party differences, the present government collapsed on May 5th, 2009. As a result, different political parties are trying to form a new government but no one knows when the constitution will be written. Within this pretext, it is clear to note that, issues related to aging, disability and long-term care are not the priority of the present decision-makers’ irrespective of their political ideology or party.

Nepal as a nation cannot ignore to devise policies to create a conducive environment for its aging population including those with disabilities. If the government of Nepal fails to recognize the changing realities as described in this study, misery and suffering will be inevitable for the vast majority of its older population and older people with disabilities.
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34


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Appendix 1:

Interview Questions
[Note: What do they think about the aging issues of Nepal? This will be the overarching questions for the research purpose. With this overarching question, how much knowledge the person has about the aging issues and the long-term care will be explored.]

ID#
1. Are you familiar demographic changes in the country? If so, explain.
2. Would you explain what does it mean to “old”?
3. What kinds of challenges associated with the aging population of Nepal?
4. Do you many people have disability? How big a problem is this for the country?
5. Do you think is disability in younger adults or older adults is a major problem?
   (Probe: Do you think disability with non-elderly is a problem is a problem in Nepal? Do you think disability with older people is a problem is a problem in Nepal?)
6. Where do older who are disabled get help?
7. What do you think this nation should do to meet the needs of disabled population?
8. Have you heard about long-term care?
9. Whose responsibility is it to provide long-term disabled individual?
10. Have you ever been to a “Briddha Ashram” (old people shelter home)? If yes, name and please tell me what do you think about this Briddha Ashram?
11. Who will take care of you or spouse once you become old and need help?
12. As a policy maker, do you think Nepal urgently needs to initiate a policy related to aging, disabled issues especially long-term care?