자 유 발 표

Moving to a Holistic Model of Health:
The Need to Join Person and Environment for Persons with Mobility Disabilities

김 경 미*

Ⅰ. Introduction

The most widely accepted definition of health has been the absence of disease, injury, and impairment (Rimmer, 1999). Therefore, people with disabilities have been understood to have poor health due to the presence of a physical impairment or deficits, and they are often excluded from health promotion efforts (Marge, 1988; Public Health Service, 2000; Simeonsson, & McDevitt, 1999; Zajicek-Farber, 1998). Although people with disabilities have a great need for health promotion, such programs have been a neglected area of interest since the aim of health promotion has not been to take care of the "sick"and "disabled," but rather to prevent disease and disability in the "healthy" (Patrick, 1997; Rimmer, 1999).

Healthy People 2010, a recent initiative funded by the federal government and designed to improve the health of Americans, largely neglected people with disabilities though it mentioned "Disability and Secondary Conditions" in one section (Public Health Service, 2000). The initiative notes the disparities in health between people with and without disabilities. These disparities include excess weight, reduced physical activity, increased stress, and less frequent mammograms for women over age 55 with disabilities (Public Health Service, 2000). Moreover, people with disabilities are often not included in programs for the primary prevention of chronic conditions, such as diabetes, cancer, heart disease, and stroke (Patrick, Richardson, Starks, & Rose, 1994). However, health promotion efforts should be emphasized for people with disabilities because their

* 한국여성개발원 연구위원

quality of life and their level of independence rely heavily on maintaining "the narrow margin of health" (Stuifbergen, 1992). During the past 30 years, people with disabilities have gained many more societal opportunities, such as employment and relationships with others, due to protective legislation and changing social attitudes. Health promotion is important in that people need to be as healthy as possible in order to take advantage of and enjoy these increased opportunities.

Some define health as being associated with a sense of personal well-being and with such multidimensional aspects as physical, mental, social, and spiritual well-being (Zajicek-Farber, 1998). Pender (1987) suggests that the concepts of health and illness are qualitatively different. He defines health as the actualization of inherent and acquired human potential through goal-directed behaviors, competent self-care, and satisfying relationships with others, while making adjustments to maintain structural integrity and harmony with the environment. The World Health Organization (WHO) in 1947 proposed a definition of health that emphasized the positive quality of health: "Health is a state of complete physical, mental, and social well-being and not merely the absence of disease"(Tempkin, 1953). This definition of health is worth close attention, for the absence of illness or impairment is not the prerequisite of health for people with disabilities (Stuifbergen, Becker, Ingalsbe, & Sands, 1990). After all, people with disabilities can be considered healthy, and health promotion efforts can be targeted to this population.

The concept of health for people with disabilities is related to three factors. First, the concept of health is unique for the individual based on individual circumstances (Carla, 2001). Second, the health for people with disabilities has to be approached holistically since all things are connected. The health of people with disabilities involves spirit, body, and mind (Carla, 2001). The spiritual aspect of health is to seek meaning and purpose in one's life as well as to develop creativity. The body is related to physical conditions. The mind includes memory, thoughts, knowledge, and emotional aspects, such as feelings. Third, the health of people with disabilities is a social construct that extends beyond functional limitation or an absence of illness (Stuifbergen, Becker, Ingalsbe, & Sands, 1990). Therefore, Stuifbergen & Roberts stated that "individuals with disabilities can be viewed as fully capable of health and well-being within the context of their chronic condition or disability" (1997, p.S-4).

Empirical Research on the Definition of Health and Perception of Health from the Perspectives of People with Disabilities

It was found that the concept of "health" for people with disabilities is a multidimensional construct including physical, psychological, social and external attributes (Putnam et al, 2003; Stuifbergen, Becker, Ingalsbe, & Sands, 1990; Silverman, Smola, & Musa, 2000). In contrast, the concept of being "not healthy" is more narrowly focused on physical health, a conceptualization which corresponds with the medical model of disability (Silverman, Smola, & Musa, 2000).

Stuifbergen, Becker, Ingalsbe, & Sands (1990) examined the definition of health and perception of health status of adults with long-term disabilities such as 'neuromuscular impairments,' 'visual impairments,' 'neurocognitive impairments,' or 'chronic medical conditions.' The definitions of health were described as "never to be sick or taking medication," "being able to function as expected," "carrying on the normal functions of daily living," or "able to take care of my self". Also, one-third mentioned health as absence of illness or pain. By contrast, some participants defined health as "enjoy life each day." This study is worthwhile in that the concept of "health" of people with disabilities can be defined multidimensionally. There are huge variations in the definitions of health among people with disabilities.

Another study that explored differences of self-rated health status among 48 persons older than 65 was conducted by Doorn (1999). Persons with poor physical health indicators and good self-rated health viewed their health positively by comparing themselves to others in their lives and by down-playing their health indicators as not surprising and not bad given their advancing years. Also, the study revealed that good self-rated health is a more complex construct including social and demographic advantages and self-image. By contrast, poor self-rated health was based more on the physical aspect.

Another study that explores the meaning of being healthy and not being healthy reveals that "healthy" is a more multidimensional construct that is connected to one's total life experiences, whereas "not healthy" tends to relate only to medical symptoms." (Silverman, Smola, & Musa, 2000). The study revealed that the "not healthy" were narrowly focused on the symptoms, or medical/physical health or the experience of illness of the medical model of disability. In contrast, "healthy" was defined as a construct including physical, psychological, social and external attributes, such as transcending their health problem. More importantly, "healthy" may be experienced by persons with severe and multiple illnesses.

The previous studies increase our understanding of the meaning of disability for people with disabilities. Also, these studies indicate that people with disabilities are not necessary "sick," rather they have an ability to be healthy. However, there is still a fragmented picture of how

people with disabilities view the meaning of health and health promotion from previous studies.

This study intends to obtain rich information about the meaning of health and health promotion as complex phenomena through investigating both individual experiences of people with disabilities and their collective experiences as members of the disability community. A qualitative design was employed to facilitate the understanding of perceptions of health among people with disabilities and to explore how they structure and give meaning to the concepts of health and health promotion within their daily lives (Dunbar, Mueller, Medina & Wolf, 1998; Smith, 1995; Young & McNicholl, 1998). As stated above, this study explores the perspectives of people with mobility disabilities on the meaning of health. Two subtopics of inquiry are involved in exploring their perspectives: 1) How people with mobility disabilities experience being healthy; 2) What personal and environmental factors promote or impede their health.

Ⅱ. Methodology

People with mobility disabilities were selected as study participants for two reasons. First, since people with mobility disabilities often face similar problems, such as inaccessibility to physical environments, they share similar experiences. Secondly, people with mobility disabilities may more readily identify themselves as having disabilities, compared to people without physically obvious mobility disabilities. When people perceive themselves as having disabilities, they also tend to have a clear understanding of their disabilities and how the disabilities impact their health. In addition, people without disabilities may treat individuals with or without mobility disabilities differently. This offers a clear social context of disability(Crose, Nicholas, Gobble, & Frank, 1992).

There were two sub-samples: 1) people with mobility disabilities who were consumers of Centers for Independent Living (CILs) services, and 2) social workers with mobility disabilities who have worked with people with disabilities either in a clinical or administrative capacity. Potential consumer participants were recruited from three offices of CILs located from throughout the mid west state and potential social worker participants were recruited state-wide using snowball sampling. The 18 persons with mobility disabilities were selected to reflect a variety of demographic characteristics. Eleven participants were female, with participants ranging in age

from 20 to 65. There were five persons of color, eight who lived within a family unit, and 12 who were employed in some capacity. The types of disabilities included persons with multiple sclerosis, cerebral palsy, spina bifida, and a variety of others, with an average duration from onset of 19 years.

The researcher interviewed participants during a three month period in 2002. The interviews took approximately one to two hours and semi-structured open-ended interview guides were used for the interview. Interviews were transcribed verbatim and coded, sorted, and analyzed, by constant comparative analysis. Patterns of themes and variations within themes were identified with the assistance of NU*DIST (QSR, 2002). The constant comparative method is very useful in order to generate and refine understanding based on themes and patterns of similarities and differences (Creswell, 1998; Erlandson, Harris, Skipper, & Allen, 1993). Major themes and sub themes were identified to illustrate the perspectives of the participants. Member checking was performed to determine the faithfulness of the researcher's representation of participant's views. The credibility of the findings was further supported by the incorporation of participant reactions to a preliminary participants enhanced credibility further.

Ⅲ. Findings

The research investigated both the meaning of health and factors impacting health, and that the findings reflect those two questions.

1. Description of the Meaning of Being Healthy

Participants did not define their health merely in terms of impairment. As they looked at the positive and negative sides of health, 17 participants evaluated their health status overall as good and did not focus on their impairments. They understood how their disabilities affected their health. However, they knew how to live with the impairments or how to prevent the impairments from blocking things they wished to accomplish. They also differentiated between disability and health. Disability was understood as only one part of their life and not the sum of who they are. The disability is only one of their attributes, like gender or age. Participants also viewed the

concept of health in relation to their impairments. This means that they saw disability and health as an interconnected whole, not separate:

My life does not revolve around my spinal cord injury. My life revolves around the activities that I choose to participate in. I happen to be disabled, but I don't define my health on my disability. I consider myself to be a healthy person and I'm limited only by the things that I cannot do. But I don't relate those things as an affect from my disability.

I recently went to the doctor and I've had a breast cancer and I've had MS for a lot of years and a few other chronic things and after telling the doctor all that I said I'm really in good health... I live easily with my chronic illnesses. I've had them so long that they are not forefront in my experience of how I live my life. So that's what I mean by being healthy.

I think my health, as far as feeling good in my body, I feel good all the time. That's something that's undescribable with people with MS... But the only thing is that I feel a weakness in my body and when I try to do things I can't do them.

The majority of participants' descriptions of the concept of health encompassed five domains: biological/physical, mental/emotional, financial, relationships with relational with others, and spiritual. The biological/physical domain was most commonly described in functional terms in relation to physical ability. Definitions of physical abilities ranged from "being able to get up" to "doing things to maintain myself independently." In addition, taking care of oneself with good nutrition, exercise, medicine, and doing preventive activities were mentioned as components of the biological/physical aspects of health. The mental/emotional domain was most commonly described in relation to having positive attitudes towards life and feeling independent. Positive attitudes included having a positive sense of self-esteem. The domain of relationships with others represents the importance participants placed on having good relationships, including those with family, friends, coworkers, health care providers, and communities. Healthy relationships included "being able to associate with others" or being "socially adjusted - meaning having friends, having contact with co-workers and participating in society." Financial security through work or livable income was also commonly mentioned in relation to the financial domain of health. The spiritual

domain was described in terms of having strong faith and having a relationship with God. Sixteen participants mentioned having faith as a strength and an integral aspect of their overall health.

Participants described health as harmony between the five domains. Balance or harmony indicates that all five domains contribute to the concept of health, and that each domain relates to the others. The following example illustrates the meaning of balanced health according to one participant:

> *Well, I think of someone who is physically fit, someone who is mentally stable and someone who is socially adjusted. I look at it in a broad sense. Physically, I think you don't have to be a workout nut or an Arnold Schwarzenegger but I think if you're able to do a minimal task without many difficulties, then I think you're relatively healthy physically... I don't think just being totally physically healthy, I think it's a good thing to be physically healthy, but I think if you're not a well-rounded person mentally and socially, then I don't think you're a totally healthy person... If you're not socially healthy and mentally healthy you're kind of isolated.*

This holistic description of the concept of health as having a balance among physical, mental, relational with others domains is different from the conventional medical model, which focuses primarily on the physical aspect of health. Instead of focusing on their impairment itself, the participants stated that health is not solely a function of medical issues.

2. Health–impeding and Health–supporting Factors

In this section, the effect that factors were distributed across different levels is discussed. All factors at the personal and environmental levels affect the health of people with disabilities. Interaction among factors within the personal level can impede or support health. Moreover, interaction of the person with the environment impacts health. Personal-level factors are defined as those related to the individual's own qualities and resources, and environmental-level factors are defined as those related to the social policies and institutions and the constructed physical environment that shape the individual's resources.

1) Personal Level

Just as with participants' concept of health, the personal level of factors affecting health are distributed across five domains: biological/physical, mental/emotional, spiritual, financial (including health insurance), and relational with others. Particularly in the areas of financial factors and relationship with others, the boundaries between the personal and environmental levels are not distinct.

Participants mentioned a number of biological/physical factors that support their health. Fifteen participants took care of themselves proactively, maintaining their current health status by engaging in regular daily exercise, watching their diet carefully, monitoring their water intake, and getting enough rest. Participants have learned about their bodies' functioning and are able to take care of themselves in a way that maintains their health. They have also experienced the benefit of health-improving activities. They can manage his health rather than that their health is precarious. One participant explained the importance of working to stay healthy:

> *It's important that when a person becomes disabled something they should do is learn about their body. One of the best things they can do is learn how their body functions and listen to their body because they can learn a lot. And the more you learn about your body, the better you are able to take care of yourself and be healthy or become healthy or identify a problem that may need medical attention to resolve that. And so to have a good knowledge of what is healthy for you as an individual helps you better able to get through each day because you know your body better than anybody.*

Adjusting to physical limitations and taking medicine were also mentioned as enabling factors. Most importantly, nine participants viewed physical factors as less important than mental outlook in determining health. They also saw physical aspects as being strongly related with mental aspects of health. Keeping one's mind healthy directly contributes to having a healthy body and an overall positive sense of health.

Pain and functional limitations adversely affect health. The fluctuation in physical functioning also impedes participants' health. However, by knowing that their health conditions will vary day by day, participants could predict and prepare for the fluctuations of their health. By self-managing this fluctuation, participants are able to turn health-inhibiting factors into

opportunities to develop health-enabling behaviors. This provides but one example of ways in which inhibiting factors can ultimately be transformed into enabling factors.

Positive attitude or outlook is a significant health-enabling factors. Participants mentioned that the disability itself does not identify who they are and that they do not dwell on their disabilities. They accept their impairment, make adjustments or changes if needed, and transcend their disabilities through their holistic view of themselves. One way of making adjustments is to accept that one accomplishes things differently than people without disabilities. A disability can be a challenge but can be used as a chance to grow. Related to positive attitude is participants' strong determination to have control over their lives with regards to environmental factors, including other people:

> *I don't focus on any of my health problems. I've got another bigger world out there than my health and what I think... So I'm sure it's evolved over time, but I just have such an interest in things other than my narrow health that I just don't want to spend very much time talking about it.*

Spiritual belief was a source of strength for our participants, supporting the findingsof Boswell, Knight, & Hamer (2001), Canda (2001a and 2001b), Marshall, Olsen, Mandleco, Dyches, Alfred, & Sansom (2003). Sixteen participants believe God will help them keep going and said that believing in God helps them to keep going. Instead of blaming God for their disabilities, they believe God gives them the strengths to cope with their disabilities. Spirituality appears to have a huge role in improving participants' health. Mental factors appear to be related to spiritual factors. Believing that God will help them to deal with their disabilities allowed participants to have a more positive outlook and attitude.

Earning a livable income through work was also mentioned as a factor that affects health positively. Consumer participants are recipients of entitlement programs such as Medicare, Medicaid, Social Security Disability Insurance, or Supplemental Security Income and have learned to live on relatively little income. Some participants have difficulty relying only on entitlements. While financial security is related to having a job with access to extended health insurance coverage, it is difficult for participants to obtain and keep a job because some employers prefer not to hire them. Work is very important to the participants' health. Work gives them a livable income, affordable health insurance, and high self-esteem. Working means that participants have

the freedom to manage their own lives. Employment improves overall long-term health conditions for individuals with disabilities.

2) Environment Level

The environmental level includes financial resources, relationships with other people, social service programs, social attitudes toward people with disabilities, and the physical environment.

Financial factors can lead to disincentives to employment. This situation is especially troublesome because work can be crucial to managing participants' lives. When people with disabilities work, they may not be eligible to apply for government programs such as personal care assistance services and Medicaid or Medicare. They have to pay for disability-related expenses with their own money which creates an economic hardship for them. This interaction is another example of how factors within the personal and environmental levels impact each other. Financial aspects exist on both the personal and environmental levels, in that employment opportunities and financial resources are factors at the environmental level while employment or financial status are personal level factors.

Relationships with others such as family, friends, health care providers, and the disability communities or support groups have a significant impact on health. Relationships with others are considered part of the social environment and are also one of the personal domains of the concept of health. Emotional and financial support from significant others give participants strength to deal with their disabilities. Involvement in disability communities or support groups offers opportunities to share a common understanding of experiences in relation to the environment as well as a chance to share specific strategies for living independently.

Relationships with others can involve issues inhibiting a sense of health, such as difficulty making friends or dating. One participant had difficulty making friends. She reported that since she had moved from a small town to a metropolitan area, she did not have friends. If she just wanted to go see a movie, she had to pay for her personal care attendant to go with her. She wanted to have more friends and more ways to get out without paying attendants all the time:

> *I need more friends... Like for instance, every time I go to a movie, which I don't very often, I have to pay somebody to take me to a movie. Pay them $8 an hour to sit beside me for three hours or whatever, whereas normal people, people without disabilities, will*

just hop in the car and go with them. And you go out to eat and have a good time. Well for me it's not that way. I always have to think do I really want to pay somebody.

Regarding barriers to establishing relationships with doctors, participants mentioned that some doctors were not helpful because they had a poor understanding of disabilities, lacked knowledge about certain medical treatments, and in general did not promote health. Participants reported some doctors have very negative attitudes toward people with disabilities. One participant mentioned that doctors did not realize people with disabilities become sick just because got/get is kind of casual. When she was sick with the flu, her doctor would not give her medicine and said she would get back to her in three months. The delay of treatment for simple illness made some consumers sicker:

Just because we're disabled does not mean we're not going to get sick. I mean we get sick... Most of the doctors talk to me, I think it's this, or I think it's that. But I don't know, but I'll get back to you in 3 months. I'm like I don't need you to get back to me in 3 months. I need you to get back to me in like a week, not 3 months from now.

Some participants found support groups unhelpful because the groups had an atmosphere of negative thinking about disabilities and members only focused on their disabilities rather than their disabilities. They described that the members of the support group became more and more involved in their problems as they were not able to move beyond those problems.

Among factors at the environmental level, social service programs, attitudes towards people with disabilities, and the physical environment are described below. The majority of consumers used social service programs. Social service programs included government benefits programs, Centers for Independent Living (CILs) services, and specialized programs offering personal care services. Even though government benefit programs support individuals with disabilities, there are disincentives to work. For individuals with disabilities considering employment, incentives such as affordable health care insurance must be available. There is variation among CILs in terms of providing services. Some are better than others (Nosek, Zhu, & Howland, 1992). Personal assistance services (PAS) were mentioned as facilitators in maintaining the health and independence of the participants. However, there are some difficulties recruiting and retaining personal attendants.

Social attitudes toward people with disabilities impact health significantly (Longmore, 1985). While there have been some positive changes in attitudes among members of the public and health professions alike, negative social attitudes still isolate people with disabilities from society and make them feel depressed. Therefore, external oppression becomes internalized and impacts negatively on people's emotions. One participant, who learned from society to value only people without disabilities, had to bring a great deal of energy and strength to her quest to be healthy:

These external oppression became internal. It became I don't feel well... I'm deficient. I don't live up. And it all did translate to a health issue because if you're depressed most of the time, there are things that are going to be happening chemically... We say isms like ageism, ableism, disability. Before those terms came along, it was just simply called otherism. Other than what? Other than the bell curve. If the majority of humanity falls in the bell curve, we've learned to value only the bell curve center. We have not learned to value a continuum and it does take a lot of psychic energy.

Instead of those with disabilities being disconnected from society, connections between people with and without disabilities must be made. The overall view of individuals with disabilities can be a barrier on a societal level. Socially entrenched barriers include perceiving people with disabilities as physically limited, mentally affected by their disabilities, and being inferior relationship partners.

The physical environment includes the built environment, transportation, housing and weather. Although during the past 10 years there have been major improvements in the built environment, public transportation, and accessible housing which can enhance health, there is still a lack of access to many physical environments. When people with disabilities feel uncomfortable or endangered in a particular environment, they may not want to put themselves in that environment. Since physical accessibility is a legal right under many circumstances, society should accommodate their needs (Mueller, 1990). Lack of accommodation in a society impedes the health of people with disabilities. One participant said there was no public transportation during the weekends in her area, and she had to pay for her personal assistant to take her if she wanted to do something:

What does society think, that we're all disabled, we go to work, the ones of us that can

go to work all week and we work, it takes us about 11 and 1/2 hours a day to accomplish, for me that's what it does by the time I come and go, but on the weekends we do nothing? I do something, but I mean if I had public transportation I would be doing a lot more. That way I would not have to be so dependent on everybody. But if I had a bus, if I could hop on a bus I could go shopping or I could go to the movies or I could go out to eat on my own without having to pay somebody. I think that it's a very injustice not to have transportation available to anybody.

Ⅳ. A Conceptual Model of Factors Affecting Health and the Concept of Health

As described above, all factors under the personal and environmental levels affect each other. The personal level has five domains: biological/physical, mental/emotional, spiritual, financial, and relational with others. All factors under the personal level affect each other. The environmental level has five domains: relationship with others, financial resources, social programs, social attitudes toward people with disabilities, and physical environment. All factors under the environmental level also affect each other. Health of people with disabilities is not solely a part of the person, but rather it is a function of the interaction of the person with the environment.

The conceptual model developed in this study expands on the existing concepts of health by considering multiple factors at the personal and environmental levels, as well as interactions among factors and between levels. As would be expected, enabling factors at the personal level are connected with the concept of health. However, being healthy is the outcome of the interaction between personal and environmental levels.

Ⅴ. Discussion and Implications

This research developed a holistic conceptual model of health from the perspectives of people with mobility disabilities. The holistic model of health for people with disabilities proposed here

takes proper account of both the personal and physical experience of disability, and their social dimensions (Shakespeare & Erickson, 2000).

In order to enhance health for people with disabilities, it is important to realize that individuals with disabilities are not inherently unhealthy or ill and that disability and health can coexist. A paradigm shift towards a holistic health view would offer a perspective of people with disabilities as whole people, rather than one focusing on their impairments. Disability policy and practice must be founded upon respect for people with disabilities as individuals who have strengths and tenacity on their own and who need control over their lives. It also must be understood that people with disabilities are heterogeneous, and that individual experiences with disabilities must be respected. Even though the medical model presumes that medical professionals know best, individuals with disabilities have expertise based in their own life experience, and are therefore the best managers of their own health.

There are few studies exploring the meaning of health from the perspectives of consumers. My work aimed to maximize descriptive information and to contribute to a new understanding about health for people with mobility disabilities. Health is a state derived from interactions between the person and environment, even though it is not correct to draw distinct boundaries between the two. This study demonstrated that people with disabilities have the strength and resiliency to be healthy. Health is attainable for people with disabilities, particularly when environmental and cultural barriers are addressed. To further extend the holistic health view of people with disabilities, future work needs to probe further the meaning of health and factors affecting health for people with other types of disabilities. In doing so, future studies can continue to develop a framework for inclusive and strengths-based policy and practice for individuals with disabilities.

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Abstract

The purpose of this study was to explore the concepts of health among people with mobility disabilities in order to develop a new holistic model of health and to identify implications for social work practice. A qualitative study based on face-to-face interviews with people with mobility disabilities was conducted. Nine consumers and nine social workers with mobility disabilities participated in the study. Social constructionism, heuristic paradigm, empowerment paradigm, and strength perspectives were used to form conceptual foundations to guide the study.

Study participants' holistic descriptions of the concept of health encompassed five domains: biological/physical, mental/emotional, financial, relationships with others, and spiritual. Participants described health as harmony among these five domains. Harmony indicates that all five domains contribute to the concept of health, and that each domain is related to the others. Participants also viewed disability and health as an interconnected whole, not separate concept.

The conceptual model developed in this study expands on the existing concepts of health by considering multiple factors at the personal and environmental levels, as well as interactions among the factors and between the levels. The personal level has five domains: biological/physical, mental/emotional, spiritual, financial, and relationships with others. The environmental level has also five domains: relationship with others, financial, social programs, social attitudes toward peoplewith disabilities, and physical environment. All factors under the personal and environmental levels also affect each other. The holistic concept of health for people with disabilities is not solely a part of the person, but rather is a function of the interaction between the person and their environment.

The study demonstrated that people with disabilities have strength and resiliency, and health is an attainable goal for them, particularly when environmental and cultural barriers are addressed. The focus of social work practice should be the removal of those barriers encountered by their consumers with disabilities, as well as, the enhancement of internal factors that facilitate well-being.