Measuring the effects of social interactions and interpersonal relationships on social participation and community integration for individuals with mobility impairments as measured by the CPPRS-Revised.

A Literature Review

Completed for:
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Problem/Issue

People with disabilities spend significantly less time outside the home, socializing and going out, than people without disabilities. They also tend to feel more isolated, and participate in fewer community activities than their non-disabled counterparts. According to Dr. Gerry Hendershot, senior research advisor for the National Organization on Disability, “fully 4 out of 10 people (40%) with severe disabilities are not at all involved in their communities, almost twice the percentage for people without disabilities (21%).”

The National Health Interview Survey found that among adults with severe mobility limitations (completely unable to walk 3 blocks without special equipment or personal assistance), only 47% had recently participated in community activities. That compares with 78% among adults with no mobility limitations and 65% among adults with moderate mobility limitations. Community participation was measured by answers to questions about participation during the last two weeks in a place of worship or in group activities such as going to a show or movie, sports event, club meeting, or class. Data from the same National Health Interview Survey also showed that community participation is important for general life satisfaction. Adults were asked “In general, how satisfied are you with your life? Would you say very satisfied, satisfied, dissatisfied, or very dissatisfied?” Among people who were active in both worship and other group activities, 54% said they were “very satisfied” with their life, but among people who did not participate either in worship or other group activities, only 31% said they were very satisfied.

Social interactions and interpersonal relationships are frequently measured by the analyzing the underlying causes of negative attitudes of communities and its’ members
towards individuals with disabilities. According to Mitchell (1993), community attitudes
towards people with disabilities are frequently negative, and these attitudes are largely
responsible for many of the social disadvantages disabled people experience. Negative
attitudes are often expressed in terms of exclusion from various aspects of life such as
relationships, employment, and access to community facilities (p.179).

According to Noreau & Fougeyrollas (2000), the long term consequences of
disabilities following a spinal cord injury can be readily seen in the accomplishment of
daily living activities and in the achievement of social roles which are typically
rewarding to a person in the context of his/her life. These two elements are essential
components of social participation and therefore, disruptions in the accomplishment of
some activities or roles can have a significant impact on the person’s long-term health
(p.177). Health is defined by the World Health Organization as a state of complete
physical, mental and social well-being and not merely the absence of disease or infirmity.
In more recent years, this statement has been modified to include the ability to lead a
"socially and economically productive life."

The Americans with Disabilities Act (ADA) states that a main goal of the Act is
full participation in major life activities by people with disabilities. Most measures of
ability are based on a disease-based, clinically oriented framework and are used as
benchmarks for health care reimbursements (Jencks, Cuerdom, Burwen, Fleming, Houck,
functional and social outcome measures have not been developed that address specific
person-environment interactions that enhance participation in community settings. Gray
et al. state that although legislation, reports, and classification schemes promote the
concept of participation in context as an important component of disability, the
development of measures for capturing the essence of participation has just begun. An
important goal of rehabilitation is returning individuals with chronic conditions back to
their communities to participate. Nevertheless, many outcome measures in the
rehabilitation setting are focused on reducing difficulty in performing activities that are
open to objective measurement while the individual is at the rehabilitation facility. As
stated by Gray, Hollingsworth, Stark, & Morgan (2006) the influence of rehabilitation
and medical interventions on the participation of people with disabilities in home and
community activities has not been incorporated into health care payment plans, which
reimburse only those interventions that qualify as medically necessary.

As the extent of disability increases in society, there is an increasing need to
understand related consequences in many aspects of social participation and community
integration. Past research has shown that negative attitudes towards individuals with
disabilities have resulted in lower social participation within a community as well as less
community integration, and even lower quality of life. What research has not shown is
how social interactions and interpersonal relationships of individuals with disabilities
affect their social participation as well as their community integration. Therefore, the
purpose of this research is to determine if social interactions and interpersonal
relationships act as facilitators or barriers in relation to social participation and
community integration in individuals with mobility impairments.

**Theories/Models/Classification Systems**

Over the past several decades, several models and theories have driven the
research and investigation of disability and changed the way disability is conceptualized.
Several theoretical models explore the connection between participation, health, and environment. Many changes in these models have greatly influenced the view of health care and the empowerment of individuals with disabilities.

One of the most significant events in history for individuals with disabilities was the development of the Independent Living movement. The Independent Living movement began as a social movement, which resulted in the transformation of the disability and rehabilitation research paradigm from a medical model to a construct that involves the person in their social environment.

This particular movement went hand-in-hand with the 1973 Rehabilitation Act; this Act sought to prohibit discrimination against individuals with disabilities from federally supported programs and activities. This movement sprung from two main sources: (1) the efforts of disabled persons to seek a more fulfilling life in an able-bodied world, and (2) the efforts of rehabilitation professionals to reach disabled persons for whom a vocational goal was obtainable (DeJong, 1979). The Rehabilitation Act of 1973 was followed shortly after with the signing of the 1978 amendments to this particular Act. This law created a new title VII which was entitled “Comprehensive Services for Independent Living.” This established a four-part program that gave support, protection, and funding towards the Independent Living movement. The Independent Living paradigm that resulted from these significant events takes the focus of disability off a person’s physical impairment and shifts attention to the environment. The solutions are found in advocacy, removal of barriers, and self-help rather than remediative intervention by healthcare professionals.
Rehabilitation is a process which assists people with disabilities, to optimize the use of their physical, mental, and social abilities. This means that rehabilitation is multifaceted, but for the most part rehabilitation services take place within the medical setting (hospitals, clinics, etc.). These services often serve a temporary role in the lives of individuals with disabilities; once an individual is “discharged” and ready to go home the process is seen as complete. The individual is then left to face his/her home, workplace, and community alone. This is not the case with the Community Based Rehabilitation Model which sets seven goals for an individual with a disabilities: (1) the right to self-determination; (2) to be self-motivated to become an active and responsible family member; (3) to enjoy the benefits of family membership; (4) to be an active and responsible community member; (5) to enjoy and use the same opportunities that are available to all community members such as access to education, skills training, work and recreational activities; (6) to give serious consideration to becoming a family trainer for another disabled person, but at least be prepared to play a significant role in the Community Based Rehabilitation program; and (7) to participate in the organizations which cater for disabled persons, acquire leadership skills, contribute to the achievement of community, regional and national health goals, and act as a lobbyist for the disabled and their families (Mitchell, 1999). Community Based Rehabilitation has as a unique feature the use of family and community resources for the rehabilitation of individuals with disabilities. The rehabilitation process provides individuals with disabilities the opportunity to develop their physical, mental and social skills. The goal of rehabilitation is for individuals with disabilities to fully participate in normal roles within their families and their communities. Fragmented rehabilitation services which do not reach the
community level are less likely to either provide or stimulate the necessary opportunities for individuals with disabilities to participate in their normal roles. The development of services at the community level through the development of models such as the Community Based Rehabilitation model provides disabled people with the variety of assistance they require, and does so in the setting where the goal of rehabilitation can be achieved in the home and the community (Mitchell, 1999).

The International Classification of Functioning (ICF) was developed by the World Health Organization (WHO) and was formulated to encompass the concept of health related concerns as well as individual’s activities and participation. The ICF originated from the ICIDH (International Classification of Impairment, Disabilities, & Handicaps) and the ICIDH-2 (WHO, 2001). The original ICIDH lacked information pertaining to the environment and did not give a concise and clear difference between the terms impairment and disability and then between disability and handicap (Gray & Hendershot, 2000). The ICIDH-2 improved on the original by attempting to continue putting a stronger focus on the environment and the person interaction within that environment (Gray & Hendershot, 2000). The ICF is “a conceptual framework for information that is applicable to personal health care, including prevention, health promotion, and the improvement of participation by removing or mitigating societal hindrances and encouraging the provision of social supports and facilitators” (WHO, 2001). The ICF gives a loose definition of participation and includes the role of environment in influencing participation of people with disabilities. Adding these components helps individuals look at the different ways that social interactions and interpersonal relationships can affect social participation within a community.
The Disability Creation Process considers that disability is not an end-state, but rather a dynamic process closely related to the interaction of three variables: personal factors, environmental factors, and life habits. Life habits are the daily activities or ambitions, social and cultural roles that contribute to the physical and psychological well-being of an individual (Blanchet, 1999). The personal factors, i.e. the individual’s capabilities and potentials to carry out these activities, will be also linked to the obstacles or ease of interaction within their direct social and physical environment (Blanchet, 1999). Disability is therefore clearly seen as a situational state that varies from individual to individual and depends on the environment which the person lives.

Bronfenbrenner’s Ecological Systems Theory looks at an individual’s development within the context of the system of relationships that form his/her environment. To be able to study an individual’s development we must not look only at the individual’s and his/her environment, but also at the interaction of the larger environment as well. The Brofenbrenner’s Ecological Systems Theory is composed of five systems which structure the environment around us. The first of these is the microsystem which is the closest to the individual and contains the structures with which the individual has direct contact. Within the system is the concept of relationships and interactions with immediate surroundings (Berk, 2000). The mesosystem is the second layer which provides the connection between the layers of the individual’s microsystem (Berk, 2000). The exosystem defines the larger social system in which the individual does not directly function. The structures within this layer impact the individual’s development by interacting with some structure in his/her microsystem (Berk, 2000). The macrosystem is considered the outermost layer in the individual’s environment. This
layer is compromised of cultural values, customs, and laws (Berk, 2000). The chronosystem encompasses the dimension of time as related to an individual’s environment (Berk, 2000). The environment affects almost every aspect of our daily lives. This specific model allows us to show how each concept such as social interactions, interpersonal relationships, the environment, and participation all can affect one another in more ways than just one.

**Measurement Tool**

The measurement tool to be used within this particular study will be the Community Participation and Perceived Receptivity Scale revised (CPPRS). The original Community Participation and Perceived Receptivity Survey (CPPRS) measured the quality of participation across sites in the community. The survey is personalized to the participant based on where they go and how important going to that particular community site is for them. The Community Participation and Perceived Receptivity Survey (CPPRS), was developed to measure factors that influence the participation of people with mobility impairments in doing community activities. The Community Activity Form (CAF) is used to determine which sections of the CPPRS the respondent will complete. The CAF asks the respondent to indicate which community sites they have visited in the last month (ex: grocery store, place of employment) and within the last year (ex: doctor's office, sports arena) as well as if visiting these sites is important for them. For each site included in the CPPRS the person may indicate barriers to community participation including personal factors (pain, fatigue, illness), environmental factors (physical factors in the environment, social attitudes, and lack of transportation), and level of assistance needed (such as a personal assistant or an assistive technology device) while visiting the
site, as well as evaluative questions related to how satisfied and how much choice they have while visiting the site.

The revised Community Participation and Perceived Receptivity Scale is used to examine the social interactions and interpersonal relationships between an individual with a disability and the community or environment in which they live and participate.

**Review of Literature**

The physical environment in which public participation takes place has been altered by evolving social, political and technological environments in a reciprocal process of mutual influence (Schur, 1998, Latour 2002, 2003). Context provides a critical grounding to the discussion of public participation, and community and is the context in which public support for the integration of disabled people has the most immediate consequences for public participation (Bedini 1993, Pretty, Rapley & Bramston 2002). The public participation of individuals with disabilities lies at the core of physical and social space where the narratives that define the character of society are given voice, and where the dramas of wealth and want are played out (Bricout & Gray 2006). Public participation, which supports the social and psychological needs of persons with disabilities, has important consequences for their physical and economic well-being (Sinnema 1992, Cummins & Lau 2003). Many aspects makeup the context of public participation including housing, healthcare services, education, employment, civic life, recreation, entertainment; as well as engagement in community events. Disabled people, like everyone else, not only move through this environment, but construct their lives in a kind of dialogue with the physical environment out of which emerges the narrative of
everyday life. Simple inclusion is not a sufficient condition to ensure the benefits of public participation. Social inclusion, which requires that people with disability actively define how, when and where they participate, makes public participation meaningful rather than compulsory engagement in normative roles and responsibilities (Bricout & Gray 2006). Communities remain, however, important location for positively influencing the public participation of disabled people, because of their position at the gathering of individual and societal forces that shape public participation. Communities are shaped by macro influence in the form of social policies, and micro influences in the form of family and neighborhood norms (Bricout & Gray 2006).

One of the greatest challenges facing researchers of public participation in community settings lies in defining precisely what “community” means; in other words, whether a clearly delineated physical, psychological, social, temporal, or cultural space or something more fluid, and not reducible to bounded space of any kind constitutes a community (Brent 2004, Fryson 1999). A community is often defined in terms of outer geographical borders, members and government bodies; and the way in which community is conceived is of supreme importance to disabled people as a socially disadvantaged group (Bricout & Gray 2006). In communities is where persons with a disability conduct their lives and make their plans for the future. Precisely how the community welcomes or discourages the public participation of persons with disabilities is, therefore, an issue of primary concern for interventions aimed at enhancing their role as full and equal members of society. Community readiness and support for the public participation of persons with a disability can be assessed with reference to the concept of community receptivity.
Community receptivity refers to the willingness, values, and knowledge of people in the community that facilitate the participation of people with disabilities in valued activities and events, including social events, religious worship, employment, entertainment and travel outside the home (Bricout & Gray 2006). The social dimension of community receptivity is not only what community members think, but also about their awareness and their value system; positive attitudes in the absence of knowledge, or good intentions without a value system that accords persons with a disability equal respect, may demonstrate good feelings, but will not produce receptivity (Bricout & Gray, 2006). The physical dimension of community receptivity constitutes the disposition of the built or natural environment and community resources toward disabled person’s public participation. In other words, the degree to which the physical environment renders public participation venues and events accessible (Bricout & Gray, 2006).

According to Yuker (1988), estimation of the predominant attitudes of various populations concerning persons with disabilities, together with study of the interrelations of knowledge, attitudes and behavior, is necessary for suggesting desired ends to policymakers, designing intervention programs to modify attitudes towards persons with disabilities, and evaluating professional training programs in counseling, rehabilitation and special education. Negative attitudes towards persons with disabilities create real obstacles to the fulfillment of their roles and the attainment of their life goals. Knowledge of attitudes of persons without disabilities towards person with disabilities helps us to understand the nature of the interaction between the two groups. Attitude measurement techniques have continuously been changing, becoming increasingly sophisticated both theoretically and technically. Techniques range from traditional overt and obtrusive
measures to new alternatives which can be used to measure attitudes especially when the targeted attitude referent is socially sensitive and where conscious or unconscious mechanisms may interfere and alter the respondent’s attitudes (Antonak & Livneh, 2000).

The impact of the environment is understood in an interactive context because the primary tenet of the disability rights movement proposes that environmental factors place important restrictions on the degree to which people with disabilities can fully participate in society (Rimmer, 1999). In fact, physical, attitudinal, and policy barriers in the environment are viewed as having as great an impact, or greater, than the underlying organ system impairments in determining a person’s activity limitations, participation restrictions, and the development of many secondary conditions (Whiteneck, Harrison-Felix, Mellick, Brooks, Charlifue & Gerhart, 2004).

Direct methods as well as indirect methods are used to measure attitudes of individuals. Direct methods are those in which the respondents are either informed that their attitudes are being measured or are made aware of being measured by the nature of the attitude measurement technique (Antonak & Livneh, 2000). Indirect or alternative methods have been developed for those attitude measurement situations in which: (1) the act of measurement itself may create in the respondents an attitude towards a referent to which they were previously unaware; (2) other methods may lead the respondents to a reply that is inconsistent with their true attitude; or (3) the referent is so sensitive or so charged with emotion that the observed response may be non-purposefully distorted by unrelated but powerful personality characteristics (Antonak & Livneh, 2000).

**Role of Occupational Therapy**
Occupational therapists are probably the closest medical professional that relates in a meaningful way to the distribution of services to the Independent Living movement or paradigm. Occupational therapists want what is important to the client and work extremely hard to provide client-centered care and services. A greater amount of satisfaction and knowledge comes from the partnership that is formed between an occupational therapist and his/her client; in turn, this results in a more meaningful participation in all areas of life.

Occupational therapists are trained to assess the personal and environmental factors that influence performance. Community receptivity plays an important role in the lives of almost every client that comes to us. Occupational therapists have much to offer people who are passionate about becoming independent, fully recognized, and participating citizens of their community. The occupational therapist can contribute a greater in-depth understanding of the lived experience and play an advocacy role in their local community or even a more global community of medical professionals.

Occupational Performance is a unique term used by occupational therapy practitioners to describe the transaction between the person, the context, and the activity that results in the observable accomplishment of a selected activity (Law, Cooper, Strong, Steward, Rigby & Letts, 1996). Participation as defined by the International Classification on Functioning, Disability and Health (ICF) is the involvement in a life situation (World Health Organization, 2001). Occupational performance and participation are main goals of any occupational therapist within any setting and are important to the everyday quality of life of individuals. All of our outcome measures should take these concepts into consideration. By being able fully participate in the community that an
individual with disabilities lives in, he or she can feel like they can contribute and be a part of their community.

The negative attitudes towards individuals with disabilities create real obstacles to the fulfillment of their roles and the attainment of their life goals. Attitudes often are different depending on which culture, community, population, vicinity, or neighborhood you are in. Attitudes can also influence a person’s thoughts, actions, feelings, beliefs, and their overall approach to life. As occupational therapists, we should be an advocate for our clients and strive daily to eliminate these negative attitudes to better the lives of the individuals with which we work. These negative attitudes could be a barrier that keeps the individuals we work with from reaching their goals. By having background knowledge about individuals attitudes concerning disability, occupational therapists are able to have a better understanding of their client’s “lived experience.”

**Aims for My Research**

So often research looks at the communities in which individuals with disabilities live in and the negative attitudes of those communities that contribute to a poorer quality of life in individuals with disabilities. What research has failed to look at is how social interactions and interpersonal relationships of individuals with disabilities affect their social participation within their community. Through the use of the newly revised Community Participation and Perceived Receptivity Scale (CPPRS) I will hopefully be able to determine how social interactions and interpersonal relationships affect social participation within the community setting in individuals with disabilities. Focus groups and informant interviews will be conducted both pre and post-test with individuals who are going to be taking the revised version of the CPPRS. This will allow us discover a
more in-depth understanding of the social barriers to participation that individuals with disabilities face on a day-to-day basis. I hope to prove through my research that the newly revised CPPRS is a valid and reliable measurement tool to determine how social interactions and interpersonal relationships affect the social participation of individuals with disabilities.
References


