INFORMATION SEEKING BEHAVIORS IN A POPULATION OF
ASSISTIVE MOBILITY DEVICE USERS

Mel White, BSc, MSc, MSc

Dissertation Prepared for the Degree of

DOCTOR OF PHILOSOPHY

UNIVERSITY OF NORTH TEXAS

May 2014

APPROVED:

Brian O’Connor, Major Professor
Beverly Daverport, Committee Member
Ana Cleveland, Committee Member
Herman Totten, Dean of College of
    Information
Mark Wardell, Dean of the Toulouse
    Graduate School

The author explores the current state of information exchange and access in the procurement process for mobility assistive equipment. While the idealized model is of a linear process starting with a need and ending with the purchase, in practice the procedures for acquiring a device such as a wheelchair or electric scooter can be a time-consuming task that involves client, family, medical care specialists, vendors, manufacturers, insurance companies and possibly alternate sources of funding. This study utilized Participatory Action Research (PAR) to collect both qualitative and quantitative data about information sources such as the Internet, the medical community, and vendors. The findings of this study suggest that in spite of the presence of the Internet, overall primary sources are similar to the traditional model and that for most there is no one source that could be easily accessed for information. A brief examination is made of the “Information landscape” utilized in the process and a brief discussion of two relatively unmentioned information sources: expos and the wheelchair sports community.
Copyright 2014

by

Mel White
ACKNOWLEDGEMENTS

I would like to extend my thanks to my committee chair, Brian O’Connor, who listened to my ideas, offered innovative insights, and suggested concepts that strengthened my foundational ideas. To Beverly Davenport, who was an invaluable mentor throughout the process, offering advice and support and cheerful optimism during some of my struggles and moments of pure frustration. To Ana Cleveland, who very kindly stepped in at the last minute to fill a vacant position in my committee, my deepest appreciation. A very special thanks is extended to my husband, who believed in me and encouraged me at every turn, who was there through the bright successes and the dark swamps of despair, who listened patiently to me as I mulled over theories, and who stepped in proofread and edit the manuscript. Especially to Kymn Martin, Lee Martindale, and Rebecca Cagle. To the three who sadly are not with us any longer: my parents, Mildred M. Coker, James D. Coker, and Suzette Haden Elgin, PhD – author, musician, poet, and linguist, for her insights that suggested the focus for this and other research. To all my dear friends, family, and World of Warcraft guild members (who are family, too) who cheered me onward during these long years, thank you. I couldn’t have done it without you. To Sally Helmerich, PhD, whose question “so if you don’t do it, where will you be in 5 years anyway?” started me on this whole strange journey.

Warm thanks also to Ron Tykoski, PhD, director of the Perot Museum’s fossil preparation lab, who provided me with wise advice, jokes, and complicated blocks of dinosaur fossils to prepare. I have discovered that a cubic yard of Alamosaurus vertebra and limestone is the perfect long-term meditation exercise for a scholar.
# TABLE OF CONTENTS

ACKNOWLEDGEMENTS.................................................................................................................................................... iii

CHAPTER 1 INTRODUCTION.............................................................................................................................................. 1
  1.1 A Question for the Docent........................................................................................................................................ 1
  1.2 Hunting through Cyberspace.................................................................................................................................. 3

CHAPTER 2 SEARCHING FOR ANSWERS – MOBILITY AND DISABILITY.............................................................. 8
  2.1 Background............................................................................................................................................................ 8
  2.2 The Demographics of Disability............................................................................................................................. 16
  2.3 The Device Procurement Process.......................................................................................................................... 22
  2.4 The Information Needs of the Disabled.................................................................................................................. 32
  2.5 Theoretical Aspects: The Small World of the Disabled............................................................................................ 37
  2.6 The role of the Internet............................................................................................................................................ 42

CHAPTER 3 METHODOLOGY........................................................................................................................................... 52
  3.1 Known Issues for Researchers............................................................................................................................. 52
  3.2 Selecting the population ........................................................................................................................................ 55
  3.3 Methods............................................................................................................................................................... 59

CHAPTER 4 INFORMATION GROUNDS AND INFORMATION POOLS............................................................... 47
  4.1 Information environments.................................................................................................................................... 47
  4.2 Peer-to-peer information exchange ......................................................................................................................... 88
  4.3 Liminal Events: Sports and Trade Shows............................................................................................................... 88
  4.4 Movin’ Mavs: Wheelchair Basketball .................................................................................................................. 95
  4.5 Abilities Expo: Trade Show, Information Grounds, and more .......................................................................... 103
  4.6 Universities and information commons ............................................................................................................. 110

CHAPTER 5 DATA COLLECTION AND ANALYSIS..................................................................................................... 70
  5.1 Data Coding and collections ................................................................................................................................. 63
  5.2 Process Analysis .................................................................................................................................................... 65
  5.3 Survey Results ....................................................................................................................................................... 70
  5.4 Followup Feedback.............................................................................................................................................. 88
  5.5 Ephemeral Information Events, Information Commons, and Information Grounds ...................................... 114
  5.6 Observations on Social Capital and Information Access ....................................................................................... 118

CHAPTER 6 CONCLUSIONS AND RECOMMENDATIONS......................................................................................... 127
  6.1 Mobility, Access, and Information ....................................................................................................................... 127
6.2 Topics for Further Study ..................................................................................................................................... 134
APPENDIX A LETTER OF INVITATION .................................................................................................................. 141
APPENDIX B QUESTIONNAIRE ........................................................................................................................... 145
BIBLIOGRAPHY ...................................................................................................................................................... 146
CHAPTER 1

INTRODUCTION

1.1 A Question for the Docent

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.
T.S. Eliot, Little Gidding

The foundational seed for this dissertation springs from an encounter that I had as a volunteer at the Dallas Museum of Nature and Science. As a long-term volunteer who knew computers and operating systems and who had experience with robotics, I was permitted to demonstrate the Segway, a two-wheeled self-balancing scooter developed by Dean Kamen. This particular machine, one of the first 50 manufactured, had been donated to the museum's technology collection. In my position as docent, I used the Segway as a mobile exhibit, demonstrating robotics and technology to visitors. During the Texas State Fair in 2006, I was demonstrating the ease of use and agility of this device to a group of people, and when I finished, a woman approached and shyly asked if it was usable by people with Multiple Sclerosis. I answered that I didn’t know whether it was and we struck up a conversation about the Segway.

She told me that she was a school teacher with Multiple Sclerosis and dreaded the days when she had a “flare up.” Because these episodes were so debilitating, she had to use her wheelchair to get to the classrooms; a symbol to every student that she was not as
“whole” as other teachers. She felt that during these episodes, her classes reacted
differently to her and wondered if she’d be treated otherwise if she rode to class in a “cool
device” rather than an “old person’s wheelchair.” I gave her the name of the machine and
the name of a local dealer, but her question sparked both my curiosity and my sympathy.
The Segway was a fairly high profile piece of equipment and had been mentioned in the
press numerous times over the years. Information about it could easily be located on the
Internet.

Why wasn’t information about this machine in her hands already?
1.2 Hunting through Cyberspace

"What a paralyzed person needs the most is knowledge and time (Pearce, 2013)."

A search of the Internet later that night confirmed that information about Segways was readily available. There were several easily-found articles and blogs about Segways and their use by the disabled, including message board posts about people with Multiple Sclerosis who were using them and were very satisfied with the experience. It soon became
apparent that this machine was in demand by the disabled and that those who used them promoted their use as a mobility aid. One of the Segway message boards mentioned an organization called Segways for Vets that made charitable donations of these devices to military personnel who had been injured in Iraq and Afghanistan, and there a number of veterans posting in the forum who talked glowingly about their Segway scooters.

However, further reading on this message board revealed that the Veterans Administration seemed to feel that this device wasn’t as good or as suitable as a wheelchair in spite of this group’s efforts advocate for them. Other disabled community members who were not veterans reported that Segways could sometimes be bought with the cooperation of insurance companies, though this required a physician’s prescription – and usually required the patient to educate the physician about the Segway and why it would be an appropriate solution for their problem. Their comments indicated that others thought that the Segway was regarded as an exotic and untested technology. Even when these Segway users brought literature to agencies and physicians showing that these devices were involved in fewer accidents than mobility scooters were, they encountered public resistance. Disabled Segway owners on the Segway forums report being asked to leave facilities and not being permitted to ride them in spite of appropriate licensing and prominently displayed handicapped stickers. The demonstration that the device is safe and useful – is overridden by the context of a device of unknown function and unknown trustworthiness (Latour, 1991.)

Further browsing uncovered the names of a number of prominent people who were disabled and who were using Segways or other extraordinary technology to overcome mobility limitations – theoretical physicist Dr. Stephen Hawking, runner Aimee Mullins,
radiologist Dr. Peter D. Poullos, film star Christopher Reeve. Although the devices they used to address different areas of their disability seemed reasonable and practical solutions for their lifestyles, these same devices didn’t seem to be widely available to or widely discussed in the community of the disabled.

Supplementary searches of websites and blogs that focused on disabilities indicated that government agencies’ and insurance companies’ acceptance and support of new technology for the disabled varied wildly. In some cases, insurance companies were only willing to pay for devices that had been the standard recommendation for the past 50 years. In other cases, insurance companies agreed that unusual devices such as Segways were suitable and reasonable solutions to a client’s needs, but attempts by these same clients to purchase and use these technologies met with resistance and hostility (Paulos, 2008). The overall impression given by these stories was that the actual availability of any particular device was based in vaguely constructed policies relied on subjective evaluation which changed as the personnel in positions responsible for the decision changed. Discourse on Internet forums for the disabled reflected anger and frustration at the health care systems and insurance companies and the limited information exchange between consumer, provider, and technology companies involved in the rehabilitation industry.

Even communities that were specifically created to support the elderly and had good access to hospitals and rehabilitation facilities did not function as an information ground about mobility devices. One informant, a retired military officer who lived in a gated community where ownership was limited to those over 50 years old, explained that the churches that served the community did take in and redistribute medical equipment that was donated after a church member died and that his own church had a ready supply of
push-type wheelchairs that could be given or loaned to those in need. Although there were
people at the church who used mobility scooters, but there was no active seeking or sharing
of information about new or easier to use technology and no readily apparent “information
ground” (Pettigrew, 1999).

In reflecting on the conversations and the results of the web searches, it seemed that
the basis of the problem revolved around the matter of access and acquisition of
information about these devices and the choice of information grounds. The Internet
overcomes many obstacles to information access, but in this case there seemed to be
barriers that prevented new technology from reaching those who desperately wanted it –
the very community likely to embrace and adopt it.

This led to the central question of this dissertation: What information resources do
users of assistive mobility devices use when they are making purchasing decisions and has
the Internet become a prominent part of the information grounds that they commonly use?

While the Internet has become a major information resource for people with health
related questions, there have been no recent studies to see whether it specifically impacts
the acquisition of medical equipment. The picture that emerged from this research shows
that the Internet plays a smaller part than anticipated in the “information territory” used in
for decision making about these devices. In addition, the data revealed that the overall
information territory is divided into sections where policy, procedure, and culture tightly
restrict access to information that clients and agencies need in order to facilitate the
procurement process – to the point where these conflicting needs and resources often
interfered with the device acquisition itself.
“I was born with my disability ... and sometimes it's just really tough to get access to the information that you need; the services that you need in order to live more independently.” -- Michelle Colvard, Abilities Expo Houston Ambassador

2.1 Background

We live in a globally mobile culture, where citizens expect easy access to places that once would have required months or years to reach. Automobiles, planes, and various modes of public and private transportation are crucial to the integration of business and quality of life across the globe. But this social benefit is not extended equally to all. There are transportation barriers that block the very young, the elderly, the disabled and ethnic minorities from fully participating in mainstream society. For those with the most
profound mobility impairments, the difficulties involved in using common modes of public or private transportation restricts their ability to obtain critical services such as medical care. Those who experience difficulty walking later in life find it more frustrating as their limitation blocks them from activities and environments that they once enjoyed or took for granted. Disability is seen as a malady, even by the disabled themselves, who struggle against the roles of “outcast” or “object of pity.” (Pearce, 2012).

In many societies throughout history, the most common cause of mobility impairment was accident or war. Medical information about the causes of birth defects does not develop until the late 1800’s. Before that time, prevailing public opinion was that anyone born with disabilities was the result of a curse. These children were often deliberately killed (Clapton & Fitzgerald, 1997). This opinion can still be found in some areas of certain third world countries.

Those who developed disabilities later in life stayed usually within their original community as wards of their family, wards of the church, or wards of the government. In industrialized countries, the paradigm of sending the impaired to be taken care of the state became common after the industrial revolution. During the middle to late 1800’s and onward, the most common practice in the United States has been to institutionalize people with more severe forms of disabilities in schools or sanitariums or nursing facilities and turn them into wards of the state. This was often done without the consent of the individual. These were extremely restrictive environments. Patents had no ability to decide even the smallest details of their living arrangements and could not even choose who to associate with or live with (Pearce, 2012). In many cases there was no attempt to rehabilitate or improve their ability to function once they arrived. Technological changes
came slowly; most were left to deal with their disability using devices that were already old by the Middle Ages.

Reform has been a long time in coming, as can be seen in the recent reports on the experiences of those who survived the polio epidemics of the 1950’s. As children, these patients who were separated from parents and left in the hands of hospital staff had little say in their treatments or the devices given to them – if any. Often they were told to “just deal with it,” by staff members and family members. Only limited amounts of information was shared with the families; children were not usually given any explanations other than they had a disease and the doctors would make them better. Complaints or questions about treatment were often met by anger or punishment.

Cut off from access to parents and family members, many patients believed that in order for them to survive, staff members had to be kept placated. By the time that these children finally returned to their homes, they had been trained to listen to authority, never question things, and to be as invisible as possible. But these coping mechanisms served to isolate them, and fear and ignorance about polio kept them in a kind of social quarantine. Friends and acquaintances were afraid to associate with them, and it was not uncommon for neighborhood children to be told to not play with them. Families, ashamed of the stigma, would force them to try to walk and “look normal”; those who couldn’t were often punished or barred from society (Hayden-Elgin, 2012). They were supposed to recover completely and to “forget” they ever had a debilitating illness (Bruno & Frick, 1991).

School experience post-polio was not pleasant, due in part to society’s misconceptions about polio and its aftereffects. Many former patients were put into classes with the mentally disabled. Those who could pass entrance exams found that college
offered an escape from these expectations (O’Briant, 1969), and most managed to make their way into society, albeit with some difficulty. Although this new environment enabled better interactions with society, a new problem arose – that of finding reliable vendors and technicians to deal with their mobility devices. It was not unusual for polio survivors to travel long distances to obtain medical equipment and to access one of the few trained therapists who could help assess their needs. As a group, polio survivors often exhibit signs of posttraumatic stress disorder as a consequence of their experiences during recovery and rehabilitation and many of them find it difficult to question decisions made for them by doctors or therapists (Moore, 2012).

Although considerable improvements have occurred since that time, today’s disabled population still suffers from many of the problems experienced by the disabled of earlier centuries. They often find themselves isolated within their own society and few have extensive opportunities to engage others or participate in their community. (White, Simpson, Gonda, Ravesloot, & Coble, 2010) Even within a clinic or a hospital setting, mobility impaired patients are sometimes faced with barriers to care and services, as indicated by recent reports that some physicians are refusing to accept disabled patients in their practice (Lagu, et al., 2013). This can become a critical issue for those who whose mobility limitations prevents them from being able to conduct suggested health routines such as breast exams for early cancer detection (Iezzoni, McCarthy, Davis, & Siebens, 2000).

Those who are physically impaired but who are not cognitively impaired often end up being shunted into groups of people who have both physical and cognitive impairments, further isolating them from contact with their communities (O’Briant, 1969). These are the ones who are most alone; sent to sit in a room full of strangers who do not share similar
backgrounds and interests (Wielawski, 2011). It comes as no surprise that 96% of adults surveyed in a 2007 public opinion research poll by the Kaiser Family Foundation disliked the idea of moving into a group oriented situation such as a nursing home or an assisted living center after a surgery or other extensive medical intervention (Wielawski, 2011).

Studies have shown that their negative opinions are founded in historical fact. Even with current advances in medical practices, long term living arrangements for the elderly in group care may not provide many benefits, particularly if the patient is old and in poor health. Even for those who are not recovering from a medical crisis, life in a Medicaid-sponsored public nursing home is often characterized by a rapid and usually permanent decline. They are stripped of the ability to make personal choices, placed in situations where familiar social contacts are lost leads to an increase in social isolation (Magasi & Hammel, 2009). Many of these centers are understaffed and have few diversions for their clients. For patients in these facilities, there is little talk of future plans and most experience short term or long term depression. With the loss of opportunities for activities that encourage learning and personal growth, they show little interest in looking for technology and show no effort to look for options that would allow them to gain more independence and more mobility (Wielawski, 2011). As a result, this population experiences restricted activity and community participation, which results in poor quality of life and a lack of access to information that could change their situation. With no place to go and no one to enjoy activities with, interest in personal mobility declines and subsequent to this is a marked disuse of assistive devices (Brandt, Iwarsson, & Ståhle, 2004).
In addition, the use or non-use of mobility devices by those who are mobility impaired has additional consequences within the larger community. With age comes declining muscle strengths that can lead to functional disorders and restrictions on the types of activity such as shopping that the younger and healthier populations enjoy (Hedberg-Kristensson, Ivanoff, & Iwarsson, 2007). Access to shopping, medical facilities, social support groups such as churches, and transit bus lines factor heavily in their choice of where they will live and whether they will use community services such as libraries and public transportation and affect how many sources of information they have entering their lives. These choices impact neighborhood demographics and spatial distributions within urban and suburban areas (Hedberg-Kristensson, Ivanoff, & Iwarsson, 2007).

As a result, governments are dealing with a population shift out of metropolitan areas into communities that are unprepared to deal with the new influx. Established agencies see a decline in the number of clients, resulting in a corresponding mismatch between the location of services and agencies designed to assist the elderly and the disabled (Truong & Somenahalli, 2011). In newly populous areas, infrastructure issues rising from overburdened resources contribute to the problem.

Transportation problems are one of the more frequently encountered challenges encountered by the disabled. Wheelchairs are bulky and awkward and difficult to maneuver in and out of cars. In more established areas with a population that uses public transportation, cabs and buses and trains will often be outfitted with ramps and accessibility features. However, because these options are usually not available in newer areas, it is common to see power chairs and mobility scooters used as a form of transportation (Truong & Somenahalli, 2011). But even in areas with fairly well
established and supported infrastructure, those without cars find that it is more expensive both in terms of time and effort to use public transportation than it is to use an automobile, and it is not unusual to see one of these devices on the shoulder of a road or even traveling down a road intended for automobiles (Dalton, 2007).

One unintended consequence of the emergence of the mobility scooter as a cheap and easily accessible form of transportation is that there now is an active market in used scooters. Many of these are reportedly purchased by the non-disabled for personal transportation use (Gentleman, 2012) so that the rider can more quickly reach destinations within a few miles of their home. Communities have reacted to the use of scooters by the non-disabled with some hostility, leaving those with true mobility impairments in the uncomfortable position of trying to “look disabled.”

Local communities struggle with issues of how to regulate their usage. In Great Britain as in most of the United States, class 2 and class 3 powered wheelchairs and scooters are allowed on roadways if the driver is disabled and if there are no available sidewalks or paths beside the road, but monitoring and enforcement is not possible on a wide scale (Laws pertaining to Mobility Scooters, 2013). This community infrastructure problem is projected to grow over the next several decades as the number of elderly increases and as medical advances increase longevity overall (Häggbloom-Kronlöf & Sonn, 2007).

Although technology opens the door to many new opportunities, its application has not led to universal benefits. Infrastructure – or the lack of it – also impairs access to many important environments for those who are disabled. Sometimes the barriers are not blatantly evident, as in the case of hospitals and doctors’ offices with tight corridors and
examination rooms that not set up to examine patients who cannot rise from their wheelchairs and who cannot be easily lifted to an obstetrical examination table (Gilmer, 2013). These infrastructure problems are expected to have far-ranging impacts as the so-called “obesity epidemic” causes the number of people who need mobility assistance to rise, and obesity exacerbates medical problems in those who already have other disabilities (Diament, 2013) (Gentleman, 2012).

But crafting good policy for infrastructure requires access to solid assessments of the needs of members of a community and detailed information about their needs so that public resources can be allocated in a meaningful way. In some sense this represents a “hidden problem” in society – one that will become more prominent in the next decades as the number of mobility impaired people rises. If environmental barriers, personal choices, and socio-cultural factors that lead to limited participation in a community are addressed and remediated by the community itself, the quality of life increases (Pape, Kim, & Weiner, 2002).
2.2 The Demographics of Disability

_The largest barriers faced are the attitudes & expectations- often incorrect- of able bodied society._ - (Respondent 9)

Mobility impairment and disability are not necessarily “invisible” conditions, although most associate it with the elderly. Disability can occur at any age, and the prevalence in the population increases with the age of the cohort (Fricke, 1998). Mobility issues that are a significant concern for the aging and elderly in any culture are not unique to them. The elderly do represent, however, the demographic with the largest number of disabled and as the world ages the problem of what kind of social and economic power they can enjoy, what kind of access to technology they have, and how to serve those with varying degrees of mobility problems becomes important for society to solve (Clapton & Fitzgerald, 1997). It’s a very costly problem for society -- The Christopher and Dana Reeve Foundation reports that the cost of treatment and technology can reach upward of three million dollars per individual over the course of their lifetimes (Paralysis Facts and Figures, 2013); far more than many people can easily afford.

Because of the use of different measurements in studies of the disabled population, it is difficult to build an accurate picture of just who should be included in this category, where they live, and how long they have been disabled. Research that relies on self-reporting makes up a significant percentage of the statistical articles. Here in America, over three million people are significantly impaired enough to require a mobility assistive device for everyday activity (Plummer, 2010). Most of these are manual wheelchairs, with electric wheelchairs comprising a much smaller percentage of purchases (BraunAbility, 2011) and
an unknown number of “electric mobility scooters” – personal mobility devices that are frequently advertised on television. According to literature reviews, 25% of adults aged 65 and older own some sort of assistive technology, and one third of this population will have more than one device (Pape, Kim, & Weiner, 2002) (LaPlante & Disability Statistics Center, 2003).

Although they are not disabled themselves, family members who act as caregivers and trained aides who receive compensation for their assistance are significantly impacted by issues affecting the mobility disabled. The numbers are startling: a 2013 report from the Pew Research Center found that 39% of adults in the United States provide care for a loved one (adult or child); an increase of nine percent within the past three years. These are adults who are currently in the workforce or who are in that 30 to 64 age bracket. One third of this group provides care for more than one disabled individual (Fox, Duggan, & Purcell, 2013).

<table>
<thead>
<tr>
<th>Ambulatory difficulty: sex by age (2011 American Community Survey 1 year estimates)</th>
<th>United States</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimate</td>
<td>Margin of Error</td>
<td></td>
</tr>
<tr>
<td><strong>Males</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 to 17 years with an ambulatory difficulty</td>
<td>191,948</td>
<td>+/-7,709</td>
<td></td>
</tr>
<tr>
<td>18 to 34 years with an ambulatory difficulty</td>
<td>512,642</td>
<td>+/-11,354</td>
<td></td>
</tr>
<tr>
<td>35 to 64 years with an ambulatory difficulty</td>
<td>3,990,527</td>
<td>+/-34,737</td>
<td></td>
</tr>
<tr>
<td>65 to 74 years with an ambulatory difficulty</td>
<td>1,429,389</td>
<td>+/-16,208</td>
<td></td>
</tr>
<tr>
<td>75 years and over with an ambulatory difficulty</td>
<td>1,975,754</td>
<td>+/-18,308</td>
<td></td>
</tr>
<tr>
<td><strong>Female:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 to 17 years with an ambulatory difficulty</td>
<td>158,831</td>
<td>+/-7,573</td>
<td></td>
</tr>
<tr>
<td>18 to 34 years with an ambulatory difficulty</td>
<td>514,732</td>
<td>+/-11,960</td>
<td></td>
</tr>
<tr>
<td>35 to 64 years with an ambulatory difficulty</td>
<td>5,053,614</td>
<td>+/-39,894</td>
<td></td>
</tr>
<tr>
<td>65 to 74 years with an ambulatory difficulty</td>
<td>2,113,648</td>
<td>+/-18,728</td>
<td></td>
</tr>
<tr>
<td>75 years and over with an ambulatory difficulty</td>
<td>3,951,487</td>
<td>+/-23,427</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 1 Demographics of people with an ambulatory difficulty*
Precise demographic information is difficult to find because of disagreements in terminology and studies that rely on self-reporting, but there are some broadly applied statistics that help further define the picture of disability in the United States. The Census Bureau’s American Community Survey for 2011 showed that there are approximately 20 million people who do not live in institutions and who have an ambulatory difficulty (Census Bureau, 2013). In September 2010, Pew Research reported that 27% of American adults currently self-identified as having a disability that affects their ability to function in society.

The Christopher and Dana Reeve Foundation’s website noted that one in fifty people live with some form of paralysis; a number higher than previous estimates showed (Paralysis Facts and Figures, 2013). The Veterans Administration indicates that in 2011 there were 3.4 million people who had become disabled while serving in the armed forces and that the amount of money paid to them had doubled within the past ten years (Zoroya & Hoyer, 2013). During that time frame, the number of veterans that are identified as "seriously" disabled tripled from 1.3% to 4%. Projective models, such as the one used by the Social Security Administration, show that the number of people needing assistive devices of some sort will continue rising; their current model predicts that today’s average 20 year old American worker has a 33% chance of becoming impaired or disabled before they reach retirement age.

The 2013 survey commissioned by the Christopher and Dana Reeve Foundation breaks down the causes for disability on the approximately 6 million people who self-reported some form of paralysis. Stroke accounted for the largest category (29%), with some form of spinal cord injury (23%) being the second leading cause of paralysis. The
degenerative disease, Multiple Sclerosis, came in third with 17% of reporting this as the underlying cause of their disability (Paralysis Facts and Figures, 2013).

Many of the disabled in the United States who need medical and rehabilitation services find themselves in an economic trap that's difficult to overcome. As one poster on Disability Scoop explained, “It is what has been deemed by some as the welfare trap. I found myself in a position where I have Social Security and Medicare but am in need of Medicaid in order to pick up a 20% co-pay that Medicare doesn’t. However, I have been told that I get too much Social Security to qualify for Medicare. With the power wheelchair that is beyond its sixth year and is falling to pieces as we speak, I am greatly in need of another. However 20% of the cost of my specialty (chair) would be close to $4000 less service.” (Disability Scoop, 2013)

Sociological studies of disability indicate that non-disabled members of society tend to frame the issue of disability in terms of being a tragedy, impairment, or a type of “otherness” that is also consistent with representations of women and Blacks within a patriarchal society. Not infrequently the society itself views the disabled through the lens of social values, seeing them in terms of their assessed value to society, their use of the physical environment and demands for accommodation to their needs, as well as a permanent part of the welfare system (Stone & Priestley, 1996). They are, in Chatman's terms, “outsiders” who are denied the common experiences and interactions that others in society experience (Chatman, 1996.) They are not part of the everyday information exchange that the general public is involved in; instead they are outsiders who are dealing with a very tightly knit world of “insiders” – those who are providers in the health care system.
In addition, research that clarifies and explains the patient’s personal experiences with mobility devices is less common than research about the expected physical benefits and impact of the technology. The medical gaze moves over the patients, objectifying and categorizing their condition, but does not acknowledge them as human beings who interact with others within complex physiological and psychological environments (Davenport, 2000).

This lack of “witnessing” (Davenport, 2000) is part of the basis of the long-standing complaint against the medical and rehabilitation community -- that the patient is forced into a position of almost no power while the doctors and therapists take on a more paternalistic role (Coulter, Entwistle, & Gilbert, 1999). The patient is forced to become one of the “outsiders” (Chatman, 1996) whose access to information that they desire is controlled by the closed world of professional medicine. And while physicians and therapists position themselves as the gatekeepers of who qualifies and who does not qualify for mobility assistive equipment, recent news stories (CNN, 2013) and publications from the Human Health Services Department (Most Power Wheelchairs In The Medicare Program Did Not Meet Medical necessity Guidelines, 2011) indicate that physicians themselves may not have good or accurate information about mobility devices.

Sales brochures and other targeted literature delivered to physician offices may mislead physicians who do not commonly deal with or prescribe mobility devices. This can lead to mistakes in prescriptions or even denial of an insurance claim. According to publications by the Office of the Inspector General, seven percent of the power wheelchairs bought through Medicaid were not correctly matched to the beneficiary’s medical condition.
Differences in the vendor’s documentation of the patients’ needs and physicians’ assessments of these same needs show a disjuncture between needs and wants. Though review of the case material is beyond the scope of this dissertation, it does support the idea of an information ground that is in complete disarray. In an attempt to address this situation, the Office of the Inspector General called for more physician training and enhanced regulation of vendors by the Centers for Medicare and Medicaid. However, such a move has done little to clear up the tangled chains of information already in place.
2.3 The Device Procurement Process

Every manufacturer below has some items in common (pretty much), but you will find they have an astounding variety of solutions to problems. You pretty much have to follow each and every link on the sites, whether or not you think it’s something worth checking out for your situation. It really is worth your time, especially since you will have to keep for years whatever you wind up with.

--“Wheelchairdude” on Yahoo Groups

Our current methods of addressing physical disability generally involves supplying individuals with various assistive technology devices designed to restore or replace function to some degree and help them to enhance and maintain their independence, generally through organizations such as state disability offices or insurance programs. In theory, the purchasing process is straightforward and starts with a decision that purchasing a mobility device is a good solution to a problem that the client is experiencing.
This may be caused by a change in health, a catastrophic failure of a current device, or a planned replacement for an older device.

**Purchasing Process Flowchart**

![Flowchart](image)

Figure 2: Process flow diagram for device purchase

On the surface, this seems to be an efficient method for delivering medical devices to patients who need them, but in reality the actual process is hampered by lack of information flow among the many stakeholders. Limited choice and lack of detailed data at each stage in this scenario results in delays in delivery and client frustration with an end product that does not meet their needs (Kittel, Di Marco, & Stewart, 2002). The information gap at this stage is both broad and deep. Stakeholders often work at cross purposes to each other, to the frustration of all involved in the exchange (Brandt, Iwarsson, & Stahl, 2003). For the most disenfranchised populations, the situation is even more difficult. Inequalities in basic services result in ineffective and often inappropriate services and technologies doled out to those in need without any understanding of the real needs (Fricke, 1998). For the financially disadvantaged there are no easy solutions. The myth of the spoiled welfare queen who buys power chairs to save her from walking unravels quickly when the details of the exchange are examined.

Although these devices are most commonly recommended by a therapist or medical staff, not infrequently it is the patient who initiates a request for a wheelchair or a walker as a response to their own health needs (Ward, et al., 2012). Although some problems –
such as the need for a simple cane or a frame walker – can be quickly addressed, the task of matching a more complex technology to a client’s specific needs is a challenging process (Scherer, Sax, Vanbiervljet, Cushman, & Scherer, 2006). When people are forced into accepting one of these items as a permanent part of their lives, it becomes bundled into the emotional and psychological reactions to the idea of “no longer being whole.” Wheelchairs and other mobility aids become unpleasant necessary medical devices which are time-consuming to acquire and difficult to give up (Sapey, 2004). Those who use them are well aware that they foster the image of the owner as someone who is helpless and dependent on others (Scherer, Sax, Vanbiervljet, Cushman, & Scherer, 2006).

It is clear that much of the power in these exchanges belongs to groups other than the client. Some researchers have reported that their study participants were told to obtain an assistive device without the need for this purchase being clearly explained (Häggbloom-Kronlöf & Sonn, 2007). Some reported that patients complained that they received very little or no instruction in the proper use of their device (Brandt, Iwarsson, & Stahl, 2003). Perhaps more troubling here is that the medical staff who recommend devices are often not familiar with the scope and range of technology available and need additional training or seminars to round out their knowledge (Ward, et al., 2012).

While new technology has increased the number of wheelchair types and designs that can be customized to answer a wide variety of needs, it has made the purchasing selection decision more complex for the client and more expensive for the funding agency (Mortenson, Miller, & Auger, 2008). In cases where there is no central government authority that supervises the acquisition of medical equipment, insurance companies and more localized organizations such as hospitals assume this role. In this case, the
information resources available to each client vary considerably. For example, individual state healthcare systems and insurance companies in the United States demonstrate this diversity the inconsistent definitions of what constitutes a disability and different interpretations of how disabilities can be best served. This can be seen in the inconsistent way that “L-codes” – reimbursement codes used in the healthcare industry to identify services and devices provided to clients – are used. The disabled have railed against this uneven application; for them it is one of the sources of mistrust and dissatisfaction with medical procedures and devices (Stone & Priestley, 1996). This inconsistent presentation of information from different sources affects the client’s ability to fill out the picture of what they need to know about the process or the technology, and impacts their ability to integrate the device into their lives. (Kittel, Di Marco, & Stewart, 2002)

Researchers studying the abandonment of assistive technology report that during the first five years of use, 30% of the clients will stop using or will refuse to use their medically prescribed devices (Philips & Zaho, 2000). A similar study in Sweden showed an abandonment rate of 34% (Brandt, Iwarsson, & Stahl, 2003). Walkers and canes are frequently discarded, but wheelchairs are not as frequently abandoned. In some cases this abandonment is the result of a positive medical outcome, where there is a functional improvement in a patient’s condition (Häggblom-Kronlöf & Sonn, 2007). In other cases, the patient will discard the device because of dissatisfaction with either the look and feel of it or disappointment over how fatiguing or inconvenient it is to operate in the spaces they traverse every day (Kittel, Di Marco, & Stewart, 2002). Canes and walkers are likely to be rejected on an emotional level because they are viewed as “something that only old people use.” The trade-off in mobility and convenience are relatively slight; those who use these
devices are often able to move around without them. Interestingly, there seems to be no stigma attached to the use of mobility scooters (Sousa, et al., 2010).

Conflicts between embodiment and ownership affect how and when a device will be used (Murray & Fox, 2002). In order to be useful, technology has to be integrated into the client’s life. Forcing patients to use a particular device can foster anger and resentment and interferes with the ability of the patients to integrate the device fully into their lives and may contribute to a sense of depersonalization (De Vignemont, 2011). This depersonalization leads to a sense of social isolation in the patient, along with a host of negative consequences such as declining health and increasingly poorer motor skills. This is particularly true for the elderly and the poorly educated or those who live in rural areas.

Failure to use the recommended devices may be detrimental to both the patient’s health and safety – for example, when physical therapists recommend use of a walker because of balance and strength problems and the client insists on using a cane instead. In this example, the patient’s preferred technology actually places them at higher risk of injuries from falling. Non-useful and abandoned technology such as that in the example will have a direct impact on the social costs of health care in the future. Steel and Gray (2009) argue that the degree to which the client’s changing needs and health are considered in the decision making process strongly affect how well the devices are integrated into the patient’s lifestyle. Scherer et al (2006) found that patients who positively scored their subjective quality of life and interpersonal relationships on an assessment instrument were more favorably disposed to their assistive technology and had an overall better satisfaction rating with their devices. These changes are frequently an outcome of the progression of a patient’s condition, as in the case of those diagnosed with
Multiple Sclerosis who find it more difficult to negotiate through their environment as the disease advances. (Sousa, et al., 2010)

Once someone has decided that there is a need for a mobility assistance device, there are several routes they can use to acquire both new and used technology. One fairly common practice for the least expensive items is to obtain them through gifting or donation from a patient who no longer needs them or from family members who pass them along to others after a patient dies. Walkers, canes, and rollators (also known as “rolling walkers”, these are frame walkers with wheels attached) are the items most frequently donated to charitable organizations and to churches. One pastor who responded to a request for information reported that the church had a part-time nurse on staff whose duties were to help elderly members of the congregation who had little income. He said that they always had several walkers and push-type wheelchairs available in their medical supply room that could be donated to community members in need.

For the client, negotiating the terrain of terminology is one of the earliest barriers to investigation of these medical appliances. One type of device may have several different names that depend on who is using it or describing it. Among the medical and insurance companies, electric wheelchairs are defined as heavy, stable devices with four to six wheels and four-point tie downs that make them safe to use as seating in a vehicle. They are driven by joystick controls located on the arm or positioned on an elevated screen that can be touched by a mouth held pointer. (Mobility Scooters Versus Wheelchairs, 2010) These same sources recognize three main types of mobility scooters available at the present time – three wheeled scooter, four wheeled scooter, and the compact mobility scooter that is designed to be taken apart quickly for transport and reassembled at the area where it will
be used in less than thirty seconds. (Mobility Scooters Versus Wheelchairs, 2010) They are less expensive than electric wheelchairs and are also less rugged and have a shorter range than a standard electric wheelchair. But to others, the words “wheelchair”, and “scooter” and “zippy cart” and “Hoverround” may be used interchangeably and inappropriately to describe a particular type of mobility device, making it difficult to locate suitable used equipment.

Less expensive mobility devices such as rollators and some scooters and some of the low-tech push wheelchairs present less of an information problem. They are relatively simple non-motorized devices and have fewer available enhancement options. These items are often bought directly by the patient or family, and these direct purchases may not be done through a standard medical evaluation and prescription process. Equipment that is obtained by these methods may not be the same type of device that a therapist or physician would have recommended; however, the client and family as major stakeholders in the situation have more control over the outcome.

Because of the cost involved, the high-end push wheelchairs and the power chairs are bought with the help of insurance companies or Medicare. This brings a number of new stakeholders into the decision making process. In addition to the patient and the patient’s immediate family, clinicians, rehabilitation counselors and insurance representatives may all have a say in the matter – and some will have a greater impact on the process than others. Some of this influence is not readily apparent to outsiders. Vendors who supply the devices often sponsor or help sponsor seminars and educational sessions for other medical professionals and may offer small gifts and promotional items to make sure they have an advantage when devices are recommended. Some of these vendors also offer
incentives to service technicians, medical staff, and the client themselves to purchase the device that they are selling (Eggers, et al., 2009).

In order to receive a Power Mobility Device through Medicare, the client must collect a number of documents including a documentation checklist which includes a face-to-face meeting with a physician, a prescription from that meeting, the official diagnosis and a statement of how long the device will be needed (Power Mobility Devices, 2013). During the initial appointment with the physician, the patient’s physical condition will be evaluated and they or their aides will be asked about their physical environment, special needs, and funding sources before writing a prescription for a device (Mortenson, Miller, & Auger, 2008). The prescription is written at the end of the encounter and then becomes the base document used for deciding how much will be paid for a mobility device and which device will be selected. In cases where the patient is a minor who lives in the United States, the acquisition of mobility devices may also be guided by the state’s Department of Education. Many times the ideal set of requirements can’t be met because of technology and environment, and what is prescribed in the end may be a compromise that does not completely satisfy any of the stakeholders.

Local and regional regulations add to the complexity of the situation. In the United States, recent changes to mobility devices covered by Medicare means that these items are now are not “bought” outright but instead are “rented to the patient” for a period of thirteen months (Power Mobility Devices, 2013). Prior to 2011, patients who qualified for coverage of a power wheelchair were given a lump sum equal to 80% of the purchase price to buy the equipment. After January 1, 2011, Medicare dropped this option from all but two classes of chairs and will now only cover 80% of the costs of renting a wheelchair for the
first thirteen months. Medicare’s payments cannot exceed 80% of the total allowed purchase price. (Power Mobility Devices, 2013) Some states may offer insurance or programs to help those in poverty afford the cost of their chairs, but this policy varies from state to state. In the wake of this change in rules, the information scene has changed for those who require complex rehab power chairs, and vendors and patients are struggling to locate updated documents and policy statements.

Unlike the United States, where there is a single governing agency, in the European Union, decisions about which devices are authorized for funding is made by 82 “notified bodies” that receive manufacturer applications and issue certifications for their use. In the case of low risk devices, the only proof needed is a definition of the intended use of the device. For highest risk devices, human clinical investigations are required. Although there are a number of inherent problems in this system, European users, on the average, have access to new technology two years before it is available in America. Some devices used in Europe never manage to make it through the FDA approval process (Cohen & Billingsley, 2011).

Eggers et al (2009) have identified four major influences impacting the ability to acquire wheelchairs that exist within the health care delivery system. These include the wheelchair funding source, the ability to pay all or some of the cost out of pocket, the decision making capacity of the client, the client’s perception of their own needs, the clinic and the client’s familiarity with various products, and the influence of family and caretakers. One factor mentioned in this study as present but difficult to evaluate is the decision making structures of the organizations involved in the process and the degree to which any of these entities uses an interdisciplinary approach to meeting the needs of the
client. They also hypothesized that the location where the mobility device was turned over to the client – whether home, hospital, clinic, or other facility – had a significant influence on the providers and the decision making process but they did not elaborate further. Other factors that impact the selection of mobility devices include the clinician’s relationship with the client, the client’s familiarity not only with mobility devices but also with the acquisition process (Eggers, et al., 2009).

Inefficient and burdensome regulatory policies are one of the major contributing factors, particularly where innovation comes from small startup companies rather than large corporate giants (Makower, 2010). Due in part to the complex and confusing system for FDA licensing the disabled population in the United States is at a distinct disadvantage compared to their European counterparts. Although the FDA’s conservative rules are in the process of being rewritten, it’s not clear just how much less restrictive the new policies or whether it will help overcome some of the barriers insurance companies place against new medical mobility equipment. But the less restrictive atmosphere in Europe means that mobility impaired clients in those nations also have a far greater range of options available to them (Makower, 2010). American critics of these policies argue that this is inherently more risky to the clients but in spite of the complaint there does not seem to be any hard data indicating poorer outcomes for Europeans (Cohen & Billingsley, 2011).

While patient satisfaction is reported to be higher when medical information is shared, there exist barriers to this ideal situation (Coulter, Entwistle, & Gilbert, 1999), and issues involving poor communication and poor information exchange among all parties involved in the decision are primary factors commonly cited by patients as leading to device dissatisfaction. This is particularly true when the disability occurs suddenly and later in life.
and the client is thrust into the situation without having adequate knowledge about the nuances of living with a mobility device and what to expect from it. Regardless of whether the equipment is a high tech power chair or a simple rollator, abandonment is costly in terms of health outcomes and from a financial perspective. (Philips & Zaho, 2000) (Sousa, et al., 2010).

2.4 The Information Needs of the Disabled

"What a paralyzed person needs to think about is not a time when there are no more wheelchairs but instead a depth of knowledge about the wheelchair industry. They need to learn how to check their skin daily and determine what wheelchair cushion they should be sitting on. They need to learn how to manage one’s bowels and bladder. They need to learn transfers of all kinds. They need to learn how to repair a wheelchair. (Pearce, 2012)"

Information about mobility devices is part of the gestalt of disability – part of the system of ideas, standards, expectations, and values (Chatman, 1999) that go along with the concept of an idea called the “sick role.” (Parsons, 1951) Although the terminology has fallen out of use, the understanding that being disabled in society is a disempowering role that brings with it a set of strictures and restrictions is still valid. For the disabled, this means that information is generally held by others and is not shared with them, even in cases where they are the decision makers and where they have a need and a legal right to know.

Lack of access to good quality information about devices was one of the primary concerns mentioned by the individuals in many studies about disability (Coulter, Entwistle,
& Gilbert, 1999). Although their non-disabled family members may have been given pertinent information or had access to it, this kind of information was frequently withheld from the disabled (Sapey, 2004). This situation does not improve after they are discharged; when away from a clinical setting, the task of finding answers to questions about health and devices does not improve. As Jetha et al noted, when individuals transition from rehabilitation settings back into their home and into the community, “…they often face challenges in obtaining health-related information (e.g., nutrition and PA recommendations, self-care tips, and new treatment and therapy options).” (Jetha, Faulkner, Gorczynski, Arbour-Nicitopoulos, & Martin-Ginis, 2011) This lack of access has been noted as affecting the client's perception of health care. Steel and Gray (2009) stress that the relationship between the client’s changing needs and empowerment in the decision making process strongly affect how well the devices are integrated into the patient’s lifestyle; however, there are only a few journal articles that explore aspects of this process.

Information about form and function is critical to making a good match between device and client; a process that relies as much on an understanding of the client's attitudes as it does on the nuances of the equipment. Access to specialists who can deal with a large range of information needs will become more important in the next few decades as the largest present age cohort – the “Baby Boomers” reaches retirement age. As a large percentage of them begin to experience a decline in mobility and physical activity, assistive devices will likely become a significant part of their daily lives.

The most common technology used to deal with mobility limitations is the simple cane although frame-type walkers are frequently encountered in public venues, particularly
for clients who have suffered a stroke (LaPlante & Disability Statistics Center, 2003). Other
types of mobility devices are less commonly seen, though the public’s familiarity is
expected to increase either through personal needs or through a process of assisting a
family member or friend as the number of people with some form of mobility impairment
rises. The transition will not be a smooth one in every case. Although many clients feel that
using mobility devices helps them move around more safely and steadily, a significant
portion of the users have negative opinions of this technology clients who use them often
report that they are treated paternalistically – or ignored-- by the public and by the medical
community. An increased presence of these devices in public areas has not managed to
dispel the attitude of some of the able-bodied anyone using a mobility assistance device is
too impaired to communicate with others. Like children, their desires and wishes are often
ignored (Gilmer, 2013).

The role of finances cannot be ignored in the overall picture, since economic issues
are a driving force behind the specific device selected and the acquisition process. While a
simple cane is relatively inexpensive and walkers cost around a hundred dollars, scooters,
wheelchairs, and accessories needed to make them comfortable for long use can cost as
much as $45,000 – the price of a new car. Because of this expense, low technology solutions
tend to be favored over more advanced devices. Cost may not be the only factor in choosing
low technology, though. New technology can seem like a riskier choice and clients who
choose pre-programmed devices like power wheelchairs with an integrated electronic
controller must spend time and effort learning to operate them (Häggbloem-Kronlöf & Sonn,
2007).
Language is a major barrier to information about disability rights, mobility device acquisition, and financial aid. Those who do not speak or read English fluently are at great risk of having their needs and complaints misunderstood or of not being able to comply because the instructions they are given are not clear (Flores, 2006). A full investigation of this matter as it pertains to mobility assistive devices is beyond the scope of this paper, but an example of the problem can be found on the web pages of the State of Texas’ Department of Disability And Aging. While government policies state that web pages for public programs must be offered in languages appropriate to that area and the landing page has a “Welcome” page in Spanish with links in Spanish, all links lead to pages written in English. As a contrast, California does have pages in Spanish but few direct links. In order to access the bulk of the Spanish language pages, the potential client needs to be able to use a search engine.

Sapey’s (2004) study of a population of disabled wheelchair users in Great Britain revealed how difficult it to locate information about their technology. Most of the respondents (71.8%) knew nothing about wheelchairs before receiving one. Most simply relied on the government’s Disablement Services Center staff for help purchasing their original equipment. However, the government services office was not a universal preference for information. After the initial purchase period, 34% felt that they got better information from the private sector and from manufacturers, while 43% felt that the Disablement Services Center was more helpful and a better primary source. Over 40% of this population developed a relationship with a vendor or repair shop that they regularly relied on for advice.
Without a central supervising organization or central repository of information, there is no straightforward method that empowers clients by allowing them to access materials that would enable them to actively deal with the situation. Although the Internet has changed this paradigm to some extent, many of the papers and technical specifications are still hidden behind paywalls or are couched in such complex technical language that the client cannot make use of them (Jetha, Faulkner, Gorczynski, Arbour-Nicitopoulos, & Martin-Ginis, 2011).

Information about mobility devices carries a very specific purpose; to direct the consumer’s attention to the positive benefits that society expects they will experience through the use of these devices, carrying with it a message of conformity. Anthropologist William Pearce (2012), writing in his “Bad Cripple” blog, labels these messages as “inspiration porn.” These messages are common social interactions about events and circumstances that are seen as tragic and are meant to be “uplifting” while acknowledging something that is seen to be a tragedy. These messages about “a time when there are no wheelchairs” offer neither comfort nor information content to the disabled and are simply controlling narratives that illustrate what is expected of them (Chatman, 1999)(Pearce, 2013). Society has a plan and the disabled are expected to agree with the agenda.

This information control is predicated on the belief that assistive technology devices will be obtained through the services of a professional such as a therapist or physician and that the use of the technology will be supervised by family members or other assistants. The patient is expected to be passive and compliant in matters of their own care and to not question the authority of the prescribers and to not complain about the device that was assigned to them. The idea that the disabled would become experts in their own
physiology and their own needs is foreign to this paradigm, though it is central to the “Independent Living” model of disability. (White, Simpson, Gonda, Ravesloot, & Coble, 2010)

Mobility equipment research and innovation is hardly at a standstill. In the past decades many forward thinking innovators have created machines such as Dean Kamen’s iBOT, which allowed its rider to elevate the seat to put them eye-to-eye with most people and that was capable of climbing stairs; devices that addressed many of the problems encountered by the disabled. Although it did pass FDA approval, insurance companies did not rush to authorize its purchase and as a result it was discontinued. If, as Rogers says, diffusions of innovations are a “universal micro-process of social change” then the highly restricted world of the disabled appears to suffer from multiple stagnating social processes that block access to information about innovations (Rogers, 2004). Such a paradigm serves to explain why the woman who asked about the Segway had never heard them mentioned by anyone in her network.

2.5 The Small World of the Disabled

_I am aware of the fact that my life has become very small. I have not been away from my daughter overnight in 9 years. I have not traveled further than 2 hours away in 9 years. I haven’t eaten in a restaurant in about 2 years. Acquaintances have disappeared, family dissipated, holidays have no meaning. I live in my house. I walk on my block. It’s as though the large puzzle of my life has slowly been taken apart, piece by piece, each one set in a box soon to be discarded. A very last piece sitting lone on the table. It’s meaning unknown without its frame of others._

_Blogger “Claire” at http://severedisabilitykid.blogspot.com_
“Claire’s” words highlight one of the major problems experienced by the disabled and their caregivers; the lack of contact with society in general. Although there are friends and family relationships, most of the social network of the disabled is made up of a series of relationships with individuals or groups in which they have little trust but with which they are forced to associate (Chatman, 1999). Some family members may leave, marriages may dissolve, and the number of acquaintances gradually drops as the years pass – or may never develop in the case of someone born with mobility limitations that prevent them from fully engaging in social activities. Strangers may be hesitant to interact with them.

The blogger “David”, writing about a trip that he took with a group to visit Costa Rica explained that even the people he traveled with noticed how differently others behaved toward him: “Ryan observed that many able bodied people in both the United States and Costa Rica seemed initially scared of me. They did not know what to say or how interact with me. However, once a conversation with started by me, they realized that we did indeed have commonalities... those of us with disabilities spend a lot of energy making other people feel comfortable with us.” (David, 2007)

“Othering” (also known as Constitutive Othering”) is a concept that is defined by exclusion from a group or association. These are the “outsiders” of Chatman’s(1996) impoverished information world, who live in an environment where knowledge is stratified into “that which is easily attained” and “that which is often not accessible.” For those who are “Othered,” information and resources in social and community networks are limited in both quantity and quality. To be disabled in todays’ society is to be “Othered.”

Disabilities make the “Other” into an object of pity and tragedy. Under this paradigm they become part of a discourse of “charity” where the rest of the community treats them as
perpetual children and wards, offering the non-disabled a chance to do “good and virtuous works” for them and they, in turn, are expected to be grateful for this bounty (Clapton & Fitzgerald, 1997). Although components of this charity may be extended to including them into social events, the inclusiveness is limited and in the end, they are locked again in their small network where they are expected to behave decorously and keep quiet about contrarian thoughts (Chatman, 1996).

A very small world network is also characterized by very limited access to information brokers – actors who can broker access to networks with more power and more information access. This pattern makes the acquisition of knowledge far more time consuming for those with few resources than it does for the average person. Without an adequate basis for making judgments, decision making becomes more difficult and people often rely on “gut feelings” or “instinct” when they attempt to make choices in health care matters. Family opinions and cultural norms will have a greater impact on decisions when there is no other basis for knowledge and people of lower socioeconomic classes are most likely to use the same information sources that they have always used (Baxter, Glendinning, & Clarke, 2008)(Chatman, 1996).

The mobility impaired who live in community homes or assisted living facilities eventually find their private views of reality are overridden by the communal view of what their lives and information access should be (Chatman, 1999). Most of the information power in the network is held by physicians and technicians, who exhibit high levels of “betweenness” and are able to access information from specialized publications, from vendors, and from peers. Historically they have controlled most of the information flow to
the client, and there is little or no consumer control (White, Simpson, Gonda, Ravesloot, & Coble, 2010).

Information poverty is more than just a lack of knowledge. It is also confounded by an unwillingness to approach those in the wider community for information along with hiding information needs because they do not match the social norms of what is allowed (Chatman, 1996). As a result, they see themselves as being devoid of information sources even though they are not actually barred from access and in fact there may be others willing to assist them with their search. These factors can combine to create true information poverty in an information rich area. (Hasler & Ruthven, 2011)

A “small world” consists of cliques with few ties to other networks. Although the individual actors in the network may be emotionally supportive of each other, if their knowledge base is limited by poor education or other factors, their ability to develop resources and access information is small. The difficulty in finding information may be tied to people's information seeking habits. Fisher and Naumer (2006) observe that people tend to use a preferred set of information grounds and information sources just as they have a preferred route to travel to go to their workplace. This strategy, which may be emotionally or intellectually satisfying, will tend to strongly direct the information that is attainable through this source.

The disabled are often isolated from the rest of society and networked with only a few individuals by serious social obstacles such as a low rate of employment and stigmatization, (Mortenson, Miller, & Auger, 2008) in addition to the limited ability to physically access many spaces and to participate in recreational activities that the non-disabled enjoy. Whereas many people develop friendships and contacts that last much of
their lifetime from interacting with others in the same schools, individuals with significant mobility impairment are often barred from school or find it difficult to remain in school because of physical barriers such as classroom door access. They tend to be less educated than the rest of the population (Fricke, 1998). In the United States, over 10% of those who use mobility devices never complete high school and only 1.8% go on to get a Bachelor’s degree (BraunAbility, 2011).

The real test of information access is the scope and reach of the individual’s network. Social networks are fluid and dynamic structures that are commonly conceptualized as a web of connections that define relationship ties between members and resources available to them (Otte & Rosseau, 2002). Individuals within these networks are referred to as actors or “nodes” and connect to others via a web of relationships. If two actors have a regular pattern of communication, then social network analysts say that they are “connected.” Actors within a network who have the most connections (“centrality”) are considered “hubs” but the amount of information available to them depends on the quality of the other nodes in their network. Those who are only connected to a clique and not to the outside world may have a high degree of centrality but are information poor.
2.6 The Role of the Internet

“*My son is 45 years old and has Cerebral Palsy. My husband and I have always been his caregivers. I would like to know what online resources have been helpful to others in providing care. I have never found anything on line*” (Disability Scoop, 2013)

During the timeframe that the survey of information sources for wheelchair users in Great Britain was collected, only 9-11% of the world’s population had any form of Internet access. In the decade since that time, social and technical changes have made the World Wide Web more accessible to a greater number of people. Facebook, which was in its infancy at that time with a mere one million subscribers now has over a thousand million subscribers as people with cellphones and tablets and other devices connect and interact with each other. As of March 2013, estimates show that approximately 38.8% of the world has some sort of access to the Internet (Internet Growth Statistics, 2013), however this is moving at a slower pace into the disabled community because adaptive technologies such as speech to text computer controls can be difficult to obtain and complicated to set up.

As the Internet becomes more of a global community, the issue of how to access information becomes more important. Societies in the wealthier countries today exist in an information rich environment. Today’s digital information consumer is very different from the digital information consumer of the 1990’s; a change that is reflected in the nature of the material available online. The archival and document-based internet of that decade has been replaced by something more global and dynamic that contains “life-dependent” or “fundamental to living” services and information that was previously only available to professionals in specialized courses. (Nicholas, Huntington, Williams, & Dobrowolski, 2006)
Our information technology has become pervasive throughout the economic superpower nations of the world to the point where schoolchildren in these countries have the opportunity to explore and to be exposed to information sources on a previously undreamed of scale. Although “accessibility” is often thought of in terms of “findability,” for some, the issue becomes a question of whether they have the technology to allow them to read a web page or a file they have retrieved from Internet (Williams, Rattray, & Grimes, 2007). The ability to make a successful query of a search engine requires an understanding of how information may be presented and of how to discover synonyms and alternative terms for the problem being researched. “Webspam” – web pages that trick search engine robots into thinking they are presenting material that the searcher wants – and advertising can burden the search process and make it difficult for the user to access the information that they need.

Tracking down the product specifications for any particular device is not as simple as one might assume. In order to obtain reliable information on any of the wide variety of available scooters and wheelchairs, a potential customer has to negotiate a vast tangle of feel-good advertising and hype with few guidelines to help them distinguish essential information from trivial information. To compound this problem, there is no uniform standardization of terminology. One study identified four different names for “rollators”; a commonly acquired mobility device that similar to a walker (Brandt, Iwarsson, & Stahl, 2003). Depending on which source you use, there are anywhere from three basic types of wheelchair to nine different types of wheelchairs (Ebay, 2012). The United States government’s Medicare site talks about four types of mobility devices but has little else in the way of guidance for clients, offering only a lone PDF file with the warning that Medicare
will only cover 80% of approved devices and that prospective clients must have seen a physician and obtained the correct forms to be considered for assistance (Medicare’s Wheelchair and Scooter Benefit, 2011). In this document, wheelchairs, rollators, and mobility scooters are mentioned only in very broad terms and clients who have a legitimate need for a particular type of device such as an “all-terrain” type power chair have no way of determining whether or not their device will be covered in any part by Medicare benefits.

In spite of all this, many people think of the Internet as one of the preferred information sources (Internet Growth Statistics, 2013) for medical supplies, medical equipment and health related information (Jetha et al, 2011). A number of specialty sites such as organizations built around people with specific disabilities offer guidance for common issues and recommend specific products while other sites such as Disability Scoop function as a news aggregating service and focus more on news delivery than they do on community building.

A common strategy that computer users often use is to seek out community recommendations to help them in their information searches using Facebook or community message boards or other types of interactive discussion forums to make their request; however, the effectiveness of this tactic will depend on the nature of the community itself. Questions asked of a generalist site such as Yahoo return answers that are often off topic or meant to be emotionally hurtful. Questions can go ignored for months or years until someone discovers them by accident and decides to respond. The experience is different among user groups that are actively involved in some form of collaborative community effort. Those that are centered around some sort of learning process are more effective in discovering and adopting new technologies and information than general conversation
groups (Cho, Stefanone, & Gay, 2002). In particular, groups with strong “key communicators” who occupy a prominent central position within a social network will tend to have dynamic and energetic strategies that enable the group to more easily access difficult to locate information.

Other factors work against the use of the Internet as an information resource. There is an assumption that anyone with sufficient reading and intellectual skills can access the Internet through some channel, however, in practice this may not be true. Srinuan and Bohlin (2011) identified a number of parameters across cultures and countries that impact digital and information divides. These include technology access, amount of infrastructure, socioeconomic group, technical skills, geographic location, education and literacy, family structure, age, cost of access, occupation, marital status, government policies, ethnicities, gender, culture, fluency and literacy in English, attitudes towards technology, and whether the content is interesting or attractive to the consumer.

However, once persons seeking information on mobility assistive devices step off the Internet their primary information grounds for medical devices become local sources that are often very similar to the chiropody clinic described by Pettigrew (1998): a carefully planned arena with very carefully selected literature and social interactions limited to the community of the disabled and their medical caretakers. Information may be so limited in scope that it becomes more of a behavior modifier than a source of information. Patients are offered only that information that the local clinic is comfortable with them having.

Those at greatest risk from this are the disabled who live in group homes or nursing homes; those who experience an unusual isolation even in our culture because their environment is so tightly controlled in order to maintain patient compliance with medical
standards (Magasi & Hammel, 2009). With limited access to computers and news sources to find out about devices, social programs, advocates, and regulations that could improve their lives. Environmental infrastructure also works against those who live in group homes or nursing homes; because of this, patients are encouraged to be passive about their needs and wants and to be subordinate to the needs of the institution so that they as a population are easy to take care of. This is accomplished by means such as behavioral management, opinion dominance by professionals, and information withholding (Magasi & Hammel, 2009).
3.1 The Scope of the Information Environment

“I stopped supporting them when it became clear they were more interested in $$ than helping me.” – Respondent 19, in answer to a question about group membership.

Locating reliable information about mobility devices and issues important to those who use them is surprisingly difficult. There are numerous types of resources, from pamphlets to counselors to websites and more and a potential client has to learn to negotiate this web of information, dealing with gatekeepers that restrict access and determining which sources are unreliable or unsuitable. This web of resources functions as a delivery service for a tightly-framed selection of topics. Taken together as a thematic unity, they form an “information territory” with the following characteristics:

- The information is contained in multiple “information pools”
- The Information Territory is strongly centered around one fairly narrow topic (theme)
- Some information pools may overlap, but each pool has at least one item that is exclusive to it. All pools have a common and narrowly defined theme.
- The networks that contain the information pools are not mutually interlinked – some networks (such as local clinics) may not be linked through the Internet)
Has different types of information pools (information grounds, etc)

For the purposes of this study, an “information pool” is described as an aggregation of information, related by theme and access method. An example of this is the online service, YouTube, where video reviews of wheelchairs can be found. Each individual video is an element; YouTube itself is an information pool since all videos are accessed through the same method – video capable browsers. Information structures such as Pettigrew’s (1999) “information grounds” or Oldenburg’s (1989) “great good place.” This also avoids difficulties with websites and self-identified “clearinghouses,” which often prove least useful when it comes to specific questions about specific types of technology for anyone with mobility impairment. These do not meet the test of an “information grounds”; a place where people gather for a specific purpose that also serves as a place where information is shared in a series of conversational interchanges (Fisher & Naumer, 2006) although they are useful and utilized resources.

Information pools within the information territory that relates to mobility devices are often highly restricted, as in the case where an individual is attempting to gain information about alternative technologies and alternative strategies. Physicians and therapists do not offer information about devices they consider inappropriate in some fashion and will discourage the client from exploring these options (Coutler, Entwhistle, & Gilbert, 1999).

3.2 Large-scale Information Pools
One of the most prominent types of information pool is that which is generated by and can be accessed through national organizations for and about disabilities such as the Alliance for Technology Access (ATA), National Association for Down Syndrome (NADS), and Disabled American Veterans (DAV). These groups have a large presence in our society, and our awareness of their names and sites is fairly high, thanks to their community efforts such as charity drives, “fun runs”, sponsored events, and similar activities. Although they may have thousands of members, it is often difficult to find information about specific services offered by them. In many cases the information that they offer potential members is fairly basic and aimed at those who are newly diagnosed. However, the reach and scope of each organization is not unique; there is not just a single organization to support caregivers of people with Down Syndrome. An exploration of these information pools via search engine shows that there are well over fifty such organizations. As a consequence, when caregivers and clients are trying to locate information, they also have to evaluate multiple information pools in order to decide which one of these will offer the best information.

Because they tend to be overly generalized and overly simplistic, they were not considered primary information resources to utilize when considering purchase of a mobility device by any of the participants in this study. This negative finding was also noted in blogs by disabled people, who generally do not include links to these organizations in their lists of recommended resources.

Housing facilities for people with disabilities generally are not and do not become an information ground for their clients and the acknowledgement that they may create as many problems as they resolve has led to alternatives developed within the community of
the disabled. One outgrowth of the civil rights movements of the 1960’s was the establishment of the Centers for Independent Living (CIL). These facilities, which are run by private nonprofit agencies that are community based and consumer controlled, are designed and operated by individuals with disabilities and provide a cross-disability array of independent living services. It is difficult to assess their impact because they are private agencies that deal with local populations and the number of clients that they serve is relatively small. White et al (2010) report that they offer consumer advocacy training and other information, but add that these services may not be sufficient to guarantee an increase in the number of disabled able to participate in society. Since the program is currently overseen by the U.S. Department of Education, it has the funding and resources to emerge as a major information source but programs to address community needs are specific only to the surrounding community and not to the nation in general.

One consequence of the increasing importance of the Internet as a means of interaction and information exchange is that the social network of the disabled can expand beyond the usual small worlds boundaries of interaction with family members and their peers within the disabled community and medical staff. The potential for easier access of information is there, but the question remains as to whether the promise of the Internet has made a significant impact in the information seeking process used by the disabled. Twenty years ago, Internet access was prohibitively expensive for many. Recent changes in technology and infrastructure has made the Internet cheap and easily available and access has become part of the marketing strategy of hotels and restaurants that offer complementary WiFi access to patrons. The availability of infrastructure predicts the likelihood of any technology being used or useful. The greater the infrastructure, the faster
the rate of diffusion into the general population of an area. (Srinuan & Bohlin, 2011) The
down side to this is that changes in technology may also require retraining in order to learn
to retrieve the desired information. (Thompson & Afzal, 2011)

However, where there is no supporting infrastructure, the only way that information
can be shared is by older forms of personal communication such as face-to-face interaction
and telephone, and non-interactive media such as television, newspapers, magazines, and
radio. While the latter can be good vehicles for researchers and the medical community to
present technology and treatments, they do little to allow the mobility impaired to have a
voice in these matters. With the loss of interactivity comes the loss of individuality and in
the end, conditions and treatments are lumped together and the advantages of discourse
are lost.
CHAPTER 4
METHODOLOGY AND COLLECTION OF DATA

4.1 Known Issues for Researchers

This man highlights a divide I have written about in the past: there is a dichotomy between people such as myself that came of age well before the ADA was passed into law and those that came of age after the ADA. (Pearce, 2013)

There are a number of challenges in studying groups of people who are classified as being disabled. Perhaps the most personally significant to the population is that the researchers seldom are disabled themselves and instead are outsiders studying a very complex situation. They are talked about, but their voices are seldom heard. More disturbing to them is that much of the research seems to perpetuate the image of the physically and cognitively impaired as a pitiable marginalized and segregated group whose disabilities are couched in terms of personal tragedies. They are seen as being unable to participate in normal society and they often find their impairments viewed in terms of societal values; a view they strongly dislike (Stone & Priestley, 1996). Research is often seen as a violation of their experience and irrelevant to their needs, with little or no improvement in outcomes and conditions from decades of studies.

As a result, the approach currently favored by many who study the disabled community is based on an emancipatory form of “grounded theory”; a qualitative research methodology that generates theory and metatheory based on data generated from research subjects or a mixed method approach (Turnbull, Friesen, & Ramirez, 1998). It is a
methodology rather than a method (Walter, 2009) imbued with value systems and problem frameworks that value the input of the community of interest. The advantages of this methodology are that it allows for rigorous research, increases the relevance of research, decreases logistical problems, and empowers the study group and provides insight on how the research might be further utilized by the participants. Stone and Priestley further recommend that the research paradigm be framed in terms of disability as a social relationship that has been created by environment and attitudes constructed around the themes of incapacity and inability. (Stone & Priestley, 1996)

The grounded theory methodology is not without its drawbacks. It can be more expensive than other types of research and because of the collaborative nature of the investigation it may take far more time to collate and assess information from all the sources to be incorporated into the final product (Turnbull, Friesen, & Ramirez, 1998).

In addition to the considerations outlined above, one of the initial problems that arises in any discussion about assistive mobility devices is limiting and defining the category. For the purposes of this study, an assistive mobility device is defined as technology which is described by the rehabilitative technology industry as “durable medical equipment.” Durable medical equipment is defined as a type of device that is prescribed by a physician, and is used in the home to improve the quality of living for a client. In addition, durable medical equipment is a benefit covered by most insurance policies, as defined by Title XIX for Medicaid. Under this policy canes are not considered durable medical equipment, and some rolling walkers, walkers, and rolling chairs do not meet the standards to be included in this category. To avoid confusion of data, this study considers only durable medical mobility equipment that is covered by Medicare without
additional qualifications: manual wheelchairs, power wheelchairs, scooters, and specially-sized wheelchairs. It also includes devices known as “complex rehabilitation” technology, which describes wheelchairs that are modified versions of medically necessary manual or power wheelchair systems as well as their seating accessories which include special positioning cushions. These items are designed to meet specific medical and functional needs of individual clients and are prescribed by a team which usually includes a physician, therapist, and vendor (‘Complex Rehab: What is it? Why Should We Care?, 2010).

The basic approach for this ethnographic investigation was based on the case study design model used by Woo (2002) in her dissertation on information seeking behavior of older adults; a design that is considered well suited for research of contemporary issues in real-life contexts where multiple sources of evidence are used and where there are multiple nuances within the evidence to be collected (Yin, 1984). Such a situation exists with the mobility impaired because there are many different types of scooters and wheelchairs and it would be difficult to collect a sample of people in the same socioeconomic group with the same diagnosis, same duration of disability and who own the same devices and have the same marital status and living arrangements without having access to the patient records of a large facility devoted to rehabilitation and therapy. The advantage of a small case study model is that it is suitable for examining knowledge from a “sense-making”, user-centered perspective. (Dervin, 1992)
4.2 Selecting the population

I think each of us need to keep in mind that we are individuals each dealing with highly sensitive and personal issues whether we have a disease or have a loved one with a disease. All of us are going to have bad days when we say things we might not normally say or get our feelings hurt when we might not normally. What is important is that we each are able to speak our feelings (negative or positive) and not be judged too harshly for what we say. -- Julia, Yahoo Wheelchairs Group

Sociological studies of disability indicate that members of society tend to frame the issue of being disabled as something that is a personal or familial tragedy, impairment, or as a type of “otherness” that divides the disabled from the rest of society. In cases where the disabled are immersed in a patriarchal system, they find themselves cast into a role similar to women and minorities: viewed through the lens of social values, productivity, physical environment, and welfare systems (Stone & Priestley, 1996). Because their lives are dominated by the “sick role” paradigm as well as limitations to physical access, they tend to become marginalized (Parsons, 1951) and gradually become enmeshed in a very small world such as Chatman (1992) describes. Their information network of first choice (family, friends, neighbors) becomes more narrowly restricted by an attitude of protective paternalism (Peers, 2009), and makes it harder to access secondary networks of information such as medical personnel (Chatman, 1992).

To the disabled, much of the research seems to perpetuate the image of themselves as a marginalized and segregated group; a view they strongly dislike (Stone & Priestley, 1996). In response to this issue, both disabled people and disability researchers have attempted to create and publicize standardized paradigms for studying this group of individuals. A key point of this process is the attempt to bring to the researcher an understanding that the disabled person is the expert and “knower” that can identify social
and physical barriers which need to be addressed rather than a glorified lab rat to be observed. Within this approach, research is seen as a means to empower its subjects and to provide some benefit to them rather than being merely an abstract query, and the subject’s individual experience or voice is a necessary addition to the quantitative data. In order to facilitate this outcome, Stone and Priestley recommend that the researcher adopt a plurality of methods for data collection and analysis.

Because of the difficulty reaching this population and because the research question is primarily explorative and qualitative, the “snowball sampling” methodology was chosen as the best approach for recruiting participants. To frame the initial questions, I met with four disabled friends at two local science fiction conventions we all regularly attend and listened to their answers for the proposed survey questions. Based on feedback from them and on an analysis of the results, the questionnaire was modified and two other friends were enlisted at a different convention to take the survey to see if the answers gave a clearer result. Once the final format was approved by the IRB, the questions were loaded onto the SurveyMonkey site and flyers were placed at two science fiction conventions (Apollocon and Soonercon.)

Finding a population willing to take the survey was a lengthy process. Rebecca Cagle at the UNT Office of Disabilities Assistance helpfully suggested a number of contacts but none responded to queries. Announcements made on Facebook and on DailyKOS’s disability forum led to ten people taking the survey. However, similar announcements elsewhere on the Internet did not get any response.

A number of people in the local communities kindly allowed me to place information flyers where they could be seen and to interact with their clientele. Doug Garner, head
coach of the University of Texas Arlington’s “Movin’ Mav’s” Wheelchair basketball team gave permission to approach his athletes to see if any were interested in participating in the survey and suggested that the best strategy would be to attend a game and directly interact with the players. Two proved willing to participate. Several who declined to take the survey did discuss their experiences and permitted note taking.

The City of Garland’s Senior Center would not allow me to approach individuals or set up a table but they did give permission to place flyers in the recreation area. However, there were no responses to this effort. Attempts to contact Catholic Charities were also unsuccessful. Two science fiction conventions, Apollocon and Soonercon, allowed me to talk to people and to place flyers. Approximately half the respondents were recruited at these events. Several people at these events were interested in speaking about their experiences but declined to take the survey. In cases where the participant seemed leery of the digital recorder, I summarized their words and then had them review what I had written to make sure that I had captured their thoughts correctly.

Requests on Facebook and on Twitter for people willing to take the survey produced another two responses, though a number of people responded when I posted a request for subjects on DailyKOS.

As a result, there are a number of common factors in this population that may not reflect the experience of some other groups of mobility device users. Most of the respondents live in Texas, most are still mobile enough to participate in group meetings and conventions and hence are less isolated than many of the disabled population. In addition, there is a lack of social distance between individuals since participants have enough education and economic stability to own and use computers (Faugier, 1997) which tends to
bias the preferred information resources. Recruiting through announcements in online forums where permission was given to approach the group also added a level of bias. Although attempts were made to gain informants in minority communities and those who are very poor, outreach to these groups was unsuccessful during the time of this study.

All of those interviewed spoke English as their first language, so it was not possible to assess information access by those whose were not proficient in English. The group was further narrowed to “wheelchair users” rather than a broader spectrum of users of mobility devices. Efforts were made to contact manual wheelchair users but there was not much response from this group.

Because of the small size of the group, a fully implemented participatory action research project could not be reasonably undertaken. The concept that the cyclical process of PAR does not finish until the problem is resolved is, in Walter’s words, unfeasible. As she points out, in the real world of social research, PAR-based investigations take place in small groups such as classrooms. (Walter, 2009) Solutions generated with such a small group may not represent the questions or needs or solutions desired by the larger population and should not be viewed as something with which to formulate policy.
4.3 Methods

As befitting the paradigm of Participatory Action Research (Walter, 2009), the investigation arose from a question asked by a member of the disabled community about why information about innovative technology was difficult to locate in her network of trusted resources. To establish a background of current discourse topics, extensive data mining excursions via Google searches of Facebook, disability sites, and Twitter feeds were done and content analysis was done by using a grounded theory method (Corbin & Strauss, 1990). “Grounded theory” is an approach used when performing qualitative research that involves a number of different types of data surrounding complex social phenomena. Since the activities that are measured – in this case, the process of acquiring a mobility assistance device – is not a static function with a fixed number of clearly defined steps but instead is dependent on many variables that are in a constant state of flux throughout an individual’s lifetime, the choice of research methodology needed to be both flexible and capable of dealing with change. The process also needed to have procedures for the analysis and integration of data from multiple interview and observations as well as from government documents, video, and other sources. Nvivo was the software chosen for this because it facilitated integrating codes from multiple disparate sources and was not functionally limited for students.

In designing the instrument itself, a number of questionnaires commonly administered to disabled population were mined for questions that presented a picture of the extent of disability and the nature of the assistive devices. The first section of questions collected basic demographic information about age, gender, marital status, income, internet
access, and education attainment. The second section explored basic information about the respondent’s non-medical social circle as it related to their disability and asked about social groups with whom they were in contact. The third part consisted of several multiple choice questions that defined their relative levels of disability and assistance requirements as well as the type of mobility device or devices owned, length of ownership, and how they were acquired. The final section was qualitative in nature, asking the participant’s opinion on the best and worst resources to use in buying a new wheelchair, what the important considerations were in buying them and advice and resources for new wheelchair owners. A last question offered the opportunity to relay an anecdote about wheelchair purchases. Participants were given an opportunity to leave their email and receive a follow-up report so that they could give feedback on the data.

Before finalizing the list of questions, a series of informal dinner discussion meetings were held at two conventions with five mobility device users who were interested in being part of the study. During these sessions, they explained the process that they used for acquiring their mobility devices, identified their main information sources, and spoke generally about issues that they felt were among the more difficult or complex to resolve when acquiring a new mobility device.

One question asked of this group was how often they looked at stories or looked for information on mobility devices. The universal response was that they almost never sought this information – that they were happy with what they had and that they did not look for new technology unless they were having a problem with their current devices. Close friends usually did not forward stories on technology to them, though slight acquaintances might post links on their Facebook pages to something they thought was interesting. When
participants in the discussion groups were asked their opinion of new technology during the preliminary information gathering, all four of them expressed a reluctance to seek out new technology for themselves. When asked about the rationale for this, they explained that their hesitancy was due in part to the cost of novel technologies. They reported that money to purchase unapproved devices is difficult to obtain, even with community fundraising support and the inconvenience of trying to get in contact with the manufacturer to arrange a trial of a device which may not be approved for purchase either by Medicare or by their own insurance company adds more barriers to the attempt.

Once the interviews and small group discussion ended, data and field notes were transcribed and analyzed using a comparative ethnographic approach to investigate patterns. An iterative data analysis was done at each subsequent stage, continuing throughout the research process. Once the initial key points had been designed, a search was done through diagnostic surveys and instruments commonly administered to disabled populations in order to identify appropriate existing questions that could be set into the SurveyMonkey questionnaire. After creating an initial survey, two of the focus group participants took the preliminary survey and gave feedback on the questions and ease of access. Answers that they gave were evaluated to see how well they matched the data being sought. As a result of this trial, adjustments were made to the final questionnaire before it was put on SurveyMonkey for data collection.

The initial request for respondents was done through a post on my personal page on Facebook, the Healing Storytelling Listserv, and the DailyKOS disability community, asking for survey participants and asking others to pass the query along to others who might like
to take part in the study. Although the initial groundwork drew from a pool of over thirty informants, only a small group of those were available for the follow-up feedback sessions.

Additionally, Doug Garner, head coach of the Movin’ Mavs wheelchair basketball group, gave permission to visit an evening practice session at the University of Texas Arlington and invite players, parents, and coaches to participate. Two players and a parent agreed to be interviewed. Two other players felt that they did not know enough to provide useful comments but did speak about their experiences as members of a wheelchair basketball association team.
4.4 Data Coding and Collections

In addition to survey data, the Disability Scoop website and the old Disaboom website both gave permission via email to data mine their public web pages and comments sections. Coding and analysis began as soon as the first group of blogs and disability news sites had been collected. During this period, defined as “open coding”, responses were compared with others to determine matching concepts and divergent concepts. Relevant quotes were collected in order to give a voice to the aggregated data (Davenport, 2000). Once these codes and categories were identified, these became the basis for further sampling on theoretical grounds, and a second set of disability news sites and blogs was mined as a test of the theoretical findings and to examine more closely the concept of who owned the information that was being exchanged. Public comments on a disability news website, on AARP’s website, and on a Facebook disability group were also mined. All categories were unified around the core category and individual categories that needed further exploration were filled in with descriptive detail.

Information collected from the Internet was imported into Nvivo and scanned to determine common themes and elements using the software’s integrated tools and functions. Common themes were assembled using Nvivo’s word and concept frequency query, particularly as they related to the sequence of events that leads to a purchasing decision. From this subset of data, timeline was determined that started with the client’s decision to acquire a new mobility device and ended with the final product being delivered and accepted by the client.
The initial condition question, “what prompted the client to purchase a new mobility device”, revealed that there were three basic starting points for this decision: clients who had a current device that was inoperative or malfunctioning, clients who understood an upcoming need for a mobility device because of factors like weight or changing health, and clients who had these devices thrust upon them through “assignment.” In this last case, the client does not perceive a need for the device but a caregiver or physician or family member or other person with some sort of authority in the situation decrees that the best solution was to obtain a mobility device. Items from these larger stories were inspected and broken down into a second set of information container nodes.

Data mining using Nvivo’s query wizard on a sample of bulletin board posts revealed that in addition to looking at overall information about mobility devices, users occasionally searched for specialty features such as locking seat belts and extended push handles as well as information about the types of metal used in the frames. These details, though apparently trivial, have an impact on how heavy the final product is and how easy it is to maneuver in certain situations. Another topic that evoked interest and discussion but was not the topic of frequent searches was seat padding. In making an initial purchase, this is a critical issue for disabled clients since poorly fitted seats or poorly padded cushions can contribute to circulation problems and pressure sores. Such cushions are expensive and are often customized to fit a client’s prescription, and acquiring one may require working with several specialty vendors.

Observations of Abilities Expo and the Movin’ Mavs’ basketball camp sites and notes about the interactions of the participants were made using standard anthropological methods. Notes of conversations with several people at each location who were interested
in the research and wanted to give their opinions but who declined to be formally interviewed were also typed into a document to be added to the material for analysis in Nvivo along with time-stamped photos and advertising material collected by my assistants at Abilities Expo.

4.5 Process Analysis

“My first w/c purchase, I went to a medical equipment store & explained my situation. Somebody who presented themselves as trained, knowledgeable, etc., set me up with my first chair. Two weeks & multiple comments from other people with disabilities [sic] & a stress injury later, I found out that this person was simply a sales lady. She had no training in how to evaluate my needs or the right fit. Because I was paying out of pocket, I had no information or advice from anyone. I have learned by trial & error. In 8 years I have built a network of friends with disabilities [sic] and we share information & advice. “– Respondent 8

When using grounded theory methods, analysis begins as the data is collected. Broad topics are loosely defined and data aggregated into loosely defined categories. These are then sifted to identify types of actions and phenomena, and these units are then assigned conceptual labels. Once a structure has been established from a set of foundational documents and videos, new data is approached with the initially defined sets and evaluation and coding begins with the new material. As new concepts and categories are uncovered, these are added to the existing databases. Patterns and variations in the
data should be reexamined to see how they fit into the assumptions and to clarify points where individual behaviors develop and emerge from the progression of events. Through this continual expansion of definitions and codes, the entirety of the process can be better understood.

In order to fully understand the information grounds aspect of information acquisition, a brief process analysis was done using notes from the initial fact-gathering sessions to identify the steps that took place between the realization that mobility equipment was needed to address a problem and the actual point at which the device was turned over to the client.

The choice was made to divide the acquisition process into three categories based on the initial type of request. The first category was defined broadly as needs that had arisen out of a sudden crisis such as failure or loss of a mobility device currently in use. The second category was defined as acquisitions that had been planned because of a decline in the patient’s mobility, and included situations where the client’s mobility was increasingly compromised to the point where the intervention of family or a caregiver initiated the purchase. The third category was defined as a process that was in the hands of the medical community, such as acquiring a mobility device during therapy after a limb amputation or other change of health.

Patients whose needs fell into the first category are those who have already established a need for the device and whose current device is unsuitable either through breakage or through a change in the patient’s normal functions. In some cases, the request is actually initiated by a caseworker or a clinic to comply with the recommendations of Medicare that a new chair be purchased every five years (Ward, et al., 2012). The most
commonly seen strategy among these clients is to return to a vendor or repair technician with whom they have established a relationship for recommendations and advice. Those who have a good relationship with these entities often do better than other groups because the recommendations are coming from someone who is familiar with their particular needs and who has experience with problem solving and meeting the needs of clients beyond what the vendor is often willing to support. In this case, the repair vendor acts as an “expert node” in a social network – a person who has a large number of contacts and who is a central agent in the social world of the disabled. From an information network standpoint, these vendors also exhibit a “betweenness centrality” within networks; that is, they act as a bridge between two important constituencies – the vendor and the client. They play the role of broker both in the acquisition process and in the information exchange process.

In cases where no relationship had been established because the client was new to an area or because they had a bad prior experience with the repair vendor, the client has to rely on his or her own information finding ability to try to match available technology to their needs and to the parameters set by the insurance company. As Connaway et al (2011) observed, “Under some conditions, the idea of options of any kind is alien to users. They grab whatever is quickest and easiest. Under other conditions, they reach for more but have an acute awareness of the exigencies of life facing.” They conclude that 74.5% of the time that the subject is focused “in the present horizon of time”; wanting quick answers that did not need to be based on all available options but that they judged as “good enough” to meet the need.
In spite of the fact that it was obvious that some sort of mobility assistance device would be needed, there was no solid strategy for funding. Some individuals planned the acquisition and saved for it, but others simply approached family and friends and asked if anyone knew of a wheelchair or scooter that could be bought. Ebay and Craigslist were mentioned as sources.

In the case of the third category, where the patient had been in a hospital and had received a diagnosis that included a necessary piece of durable medical equipment, the patient had little to no control over the device acquisition process. These patients typically undergo one or more measurement and custom fitting sessions by trained physical therapists who will prescribe the device that they feel best matches the patient’s needs. The patient, who may be dealing with many complex emotions following a catastrophic change in health, is usually an outsider in this aspect of his or her own care. In the United States, the health care professionals and insurance providers remain in control of the acquisition process from start to finish. In cases where the patient has little or no insurance, the very minimal and least expensive technology is commonly selected for the patient’s use even though a more expensive technology might be a better solution.

With these three primary nodes established, documents were reviewed to see what the next steps in the process were. In order to verify the initial node identity, the internet was data mined through search engines for terms related to acquisition of mobility devices and for news stories and product announcements related to this topic as well as white papers and information pages from insurance websites and Medicare and Medicaid. Personal stories were collected from online diaries and bulletin boards.
One of the strong themes that emerged from the preliminary coding which produced the survey questions was the need for information that was not usually part of an advertising package designed to sell products or services. One commenter wrote about an encounter with a vendor. Her motives were to gather information; the vendor representative’s motives were to make a lot of sales at the trade show. "It's durable, and we manufacture them with the lift protected," she pressed on. "And ..." (pause for dramatic effect) ... "it's financeable."

Other topics brought up were the difficulty in obtaining information on particular features that had an impact on health. Chair seats and chair padding were frequently discussed topics, along with mechanical nuances such as device durability under different conditions of usage -- whether the chair is used for only part of the day and only for certain activities as opposed to full-time use. Difficulty of use, as when a chair becomes too hard to push in areas that the user needs to access or difficulties related to breakdowns and lack of information on failure rates were mentioned less frequently.
CHAPTER 5
DATA ANALYSIS

Data collection and analysis conform to the ethical guidelines for the University of North Texas as applied to research on human subjects. In order to protect anonymity and confidentiality, codes are used throughout this document. Aliases were given to two respondents who provided extensive information in a lengthy series of interviews.

5.1 Survey Results

“Since then, he is functionally housebound and wheelchair-bound. The air line on his oxygen concentrator is long enough for him to get out on the front porch occasionally, if there is someone handy who is strong enough to get the chair wheeled over the front door sill.” – Respondent 1’s caretaker

A total of twenty one people responded to my request to participate in the study. Eighteen people in this sample are residents of the United States. Six (28.6%) were male, fifteen (71.4%) were female. Seven of the respondents (33.3%) had an income range of below $25,000 per year for their family – the level defined as “poverty” by the Federal government. Because state median incomes vary between $39,000 and $69,000 per year; (Measuring America—People, Places, and Our Economy, 2010) and median incomes for other countries varied even more, the issue of income versus service was not explored further. The level of disability varied greatly in this sample, from those whose only
problems were walking more than a short distance to those who were completely wheelchair bound.

Figure 3 Age range

Informants’ age groups were unevenly distributed with equal numbers in each of the 30-60 age group cohorts. The largest age group was made up of respondents over the age of sixty (28.6% of the sample).
Figure 4 Marital status

Nearly half of the participants (47.6%) are married. One was widowed, two were divorced, three lived with family members, and three lived with non-relatives. Three had never been married.
Most of the participants had more than one mobility assistive device. In addition to using canes and walkers and medically prescribed shoes, fifteen (71.4%) of the participants used a manual wheelchair, Five (23.8%) used electric wheelchairs, and five (23.8%) also used mobility scooters. One student had a wheelchair and a therapy dog that helped her maintain her balance when she walked during times when she did not use her wheelchair.

The most severely disabled participants in this group, who required a full time assistant or part time help from their spouses were also the only ones to have only one electric wheelchair as their sole mobility device. Those who had fewer mobility problems were more likely to have several different appliances, including canes, crutches, and prescription footwear and one or more wheelchairs along with a mobility scooter. Usage of these devices was to support activities outside the home such as shopping.
Specialty shoes were a prescription fit item and the two informants who discussed them indicated that they purchased their footwear because of recommendations made by therapists. Although orthopedic shoes are available online and sold retail through outlets like Amazon, they worked with their therapists and were leery of footwear that they couldn’t touch and try.

Ten people had wheelchairs that were paid in full or in part by insurance. Four had no assistance and paid cash for their wheelchairs or scooters, “while six got theirs through a variety of methods including family hand-me-downs and grants. One participant’s primary mobility aid is a cane but she rents scooters and wheelchairs as needed for long trips and public events such as fairs and conventions. She also relies on scooters that are available in public spaces such as grocery stores most of the time and is not currently planning to purchase a scooter.
All members of the group had access to the Internet and all owned computers. Education levels were considerably higher than the reported median education levels in the United States. Two of the respondents were finishing high school. The other nineteen had all been to college with 11 (52.3%) earning what the US Census calls “a Bachelor’s degree or more” compared to 27.9% for Americans recorded in the 2009 census (Measuring America—People, Places, and Our Economy, 2010), and 14.3% (two individuals) earning a Masters’ degree. Nine individuals in this group also had professional certifications in at least one field.

Eight individuals (38.1%) belonged to one or more groups that exchanged medical information and information on disability topics that related to their specific medical condition, but only two of them mentioned these groups as an information source that they
would use specifically to obtain information about mobility devices. One person (4.8%) belonged to a local group that did not have an online forum yet. She reported that conversations in this group mostly focused on childcare and family issues and that very few interchanges were about devices or technology. Although people were observed asking each other about mobility devices at the Abilities Expo, none of those interviewed reported seeking out disability oriented events to find connections in order to obtain information.

When asked for preferred sources for information, two people who had complex power rehab wheelchairs reported that they preferred going directly to the manufacturer or vendor because they had very specific questions that could not be easily answered by other sources. Four people indicated that their chosen source was their insurance company, since it was the final decision maker on which mobility device could be purchased, four answered that they preferred a physician or physical therapist’s recommendation, and three specified their information state government as a preferred source since this was the entity that paid for their devices. One respondent commented that approaching anyone other than the approved companies was useless since the insuring agency wouldn’t consider purchasing devices that were not on their “master list.” Only two of those surveyed obtained their information from the internet, and those were the two who had the financial resources to have some element of control over which device was purchased. Those who played wheelchair basketball preferred their team’s coach as an information source.
In order to assess the difference between those who rely primarily on government assistance and those who have access to insurance and other methods of funding, the group was divided into those who made over $25,000/year (the Federal poverty limit) and those whose annual income was less than that. Seven people (33.3%) fell below the Federal poverty line. No one in this group used an electric wheelchair, though two had scooters. This was the group that relied most heavily on government assistance or on personal finances to purchase their mobility device, though some were forced to rely on donations of money or mobility devices from family members or other sources. Members of this group did research devices online, though in this they are probably not similar to others in the same cohort. Those who required expensive and complex power wheelchairs researched the approved vendors online but nobody looked for new technology.
Education level was no defense against unemployment and poverty. Respondents with an income of over $25,000 per year also had spouses who worked. A spouse with a job, however, was not a guarantee of income, since those who are mobility impaired often have to struggle to balance technology needs and feeding their family. One respondent, who also has a mentally disabled child, struggles to feed her family on their social security income and often delays nonessential repairs and tightly budgets medical expenses. Her blog often details times when she is forced to cut prescription tablets in order to wait a week or two for refills so that she can buy groceries that week.

When poverty limits were ignored, there were some differences between the genders. In general, the women answering the survey tended to be better educated than the men, though this is undoubtedly an artifact of the sampling method. Nearly half (46.7%) had some sort of professional certification. Although one of the initial
interviewees who helped shape the questions for this research was male, he was unavailable for the survey and the follow-up. Hence, all the respondents who use electric wheelchairs in this study are female. Nine participants who were members of associations and groups for the disabled, but only two of these approached their group when they sought information and recommendations for wheelchairs. Only two members of this subset advised that new patients should contact a disability support group when planning to purchase a wheelchair or wheelchair accessories.

The Internet was mentioned as a primary source in the preliminary interview session by an engineer who used a manual wheelchair, but the survey responses showed that it was used more as a quick reference than as a primary resource for most of the individuals who participated in this study. Internet social groups were not significant sources of information about mobility devices, although several belonged to internet groups such as Facebook. Websites such as the Muscular Dystrophy Association Website (which has information about using wheelchairs but not reviews of specific wheelchairs) and the National Spinal Cord Injury Association (which does have a “featured product” review section) were not mentioned as resources. There may be a “bias by diagnosis” filtering effect in place. One interviewee commented that she did not consider doing searches on sites for medical conditions that were not related to her disability. Another, in a follow-up response indicated that groups often turned into battling cliques, adding “And there’s a lot of one-upmanship out there, too, which doesn’t help.”

There was no particular resource that stood out as a significant player in the information process, and no one interviewed identified a place in their town as a good information source. There was a clear preference for oral information. This seemed to be
based on the idea that if they spoke with someone, they had the chance to negotiate and to probe for additional information. One person mentioned developing a circle of friends with similar needs that provided opinions and feedback on mobility device decisions. The preferred information source for two people was a therapist/occupational therapist. Most of the participants did not mention the medical community as their first source of information. One commented cynically about the diagnosis and assessment process: “Often, health professionals do not have a clue about how things work & how to assess needs of a person’s daily life. They have categories that one is supposed to fall into & base their suggestions on that.”

Responses about which sources of information were least reliable and which were most reliable reflected the individual’s social connectedness and individual experience with the medical community, help groups, and with insurance providers. Unlike the clients in Pettigrew’s chiropractic clinic study who had a rich and varied information exchange process with each other and the clinic staff, none of the responses from participants who had either basic manual wheelchairs, scooters, or electric wheelchairs revealed any online community groups or sources that acted as information grounds for the participants of this study (Pettigrew, 1999.) The exception to this rule was the group of people who participated in wheelchair sports and who had acquired specialty chairs for this activity. Here, as noted elsewhere, coaches and areas where they engaged in sports functioned as an information grounds.

Although the Internet has had a very strong influence on how our society uses information, it is not the source of a large number of information pools and does not make up much of the information landscape for people purchasing mobility devices. It had little
impact on those who relied on some form of government assistance, in part because their ability to choose was very strictly limited to a small set of acceptable devices. Primary sources also tended to be entities that very tightly controlled access to their information pools and who had a narrow range of devices that they considered to be both suitable and acceptable.

Those born with a disability or who became disabled at an earlier age did not necessarily have an advantage in finding information though they did have an advantage in understanding the process of acquiring mobility devices. For those who were not born with a disability and who acquired a mobility limitation later in life, accepting a mobility assistive device may be difficult because it represents an expense that they may not be eager to undertake and because it also signifies a loss of independence and control (Pape, Kim, & Weiner, 2002).

### Summary of Trusted Sources

<table>
<thead>
<tr>
<th>Complex power rehab wheelchair users: (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>100% - manufacturer or vendor (specific information needs)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other mobility device users: (n=19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>21% - insurance company</td>
</tr>
<tr>
<td>21% - medical specialist</td>
</tr>
<tr>
<td>16.1% - other (family, friends, self)</td>
</tr>
<tr>
<td>15.7% - state government</td>
</tr>
<tr>
<td>15.7% - athletics coach</td>
</tr>
<tr>
<td>10.5% - Internet *</td>
</tr>
</tbody>
</table>

*These respondents financial resources which enabled them to have some element of control over which device was purchased, had Internet and support groups were used as resources to enrich or to clarify these choices but are not the primary information source.*
One theme that emerged with those who did not have funding from other sources was a feeling of “independence” or pride and a reluctance to depend on any form of assistance or charity. One responded to the question with “We do not and will not seek help as we have enough funds to buy what I need and so we prefer to let charities help those who are worse off than we are.”

Maneuverability and comfort were the two issues of greatest concern among all age groups in this survey, a finding that matched the data mining results and was similar to that reported by Ward et al (2011.) Those interviewed for this study did not spend time searching for new information about walkers, canes, or rollators. They used the devices that they had acquired and unless there was a complete breakdown or some other external stimulus such as a child’s outgrowing their chair, there was no interest in searching for new devices or new solutions.

There was evident frustration over the amount of control wielded by the insurance companies. One user of a mobility scooter commented, “We’ve sent away for all sorts of information, only to learn I don’t qualify for ownership of any of the devices. This is frustrating. I often see individuals with zippycarts bragging about who they had to see to get it for free.” Another lamented the “cookie-cutter” approach to recommending devices to the disabled: “Often, health professionals do not have a clue about how things work & how to assess needs of a person’s daily life. They have categories that one is supposed to fall into & base their suggestions on that.” One informant, who had worked in the rehabilitation industry, commented on how poorly information was conveyed: “My clients, however, seemed to have lots of problems dealing with the medical supply people, many of whom seemed to have few to no skills in communicating with disabled or elderly.”
Satisfaction with government agencies was not high. “When dealing with my provincial and federal government health agencies, I was repeatedly [sic] provided with bad information about the quality and price of products. They would always attempt to provide the lowest of the low in product quality and price. (due to our health care system) Although[sic] private insurance did in the end take care of everything, dealing with public servants aws[sic] by far the worse experience.”—Respondent 4.

One of the more unusual findings was that wheelchairs and mobility scooters as commodities were not treated equally across the board. The methods of acquisition varied with the type of chair, and information needs and access and information grounds differed markedly among the mobility scooter; the electric wheelchair, the manual wheelchair, and the sports wheelchair; and varied wildly from vendor to vendor. Websites and advertising brochures sometimes skated over things that the prospective client wanted to know – such as wheelbase size and what the carrying weight capacity was.

Participants in this study obtained their wheelchairs and scooters through two distinctly different methods: purchasing and gifting. Except in the case of sports wheelchairs, purchasing of push wheelchairs was usually done through personal funds or with the assistance of insurance companies or charitable grants. Government assistance grants are available for those in need.

The general attitude of the non-disabled towards this type of wheelchair tended to be “a chair is just a chair” and as a consequence these are viewed as easily acquired and easily disposed commodities. A number of charities such as Minnesota’s Donor Select Program exist to bring unused and unwanted mobility devices into the hands of those who need them. Because they were so relatively inexpensive compared to other mobility
devices and because basic wheelchairs had the fewest accessory options, this type of wheelchair was the item that was most often donated or gifted to those in need. Wheelchairs as gifts usually come from charitable donation programs or as gifts from acquaintances and relatives.

The type of device affected which age group it was donated to. Electric wheelchairs and sports wheelchairs are far more frequently donated to children and are seldom donated to adults. However, push-type wheelchairs, which range in price from $100 to over $1,500, were the item most often involved in gifting between adults. These chairs are relatively inexpensive compared to sports wheelchairs, scooters, and electric wheelchairs and can be bought both with and without a prescription. They are frequently accepted as donations by churches and charitable organizations because they do not require expensive maintenance and upkeep, the user’s role with these is generally a more passive role, and the liability on these items is low. Two of the study participants who had push-type wheelchairs got their devices from family members who no longer needed them. One contact, who did not qualify for the study, told about getting a wheelchair as a gift from a stranger she encountered in the grocery store:

> I was standing in line at the bank and the customer in front of me asked the clerk if she had any big plans for the weekend.
> The clerk said she and some friends were taking furniture and supplies up to Moore to the tornado victims.
> I asked, "You don’t happen to have a wheelchair you’re donating do you?"
> The clerk said no, the customer asked why. I told her my husband had cancer and was having difficulty walking and I needed a wheelchair. She said she had two, and was glad to give me one, but she would be out of town over the weekend and if it could wait until Mon she’d be happy to have me come and pick one out.
> Another man walking out of the building had overheard our conversation, he turned around, came back in, and told me he had one in his garage that had never been used and I was welcome to it right then if I wanted to come by and pick it up.
The recipient’s view of the wheelchair-as-gift may not be as positive as that of a family member. To the family member, the gift often represents a financial boon where money that would be spent on an assistive device can then be turned to acquiring other needs such as food and housing. To the disabled person, gifting as a form of charity can come with its own set of burdens. As one disabled blogger explained, it forces the receiver into the position of a “have not” – an outsider in society and one who is not included in normal activities. The recipient is expected to be grateful for what they are given – even if it wasn’t something they really wanted. In addition, there is also the expectation that this gift satisfies the giver and with the donation, the recipient’s need for help is satisfied – even in cases where it is apparent that the gift would not solve all of the recipient’s issues (David, 2007).

Mobility scooters are also in demand as a donation; however it was not possible to assess whether those being gifted with a donated scooter feel this same sense of obligation. Additionally, although there are concerns about hygiene with donated medical wheelchairs, there seems to be little concern about this where mobility scooters are involved.

An abbreviated summary of the qualitative findings was emailed to 15 people who had responded to the survey in order for them to comment on the findings. Most did not respond within the two week time period, though three of them returned some detailed feedback on the findings.

Everyone in this last part of the iterative process agreed with the statement that in spite of the prevalence of Internet in our lives, it’s still not the preferred information source for any particular group or technology. In spite of the fact that everyone in the study used computers and was familiar with search engines and online groups, the Internet was not
universally the first place that they turned to when they sought information. As one informant reported, "A lot of the times if you do start your search on the Internet before you reach out to friends, you get poor results from a basic search. You know the information is there but the words you use to search somehow don’t bring up what you want."

Many times, information that was important to the client, such as the kind of foam in a seat chair, was never published by the company and could only be learned if they could put in a phone call to the vendor and gain access to one of the technicians who worked on chair modifications. Some data mentioned in other studies, such as the amount of effort required to use the device (Brandt, Iwarsson, & Stahl, 2003), was not listed as an area of concern even among the non-powered mobility device users of this study.

Although YouTube was not mentioned in the first round of responses that was collected, two respondents who commented on the results mentioned YouTube as an excellent resource for personal stories and reviews of new and specialty wheelchairs. A search of YouTube reveals that these customer reviews are predominantly evaluations for mobility scooters, with a lesser number of reviews for power chairs and electric wheelchairs. In addition to user reviews, stores and vendors also post in-house video ads for particular products. There are evaluations of manual wheelchairs on YouTube, but locating the ones most useful to the client depend in part on the search engine and the terms used. A search using Youtube’s own search function for “manual wheelchair review” returned approximately 4,100 hits while Yahoo’s search for “Youtube manual wheelchair review” returned 43,300,000 hits. A Google query for the same terms returned 164,000 hits and the Bing search engine claimed to have found 299,000 results. On the day of the search engine investigation, no one video was consistently at the top of the search results.
The first five videos from Youtube, Google, and AOL for the concepts “wheelchair review” and “mobility scooter review” were viewed. Videos for mobility scooters were mainly miniature ads from vendors that focused on a review of the features. In contrast, more than half of the videos of wheelchairs and power chairs were micro-documentaries of people enjoying and participating in wheelchair activities such as travel, dancing, hunting, and wheelchair sports. To the uninitiated these “family video” reviews seem to be less than useful, however; Respondent 18 pointed out that to someone in a wheelchair, these video reports give some sense of how the device performs in certain settings; information that is not as readily available as technical specifications like chair weight, weight limits, width, and optional accessories. In addition, videos of usage give the experienced user some sense of how difficult it is to operate and whether it will act as an enabler or a disabler in their environment (Häggblokm-Kronlöf & Sonn, 2007).

Additionally, respondents commented negatively about much of the information that was “pushed” in the form of advertising. As Responder 1 put it, “And sometimes what you do get is misleading, both for accessories and for warranties and expected use. Hoverround for example shows all those ads with people using their chairs outside. When we had an issue with the chair due to using it outside they didn’t want to cover the repairs because it ‘wasn’t intended for outdoor use’. We were never told that before that point, and the commercials and information packets were completely disingenuous about that fact.” Responder 2 added: “They all have an agenda and they would spin the information to reflect positively on their agency or industry.”
5.2 The Information Territory of the Mobility Impaired

“The manufacturer will tell you how great his is, of course, so take that with a grain of salt. Insurance companies and caseworkers usually give only general information, but if you happen to have an agent who is associated with a disabled person, you’ll get much better service.” Respondent 19

Although the intended process is presumed to be a straightforward exchange of information from a patient to their provider to the funding source to the vendor, informal discussions with a number of my respondents revealed an information territory that is fragmented by influences that often prefer to dictate a course or recommendation and that the dialogue is frequently one way – particularly when the patient is involved. Patient and caretaker in this system are not co-equal, as many studies have noted.

Diagram of Influences

On a small scale – when considering the interactions of these information pools within the information territory accessible to the mobility impaired client – there is a fairly tight lock on
resources. Each of these “gatekeeper” information pools shares data with their peers; however they do not always share their full data with outside sources. For example, a physician will send only the prescriptions and notes pertinent to a diagnosis to the device vendor, but will not send the patient’s full medical file. The amount and quality of the information varies -- as indicated by the arrows in the diagram, some channels are willing to accept information but release only small amounts of the material that they have in return. Media sources are almost always “one way”; delivering news stories and articles but seldom accepting material from these sources.

The picture of the information territory that was presented by these respondents is very similar to the situation that Chatman's prisoners found themselves in (Chatman, 1999.) Both the mobility impaired and Chatman's prisoners receive information that
presented in a specific context and is designed to promote a specific worldview – in the case of the disabled the message is that the provider has a perfect solution and major issue that the client finds unsatisfactory is simply caused by the client being non-compliant. Unlike the prisoners, the disabled and their gatekeepers can adjust the levels of access to certain parts of their information territory by strategies such as changing primary physicians or device vendors.

5.3 Peer-to-peer information exchanges

(Response to question about where to find wheelchair information) “Online reviews, recommendations from other w/c users who have similar needs. Trying out other people’s chairs”

Respondent 8

One interesting category of transitory information pools revealed by discussions with the original group of was a type of peer-to-peer interchange that takes place in certain public spaces. They report that it is not unusual for a disabled person to be approached by another disabled person, caretaker, or a partly-disabled person to request information about their current mobility devices and accessories. These exchanges are described as quick interactions that often take place in grocery stores, parking lots, or other public spaces such as a church or hotel. Further exploration of this subject revealed that those who approach the mobility aid user tend to be demographically similar to them as respect to age and economic status and that the conversations are initiated in areas where one would be likely to feel safe – well-lighted public spaces with others around. Ethnicity did not seem to be a barrier to asking for information, however, the sources reporting this live
in Texas and are people who participate in events and traverse spaces with wide social diversity.

In general, this peer-to-peer interaction is not overly common, nor is it a function of their social network since this exchange represents a single event with someone they have never encountered before and may never encounter again, even if they live in the same neighborhood or building. For the mobility impaired, venturing outside their house or apartment can be a tedious process that involves learning about and selecting spaces where they can operate their devices to reach their chosen location. Although many areas are touted as “accessible”, in practice they are often difficult to navigate, with heavy doors to push open, tight turns, and isles too narrow to allow a wheelchair or scooter to turn or maneuver. For those whose mobility needs require the assistance of an attendant, leaving their usual living space also requires coordinating schedules with their helper in addition to managing the logistics of getting someone and their mobility device to a specific location.

On the internet, blogs represent another form of peer-to-peer information exchange that is similar to the parking lot experience though it takes place on a slightly larger scale and involves more participants. This is not a transitory, one-time exchange of information – and yet it does not quite fit Fisher’s concept of an Information Grounds. Rather, it fits the model of a “Great Good Place” or a “third place” (Soukup, 2006). Like a “virtual community”, these “third places” or “Great Good Places” are spaces that exist outside the home, are on neutral ground, act as a social leveler, have conversation as their main activity, engender a sense of “home away from home” and provide a space for playful or informal talk between the participants. Identities can be masked, and consciousness of conditions and time often slip away, even when the response does not take place in “real time” and becomes
asynchronous rather than synchronous. It is comment that fosters community, and as interactions are exchanged on the blog networks, online associations and friendships develop (Soukup, 2006).

To the disabled, access to a physical “Great Good Place” such as Oldburg envisioned may not be possible or desirable. To be disabled in a public space is to be an object of attention and perhaps pity. The wheelchair or scooter sends a subtle message that the person using it is “outside” the normal community. Whereas the non-disabled can find companionship and communitas in a neighborhood bar or coffeehouse, the disabled find that achieving this in person is difficult. The Internet becomes a refuge where no one knows if you have some sort of physical disability or dysfunction unless you choose to reveal it.

An examination of twenty blogs written by self-identified disabled bloggers featured on three sites -- Blogspot.com, DailyKos, and Livejournal -- revealed that the people commenting on the blogs of disabled bloggers were not exclusively other disabled bloggers. Internet friendships form around the blogger’s other interests or life experiences such as parenting. For most of these blogs, disability issues are not the main theme of conversation though they may be touched on sometimes. As with any conversation there is a free exchange of ideas and advice and a sharing of information. Even with bloggers like “Bad Cripple” William Pearce who frequently post on disability topics, a conversation circle forms and dialogues around news stories and legal issues develops. However, these peer-to-peer exchanges seem to have only a limited impact. No one who participated in the survey was aware of any well-known and solidly established community of bloggers exchanging information on disabilities, rights, and technology.
None of the blogs that were examined linked to any large online information exchange or large community for the disabled in their resources. Sites that these bloggers recommended turned out to be other blogs with which they felt some connection. Responses by the original blogger to these comments showed a give-and-take process, where those who frequently responded to the blogs offered support and advice to the blogger and to each other. Although these writers were known within their own website community, they did not indicate that they had strong connections with device makers, vendors, or policy makers.

5.4 Information Pools and Liminal Events: Sports and Trade Shows

While collecting information from local informants, several people made recommendations for events and offered introductions to people who might give me further information and insight on how the mobility impaired got information about wheelchairs and how the industry disseminated information. This resulted in invitations to two events targeted for the disabled community and their caretakers.

The liminal nature of these events makes them more difficult to study and to place in context within the community. They take place during a relatively short time frame and in settings that often allows expression and exploration of some subjects that are difficult to explore in other contexts. For those who attend, occasions such as these provide both a sense of community and offer social bonding experiences. Frequently they become an ongoing source of social imagination and innovation that encourages the participants to experiment with different things and different experiences (Chalip, 2006).
Due to the abrupt notification and ephemeral nature of the two events that arose during this investigation, a decision was made to collect information from these resources using an ethnographic type study modeled on anthropological research of festivals where participants were observed with the permission of the stakeholders. As there was no time to do extensive recruitment or advertising for my research at these venues, a preliminary investigation was made using standard ethnographic qualitative research techniques of content related to each event. This included content analysis of websites and YouTube videos, and email correspondence and with the stakeholders using the text analysis tools of NVivo. Once on site, standard ethnographic techniques were used to gather information from the sites themselves through participant observation, and field notes. Information sources were analyzed for content and coded for emerging themes on the types of information exchanged between participants as well as vendors and other attendees.
A series of emails were exchanged with Doug Garner, head coach of the University of Texas at Arlington’s “Movin’ Mav’s” Wheelchair basketball team and he extended an invitation to visit the group during a summer camp evening practice session. The "Movin’ Mavs Adapted Sports Camp" is a co-ed event that offers both wheelchair basketball and wheelchair tennis games and clinics and provides opportunities for participants to talk with wheelchair sports professionals. It is marketed to student athletes and veterans around the country. In order to be accepted to this recreational event, participants had to be between the ages of 8 and 25 and have a primary diagnosis with some form of mobility impairment.

This summer’s camp was a four day event. In order to accommodate people from other districts and states, arrangements were made to provide student housing and meals.
for those who were unable to commute to the campus. The brochure for the camp stressed that participants had to be able to live independently, but that even those with fairly severe limitations could come and learn the sports.

The man who coordinates this, Coach Doug Garner, is well known in the wheelchair sports community. He has spent the past 21 years coaching disability sport including wheelchair basketball and has served on several US Paralympic/NWBA selection committees. The Movin’ Mavs wheelchair basketball team has participated in the National Wheelchair Basketball Associations’ Intercollegiate Division since 1990. Their seven national championship titles are a tribute to the success of the program. (Garner, 2013)

The session was held in the older PE building on the campus of the University of Texas at Arlington, which has swimming facilities and additional gymnasium floors with basketball courts set up on them. The main hallway was used as a “parking area”, where athletes left their everyday wheelchairs and transferred to their sports wheelchair. The playing areas were on the first floor and the second floor, but access to the second floor was with an elevator that could only accommodate two wheelchairs at a time. Coach Garner announced the research project to the assembled teams and allowed me to watch and to interview subjects in both the high school age group and the adult age group during the two hour long practice session.

On this particular night there were about fifty people in attendance including players, coaches, and parents. Most of the athletes had two wheelchairs with them – their sports chair and their wheelchair for everyday use. There were more female participants in the younger group. Women were represented in the college age group but in smaller numbers. Participants came from other states (including Washington) and their travel
expenses were sometimes covered by donations from charitable organizations. Some were there as representatives of associations or companies. As Moving Mavs’ player John Soto says in his YouTube video, the level of competition in the college level division is high (MovinMavsTv, 2012).

Conversations with participants who played wheelchair basketball and with parents and friends revealed that those who participated in wheelchair team-based sports had a markedly different information territory than other wheelchair users. In many respects it is a very broad and efficient system which gives disabled athletes access to rich information pools that contained detailed information about these highly specialized mobility devices. In addition to the coach’s understanding of how different styles and brands of wheelchairs work for different body types, teammates and vendors also provide personal reviews of the equipment, and information about funding options for purchases. These devices, which can cost upwards of $3,000, are not approved by the FDA for medical use and the parents who were interviewed were particularly interested in financial help so that their children could continue to play. Although the insurance companies label sports wheelchairs as non-necessary, participants and parents of these athletes stated that they disagreed with this view. As one mother observed, wheelchair sports are critical to the health and well-being of their children both physically and emotionally.

When asked about the equipment, the players explained the specialized features their chairs and talked about the ways that wheelchair sports chairs differ from other types of wheelchairs. These differences can be subtle and are not always evident to the novice. Modifications include lap and leg straps to keep the chair attached to the athlete, extra caster wheels to provide additional stability, the presence or absence of a bar in front of the
player’s feet, in addition to the almost nonexistent back rest. Additionally, because the sport requires high energy expenditure in order to achieve some measure of success, design emphasis is on efficient and precisely balanced wheelchairs that must fit well in order to ensure safety for the participants. It is critical for the athletes that they be able to fully integrate the chair with their body image, so that their bodies move as a whole (Jetha, Faulkner, Gorczynski, Arbour-Nicitopoulos, & Martin-Ginis, 2011), (Gailey, 2004).

Coordination can be difficult (MovinMavsTv, 2012). Chairs need to respond quickly to changes in the center of gravity of the athlete’s body as they glide into position to make difficult shots – often while the chair is still in motion.

While the younger group played for the sheer joy of playing, the older group played with fierce intensity. Chairs collided and tipped over from the force of the collisions and players raced down the court and made hairpin turns at high speeds. Those whose chairs overturned did not need anyone to help them get upright – they simply twisted their bodies around to a kneeling position and then shoved hard against the floor, flipping themselves upright. Coaches occasionally pulled players off the court and helped focus their game by talking to them about techniques and tactics. During breaks, the players watched the other teams intently and talked with each other about the strengths and weaknesses of the playing styles of teammates and opponents.

One of the players was an ambassador for a sports wheelchair company, and proudly showed his picture and video on the company’s website. He said that being the company representative was a “dream job” and was something for which he had worked hard. He was the most talkative of the group of athletes who responded to my request for an
interview and spoke enthusiastically about the emotional and physical changes in his life since becoming involved in the sport.

All of the people responding to the survey who participate in wheelchair sports have a secondary mobility device such as artificial legs, crutches, manual wheelchairs, and so forth that was paid for in part by insurance. However, since their sports wheelchairs, which range in price from $1,200 to over $8,000, are not suitable for everyday use, they are not deemed necessary medical equipment and are not covered by insurance companies (Medicare’s Wheelchair and Scooter Benefit, 2011). In order to overcome this barrier, many of them apply for some of the grants funded by charitable organizations such as the Kiwanis Club. These grants often cover the full cost of the chair, thus enabling many people to become part of an athletic team – people who would otherwise be shut out of the sport by the expense.

Central to this system are the wheelchair basketball coaches. These individuals, who have spent years working with disabled children and adults, function as nodes in a network that have a high degree of betweenness, centrality, and connectivity. They are the agents who bring the most information into the network because of their contacts with various manufacturers, repair technicians, and vendors. Within a small world network of the disabled and their family, the athletics coach bridges the difficult information territory that the wheelchair user cannot reach. They are the experts that players and family members approach when they have questions about chairs – a process of information exchange that is "energized by, maintained, refined, changed, and created by individual acts of communication", as Dervin (1992) puts it. In selecting and presenting information to players and parents, they behave very much like Taylor’s “question negotiator” librarian,
who determines the subject of the request, understands the motivation and needs of the client, understands the nuances of what resources are most likely to contain information that answers the question and knowing what kinds of answers the patron will deem acceptable (Taylor, 1962). In addition to acting as mentors, they also take on the role of advocates. One parent of a young man told of a series of exasperating encounters with their insurance company during their efforts to replace a wheelchair that the child had outgrown. Her child’s wheelchair basketball coach listened to their problems, helped them locate and apply for grants, and additionally provided information and references when they approached their insurance company again.

The sample is too limited to determine whether coaches play the role of early adopters in the diffusion of sports wheelchair innovations, but Rogers’ (2004) suggestion that those who act as agents for diffusion are in general better educated than many and tend to be early adopters of new technology seems to fit the picture of the academic sports coach as facilitator and mentor in wheelchair sports programs.

There are numerous websites dedicated to wheelchair sports and to teams and star athletes, and information on these organizations and personalities is relatively easy to locate. Online resources include examples of coaching manuals and names of professional organizations that help certify individuals as coaches and referees. Innovations and alternative technologies are spread through meetings at tournaments and in emails and websites. For example, a set of documents on the Wheelchair Fencing Association site includes instructions on how coaches can make practice frames for training athletes who cannot afford one of the specialty European chairs (Rodriguez, 2010)
Physical therapist Robert Gailey writes, “Disabled athletic adaptive equipment is a specialty, and only a few clinical professionals specialize in this area because of the occasional demand. Ill-fitting equipment can be more harmful than helpful and, in some cases, even be dangerous. Caution should be exercised by the coach and athlete when selecting a clinical professional.” He stresses that those who coach disabled athletes need to keep current with technology and to look for creative solutions to address the unusual problems that the athletes may experience because of their disability. (Gailey, 2004) He notes that much of the specialty equipment has been designed by athletes who are themselves disabled or with the help of disabled athletes and mentions networking with both athletes and coaches as a way to help the coaches better serve their team members.

Sports camps and games serve as an active information grounds for the participants, and Coach Garner commented that in his opinion vendors at these events do not pressure athletes to make a quick purchase. His description of these camps gave the impression that these were venues where information is exchanged in a collaborative and problem-solving environment. Wheelchair sports events such as team tournaments and special events and conferences play an important part in the information exchange. Because of the international popularity of wheelchair sports, there is a constant string of tournaments around the country and across the world for everyone. Business such as C&R Medical and Top End Wheelchairs sponsor athletes and teams as well as participate in events as sponsors or advertisers. For large conferences, they may have an onsite presence that includes salespeople who demonstrate their current and planned technology. Neither age nor gender is a barrier in this sport, and local teams are often made up of both men and women who are matched in terms of speed and ability. (IWBF) Children as young as four
can and do participate in the sport. The governing body, the International Wheelchair
Basketball Federation is recognized by the Paralympic Committee as the sole authority for
the game. The IWBF is responsible for establishing guidelines for acceptable equipment,
training and certification of coaches and referees, establishing the rules of the game, for
classifying players into teams and leagues that are comparable with each other, for
collecting funds to promote and sustain the sport, and for increasing the awareness of the
sport through marketing to reach those who could benefit from playing. (IWBF, 2013)
During the second evaluation phase of the survey feedback process, one of my respondents contacted me about Abilities Expo, a consumer event for the disabled and their caregivers that was coming to Houston the first week in August, 2013. She was planning to attend so that she could find a vendor for her newly approved electric wheelchair and asked if I would like to go with her. I contacted the Abilities Expo media contact and received permission to attend as a researcher and to interview people interested in participating in the research. Because it was a large event and was taking place in a sports arena, I was able to interact with many people who were engaged in a variety of physical activities. The atmosphere was one of energy and enthusiasm, and I was impressed by the range of products and services that were on display. It was clear that this event was designed to provide a positive experience for everyone involved, regardless of their physical abilities. I was particularly struck by the dedication and spirit of the Abilities Expo Ambassador, Bob Coomber, who stated, "I have to do something to prove to myself that I haven't reached the zenith of my life yet."
arena, two assistants were recruited to help capture data by taking photos of booths so that I could examine them later and reflect on the vendors and presentation. They also helped by collecting the free brochures and catalogs available from these booths while I took field notes. Since I was at that time having frequent episodes of pain when I stood or walked for more than an hour, my friend suggested that I use her other electric wheelchair so that I could cover more of the event -- and so that I could get a “first-hand” look at how these events appeared from the perspective of a wheelchair user.

Abilities Expo has, over its 34 year history, taken a somewhat different approach to reaching the mobility impaired community. Rather than being an event exclusive to the disabled, the owners are currently extending their marketing to target anyone who may have mobility issues and caretakers of individuals with a disability. In its advertising channels Abilities Expo presents the event as a meeting ground for vendors, developers, community activists, therapists, and others who offer products and services to the disabled community. There are seven planned events for 2013; six of them in major metropolitan areas of the United States and one event in Singapore. In addition to advertising on billboards, newspapers, radio, television and the Internet, it recruits and uses community ambassadors in part of its outreach effort. These ambassadors are disabled people – often wheelchair users -- who live in the community where the exposition is being held. They are a diverse group and serve to show that disabilities are not exclusive to any one age group, ethnicity, or gender. They are often featured on the YouTube channel that Abilities Expo maintains, along with interviews and short programs about events in different cities.

The August 2nd Houston event seemed well attended. Approximately 100 companies and organizations attended, and when we arrived (an hour after the gates
opened) there was a line of about 20 people waiting to get their wristbands that gave them access to the show. The majority of the vendors who attended offered products that related specifically to mobility, including makers of health related supplies, handicapped van outfitters, mobility accessories, makers of technological solutions for the disabled and major wheelchair manufacturers. Many of the information products that we collected had pictures an articles relating to travel and mobility, with a subtext of adventure that promoted the idea that the disabled could get out and do things that the able-bodied enjoy with the new technology. Salespeople offered brochures and promotional items to anyone who paused to look at the displays. The devices in the “new technology” group were not devices that were being introduced for the first time at the event – those familiar with the Internet could have easily found reports about them. The technology vendor indicated that internet access was becoming more common among the disabled and that current devices made it possible for those with a wide range of disabilities to still interact with a computer and gain information from Internet.

Near the food vendors was an area with large tables set far enough from each other to allow wheelchairs to maneuver through, even when people were sitting and dining. At the edge of the dining area was a broad space in which a smaller rectangle was delineated by short stanchions; this was an arena where wheelchair sports and wheelchair dancing were demonstrated. This area proved to be a strong visual attractant that fostered social interactions (Chalip, 2006) as people gathered to comment on the athletes, the dancers, and the service dogs that showed off their skills in the ring. The pace of these special performances seemed unhurried, which allowed onlookers time to exchange comments with friends or to strike up conversations with strangers about the activities.
The communal effect of the event was similar to that of a public performance (Chalip, 2006). Here was a liminoid event -- an occasion that evoked a feeling of unity among its participants in a secular rather than religious sense. Participants often halted a short distance away from booths featuring devices and accessories, where they could look at the display and talk about it with companions without being approached by the sales staff. Program items were well advertised, and event announcements helped coordinate the schedule and direct traffic to other stanchioned-off areas that served as “classrooms.” Because there were no walls to block the view of the speaker and the speech-to-text display on the wall next to them, passers-by who did not enter the area at the beginning of the presentation would often stop and watch portions of the presentation.

The wheelchair and walker vendor booths were the busiest during all the observation periods. One person who had attended the event the previous year remarked that returning vendors seemed to have reserved spaces, because their booth locations were in the same spot as they had been the previous year. The top sponsors had large and visually uncontested areas at the front of the exhibit hall, with plenty of space for the crowds of curious onlookers and information brochures set easily within reach of prospective customers.

All of the durable medical equipment companies and all of the social organizations had an Internet presence in the form of a website that they promoted. Some of the vendors said that they are beginning to actively invest in social media and the Internet. The Quantum Rehab Company had the greatest investment in creating and maintaining a presence on the web. The Quantum Rehab manager reported that their website averaged 80,000 hits per month and said that their Facebook posts sometimes had as many as
60,000 people viewing them. He explained that a recent revamping of their website had refocused their attention around questions that potential customers were likely to ask. This was intended to make it more attractive to prospective buyers rather than being simply an online information sheet of technical specifications that were useful to therapists but that did not engage their end market client.

There was a delicate balance of commercial interests versus information activities. The largest companies representing mobility devices were clearly aware of the peer-to-peer information exchange process. It was not unusual throughout the day to see vendor representatives seated in wheelchairs propelling themselves through the crowd at a moderate pace. Two instances were observed where attendees stopped the salesman to ask a question about the wheelchair and the salesman who was seated in it directed them towards the vendor’s booth. The vendor’s sales staff, though they were not disabled, often sat in the vendor’s display chairs to talk face-to-face with prospective customers. Although most attendees seemed cautious of engaging the salespeople, they would move closer and ask questions once the vendor’s representatives started helping someone with a demonstrator model. One vendor’s sales staff rode their demonstrator chair around the event twice during the six hours that we were present.

One of the down sides of a vendor-run and vendor-sponsored information grounds is that it turns the space into something that one blogger who visited an earlier Abilities Expo described as “Disneyesque.” The element of showmanship was present at the spaces of the largest vendors, where flashy demonstrations mixed with an appeal to the viewers to imagine themselves traveling from point to point using a device designed by someone who
was also disabled: "Watch this, folks; this was born to climb curbs! Won’t tip over! Designed by a quad!"

Frequent micro-exchanges occurred between strangers who were next to each other and viewing a vendor’s products. Longer conversations were observed between strangers who sat next to each other at a workshop or sat at one of the large lunch tables away from the general vendor area. Of the seven interchanges that strangers had with the members of my party, four were questions about the seat on one of the power wheelchairs and three were questions about the very robust platform base of that same power wheelchair.

Overheard conversations included a discussion where two acquaintances were discussing what each had been told by different vendors. One of them commented, "What I’m seeing on the spec sheets is not what I’m being told," as he produced a product specification sheet that he had gotten from a rival of the first vendor.

Particularly noticeable at Abilities Expo was what Chalip (2002) calls theming. Symbolic elements – cars, pictures of outdoor spaces, and triumphant people in wheelchairs – were layered in many ways to create a notion of celebration and the most successful booths incorporated some of those elements of excitement and freedom in their displays (Chalip, 2002). The unvoiced message seemed to be that if the observer could simply make use of these products; that they could have the same kind of mobility advantages that the rest of the population has.

Examination of event calendars on websites such as Disabled World and the Christopher Reeve Foundation showed that these events are not commonplace. The few that are designed to reach the end consumer are still a relative novelty for the disabled. While there are many conferences on disabilities and technology for physicians, for
vendors, and for therapists, Internet searches for consumer-oriented festivals and events specifically for the disabled mostly returned hits for various Abilities Expos around the world. Some of the sports events offer trade shows geared toward the consumer, but in general, these events are not well known even within the online disability communities.
There are still stereotypes that people in wheelchairs are mentally inept. In reality, many people with mobility disabilities have no mental disabilities while many people with mental disabilities don’t appear physically disabled at all.  

UNT graduate Holly Wyman, Miss Wheelchair Texas 2002

For those who transition from public high school to college life and from the relatively structured health information system of the school to the much more chaotic information grounds of adult life, large colleges and universities are among the best
resources for learning about technology. From job assistance to volunteers who can repair high technology equipment, institutes of higher learning offer a lot to their members. One central coordinating body of any university or college is their Office of Disability Accommodation.

In general, the quality and quantity of information about services and resources for the disabled is better at large universities and large colleges and extends to the nearby community and its infrastructure. Within these areas and adjunct to campuses are places that serve as information grounds among university students, including coffee shops, social gatherings, sorority and fraternity houses, and certain restaurants (Fisher & Naumer, 2006). Those that are ADA compliant allow the mobility impaired to extend their information resources and to participate in the microcommunities that develop at these sites, becoming familiar with the faces of regular patrons and interacting with the local “information commons” and exploring shared interests.

Academic institutions are aware of the issues that disabled students face in part because of advocacy by students and faculty members and their websites include pages that deal with common issues that people with disabilities encounter on campus. Most sites maintain a webpage with documentation requirements that students and faculty will need to request services along with links to forms for government assistance, links to student handbooks, and information about special accommodations. Although these are not true information grounds, they serve as a resource pointing to campus resources for specific needs. More importantly, these serve as contact points for disabled students who may wish to interact with others who have similar needs and peers who can serve as mentors when questions arise.
One information source that proved helpful throughout my investigation was the University of North Texas’ Office of Disability Accommodations. Their staff is highly trained and has the advantage of being able to attend conferences on disabilities and access, where information is exchanged and new technology is presented and informal discourse about problems and solutions takes place in the conference social areas. Rebecca Cagle was particularly helpful, sending lists of resources and contacts as well as identifying some of the common challenges that the office faces in helping those who are mobility impaired.

UNT’s Office of Disability Accommodation serves approximately 900 students with a broad range of diagnoses, including disabilities such as deafness which are not readily visible to the casual observer. In addition to a friendly and well-trained staff, their website has been carefully planned so that students and parents can easily access information and forms that UNT requires in order to provide services. The website includes lists of services, helpful hints on practices such as teaching the student self-advocacy, informing parents and students of how disability services for college students differ from those offered to public school students, and information about unusual decisions that may need to be made for a disabled student which would not normally be an issue for non-disabled students. The site also includes information for teachers and professors on how to accommodate disabled students and how to deal with temporary disabilities.

A similar situation exists at Rutgers University, which hosts the CareCure message board in collaboration with the W.M. Keck Center for Collaborative Neuroscience. Although aimed primarily at those who suffer spinal cord injury, the CareCure message board has a fairly broad reach of topics. Because it is associated with the university, news stories about research or new technology are frequently posted there. The section of the Cure
Community message board that is devoted to wheelchairs, stimulators, and other devices shows that an information grounds is indeed possible in cyberspace, but that it requires a very invested community and a lot of community management. Although it is not the largest message board on the internet or the most frequently accessed, it has grown to an impressive size since 2002, with 39,812 registered members.

One of the emerging ideas of the beginning of the 21st century was the concept of using the Internet to create an “information commons;” a concept that generated a lot of interest but in practice was rarely seen outside of university settings. It was seen as a means to provide access to works on a global scale, which would allow international sharing of ideas. But the Internet itself outstripped the idea, which also suffered from a lack of a clear formal description. Most sources seemed to agree that it would be some sort of location such as a library that was designated to deliver electronic resources for research and production; a site that was maintained by a technically proficient staff. (Cowgill, Beam, & Wess, 2001) The assumption seemed to be that access would still be expensive and that the ability to reach information housed in special repositories would be severely limited.

A 2001 report indicated that the information commons on university campuses were generally run either by the library or by the computer science department (Cowgill, Beam, & Wess, 2001), with the infrastructure being the responsibility of the university itself. For the disabled students, this had an advantage because it was possible to gain physical access to computers and servers associated with this service and that they were being maintained by staff dedicated for this purpose (Cowgill, Beam, & Wess, 2001). Students who had been barred from other information commons because of the time and
effort needed to travel to such a place could meet with others and participate in the activities through Internet.

One distinct advantage of having a university library serving as an information commons for the disabled is that the building itself is one of the most physically accessible on the campus. During the hours that it is open, trained research staff are present to help patrons locate accurate information, and it is free of the tyranny of the marketplace (Cowgill, Beam, & Wess, 2001). Resources such as the CareCure message board can be maintained as areas free from both direct and indirect sponsor control over the messages and content of the posts. In this egalitarian realm, it will be easier for the disabled to get accurate information.

5.8 Ephemeral Information Events, Information Commons, and Information Grounds

"This is why people get frustrated and quit seeking help, or turn to drugs. There’s no one place to go to get information, no one anywhere can really help you, but still $$$$$$ disappear down that rat hole with no one getting anything they need. Yet some people/groups have learned to milk the system, which only frustrates and angers everyone else even more." -- Respondent 12

Even the most computer literate respondents had trouble locating information details that they were interested in, such as seat cushion options and accessories such as tray attachments for power wheelchairs. The ability to access information depends on physical, intellectual, and socio-cultural constraints that interact at the individual and at the group level (Thompson & Afzal, 2011), and all of the respondents to this survey had some sort of advantage such as education and Internet access in more than one of these realms. They used both expert sources in the form of clinical medical staff and vendors and public
information sources such as information commons and information grounds – both permanent and transitory.

“Information grounds” as described by Pettigrew (1999) are places -- most often a physical location -- where people meet and exchange information informally. This is an established location such as a university student union, Internet message boards, or a disabled sports association where a permanent or semi-permanent community can form. One of the discussions central to the idea of an “information grounds” is the determination of what is meant by “place.” According to Fisher and Naumer (2006), certain qualities are needed for an effective an information ground. Among these, an information ground must be a neutral place, must be an inclusive leveler, must be accessible and have regular visitors, have a persistent and playful mood and feel like a “home away from home. The environment should be welcoming enough that it is easy for strangers to strike up a conversation, but there should be no mandated set of permitted topics. Pettigrew (1999) theorized that in such a setting, information needs could be expressed indirectly and information exchange could be informal and conversational.

In contrast, an information commons serves more as a resource archive than a true meeting place. The idea of an information commons as expressed by the American Library Association (Brollier, 2002) is one that was popularized in 2002 as a futuristic concept of how the capabilities of technology-enhanced libraries could be expanded. The dream of the founders was to create a space where the principles of the commons could be applied to information -- where the market’s discourse could be shut out in favor of the needs of the individuals -- including social, civic, and humanistic concerns. As conceptualized, this ideal resource would include information transparency, the promotion of feedback and
knowledge sharing, some form of group decision-making, information diversity, social equality, and some structure that allowed peer-to-peer sociability, though this interpersonal activity is secondary to the archival purpose.

One of the questions that arises from this data is whether an electronic “information commons” for the disabled can actually be implemented. While having an actively maintained archive of documents and records relating to mobility devices and disability issues would be of great benefit to mobility impaired clients and their caregivers, a number of barriers exist that are familiar territory to librarians. Documents would need to be acquired and verified for accuracy and made available in multiple formats, and some decision would have to be made about who buys and who maintains and supports the hardware and software for such a project. To be effective, any group that manages an Information Commons needs to have staff with broad skills who are capable of handling a broad range of issues along with a core group of staff who can address complex hardware and connectivity issues. (Cowgill, Beam, & Wess, 2001) In the past, attempts at information commons have often been built on university resources. Although it would be possible to develop an Internet based information commons for users of mobility devices, as of this writing no such structure exists.

For those who are limited by in their ability to access knowledge because of physical or cognitive barriers, an information commons could do much to address several issues faced by this population and their caretakers. As consumers, their current ability to access diverse sources of technical and device-specific content is tightly controlled by manufacturers, insurance companies, and the medical community. As citizens, the disabled may not have easy access to free or inexpensive means to access the government
information concerning public issues of disability and assistance that their tax dollars have financed. In the case of individuals with unusual or rare forms of disability with complex mobility assistance needs, access to national and international documents could help guide and standardize policies and service requests and cut down the amount of time needed to acquire new devices.

The Internet is not necessarily an ideal environment for everyone who is mobility impaired and socializing via computer does not take the place of face-to-face interactions of the kinds that occur at a fair or an exposition. For those who are more mobile and who are able to leave their homes to join others in the community, events such as sports camps for the mobility impaired and similar activities can offer all the benefits of liminality: energy, excitement, and communitas (Chalip, 2006).

Ephemeral events such as Abilities Expo have the potential to impact the lives of the mobility impaired in a very meaningful way by becoming an open marketplace for information. As Chalip (2006) states, the temporal nature of these occasions is liberating -- there are no set roles for attendees other than that of observer or participant. Passers-by are free to act as observers or to engage vendors and attendees on an equal social footing. For those with an interest in sports, sporting events are often the most fruitful source of interaction and information and a powerful resource for identifying repairs and discussing technology and access options and laws that pertain to their interests. Event sponsors and featured vendors, who bear much of the cost of these functions, influence the dialogue and the information exchange. However they also provide a venue to showcase new technologies and new systems, which can speed up the process of technological diffusion into the general population.
Not all ephemeral events have this kind of impact. Health fairs are more limited in scope. They may feature visiting vendors with some mobility devices or offer pamphlets and advice from the medical community but they function more as an information kiosk than as any sort of participatory event and information exchange area.

5.9 Observations on Social Capital and Information Access

There is a reason people with a disability live at or below the poverty line. There is a reason people with a disability are unemployed in great numbers. There is a reason people with a disability do not get an adequate education or advanced degrees. The history of disability is as shocking as it is depressing. The legacy of exclusion is ever present and still profoundly influences the lives of people such as myself and others. (Pearce, 2013)

One factor that was difficult to assess directly is the issue of the amount of individual influence – “social capital” -- held by individuals. Portes (2000) defines social capital as the ability to acquire actual or potential resources linked to certain relationship networks and further notes that it is based on the individual’s investing in relationships within groups. It is frequently used in sociology and the social sciences as a means of explaining disparity in treatment, services and access. During the initial exploratory conversations with friends and participants there were early indications that social capital had an impact on the ability to access to information; a finding that is also suggested by Chatman’s (1999) “small worlds” concept.

The benign and well-intentioned paternalism that Coulter (1999) finds rife in Great Britain’s National Health Service leaves the physician as the guardian of the patient and disempowers the patient in matters of health care. Interviews and casual discussions with
participants indicate that Coulter’s observations reflect a paradigm that is still present in the medical community at this time. Several respondents in this survey remarked that their attempts to influence certain choices over their mobility devices were ignored and that they were treated dismissively or scolded lightly when they attempted to protest. One of them related that a vendor scolded her when she told him that she would not buy the wheelchair that he loaned her for a trial because it was too wide to fit through the doorway of her bedroom. She related he seemed to think she was just being a troublemaker. Her assessment of the situation was that they did not have anything in stock that matched her needs and she was given an unsuitable loaner chair to placate her without making any attempt to match her needs. She added, “They just want to fit me into an out-of-the-box chair. And that’s just not going to work.”

A second respondent told a similar story, “The representative from the Scooter Store who fitted me for my new wheelchair convinced me that it would be better than my old one because it would be custom fit. The seat is definitely more comfortable, but the usability is much worse. They designed the chair purely for indoor use, even though I told them that I am a student who needs to get to campus everyday [sic]. I should have been more pushy about what it could actually do.” Another survey participant related the story of her initial diagnosis where the physician repeatedly insisted that her problems were “all in her head” and who ignored her and talked to her husband throughout the visit. She changed providers after that visit and the new doctor proved to be more responsive and ordered a series of tests that provided the basis for her diagnosis.

Occasionally this type of interaction moves beyond the level of a personal story and becomes a newsworthy event and a flashpoint for acts of public activism or protest. A 2012
news story about a first grader who was banned from using her walker in school and forced to use a wheelchair instead generated at least one petition and the online edition of the report generated a number of angry comments about the helplessness of families to deal with bureaucracies. (Heasley, 2012) A user who identified himself as “Wes Harley” neatly summarized what many of the others said: “Physically and Mentally[sic] challenged individuals must not only conquer structural barriers but also educate the “educators” that subsists in our public schools.” For the disabled, access to information about mobility devices and their use did not always equal the ability to obtain a satisfactory outcome. The girl’s mother was one of a number of individuals in 2012 who attempted to leverage social capital in the form of public petitions on sites such as Change.org to bring about their desired resolution to an issue.
5.10 Two Women

“After thirty years of wheelchair use this is what I think when I see another paralyzed person: are they employed, married, do they have a car, if so what kind, and where do they live? If the person in question is married, employed, owns a house, and has a family I am sure of one thing: they are skilled problem solvers.” (Pearce, 2013)

Two incidents that occurred during the data collection phase of this dissertation served to highlight the disparity in information response and information access between those who are highly connected and who have high social capital and high centrality within a network versus those who are only moderately connected to social networks and information sources and who have only a moderate amount of social capital. In August 2012, a friend and World of Warcraft guild mate (“Tina”) who has been disabled since birth and who had agreed to participate in the study experienced an electrical problem in one of the motors of her very old power wheelchair. As a result of this malfunction, the wiring overheated and started a smoldering electrical fire that damaged and rendered inoperable the motors that raise and lower her sear chair. Coworkers quickly rushed in to put the fire out with a fire extinguisher but it was clear that the twelve year old chair that Tina had been nursing would need to be replaced.

She had put off getting a newer chair in part because her device is a “complex rehab chair” with special seating that allows her to maneuver in and out of bed and furniture in her home and to use public restrooms and the cost of a comparable new wheelchair would be over $30,000. Because she and her husband did not have enough income to purchase a new power chair and because she had little insurance at her place of employment, she turned to the State of Texas to ask for financial assistance. She was aware that she would
have to negotiate details with the vendors since her old chair needed several modifications to accommodate her needs and make her fully able to participate in the workforce.

However, her status as a working woman with a known and verified diagnosis who has been a client of the State of Texas’ Disability Services since her birth offered her no advantage in terms of service or information. After a ten month struggle involving caseworkers who did not return calls and who missed appointments and who lost her paperwork, Tina finally made it through the approval process and was given a purchasing order and a list of vendors who had approved products. She had done her homework well and had found several chairs on the Internet that looked as though they would be possible matches. Voucher in hand, she approached the vendors.

However, interactions with the vendors did not go smoothly. She was offered a “test drive” of a chair that did not match her specifications but one she was told could be made suitable for her. However, when it was delivered it became apparent that in spite of her relaying very specific details on the chair size and features, the vendor ignored her input and instead delivered an “out of the box” model. This new power chair was wider than the one that she was trying to replace and it could not be maneuvered around her home or her workplace.

When Tina contacted the vendor and told him that the wheelchair was too wide to fit to through the doorways inside her house and that she couldn’t even get it into the bedroom, she was scolded and told to “not judge too soon, finish out the weekend and try it at work.” Because of the problems with her damaged chair, she reluctantly complied with his suggestion. When the vendor contacted her after the weekend test-drive, he was
astonished that she had not changed her mind and still firmly maintained the chair was
unsuitable.

Four months after being approved for funding and more than fourteen months after
the electrical fire that damaged her old power wheelchair, Tina has still not been able to
purchase a replacement chair. Although she found a suitable power frame, she explained to
me that the chair vendor and the company that makes the molded cushion seat that she
needs to have for her chair are still mired in a discussion over what kind of information
needs to be included into the existing physician’s prescription for her wheelchair. She
explained that although her physician had written the prescription for her chair twelve
years ago, the information that was considered suitable at that time did not include certain
details that her chosen mobility chair vendor wanted. In addition, the Texas Department of
Aging and Disability Services (T-DADS) determined within the last month that Tina needed
to have another piece of documentation in order for them to release the funds to buy her
chair -- a document from her own insurance company declaring that they would not pay for
her new power wheelchair. Tina reported that the insurance company representative
seemed confused by the request and she is currently attempting to resolve the problem via
phone calls to the insurance company and to her caseworker at T-DADS.

In the middle of Tina’s long battle to buy a new electric wheelchair with assistance
from the Texas Department of Aging and Disability Services, a second friend’s (“Lucy”) power wheelchair also malfunctioned catastrophically and became unusable during a
weekend trip. Both women use complex power chairs and both need assistance with most
of their daily tasks, and the design of their chairs is similar. However, Lucy is a noted author
who has several public speaking engagements and book signings across the country each
year. Lucy’s chair malfunctioned at an event where she was a guest, and the entire group that was hosting her rushed into action to help resolve the problem. A technician arrived to diagnose the problems with Lucy’s chair within a few hours and she had a replacement chair delivered to her within eight hours. In the interim, friends and staff found a push-type wheelchair so that she could travel throughout the convention and participate in the program items that were on her schedule.

On her homeward trip the airline baggage handling system dropped this replacement chair and damaged it. On her blog, she wrote that she spent three weeks dealing with the damage claim and with vendors, which included time spent dealing with one technician and a shop supervisor who treated her in what she described as “a less than professional manner”, including the demand that she rearrange her daily schedule to accommodate their demands. Lucy took her complaints to the company’s administration and her issues were resolved and her account was transferred to her local service technician who was familiar with her chairs and her specific needs. She received her new replacement chair with customized modifications that included seat cushions within three months.

The contrast in their experiences highlights some of the key points of the survey data. Lucy is well connected socially and has a great deal of social capital because of her identity as a public figure. Having a two-income family, Lucy has more economic power and better insurance than is available to Tina and she has been able to locate and maintain relationships with a nearby shop that repairs wheelchairs and medical equipment. Lucy has always been a fairly outspoken woman, but because of the support of her husband and family, she has also become a disability activist who interacts with airline companies on
behalf of disabled travelers. Because of this, she knows how to get the attention of
organizations and has developed a variety of strategies to ensure her voice is heard. In
addition, she has a number of socially connected friends whom she can call on when she
has a problem getting information or has a problem dealing with an institution. As someone
who is a public figure, her audience includes a number of people with disabilities and a
number of people with high level computer skills who can serve as knowledgeable
information points when a call for information goes out. These were the people who
helped quickly find loaner equipment for her when her chair malfunctioned while she was
at her speaking engagement.

The extent of Tina’s social network is much smaller than Lucy’s. Both Tina and her
husband are technophiles and have a number of computers in their home. Tina runs her
own webserver and hosts a small gaming site and a server for two voice chat programs for
small groups. Although she has a larger set of social connections than many of the disabled
because she works a full-time job and is active on the Internet and she is comparatively well
educated, her relatively low wages meant that she could not afford to fix minor problems
with her old wheelchair and did not establish any sort of long term relationship with a
repair vendor. Although her close friends (who are all aware of her situation) include
computer technicians and computer professionals with good information retrieval skills,
none of them are disabled, and none have any strong connections to the rehabilitation
technology community, disability advocates, or specialized resources that were useful to
her. In this respect, her situation is similar to that of Chatman’s (1999) model of “life in the
round”, where seeking certain types of information made more difficult by those who
control the information and where shared and accessible information is not necessarily sufficient to address a particular situation.
6.1 Mobility, Access, and Information

“I don’t know how my mother managed to buy my first electric wheelchair before the Internet arrived. When I go to look for vendors now it’s almost impossible. I don’t know how she did it before.” – Respondent 15.

While the need for a clear and understandable process for obtaining information about mobility assistive devices can be seen, the survey results indicate that the information process is in chaos. There is no central authority or repository and unlike the European Union, there is no agreed-upon set of forms that documents the client’s needs and there is no standard process for acquisition of mobility assistance devices in the United States. The responses from this survey indicate that ability of state governments to respond to clients in need is hindered by this non-standardization and that this interferes with the ability to access, process, and archive knowledge in a useful way. Information collected during the course of this research suggests that vendors and manufacturers control a considerable amount of the information that clients are interested in and that as a result, these clients tend to direct their searches for information along many channels, trending toward personal communication via phone calls or meetings with seemingly well-connected nodes such as physicians, therapists, and insurance companies rather than
turning to the Internet as a primary resource, though the Internet is used as a secondary source of information.

“Tina” commented during one session where we searched for information on about chair seat height that searching effectively for information about specific features for a mobility device required the user to be able to select and use a good set of search terms on their favorite search engine. She walked me through a sample search and demonstrated searching for information about mobility devices is not a trivial task because of the many different words used to describe these devices. Vendor sites that she showed me referred to her type of wheelchair as a “power chair” or “power wheelchair” or “complex rehab chair”, but Medicare and Medicaid sites referred to them as a Power Mobility Device or Durable Medical Equipment. Searching for information about mobility scooters showed a similar pattern of naming confusion. Medicare and Medicaid sites refer to them as “Power Operated Vehicles” and categorize them along with power wheelchairs as Power Mobility Devices (PMDs) and as Durable Medical Equipment (DME) (Power Mobility Devices, 2013). This overlap in terminology can make locating information about acceptable devices and options more difficult. Sometimes the information was simply not presented on the website. Connaway, Dickey, and Radford (2011) suggest that this kind of material will not be placed on the web unless there is some motivation for the vendors and developers and insurance companies to make it available to others.

The resources people use to get information depend in part on the initial need that sparks the search. If the material that is being sought is for a professional or academic situation, the sources that are accessed will be different than if the information will be used in a casual conversation such as a blog comment. In addition, there are generational
differences in the methods chosen for different types of searches. The “millennial generation” is more likely to turn to friends or Google for a quick answer than they are to use other sources. (Connaway, Dickey, & Radford, 2011)

Information inconvenience is an emerging theme in our digital world, based on the acknowledgement that one may not have access to or be able to use a resource that is actually common in the community. Studies in gratification suggest that those who are economically disadvantaged will select information strategies that result in the quickest responses (Connaway, Dickey, & Radford, 2011). Although some of the factors such as convenience, speed, and interactivity are present in these types of information sources, it remains to be seen if they will become a significant factor in the future for those seeking information about mobility devices.

The results of this study show that while the Internet is often the first place that people turn for quick advice, respondents in this study indicate that it has not taken the place of traditional channels (Sapey, 2004). In part, this is due to the financial cost and the effort needed to create and maintain websites and archives. Without a team committed to maintaining good archival information and acquiring new information, websites that are designed to be resources for the disabled often stagnate after an initial effort. In the end they become monuments to history, presenting information that is years or decades out of date and pages of links to websites that have vanished. For clients who are newly disabled and are struggling to find solutions that work in their environment after they leave the medical facility, outdated and incorrect information such as this can be dangerous (Jetha, Faulkner, Gorczynski, Arbour-Nicitopoulos, & Martin-Ginis, 2011).
Mobility aids such as canes and walkers that can be bought without a doctor’s prescription and without consultation with therapists and physicians are not complex and do not trigger many search requests. But those who need assistive mobility devices have more complex information needs. In addition to basic facts about the technology, these clients may have to deal with an acquisition process that is complex, full of paperwork, and that varies from one agency to the next (Plummer, 2010). Important resources such as lists of T-DAD’s approved vendor list and lists of funding sources that were difficult to find in the past are often still inaccessible (Moore, 2012). The number of forms and supporting paperwork requests slows the acquisition process in the United States and often impacting the client’s health in a negative fashion (Cohen & Billingsley, 2011).

In spite of the number of disabled who have access to the Internet, it has never been fully realized as an information grounds. Browsing Ebay for mobility devices shows that there is a worldwide market for them, though Ebay itself does not have a forum for them. The number of mobility devices offered through Craigslist is too small for the website to create a section devoted to them. Yet the potential is clearly there. While information about chairs and other mobility devices is exchanged and offered for purchase on places like the Keck Center at Rutgers University’s Care Cure Community message board, there are no community sites with thousands of community members that are actively discussing mobility devices and options in the same way that users of automotive boards discuss automobiles. Consumer oriented online sites like WheelchairJunkie and USATechGuide, have positioned themselves as mobility resources, but they are still relative unknowns. While they do offer customer reviews and online help from company representatives and technicians, there is little of the peer-to-peer interaction shown on Care Cure. The
explanation may lie in comments made by two respondents to the survey – that often they seek advice from people who have the same diagnosis as they have and that generalized disability websites often lack information that is pertinent to their needs.

A usable model of how this group is finding information can suggest strategies for more efficient collection and delivery of information to these clients about their devices. An information grounds needs to be a place that is playful; to be something more than a news feed with a problem solving section. It needs to foster the idea of community and inclusiveness and it needs to foster a spirit of hope. There needs to be a core of “regulars” who visit and act as community mentors and trusted advisors. (Fisher & Naumer, 2006) Groups with multiple community leaders or mentors seem to be friendlier, but those seeking information may become frustrated with the high level of casual social chatter. Yet the obvious cyberspaces that have these characteristics -- such as Yahoo Groups or Facebook Groups -- seem to never quite rise to the level of an “information grounds” and remain more areas for socializing. Some collaborative information behaviors can be observed in these groups, but because it is not the focus of the group, the quality of information delivered varies wildly from personal stories of experiences with devices to wildly improbable information copied from inferior sources including entertainment and satire sites. It is difficult to say whether this paradigm will change.

In spite of the improved access to information given by the Internet, control of the product and the outcome is still very much in the hands of the vendors and the insurance companies who act as the gatekeepers of the information. At this point in time, access to the information depends in part on wealth and social capital. For those with few advantages, finding information about mobility devices and vendors for specific needs can
be a long and challenging process. Although there are advocacy organizations and mentors, it may be difficult for the disabled to reach and establish a relationship with someone who can help them with their information needs. Usenet groups, taken over by Google groups and by Yahoo groups have declined as information sources. Many groups are now a haven for spammers, who post several thousand messages a month. Useful information that these groups may have had is buried under a deep layer of advertising for pornography, pharmaceuticals, and dubious get-rich-quick schemes.

Much current thinking revolves around helping the mobility impaired to have better access to the Internet on the grounds that this will empower them to do research on the options available to them and to make better decisions. Entities such as the Texas Technology Program work to help the poorest groups of disabled clients find a way to connect to the rest of the world through the Internet. The problem is that this model may not represent the best solution. Nonstandard terminology, mislabeled web pages, advertising traps and a host of other issues related to spam and advertising impact the ability of users to access the information they want. To further confound the problem, keywords and key phrases may not be exclusive in their usage. A quick search on Facebook for the word “wheelchair” gave some insight into the information noise encountered by people interested in joining a group where they could discuss topics relative to their health concerns. The initial search returned over a hundred hits on organizations and pages that included “wheelchair” as part of their name, including wheelchair users, others are wheelchair athletics associations, wheelchair crowd funding pages, vendors, as well as a number of pages for apparently non-disabled people living in countries where English is
not the first language who use “wheelchair” as part of their name. The only way to find a suitable group would be for the user to go to each of the pages and evaluate each one.

The disabled would benefit greatly from having access to specialized librarians who can wade through the morass of bad information and who are not bound by salary and company obligations to recommend specific products and services. The presence of the Abilities Expo and other similar fairs suggests that information grounds model is developing that will be somewhat similar to the one that exists for wheelchair basketball, where vendors come together in an open market atmosphere to compete directly for clients rather than pressuring physicians and therapists into recommending their devices; a situation where information mentors take on the role of research librarian to interpret user requests and locate new and appropriate adaptive technology.
6.2 Topics for Further Study

A number of interesting side topics emerged in the data analysis that were not directly applicable to the research but that offered further opportunities for exploration. One of the most unusual was the topic of technological modification and innovation using readily available sources to mend or extend the usefulness of a mobility device. Oftentimes they represented a significant cost savings to the family – such as having wheelchair tires repaired by a local bike shop rather than taking them to the vendor.

One potential area for further investigation is the issue of whether having high social capital means that there is a “push” in the flow of information – that is, whether friends and others in a social network tend to “gift” or offer information to a prominent person more actively than they do a person of lower status. Portes (2000) points out that the impact of social capital can be overemphasized and that the apparent impact can be attributed to other things. However, a discussion with a family member of Dallas Jungian psychiatrist and analyst, James Hall, who suffers from Locked-In Syndrome, suggested that this might be an avenue worth exploring. With further data it is possible that a mathematical model of information filters in a Bayesian network can be constructed.

In the end, both hard and soft data fails to reach deeply into the experiences of the mobility impaired. Here in the United States, the voices of Native Americans, Blacks, Hispanics, Asians, and others... are sadly very quiet notes in the chaos of information. Under certain circumstances the terrain of their information territory will have much steeper access points and higher barriers than many of us will experience. Some of the
findings from this research suggest the need for multiple information grounds and
information commons for the mobility impaired. On the surface, it might be an elegant and
obvious solution for libraries to become central repositories of formal documents relating
to health care services, though the level of commitment and services needed for this may
not be something that they wish to undertake. It would appear that American Library
Association has shelved the idea of an information commons as a workable future direction
for libraries, however, poor availability of standardized information about processes and
documents needed to acquire specialty mobility devices and the poor coordination of
information in the industry shows a very real need for some kind of egalitarian and
cohesive archive space to be developed and maintained.
APPENDIX A

LETTER OF INVITATION
**Letter of Invitation**
Research in Information access for wheelchair/scooter users

My name is Mel White, and I am a PhD student in Information Science at the University of North Texas. For my dissertation, I’m studying advice – the advice that experienced wheelchair or scooter users would give to a new user. I’m interested in where the best advice comes from, what kind of advice is most needed, and the best way to find help when you need advice about your chair or scooter or financial aid programs for the disabled.

**What will I be doing if I agree to be in the study?**
If you agree to participate, I will ask for some basic information about your age and your education and where you’ve lived. I’ll ask when you got your first wheelchair/scooter and how you got it, why you needed it, and where you think the best places are to get advice if you need a new wheelchair or scooter. I’ll ask a few questions about the groups you think were most helpful and about ones that weren’t very helpful and what questions a new patient should ask when getting a wheelchair or scooter for the first time.

At the end of the question and answer session, you will be given a chance to participate in a review session.

**How much time will this take?**
Collecting the basic information (your age and background) will only take 10 minutes or so. The conversation about advice can be as short or as long as you like. We can do this by email or phone call.

Everyone who responds will be anonymous – names will not be revealed, nor will I reveal the names of anyone or any company or organization that you’ve talked about. When the study is done, I will make a one-page summary of what I’ve learned available to you (you can have a copy of the dissertation if you like.) The transcripts of our conversations will be kept at the University of North Texas but won’t be available for anyone to study.

If you have any other questions, please contact me. If you’d like to participate in the study, please sign the consent form and mail (or email) it to me. I’ll contact you within a week of getting the form to set up a time for our interview.
Informed Consent for Participation in:
Information Access for Mobility Device Users
Principal Investigator:
Mel White, PhD Candidate
5338 Heather Glen
Garland, TX 75043
Melwhite99@gmail.com

Disclosure:
Funding Source: No funding source
IRB approval #

What is the study about?
The purpose of this study is to investigate information sources about mobility devices such as wheelchairs and scooters. This study will identify the strengths and limitations of current practices.

Why are you asking me?
This study is seeking input from people who have current knowledge about wheelchair procurement. There are many opinions on how information reaches clients and what wheelchair clients consider the best sources. The information I collect and model will help form a better understanding of this process, which could lead to better ways reaching people who need this information.

What will I be doing if I agree to be in the study?
If you agree to participate in this study, you will be asked a brief set of questions about yourself (gender, education level, computer access, general income level) and that will be followed by ten questions about your, devices, how you found out about them, what problems you had, and where you look for information if you want a new chair. I will also ask what advice you’d give to others who are getting a chair for the first time – who they should contact, who they should avoid.

If you are interested in being a follow-up participant, I will contact you after the first round of data has been collected (about two to three months after our first conversation) and will ask you for feedback on my summary of the information I’ve collected.
Is there any audio recording:
This research project will not include audio recording.

Is there video recording:
No..

What are the dangers to me?
There are minimal risks involved in participating in this research project. Your privacy will be respected, and you may leave the study at any time and ask that your responses be deleted.

Are there direct benefits to me for taking part in this research study?
There are no direct benefits for being involved in this research project, but I will be happy to give you a summary of my research when I present my dissertation in 2013. You may also request a copy of my dissertation in PDF format when it’s approved by committee.

Will I be paid for being in the study? Will it cost me anything?
There are no costs to you or payments made for participating in this study.

How will you keep my information private?
Your initial survey about who you are will be kept confidential – you will be assigned a number, and this number will be substituted for your name on all data that’s collected.

Any paper documents will be shredded 36 months after the end of this study. All e-mail exchanges will be deleted 36 months after the end of this study. Electronic data collected during the study will be stored offline in a locked area. CD’s containing the records will be destroyed 36 months after the dissertation has been approved.

Use of Protected Health Information (PHI):
This study does not require the disclosure of any Protected Health Information

What if I want to leave the study?
You have the right to refuse to participate or to withdraw at any time. If you chose to withdraw, you may request that your data be destroyed.

Voluntary Consent by Participant:
I have read the preceding consent form, or it has been read to me, and I fully understand the contents of this document and voluntarily consent to participate in the research study entitled “Participatory Action Research to Examine the Current State of Practice in Wheelchair Assessment and Procurement”. All of my questions concerning the research have been answered. I hereby agree to participate in this research study. If I have any questions in the future about this study, they will be answered by Mel White. A copy of this form has been given to me. This consent ends at the conclusion of this study.

Participant’s signature: __________________________________ Date: ______
Witness’ Signature: ___________________________________ Date: _____________
APPENDIX B

QUESTIONNAIRE
### Mobility Device Information Survey

Thank you for helping me with this research!

My name is Mel White, and I am a PhD student in Information Science at the University of North Texas. My contact email is: melwhite99@gmail.com

For my dissertation, I'm studying advice – the advice that experienced wheelchair or scooter users would give to a new user. I'm interested in where the best advice comes from, what kind of advice is most needed, and the best way to find help when you need advice about your chair or scooter or financial aid programs for the disabled.

There are 19 questions. At the end of the form is a box where you can leave comments. Everyone who responds will be anonymous – names will not be revealed, nor will I reveal the names of anyone or any company or organization that you've talked about. When the study is done, I will make a one-page summary of what I've learned available to you if you leave your email.

Data will be housed in a secure location and all data will be erased on January 1, 2016.

1. **What is your gender?**
   - [ ] Male
   - [ ] Female

2. **Which category below includes your age?**
   - [ ] 17 or younger
   - [ ] 18-29
   - [ ] 30-39
   - [ ] 40-49
   - [ ] 50-59
   - [ ] 60 or older

3. **Are you now married, widowed, divorced, separated, or never married?**
   - [ ] Married
   - [ ] Widowed
   - [ ] Divorced
   - [ ] Separated
   - [ ] Other (please specify)

4. **What is your approximate average household income?**
   - [ ] $0-$24,999
   - [ ] $25,000 and up

5. **What country do you live in?**
6. What is the highest level of education that you have completed?
- Did not graduate from school
- 1 or more semesters of college
- Masters or PhD
- GRE
- Graduated from college
- Graduated from high school
- Some graduate school

Professional certifications

7. Do you belong to any disability organizations (Multiple Sclerosis Association, American Association of People With Disabilities, Disabled Veterans, etc) or online disability groups (Facebook groups, KosAbility, etc?)
- Online groups
- Local groups
- Do not belong to any disability groups

If you said “yes”, what associations do you belong to?

8. What medical condition do you have that makes a mobility device (wheelchair/scooter/walker, etc) necessary?

9. Which of these devices do you use right now (check all that apply)?
- Cane
- Catches
- Medically prescribed shoes
- Walker
- Manual wheelchair
- Electric wheelchair
- Scooter

10. Which of these have you used for more than 12 months?
- Cane
- Catches
- Medically prescribed shoes
- Walker
- Manual wheelchair
- Electric wheelchair
- Scooter

11. Which of these activities do you need your wheelchair/walker/cane/scooter for?
- In the bathroom (to get to tub or toilet)?
- Getting out of bed?
- Moving around in your house?
- Walking around outside your home?
- Getting outside?
- Preparing your own meals?
- Shopping for groceries?
- Doing heavy housework?
- Doing light housework?

Other (please specify)
12. Does someone regularly help with things like getting into the bath, dressing, preparing food, doing housework, going to places?

☐ Yes (home care worker)  ☐ Yes (member of household)  ☐ No

(Comments)

13. How did you buy your current wheelchair/scooter (did the doctor suggest it? Through the VA? Insurance company? Medicare?)

14. What brand of mobility devices (scooter/wheelchair/etc) do you have?

15. What sources of information do you use when choosing a wheelchair, walker, or scooter?

16. The next time you buy a mobility device, where will you go to get information on the device and what agencies or resources will you approach for help?

17. What resources (agencies, companies, individuals) are the LEAST helpful when you want information about mobility devices?
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. What are the most important things a person needs to think about in selecting a mobility device?</td>
<td></td>
</tr>
<tr>
<td>19. What advice would you give to a person getting a wheelchair for the first time – what do they need to think about?</td>
<td></td>
</tr>
<tr>
<td>20. What agencies and resources would you recommend to someone getting a new mobility device such as a scooter or wheelchair or walker?</td>
<td></td>
</tr>
</tbody>
</table>
III. “Tina’s wheelchair”

Tina and I had often joked about whether she would get her new wheelchair before I managed to defend my dissertation. She did get her chair a week before my defense. Although it still has a number of problems (unlike her damaged chair, the new chair seat can’t be lowered enough so that her legs fit underneath her desk) and there are some issues with the seat itself that need to be resolved, she is no longer concerned that her wheelchair will suddenly have a catastrophic failure that leaves her stranded.

She faxed me a copy of the “denial of request” letter that she got from her insurance agent – the document that finally cleared the way for funds from the State of Texas to be used to pay for her chair. This particular section with the absurd statement that neither she nor her doctor could prove that she was unable to use a walker may have consequences for her the next time she tries to replace her chair:

A partial version of the document appears below:
October 8, 2013

Re: Participant: [Redacted]
Participant ID #: [Redacted]
Reference Code: [Redacted]
Cigna Health Management, Inc.*, on behalf of Cigna Health and Life Insurance Company

Dear [Redacted],

Cigna Health Management, Inc.*, a licensed utilization review agency, reviews certain health care services for medical necessity for Cigna. We received your request to cover the following service(s):

- Power Wheelchair Grp 4 std multi power option (K0884)
- Wheelchair accessory-power seat-tilt and recline-mechanical shear reduction (E1007)
- Power wheelchair accessory-power seat elevation system (E2300)
- Wheelchair component or accessory - Power Elevating Center Mount Leg Rests (K0108)
- Wheelchair component or accessory - Mini Cup Switch (K0108)

Based on the information we have, we cannot approve this request. This letter explains why. It describes your right to ask for another review. It also describes the steps you or your health care professional can take to make that request. If you have questions after reading this, please call us at the toll-free Customer Service number on the back of your health care ID card.

Summary of the Coverage Decision

Date received:
09/26/2013

Coverage decision:
The service you requested is not covered.

Please understand: If you have or had this service, your plan will not pay for it.
Why:
We reviewed information from Dr. [Redacted], MD, your benefit plan and any policies and guidelines needed to reach this decision. We found the service requested is not medically necessary in your case.

(K0884)

LETTER GUIDELINE: CIGNA Medical Coverage Position 0030 Wheelchairs/Power Operated Vehicles

After a complete review of this request and available information, the following decision and reasons for making the decision are provided by Dr. Melvin Watson:

A Group 4 Power Wheelchair (PWC) (K0877-K0880, K0884-K0866) is considered medically necessary when all of the following criteria are met:

- a mobility limitation that significantly impairs the ability to participate in one or more mobility-related activities of daily living (MRADLs) in the home.
- the mobility limitation cannot be resolved by the use of an appropriately fitted cane or walker
- the individual lacks sufficient upper extremity function to self-propel a manual wheelchair in the home to perform MRADLs.
- the individual has the mental and physical capabilities to safely operate the PWC being requested or has a caregiver who is unable to adequately propel an optimally configured manual wheelchair, but is available, willing, and able to safely operate the PWC being requested.
- the individual's weight does not exceed the weight capacity of the PWC being requested.
- the individual's home provides adequate access between rooms, maneuvering space, and surfaces for the operation of the PWC being requested.
- the use of a power wheelchair will significantly improve the individual's ability to participate in MRADLs in the individual will use it in the home.
- the individual is agreeable to the use a PWC in the home.
- the individual's mobility limitation is due to a neurological condition, myopathy, or congenital skeletal deformity and either of the following Group 2 multiple power option criteria is met:
  - the individual meets any of the following coverage criteria for a power tilt, power recline, or combination power tilt/power recline seating system and the system is to be used on the wheelchair
  - the individual is at high risk for development of a pressure ulcer and is unable to perform a functional weight shift.
  - the individual utilizes intermittent catheterization for bladder management and is unable to independently transfer from the wheelchair to bed.
  - the power seating system is needed to manage increased tone or spasticity.
  - the individual uses a ventilator which is mounted on the wheelchair.
- the enhanced features of a Group 4 PWC are needed for participation in activities of daily living in school and/or employment.
Bibliography


MovinMavsTv (Director). (2012). *Movin` Mavs` and Army team captain Juan Soto* [Motion Picture].


