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LIVING WITH PHYSICAL DISABILITY IN THE AMISH COMMUNITY

DISSERTATION

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By

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*****

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ABSTRACT

With significant changes in the nation’s demographics as well as the enactment in 1990 of the Americans with Disabilities Act, health and social service providers have had to respond to changes in client needs and service delivery. Concomitantly, in recent years, social workers have begun to pay increasing attention to multicultural issues among their clients. The pluralism of beliefs and values woven through the fabric of American life has, unfortunately, often been overshadowed by the dominant culture. As such, it has perpetuated stereotypes and myths about minority groups, including people of diverse ethnicities and abilities.

In an effort to dispel stereotypes, enhance multicultural awareness, and improve professional knowledge and competence, this study explored the lived experience of a dual minority group that has rarely been heard: Amish persons with physical disabilities. The researcher investigated the perceptions of twelve Amish persons with physical disabilities who use wheelchairs. He utilized a grounded theory approach. Data was collected through in-depth face-to-face interviews within each participant’s home in the largest Amish settlement in the United States. Data was then analyzed by the constant comparative method and negative case study in order to delineate and describe emergent themes. The six emergent themes were: 1) acceptance, 2) gathering, 3) accommodation, 4) slow-time, 5) self-reliance, 6) healthcare.
My source of strength and hope is Christ alone. May all glory be given to Him.

Dedicated to Jodi, Hannah, Seth, Daniel, Ethan, and Claire who are my constant reminders of what is important in life: being a loving husband and father.

In Loving Memory of Prue Geiser
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CHAPTER 1

INTRODUCTION

With significant changes in the nation's demographics as well as the enactment in 1990 of the Americans with Disabilities Act (ADA) during the first Bush Administration, health and social service providers have had to respond to changes in client needs and service delivery. Concomitantly, in recent years, social workers and rehabilitation professionals have begun paying increasing attention to multicultural issues among their clients. The pluralism of beliefs and values woven through the fabric of American life has, unfortunately, often been overshadowed by the dominant culture. As such, it has perpetuated stereotypes and myths about minority groups, including people of diverse ethnicities and abilities. As McGinn, et. al. (1994) noted: “counselors are bound by their own cultural assumptions and lack the appropriate knowledge and competencies necessary to deal with a cross-cultural counseling experience” (p. 263).

In an effort to dispel stereotypes, enhance multicultural awareness, and improve professional knowledge and competence, this study explored the lived experience of a dual minority group that has rarely been heard: Amish persons with physical disabilities. The researcher investigated the perceptions of twelve Amish persons living with physical
disabilities and using wheelchairs in Holmes County, Ohio, one of the largest Amish communities in the United States. Both persons with physical disabilities and the Amish are “outside” mainstream American society. However, as former New York Governor Mario Cuomo (1994) once asserted, diversity is the right to be different, and is one of America’s most powerful and unifying values.

People with Disabilities

In 1990, with widespread bipartisan support, the Americans with Disabilities Act (ADA) was enacted for the purpose of ending discrimination against people with disabilities in many aspects of life, including employment, public services, public accommodation and commercial facilities, telecommunications, and transportation. This landmark law resulted from the way able-bodied people perceive the rights, responsibilities, and abilities of individuals with disabilities over the last quarter of the 20th century. The Law held promise for equal access and equal opportunity for all people with disabilities. Senator Ted Kennedy (1990), who supported the ADA, considered it in the following manner:

For generations, society has viewed people with disabilities as citizens in need of charity. Through ignorance we tolerated discrimination and succumbed to fear and prejudice. But our paternalistic approach did no more to improve the lives of people with disabilities than labor laws restricting women in the workplace did to protect women. Today we are shedding these condescending and suffocating attitudes and widening the door to opportunity for people with disabilities…People with disabilities
are here today to remind us that equal justice under the law is not a privilege but a fundamental birthright in America.

With the ADA, a new perspective on disability emerged in both law and policy. The ADA facilitated a move away from the medical model of disability to a view of disability as a civil rights issue, one that focuses on removal of societal barriers to full participation in life’s activities. The disability community has embraced the ADA as its declaration of independence, one that can make the United State an accessible and equitable society.

Many persons would attribute the passage of the ADA, and its continued influence, to the persistence of people with disabilities in the independent living movement. The three cornerstones of the independent living movement are consumer sovereignty, self-reliance, and political and economic rights. The philosophy in which this social movement is grounded views disability as an interaction with society and the environment rather than attributable to physical or mental impairments (DeJong, 1979). The independent living movement offers the most succinct political statement about how people with disabilities want to be viewed in American society. Rather than passive victims who need constant professional intervention, they are self-directed individuals seeking to remove environmental barriers that prevent their full participation in mainstream society. Independent living is a movement of people with disabilities who work for self-determination, equal opportunity, and self-respect.

People in the disability movement continue to lead the way both in challenging age-old myths and stereotypes as well as asserting that they must view themselves, and, thus, be viewed by others, as a minority group whose difficulties are caused more by societal
prejudice and discrimination than by disability (Schriner and Batavia, 1995). A recent Presidential Task Force on Employment of Adults with Disabilities (1998) report admonished others of the message that the grassroots movement is now screaming:

"Come with us and experience this discrimination, the frustration, and the doors to employment that never open. Live with us in the poverty of the human service system whose policies too often derail rather than support our efforts for self-determination, full participation, inclusion, recognition of our competencies and our contribution" (p. 6).

People with disabilities and other minorities are forced to continue the battle against mainstream society’s stereotypes, myths, misperceptions, and misinformation. This battle is staged on many fronts in our social institutions, most unfortunately within the health and social services systems, the primary sources of help for people with disabilities.

The Amish

The second cultural group to be discussed is the Amish. Kraybill (1989) noted that non-Amish individuals easily misunderstand the Amish culture because of the lack of research related to the population. Therefore, social workers and other human services professionals have had to rely on fiction or myths to understand Amish society.

A century ago the distinctions between the Amish and the "English" living in rural Ohio would not have been significant. Both groups shared such common ground as religious fervor, utilization of horse-and-buggies, candlelight, and outhouses. Rapid change however, occurred during the industrial and technological revolutions, which altered dramatically the social and physical environments that distinguish life among the Amish and "English."
However, the Amish way of life is not stagnant or laying fallow like untended wheat fields. Amish society may be on “slow time” but it still moves forward. Donnermeyer, Kreps, & Kreps (1999) wrote that, “Amish society is dynamic and changing, and as they change they must successfully maintain the core of their religiously based lifestyle, or if not, they will lose their Amish identity. Their challenge is to move their cultural fence without wrecking it” (p.3). Stereotypes of the Amish persist. Subjected to misinformation and popular fiction, many outsiders do not truly know and understand the Amish. As Donnermeyer (1997) observed:

The outsider image of the Amish as a homogeneous group of simple, rustic people belie the complexity of their culture and the diversity that exists within the Amish themselves. Without an understanding of the Amish, their religious beliefs, and their cultural values, outsiders often misinterpret the partial knowledge they have of the Amish. (p.7)

Stoltzfus (1951), a Mennonite clergyman, who was frustrated with “cheap, tawdry literature on the Amish and Mennonites,” wrote in his Memorandum to Persons Interested in Disseminating Information about the Mennonites and the Amish and Their way of Life, “Scholarly works have their place, but the hour’s most pressing need is the production of good popular pamphlets on Mennonite and Amish life”(p.7). Even today, there continues to be a proliferation of Amish pulp fiction, tailored to the tourist, in contrast to relatively little scholarly research. Thus, a substantive and useful knowledge base is not available to those of the “English” who interact with members of Amish communities.
It is especially problematic for health, special education, and social service professionals who are increasing outreach to Amish persons living with disability.

This study will give voice to two populations that are often written about but rarely heard: people with disabilities and the Amish. Because these populations are rarely heard, problems exist for social service providers who attempt to serve Amish persons with disabilities in a culturally sensitive manner.

**Problem Statement**

The social worker must “know” the client’s culture even if the client is resistant to being “known.” However, clients who are part of subcultures or more self-contained ethnic and religious communities, such as the Amish, may face unknown obstacles in seeking aid from mainstream professionals. Kraybill (1989) noted that non-Amish individuals easily misunderstand the Amish culture. Because of the lack of research regarding the Amish, professionals have had to rely on myths and limited information to understand Amish clients. As Gaston (cited in Montagu, 1997) observed:

> Myths are not polite euphemisms for falsehoods, but are combinations of images and symbols that reflect a people's way of perceiving truth. Organically related to a fundamental reality of life, they fuse the real and the imaginary into a blend that becomes a reality itself, a force in history.

(p. 42)
Montagu (1997) further elaborated:

We may realize that myth is a faulty explanation leading to social delusion and error, but we do not necessarily realize that we ourselves share in the mythmaking faculty with all people of all times and places, or that each of us has his own store of myths derived from the traditional stock of the society in which we live, and are always in ready supply. In our own time we have lived to see the myth of race openly adopted by governments as an expedient fiction. Myths perform the double function of serving both as models of and models for cultural attitudes and behavior. (p. 41)

Perhaps the best way to dispel myths about the Amish, especially Amish persons with physical disabilities who require the use of wheelchairs, is to listen to what they have to say about their lives.

Concomitant with an inadequate knowledge base on Amish culture is a dearth of research on Amish persons with disabilities, especially qualitative research that focuses on their lived experience within their own communities. The National Council on Disability (1993) reported that the lack of research on disabled minority populations might be the result of two reasons. First, minority populations have been preoccupied with survival needs and with the struggle to eliminate discrimination and racism. Thus, disability issues have not been a priority. Secondly, the community has been preoccupied with disability issues like access to health insurance, personal assistance services, and assistive technology. They, too, have not emphasized a broad range of issues affecting minorities with disabilities.
Purpose

Dramatic changes in our nation's demographics, reflecting a growing population of individuals from diverse backgrounds, warrant the development of knowledge and understanding necessary to serve effectively people from other cultures. To these ends, this study gave voice to a dual minority group that is rarely heard: Amish persons with physical disabilities. The research explored the perceptions of twelve Amish persons with physical disabilities regarding their lived experiences within the Holmes County, Ohio Amish settlement.

The researcher chose to focus on one particular group, persons with mobility impairments. The study gave voice to those distant from the mainstream and not a part of the dominant culture. It facilitated learning about the experiences of living with a mobility-related disability within a culturally unique social environment. This study may contribute to a model of cultural diversity and outreach for serving self-contained communities who have been traditionally underserved in social services.

Carson (1998) wrote that the Amish sub-culture are, "people with distinctive values, and behaviors who have a long history of dealing with economic and cultural pressures from the broader, outside world with which their values are not compatible" (p.8). According to Kraybill (1994), the Amish are "a special example of how a subculture in modern society maintains its separateness and offers interesting examples of social control and personality socialization" (p. 8). Especially relevant are the perceptions of Amish people with disabilities regarding their full participation in important life activities such as employment, socialization, economic support, lifestyle, and religious rituals.
Importance of the Study

There are several important aspects of this study. The study will facilitate and contribute to the development of a knowledge base that is lacking in the social service literature. Current knowledge about the Amish community and the level of functioning of Amish persons with disabilities is necessary before various forms of disability services can be offered, accessed, and utilized by the Amish. In addition, this knowledge base may aid social workers and rehabilitation professionals in serving other separatist or self-contained communities.

It is also vitally important to sort out myth from fact about the Amish in order for service providers to offer culturally appropriate programs. Ayers (1977) wrote that, “Societal attitudes not only dictate the type of treatment provided the handicapped, but also influence the development of programs and services to meet their diverse needs” (p. 53). Atkins (1980) echoed similar thoughts: “Perhaps the most powerful barrier to human rights is majority attitudes. Majority persons tend to view minority individuals as a negative deviation from the norm resulting in labeling, stigmatizing, and negative attitudes” (p. 47). Ross and Biggi (1986) added that programs and systems developed for the normative and/or dominant culture do not necessarily meet the needs of minority-disabled persons.

This research is also significant in that it responded to the charge that the profession of social work has ignored people with disabilities as an oppressed population. As Mackleprang (1996) asserted: “The social work profession has not shown a consistent commitment to people with disabilities. The numbers of social work students and
educators who have disabilities are low, there are few disability related articles in the social work literature, and social work conferences are nearly bereft of presentations on disabilities” (p. 7). Gilson, Bricout, and Baskind (1998) agreed: “Social work literature, research, and practice on disabilities have lagged behind other topical areas dealing with oppressed groups. The social work literature remains expert focused and generally fragmented into discussions of specific disabilities or subpopulations” (p. 188). Gilson, et. al, (1998) claim that social workers have historically engendered dependence and diminished self-advocacy, growth, and empowerment while working with people with disabilities. Thus, this project addressed both the general need for research on persons with disabilities, and, more specifically, contributed to filling a critical gap in the social work literature on persons with disabilities who live within a separatist community, i.e., apart from mainstream society in a different physical and social environment.
Background on the Amish

Following over 300 years of resistance to acculturation and change from mainstream society, the Amish today are stereotyped as a backward, separatist, farming subculture maintaining their antiquated horse and buggy lifestyle. Hostetler (1980) articulated the history of the Amish, which began in the 1690's when a young Anabaptist minister, Jacob Amman, disagreed about shunning. This controversy was the cause of the main rift that exists today between the Amish and the Mennonites. Amman, the Amish namesake, believed that the Mennonites were becoming too permissive about shunning and began his own following. The Amish and Mennonites also differed on areas as specific as dress codes. According to Hostetler (1980), the Amish were known as *Haftler* (Hook-and-Eyers), and the Mennonites were the *Knopfler* (button people).

Yutzy (1961) defines the Amish as: “Anyone associated with the groups population who practices a ritual separation from the world by way of social, cultural, and religious distinctions” (p. 17). Hostetler (1951) noted that the term Amish historically is properly used to designate all Amish in the United States before 1862. But it also is the generic name used by persons who do not differentiate between the various branches.
The Amish, a socio-religious community, are trilingual. The language spoken in the home is Pennsylvania Dutch. It is a language that may be traced back to the Rhineland in Germany. Children learn Pennsylvania Dutch as their first language and learn English, a second language only when they begin school. The third language is High German, which is used in church services, and ceremonies. The use of Pennsylvania Dutch may be a further exercise of isolation from non-Amish outsiders referred to as the English (Hostetler, 1980).

Reiling & Nusbaumer (1997) described the Amish as an ethno-religious, fundamentalist Christian subculture. Within this subculture, “Amishness” has developed as the primary social identity. Historically, this social identity has contributed to both their persecution and their survival. The same authors further noted that the two primary components of the Amish resistance models are their high level of boundary maintenance and their high level of intra-group identification and participation in all group processes.

Wasao (1995) believed that the Amish accomplish boundary maintenance by basing their whole lifestyle on a particular interpretation of Christian beliefs and norms from the Bible. Additionally, they maintain a physical, geographical distance from non-Amish people whom they call the "English" after the language spoken by the citizens of the U.S. and Canada. They also do this by creating social and economic distance from the rest of society; they ensure that their economic structure is minimally dependent on the non-Amish world (Kreps et.al, 1994).
Social Organization and Demographics

Garrett (1996) provided an overview of Amish communities in the United States. There are over 150,000 Amish in America, located within 21 states and 431 different zip codes, with 228 permanent communities and over 1,010 church districts. Ohio has the most church districts with 276; followed by Pennsylvania with 248; and Indiana with 183. Furthermore, the largest Amish community is the Holmes County area in Ohio, with approximately 35,000 Amish (pp. 27-29).

Amish community organization might have at least four social and spatial components: the family household, church district, settlement, and affiliation (Hostetler & Huntington, 1992).

The family household is typically comprised of married couple and their dependents. A farm may have two or even three houses to accommodate the parents or other extended family members. Family farms are owned by the family and are not property of the community church.

A church district is an Amish congregation. It has specific geographic boundaries, which enable members' access by horse and buggy. A church district is a congregation that serves as a governing unit. The church district also has an ordained leadership. The church district provides a venue for activities such as worship, baptism, communion, and marriage and funerals. The size of the district may vary from a few families to as many as approximately forty members.
Each congregation ordains its leaders: usually one bishop, two preachers, and a deacon. They are chosen by lot for life and serve without financial incentives from the congregation.

A church affiliation is a group of church districts that have a common discipline such as the Swartzentruber, Old Order, and New Order Amish. These church affiliations have developed over time due to schisms or differences of opinion. These differences in church affiliations range from fundamental minutia to extreme theological rifts.

The settlements are concentrated in limited geographical areas that are predominantly agricultural. The “English” may define this term as “neighborhood.” A settlement may be small, consisting of a few households, or it may expand to several counties. The Amish live in settlements that serve as the geographic basis for regulating contact with the rest of the world. These settlements are usually located away from a city and consist of church districts, each of which has about 20-35 nuclear families (Kreps et al, 1994).

Kreps, et. al. (1997) wrote that the district organizes the internal power structure of Amish community. A district is made up of between 20 and 40 families, and is led by a bishop, who usually leads another district as well. Each district also has one or two ministers and a deacon. Amish males hold all these positions and as Cong (1992) notes, these appointments are made by nominating and casting lots, and involve no monetary compensation. Kraybill (1989, pp. 83-84) also notes this, "flat, two tiered structure links grass-roots members directly to the citadel of power. The power structure of the bishops
themselves, however, is based on age and tenure. Wasao (1995) observed that the Amish elders (i.e., ministers, deacons, and bishops) wield an inordinate amount of power and influence over the community. In fact, the senior bishops regulate the acceptance of major changes among Amish. If the bishops do not like a practice, it may not be accepted until after their deaths when others deem it appropriate.

Amish History

Forell (1968) asserted that a study of the history of a religious community provides insight as to the identity of the community as well as the individual. Within the Amish religious community the imperative to remain separate is the common theme in a history spanning 500 years (Donnermyer, 1997).

Yutzy (1961) identified the American Amish family tree stems with roots grounded primarily in northern Switzerland, Alsace, and southern Germany. Religious practices were developed from the Swiss reformation initiated by Zwingli. A group of dissidents believed that the Zwingli reformation was moving too slowly and did not address main concerns and practices. The main premise of the controversy became the rejection of infant baptism, which some people felt should be addressed in the adult confession of faith. Consequently, these dissidents were labeled Anabaptists and branded as heretics. Persecution ensued throughout the 16th and 17th centuries. According to Smith (1958), the Anabaptists united around the following premises: 1) excommunication, or shunning of members who broke moral laws, 2) refusal to bear arms, take an oath, or hold political office, and 3) attempt to live their lives in accordance with Christian ideals as described in the Bible.
Hostetler & Huntington (1971) asserted that the American Amish are direct descendants of the Swiss Anabaptists of the sixteenth century. The Anabaptists originated in a number of areas simultaneously: there were the Mennonites in Holland and North Germany, the Hutterian Brethren in Moravia, and the Swiss Brethren in Switzerland, all of whom emerged between 1525 and 1536 as forerunners of the "free church" movement. Those Anabaptist groups who survive share a common heritage and ideology that includes the maintenance of a disciplined community, pacifism, separation from the world, adult rather than infant baptism, emphasis on simple living, and regeneration of character (Hostetler & Huntington, 1971).

The name "Amish" comes from their leader Jacob Amman, an elder who emphasized conservatism. The differences which separated the Amman group from the Swiss Anabaptists (Mennonites) centered on the practice of shunning and the strictness of conformity to specific social and ritualistic practices. The Amman group, for example, began holding communion services twice instead of once each year. Their leader introduced the practice of foot-washing in connection with the communion service and advocated greater uniformity in dress. He taught that it was wrong to trim the beard and that persons who attended the state church should be excommunicated.

The Amish Anabaptists were severely persecuted for their beliefs. Basically farmers, they retreated into the Swiss mountains and eventually to the Alsace section in France where they remained until they immigrated to the United States hoping to find religious freedom. According to MacMaster (1985), the Amish seemed to have arrived in the New World with reliable financial resources especially in comparison to the other religious
minorities. It is estimated that approximately 500 Amish arrived in the United States during the 18th century and, by the beginning of the 19th century, there were about 1,000 Amish living in America (Hostetler, 1993).

**The Ohio Amish**

Subsequent to the Ordinance of 1787 land became readily available west of the Allegheny Mountains. This led many land hungry people, such as the Amish, through Ohio in search of fertile land. Fletcher (1932) reported that in 1807, Jacob Miller was sent by Amish settlers from Pennsylvania to find a new location for an Amish settlement. They traveled through present day Holmes County, Ohio and were impressed with its wildlife, fertile ground, and productive appearance. Jacob Miller and his two sons, Henry and Jacob, were the first Amish pioneers to locate in Ohio, staking a claim in Tuscarawas County in the fall of 1808. Twenty-one year old Jonas Stutzman traveled five miles further than the Millers, settling in neighboring Holmes County. Not only was he the first Amish person to settle there, but also some historians say he was the first non-American Indian to live in Holmes County (Fletcher, 1932).

It is important to note that the Old Order Amish encompass the entire community. The name Alt Amisch, "Old Order," emerged in 1878 when an attempt was made to establish a national organization. The congregations that preferred to maintain the old traditions as much as possible became known as the Old Order. Before this the word "Amish" or "Amish Mennonite" was sufficient to describe any group (Hostetler, 1980). A major schism occurred in Ohio around 1912 (Scott, 1981). No one seems to know much about it, but it resulted in the formation of the Conservative Mennonites and the Yoder
Amish Order. Another break occurred around 1930 when the Swartzentruber and Troyer Orders were established in Ohio. Both Orders are extremely conservative and even today shun the outside world as much as possible.

**Amish Demographics in Ohio**

There are over 35,000 Amish in Holmes County, Ohio and parts of Wayne, Tuscarawas, and Coshocton Counties. These locales account for the largest concentration of Amish anywhere in the world (Garrett, 1996). This geographical area is located approximately 75 miles south of Cleveland, Ohio.

The Amish settlement in the vicinity of Holmes County, Ohio not only hosts the largest concentration of Amish in the world but it is also one of the more interesting because of its complexity. Some twenty different Amish and Mennonite groups have emanated from the original Amish settlement that took root in Holmes County in 1809 (Kraybill, 1994).

The population of Amish in the U.S. is approximately 160,000. If estimates hold true, these numbers will double in the next 25-30 years (Donnermeyer, et. al., 1999). Kraybill & Nolt (1995) noted that today across America, the Amish population of adults and children exceeds 150,000. Although about 65% live in Ohio, Pennsylvania, and Indiana, church members also reside in twenty-two states and the province of Ontario.

During the twentieth century, the Amish population has doubled about every twenty years. The social organization of Amish society has several distinctive features. It is small, informal, local, compact, and homogeneous.
Donnermeyer, et. al. (1999, p. 49) wrote that the old German word “gemeinde”, meaning small community, is often used to depict Amish society.

The Amish community, however, is much more than a physical setting. Kreps et. al. (1997) suggested five important roles of the community that serve the Amish: the maintenance of a self-sufficient economy; socialization; social control; social participation; and, mutual support (p. 62). Hostettler (1993) described the six age related stages through which the Amish individual will pass from birth through death. Social functions in each stage are prescribed by Amish culture. The first stage of Amish life is characterized as babies and runs from birth until the child is walking. The little children stage encompasses the time period between walking and entering school. The important learning issues are respecting and obeying those in authority, sharing and helping others, and enjoying work. Children are not conditioned to ask “why” but rather to emulate behaviors of Amish adults.

Scholars are children between the ages of 6-15. This is the time period of school and vocational training. Unlike mainstream America, formal education terminates at 15 rather than 18. The stage of young people extends from adolescence to marriage. Hostetler (1993) indicated that adolescent rebellion is expected. Bial (1993) wrote that this sowing of wild oats is tolerated so that children may get a taste of the outside world and decide for themselves whether they wish to experience adult baptism into the Amish faith. This wild period is referred to as “rumpaspringa” (Hostetler, 1993). Adulthood is defined as marriage, work, and family. Lastly the period between ages 50-70 includes retirement. However, the decision to retire is affected by health and family needs.
Core Features of the Amish

According to Donnermeyer, et. al. (1999) there are five core features that facilitate a better understanding of the Amish. The first and most important core characteristic of the Amish is that they are a subculture. A subculture refers to a group that has distinctive beliefs, values and behaviors from those of the larger culture. A subculture is a variation of the main or majority culture. Today, there are several distinctive orders of Amish in Holmes County. The Swartzentruber and Andy Weaver Amish are both more conservative than the Old Order Amish. In the mid 1960’s, a group called the New Order Amish began when one hundred families dissenting from the Old Order Amish of Lancaster County, Pennsylvania created two new church districts. These districts agreed, among other things, on the need to maintain high moral standards on courtship practices and to restrict the use of tobacco.

The second core feature is the Ordnung, which is an individualized church district’s list of rules that members must follow. There are about 1100 Amish church districts in the US and Canada. Each church district comprises of approximately 20-35 families with a hierarchy of leaders made up as a bishop, a deacon, and two ministers. The bishop is the spiritual head; the deacon assists the bishop and is responsible for donations to help members with medical bills and other problems; and the ministers help with the preaching.

A third core feature of Amish society is the selective utilization of technology. The fourth core characteristic of the Amish is called “meidung”. This is the practice of shunning excommunicated members, that is, persons who have violated the Ordnung’s rules.
The fifth and final core feature of Amish society, according to Donnermyer (1999), is “gelassenheit” which means yielding to a higher authority. It represents the high value that the Amish place on maintaining a sense of community, which would be destroyed by too much individualism.

Earlier, Kreps, et. al. (1997) wrote that the Amish, much like every subculture, have distinctive elements, which define their core values. The authors suggested that there are ten characteristic of contemporary Amish life: 1) Farming is the cornerstone of the Amish community and represents the preferred occupation of choice; 2) In most cases, the Amish do restrict the use of electricity and telephones in the home; 3) The “Ordnung” is a set of rules, determined by the bishop, and can be described as a “cultural fence”; 4) “Meidung” or shunning, means the excommunication and avoidance of members who have been in violation of the Ordnung; 5) “Gelassenheit” means yielding or bowing to a higher authority. It is a term that denotes humility and reverence to God; 6) Amish church services are conducted in the church members' homes rather than separately constructed church buildings; 7) The Amish speak Pennsylvania Dutch and American for their every daily language and High German for church services; 8) The Amish dress in clothes that depict a plain and modest appearance; 9) Horse and buggies are utilized as the Amish mode of transportation; 10) The Amish and Mennonites have the same historical roots but they differ in belief systems.

Hostetler & Huntington (1971) also suggested core features by writing that the five cultural themes are symbolized by the following: separation from the world; voluntary
acceptance of high social obligations symbolized by adult baptism; the maintenance of a disciplined church-community; the practice of exclusion and shunning; and, a life in harmony with the soil and nature. Perhaps the most salient of the Amish characteristics is that of the Ordnung. Although slowly changing over the years, the Ordnung is the tie that binds and guides the direction of the Amish community. Bishop David Troyer (cited in Yoder, 1991, p. 100) said, “While rooted in tradition, the Ordnung is a spiritual fence without which a church could not survive long.”

The Ordnung

The "Ordnung" is a set of rules and regulations, a code of conduct that governs the lives of the Amish people. These rules and regulations have evolved over a number of years and they are normally not written down, but are orally transmitted. They are clarified and modified each year at special meetings before communion (Good, 1985). Those who violate them are subjected to the "Meidung" or social shunning (Schreiber, 1962). Such individuals are deprived full fellowship by being excommunicated partially or fully, depending on the seriousness of the violation, for breaching Amish norms (Kraybill, 1989).

Kraybill & Nolt (1995) provided the following examples of items prescribed and prohibited by the Ordnung. Some items prescribed by the Ordnung include the color and style of clothing, the use of horses for fieldwork, and steel wheels on machinery. Examples of things prohibited in the Ordnung include not filing a lawsuit, not attending high school, no ownership of automobiles, and no use of tractors for fieldwork.
Many think that the Amish are slaves to tradition. However, Olshan (1981) wrote that they accept or reject innovations or practices based on whether or not the innovations or practices are compatible with their core values and beliefs. They are flexible in adopting changes that are appropriate to their scale of operations on the farm and that are not disruptive of their way of life. For instance, although they generally reject the use of tractors, they have adopted the use of other new agricultural implements such as mechanical hay loaders and manure spreaders (Olshan, 1981).

Cong (1992) asserted that the Amish distinguish between "high" and "low features" in decisions concerning technological change and that a seemingly small change involves multiple considerations in the decision making process. He further stated that an Amish community's values and goals are governed by "ordnung," which "represents the traditional interpretation -- the rules, regulations and standards -- of what it means to be Amish (Cong, 1992, p. 216).

Olshan (1981) wrote that the Amish exhibit a remarkable sensitivity to, and control over the process of change and are guided by a self-conscious awareness of who they are and where they want to go rather than by blind traditionalism. This may be most evident in the fact that in the majority of cases, the Amish disagree and create new groups that are accepting and accommodating of change rather than entirely abandoning their way of life.

Amish Affiliations or Orders

The Amish community has an especially complex organization in those settlements where there are a number of different types or affiliations of Amish. Such differences arise from liberal-progressive interpretations of the discipline. Despite these variations, the Old
Order Amish generally have the following in common: worship services in the homes of the members, use of horse-drawn carriages, use of the Pennsylvania German dialect, a distinctive plain and simple dress for both men and women, beards but not mustaches for all married men, long hair (which must be parted in the center if parted at all), hooks-and-eyes on dress-coats, and taboos against electricity, telephones, automobiles, and tractors with pneumatic tires. No formal education beyond the elementary grades is allowed and, consequently, high school and college education are forbidden (Hostetler & Huntington, 1971).

Wasao (1995) delineated four major fellowship groups or church affiliations that can be categorized along a conservative-liberal continuum. These are the ultra-conservative Swartzentruber Amish, the conservative Andy Weaver Amish, the moderate Old Order Amish, and the liberal New Order Amish. Although each group shares with the others the basic Amish characteristics such as conservative dress and the use of buggies for transportation, they differ in doctrinal values and practices that set them apart and preclude fellowship between them.

Hostetler (1980) suggested that "orders" are classified according to their degree of worldliness. Kraybill & Olshan (1994, p. 57) provide a table, which profiles the Holmes/Wayne counties settlement according to the differing degree of conservativeness relative to the enforcement of shunning and living according to the "Ordnung."

The most conservative of the four affiliations is the Swartzentruber Amish. They were separately identified in 1913 and are estimated to consist of about 20 church districts (Kreps et.al, 1994). They are approximately 3,000, and they live primarily in Wayne
County, Ohio. Several other Swartzentruber groups are scattered in parts of northern and western Ohio. They do not use indoor plumbing, refuse to use slow vehicle emblems on their buggies, and they do not participate in the Ohio Amish Directory Project. The Ohio Amish Directory Project lists all the names and addresses of each Amish family in the Holmes County, Ohio settlement.

The next group, rated in descending order of conservativism is the Andy Weaver group. This group is so named after its leader, Bishop Andrew J. Weaver. They were formed about 1955 because of a schism with the Old Order fellowship. They disagreed with the Old Order on the practice of shunning, favoring strict shunning of deviant members rather than a softer and more accommodating attitude preferred by the Old Order. They also rejected changes in farm and household technology that were slowly incorporated into Old Order homes (Nolt, 1992).

The mainstream of the Amish culture is the Old Order group. This is the largest affiliation in the Wayne/Holmes county area and is estimated to be a population slightly over 14,000. In comparison to the Andy Weaver group, they allow the use of gas and kerosene refrigerators and central heating in the home. They also allow the use of power units in the back of their wagons in the field. They do not allow the use of tractors, automobiles, electricity or telephones in the homes. They use horses for plowing and horse-drawn buggies for transportation. Because they are the largest group among the Amish, they have been the focus of most studies available on the Amish.

The old order Amish ideas on self-sufficiency, separation from the world, and mutual aid have led them to have a history of generally rejecting any kind of formal assistance.
which comes from outside the Amish community (Hostetler, 1993). However, as stated previously, the Amish “cultural fence” continues to widen and expand, slowly but surely. Rejection of the outside world is preferred but not absolute.

The New Order Amish split from the Old Order in 1966 when the former adopted the use of farm equipment. Although collectively known as the “New Order,” the group consists of several variants or sub-orders. The group began when one hundred families dissenting from the Old Order Amish of Lancaster County, Pennsylvania created two new church districts. These districts agreed, among other things, on the need to maintain high moral standards on courtship practices and to restrict the use of tobacco. They established Sunday schools and other church activities for their youth (Nolt, 1992). Subsequently groups in the Holmes-Wayne Counties area, sympathetic to the New Order group in Pennsylvania, also split with the Old Order. They remain a loose yet well defined fellowship group balancing what they see as the strengths of the Old Order with new spiritual insight into the way to live the Amish life amidst their rapidly changing social and economic circumstances.

Donnermeyer (1997) claimed that there are three important trends in Amish society, which will greatly influence change in the next century: One trend is population growth. In 1900, the estimated population of Amish was about 5,000, which represented the approximate number of Amish who immigrated to the United States in the 18th and 19th centuries. The lack of population growth during this period was due to attrition in church membership and schisms. However, since 1960 the situation has improved, and the population of 85,000 in 1979 has increased to 160,000 today.
The second trend is growing diversity. There is a growing diversification of Amish denominations all of who remain committed to the Amish fundamental beliefs. Each area's geography, economy, and people will influence a settlement in different ways. Lastly, occupational shifts comprise the third important Amish trend. The shift out of farming has occurred for two reasons: population growth and the cost of farmland. In 1961, 71% of head of households were farmers in Holmes County. In 1995 the percentage of farmers was only 32.9%.

The overall test for the survival of the Amish way of life may not come from continued schisms but rather, the movement away from an agrarian lifestyle to one of non-farming employment. In addressing economic survival, the Amish have redefined their boundaries to accommodate alternative occupational opportunities that fit within the ordnung.

**Amish Occupations**

Kraybill and Nolt (1995) note that the adaptation of micro-enterprise activity is perhaps the most recent Amish manifestation of compromise with the outside. In interacting with the “English” free market economy, the cultural fence has moved to facilitate more frequent and more profitable business transactions between the two.

The Amish have been a people of the plow for more than three centuries. An agrarian tradition and a love of the land have shaped their distinctive faith and culture in many ways. Deep cultural changes also lurk beneath the surface of this transition from plows to profits. The plow is more than a mere occupational tool; in many ways it also symbolizes a worldview (Kraybill & Nolt, 1995, p. IX).
This Amish worldview may be becoming less tenable. Circumstances such as scarcity of farmland, machinery prices, and development have forced the Amish to construct new occupational and income opportunities. Olshan (1994) reported that “changes at the macro-economic level may translate into altered definitions of what is appropriate behavior, and finally into a corresponding shift in values” (p. 379). Schwieder & Schwieder (1975) observed:

As long as land remains available and they continue to move and establish new communities, the Amish will have a safety valve for their disoriented. Dissidents will be able to continue moving out of communities where they are dissatisfied, resettling in an area where they feel more in harmony with the membership. If, however, conditions arise that restrict this opportunity, Amish society will undergo significant change (p. 93).

Wasao (1995) agreed that that the Amish readily accept changes that result in economic benefits to them, including work off the farm among non-Amish persons. However, as noted earlier, shifts in the Amish way of life are gradual. Kraybill (1990, p. 84) wrote that non-farm work has developed in three stages. First, as cars became popular in America, the Amish developed their own shops to manufacture and repair buggies and harnesses. The second stage began as tractors gained a monopoly in farming. The Amish developed machine shops to adapt tractor equipment for horses. Finally, the third, and largest jump to non-farm jobs came in the ‘70s and ‘80s as the Amish developed small manufacturing shops and cottage industries.
Donnermeyer, et. al. (1999) reported that the dramatic shift away from farming can be illustrated with the Holmes county community. In 1965, 71% of male household heads were farmers. The proportion of farmers declined to 55.4% in 1973, then to 46.8% in 1981, to 43.1% in 1988, and finally, to 32.9% in 1995. (p. 78).

Although few Amish-owned firms existed before 1970, within twenty years nearly a thousand shops had sprung to life. In fact, 60 percent of all Amish businesses have been started since 1980, and 31 percent have opened their doors in the last five years alone (Kraybill & Nolt, 1995, p. 43). The financial scope of Amish commerce varies as well. Although many firms are small, 7% report amazing annual sales in excess of one million dollars and over 57% of Amish have reported sales in excess of $100,000 per year. (Kraybill & Nolt, 1995, p. 45).

These numbers reflect a contradiction in the way the “English” view the Amish. The fact that 14% of Amish owned businesses in Holmes County produce annual sales of over a half a million dollars is contrary to the image of the Amish as poor, ignorant, backward farmers. The largest Amish enterprises, which comprise 21.5% of all occupations, are cabinet and woodworking shops.

With the move away from farming, there is also a fundamental shift in occupations and therefore, worldview. The question of where the Amish with disabilities “fit into” this new paradigm becomes more important. Taylor, Kagay, & Leichenko (1987) asserted that employment, even more than social life and activities, excludes persons with disabilities from the mainstream of American life.
Our society expects individuals to work. Americans below retirement age, who do not work, live somewhat apart from the mainstream of life in this country.

**Health Care Among the Amish**

Literature regarding the Amish and disability is limited; however, there is a relatively larger body of research regarding Amish health care and epidemiology. Florersch, Longhofer, and Latta (1997) wrote, “For many social and natural scientists, the Old Order Amish are more than the ideal human laboratory; they are in, but not of the world. They are a perfectly closed system where humility, work, obedience, and thrift not only mark an imagined autarkic social system, but more important, are mapped onto the human genome” (p. 137). Andreasen (1993) concurred with the previous authors by describing the Old Order Amish as an “ideal naturalistic laboratory” (p. 75) for the study of behavioral genetics because of their simplicity of lifestyle, their maintenance of detailed family records, and because of low levels of out-migration from their voluntarily secluded society.

Although the Old Order Amish discourage first cousin marriage, there is a degree of inbreeding among the Amish. Therefore, certain genetically transmitted defects are associated with infant mortality within the Amish settlements. Ellis-van Creveld Syndrome, which is associated with dwarfism of extremities and, in about half the cases, single atrium heart malformation, has been identified within the Amish community (McKusick, Hostetler, Egeland, and Eldridge, 1978). Prenatal problems and congenital malformations reportedly account for nearly all deaths before one year of age in the Lancaster, Pennsylvania Amish settlement (Khoury, Cohen, Diamond, Chase, and
McKusick, 1978). Agarwala, Biesecker, Tomlin and Schaffer (1999) asserted that, genetic research on separatist, inbred populations is meaningful because these populations store rare recessive alleles and because genetic analyses of multigenic traits may be simpler in these populations. As a result, Agarwala, et. al (1999) attempt to merge Amish genealogies that span 300 years of existence.

Cross & McKusick (1967) also identified genetic problems associated with the Amish. They found Troyer Syndrome, after the name of the Amish families suffering from the symptoms. Troyer Syndrome is a form of heredity spastic paraplegia and is characterized by severe atrophy of the small hand muscles, dysarthria, mental retardation, and short stature.

Although there remains a paucity of research related to the lived experiences of Amish persons with disabilities, there has been some research related to disability among the population. Lehman (1994), a physician among the Amish in Ohio, has identified higher rates of whooping cough and cystic fibrosis among his patients. Rubella outbreaks linked to lower immunization rates have also been researched (Jackson, 1993).

Health care utilization among the Amish community varies and includes both folk remedies and scientific-based medicine. Although the Ordnung does not prohibit scientific medicine, preventive medicine may be seen as going against God's will (Yoder, 1997). Scientific-based medicine is utilized mostly in cases involving crisis. Non-crisis problems are treated by visiting an herb doctor, a pow wow doctor who heals by touch, or a chiropractor (Schweider & Schweider, 1987).
One of the most significant factors that influences Amish healthcare utilization may be that the Amish do not carry health insurance. The Amish beliefs in self-sufficiency, separation from the world, and mutual aid have facilitated a general rejection of any kind of formal assistance outside of the Amish community. Kraybill (1989) suggested that obtaining commercial health insurance goes against the principle of separation, that it implies an unwillingness to accept God's will, and that it would operate against the principle of proving mutual aid in times of crisis.

In the event that hospitalization is required, the family covers the costs through personal savings or mutual aid from the church membership. In cases where the costs are exorbitant, the church will provide mutual aid financial assistance through an assessment from its members. There are also examples of benefit auctions to help offset extreme medical costs. An Amish Hospital plan was developed in Ohio in 1965. The plan was established for health care costs associated with hospitalization and does not cover costs related to preventative medicine.

According to Hostetler (1993) the Amish define health as a good appetite, looking physically well, and being able to do rigorous physical labor. A person with an obvious physical disability does not meet the latter two criteria. Good (1995) wrote that the Amish believe that good physical health is a gift from God and requires special, individual stewardship.

Additionally the Amish believe that illness is an unnatural state and health is natural. Yoder (1987) wrote that the Amish believe that one is well if one lives ruggedly, eats good food, bathes freely with cold water, keeps the golden rule, and looks to the future
with hope and confidence. Kreider (1995), a physician practicing among the Amish, found that, “infirmity scares older Amish persons more than dying does” (p. 134).

This may be because the Amish worldview is one that stems from hard work and independence. This worldview of independent living may be compatible with the goal of English persons with disabilities to strive for inclusion into society and independent living rather than institutionalization.

Disabilities

The “English” with disabilities hinge their hope and confidence in the future on the Americans With Disabilities Act. The Law holds promise for equal access and equal opportunity for all people with disabilities. During the signing ceremony of the American’s With Disabilities Act (ADA), President Bush made the following statement: “Every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom” (Burkhauser, 1992, p. 60).

Definitions

It is difficult, at best, to find a consensus regarding the definitions of disability. Reamer (1994) suggested that, “by defining disability socially and functionally, we turn our attention away from questions of what is physically wrong with people and toward questions of what limits people’s abilities to carry out important life activities” (p. 396). Brzuzy (1997) wrote that, “How society defines populations or social concerns determines who fits the category, how many fit the category, how significant the issue, and who is eligible to receive services” (p. 83).
Scotch (1988) noted that, “Definitions and perceptions are not independent of social structure and political power. The efficacy of definitions typically depends on structural factors, not the least of which is the power held by their proponents” (p. 169).

People with disabilities, advocates, parents, and researchers generally disagree about the meaning of disability (LaPlante, 1998). Charlton (1998) asserted that the definition of disability is based on social and functional criteria and not on a medical category. This writer would suggest that the view of disability as socially constructed might be derived from the independent living movement, which postulates that the medical/disease model of disability is archaic and paternalistic at best. This is a person-first methodology with an emphasis that anything else related to the person is both ancillary and socially constructed. Montagu (1997) wrote that, “When human beings are defined on the basis of the differences in physical traits we narrow the definition of their humanity” (p. 48). Furthermore, “Impairments become disabilities when societies create structures which limit people’s opportunities and access to resources” (Brzuzy, 1997, p. 81).

According to Brzuzy (1997) disability might be conceptualized in any of fours ways. First, a traditional model that has viewed people with disabilities as supernatural or evil may define disability. Another way of defining disability is through a medical model that views people with disabilities according to functional limitations. An economic/work model focuses on one’s ability to function in employment. Finally, a socio-political model defines disability as multiple social, economic, and political forces in concert.

The WHO model provides a fundamental paradigm for a medical definition of disability. This model may be summarized as follows: "Impairment" is considered an abnormality; whereas "disability" is defined as an interference with the performance of an activity. Additionally, "handicap" is a societal disadvantage for a given individual, which limits or prevents the performance of a social role (WHO, 1980).

This writer concurs that disability refers to the state of being limited, because of a chronic mental or physical health condition, in the type or number of activities that a person is expected to perform. The conceptual definition of disability currently accepted by most is provided in the Americans with Disabilities Act (ADA). According to the ADA (1990, p.4) “The term disability means, with respect to an individual: 1) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; 2) a record of such an impairment; or 3) being regarded as having such an impairment.

According to the Rehabilitation Act (1993) disability is operationally delineated by the following categories and is self-reported by the client to the rehabilitation counselor: blindness, deafness, cerebral palsy, mental illness, mental retardation, epilepsy, brain injury.

National Demographics

McNeil (1997) presented national demographics data through the Survey of Income and Program Participation (SIPP), which is an ongoing, nationally representative panel survey of the economic status of the non-institutionalized population. Each panel of the
SIPP includes 21,000 households, and interviews were conducted every four months during a period of two and a half years. The SIPP criteria for disability are as follows:

1. Used a wheelchair or were a long-term user of a cane, crutches, or walker.

2. Had difficulty performing one or more functional activities (seeing, hearing, speaking, lifting, or walking).

3. Had difficulty with one or more activities of daily living (bathing, dressing, eating, or toileting).

4. Had difficulty with one or more instrumental activities of daily living (keeping track of money or bills, preparing meals, or taking medication).

5. Had one or more specified conditions (learning disability, or mental retardation).

6. Were limited in their ability to do housework.

7. Were 16-67 years old and limited in their ability to work at a job or business.

8. Were receiving federal benefits based on an inability to work (p. 34).

Kruse (1997) estimated that employment of one million people with disabilities would result in an annual increase of $21.2 billion in earned income, along with decreases of $286 million in food stamp use and $1.8 billion in Social Security income benefits. These data suggest the high cost that America pays for its failure to address problems that contribute to unemployment and non-employment of people with disabilities.

Data reported by the Census Bureau using information from the 1994-95 Survey of Income and Program Participation (SIPP) indicate that approximately one in five, or about 54 million Americans, have some level of disability (McNeil, 1997). The findings further
indicated that about approximately one in ten Americans, about 26 million people have a severe disability. This represented increases from the figures of 49 million people with a disability and 24 million people reporting severe disabilities when the data were examined three years earlier.

Ohio Demographics

A recent survey of persons with disabilities in Ohio (Glazier, 1994) found that there were an estimated 1,114,411 people with disabilities statewide, of whom an estimated 590,998 were of working age (16-64). Data from this report came from a statewide needs assessment, which employed a random-digit dialing telephone survey methodology and computer-assisted telephone interviewing. The interviewers called 38,545 randomly generated phone numbers. These numbers reflect an estimated 8.5% of all the working-age residents of Ohio and 53.1% of the total population of people reported to have disabilities. Based on information about functional status and receipt of Federal SSI and SSDI payments, Glazier (1994) categorized the Ohio population with disabilities in three ways: 1) The Non-Severely Disabled who represented 37% of the population; 2) Secondly, the Severely Disabled who represented 39% of the population; and 3) The Most Severely Disabled who represented 24% of the population. Currently, there is no data on the number of Amish persons with disabilities.

Disability Among the English

Harris Poll (1998) survey findings may provide the most specific data regarding disability in the United States: 1) Among people with disabilities age 16 to 64 who are not employed, seven out of ten (72%) say they would prefer to be working; 2) Two out of
three adults with disabilities say that their disability has prevented (41%) or made it more difficult (26%) for them to get the kind of job they would like to have; 3) Adults with disabilities who are working full-time are more likely today than in 1994 to say that one of the barriers they have faced in trying to find jobs is that "the jobs I could get don't pay enough" (47% versus 31%); 4) One out of five (20%) of adults with disabilities aged 18 and over has not graduated from high school, compared with one in ten (9%) of adults without disabilities; 5) Adults who describe themselves as severely disabled are even more likely not to have completed high school (22% versus 14% of those who describe their disabilities as slight or moderate); 6) Fully a third (34%) of adults with disabilities live in a household with an annual income of less than $15,000 in 1997, compared with only about one in eight (12%) of those without disabilities (Louis Harris and Associates, 1998).

**Independent Living**

Historically, disability has been viewed from the perspective of medical pathology and individual functional limitations that result from such pathology. In this traditional model, the approach to reducing the impact of disability rested almost exclusively on "fixing" the person with the disability (DeJong, 1979). With the advent of the independent living and disability rights movements, greater attention began to focus on the role of the environment as a factor in disability. DeJong (1979) documented differences between the traditional views of disability and an evolving view of disability in which the environment played an important role. DeJong (1979) contrasted what he called the "rehabilitation paradigm" with what he labeled the "independent living paradigm."
The contrasts between the rehabilitation and independent living paradigms primarily focused on professional control within the rehabilitation paradigm and consumer choice within an independent model.

This comparative analysis forms a foundation on which questions regarding the quality of life and level of independent living for people with disabilities may be based. The issue remains as to what paradigm applies to Amish people with disabilities, and whether or not they have opportunities equivalent to the non-disabled within Amish society. There is also a major question as to what the Amish consider appropriate ways of living with disability within their community. Kraybill and Nolt (1995, p. 13) believed that, “the core of Amish culture is embedded in the German word Gelassenheit which is roughly translated to mean submission.”

Negative attitudes toward people with disabilities are manifested and communicated through avoidance, paternalism, pity, segregation, alienation, institutionalization, and rejection. These attitudes affect people with disabilities negatively and culminate in their feelings of embarrassment, self-pity, self-consciousness, dependency, apathy, and lowered self-image (Lombana, 1980).

Racino (1999) wrote that the intent of community integration was the participation of people of diversity in regular environments, the antithesis of exclusionary practices and models. As conceptualized with people with disabilities, “this means full participation and acceptance in societies, which are, by their nature, culturally based, and represents a hope for better quality of life for all peoples” (Racino, 1999, p. 8).
The Research and Training Center on Community Integration (1990) provided these excellent community integration principles for people with disabilities:

First, all people with disabilities should live successfully in, and as part of, their communities that provide them the supports they need. Additionally, all people with disabilities will be recognized for the contributions they make. Thirdly, all people with disabilities should have the opportunity to benefit from enduring relationships with other people. People with disabilities will be entitled to control the decisions affecting the nature and quality of the services they receive. They will also have access to services and supports that provide choice and promote full inclusion; and, lastly, services and supports for people with disabilities will be individualized so as to be responsive to cultural and ethnic differences, economic resources, personal abilities, specific needs, and individual life circumstances.

With these fundamental criteria, one must consider how Amish persons with disabilities, as well as other closed societies, “fit” into health care and social services. Although the Amish are a subculture, they are also in some respects, a traditional microcosm of the dominant culture surrounding them. On the one hand, their history and heritage are the forces that help maintain a separate cultural identity. On the other hand, population growth, an increase in church districts and settlements, the shift away from farming, the growth of non-farm Amish businesses, tourism, and the intrusion of the English, are the forces that lead the Amish toward greater diversification and interaction with mainstream society.
The Amish are an excellent example of how a subculture survives and changes, so that lessons learned from studying their way of life may provide us with a more substantive, working knowledge of cultural diversity and its impact on persons living with physical disabilities.
CHAPTER 3

METHODOLOGY

Introduction

Currently there exists little research that focuses on Amish persons with disabilities. Because of the proscription on higher education within the Amish culture, almost all research studies that have occurred are not a part of the Amish community. Therefore, this researcher sought to give “voice” to those whose perceptions and perspectives are based on their lives within the Amish community and who can speak to their own lived experiences with physical disabilities in a technologically limited environment.

This study was conducted through the use of a qualitative methodology. Qualitative research is especially suited for social work issues because it seeks to understand the ecological and phenomenological perspectives of any given area of interest (Lincoln & Guba, 1985, Glesne & Peshkin, 1993). Taylor and Bogdan (1998) delineate several characteristics of qualitative research that are relevant to a study of persons with disabilities living in Amish communities. They emphasize that qualitative researchers are concerned with the meanings people attach to things in their lives. In qualitative methodology the researcher looks at settings and people holistically; people, settings, or groups are not reduced to variables, but are viewed as a whole.
Qualitative researchers are also concerned with how people think and act in their everyday lives and maintain that there is something to be learned in all settings and groups (p. 7).

Qualitative methods of inquiry are generally viewed as emergent. The qualitative design surfaces and evolves as the process unfolds (Crabtree & Miller, 1992). Glesne & Peshkin (1992) explain this in the following way: “Unlike quantitative inquiry, with its pre-specified intent, qualitative inquiry is evolutionary, with a problem statement, a design, interview questions, and interpretations developing and changing along the way” (p. 6). Additionally, the naturalistic paradigm assumes that there are multiple realities with differences among them that cannot be resolved through rational processes or scientific approaches seeking increased data. As Glesne & Peshkin (1992) further observed, “Qualitative researchers deal with multiple, socially constructed realities or qualities that are complex and indivisible into discrete variables, they regard their research task as coming to understand and interpret how the various participants in a social setting construct the world around them” (p.6).

The qualitative paradigm encompasses designs that support the premises that reality is ever changing, that knowledge consists of understanding, and the goal of research is examination of processes (LeCompte and Preissle, 1993). Furthermore, Taylor and Bogdan (1998) wrote that, “In qualitative studies, those whom society ignores…often receive a forum for their views” (p. 9). Another expert adeptly observed the relevance of this type of research for people with disabilities:

In the disability fields, the promotion of qualitative research is intimately linked with efforts to promote the voice of the service users and consumers
and to reform movements toward a new generation of services more closely tied to community membership and person autonomy (Racino, 1999, p. 347).

People with disabilities have historically belonged to those groups of devalued people without much say in what was done to and for them by those with more power and authority in mainstream society. As Becker (1966) observed, “The perspective of the unheard can emerge because qualitative research implicitly challenges the hierarchy of credibility that gives progressively greater credence to those at the centers of power and society, those who are furthest from the edges of life” (p. 239). To this end this study gave voice to two minority populations that are often written about but rarely heard. The Amish and people with disabilities constitute two cultural groups on the “edges of life.” Thus the lived experiences were the subjective realities of those who are simultaneously members of both groups and were the focus of this study.

**Grounded Theory**

Because of the lack of existing research related to the lived experiences of Amish persons with disabilities, this study uses a qualitative approach, specifically grounded theory. According to Glaser & Strauss (1967), grounded theory is the generation of theory through inductive analysis of qualitative data. In other words, rather than imposing theory a priori to an area of study, hypothesis and theory emerge from the data and are “systematically worked out in relation to the data during the course of the research” (Glaser & Strauss, 1967, p. 6).
Glaser (1999) asserted that, “Grounded theory refers to a specific methodology on how to get from systematically collecting data to producing a multivariate conceptual theory” (p. 836).

Qualitative ways of knowing are compatible with the concerns, practices, and values of social work. The profession emphasizes individual stories and observations, descriptive documentation, subjective and contextual meanings, understanding of multiple realities, empathy, and respect for the inherent worth and dignity of all people, all of which are compatible with and fundamental to qualitative approaches (Schriver, 1995). Also, qualitative methodologies assume that there are multiple realities with differences among them that cannot be resolved through rational processes or scientific approaches seeking increased data (Lincoln & Guba, 1985).

Glaser (1999) suggested that the grounded theory researcher has three important characteristics: an ability to conceptualize data, an ability to tolerate some confusion, and an ability to tolerate confusion’s attendant regression (p. 838). According to Glesne & Peshkin (1992), a qualitative researcher must categorize, synthesize, search for patterns and interpret the data that have been collected. As Glasser & Strauss (1967) indicated,

A grounded theory that is faithful to the everyday realities of a substantive area is one that has been carefully induced from diverse data....Only in this way will the theory be closely related to the daily realities of substantive area, and be highly applicable to dealing with them. (p. 238)
Participants

The researcher found participants by utilizing purposive and snowballing techniques. Stainback & Stainback (1988) have suggested that in purposive sampling methods, participants are included according to relevant criteria determined by the researcher. Mason (1996) stated that purposive sampling means selecting "groups or categories to study on the basis of their relevance to your research questions, theoretical position and analytical framework, your analytical practice, and most importantly the explanation or account for which you are developing" (p. 94). Therefore, the participants in this study were Amish persons with mobility impairments who live within the Holmes County Amish settlement. All participants were adults over the age of eighteen. As mentioned above, they were selected through purposive sampling and snowball networking, utilizing referrals from community members and Dr. Elton Lehman, a respected physician in Holmes County, who has delivered over 6,000 Amish babies. Dr. Lehman is a primary source of healthcare delivery to the Amish. Before referring, he told prospective participants about the study, and after obtaining their expressed permission provided this writer with their names. It is important to note that none of the referred participants are his patients. Next, this researcher mailed a letter that described the study to each prospective participant. Then, Dr. Lehman and/or Mr. Leroy Miller, an Old Order Amish community member, introduced this researcher to the prospective participants at their homes. When the researcher met the potential participants, the description of the study and letter of consent were read aloud to them.
Setting

Qualitative studies often investigate phenomena in the setting in which they occur. Lincoln & Guba (1985) suggested that, “Realities are wholes that cannot be understood in isolation from their contexts, nor can they be fragmented for separate study of the parts” (p. 39). It is very important to accommodate the limited technological lifestyle of the Amish in collecting data, and to respect their decision to live in their separate communities. Therefore, the researcher did not expect the participants to leave the Holmes County Amish community to be interviewed. Rather, the interviews were conducted at the Amish participants’ homes and at the participants’ convenience.

Data Collection

Data collection was based on in-depth interviewing with Amish individuals who live with physical disability. Taylor and Bogdan (1998) suggested that interviewing in a qualitative study involves face-to-face discussions between the researcher and the participants. Its purpose is to understand the participants’ perspectives on their lives, experiences, and situations in their own words. The interview is modeled on a conversation between equals and emphasizes non-standardized, open-ended questions. Glesne & Peshkin (1992) wrote, “The opportunity to learn about what you cannot see and to explore alternative explanations of what you do see is the special strength of interviewing in qualitative inquiry” (p. 65). The interviewer must pay attention to what the participant does, says, and feels as well as what evolves by these conversations and perceptions. According to Cottle (1973), “Paying attention implies an openness which translates as a watch on oneself, a self-consciousness, a belief that everything one takes in
from the outside and experiences within one's own interior is worthy of consideration and essential for understanding and honoring those whom one encounters” (p. 361).

The main objective of in-depth interviewing is learning how others define and experience the world (Taylor and Bogdan, 1998). Thus as Glesne & Peshkin (1992, p. 66) advised:

By whatever means obtained, the questions you pick must fit your topic; the answers they elicit must illuminate the phenomenon of inquiry. And the questions you ask must be anchored in the cultural reality of your respondents: the questions must be drawn from the respondents’ lives.

The questions asked were posed in a semi-structured format that began with a series of open-ended questions and then proceeded to probing questions. Deutscher (Taylor & Bogdan, 1998, p. 99) wrote, “Real expressions of attitude or overt behavior rarely occur under conditions of sterility which are deliberately structured for the interview situation.” Thus the interviewer attempted to create an atmosphere that was relaxed and attempted to keep the dialogue conversational.

As noted earlier in the literature review, the Amish are trilingual with a daily living emphasis on Pennsylvania Dutch. The interviewer, therefore, must be aware of cultural and language barriers during the interview process. Glesne & Peshkin (1992) wrote that, “Your questions must be free of words, idioms, or syntax that will interfere with your questions and the respondents’ understanding of them” (p. 67). This is especially important in speaking with the Amish, whose use of the English language is usually free of phrases often heard in contemporary mainstream society.
In general, the questions focused on growing up with a disability, involvement in community activities, schedules of daily life, and responses from other members of the community.

A battery-operated tape recorder was utilized during all the interviews with the explicit consent of participants. Subsequent to the interview, the tape recordings were transcribed verbatim. A research journal and field notes were also maintained in order to record reflective notes on non-verbal and ancillary communication.

**Data Analysis**

In qualitative research a constant comparative analysis and theoretical sampling of data facilitates grounded theory. Theoretical sampling was employed, within this research, through the use of a negative case example, which is utilized where the researcher explores cases that do not appear to fit a theme (Richardson, 1996). The method of constant comparative analysis is used to continually compare and examine qualitative data for dominant themes and categories. The method of constant comparative analysis involves: (1) the comparison of data within each conceptual category; (2) the integration and linkage of categories; (3) the definition and specification of emergent theory; and (4) the writing up of the theory (Glasser & Strauss, 1967). According to Stern (1980), "Considerable similarity exists between treatments of data in the constant comparative method and in the computer method of factor analysis...data are coded, compared with other data and assigned to clusters or categories according to obvious fit" (p. 21).

According to Crabtree & Miller (1992) the "Analysis of data is the subjective/objective dance toward contextual truth" (p. 13). Yet there is no precise point at which data
collection terminates and analysis begins (Patton, 1990). Lincoln & Guba (1985) believed that, “Data analysis must begin with the very first data collection, in order to facilitate the emergent design, grounding of theory and emergent structure of later data collection phases” (p. 242). The data that were analyzed consisted of the participants’ interview text. The texts of interviews were transcribed verbatim from the tape-recorded interviews conducted by this researcher. Qualitative research designs are emergent; therefore, data analysis must also be an ongoing, emergent process. Text of the transcribed interviews were examined for participant described events, actions, concepts, and perceptions. Data were examined and analyzed inductively from the collection of “data bites” which were defined by Lincoln & Guba (1985) as “raw units of information” (p. 207). Ryan & Bernard (cited in Denzin & Lincoln, 2000) described that one method to analyze free flowing text, such as responses to open-ended interview questions, was to perform keywords-in-context analysis. One example of this method was this researcher’s ability to locate the theme of “acceptance” because of the multiple times it was used by every participant.

The emergent categories were tagged and coded into data bites of information through application of the constant comparative method defined by Glaser and Strauss (1967, p. 106). Constant comparisons of the data bites collected from participant interviews also occurred. This process continued throughout the data collection process until a complete range of categories was established. The relationships between categories was constantly examined and reshaped by incoming data.
Eventually a narrowing of focus within each category generated grounded constructs, categories, and core categories. Per Ryan & Bernard (cited in Denzin & Lincoln, 2000), as the themes developed, this researcher coded the words in like groups and provided a “tag” for each grouping.

Schema analysis is another method for discovering themes by reviewing content for metaphors, repetition in words, or shifts in content (Agar & Hobbs, 1985). Additionally, using a method proposed by Spradley (1979), the researcher explored the text for examples of social conflict, cultural contradictions and informal methods of social control.

Theoretical sampling also occurred throughout the active sampling of new cases as the data analysis proceeded so as to extend or alter emerging understanding. Pidgeon suggested that the negative case example is important in this regard because it helps delineate parameters by challenging assumptions and facilitates construct categories of meanings (Richardson, 1996). As the themes emerged (Ryan & Bernard, in Denzin & Lincoln, 2000), this researcher began to identify negative case examples, which did not conform to the theme.

The subsequent stages were adapted from Burnard (1991) and provided the framework that guided the data analysis. The first stage of data analysis involved the use of a personal journal. The journal was used as a record of impressions after interviews and meetings. It also served as a record of observations and reactions to the participant’s environment, demeanor, and non-verbal communication.
The journal documented the process and course of the study, as well as emergent concerns and adaptations. For example, the journal describes the researcher's concern over some of the questions subsequent to several interviews.

Analysis of the data presented was completed within the two-stage process. The first stage incorporated the actual data collection process while in Amish communities and the participants' homes (Mason, 1996). The primary focus was on the data generated by each participant within the face-to-face interview. During the interview process, this researcher was cautious to maintain the balance between structure within the interview and allowing the data to guide the interview process.

As each interview was completed, transcribed, and reviewed, the new data bites were compared with previous data bites, and filled into the category that best fit the tacit feel of the data bite. However, there were units that did not fit into any category. These were placed in a miscellaneous pile that was reviewed frequently through the editing process. As time progressed, the miscellaneous pile became integrated into the emerging categories, and, at times, new categories emerged, and were tagged, from the miscellaneous pile. Throughout this process, this researcher monitored the information contained in each category. Over a period of time, the categories began to change. Some merged together. Others were separated into two or more categories as additional data were reviewed. Still others were separated into related categories following review. These were not final names for the categories, but served as tentative decision rules for inclusion or exclusion from the various categories. (Erlandson, et. al, 1993).
Strauss (1987) defined core categories as those categories from which theory evolves. As they emerged, core categories were examined to determine the following: frequency of appearance, relatedness to other categories, and implications posed for the development of themes. The process of integration of concepts as described by Strauss (1987) is the procedure associated with determining the importance of identified categories, coded terms, and the eventual building of these categories into a collection of themes.

Coding

Coding is the process described and utilized by Strauss (1987) for naming and conceptualizing data. The process of coding was multi-tiered beginning with "open coding" which identified provisional codes and progressed to more selective data coding as the analysis progressed. "In vivo" and "sociologically constructed codes" were also utilized. Examples of “in vivo” are terms that use the participant's words, e.g., "handicap." On the other hand, "sociologically constructed codes" are codes that the researcher will assign names to other bases of the data that emerge from the interview process, e.g. “accommodation” (Strauss, 1987).

Member Checking

According to Earlandson (1993) member checking is critical because the participants who rendered their thoughts should verify interpretations obtained. Member checking is the processes of having participants review the transcribed interviews and providing them the opportunity to clarify information (Patton, 1990). Each participant was provided an opportunity to make additional comments to any part of the transcribed interview, or to restate any part of the transcript. The goal of member checking in this research project
was to report as accurately as possible the participants' views. The process of having participants evaluate the accuracy and overall fit of the data provided was completed to provide enhanced trustworthiness of this study. Member checking in the form of review and comment was utilized to verify accuracy of practice techniques discussed among direct care providers in the second phase of data collection. This process was utilized to reduce the bias that could result from a single researcher perspective in the evaluation of data. Member checking is one way of refining the data collected. It is also considered a method for establishing "face validity" in qualitative research (Mason, 1996).

**Trustworthiness**

Criteria for trustworthiness provide an appropriate framework for judging the quality of the research (Guba & Lincoln, 1994). This researcher utilized Lincoln and Guba’s (1985) guidelines to address the issue of trustworthiness within this study, which included credibility, transferability, dependability, and confirmability. In the naturalistic approach to inquiry, credibility serves to replace internal validity, transferability is utilized in the place of external validity, dependability replaces reliability, and confirmability is utilized in the place of objectivity (Lincoln and Guba’s, 1985).

Credibility suggests the degree to which the interpretations constructed by the participants mirror those presented by the researcher (Lincoln & Guba, 1985). The techniques used to facilitate an increased probability of credible findings, in this study, were prolonged engagement, negative case analysis, and member checking.
Lincoln & Guba (1985) described prolonged engagement as necessary to “overcome the effects of misinformation, distortion, or presented fronts, to establish the rapport and build trust necessary to facilitate immersing oneself in and understanding the context's culture” (p. 21). Prolonged engagement was established in the study through the in-depth interviews with the participants. Combined with review of the transcribed interviews, the amount of time interacting with these individuals was sufficient to establish a trusting rapport with each participant. This researcher maintained contact with the participants throughout the study’s data analysis process and through the writing of the study.

Negative case analysis called for revising hypotheses based on reflection and review. The negative case analysis was possible because of alternative points of view among the participants. In many issues, the Swartzentruber Amish participant had a significantly different view from the Old Order Amish participants.

As stated above, the researcher also employed the use of member checks to ensure that the data presented in the interview served as an accurate representation of the Amish participants’ beliefs related to living with a physical disability. In each initial interview, participants were skeptical and very concerned that the interviews accurately portray them. This researcher provided two opportunities for member checking. The first opportunity was immediately after the taped transcripts were written verbatim and then after the analysis portion of the research.
Transferability demonstrates the applicability of a study's findings to another context (Lincoln & Guba, 1985). Erlandson, et al. (1993) asserted that as opposed to attempting to select isolated variables that are equivalent across context, the qualitative researcher attempts to describe extensively the interrelationships and intricacies of the context being studied. Other people with similar backgrounds, disabilities, and beliefs to those of the sample population will most likely receive the benefits of transferred knowledge, which in this case to other Amish community members in the United States. To establish the degree of transferability, "thick description" is necessary. Geertz (1973) used this term to "create conditions to allow the reader, through the writer, to converse with and observe those who have been studied" (p. 23). Erlandson, et al. (1993) added that processes that will provide rich detail about it must guide the search for data. The Amish persons with disabilities participants will offer insight that only they could provide, given their collective and individual realities and perceptions.

Dependability and confirmability also ensure trustworthiness. Dependability (Guba & Lincoln, 1989) was defined as a parallel to the conventional criterion of reliability in that it is concerned with the stability of the data over time. This researcher used field notes, memos, and the researcher's personal journal to lay the track for an audit trail. The need for an audit trail was to make available this researcher's process of gathering information so that an examination of the audit trail could determine the dependability of the final research. Confirmability parallels objectivity in quantitative research. Its intent is to demonstrate that data, interpretations, and outcomes of the inquiry are linked to contexts and people aside from the bias of the researcher. It is the process of determining the
accuracy of the data. The confirmability audit attests to the quality and appropriateness of
the accounting process, whereas the dependability audit attests to the quality and
appropriateness of the inquiry process. These were accomplished in this study by noting
the contributions of the participants and academics whose works were referenced.
CHAPTER 4

ANALYSIS

The purpose of this qualitative research study was to explore the life experiences of Amish people with mobility impairments (i.e., Amish persons who use wheelchairs) who reside in Amish communities in Holmes County, Ohio. The voices presented are those of twelve participants who essentially hold the same worldview but relate their subjective experiences and perceptions of living with a physical disability. All of the participants appeared willing to tell their stories during the interview. All of the participants appeared alert and active. All were involved in an occupation. Additionally all of the participants completed schooling through the eighth grade in either Amish parochial or public schools. Profiles of the twelve participants follow.

Participant Profiles

participant 1 (P1)

P1 is a 49-year-old, Old Order Amish, married male with two adolescent children, who has been paraplegic for twenty-five years. He sustained a spinal cord injury when a steel roll bar crushed his back at the age of twenty-four. At that time, he spent two months in the hospital, two weeks of which were spent strapped to a Stryker bed frame where he
was turned every two hours. Subsequent to leaving the hospital, P1 spent three months at an inpatient rehabilitation center at a university medical center.

P1's office at the lumberyard was furnished with big game animal heads and trophy-sized fish mounted on the walls that showed off proudly his outdoors acumen. This décor was significantly different from the other participants' modest and humble furnishings.

participant 2 (P2)

P2 is a 32-year-old, Swartzentruber Amish, single male born with spina bifida. His families are subsistence farmers. The tree stump located next to the lane, which displayed an axe, blood, and feathers where a family fowl had recently met its demise graphically illustrated his social and economic reality. Unlike P1, who was probably the most progressive of all the Old Order Amish participants, P2 has lived among the ultra-conservative Swartzentruber Amish.

participant 3 (P3)

P3 is a 52-year-old, Old Order Amish, married male with no children. He became paraplegic because of an occupational accident twenty-eight years ago at the age of twenty-four. He spent one month in the hospital on a Circ-O-Lectric bed and then a month at a rehabilitation hospital. P3 looked repeatedly at his wife while responding to each question, seeking nods of approval or frowns of concern. Although he appeared comfortable with the interview, he seemed concerned with disclosing anything negative.

participant 4 (P4)

P4 is a 41-year-old, Old Order Amish, married male with severe cerebral palsy from birth. The only time he smiled during the interview was when he talked about his 12
healthy children. He manages the family woodworking shop and speaks very little. His speech was somewhat difficult to understand; however, he appeared comfortable communicating his thoughts. P4 works 12 hours a day within the business and spends the rest of his time with his large nuclear family. He does not appear to socialize as much with the Amish community as do the other participants.

participant 5 (P5)

P5 was the first woman interviewed and was by far the most animated and articulate of all the other participants. She is a 54-year-old, Old Order Amish, married woman with a spinal cord injury. She is the mother of three biological sons and one adopted daughter. In 1965, at the age of nineteen she was doing chores in the barn and fell through a hole in the haymow landing onto the cement basement floor. The fall severed her spine. Consequently she spent three and a half months in the hospital.

participant 6 (P6)

P6 is a 47-year-old, Old Order Amish, married male with a spinal cord injury. He has nine children one of whom has Down’s Syndrome. He was a farmer for 24 years but subsequent to becoming paraplegic, he worked on wood crafting. His accident occurred in 1987, at the age of thirty-four, while working for an English lumberyard. Therefore, he is entitled to and accepts worker’s compensation. P6 would best be identified as the one participant who seems not to have accepted his disability. P6 holds hope for a cure by incorporating home remedies and alternative medicine into his lifestyle. One poignant moment occurred when he emotionally spoke of his daughter’s Down’s Syndrome, and explained that he became closer to her through his own experience with disability.
participant 7 (P7)

P7 is a 39-year-old, Old Order Amish, married male with no children. His spinal cord injury occurred in 1973, at the age of 12, when he had a bicycle accident. He also had an extended stay in a hospital, and wore an orthopedic device called a “halo” for one year after the accident. The “halo” marks are still prominently displayed on his forehead.

He was by far the most informed participant regarding disability and even spoke of the Americans with Disabilities Act and its impact on the Amish. He appeared to be the most comfortable talking to an English person, which may stem from his advertising job with a major lumber company. In that role he interacts with the English public. P7 is the local organizer for the Amish Handicap Gathering and is best known in his community for the golf cart he drives.

participant 8 (P8)

P8 is a 57-year-old, Old Order Amish, married male who contracted polio at the age of nine. He has one daughter and claims to be the first Amish person using a wheelchair to marry. He indicated that his wife’s family was opposed to the marriage, but admits that, “If they haven’t gotten used to it in 27 years they never will.” He has been a retail woodcrafter over the past 20 years and is an avid hunter.

participant 9 (P9)

P9 is a 54-year-old, Old Order Amish, married male who became paraplegic in 1987, at the age of forty-one, when he fell out of an apple tree. He has three daughters and works as a retail woodcrafter. Prior to his accident he was a dairy farmer. P9 has received permission to use a battery-operated wheelchair, but has not received permission
from his church to charge the battery with electric power. Therefore, he uses a gas
generator to charge the battery out in the barn.

participant 10 (P10)

P10 is a 69-year-old, Old Order, single Amish male who contracted polio as a young adult. He is single because, as he stated, “Who would want to marry a handicap?” He spent 36 years as a successful watch and clock importer and now resides in a nursing home. He went to the nursing home because, as he claimed, he didn’t want to burden his family with care giving. P10 indicated that he has good days and bad days. He appeared willing to talk about his disability. He seemed to personify some stereotypes of the Amish because of his utilization of a wooden wheelchair purchased in the 1950’s.

participant 11 (P11)

P11 is a 34-year-old, Old Order, single Amish female who was diagnosed with muscular dystrophy at the age of ten and has used a wheelchair for 16 years. She also indicated that marriage was impossible because she cannot “do” anything. P11 spends a large portion of her day stringing beads for necklaces. She is able to string three a day and then sells them to area merchants. Her family farm is nestled within the Holmes, County hills and is almost impossible to reach with an automobile; therefore P11 does not go outside the home very much. She appeared to exert great physical effort in just speaking.

participant 12 (P12)

P12 is a 21-year-old, Old Order, single Amish male who became a paraplegic in 1999 because of a severe motorcycle accident. Although the Old Order Amish do not believe in the use of automobiles, many young men buy cars before joining the church. It is
understood, within the Amish community, that there is a time for men to “sow their wild oats” prior to joining the church. P12 enjoys going daily to the Wooster Ida Sue School where he receives physical rehabilitation and fellowship with other handicpaps.

Emergent Themes

Chapter four presents the shared and unique lived experiences of the twelve Amish participants interviewed. The researcher used the constant comparative method to identify emergent themes. Themes were selected on the basis of frequency within the discussion, repetition, the emphasis the participant placed on the theme, and the relevance of each theme to the study. The initial analysis of the interview transcripts yielded twenty-two general categories. The next phase of the analysis determined six primary themes that emerged during the interviews. Cote, Salmela, and Baria (1993) wrote that the presentation of results in qualitative research might be presented through an analysis of themes that best describe the data. The themes of this study are presented as follows: 1) acceptance, 2) gathering, 3) accommodation, 4) slow time, 5) self-reliance, 6) healthcare.

The goal of the analysis was to identify the major ideas and perceptions of the participants that would facilitate understanding of the lived experiences of Amish persons with mobility impairments.

Acceptance

The theme of acceptance provided a foundation for all of the interviews. Each of the participants emphasized the need to accept their disability. Acceptance is an important component in coping with any type of loss; however, these Amish participants indicated that acceptance also includes a realization that God has pre-ordained the event. Within
the Amish worldview, there is no need to improve or change that which God has already ordained. For example, P3 indicated that he had always had his heart set on farming and now he is not able to be in the field that he once plowed, planted, and harvested.

Well, I was a farmer and always set on farming or carpenter work. So, I ended up doing this. Yeah. I was working for somebody. Well it just even now, all these years, 28 years in the wheelchair, when I watched the spring comes in I just think boy I gotta be out there plowin’ . A lot of times I just think I should be out there. It just hurts to think about it. I accept the way I am and call it good to be alive. It’s just like because I’m on the wheelchair I just do things what I can do.

P3 accepts his limitation and the restrictions of the church and its rules, which do not allow the use of field tractors that would accommodate his disability and allow him to farm. All of the participants in this study work. However, none of them are in the occupation they wanted to pursue prior to their disability. Each participant expressed the loss of an aspired work role because of disability. Yet each articulated the need to accept the disability. As P3 indicated, adaptation to a new role and full acceptance of one’s situation are a lengthy process:

Well, yeah, I learned to accept a different way, in a different way that takes a lot of patience. Um, I don’t know what else. What else would you say? Depending on how it is, you have to accept it one time or another. Now my brother he just hasn’t accepted that he will always be in a wheelchair. Why um, his friend, he tried to give him a job of doing things. They want
to get him back to doing something, something to do on a wheelchair.

Yeah, just keep busy. He just wanted to be back on his job doing' steel work. He just thought if I can’t do my big job, I’m not going to a small one. Well that was a little bit about the way he kind of kept it. I usually say it takes five years to really fully accept everything.

P5 echoed the same theme but appeared to still struggle with the limits of her disability. In fact, she began to weep over being left out of even the simplest of events because aspects of physical environments obstructed her involvement and interaction with others.

Well at first I was used to life before this you know. It’s kind of hard to accept, you know at first cause I had a very tender age there being 18 you know. And, but it was hard to accept but I finally eventually got there, now it really don’t bother me. I mean there are times yeah, you’ll see other people on the go, goin’ away and you think, gee I wish I could do that. I mean that’s hard for me to do. I try to accept it. And then another thing, something I think should be changed but you can’t do that and that is if you’re with a group of people, let’s say there’d be a lot of friends here, and they do something that’s upstairs that they want to see and they all run up but you sit here by yourself. You know what I mean? That is a hard thing. That is hard. I say that’s one of the hardest things I’ve got, is to accept that. (Sniffles) I guess they just don’t think of it because they can run and they just go and they don’t think of you. In fact my own sister does the
same thing. You know she'll go too, and let me sit. Now I think she
ought to think of it, you know what I mean?

P6 offers the negative case example in regard to acceptance. Although he generally
verbalized the importance of acceptance, his specific actions spoke otherwise. He
continues to try alternative medicines such as expensive healing oils and even high-risk
home remedies which will be described later in the healthcare theme.

Well, I tell ya, when this happened, I, uh, you know when I found out it
didn’t soak in but my wife told me that I’m going to be paralyzed, you
know? When I woke up and found out at first, I thought, oh I don’t want
to give up. And, uh, it was pretty hard for me to accept it. I mean it’s so
different of course you can’t do what you used to do. I used to always be
goin’ out running’ around and doin’ work and you just got a different pace.

It’s just a different, a different world.

Perhaps the sum of the participants’ comments on acceptance were best articulated by
P7. As he pragmatically philosophized, life continues and one must confront one’s reality
and one’s limitations. Living with a disability means constructing a new life, one built on
remaining strengths and abilities. In his optimistic view:

Uh, it means changes of lifestyle. Uh, but it does not mean that it stops.

It’s uh, your life you just have to accept it. We need to prove to ‘em that
we can. That you can uh, do the job and that there’s things that you can’t
do, and you need to accept that. There are a lot of people um mad at other
people because you can’t do what they can do. Uh, but you need to face
those facts and accept those facts, and try and work with what you still
have left. Try to do the job that you can do. And if there is a job that you
can do why, you need to prove that you can, because there's always
something to do if you want to do it. Always!

All of the participants, including those who grew up with a disability, believed that it
would be easier to accept a childhood disability than to accept an adult onset disability.
Participants assumed that a person who grows up with a disability understands his/her
limitations and does not dwell on loss. From their perspective, adults who experience
disabilities are more aware of what they have lost; whereas, children do not understand
what has been taken away. P1 articulated this view by suggesting that adults may resist
adaptation and acceptance:

You know most adults they'11 adjust to it after years where a kid just grows
right into it. I think they probably grow into it probably easier but that's
probably the only difference. Once you're an adult and you get into this
situation you can either fight it or you can work with it, one or the other. I
mean you know it's not gonna go away, you know. I don't care how hard
you fight.

P5 believed that the most difficult part of accepting a mobility disability as an adult is
that one remembers how one was able to function, and one felt exhilaration with
movement. She suggested that a child with a physical disability does not have that frame
of reference.
I would think that if I had been born like this there would have been some things you wouldn’t think back. Like that I used to be able to run. They probably wonder how it would feel to do it. Like I remember how it used to be. I have people askin’ already now, some of us handicaps were together and someone would ask it now what would you do if you weren’t on the chair? What would be the first thing you’d do if you wouldn’t be a handicap? What do you think my answer was? Run. We just like to run once. I don’t know why just think it would feel so good to go.

In addition to self-acceptance, another aspect of the theme of acceptance was how others view and accept people with disabilities. P3 believed that other Amish involve him in activities and the result is beneficial:

I know some of the people think it’s something to be in a wheelchair and some of ‘em says well it’s good that you accept it or something like that. I just say that in our community around here I always say that the neighbors and the people in the church and everything they use me good and that makes my life a lot easier.

All of the other participants, however, felt that although members of their church are always willing to help, they don’t really understand disability. P7, who has worked with the English and the Amish and displays an awareness of the two cultures, drew a comparison between them:

Uh, the Amish are probably one of the tougher ones to educate. Um, basically, because the non-Amish handicap awareness groups were out
there working with it. They worked with television and bigger schools. They were in contact with the handicapped society already and the Amish were not as much. Uh, there were some handicaps in and around but um, basically, unless you were in the same church district with another person in a wheelchair, uh, you probably knew of him but that was about it. So the Amish were not as far advanced in the handicap awareness during that time as they are today.

P5 also articulated a difference in the way an English person would treat a person with a disability and the way that an Amish person behaves. She agreed with P7’s comments that the Amish really don’t understand disability and, consequently, they are not empathetic. P5 indicated a preference for social interaction with the English. She articulated the following in a very hushed, secretive tone:

You know I hate to even mention this but it is true, any place I would go the non-Amish feel more concerned about you. They want you to be able to be comfortable. The Amish, I think they just look out for themselves so much. I hate to say this because I’m Amish but it’s true! It’s definitely is. I think it’s better than it used to be because I think there’s more handicapped people than there used to be. But like as I tell you, I hate to see this because I am Amish and I want to be Amish. Now, if I were supposed to go someplace where I know there’s a house full of Amish people, I would just dread to go. But if there would be a house full of non-Amish people, I wouldn’t mind to go.
P5 and P7 both expressed their frustration when other Amish persons stared at them and offered no assistance in time of need. One of the most salient moments during P5’s interview was the time that she tearfully recounted how she felt left out of Amish events and that people in her church always stared at her. She feels that she can contribute to the community and works very hard each day. This researcher had the opportunity to smell the homemade pies that she had made for that evening’s company, but unfortunately, did not partake of the fruit from her labor. She sighed and wept when relating the following:

It’s the funniest thing but the Amish people they love to stare, a lot of them, and I just hate that. I just hate that. You know they want to see now how’s she going to do this? You know how’s she going to get that through here. Instead of jumping up and helping and making room to get through there you know what I mean? I wish it wouldn’t be like that. You kind of really don’t think you’re a handicap but then next you come to a crowd and they’ll just have to stare an eye and you don’t see everything you know what I mean?

P7’s frustration over being the focus of staring also continues to be a source of discomfort as it was immediately after his accident at the age of twelve. The analogy he used to describe his experience in these situations made clear his sense of objectification:

I’ve always said this jokingly but when I was 12 it wasn’t funny. I know what a dead body feels like. I was for the first year basically in bed after my accident. I could sit up some but for the most part, I was in bed and on the weekends we had a lot of company. A lot of people would stop in and
that's the type of support I'm talking about. But those that stopped in to visit you had no idea what to say or what to do. They'd come in and uh, you know they'd be rubbin' their hands and uh, they'd walk up to the bed and they'd kind of look you all over. Then they'd turn around and ask your mom how old he is and kind of whisper, you know, and I always said, after they left the house now, I know what a dead body can feel like when people go through a funeral. I know what it feels like because it was the same atmosphere. The turning around and the whispering and the how old is he?

P7 also verbalized feeling frustrated with the stereotyping of both Amish and English people with physical disabilities. He asserted that able-bodied people believed that a person with a physical disability who uses a wheelchair is also mentally impaired or intellectually compromised. In his words:

I'd want to change that as far as associating wheelchair with mental illness, or retarded or whatever. I would like wipe all that out if I could, uh because it's not only for myself because I think I can handle it uh, but for other people that, um can't handle it. I just hope and pray that my attitude towards life and toward other people can stay like it is today and if it does, then I don't really think they need to see me any different. I think they'd see me the way they should be seeing me if I if I act accordingly. People need to see you as a human being and that there's nothing wrong with you and that your mind works.
For P1, the ability to work is essential to one's mental health and self-identity. He suggested that the ability to work proves a place in the community for Amish persons who use wheelchairs. In this way, they still contribute and participate in the community at large. A place in the community may be the most important issue for Amish people with disabilities. It may be that community, for the Amish, is more vitally important than the needs and wants of the individual.

**Gathering**

The community environment among the Amish is another theme that weaves through each of the participant's stories. The best way to describe this theme may be to use the participants' word, "gathering."

The Amish have always had a strong emphasis not solely on family but also on community. When the English think of the Amish, they most often envision scenes out of the film "Witness." They picture barn raisings and huge home cooked meals with the whole community preparing and taking part in collective dining at large, antique log tables. However idyllic such scenes are, they do not in themselves convey the diversity and purposefulness of social interaction among the Amish in modern times. One example of the evaluation of Amish community meetings is that of the Amish handicap gathering, a social support system initiated by an Amish person with a physical disability.

Once a year, at the local and national levels, Amish persons with disabilities assemble together in what they refer to as the "handicap gathering." This theme of "gathering" was repeated throughout the participants’ responses in relation to the handicap gathering, the role of friends, and "showers", which are a social ritual that emotionally and financially
supports the Amish person with a disability. P1 describes the gathering in the following way: "Well it's just you know people here are all a nice community and it's got the handicaps between the amputees and whatever uh, the paraplegics in the area just come together for a day of social."

P3 agreed and added that a directory of all the attendees is developed and is provided to each person with a disability who attends the event. People may use the directory to write or visit one another throughout the year. As P3 described the "gathering":

Well, it's just a time to get together and visit. A lot of the local people around here don't go to the big one, you know, in other states, so we start to have one in Memory Park. I keep in touch with them once in a while, yeah. They are a lot of friends, yeah. They write down a directory. When the handicaps go in they register, you know, and write down what their occupation and uh, what's the matter with them and stuff like that. Then you get this all together and then have a record of your name and what you do and your address.

P7 is now the local organizer of the gathering. He also is responsible for the national gathering when the event is scheduled in Ohio. His responsibility includes planning the event, sending out the invitations and mailings, preparing the food, and writing the directory. It is a great deal of work; however, he did not appear disgruntled about the commitment. He seemed to enjoy the responsibility and the benefits of "gathering" with other persons with disabilities. P7 summarized the event as follows:
I go to the national ones and local, yes I do. I’ve missed a couple since ‘76 but not a whole lot of them. It means a lot to me. Uh it’s very, very important uh, just to uh, associate with other handicaps. It’s very encouraging uh, to see other handicaps and uh, we have something in common. So it’s very important and it’s good to go. Uh, Indiana, Pennsylvania and Ohio are the three that every four years get the national gathering. The fourth year then is split off and goes to smaller communities James Port, Missouri, um, Iowa. We thought with the bigger communities in Indiana, Ohio and Pennsylvania uh, we needed to take our turn. It takes a community effort to get in handle 600-650 for lunch.

P2, who provided the negative case for most of the themes, enjoyed going to the event for a few years, but was told by his Swartzentruber Church to stop. No explanation was offered for this mandate. He believed that it was because the Swartzentrubers like to keep to themselves and think that they alone should take care of one another’s needs. However, he never questioned his church leaders as to why he was told not to go.

I used to go years ago but don’t anymore. I have 14 or 16 friends with spina bifida that I write to. They are single friends that are not married. I don’t go anymore. Well, we’re really not allowed to go. I am not allowed to go. I was just told that I couldn’t go. I didn’t ask why not. I enjoyed going but it’s ok that I don’t go.

The component of friends is also present within the theme of gathering and appears to hold a great deal of importance among the participants. Although most people view the
Amish as being a distant and closed community toward English people, it was interesting that all the participants referred to English friends with pride. P3 shared a way that he gathers with Amish family and English friends:

Oh well, I don't want to say anything bad about 'em you know. Yeah, I have a lot of wheelchair friends. Well my brother and his two sons and my nieces and nephews were here to do my weed eating. About once a year we do that. Then afterwards we have wiener roast, ice cream, and chips. That is one way to get together and share our life. And since I've been on the wheelchair, why it seems about every wheelchair fella that's on the wheelchair that I know of they're all happy.

P5 spoke about gathering with friends who were both English and Amish and jubilantly described her evening plans with English friends that she has known for several years. Furthermore, P5 describe her English friend as a "sister" and, ironically, described how she and her English friend "have so much in common." She wrote the following:

I write letters to another handicap but I've never met her but I'd like to meet her once because they say she's such a jolly woman. She wrote me a letter last summer when I had my surgery and it was really interesting. You could tell she's a really talkative person, I would say. We have friends coming tonight uh, they're not Amish. They're from Ottawa, Ohio. We got to know them from the shop. The husband came in a couple of times and she'd sit out in the car and she'd never come in. Then finally she happened to come in too and I was in there and her husband stayed and
started talking about grandchildren and they never quit yet. You know we’re always talkin’. I’m really lookin’ forward to seeing them tonight. You know they take us out to supper and they’re real good friends. Now my other best friend is back by Mt. Hope and she’s a handicapped too. We are very close; really we’re like sisters. In fact, Sharon, from Ottawa, Ohio we’re like sisters too even if she’s not Amish. I mean we have so many things in common. She says, “Oh, I don’t think of you as handicapped.”

P9 also has friends who are English, one of whom is an African-American with a disability. Given that there are relatively few African Americans living within Holmes County, the fact that an Amish person befriended an African American may indicate that the Amish are not as separatist as most people believe them to be. P9 described his friendship in the following manner:

Oh, OK, when I was in Cleveland in the hospital, I got to know some black person. He broke his back and he can walk but his bladder wasn’t working. He’s a good friend. Yeah, he’s the English. Then the first summer he came over here and I was working and asked me if he could help me. I said yeah but I can’t pay you much but he just wanted something to do. He helped me all through that fall and winter and we’ve been good friends ever since.

The final component within the theme of gathering is that the Amish show community gathering through the custom of showers. Showers are listed in a local newspaper. Each edition has a section of showers for people who are ill or injured. The result is that
persons in need are “showered” with cards, money, and company. The following are a couple of examples that were listed in The Budget (2000, p. 14) shower section:

We wish to announce a cheer up and get well money shower for … She is in the hospital with severe burns from the waist down. She probably has a lengthy hospital stay yet as needs to do surgery and do skin grafting. They have seven children, oldest is 12. Is hard on the whole family. Please would some folks send them an encouragement letter? She wanted to start a fire underneath a kettle and her kerosene jug exploded. God loves a cheerful giver.

We wish to announce a get well and money shower for… She got her left hand in a strait line ripsaw machine while helping her husband do millwork. She had surgery but will need more surgery later. She has a lot of pain. They have 6 children and one is a special child who really misses mom’s care. Let’s help her pass the time and fill her mailbox.

All of the participants in this study received showers through the Budget newspaper. The participants, however, did not all feel the same way about receiving the attention and the “fuss”. Some appeared embarrassed; however, all of the participants appreciated the thoughtfulness of their neighbors. P5 explains her feelings this way:

Ok in the Budget there’s a special section, you know what I’m talkin’ about, the Budget? There’s a special section in every budget that says “Showers”. Then there’s a new paragraph there that somebody may put in
there, a let’s have a cheer-up and get-well shower for... or something like that, you know? Then people with something gives to somebody that really needs the money. Sometimes they’ll have a money shower for ‘em, you know to help’em out. That’s what that is. Mmm-hmm, oh I got a cards and money. I mean it was really something. We really appreciated that.

P6, who articulated his experience with the showers, was very impressed with the amount of visitors and well-wishers. In fact, there were only two days, out of three months after his accident, that he did not receive visitors. His voice was filled with emotion as he recollected his feelings regarding the school children’s scrapbook.

The first three months that I was in the hospital there was always a lot of visitors, yeah. And there were only two days that I didn’t have visitors. Yeauh, and then I came home and they had scrapbooks that they had made up from um different church schools, included with my name, and they had kind of a poem written in there, it was really somethin’ for me to read through and spend my time. Then they had a shower you know, people sent in money and they worked out real good. I had two showers in the Budget.

P8 remembered fondly his showers and the support that he received. He expressed bewilderment that someone would send seven, one hundred dollars bills without telling his or her name. He also poignantly defined this theme of “gathering” by recounting the story
that his neighbor provided a fundraiser to pay for needed orthopedic equipment. He related the following:

Well I remember being in the hospital first and they told me I’d need a brace that would cost $1,300. Well my neighbor works up at a local cabinet shop and he came up with all that money. I know I got a lot of money in the mail too. I know one week you know, I got a lot of greetings and I got a card with a ten and a twenty-dollar bill in it. One day I got a greeting with I think it was seven one hundred dollar bills and one dollar and no name. They uh, put it in the *Budget* then and that is that how folks know. I never knew who sent that. It was from Pennsylvania and I have no idea who it was.

P12 responded that he received “an awful a lot of money. Oh, I got about $1,600.” The Holmes County Amish community also provided a benefit for P12 in order to send him to a “special” chiropractor in California who provided acupuncture therapy. P7 was gracious in receiving the support; however, he was one of the participants that had difficulty with the ritual of the “shower.” He described his uncomfortable feelings with receiving gifts this way:

Uh yeah, there were a couple of showers. Oh it’s uh, it’s great and I love to help but the receiving end is always bad, you know. Well it’s uh, it’s Scripture says its more blessed to give than to receive, but and that’s probably true, but I think the blessing to be a graceful and grateful receiver is just as big as the giver. I like the giving a lot better than the receiving.
P2, of the Swarzentruber Amish community, again provided a negative case. He suggested that the Swartzentruber Amish do not participate in the “showers” because if someone needs help, the people in their own church will help them. P2 stated, “No, no, we don’t believe in that. We [Swarzentruber] don’t do that. We just help each other when we need to. We have our own way of helping each other.”

Accommodations

While many of the responses provided by the participants have a common thread of community acceptance, the theme of accommodation is another important element that illustrates, and perhaps, contradicts the theme. P5 indicated this possible contradiction between community acceptance and accommodation when she stated the following:

You know our church is always involved in doing something but I am never included. I understand the problem that I am in the way. But there are things I could do, I mean hey, just before noon today I baked 7 pies. You know there are things I could do. I’m not handicapped at all when in the house like this. I can’t stand up to get something in the cupboard any more and you know it makes you feel kind of left out. Know what I mean?

In spite of the important need for community among the Amish, some gatherings are not accessible to people using wheelchairs. The theme of accommodation was pointed out by each participant and perceived as a lack of accommodation at major social gatherings. Perhaps the most important gathering for the Amish is the church service because religion is the cornerstone and root of their existence. The Amish church services are held every other week in alternating members’ homes. Services often last the entire day. Each of the
participants talked about difficulties with accommodation at church services, but also indicated that members of the church were available to carry the person with a disability if the individual required such assistance. P3 stated the following:

Sometimes I can’t get through doors or somethin’. Those steps and doors, yeah well I know I’ve been in pretty tight squeezy places like that. So far the people are always willing good friends that help ya. It seems like; I don’t know I have a ramp in my house but not for any of the other church homes. Yeauh, then we gotta go up steps. It’s a problem but people are always willing to carry me up.

P5 articulated the lengthiest description of the serious problem with church accommodation among the Amish. She again stated the following in a hushed, secretive manner in which she was almost afraid to utter the words and feared that someone may hear her complaint:

The main problem is, uh, a lot of homes are not built for a wheelchair.
Now our church is better now than it used to be. I think there’s almost everyone I can get in now but there’s a lot whom I can’t get in the bathroom because the bathroom is too small. That’s the funniest thing why everybody thinks the bathroom door does not have to be wide like other doors. The bathroom door gets used just as much as any door. Church can sometimes be an all day event and it is very difficult sometimes if its all day when I can’t get in like that. That’s something very hard you know, people say come and visit us sometime. Yah, but maybe they got a whole
row of steps you can get in the house, you know, and you know the
bathroom door's just real small. I feel they don't understand that and they
think you don't want to go. I think there are people like that. In fact, I
think our church used to be quite a bit like that but they have really
changed. We had this one family especially, I mean they go so upset cause
I wouldn't come to church when they were on but I couldn't, you know I
couldn't. There was no way I could get in because they had big steps but
they had no railing. And in fact I mentioned something to them once,
which you might put in railings so I could come in. Oh, we don't need no
railings! OK, that's it. That's just like this friend back at Mt. Hope I have,
we're going to have church here in September and I wrote her and I said,
you know what I got on my mind now is getting ready for church. She
wrote back and she said yeah I could understand you got this on your mind
cause she says I know it's hard for you to do it. She said a lot of people
see that smile but they don't know what's behind that smile and that is
true!

P7 also felt concern about the lack of accessibility for church services in Amish homes.
He suggested that since he has been disabled someone should have at least built a ramp to
accommodate his need. He again articulated that able-bodied Amish persons do not see
the need because they will always help and "drag you up the steps”.

There aren't ramps and accessibility to homes in our district. It would
make you feel better in the last 27 years if somebody would have redone
their house or when they go build a new house anyway if they would have accommodated a ramp at the top. In a lot or places it would have worked instead of going up three steps you had a ramp there instead of three steps. It wouldn’t have ruined the look of the house or landscaping or anything and it would have made you feel a lot better. The need is not seen because while we’re there we’ll take you up there you know and they drag you up the steps. They’ll do anything for ya and they will. Uh but yet the building of the ramp there would be nice. Just as a neat thing that they knew you would need.

Church services are not the only events that pose a problem with physical accessibility. Church and community functions such as weddings and funerals also were identified as problem areas for each of the participants. P5 provided the following description of the problems related to social events.

You know if somebody dies just to go to the viewing especially among the Amish, is very difficult. I don’t mind it so much if they’re not Amish because usually it’s at a funeral home or someplace like that and a church and it’s fixed for handicapped people. But going in Amish homes where it’s a viewing you just can’t get around. You know because there are things just sittin’ all over the place. You come in the door and people gotta stand up and gotta move, I stay home. And a lot us handicapped do that. You can’t go because you can’t get in. Oh maybe not so much really with weddings but it is with funerals, really. Yeah, it’s not fun to go
through a lot a people. And an auction, that’s one thing if you go you sit
there and people stand up here because they want to be up front so you
can’t see, what’s the use to go? You know what I mean? But now, not
everybody’s like that because there are people that are very nice to you. In
fact my daughter-in-law says I love to go shopping with mom, and I said
“why?” “Because when you come down the aisle people just move.”

P7 agreed that funerals are difficult to attend because of accessibility, but not as much as
weddings that are held in homes. P5 and P7 agreed that any major event that is held in
individual homes is difficult to attend. P7 said the following:

Weddings I go to, and there again, mostly any more the weddings are in
sheds and big shops that have the room. So it’s pretty, uh, pretty
accessible. Um, funerals or viewings are in the house and unless it’s
necessary for me to go I don’t go. Usually it’s not like calling hours from
2-4 and 6-9 it’s all day long. Our viewings and stuff are any time of day so
generally I try to go oh, mid afternoon or between 3 and 4 or before
suppertime. Less people there and a lot better for a wheelchair to get
through. You don’t move, when you’re there because there are hundreds
of people. Yeah, then there was a time I didn’t go to a viewing at all when
I go to funerals it’s usually in the summer anyway because they are in the
shops or in the barn and it’s a little bit easier to get to.
P9 echoed these concerns of being in crowded places; therefore, he doesn’t attend the event unless the honored guest is someone “real close”. He expressed the difficulty in relying on others in this way:

Yeah, going to weddings is a little bit of a problem. Well I use this wheelchair and this thing weighs 240 pounds when I’m on it. It’s hard when I have to use the other people to count on. Funerals, unless it’s real close, I usually don’t go because it’s just so crowded, you know. They have a viewing a couple nights before the funeral and usually it’s so full unless it’s a real close relative I don’t go.

P5 also indicated that there is a problem with physical barriers within local stores as well, because most of the bulk food stores are in private homes. She said that she was very excited to visit the local store, once she was able to get about with her Steiner tractor. A local distributor specifically manufactures the Steiner tractors for the Amish. These are small engine, motorized carts that allow the person to wheel into the cart and steer using handlebars similar to those of a motorcycle.

P5 recounted, however, that she was unable to get in the front door of the bulk food store. Although people were always willing to retrieve what she needed from the shelf, it just wasn’t the same as shopping yourself:

There’s a couple stores I can go to, not that I can get in, that’s, there’s another thing, ‘bout your Amish stores, the one that’s a dry goods store with good credit, but ah, I can’t get in. Then there’s one up here have you seen that? Well they got a ramp up their porch. How wonderful but there’s
a step to get in. So I can’t do it myself. You know, it would be that I could get in myself; I could just go in and get whatever I want, you know, but I can’t do that. In fact, they gave in down at the package store. I told them and they said, "you just come and I’ll get whatever you want", you know. So I just drive there and she’ll hear me and she’ll come out, and, but you know, sometimes you see something you want to buy, you know, the other way, you don’t really know what’s in there. Oh, well.

It is important to note that the lack of accommodation observed by the participants may be changing among the Amish. All of the participants agree that conditions have improved for the Amish handicap. P7 explained the situation this way:

Yeah, things have changed for handicaps. It probably has something to do with we’re not all farmers anymore. So you tend to be out in factories more and you are rubbing shoulders with non-Amish people and I think that has educated the people more than anything else. Our school systems are starting have in the past years have had more handicapped awareness in our public schools. So that has helped as much as anything.

P5 specifically felt that the situation is improving for people with disabilities within the Amish Church, especially in the area of technology.

She indicated:

I have to say our church has really changed, and I am very thankful for that. Honestly if I tell you the truth ten years ago, I wouldn’t have been allowed to have my Steiner cart, I’m sure of that.
Accommodation, like any change among the Amish, is evolving on their own timetable. This time table may best be described as the Amish practice of slow time.

**Slow Time**

As described in this study’s literature review, the Amish are not stagnant. They do adapt and change over time. These seasons of change, however, are not on the English time clock, but are determined by each church district. This writer suggests that this time clock is best described utilizing the Amish concept of slow time. PI literally described the Amish practice of slow time as follows: “Well, in the summer time they’d have slow time and you’d have fast. You turn the clock up one hour in the summertime and turn it back then in the fall. Where they just don’t turn the clock.”

The theme of slow time will incorporate the participants’ perspectives on the areas of progressive technology and government support. However, in a more figurative sense, slow time also conveys the reality of changes in the Amish way of life. As the previously rigid boundaries of separatist communities have begun to bend, the result is the limited incorporation of technology and the limited use of government programs for persons in need. In short, Amish persons with disabilities are making use of assistive devices and economic supports previously denied.

One of the most important issues for people with mobility impairments, in all of American society, is the advance in technology. For many people with physical disabilities, advances in technology are facilitating more opportunities for employment, greater independent living, and fuller inclusion into mainstream society. For the Amish, technology use must “fit” within the parameters of the Ordnung established by each
church district. It would seem that the stereotype of the Amish is that technology is not acceptable; however, the participants' views and the use of the innovative Steiner made tractors would counter that claim. The Steiner tractor is a three wheeled motorized tractor with a cart attached that allows a person in a wheelchair to ascend a platform and operate the vehicle. Traditionally, such a vehicle would not be allowed because it has rubber tires and is motorized. P1 stated that his church has permitted the use of this vehicle on several occasions. As he observed:

No, they actually bent the rules a little bit or whatever when I got my Steiner tractor made. You know I had the air tires and stuff but they let it fly. Yeah they were flexible. It's just like anybody else really; I mean they knew you had to have some way of gettin' around, some freedom or whatever. Although there's other districts that don't look at it that way.

The Bishops worked with me real good as far as that goes. But there's one based in the same church district there down in Mt. Hope, that church wouldn't allow a three-wheeler. The Amish handicap had to bring it back because they wouldn't allow it. He don't get around and he's more or less grounded. It all boils down to common sense.

P3 talked about working with his Bishops on obtaining his Steiner tractor; however, P5 suggested that P3 had a more difficult time than he suggest during his initial interview. P5 indicated that P3's bishop had agreed to allow him access to the tractor. However, individual members did not support the decision. Later in the interview, P3 commented
that he just told people in his church to "just try and be on a wheelchair for awhile and see how you feel." As he related his discussion with the bishop about the Steiner tractor:

Before I got my battery chair, why, I asked the bishop. I asked the bishop if I could have something like this and he said well, I'll ask the other deacons and if they don't say anything I could go ahead and get it. That's all it was, and everyone I'd met so far that sees me on this cart why uh, they think it's great that I'm getting on with something like this. This was just a little lifesaver of a wheelchair. Cause I always wanted to get out and do things but it was just hard on a wheelchair. It's not all the same because people are different. Like some would feel like maybe you didn't accept your condition good enough if you thought you had to do everything like everybody else does. Some of 'em might think like that. P5 also talked with the Bishop who responded, "I don't care." She again noted how things have slowly changed to help Amish persons with disabilities. This is also the section of the interview where she contradicted P3's version of having church permission to purchase a motorized Steiner tractor:

We talked to the bishop about the Steiner and he said well, I don't care. And now since he's told my husband already, he said I'm so glad she's got something like that. I can tell you I feel a lot, how shall I say it, I guess I can say a lot happier since I have it because I can go places. I love to go away like that, you know. I don't think ten years ago I would have been allowed. I don't think so because at that time they just were not friendly to
me in church like they are now. It’s just, I don’t know why. (P3) really
had a problem in his church to get his. He had his years before I had mine
and he had a very difficult job. The bishop didn’t mind but there were
other members that didn’t go along with it. So, I guess they talked with...

[P3] and [P3] said, “OK I’ll tell you what, you spend one day on the
wheelchair, that’s all I’m going to ask of you, one day that you do nothing
but you be on a wheelchair.” And you know, that changed them and they
said OK you can. He doesn’t drive his around as much as I do. You
know, but I take mine everywhere in the yard. Like last week I wanted to
take the rhododendrons and put some in water. I drove up here by the pier
and I drew up a cup and poured it in then came back and got some more.
You know it makes you feel like you’re doing something. You know
instead of sitting here and watching everybody else.

P6 anticipated a conflict about having the tractor but was pleasantly surprised. He was
prepared to accept the ruling of the bishop if he wasn’t allowed. But he also provided
insight into the bishop’s procedure for addressing such issues and rendering decisions. He
stated the following:

I heard that there was gonna be a little fussy about having the Steiner.
Why I thought at first if they totaled that out why we’ll just have go from
there and see what’s next. Then different guys talked about it and they said
they couldn’t tell me to that there’s no chance that I could have that and
they would accept it. So that’s the way we kept it. They don’t look at it
that you shouldn’t have this or that. Then every twice a year they have kind of a meeting all the head bishops come together and uh, kind of discuss their rules and go from there.

P7 indicated that he has never had a problem with the church regarding his assistive technology. Of course, he doesn’t always share with the bishops what it is that he is actually doing. His rationale is that a number of Amish lack familiarity with disabilities and a modicum of empathy. He indicated previously in the interview that the Amish were very difficult to educate on disability issues and spoke of the lack of understanding of the need for ramps. The following is what he said regarding the bishops and motorized technology:

I’ve never had a problem with any of the bishops. I really didn’t ask the bishops. I, uh switched from my tractor to the golf cart and um, it wasn’t a problem at all. When I got the tractor they had talked to the people in church and you know they were very understanding, very understanding. There are probably people out there who wouldn’t, but, at the same time, they probably don’t have anybody in their family that would have needed it. There’s some negative people up there but it would make a big difference if they tried to walk in your shoes and, uh, they could make a lot wiser decisions if they had to do that.

P7’s use of a golf cart may have taken technology use for the Old Order Amish to a new level, which is the use of a motorized, gas engine, rubber tired, vehicle.
Even today, although certain types of machinery may be used for business purposes, individuals are not allowed devices for personal use.

In contrast, P9 doesn’t feel that he should use the technology at will, but only sparingly. When he first purchased the Steiner tractor he thought that he should only use it on the weekends, and not use it for leisure or business. The only legitimate purpose for the vehicle, to his way of thinking, was transporting him to church. The bishops indicated that he could charge the tractor with a generator but not from his house. Therefore, he resorted to charging the battery in the barn. This action complied with ecclesiastical teachings. In his church district, generators are not allowed in the home but may be used, in some circumstances, in the barn. For example, generators are permitted in the barn when used for power milking and other necessary farm equipment. However, there remained a problem with access, so P9 again petitioned the bishop for permission to extend a power cord from the house to the generator in the barn. A compromise was negotiated. This is how P9 discussed the events:

At first I just kind of use it over weekends. I got it in the fall and I think I just got it and used it in weekends. See, I couldn’t charge it up unless I had a generator, so at night I take it out to that little freezer house and plug it in and then I started using it more. At first the church wouldn’t let me use a generator to charge it up in the house. I could do things so much faster if I always got one hand free so now I asked the church if I could run a cord in and plug it in. The bishops said just at night. Now some churches might have been a little different but these here, our bishops here
work together real well. Of course, I’d like to see somebody in this wheelchair one day and they wouldn’t say anything. No, nobody ever said anything that I know. You know, some districts might be real strict on that but others they realize what it is.

P10 was proud to proclaim that he is using the same wheelchair that he bought 48 years ago for less than $20. He also bought a second manual wheelchair with coil springs for $15 in case the other one breaks. Prior to the manufacturing of the Steiner tractors, P10 exhibited innovation and inventiveness in making the first motorized wheelchair among the Amish. Although it was not as refined as the Steiner tractor, it did allow P10 mobility around the community. It was also the first example of technological adaptiveness for Amish people with disabilities. As he related the story of his ingenuity:

This is the same wheelchair I got 48 years ago. And it was used when I got it? You see I couldn’t push other chairs. This is a reclining back and I can lay down about flat you know. People make fun of my old wheelchair but I don’t like them folding chairs they have. I paid $20 for it. I’ve got another one similar to this but it’s got four wheels and coil springs under it. I paid $15 for it. I’m gonna keep it in case this one be broken. I also built a three wheel chair so that I could go where I wanted to. It was in ’53. The first one that was made and the bottom was a 4 by 8 foot sheet of three quarter-inch plywood. Then I built a box out around you know and I can just pull this ramp down wheel in, lock myself in place, pull the ramp shut and start the motor. Got a new one built in ’69 by my nephew. He built it for me.
and they didn’t charge me anything so I just gave it back to him. I figured maybe he’d give it to another handicapped.

P10 helped to put the differences between districts into perspective. Some bishops vary in their “slow time.” They are more restrictive and inflexible. Historically, this inflexibility has provided the catalyst for schisms among members. Amish people will move to districts more to their liking if they feel that the bishops are creating too much hardship. P10 indicated that, “there is a big difference in districts. Oh, some see a lot more modern things than others. How shall I say it, we have different rules and different laws and certain things that others don’t. Well the bishops figured it’s all right for someone who needs a Steiner, then there’s no problem with it.”

P2, a Swartzentruber Amish, is another example of the extreme differences among the Amish and provides the negative case example for this theme. As noted in the literature review, the Swarzentruber Amish change very little and much more slowly than the Old Order Amish. Differences between the Swarzentruber and the Old Order Amish became apparent when this interviewer was asked to remove his truck from the participant’s drive lane. Swartzentruber Amish do not allow automobiles in their lanes, and even require livestock haulers to park down the street in order to pick up or drop off cargo.

The Swartzentruber Amish also interpret the use of technology differently from the Old Order Amish. For example, when the tape recorder did not operate initially during the interview, the participant’s father remarked that it was God’s way of saying that they should not speak with a tape recorder; that only written notes would be allowed.
P2 also differs in the use of technology that facilitates mobility. He uses a hand operated pedal cart that he has used since childhood. It is a rustic, wooden cart on which he lies prone, and rotates the pedals with his hands. He indicated that he does not use it as much now because he has gained weight and is physically weaker than he was as a child. He relies solely on his family's assistance to travel beyond his home. Because of bladder functioning problems associated with the spina bifida, he does not travel long distances. He also requires assistance from his brothers to be placed on the buggy in order to travel to church. P2 rationalized his compliance with the Swartzentruber Amish mandates by remarking:

The church says no battery chair but that's ok because I have my hand pedal cart. I wouldn't want one of those battery chairs anyway. We just don't believe in motorized carts. Besides, what would I use it for anyways?

The second issue related to slow time is the way that the Amish view mainstream English society and its government services. Traditionally and stereotypically, the boundaries between the Amish and English have been more rigidly drawn. However, in crisis situations requiring emergency medical care and rehabilitation, the Amish have demonstrated their willingness and tolerance to use the services of medical healthcare providers as well as the American governmental sponsored programs.

P7 has not ever received support from the government but he claimed that he would consider that option if he needed the services. He also believed that his bishop would
support him in receiving government support depending on the kind of support. He expressed his view in the following manner:

No, I’ve not received any government aid at all um, I have friends in Pennsylvania that do. I’m not saying that I wouldn’t if the time would come if I would need something like that because I think it’s a great program. I don’t think the church would have an objection to it. I really don’t think so. It would depend on the kind of aid I would guess. I really don’t think today that would be a problem I don’t think.

P1 is financially secure with his ownership of a lumberyard. He indicated that he would not likely accept government help now, but admits that he utilized government services shortly after his accident and is now open to such support for other Amish people with disabilities. He said:

I wouldn’t take government help. I really doubt it. When I first had my accident, I was sent to the Bureau of Vocational Rehabilitation. Yeah BVR had helped me the first years. They helped me get this chair and get goin. Oh it was great. I would definitely recommend them. You know even then if I didn’t use BVR I could have went to the church, you know they’d have come up with some money you know for the bills if we didn’t have it ourselves or whatever.

Much like P1’s utilization of government vocational services when he needed help, P6 suggested that his church didn’t want him to use the Bureau of Workmen’s Compensation until they found out how much his hospital bills and rehabilitation was going to cost. This

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fact is especially significant because it indicates that the Amish may "bend the rules" when it is in the best interest of the community even if it may appear to contradict a fundamental principle. Allowing P6 to receive government support relieved his church of an overwhelming financial burden. As he explained:

Well at first the church they don't wanna have somethin to do with the Workmen's Comp, and of course, they found out how much it was and they didn't say much after that. They just accept it and no problem so far.

If they told me no then I would stop taking the Workmen's Comp.

P9 also receives cash payments from the State Rehabilitation Services Commission for personal care attendant services performed by his wife. He does not have permission from his church bishop to receive these monies. He indicated that the church helps with hospitalization but doesn't understand that, when one uses a wheelchair, there are other significant costs that he cannot afford. He offered the following rationale for the use of financial assistance:

No, I never did till last I have a friend in North Canton and he would come down a lot. He's in a wheelchair and he told me about this rehabilitation services that Sarah's been getting you know to help out. It's not Social Security. It's like I need help to do personal things. Personal care services? Yeah I have a good old PCA program. Yeah, I have to fill out paperwork every two weeks. See, uh since my accident the Amish doesn't realize how many more expenses I have than I had before. And, keeping up the wheelchairs I have to change the tires every year. My medicine for
my bladder problem cost me about $90 a month. So, I figure I spend two
hundred more per month now than before the accident. The Amish plans
don’t cover these costs. The church doesn’t know about it. I don’t know
if would allow it. Nobody knows. Oh, I just decided not to say anything.
That’d be the best way, I think. Yeah.

P9 was the one participant who expressed concern over expenses because of a lack of
Amish healthcare coverage. Plans do not cover prescription drugs and other ancillary
costs except hospital stays. As he indicated, “the Amish just don’t understand what it is
like to live with a disability.”

P2 and P3 didn’t see any reasons why they would need the government, because they
felt it was against their religion. Based on previous discussions in the interview, it would
appear that P3’s church bishop would not allow government “interference.” He
specifically cited Medicare as an unacceptable program. Similarly, P2 expressed how the
Swartzentruber Amish view government services. His position resonated the proverbial
separatist view from American government when he stated emphatically, “No!
Swartzentrubers don’t depend on the government for anything. We just take care of
ourselves.”

Although the participants frowned on the “interference of government support”,
several of them utilized support from non-profit agencies. P11, for example acquired a
wheelchair from the Muscular Dystrophy Association and P12 received monetary support
from the county United Way. Both P10 and P8 received support from the March of
Dimes and participants utilized other voluntary health organizations.
The theme of slow time highlights the participants' perceptions that the Amish will be flexible and change both when it is necessary and when it benefits them. The preference however, is to remain separate, self-sufficient, and slow to accept technological advances. The strong belief in reliance on oneself, one's family, and the Amish community, underscores the next theme presented by each of the participants.

**Self-Reliance**

In the English independent living paradigm, self-reliance and personal choice are extremely important elements. Ideally, control belongs to the individual rather than to professionals, government, or family members. The Amish stereotype is that the community as a whole is separate and self-reliant; however, control may be given to the community leaders, such as the bishop. The participants spoke at great length regarding their occupations and ability to contribute to the community and to make it on their own. The theme of self-reliance is heard as participants' voiced their future plans, their typical day, occupations, mobility, and their limitations.

Some of the most intriguing responses were those to questions regarding the future. The answers were the shortest responses in comparison to those of any other question. It appeared that the Amish are not future oriented. They do not have retirement programs. They seem to place the greatest importance on daily living and survival, rather than planning for tomorrow. The participants' philosophy regarding the future may be summarized as, "Lord willing." When asked about his plans for the future, P1 said that, "In five years, same thing as today, I hope. I don't see any changin.' Probably still the same in ten."
P4 had a similar response that echoed all of the participants’ voices about the future. He, like many others, laughed at the question and the interviewer. According to the participants, God has ordained a path for them, so why attempt to change or worry about it? This issue will be further defined in the subsequent discussion chapter because of its relevance to social work services to the Amish. Even P6, the participant who has not fully accepted his disability and believed that his paraplegia might be healed chuckled at the question: “Time will tell. I’m looking forward to if I can get back on my feet. Well, never can tell about ten years.” All of the participants reacted similarly. They had no plans and merely hoped that they could live and function as they are doing presently, not any worse and possibly a little better.

All of the responses to the interviews incorporated the relationship of the individual to the church, community, family, and/or occupation. These four threads are woven into the responses regarding each participant’s typical day. The part of a typical day most often mentioned concerned the participant’s occupation. P1 described his typical day as follows:

Typical day? I just, you know, get up and go to work until about 4:30, and then go home and work with the deer and whatever we got goin. Exotic animals. Well, uh, you know, I used to do quite a bit of huntin’ and then in ‘75 I got hurt. I had a cousin that was raisin’ white-tailed deer, and in ‘79 we bought our first two and started goin’ to exotic sales and stuff and it just went off from there.
Since then we’ve had, uh, the llamas, buffalo, monkeys, elk, about 150 deer and 6 wallaby. Had monkeys but they’re too stinky.

P4 also has a busy typical day with work usurping approximately twelve hours. The remainder is spent with hobbies, family, eating, and hygiene. It was also interesting that the typical day for P4 was defined according to summer hours because most of what he described, such as gardening and working on repairing his boat, are exercised in the summer months. Winter months are probably filled with the remaining activities of working, eating, and sleeping.

P5, a female participant, described a different type of day from the other participants. Although there isn’t a stated occupation, she certainly completed her fair share of household labor. As she stated:

Well, I do all my housework. I can even wash the rags if you let me. I’ve got a roll mop and I wash the walls. I mean, I really get tired my arms and stuff but hey, I do almost anything. The laundry, uh I did that for years and even hung ‘em up and got’em back down but I can’t hang them up anymore. I can do the laundry by the washing machine you know, I can sit there and do it but of course with my daughter home I don’t do it, you know but I can. I mean, it’s just a year or so ago that I did it. And I’m sure I could still do it and I do the cooking and the baking and the cleaning.

P7 also has an active day with office advertising work at a lumberyard. Of particular interest is that he spends a great deal of time working on the computer, which definitely
dispels outdated myths and stereotypes of the Amish. It was also interesting to hear his office radio playing contemporary country music during the interviews.

I get up in the morning and take my shower and get dressed. I get dressed in bed, uh, I can get dressed on the chair if I wanted to but I like to get dressed in bed because my legs are straight out and I don’t have to drag and all that good stuff. So I usually get in bed after my shower and get dressed. I’m out the door and I get back in around five. Basically, Oh, I do computer at work. Evenings are spent at home usually uh, workin’ at the house or at the garage or we go to her family, my family. There’s always something to do. Uh, just mess around in the garage. I like to go to auctions and I bought several things and refurbish them and clean ‘em up and sell them.

Participants also showed self-reliance through their mobility and travel. Stereotypes of both the Amish and people with disabilities are that they are homebound. However, all of these participants traveled across the world, including Canada and Alaska. PI provided a travel log that included resorts, international travel, shrimp boats, and even state parks. The following is his description of mobility and travel:

I can get myself in the buggy. We have a box in the back end of the buggy to put the wheelchair in the same as if it were a van or a car. I just hop up in. Mt. Hope Auction is basically where the exotic sales are and they got a handicapped bathroom in there. That Kidron Auction doesn’t have anything to use as a restroom. When we travel further than buggy we
pretty much use vans. As far as camping it kind of knocks that situation out. You know even motor homes most of them aren’t’ equipped good enough. I don’t say you couldn’t design one for it where you could get around with a wheelchair but most of them are compact enough with doors and stuff that you can’t go that way so you basically go with this van to a hotel or whatever. You know the Ohio state parks are not equipped for the handicap either. I’ve been to most of em. Years ago I found a lot more of them where some of the restrooms weren’t handicapped equipped, you know restroom-wise. You have to go from one McDonald’s to the next; you know it takes you forever. Yeah and everyone of em does virtually everywhere you can get accessible anymore. You know, it’s just, when we lived in British Columbia myself, sister and one of my brothers, went up a lake about 30 miles with a boat, and then hiked and camped. I even killed a caribou. You know, it’d be nice experience if I could go up with the boys and go up the same mountain or somethin you know. You know, it’s just for about 10 years that I’ve got friends from West Virginia that I buy lumber from. We used to go to South Carolina, just off of Hilton Head Island, there, and we used to go deer huntin’ two-three times a year, and then we’d just go to Hilton Head for a day stay on the beach and go shrimpin’ a day on shrimp boats.

All of the participants are active from sunrise to sunset and most of the day is spent enacting their work roles. Occupation seemed to be the most important
priority, excluding the church, in each of the participants' lives. Their behavior conforms to their culture's "Protestant Work Ethic." P1 echoed the theme of self-reliance when he spoke of his occupation. What matters is taking care of his family's immediate needs by providing for them. Again, there isn't a future orientation or concern about retirement. P1 indicated that his goal is to, "just to have enough health to make a livin' and support the family. That's all I'm worried about." P3 also spoke about his occupation. He was very affable and quite willing to talk about his life experiences with a disability. P11 indicated that her whole day was comprised of stringing beads to sell at local markets. Her energy capacity was limited to stringing three necklaces a day.

The most difficult moment in the interview occurred when P3 tearfully lamented over the loss of being able to farm. He indicated that it is very difficult every spring to watch the farmers plowing the fields and not be among them. P3 also stated:

Well, it just even now, all these years, 28 years in a wheelchair, when I watched the spring come in, I just think boy I gotta be out there plowin'. A lot of times I just think I should be out there. It just hurts to think about it. I accept the way I am and call it good to be alive. It's just like because I'm on the wheelchair I just do things what I can do.

P3 did not speak about his current occupation with the same passion as he had reminisces about farming. He stated more matter-of-factly:

Oh, I make corner shelves and recipe boxes. I also make flap ducks; they're a kind of a toy. When I make a batch, I make around 250. What
I'm doin' now is working with a wooden toyshop. I'm actually just like an employee for them. Wholesalers come in here and they can't buy it at the wooden toyshop so they come in here and try buying it. But I can't sell it cause the order is for someone else.

Although the Amish are slowly moving away from farming, because of the lack of affordable land, they still recognize farming as the preferred way of life. Those who were fortunate enough to have had land, and then because of disability lose the opportunity to farm it, appeared to be most affected by their circumstances. P9 also spoke about the loss of farming and the problems with finances. He explained how he taught himself to do wood crafting so that he could make a living. This disclosure was yet another example of Amish self-reliance. Just as P10 built his own motorized wheelchair, P9 taught himself woodworking in order to pay the bills:

I got a hundred acre farm here and we always farmed. I put in long days like from 4:30am to 10:00pm. I put in long days and milked cows by hand. Oh, most we ever milked was 18, just the two of us, that's nine apiece every morning and evening by hand. But then after my accident, why, I had a couple farm for me two years then he had chance so he left real good. Then a neighbor boy just got married and he asked to farm it. So he came up but he said he didn't really want to do it unless he got helpers. Then I just sold the cows and kind of rented the farm out. I did rent one year to an English guy then my neighbor wanted to farm it. So I came home from the hospital and the house did not have a ramp. So I went to
Keim lumber and bought the materials and tools and built it myself. Then I decided to teach myself woodworking and have been doing it ever since.

P6 recognized that farming did not produce enough income to provide for his family. He also knew that his sons were more interested in carpentry than farming. He rented the land prior to his accident and went to work for an English lumberyard. He recounted the following:

Well, the farming was rented out before the accident. Uh, just the neighbors doin’ it and, uh, the boys you know, I told them; hey if you want to farm, you’re welcome to it. They could do it. But you know farmin’ ain’t just too hot anymore. They just rather be doin’ construction. I’m just in the shop and I’m not in a partnership or nothin’. Yup, there is still the farm and I wish I could farm. I always liked it. I had to get up early in the morning to do the farming. I would do the milkin’ and go to work until the evening. I came home and the boys claimed I was always too tied up. So of course, I sold the cows and we just have heifers late in spring and ran’em in the pasture and then sold them in the fall. I got 40 acres here and a total of 64 acres I own.

Self-reliance involves not only the ability to work, but also the everyday limitations that the participants confront. P1 spoke, sometimes glibly, of his limitations until he began to talk and think back about how he used to hunt with his father. He began to weep at the thought that he could not follow the same trails with his sons, as he once did, with his father. P1 related the following about his limitations:
I dunno. There’re certain things you know that limits things that I can’t do. Then there are other things that with a little help, you know, I’ll get accomplished. So I can’t water-ski. I could have and thought about tryin’ with my braces. I got a set of braces where I could get my legs stiff but I mean basically all it gets down to is you can’t do whatever activity where you gotta use your feet. You know I still do some huntin’ on the 4-wheel drive tractor. But you know it limits me what I can hunt. You know as far as I used to go, I went after grizzly bear and mountain sheep. I was up in Alaska four times after rams, climbin’ mountains, but can’t go there anymore. The most difficult thing is gettin’ out of bed in the morning. Nah, it’s not that bad. I usually get up around 6:30 and part of the reason is so my feet won’t swell up. The only way to get them down is by layin’ flat layin’ in bed.

The above description from P1 illuminated that all of the participants were interested in physical labor and physical recreation. Amish men seem to enjoy hunting as the preferred recreational sport. P3 talked about getting stuck in the middle of the woods while hunting alone with his Steiner tractor. He eventually required a four-wheel drive vehicle to pull him out of the mud. P5, an Amish female, enjoyed outdoor gardening, physical labor in the home, and traveling. Although each of the participants spoke of their limitations, it was evident that each functioned physically at optimal level, and engaged regularly in a variety of physical activities. P8 also stated that he has limitations but still works and hunts:
I’m paralyzed. My legs and both sides is paralyzed. I do a lot of things that people don’t think I can do. I’ve traveled, go fishin’ and huntin’. I like to get out. I’m gettin’ ready to huntin’ tonight for groundhog probably. I think that pretty well covers it. Before I hurt my arm, I used to go to the bathroom and I could take care of myself but now my wife helps me a little bit, just to save my arm. I kind of had a terrible pain when I strained my arm. I can go to bed myself and take a shower by myself. We built our house after we was married so our bathroom is big and not on these little closet types, so I can turn around.

P7 also believes that his limitations do not make him much different from an able-bodied person. He believes that if you really want to accomplish something, then there is a way to do it. One has to live a different lifestyle, but life does not have to end. It is also interesting that P7 was the only participant that spoke of his medical condition in medical terms. He said the following:

Limitations, well I’m a T12, so that pretty well puts it from the middle of the waist down and that means there are limitations to stairways and reaching more than 6 feet out. But as far as limitations, if you want to, usually there’s a way of doing it. Oh, like I mentioned in the beginning, a different lifestyle, but there are not a lot of things you’re really limited to. It’s a daily routine for me. Sometime I get into jams, but I don’t think I’d get into any more difficult situations than, um, a normal able-bodied person
does. I have the basic frustrations that everybody else has. I enjoy life
kind of look at it a challenge.

Although all of the participants recognized some level of limitations, most comments
were limited to mobility problems and physical accommodation. Yet participants had a
variety of views on health issues. The final theme presented by the participants’ centers on
the area of healthcare.

**Healthcare**

Most Americans have concerns about access to and the rising costs of healthcare.
Such concerns are especially true among English people with disabilities. In fact, some
persons with disabilities forego employment in order to retain better government
healthcare coverage. There is also no provision in Amish healthcare for what English
persons with disabilities value, long-term care. The Amish expect that families will take
care of a person when needed.

The healthcare theme voiced by the Amish participants focused on Amish healthcare,
insurance coverage, preventative medicine, and alternative medicine. P5 explained her
health coverage in simple terms, again without mention of prevention or long-term care,
“They just have a fund when you need them. We all give to those who need it. It’s a
community and we try to help each other.”

P7 participates in the Amish Aid plan, which is provided for church members who
require inpatient hospital stays. Each member is assessed a fee to belong to the plan. P7
also maintains an English health insurance plan that is provided at work. Again, no single
Amish church district is the same. P7 indicated that some districts would not have
allowed him to participate in an English plan. He indicated that he really doesn’t need the Amish plan because of an extensive medical plan at work. However, he participates in the Amish plan to help others in the community because the more people involved in the plan, the lower the premiums and the better the coverage. He also wanted to make clear that it was purely altruistic on his part and not an effort for him to collect from both sources of insurance. The reader may recall that this is the same participant who stated that it was better to give than to receive. P7 stated the following:

"We had Amish Aid at the time of my accident. It’s a group and everybody that wants to belong to that group we’d get together and whenever there’s a hospital bill everybody chips in and helps to pay for it and that sort of thing. So that’s what happened. I do take health insurance at work now but we’re still part of the Amish plan even though right now with working now at lumberyard they offer a medical insurance. Not to try to collect from both of them. I like to stay with the Amish Aid and being part of it cause I want to help other people."

P3 like all of the other participants noted that he hasn’t seen a doctor for many years and only does so in an emergency. He explained his healthcare this way:

"All we have is this uh, in our church district is that they have church funds. They can help. We pay in so much a month. It’s a little bit like insurance, only it’s a different way. I haven’t been to the doctor in I don’t know how long. I guess since my ear burst out. It’s a long time ago. Why go?"
P8 describe two types of Amish healthcare plans: Amish hospital fund and Amish Aid. He explained as follows:

We have the Amish Hospital Fund. Well, actually there are two different funds.

We’re in the Hospital Fund. There’s one called Amish Aid and there’s one called Hospital Fund. Like when my wife had her surgery they paid about 80 percent, not quite 100 percent, but it helps.

One reality that challenges stereotypes of the Amish is that some participants’ accepted government support in the area of healthcare. P1 received vocational rehabilitation services from the Ohio Bureau of Vocational Rehabilitation, and P8 received cash payments for personal care services from the same entity. P6 related the fact that he was injured on an English job site and received services, healthcare, and cash assistance from the Ohio Bureau of Workers Compensation. P6 described the following:

Workmen’s Comp helped me because I was injured on the English job. I never found out the total and I never want to know what it is. Well they claimed it was up in about the many hundreds of thousands. Yeauh, they paid for my Pampers and all that stuff. They do pay everything. The church has a plan but they said Ok for the workers compensation when they found out how much everything was going to cost.

P3’s comment that he had not seen a doctor for as long as he can remember is consistent with every other participant. The Amish seem to avoid doctors, unless it is an emergency. All of the participants with an adult onset disability spent time in the hospital both for emergency and rehabilitation services. However, as noted in the previous
discussion about “slow time”, the Amish do not plan for the future; therefore, preventative medicine appears incongruent with their thinking. Additionally, evidence in support of their crisis-oriented approach to healthcare utilization is that annual medical examinations and prescription drugs are not covered under the Amish Aid program.

P1 was proud, almost boastful, about not seeing a doctor in twenty-five years. He verbalized his approach as follows:

It’s been about 25 years so I know about as much as the doctor does.

Everybody thinks that Amish are all the same but they’re really not. I was going to a different district when I had the accident than what we’re going now. And at that time, that particular church district just took care of their bills. We’d turn in the bills to that church district and they’d said how much each member owes. They’d make up the money that way without insurance. It never covers prescriptions. Yeah. Get drugged. I don’t take any drugs but am natural. I take some vitamin pills, but there’s no, uh, drug provision. I just don’t need to see any doctor.

P10 also felt no need to see a doctor on a regular basis. He, like many other Amish persons, utilized chiropractic for many of their healthcare concerns. It is viewed as a more natural approach to deal with illness. The chiropractors in the Wayne and Holmes counties also take great effort in accommodating the Amish by providing hitching posts for their patients’ horse and buggies and employing nurses who speak Pennsylvania Dutch. P10 stated the following:
Now, I hadn't seen a doctor, you know, since 1952. You don't want to see them for a while. I do know that one doctor I had at one time (or was it twice?) while I was still a boy but haven't seen one till a year ago when I had this stroke. That's the only time I remember that I got doctoried. I went to the doctor a few times when I had the gum abscess back here and of course he referred me to the dentist and that was it. Oh, yeah. Yeah. We have uh, hospitalization insurance or something like that. They pay all that. I went to uh a Wooster chiropractor for the three or four treatments. His aide working for him in there had polio and they told her she'd never be able to walk again and this one chiropractor she was working for gave her three or four treatments and she was back on her feet again. So she started working for him. So of course it don't work for all the people but it did for her but it cost quite a bit. I tried other things for 40 some years I was buying some minerals. I'm sure they helped mend that's been probably what kept me goin'.

P2 also only goes to the doctor when there is an emergency otherwise he counts on home remedies, over-the-counter-medication, and books. His father cares for him when he gets "sores" [decubitus ulcers]. They purchase medicated pads at a nearby pharmacy and apply them frequently. P2 indicated that there were always people in the church with home remedies to cure what ails one, but he prefers to read on his own. He indicated the following about Swartzentruber Amish healthcare and his particular approach:
I only go when there is a serious problem. Last time I saw a doctor I was 12 years old. I see a chiropractor in Mt. Eaton every once in awhile. We don't have insurance like the English. The church has some medical benefits but no insurance. We just try to help each other. I only go when it is serious, like the last time I was having trouble with my kidneys and there was a lot of pain. Now I use herbs and vitamins and home remedies. I also go to the chiropractor, not the medical doctor. I use a home remedy of vinegar and honey that helps my kidneys and some other kinds; I don't remember them right now. We just go to the pharmacy and get medicated pads. I don't use the drugs. They are band-aids. I read a lot too. That's the kind of guy I am. I read a lot of books. I have a book on home remedies.

P4 felt very strongly about seeing a doctor. He defensively dismissed the question as nonsense. "What do I need a doctor for?" He fundamentally echoed what other participants thought:

Don't see doctors. Last saw a doctor when I broke my legs. I never saw a doctor, now, till I was 15 years old. Didn't see one when I was growing up either. The church help is more or less a fund, you know, it's kind of nice to have. Just like when I broke my legs, they helped me out.

P9, like P4, held a similar view. He succinctly and emphatically asserted, "I don't need a doctor, don't have time and don't have the need. I just take care of myself and take a lot of vitamins and work."
All of the participants talked about their reliance on vitamins and chiropractor visits. As the reader may recall, P9 spoke of the chiropractor's nurse that he believed was healed from polio. There still appears to be a mystical view of healing and a substantial reliance on alternative medicines. These practices may relate to the Amish tradition of natural healing, as well as the high cost of prescription drugs and medical treatment for the Amish.

The next component of the healthcare theme is the participants' views on alternative medicine. This topic created the greatest schism between participant views. P7 provided these comments about alternative medicine and healthcare:

Oh, yeah you get about a 1,001 recommendations. Oh you need to try this, you need to try this, you need this massage kind, and you got to go to... and you can’t do everything. Basically we had a good friend that started stopping in at our house and he was a massage therapist. He was not a Chiropractor that adjusted bones and stuff like that but he was more of a massage guy. And he started stoppin in at our house and at that time. I guess we should back up a little bit in 1973 when they sent me home from the hospital they had physical therapy at the hospital which was low quality. I mean it was physical therapy but it’s not like they do today where they’ll send you to some rehab. place and your workin’ nine hours a day. They’d take you down to physical therapy for an hour a day and try to get you the basics but that was it. There wasn’t anybody in the state that took anybody under 16 yrs old. That wouldn’t work today so there’s really nothing else but to go home and this friend of ours now starts
stopping in and working with me. I give a lot of credit to him for getting me in as good a shape as I did get because he saw the need of exercise and the right diet. It was more to get me in the right shape than to try and get me back to walkin' again. He was always a very hopeful and positive thinker and I was too. Oh yeah, there are always all kinds of remedies home remedies. We grew up taking a lot of vitamins and uh, herbs for this or that, you know.

As mentioned previously, P6 has not fully "accepted" his disability. This may be best illustrated by his use of high-risk home remedies and expensive alternative medicines. When P6 was interviewed for this study, his feet were exposed because of the burns that occurred as the result of a home remedy. This "remedy" left his feet badly scarred and atrophied. P6 was told by someone in the church that he couldn't walk because of the poisons in his body that needed to be released through the toes. He recounts the event as follows:

Yeah, I put my feet in warm water with red pepper in it and then I used the shocker, the cattle prod. I put that in the water. Then when I took my feet out they looked normal. I put my socks on and the next morning I had these blisters so I don't know what caused it. They claim it was the toxic poison in my system that came out of the toes. For seven days it didn't look good it was really draining. The skin tore off loose then it was totally black. The nails I thought were gonna go because they were loose some but they're still hangin' on.
The effect of this “remedy” was harmful to P6 and required him to remain homebound for a significant period of time. However, this event did not thwart P6’s self-directed resolve toward a complete healing. P6 discovered that there was an English person who sold natural healing ointments. He didn’t want to rely on painkillers and other prescription drugs that were “unnatural” so P6 began to look for alternative:

I don’t go to the doctor much. OK, I stay pretty well natural. I used to for the first year take some medicine. I had so much pain. I knew there was gonna be some side effects. I took them pills for eight weeks. Well, then we heard about ascension oils. We started to using that a little. A guy from Utah that’s got this and some of the plants were extinct and he had to go and walk for miles to find it. Then he makes it down to just little bottles that you can get in different sizes. I mean different kinds and we’re using now about 9 or 10 different types of it. He at one time was paralyzed for 2 years. Now how bad, I don’t know. But he worked with just the oils and he’s on his feet. We just rub em on our feet and when I have so much pain she either rubs it on my feet and then my legs then here on my stomach. I lay on my stomach and she put it on my back. After about half an hour it kind of relieves it. We’re total off of them pills just workin’ with that oil.

It’s something that’s helpin’.

During the interview, a parcel post delivery arrived at his front door. There were several packages marked “fragile”. His latest shipment of “healing oils” had come. They were
small bottles of varying colors. There was a sense of excitement over the shipment. He continued to tell his story about these expensive products:

I actually was in this meeting in Cleveland about a year ago. It was just at a hotel but there was so many people that why when we got into the room they thought they’d all get in there packin’ around, trying’ to get everybody a seat. It was get so full that they were even standing in the hallway. It’s unreal how people get attached to this. He really helped somebody with their legs. There was this one lady who was kind of a volunteer to take up there and they’d start puttin’ this oil on and see you could see that she was kind of like had maybe polio or something. She was kind of crippled and she walked up and she was just a 48-year-old woman. She lay on a mat there and, uh, then he had people lookin’ at her. One in line with her head and one in line with her feet. He made a mark on her back where her spinal cord was crooked and they’d start rubbing this oil on her. I didn’t go up but an hour late, why, the spot that he had marked was just a little bit moved in that period of time. With that oil her spine straightened up. So, I don’t know. So, yeah I use that stuff. It’s expensive but it seems to work. Ascension oils and it’s somebody out of Utah that does that.

Ironically, P6 portrayed the Amish as susceptible and vulnerable to unproved cures and faith healing fads that appear in English society. P12, who was the most recent participant
who became paraplegic, also related similar feelings that P6 described. Interestingly, both P6 and P12 were the most recently disabled and both believe that they will walk again. When this researcher arrived at P12’s home, P12 was hooked-up to two batteries with wires attached to his feet and hands. Both hands and feet were also immersed in water; therefore, he was experiencing the same shock treatments as P6 had attempted. P12 indicated that someone in the Amish church had suggested the treatment in order keep the muscles active and prevent atrophy.
CHAPTER 5

DISCUSSION

In this chapter, the researcher used a discussion framework adapted from what Weiss (1994) described as a process of local integration. Local integration brings coherence and meanings from themes generated from the coded materials. Local integration evolves into grounded theory, which is a means to arrive at some general conclusions. The chapter will also incorporate reflections on methodology, limitations of the study, implications for social work practice, and recommendations for further research.

Integration of Findings

Through the process of local integration, three general themes emerged and provided a foundation for general conclusions: 1) personal and social acceptance; 2) social support and liquid boundaries; 3) changes in the utilization of technology and healthcare. These three integrated themes portray a general summary of the participants' voices during this research.

The theme of personal and social acceptance provided a foundation for all of the interviews. Each of the participants emphasized the need to accept one's disability. Livneh & Antonak (1997) distinguished between two types of acceptance, the cognitive type of acceptance, known as acknowledgement, and the emotional type, known as
adjustment. Acknowledgement is demonstrated by: a) an acceptance of oneself as a person with a disability, b) a new sense of self-concept, c) a reappraisal of life's values, and d) a search for new meanings and goals (p. 22). The above mentioned authors suggested that emotional adjustment manifests itself by: a) positive self-worth, b) realization of one's remaining and new potentialities, c) active pursuit and implementation of social and vocational goals, and d) overcoming the obstacles that arise in the pursuit of goals (Livneh & Antonak, 1997, p. 22).

Overall, there were some mixed findings among participants on both personal and social acceptance. Most of the participants appeared to have personally accepted their disabilities; whereas, some continued to search for a cure, sometimes to their own physical detriment, in hope of walking again. Participants' responses were also mixed regarding social acceptance. Some participants vigorously defended how their church and community had accepted disability; however, other participants lamented about the lack of physical accommodations, community members' penetrating staring (as though a person with a disability is an oddity) and the feelings of being excluded from important social events.

The majority, ten of the twelve participants, appeared to have arrived at the acknowledgement stage of accepting their disability. P6 and P12 continue to struggle with acceptance of oneself as a person with a disability. They continue to attempt experimental, and sometimes physically destructive alternative medical care with the belief that they will, and must, walk again. Both participants employ the use of electric shocks to their muscles, ascension oils and, for P12, the use of
acupuncture. All of the participants expressed the acknowledgment component of a reappraisal of life's values. P6 spoke of his newfound feeling about his family and how he appreciates spending more time with them subsequent to the accident.

The second type of acceptance noted by Livneh & Antonak (1997) is the emotional type known as adjustment. The component of a positive self-worth, realization of one's remaining and new potentialities, active pursuit and implementation of social and vocational goals, and overcoming the obstacles that arise, are not as clearly evident. This thinking may not be evident because concentrating on self is the polar opposite of yielding yourself to the community. Donnermyer (1999) referred to the term “gelassenheit” which means yielding to a higher authority. It represents the high value that the Amish place on maintaining a sense of community, which would be destroyed by too much individualism. Gelassenheit is a doctrine that controls the personal expressions of power. For the English with disabilities, independent living, personal choice, and autonomy are the goals; however, for these Amish participants, Gelassenheit is their ideal.

The one variation from this finding is that all of the participants, except the Swartzentruber Amish, overcame mobility obstacles by utilizing a motorized, rubber-wheeled cart that is generally forbidden technology. The participants received permission from the bishops. Subsequently, the use of motorized carts is now a practice that is tolerated within the community but only for persons with physical disabilities. This exception from the rules of the Ordnung is an example of the Amish community's acceptance of people with disabilities, and is facilitated
through decisions made by the bishop. The absolute decision-making power of the bishop is consistent throughout every Amish community; however, there is significant variation in the level of flexibility between Amish Orders and bishops.

P5 provided a summary of how the bishop, who serves for life, is selected:

The whole adult congregation has a turn to tell the elder whom they want to choose. Now he is the only one with his ear open, no one else hears the name. Nobody else hears it except the one that’s got his ear open, you know, and they have a paper and they write it down. Whoever has so many votes, usually three, will draw the lot to see whom God chooses. So, what we do is put a piece of paper in, it’s a scripture verse, in a songbook. There’s this one song that we sing in church all the time and we put the scripture verse in that page and we tie a string around the book and mix all the books up. Only one book has the verse and each of the chosen men have to pick from the songbooks and whoever has the paper is the bishop for life.

Kraybill (1989) also notes this, “flat, two tiered structure links grass-roots members directly to the citadel of power. The power structure of the bishops themselves, however, is based on age and tenure” (p. 83). Wasao (1995) observed that the Amish elders (i.e. ministers, deacons, and bishops) wield an inordinate amount of power and influence over the community. In fact, the senior bishops regulate the acceptance of major changes among the Amish. If the bishops do not like a practice, it may not be accepted until after their deaths when others deem it appropriate.
In the English independent living paradigm, self-reliance and personal choices, are extremely important elements. Ideally, control belongs to the individual rather that to professionals, government, or family members. The Amish community as a whole is separate and self-reliant. Individuals are expected to submit to the control community leaders, like the bishop. However, the participants spoke at great length about their work and their ability to contribute to the community, essentially, to make it on their own. Repeatedly, the theme of self-reliance is heard as participants' voiced their future plans, their typical days, occupations, mobility, and their limitations.

Some of the most intriguing responses were those to questions regarding the future. The answers were the shortest responses in comparison to those to any other question. It appeared that the Amish are not future oriented. They seem to place the greatest importance on daily living and survival, rather than planning for tomorrow. The participants' philosophy regarding the future may be summarized as, "Lord willing."

When asked about his plans for the future, P1 said that, "In five years, same thing as today, I hope. I don't see any changin'. Probably still the same in ten." P4 had a similar response that echoed all of the participants' voices about the future. He, like many others, laughed at the question and the interviewer. According to the participants, God has ordained a path for them, so why attempt to change or worry about it?

The importance of this discussion is that acceptance through adaptation requires a certain level of self-direction. If persons feel that they have no control over future outcomes, they may be less likely to seek solutions to their problems.
If persons have a sense of self-efficacy, they may attempt to exert control in order to achieve desired outcomes.

For these participants, there were mixed results regarding evidence of personal empowerment. Their daily living is defined by the Ordnung and by the elders of the church and none of the participants expressed future planning or activities. There was little evidence of preventative medicine and no discussions regarding retirement. The single participants indicated that they would never marry because "who would want to marry a handicap person?" P9 replied, "I don't know, it would have been hard. Well, who'd want to marry me, I'm a cripple." Throughout each interview, there was an obvious lack of self-efficacy, a belief in their own power to change their current circumstances. Each participant spoke of life as temporal and concrete. What remained important was gelassenheit and contribution to the community as whole rather than individualism.

The second general conclusion that emerged from the participants was articulated within the theme of social supports and liquid boundaries. Liquid boundaries refer to the flow of interaction and transactions between these participants and the English, specifically their use of support services within their communities and mainstream society, and participation in social events with non-Amish individuals.

As indicated previously, there were mixed findings regarding community support among the participants. Social events, family, and friends are a cornerstone of the daily life of the participants. Each of the participants spoke of
involvement in three main social environments, which were church, work, and community. Within the three, rituals and social events brought the greatest joy and pain out of the participants. Among the Amish there appears to be a central theme that weaves through each of the participant’s stories. The best way to describe this theme may be to use the participants’ word, “gathering.” One important gathering for Amish persons with disabilities is the handicap gathering, a social support system initiated by an Amish person with a physical disability.

Once a year, at the local and national levels, Amish persons with disabilities assemble together in what they refer to as the “handicap gathering.” This theme of “gathering” was repeated throughout the participants’ responses in relation to the handicap gathering, the role of friends, and “showers”, which are a social ritual that emotionally and financially supports the Amish person with a disability.

The participants also spoke fondly of their relationships with members of their families and people within their church district. Each recounted recent wiener roasts, softball tournaments, dinners, and other social events. All of the participants indicated how helpful their church members are when they need assistance. Perhaps there is no better way to describe the concept of Amish community then the practice of showers and benefits. P8 remembered fondly his showers and the support that he received. He expressed bewilderment that someone would send seven, one hundred dollars bills without telling his name. He also poignantly defined this theme of “gathering” by recounting the story that his neighbor provided a fundraiser to pay for needed orthopedic equipment.
As mentioned previously, community “gathering” also recalled unhappy realities in participants’ lives, such as exclusion from social events because of the lack of physical and perceptual accommodations. While many of the responses provided by the participants have a common thread of social acceptance, physical accommodation is another important element that illustrates, and perhaps, contradicts the theme.

In spite of the important need for community among the Amish, some gatherings are not accessible to persons using wheelchairs. The theme of accommodation was pointed out by each participant, and was perceived as a lack of accommodation at major social gatherings. Perhaps the most important gathering for the Amish is the church service because religion is the cornerstone and root of their existence. The Amish church services are held every other week in alternating members’ homes. Services often last the entire day. Each of the participants talked about difficulties with accommodation at church services, but some also indicated that members of the church were available to carry the person with a disability, if they required such assistance.

P7 also felt concern about the lack of accessibility for church services in Amish homes. He suggested that since he has been disabled someone should have at least built a ramp to accommodate his need. He again articulated that able-bodied Amish persons do not see the need because they will always help “drag you up the steps”. Church services are not the only events that pose a problem for physical accessibility. Church and community functions such as weddings and funerals also were identified as problem areas for each of the participants.
There also remain significant perceptual barriers for the participants to overcome. P7 discussed a difficult moment for him was during his adolescence. He stated that others treated him as though being physically disabled and using a wheelchair was comparable to being mentally ill. P5 and P7 summed-up the participants problems as being stared at by members of the Amish community. P7 compared it to how a dead person must feel at his or her own funeral, and P5 spoke of other women in her church who exclude her from collective baking because they believed that she could not accomplish the task.

Overall, the integrated themes of community acceptance are bittersweet for the participants. All have benefited from the fellowship and support provided by the Amish community; however, they have all been excluded, at one time or another, from important gatherings because of the lack of physical accommodations and outdated notions of people with disabilities.

Social support however, does not only come from within the Amish community. Each participant spoke about spending social time with English friends. Participant 5 referred to one friend as her non-Amish sister who she had more in common with than her own Amish sisters. Participant 1 spoke of non-Amish friends in Montana who he travels to see frequently for hunting trips. There appeared to be a sense of pride among the participants that they had branched-out from the Amish family tree to socialize with the English. This revelation appears to contradict an earlier perception that the Amish believe in total separation from the world (Hostetler & Huntington, 1971).
This liquid boundary, which is in a constant state of movement, albeit the current rate of change is slow, also includes the participants reaching out to government, quasi-government, and nonprofit groups for support. As described in this study's literature review, the Amish are not stagnant. They do adapt and change over time. These seasons of change however, are not on the English time clock but are determined by each church district. This writer suggests that this time clock is best described utilizing the Amish concept of "slow time". P1 literally described the Amish practice of slow time as follows: "Well, in the summer time they'd have slow time and you'd have fast. You turn the clock up one hour in the summertime and turn it back then in the fall. Where they just don't turn the clock." However, in a more figurative sense, slow time also conveys the reality of changes in the Amish way of life. As the previously rigid boundaries of separatist communities have become more liquid, the result is the limited incorporation of social and economic support outside of the Amish community.

The fact that many of the participants utilized government support also challenges previous ideas about the Amish view on separation from the world. Traditionally and stereotypically, the boundaries between the Amish and English have been more rigidly drawn. However, in crisis situations requiring emergency medical care and rehabilitation, the Amish have demonstrated their willingness to use the services of mainstream healthcare providers as well as the American government sponsored programs.

P7 has never received support from the government, but he claimed that he would consider that option if he needed the services. He also believed that his bishop would support him in receiving government support depending on the kind of support. P1 is
financially secure with his ownership of a lumberyard. He indicated that he would not likely accept government help now, but admits that he utilized government services shortly after his accident and is now open to such support for other Amish people with disabilities.

Much like P1’s utilization of government vocational services when he needed help, P6 suggested that his church didn’t want him to use the Bureau of Workmen’s Compensation until they found out how much his hospital bills and rehabilitation were going to cost. This fact is especially significant because it indicates that the Amish may “bend the rules” when it is in the best interest of the community even if it may appear to contradict a fundamental principle. Allowing P6 to receive government support relieved his church of an overwhelming financial burden. As he explained, “Well at first the church they don’t wanna have somethin to do with the Workmen’s Comp, and of course, they found out how much it was and they didn’t say much after that. They just accept it and no problem so far. If they told me no then I would stop taking the Workmen’s Comp.”

P9 also receives cash payments from the Ohio Rehabilitation Services Commission for personal care attendant services performed by his wife. He does not have permission from his church bishop to receive these monies. He indicated that the church helps with hospitalization but doesn’t understand that, when one uses a wheelchair, there are other significant costs that he cannot afford.

In addition to some of the participants’ acceptance of financial and program support from the government, some of the participants also utilized quasi and non-governmental non-profit groups for assistance. These groups included the former National Paralysis Foundation, Muscular Dystrophy Association, Easter Seals, United Cerebral Palsy, local
United Ways, and others. The participants received financial support and in-kind contributions of wheelchairs, assistive technology, and alternative healthcare.

The third general conclusion of this study involves the challenge of myths through the use of technology and healthcare among the participants. Donnermyer (1999) considered Amish selective use of technology as a core feature of their society. In short, Amish persons with disabilities are making use of assistive devices previously denied. The researcher originally believed that the Amish must suffer from misoneism, which is the fear of technology. This perception appears fallacious in that the all of the Amish participants, except Swartzentruber P2, utilized technology to adjust to mobility impairments. One of the most important issues for people with mobility impairments, in all of American society, is the advance in technology. For many people with physical disabilities, advances in technology are facilitating more opportunities for employment, greater independent living, and fuller inclusion into mainstream society. For the Amish, technology use must “fit” within the parameters of the Ordnung established by each church district. The Steiner tractor is a three wheeled motorized tractor with a cart attached. It allows a person in a wheelchair to ascend a platform and operate the vehicle. Traditionally this vehicle would not be allowed because it has rubber tires and is motorized. For the Amish, according to P1, the use of technology “boils down to common sense.”

As a result of this relatively substantial use of technology among the Amish, the participants may actually be the catalyst for changing views of technology within the community. Many think that the Amish are slaves to tradition. However, Olshan’s (1981) views concurred with the perceptions of the Amish participants in this study. He wrote
that the Amish accept or reject innovations or practices based on whether or not the innovations or practices are compatible with their core values and beliefs. They are flexible in adopting changes that are appropriate to their scale of operations on the farm and that are not disruptive of their way of life. For instance, although they generally reject the use of tractors, they have adopted the use of other new agricultural implements such as mechanical hay loaders and manure spreaders (Olshan, 1981).

At the very least, the church leadership has made a conscious decision to recognize and allow the need for the participants to have access to technology necessary for greater independent living. The church leadership has also permitted the utilization of government support for many of the participants, which challenges previous literature asserting that the Amish completely refuse government support.

The final component of this general conclusion derived from the emerged themes is that of healthcare among the Amish. The importance of this conclusion may be attributed to the contentious nature of the topic. Of all the issues and perceptions the Amish participants related, alternative healthcare was the most divisive. Participants were sharply divided and reactions were greatly mixed regarding the use of alternative and folk medicine. The source of this tension may be within a battle of tradition and change and how Amish persons want to be viewed. P7 suggested that the English want to portray the Amish as backward, mystical, and stuck in the 18th century.

The healthcare theme voiced by the Amish participants focused on Amish healthcare insurance coverage, preventative medicine, and alternative medicine. P5 explained her health coverage in simple terms, again, without mention of prevention or long-term care,
“They just have a fund when you need them. We all give to those who need it. It’s a community and we try to help each other.” P9 was the only participant who expressed concern over expenses because of a lack of Amish healthcare coverage. Plans do not cover prescription drugs and other ancillary costs except hospital stays. As he indicated, “the Amish just don’t understand what it is like to live with a disability.”

Because of the lack of existing research related to the lived experiences of Amish persons with disabilities, this study used a qualitative approach, specifically grounded theory. According to Glaser & Strauss (1967), grounded theory is the generation of theory through inductive analysis of qualitative data. In other words, rather than imposing theory a priori to an area of study, hypothesis and theory emerge from the data and are “systematically worked out in relation to the data during the course of the research.”

Through the methods of grounded theory, coded transcripts yielded themes and the themes produced local integration. The integrated themes have now generated grounded theory, which focuses on level of independent living and external involvement among the Amish participants.

The Amish community is much more than a physical setting of church districts within Holmes, County, Ohio. Kreps et. al. (1997) suggested five important roles of the community that serve the Amish: the maintenance of a self-sufficient economy; socialization; social control; social participation; and mutual support (p. 62). The two issues that have emerged from the participants in this study challenge and further delineate the role of the Amish community (Kreps, et. al., 1997).
It may be that this social control within the Amish community is a direct contrast to the independent living philosophy of mainstream society.

The three cornerstones of the independent living movement are consumer sovereignty, self-reliance, and political and economic rights. The philosophy views disability as an interaction with society and the environment rather than a medical condition or physical or mental impairment (DeJong, 1979). A natural comparison of the English paradigm of independent living and the extent of independence within the Amish community began to emerge in the course of the research.

The initial bias for this researcher was that Amish persons with disabilities have a greater level of independent living than the English because they do not receive government support, they all work and are self-sufficient, and they live within the community rather than institutions. PI believed that the Amish community provides a different support system from the English, which makes acceptance easier. He suggested that the governmental method of support is one that leaves a person at home and pitying oneself.

The perceptions of the majority of participants in this study appear to argue with this point. The participants exert very little individual personal control over decision-making. The rules of the bishop and Ordnung dominate the decision making process. Personal freedoms are given over to the community through Gelassenheit, which means yielding to a higher authority. An Amish quasi-governmental hierarchy supplants the English dependency on government. Not only does the bishop provide the rules, he also provides health insurance and other social service types of financial support.
Traditionally, non-compliance with the rules may lead to excommunication, a consequence that English people with disabilities do not have to endure. The participants in this study, however, have not lived with the threat of excommunication. Many of the participants have not wholly complied with the Ordnung, and have self-determined the satisfaction of particular needs. For example, most of the participants used motorized, rubber-wheeled vehicles, used generators, and received government financial assistance. Their deviance has been sanctioned, ignored, or merely tolerated by their bishops.

Secondly, the participants' level of independence was limited because of architectural and perceptual barriers. Important life events, such as funerals and weddings were inaccessible to the participants. Additionally, most of the participants believed that the Amish still have not fully recognized that people with disabilities have something to contribute. For the most part, people with disabilities are still considered an oddity that is evident by the proverbial Amish stare. Comparable to English persons with disabilities, these Amish participants are limited by architectural and attitudinal barriers.

Lastly, the Amish participants' level of independence was limited in the use of technology. The participants do not have access to the advanced technology of the English. For example, participants who once farmed cannot incorporate important technology that would allow them to continue to farm or to become viably employed within another field of interest. However, some of the participants showed significant adaptive creativity in inventing technology such as a motorized scooter from plywood and a lawnmower engine.
The Amish view on technology and technological change, however, is easily misunderstood. Although the participants are more limited than the English, they do have greater access than other members in their church. Again, the Amish view on technology does not stem from misoneism. The Amish appear to view technology as something that is ancillary to their cultural identity. However, the last component of this grounded theory section discusses how these participants may be moving the Amish cultural fence both in terms of technology and outside influence.

The Amish, as a community, try to maintain boundaries between themselves and the mainstream of American life. Yutzy’s (1961) definition of the Amish as: “Anyone associated with the group’s population who practices a ritual separation from the world by way of social, cultural, and religious distinctions” (p. 17) is somewhat challenged by the participants in this study.

Kraybill (1989) delineated fourteen methods for determining if technology would be accepted. Specifically, the participants in this study contradict the following four:

1) noticeable changes are more likely to be rejected than less noticeable ones; 2) changes that encourage regular, systematic interactions with outsiders are less acceptable; 3) changes that open avenues of influence from modern life are less acceptable; and, 4) Changes that elevate and accentuate individuals are less acceptable than those that promote social equality (Kraybill, 1989).

Ironically, the participants in this study may be moving the Amish fence. All, with the exception of the Swartzentruber Amish participant, have access to motorized, rubber-tired vehicles and even golf carts. The participants also have significant contact with outside
resources that include government supported programs and cash assistance, quasi-
governmental programs and services, national disability associations, and other social
service organizations. Furthermore, some have forged friendships with the so-called
“English” outsiders. The participants in this study may be informative about living with a
disability within the Amish community; however, they may also be revealing their role as
agents of social change in moving the lines of demarcation between their community and
mainstream American society.

Reflections on methodology and research

A reflexive journal was maintained during the entire research process, which assisted
this researcher with assessing personal biases and techniques during this study. Some of
the journal entries were later employed within the body of the research to augment the
findings. In that qualitative research is fluid, the reflexive journal also helped to keep track
of personal judgments, concerns, problems, and areas in need of improvement.

There was evidence of a language barrier at times between the researcher and the
participants. Denzin & Lincoln (1994) wrote that it is very difficult to study direct, lived
experience, because language, speech, and thought mediate and define the very experience
one attempts to describe (p. 356). It was very important for the researcher to realize that
language could be a problem given that the purpose of the research was to give voice to
the participants. Language barriers were mainly evident in the discussion about the topic
of alternative medicine. During the initial interview with the participants the researcher
queried the participants regarding the powwow. However, P8 was the only participant
that spoke of the “pow wow” faith healing technique, which he referred to as “outdated
witch-doctoring.’ It wasn’t until the end of the first interviews that this researcher stumbled upon the term “brauching” while interviewing P12. The epiphany of the importance of language with the Amish was very striking because “brauching” is very controversial within the Amish community. The term was almost completely missed because of a language barrier. In fact, P3 initially did not understand the term “pow wow”; however, once the correct term, “brauching” was used, he proclaimed that he had the gift, which he inherited from his mother.

Additionally, there was evidence of cultural barriers as well. There were times when the researcher was required to spend considerable time in explaining what seemed to be the simplest of concepts, such as: “who do you live with?” because the Amish are very concrete thinkers. It was also important to learn that the Amish do not plan for the future. Glesne & Peshkin (1992) advised:

> By whatever means obtained, the questions you pick must fit your topic: the answers they elicit must illuminate the phenomenon of inquiry. And the questions you ask must be anchored in the cultural reality of your respondents: the questions must be drawn from the respondents’ lives (p. 66).

There was also evidence of cultural differences between Amish orders. This writer immediately became aware of differences between the Swartzentruber and the Old Order Amish when he was asked to remove his truck from the participant’s drive lane. Swartzentruber Amish do not allow automobiles in their lanes and even require livestock haulers to park down the street in order to pick up or drop off cargo. The Swartzentruber
Amish interpret the use of technology in a way different from the Old Order Amish. For example, this writer’s tape recorder did not operate initially. So, the participant’s father remarked that it was God’s way of saying that they should not speak with a tape recorder, and that only written notes would be allowed.

Limitations of the study

This research embodies the limitation of the human instrument, which is the researcher attempting to understand and explain the Amish participants perceptions of living within their culture and community. The findings are also limited to Amish persons who use wheelchairs and may not be transferable to other Amish persons with disabilities. It is important to note that research findings should not make global statements regarding the Amish. There are significant degrees of variance in decision-making and levels of change within Amish affiliations and church districts. All of the participants were adults and only one participant was a member of the Swartzentruber Amish Church; therefore, the participants were mainly from the Old Order Amish community.

There are also limitations related to the sample in this study. The sample is disproportionately male, ten out of twelve; therefore, the Amish male perspective dominates the findings. Access to Amish women with physical disabilities may have been more difficult to gain because married Amish women do not usually work outside of the home, and, therefore are restricted in their contacts with English outsiders.

The study was also limited to adults. Furthermore, there were no questions regarding sexual functioning, which may be a significant issue when there is paraplegia.
The absence of questions regarding sexual functioning may have limited the study because the issue can influence self-image, marital status, and the ability to fulfill the Amish community’s expectations of procreation and large families.

Implications for social work

There has been a paucity of social work literature regarding both people with disabilities and outreach to the Amish community. Dramatic changes in our nation’s demographics, reflecting a growing population of individuals from diverse backgrounds, warrant the development of knowledge and understanding necessary to serve effectively people from other cultures. However, it is also crucial to observe from the data obtained in this study, that the Amish display much intra-group diversity. Acceptance or rejection of innovations, technology and government assistance, as well as changing beliefs and values, is clearly evident among different church districts, bishops, communities, and Amish individuals.

Through this research, it has become evident that the Amish may be open to additional health and social services that are consistent with the changes that they have initiated and implemented. Social workers should note that the Amish are not necessarily resistant; rather, they are more cautious and slow to change. Secondly, social service providers must recognize the core values of the Amish community, especially the role of religion as the cornerstone of their lives. Disability service providers should note that the values of independence, autonomy, self-determination, and individual achievement that are emphasized in traditional forms of counseling people with disabilities can be, at times, incongruent with the group-oriented values and communal way of life of the Amish.
Lastly, this research is significant to social work because it provides an impetus for further research. Gilson, Bricout, and Baskind (1998) suggested that social work literature, research, policy, and practice related to persons with disabilities, has lagged behind other topical areas dealing with oppressed groups. This research opened the research discussion on living with a disability in a traditionally closed community i.e., apart from mainstream society in a different physical and social environment. Furthermore, it emphasizes the need for increasing numbers of studies on how ethnicity and religion can alter the lived experiences of persons with disabilities.

Recommendations for Future Study

Current scholarly literature regarding the Amish is not wholly consistent with what this researcher discovered about the Amish. It is imperative for future researchers to approach the Amish without preconceived ideas garnered by popular portrayals or scholarly research. This inaugural study has provided an entry gate into the Amish cultural fence among people with disabilities. It is important that future researchers understand that they must gain access through appropriate, established channels. Ignoring this suggestion may greatly reduce the level of trust between the Amish and English researchers.

More qualitative research is necessary to assess perspectives from and services to Amish children with disabilities, Amish adults with other types of disabilities, members of other Amish settlements, as well as the more conservative Swartzentruber Amish. Additional research is needed among intra-group Amish orders to discover the lived experiences of more Amish persons with physical disabilities and to compare similarities and differences with the themes and interpretations of this study.
It is also important for future researchers investigating such groups as the Old Order Amish to gain access through appropriate protocols and by obtaining permission from established community leaders. This researcher was able to conduct this study only after working through several liaisons with the Amish. Additionally, as a white male, he had an advantage in approaching the white male authorities who are religious leaders and the white males who dominate the sample. However, as an English male he may not have had access to Amish women. Therefore, female researchers may best undertake future study of the lived experiences of Amish women. Moreover, continuing naturalistic inquiry into the social and personal realities of Amish women, men, and children with disabilities can assist social workers in understanding how to achieve success in reaching out and serving other self-contained communities and culturally diverse groups.

The three general conclusions of 1) personal and social acceptance; 2) social support and liquid boundaries and, 3) challenge of myths regarding technology and healthcare, provide a better understanding of how the Amish participants define their lived experiences with disability. This research has facilitated a new awareness of both individual and community life among the Amish. The Amish do adapt and change, albeit slowly, yet they remain faithful to their own religious and social ideals. It may be that improved professional response to the needs of Amish persons with physical disabilities might serve to facilitate better relations between the Amish community and mainstream American society.
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APPENDIX A

CONSENT FORM

I __________________________ hereby consent to participating in the research project regarding Amish perceptions of living with a disability. The researcher and interviewer Douglas Huntt, for the principal investigator Dr. Bette Speziale of The Ohio State University College of Social Work, has explained the purpose, procedure, and time commitment for the study.

The purpose of this project is to improve understanding of Amish persons with mobility impairments' and their perceptions of living with a disability in the Holmes County Amish community. I understand that I have a right to obtain additional information regarding the study and that any questions I have raised will be answered to my satisfaction.

I understand, as a participant, that the interview will last approximately one and a half to two hours and I give my permission for the researcher to audiotape the interview. I also understand that I may withdraw from this project at any time and that I have the freedom not to answer or discuss any issue that I do not want to.

I understand that my name will not be used in any publication or professional meeting. I understand that all information obtained will be kept confidential; that the tapes will be stored in a locked filing cabinet located in the interviewer’s private office and that the audiotapes will be destroyed two years after the completion of the project.

I acknowledge that I have read or heard and fully understand the consent form. My signature represents my agreement to voluntarily participate in this research study.

Signed ___________________________________ Date ______________
(Participant)

Signed ___________________________________ Date ______________
(Researcher/Interviewer)

Signed ___________________________________ Date ______________
(Principal Investigator)

Witness ___________________________________ Date ______________

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APPENDIX B

INTERVIEW GUIDE

- Who do you live with?
- What does disability mean to you?
- Tell me about a typical day in your life.
- What, if any, limitations do you think that you have?
- What are the most difficult things to accomplish during the day?
- Who helps you when you need help with personal tasks?
- What is your health care like?
- Tell me about your schooling?
- How did it feel to grow up with a disability?
- What differences do you see before you became disabled and after?
- Do you think children that grow-up with a disability have major differences then someone who experiences disability as an adult?
- How did you feel about your disability while attending school?
- If you could change the way people see you, what would the change be?
- What would you like to accomplish occupationally?
• What do you see yourself doing in 5 years from now?

• What will your life be like in 10 years from now?

• Do you think that you would ever receive support from the Government?

• What are the things that make you happy?

• What are the things that make you sad?

• Tell me about your friends.

• What types of activities do you enjoy when you are away from home?

• How do you get around in your wheel chair when you want to go to church, school, or social activities?

• How do Amish people see you?

• How do you think "the English" see you?

• What do you like about being Amish?

• How does the Ordnung affect your disability?

• How do the bishop, elders, and preachers view your disability?