ABSTRACT

An Examination of Disability Care: Contemporary Practices and Ways L'Arche
Communities May Shape Them

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L'Arche communities are Christian, faith-based communities where people with and without disabilities share life with one another. This international organization is a unique example of what it looks like to fully embrace differences between persons and practice life together. The purpose of this thesis is to examine the unique characteristics and practices of L'Arche communities, and to suggest ways in which these qualities can be adapted to contemporary practices of disability care in physical therapy. I first give a brief history of disability care in the United States, followed by a survey and analysis of contemporary models of disability in the United States, the anthropologies that support them, and how these models play out in disability care. Contemporary practices in disability care are largely shaped by the medical and social models of disability, but share a common anthropology of personhood and value. However, L'Arche challenges the account of personhood informing many of today's practices. By considering the characteristics and practices of L'Arche communities, disability care via physical therapy can be shaped and perhaps improved on.

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AN EXAMINATION OF DISABILITY CARE: CONTEMPORARY PRACTICES AND

WAYS L'ARCHE COMMUNITIES MAY SHAPE THEM

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CHAPTER ONE

Introduction

I first became interested in L'Arche after reading the works of Henri Nouwen and

Hans Reinders.  L'Arche, an international network of faith-based communities where

people with and without disabilities share life together, is a unique example of what it

looks like to fully embrace and celebrate differences between persons.  Nouwen and

Reinders have both experienced L'Arche, and each describes the profoundly

transformative relationship between assistant and core member in which each person is

fully embraced and valued for their differences, not in spite of them.  In L'Arche

communities, people with disabilities, called core members, live in solidarity with

assistants and volunteers in their community.  In *Adam: God's Beloved*, Nouwen writes

about his friendship with Adam Arnett, one of the core members in the L'Arche

community.  Nouwen was humbled by his friendship with Adam, and he felt that Adam

was a teacher to him, helping him learn more about himself and his faith.  Many people

embracing contemporary Western understandings of personhood and value might think

Adam had little to offer, but Nouwen saw gift and significance in Adam.  Upon reading

about Nouwen and Adam's friendship, as well as Reinders' experiences in L'Arche, I

began seeing a distinction being made regarding the role of assistants in L'Arche

communities: they are there to be with core members, not do things for them or merely to

take care of them.  I began thinking about how I could remember and apply this quality of

friendship and other characteristics of L'Arche that were distinctive to me when I begin

practicing as a physical therapist. It seemed to me that this type of friendship could create an environment in which both patient and physical therapist could give and receive from one another, and I wanted to explore this more.

The purpose of this thesis is to examine the unique characteristics and practices of L'Arche communities, and to suggest ways in which these qualities can be adapted to the practice of physical therapy. I will proceed by first giving an overview of the history of disability care in the United States in order to see how contemporary practices have been shaped and developed. Second, I will survey and analyze contemporary models of care in the United States and the anthropologies that support them. In doing so, ways that present-day understandings of personhood and value shape how we think about disability and disability care will emerge. Third, I discuss the history, characteristics, and practices of L'Arche communities and the anthropologies that shape L'Arche in order to similarly identify how these aspects of L'Arche shape the way it approaches disability and disability care. Lastly, I will posit ways in which L'Arche practices can help shape current theories and practices in physical therapy.

The second chapter will give a summary of the history of disability care in the United States. I will outline the different understandings of disability, models of care, and key movements for disability rights leading up to the present status of disabled care. Throughout history, care for people with disabilities has been shaped by the way society interprets disability – where it comes from and why it happens. Because interpretations of disability have changed dramatically over time, so has disability care.

The third chapter of this thesis reviews the medical and social models of disability. The former focuses on physiological impairment, while the latter on societal

constructs that prove disabling.  Both medical and social factors are involved in the disability experience.  Uniting these two models is a common, contemporary account of personhood, ultimately stating that a person is valuable if he or she can be independent and self-sufficient.  Concluding this chapter is an examination of the works of Thomas Reynolds and Hans S. Reinders, who provide critiques of the cult of normalcy permeating contemporary culture and the two secular accounts of disability.  Challenging the generally held understanding of humanity and value is the international network of L'Arche communities.

The fourth chapter of this thesis offers a history and describes the practices and characteristics that are definitive of L'Arche communities.  Jean Vanier, founder of L'Arche, began his first community in 1964 after visiting some of the institutions in France and seeing a desire for close relationship that many of the residents had.  From his initial home in Trosly, L'Arche communities spread to countries all over the world.  Many distinctive characteristics and practices of L'Arche have developed.  I will identify five in particular that can inform care practices of physical therapists.  These five include friendship, celebration, humility, vulnerability and patience.  Lastly, I discuss personhood and value as understood by L'Arche, and compare them to the more common contemporary Western understandings. L'Arche's understanding of disability, personhood, and value affect their practices and care for people in their communities. Ultimately, and very different from the contemporary account, L'Arche provides a non-exclusive account in which nobody is marginalized due to disability.

In the fifth and final chapter of my thesis, I consider how physical therapists might develop and shape current practices and theories of care by looking to certain

aspects of L'Arche and its understanding of disability, personhood, and flourishing. I review what physical therapists do, what some common goals of treatment are, and what the expected role of a physical therapist has traditionally been. Goals of physical therapy interventions tend to revolve around restoring physical function to a "gold standard of normal independent functioning."[1] Typically, physical therapists have seen their role as doing for their patients versus being with their patients. At L'Arche, the role of assistants is the reverse – they see themselves as being with core members, not doing for. Although L'Arche and the field of physical therapy are not the same thing and the relationship between patient and physical therapist will naturally have differences from the relationships in L'Arche communities, L'Arche is relevant to physical therapy. Assistants in L'Arche can provide examples of certain qualities and practices that physical therapists can adapt as their own in order to foster the same type of mutually beneficial relationship seen between assistants and core members.

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1. Sandra L. Kaplan, *Outcome Measurement & Management: First Steps for the Practicing Clinician* (Philadelphia: F.A. Davis Company, 2007), 43.

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CHAPTER TWO

History of Disability Care

Care for people with disabilities is largely influenced by the way society understands disability. Attitudes toward and beliefs about people with disabilities have changed dramatically over time, and as a result, so has the treatment and care of people with disabilities. This chapter will survey the changes and developments in how people have understood disability, and how the treatment and care for people with disabilities has progressed with these changes. Beginning with the ancient era, disability was largely understood as an effect of divine or spiritual activity, and treatment was very limited if it happened at all. The rise of Christianity as the principal religion in the West, progresses made in the Enlightenment era, and the effects of the Industrial Revolution all had an impact on how disability was understood and treated. The deinstitutionalization movement of the late twentieth century began a demand for community services for people with disabilities and many of the models of care seen today.[1]

*Ancient Era*

During the ancient era, people explained natural phenomena by attributing their causes to gods or higher spiritual beings. Infants born with a disability were seen as omens from the gods. Physical disabilities were seen as either good or bad messages to be interpreted. In Babylonian culture, infants with disabilities were highly honored

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1. I am grateful to the Minnesota Governor's Council on Developmental Disabilities for publishing an extensive outline of the history of disability, called "Parallels in Time", around which I have oriented my chapter.

because of the messages they were thought to bring to their communities.[2] From the ancient era until the Enlightenment era, when progress was made in the sciences, disability remained primarily explained by spiritual or religious ideas. There were exceptions to this belief, though. In the fourth century BCE, Hippocrates hypothesized that etiologies of disease were physical rather than divine. He contended that physical or mental illnesses were a result of an imbalance of the four bodily humors: blood, phlegm, black bile, and yellow bile. Physicians treated patients by attempting to bring balance back to the four humors. He devoted several writings to explaining epilepsy in terms of the four humors, saying that the disease was a result of excess in phlegm humor. Hippocrates also includes descriptions of therapeutic methods in his works, including fracture reduction, crutch-like devices, the use of orthotics, and methods of humoral management.[3] Recognizing physical causes of disability, Hippocrates sought to develop treatment and cures for people who were ill or disabled.

Despite Hippocrates' efforts, Greek and Roman culture continued to view disability in a negative light. Greeks and Romans valued a very specific image of the human person. These two peoples believed they exemplified the ideal human in both body and mind, and deviation from the ideal physiology of the Greek or Roman man was measured as inferiority or defect. Physiognomy was a common practice in which a

2. Kathryn L. Moseley, "The History of Infanticide in Western Society," *Issues in Law & Medicine* 1, no. 5 (1986): 346.

3. Walton O. Schalick, "Hippocrates (428-347 bce)," In *Encyclopedia of Disability* (Thousand Oaks: Sage Publications*,* 2006,) http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/sagedisab/hippocrates_428_347_bce/0.

person's inner character was measured by their physical characteristics.[4] Physical disabilities were interpreted as corruptness in moral character or lack of a specific virtue. Connected with a physiological exceptionalism was a geographic centrism.[5] The further geographically away people were from the centers of Greek and Roman civilization and culture, the more inferior they were imagined to be. Accounts of monstrous beings and frighteningly different persons were described inhabiting regions beyond the boundaries of the Greco-Roman world.

According to Aristotle, man was a highly rational animal capable of excellence in reason and physical development, and anyone with a disability fell below the set standard; they were faulty humans. Aristotle argues that there should be a law "that no deformed child shall live" (*Politics* 7.16). The Greek and Roman idealization of the human person continued until the fall of Rome in 456 CE. From the Hellenistic age through the Roman Empire, people with disabilities generally were treated poorly. It was a common practice for infants to be examined by community elders after birth for both health and spiritual reasons.[6] Newborns with physical disabilities were viewed negatively because of their disabilities, and were often taken to be bad omens.[7] Infants who were found to be deformed or weak were often killed or left on their own, a practice called "exposure". Exposure was a passive way of carrying out infanticide which involved leaving the infant alone and exposed to the environment. The rise of

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4. Mikeal C. Parsons, *Body and Character in Luke and Acts,* (Grand Rapids: Baker Academics, 2006), 17.

5. Ibid., 24.

6. Susan Hatters Friedman, James Cavney, and Phillip J. Resnick, "Mothers Who Kill: Evolutionary Underpinnings and Infanticide Law," *Behavioral Sciences & the Law* 30, no. 5 (September/October 2012): 586

7. Moseley, "History of Infanticide", 346.

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Christianity led to the establishment of penalties for infanticide and brought a change in perspectives and care of people with disabilities.

After Constantine (272-337CE) became emperor and patronized Christianity, he helped secure Christianity's wider recognition and respectability. In 318 CE, he ruled that infanticide was a crime equal in punishment to homicide.[8] The establishment and spread of Christianity as the dominant religion brought about more humanitarian virtues, such as charity and compassion. Just as Jesus showed kindness and tenderness to the lame, blind, and disabled, Christians wanted to practice these virtues, too.[9] This led to more humane treatment and care of people with disabilities. Hospitality towards others, including both the familiar and the unfamiliar, was a valued practice during the early church. Monastic orders in the fifth century developed wards that functioned as charitable refuges where people with disabilities could find care and shelter.[10] These wards continued to spread and expand through the sixth century and into the Middle Ages.

*Middle Ages and Enlightenment*

During the Middle Ages (500-1500), people with disabilities continued to be seen as "children of God"; they were seen as those that God marked for special care. The belief was that if the able-bodied helped care for people with disabilities, they would be

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8. Ibid., 352.

9. The Gospels are replete with accounts of Jesus modeling compassion and charity towards individuals with disabilities. In particular, I would highlight Jesus' healing of the man born blind (John 9:1-12) and the man paralyzed from birth (Matthew 9:1-8). Likewise, Jesus offers a broad command to hospitality and acceptance of the poor, crippled, lame, and blind in Luke 14:12-14.

10. Nancy G. Siraisi, *Medieval & Early Renaissance Medicine: An Introduction to Knowledge and Practice,* (Chicago: The University of Chicago, 1990), 9.

eternally rewarded by God. Conversely, people with disabilities were also viewed as disabled because of their sin or possession by evil spirits or demons. Facilities that were influenced by both perceptions of disability were established. "Idiot cages" and "ships of fools" were methods of containing and removing people with disabilities.[11] More humane facilities, such as asylums and hospitals, were established during this time as well in order to give refuge to those with disabilities who were neglected and often homeless. During her reign in the 1500s, Queen Elizabeth I established the first almshouses and workhouses for the poor. The aim was to shelter people with disabilities from the mistreatment they encountered in society and to give them opportunities to work and be contributing members of their communities.

The Enlightenment ideals in the sixteenth and seventeenth centuries and the increasing emphasis on naturalistic causes led to new approaches of understanding disability. Instead of being seen as having spiritual defects, people with disabilities were seen as having biological defects. Physicians and other scholars began studying education and methods of treatment for those with disabilities. In 1746, Jacob Pereire taught deaf mutes to communicate by touch and hand motions. He taught his deaf pupils to speak by using a manual alphabet that consisted of thirty hand shapes each corresponding to a phonic sound instead of a letter. Each position of the hand and fingers represented a position of the speech organs used when that particular sound was made. Using the sense of touch to help his students perceive vibrations and muscular movements that are produced by the voice when speaking, Pereire would then teach his manual alphabet to his students which allowed them to communicate. Pereire is also

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11. "Parallels in Time," *Minnesota Governor's Council on Disability*

noted for his preference of a low student-teacher ratio, allowing him to better care for his students and give them a more personalized education.[12]

*Important figures in early development of care*

Another leader in new methods of education and care for people with disabilities during this time was Valentin Hauy.  In 1784, Hauy opened the first school for the blind in Paris in order to provide shelter and education for young boys and girls who were blind.  His school, then named the Institution for Blind Children, served as a model for other schools around the world and still exists today as the National Institute for Blind Young People.  Hauy was one of the first to show that blind people could be educated. He taught his blind students to read and write by using a system of raised letters.  One of his students, Louis Braille, would later go on to develop the reading system of points and dots which bears his name today.[13]

An additional pioneer in treatment and care of people with disabilities was Philip Pinel. Pinel, a physician, was one of the first to break away from spiritual explanations of disability and contend that people with mental disabilities had some sort of physical illness or disease.  Before Pinel, physicians often treated patients with mental illness by bleeding or purging, believing that by doing so they were ridding the patient of any demons or bad spirits.  When they were not being treated, patients were contained by being locked in chains.  Pinel challenged that there was a pathological dysfunction

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12. Carol Turkington and Allen E. Sussman, "Pereira, Jacobo Rodriguez (1715-1780)," *The Encyclopedia of Deafness and Hearing Disorders* 2nd ed. (New York: Facts on File, 2004,) 168.

13. Paul Irvine, "Haüy, Valentin," in *Encyclopedia of Special Education: A Reference for the Education of Children, Adolescents, and Adults with Disabilities and Other Exceptional Individuals* (Hoboken: Wiley, 2007,) http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/wileyse/ha%C3%BCy_valentin/0.

present rather than a spiritual one, and developed diagnoses and treatments based on his close contact with and observation of patients.  He released patients from chains and prescribed psychological treatments during which he would sit down and have conversations with them.  Pinel's methods of treatment for the mentally ill influenced other physicians to attempt to provide humane care for their patients.

Jean-Marc Gaspard Itard, a French physician and student of Pinel, broke new ground on special education in the nineteenth century.  Informed by John Locke's theory of the human person as *tabula rasa*, or clean slate, Itard believed that all children, if properly trained, had the potential to grow and mature into outstanding adults.  His most famous patient was Victor, the wild boy of Aveyron. Victor, an orphan who was intellectually handicapped and likely abandoned by his parents, spent most of his childhood alone in the Aveyron forest.  Upon his capture, Victor was brought to the Institution of Deaf Mutes, where Itard was working.  Itard, who believed Victor had no malformation because he was living in the wild apart from humans, saw in Victor an ideal subject to test this theory of the *tabula rasa*.  With adequate training and education, he hypothesized Victor could be transformed into an intellectually developed and civilized person with outstanding morals.  Itard worked with Victor for five years on basic activities such as speech, personal care, and manners, as well as more advanced activities such as intellectual and emotional functions.  Although Victor did not develop the way Itard posited he would, Victor did make improvements in some behavior and intellectual skills.  Itard's work with Victor effectively demonstrated that developing personalized education programs for and working closely with someone who is intellectually disabled can lead to progress and development in both cognitive and social

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skills.  Itard's program laid the groundwork for further development of care and

educational programs for children with intellectual disabilities.[14]

Despite these gains, the Industrial Revolution brought new challenges for the

disabled such as crowded cities, terrible standards of living, and poor working conditions.

Living and working conditions were especially harsh for people with disabilities.  Many

were relegated to poorhouses or almshouses, which were supported by public funds and

used as a means to remove economic outcasts from society.  During the 1850s, social

reformers began to have more interest in people with disabilities.  Advocates began to

speak out against poor conditions in which people with disabilities were living.  Among

the social reformers seeking change was Dorothea Dix, who advocated for better services

and care for people with disabilities, especially mental illness.  Her main objective was to

improve the living conditions in the poorhouses, almshouses, and hospitals to which most

people with mental illness were subjected.  She traveled throughout the United States,

visiting these facilities and documenting the inhumane treatment that she saw.  Dix

believed that there needed to be separate facilities specifically for these people so that

there could be a focus on therapy and recovery.[15]  Working with Dix was Samuel Gridley

Howe, a distinguished social activist and advocate for deaf education.  Dix and Howe

presented their observations and reports to Congress, and asked them to set aside land

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14. Paul Irvine, "Itard, Jean M. G.," *in Encyclopedia of Special Education: A Reference for the Education of Children, Adolescents, and Adults with Disabilities and Other Exceptional Individuals*, (Hoboken: Wiley, 2007,) http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/wileyse/itard_jean_m_g/0.

15. Jessica A. Jonikas, Judith A. Cook, and Marie Hamilton, "Dix, Dorothea (1802-1887)," in *Encyclopedia of Disability* (Thousand Oaks: Sage Publications, 2006,) http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/sagedisab/dix_dorothea_1802_1887/0.

throughout the country to accommodate people with mental illness. Dorothea's work

advocating for the improvement of these facilities or the establishment of new ones

helped pave the way for the creation of public institutions.

*Institutionalization*

After working with Dix, Howe further pursued his interests in providing

benevolent services for people with intellectual disabilities. He argued that the current

methods of housing and training the intellectually disabled were ineffective and actually

made the patients' conditions worse.[16] Howe showed that for both moral and economic

reasons it was the duty of the states to help these citizens, and many states agreed. The

conditions that most people with disabilities were living in were inhumane, and care was

essentially non-existent. Howe's goal was to develop a new system of housing and

training for the intellectually disabled. In her survey on the history of disability in the

United States, Kim Nielsen notes that Howe probably convinced many states that by

developing places of residence solely for the treatment and education of people with

disabilities, the residents would hopefully become capable of working and involving

themselves in their communities thus saving the states money and resources. Another

idea that fueled the development of these training schools was that people who were

dependent on others and could not work "symbolized the antithesis of American

citizenship" and challenged the United States' identity as a place of opportunity.[17] Thus,

rehabilitation facilities were needed to correct the problem.

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16. Kim Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2012), 70.

17. Brad Byrom, "A Pupil and a Patient: Hospital-Schools in Progressive America," in *The New Disability History,* ed. Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001), 135.

In 1848, Howe helped in the establishment of The Massachusetts School for Idiotic and Feeble-Minded Youth, a school for youth with intellectual disabilities. He wanted the school to prepare children with disabilities to eventually return to their communities and live with the rest of society. Following the opening of Howe's school, several more schools for children with disabilities opened on the east coast. Pupils received physical training to improve motor and sensory skills, academic training, and instruction in both social and self-help skills. The emphasis in these schools was on training pupils to be productive members of their communities. The idea was that with the proper training and education, people with disabilities could return to their communities and lead beneficial, contributing lives. Because of this new and growing hope for early training and education, and the work of reformers like Dix and Howe, the number of schools for people with disabilities in the United States grew rapidly.

Along with the increasing number of training schools in the latter half of the nineteenth century came an increasing demand for placement of people with disabilities in these schools. The higher level of training and care that the schools offered appealed to parents of children with disabilities. Recognizing this demand, the schools started accepting persons with all types of disabilities. Many people with mild to moderate disabilities who attended these schools did find benefit from the training and education, and were able to return to their families and communities. Unfortunately, few were able to find jobs. As a result, people with disabilities who did return to their communities would often end up in poorhouses or even jail.

Although the demand for placement in schools for people with disabilities kept increasing and the number of schools kept growing during the late nineteenth century, the

quality of care and commitment to education and training did not. Schools were now

understood as institutions, and the focus was no longer on teaching and learning, but on

housing and containing people with disabilities. Custodial institutions, which provided

only the most basic of care and emphasized confinement at the lowest cost possible,

became more and more the norm. It was common to find several thousand residents

living in these facilities. Overcrowding occurred, and care within the institutions was

reduced to limited and impersonal interactions between staff members and residents.[18]

Often times, residents were left in one room for the entire day, with very little social

stimulation. Decisions about where residents would sleep, what they would eat, and what

they would do throughout the day were all made by the institution's staff members.

Institutions shifted their focus simply to housing the fast growing number of people of all

ages and with all different kinds of disabilities. Superintendents of the institutions were

more concerned about how economical they could make their facilities, and less

concerned about the actual individuals living there. Instead of training residents to work

out in the communities, the institutions used them as labor inside the school.

The dominant attitude towards people with disabilities at the time was to make

them invisible to society. Institutions moved out to or were built in rural areas, away

from the public eye, and saw their role as relieving society of a burden by removing

people with disabilities. There were government-supported policies and actions that

segregated or excluded those who looked or acted differently, and in turn acknowledged

and reinforced both public and private prejudices. These prejudices would lead to the

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18. Jane Buckingham, "Institutionalization and Segregation," in *Encyclopedia of Disability* (Thousand Oaks: Sage Publications, 2006,) http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/sagedisab/institutionalization_and_segregation/0.

creation of such legislation as the "ugly laws" being enacted in several cities, such as San

Francisco, Portland, and Chicago. These laws provided that "any person who is diseased,

maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object"

would be banned from public places of the city. [19]

*Twentieth Century*

Besides institutionalization, the nineteenth to early twentieth century saw

advances in other forms of care. After the Civil War, wounded veterans needed adaptive

devices to help them function in society again. The first wheelchair patent was issued in

1869, and between 1861 and 1871 the number of prosthetic and assistive device patents

increased three-fold.[20] Following World War I, thousands of disabled veterans returned to

the United States and society had to again develop ways to receive and accommodate

them. Congress passed the Soldier's Rehabilitation Act of 1918 to provide services, such

as vocational guidance, training, and job placement, for the returning soldiers facing new

challenges. These advancements in services and assistive devices helped not only the

wounded veterans, but also the lives of many other people with disabilities.

By the mid-1920s, there were about eighty institutions for people with disabilities

in the United States, and conditions within the institutions only continued to deteriorate.

Medical involvement in the institutions also began to grow at this time. Some institutions

started to combine various methods of education and medical practice, and referred to

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19. Nielsen, *A Disability History,* 89.

20. Ibid., 85.

21. Byrom, "A Pupil and a Patient," in *The New Disability History*, ed. Longmore and Umansky, 145.

themselves as hospital-schools.[21]  Residents staying at the hospital-schools were given

education and vocational training, but rehabilitation and treatment methods were

incorporated into their days as well.  Methods of treatment included electroshock therapy

or orthopedic surgery.[22]

The eugenics movement began to reach its peak during this time.  A commonly

held belief was that disabilities, both intellectual and physical, were hereditary.  It was

believed by many science and medical professionals that eugenics could effectively

improve society by regulating human reproductive practices so that only those with

positive or valuable hereditary traits would be allowed to reproduce.  People were

encouraged to "breed well" in order to eliminate any possibility of further propagating

negative hereditary traits and thus eliminate disability.  Herbert Spencer, a prominent

scholastic in the late nineteenth century, developed the social Darwinism theory.[23]  His

theory stated that those who could not contribute and participate in society would

eventually be eliminated from it.  As a method of social control, forced sterilizations were

performed on institution residents to prevent them from reproducing. In 1927, the

Supreme Court approved a forced sterilization procedure for a woman who was labeled

feebleminded.  In the court opinion, Justice Holmes affirms the sterilization law in place,

saying that it prevents society from "being swamped with incompetence."[24]  By the

1960s, over sixty-five thousand citizens with disabilities had forced sterilizations

22. David L. Braddock and Susan L. Parish, "An Institutional History of Disability," in *Handbook of Disability Studies,* ed. by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks: Sage Publications, 2001), 41.

23. Herbert Spencer, *The Principles of Sociology* (New York: D. Appleton, 1898).

24."Buck v. Bell", *The Oyez Project at IIT Chicago-Kent College of Law*, accessed August 2, 2013, http://www.oyez.org/cases/1901-1939/1926/1926_292.

performed.[25]  Treatment and care for people with disabilities during the eugenics movement aimed to prevent disability itself.

In the 1930s, the Great Depression led to an abnormally large increase in the number of institution residents.  Families were financially unable to care for their family members with disabilities, so they often had no choice but to send these individuals to an institution. By the middle of the twentieth century, there was at least one state-supported institution in every state.  Institutional care was still being promoted, and the number of residents in the institutions continued to increase.

*The Parents' Movement*

The outbreak of World War II and the recovery that followed opened doors for people to expose the poor conditions in the institutions.  People were finally able to turn their attention to other matters besides the economy and the war.  Parents and families of people with disabilities began to organize and meet with one another to discuss their frustrations over the poor living conditions and lack of community services for their loved ones.  These small groups of parents eventually organized into larger, statewide parent groups.  In 1950, the first national conference for parent groups of different states met in Minneapolis, Minnesota.  At this conference, the National Association of Parents and Friends of Retarded Children was formed.  This organization was one of the first major advocacy groups for people with intellectual disabilities. It would later become known as the National Association for Retarded Citizens (NARC).  Now known as The Arc, it is the largest national organization advocating for and serving people with intellectual and developmental disabilities and their families.

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25. Nielsen, *A Disability History,* 100.

Among the parents who were beginning to advocate for their children was Nobel Prize winner and American writer and novelist, Pearl Buck. Buck, whose daughter had an intellectual disability, wrote about her relationship with her daughter in her memoir *The Child Who Never Grew.*[26] In 1950 she wrote an article about her daughter for *The Ladies Home Journal*, one of the leading women's magazines that reached millions of readers in the United States.[27] Other popular advocates were Dale Evans and Roy Rogers. Roy Rogers, an American singer and cowboy actor, was one of the biggest celebrities of his era. His wife, Dale Evans, was also a popular American actress and singer-songwriter. Their daughter, Robin Elizabeth, had Down syndrome, and died of health complications shortly before her second birthday. Rather than being ashamed to be the parent of a disabled child, Dale Evans was inspired by the life of her daughter and wrote *Angel Unaware*, telling her story of raising Robin Elizabeth.[28] Buck, Rogers, and Evans were influential in changing the public view of children with disabilities. They encouraged parents to care for children at home, and helped illustrate what it meant to have, love, and care for a child with a disability.

Physicians remained adamant about institutionalization of children with disabilities, especially children with intellectual disabilities. They routinely warned parents of the demands that these children would place on them and the potentially destructive effects that these demands might have on marriages and other children in the household.[29] In spite of medical professionals still pushing for institutional care, many

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26. Pearl S. Buck, *The Child Who Never Grew* (Vineland: The Training School, 1950).

27. Pearl S. Buck, "The Child Who Never Grew," *Ladies Home Journal*, May 1950.

28. Dale Evans Rogers, *Angel Unaware* (Grand Rapids: Revell, 1953).

29. Nielsen, *A Disability History*, 14.

parents did not want to put their children in institutions.  Instead, they wanted to develop

services within their communities so that their children could remain at home and

involved in society.  Many parents started their own services, such as education, work,

daytime activity centers, recreation, and various residential models within their homes

and other community facilities.  Many of the services that originated from the parents'

movements are still in use today or provided the groundwork for further development

into models of care that exist now.  The parents' movement effectively brought

intellectual and physical disabilities out into the open and into the forefront of both

political and social conversations.

       After becoming president, John F. Kennedy had formed The President's Panel on

Mental Retardation to advise him on how the government could best meet the needs and

interests of people with disabilities.[30]  In 1962, the panel published a report containing

recommendations for research, preventive health measures, more comprehensive and

improved clinical and social services, improved methods and facilities for care, and

increased educational opportunities about mental retardation.  This report marked a new

beginning of federal involvement and aid to states regarding care for people with

disabilities.  In 1965, Senator Robert Kennedy toured the Willowbrook State School in

New York.  In his report on what he saw and experienced at the institution, he likened the

facility to a "snake pit", and declared that the institution needed major reforming.[31]  After

his visit to the institution, Kennedy addressed the New York legislature, and argued that

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30. "The President's Committee on Mental Retardation," *The Exceptional Parent* 30, no. 8 (Aug. 2000): 86.

31. David Goode, "Willowbrook State School," in *Encyclopedia of Disability* (Thousand Oaks: Sage Publications, 2006,) http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/sagedisab/willowbrook_state_school/0 (accessed March 31, 2014.).

residents were being denied equal access to education and deprived of their civil liberties. Growing dissatisfaction with the institutions highlighted by Robert Kennedy's visit to Willowbrook sparked a time of reform defined by deinstitutionalization and movements toward civil rights.

In 1967, NARC held a youth conference to educate younger individuals about mental disabilities. Its members' objective was to not only befriend people with disabilities, but also to help people with disabilities learn to live and work in the world and impact it in a meaningful way. Their attitude toward disability was reflective of society's changing view of disability. Instead of placing people with disabilities into institutions for care, more and more families with a disabled family member began to advocate for public methods of care, such as accessible public education and community services. Society began to accept that individuals with disabilities could and should live in their communities with their families and as independently as possible. The continuing existence of institutions was called into question as pressure mounted for more and better community services.

*Deinstitutionalization*

President John F. Kennedy addressed Congress in 1963, calling to reduce the number of residents in institutions and to return them to their communities. The 1970 Wyatt v. Stickney case was a major catalyst for deinstitutionalization, as it established a right to adequate treatment for people with disabilities and held that institutions should

only be used as a last resort, and only if an individual's needs could not be met elsewhere, such as back in their communities.[32]

In 1972, ABC news reporter Geraldo Rivera visited the Willowbrook State School, the same school that Robert Kennedy visited in 1965. There, he filmed a documentary called "Willowbrook: The Last Disgrace". Millions around the United States saw this documentary, which showed the deplorable conditions at the school. As the public grew more aware of the state of institutional care, lawsuits began to appear, charging that institutional confinement and the treatment of people with disabilities in the institutions was unconstitutional. In 1975, the Education for All Handicapped Children Act was passed, which required public schools to provide equal access to education for children with disabilities. As a result, the populations at the institutions fell because parents were bringing their children back home and placing them into special education classes in the public schools. From 1965 to 1980, the number of people institutionalized fell by sixty percent.[33] By the early 1990s, each state had either closed its public institutions or reduced the number and size of its institutions.

Although the intentions of deinstitutionalization were well-meant and sought to help people with disabilities escape the appalling conditions in many of the institutions, the means to help these people transition from the institutions back into their communities were not in place. There were not enough public programs and services to provide adequate support to those who were released from the institutions. Those lucky enough to find shelter and help transitioning back to their homes faired well, but there

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32. Charles S. Prigmore and Paul R. Davis, "Wyatt V. Stickney: Rights of the Committed," *Social Work* 18, no. 4 (July 1973): 11.

33. Nielsen, *A Disability History,* 164.

were many people with disabilities who ended up homeless or in jail after being released

from the institutions because they did not have sufficient support.  These negative results

of deinstitutionalization led advocates to create and develop current models of care, such

as community-based care, group homes, and independent living centers.


*The Disability Rights Movement*

The changing attitudes and perceptions of disability leading up to and through the

1960s generated several pieces of legislation aimed at reform and equal access.  In 1956,

the Social Security Amendments passed, which expanded the benefits of Social Security

to senior citizens with disabilities.[34]  Medicare and Medicaid were established in 1965

through additional Social Security amendments and aimed to improve access to and

quality of medical care for disabled and elderly American citizens already covered by the

Social Security program.  The Vocational Rehabilitation Amendments were also passed

in 1965, which authorized federal funds to aid in the construction of rehabilitation centers

and expansion of existing vocational rehabilitation programs for people with

disabilities.[35]

By the 1970s, the disability rights movement as a social and political force had

developed.  People with disabilities understood their condition as a result of society not

being properly set up to accommodate them.  Their physical conditions were not

necessarily disabling.  Rather, the social and physical organization of society prevented

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34. "1956 Social Security Amendments," *Social Security Administration,* accessed October 11, 2013, http://www.ssa.gov/history/tally56.html.

35. "Perspectives on the Historical Treatment of People with Disabilities," in *Teaching for Diversity and Social Justice,* ed. Maurianne Adams, Lee Anne Ball, and Pat Griffin (New York: Routledge, 2007), 346.

them from participating in their communities and thus created further disabilities.

Legislation was proposed in order to address segregation and unequal access to public

spaces and institutions such as employment and transportation.  In 1970, the

Developmental Disabilities Services and Facilities Construction Amendments were

passed.  States were given the responsibility to plan and implement wide-ranging services

for people with disabilities.  This legislation also approved the creation of Developmental

Disability Councils in each state to oversee this implementation.  It contained the first

legal definition of developmental disabilities, which included "persons with mental

retardation, cerebral palsy, epilepsy, and other neurological conditions closely related to

mental retardation which originate prior to age 18 and constitute a substantial

handicap."[36]  Most significant among the decade's legislation was the Rehabilitation Act,

passed in 1973.  Section 504 within the legislation prohibited discrimination against

individuals with disabilities in any federally assisted program or activity.  The

Rehabilitation Act was the first nationwide anti-discriminatory legislation, and it helped

lay the foundation for significant future legislation, namely the Americans with

Disabilities Act of 1990.  In 1978, several amendments were made to the Rehabilitation

Act, including the Comprehensive Services and Developmental Disabilities Legislation.

This legislation enabled states to start offering independent living services to people with

disabilities, and provided federal funding to do so.

The 1970s also marked the beginning of the independent living movement.

People with disabilities began to move away from dependency on others for care and

started to advocate for themselves instead.  Rather than being told by their families or by

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36. "The Developmental Disabilities Assistance and Bill of Rights Act," *The Minnesota Governor's Council on Developmental Disabilities,* accessed October 11, 2013, http://mn.gov/mnddc/dd_act/documents/FEDREG/90-DDA-LEGLISLATIVEHISTORY.pdf.

professionals what courses of action they should take regarding their health and lifestyle, people with disabilities started to seek control over their own lives. Individuals with all different types of disabilities created community groups to identify and address barriers and issues they faced. They realized that working together was going to be more beneficial than trying to advocate for themselves separately. Ed Roberts, one of the major figures in the independent living movement and a prominent advocate for disability rights, felt that it was the job of people with disabilities to take control of their lives and work towards removing the barriers that prevented them from full and equal access to society. In 1972, Roberts and others formed the first Center for Independent Living at the University of California, Berkeley. These centers, which serve and are run by people with disabilities, provide a wide range of programs and a variety of services to most effectively help people with disabilities integrate into their communities.[37] Some of the services that independent living centers offer include help with employment, mobility, residential access, assistive technology, independent living skills training, and peer counseling. The original center that Roberts started has been a model for hundreds of other independent living centers throughout the United States.

Although the Rehabilitation Act in 1973 prohibited discrimination against persons with disabilities, it only did so in federally funded programs. It was poorly regulated, and was not an effective means of eliminating discrimination and segregation of people with disabilities throughout the larger society. In 1985, the National Council on Disability

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37. Doris Fleischer and Frieda Zames, *The Disability Rights Movement* (Philadelphia: Temple University Press, 2011), 46.

released a study called "Toward Independence".[38]  This study highlighted discriminatory

patterns among programs and policies that actually promoted and maintained the

dependency of people with disabilities on the government and society.  It recommended

that a law be passed which required equal opportunity for individuals with disabilities.[39]

Congress then did further studies on the status of Americans with disabilities, and

determined several things.  First, the number of people with disabilities was increasing as

the population as a whole was growing.  Additionally, they found that in spite of all the

legislation discouraging discrimination and exclusion of people with disabilities, these

things still persisted in areas such as employment, public education, public transportation,

recreation, and health services.[40]

The National Council on Disability's study and the congressional study each

contributed to the passing of the Americans with Disabilities Act (ADA) of 1990.  This

landmark legislation prohibits discrimination against individuals on the basis of disability

in employment, housing, public accommodations, education, and public services.  ADA

gave rise to a sense of unity among people with disabilities in spite of their unique

disability experiences, and it contributed to the development of "disabled" as a sense of

identity by providing support across all different types of disability.[41]  The National

Center for Medical Rehabilitation Research (NCMRR) was also established in 1990.  The

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38. National Council on Disability, *Toward Independence: An Assessment of Federal Laws and Progams Affecting Persons with Disabilities – With Legislative Recommendations* (Washington D.C.: United States Government Printing Office, 1986).

39. Fleischer and Zames, *The Disability Rights Movement,* 90.

40. Ibid.

41. Paul K. Longmore and Lauri Umansky, introduction to *The New Disability History: An American Perspective*, ed. Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001), 5.

NCMRR's mission is to promote and enhance the health, productivity, independence, and quality of life of people with disabilities by furthering the development of medical and scientific knowledge. It is supported by the National Institutes of Health and provides the US government with medical rehabilitation research.

Since the passage of the ADA in 1990, more efforts are being made to prohibit discrimination, secure access to public spaces and transportation, and better enable the self-determination of people with disabilities. Many advocates and scholars in the field of disability studies note that there are still improvements to be made in equality of and accessibility for people with disabilities. There has also been a movement towards developing and exploring disability culture.[42] Two dominant models of understanding disability have emerged: the social model and the medical model. These models have informed many of the care practices that exist today for people with disabilities, and will be explored in chapter three.

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42. Paul K. Longmore, "The Second Phase: From Disability Rights to Disability Culture," in *Disability: The Social, Political, and Ethical Debate,* ed. Robert M. Baird, Stuart E. Rosenbaum, and S. Kay Toombs (Amherst: Prometheus Books, 2009), 141.

CHAPTER THREE

Contemporary Care

With the emergence of modern medicine and theories of disease in the twentieth

century, disability became understood as pathology and deviation from the ideal normal.

However, the disability rights movement in the 1970s challenged the dominant medical

model of disability, and brought with it a different way of viewing disability.  Rather than

seeing disability as a biological complication, advocates for disability rights argued that

disability resulted from barriers that society had put up, both physically and attitudinally;

disability was socially constructed.  This challenge resulted in two primary models of

understanding disability: the medical and the social.

Models of disability are important to consider when looking at contemporary care

because they shape and inform a considerable number of programs and practices of

caring for people with disabilities.  Anita Silvers describes a model of disability as "a

standard, example, image, [or] simplified representation" that is used to help determine

what and when disability is.[1]  Models help form understandings of disability and how the

self-identities of people with disabilities are shaped.  In turn, these models of disability

can influence how we care for people with disabilities.  The ways that medical

professionals and others involved in providing care for people with disabilities approach

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1. Anita Silvers, "An Essay on Modeling: The Social Model of Disability," in *Philosophical Reflections on Disability*, ed. D. Christopher Ralston and Justin Ho (Dordrecht: Springer Science+Business Media B.V., 2010), 22.

their work is guided by whatever model of disability to which they subscribe.[2]

Diagnostic or defining systems of disability used throughout healthcare and public policy

are largely based around one of these models of disability as well.[3]  These are simply a

few of the reasons why models of understanding disability are important to how we

provide care to people with disabilities.

Although the social and medical models are competing accounts of disability,

they share common ground in accounting what it means to be human, and as a result, will

share common values and goals in caring for people with disabilities.  After discussing

how each of these models has influenced contemporary care for people with disabilities, I

will discuss efforts being made to bring the two models together.  To conclude, I will

describe an account of being human that informs the two models, in spite of their very

different approaches to disability.

*Medical Model*

The medical model of disability took hold during the important expansion of

medical science during the mid-nineteenth century.[4]  Experimental research led to new

and improved knowledge of human histology, pathology, and physiology.[5]  With this

new wealth of knowledge, medical professionals began having more of a say in regards

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2. Julie F. Smart, "The Power of Models of Disability," *Journal of Rehabilitation* 75, no. 2 (2009): 3.

3. Ibid.

4. Elizabeth Depoy, *Studying Disability: Multiple Theories and Responses* (Thousand Oaks: Sage Publications, 2010), 26.

5. Lois N. Magner, *A History of Medicine* (New York: Marcel Deeker, Inc., 1992), 339.

to what disability was and how it should be treated.[6] Physicians started to play the role of gatekeeper when it came to providing care for people with disabilities.[7] Many considered themselves the ultimate experts on identifying disability and how to best treat it. Anything that was biologically atypical was explained away medically and labeled as a disability.

The medical model understands disability as any limitation or impairment on normal human physiological functioning that limits activity or participation in life situations, such as self-care or independent living within a community.[8] According to this model, disability is a medical problem requiring a medical solution, such as pharmaceutical treatment, therapy, assistive devices, or perhaps surgery.[9] Abnormalities or deviations are "measured against representations of a prototypical or ideal body"[10] that is located within certain physiological and biological parameters.[11] People with disabilities challenge the understanding of what a biologically normal human being is, and as a result, the primary tasks of medicine in addressing disability are to cure illness, alleviate suffering, and rehabilitate damaged bodies.[12] The goal of treatment and care for

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6. Depoy, *Studying Disability: Multiple Theories and Responses,* 26.

7. Ibid.

8. Christopher Boorse, "Disability and Medical Theory," in *Philosophical Reflections on Disability*, ed. D. Christopher Ralston and Justin Ho (Dordrecht: Springer Science+Business Media B.V., 2010), 60.

9. Bradley Areheart, "When Disability Isn't 'Just Right': The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma," *Indiana Law Journal* 83, no. 1 (2008): 186.

10. Thomas Reynolds, *Vulnerable Communion* (Grand Rapids: Brazos Press, 2008), 47.

11. Jackie Leach Scully, "A Postmodern Disorder: Moral Encounters with Molecular Models of Disability," in *Disability/Postmodernity,* ed. Mairian Corker and Tom Shakespeare (London: Continuum, 2002), 49.

12. Reynolds, *Vulnerable Communion,* 47.

a person with a disability, according to the medical model, is "to fix the defect if one can, to normalize it as much as possible if it cannot be fixed, and to hide it if neither fixing nor normalizing are effective."[13]  Medical treatments and therapies ultimately aim to improve the capacities of a person with a disability to biologically and physiologically function in a certain way which medical professionals have deemed to be normal and healthy.  Medical concepts of normality are not instinctive, uninfluenced ideas, however.  Existing ideas about the human body and cultural standards influence how medical professionals think about normalcy.[14]  Generally, a normal functioning human being in our culture is seen as able to participate in his or her community physically, socially, and economically.

The medical practice of prescribing assistive equipment and technology is one example of the medical approach to disability being applied to care.  Medical professionals recommend these devices to allow a patient to function more closely to what the professionals understand to be biologically normal. Many of these devices and the rehabilitation that accompanies them are considered by care providers to be critical in the process of treating persons with disabilities so they can improve their own autonomy and social inclusion.  They function to "enhance activities of daily living, control of the environment, recreation, mobility, and employment-related skills."[15]  A prosthetic limb may allow an individual to better perform certain employment responsibilities, speech-generating devices may allow somebody with a speech disability to communicate with his or her peers more effectively, or a computer program designed for individuals with

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13. Deborah Beth Creamer, "Disability Theology," *Religion Compass* 6, no. 7 (2012): 340.

14. Scully, "A Postmodern Disorder", 48.

15. Stephen Kaye, Patricia Yeager, and Myisha Reed, "Disparities in Usage of Assistive Technology Among People With Disabilities," *Assistive Technology* 20, no. 4 (2008): 194.

learning disabilities may help a student be more successful in school.  The benefits that come from many of these assistive technologies and devices are indisputable, but again, the primary reason for the use of these technologies is to restore or replicate normal physiological functioning.

Several contemporary patient care principles and goals in medicine appeal to the medical model of disability.  The World Health Organization published a module outlining what they believed to be important principles of care for patients with chronic conditions.  The module supports treatment plans that promote "patient self-management."[16]  Ultimately, the goal of these treatment plans is to provide medical solutions that will allow a patient with a chronic condition to function independently in his or her community. In 2012, the National Council on Disability (NCD) outlined several guiding principles for creating and implementing managed health care plans. These state-funded plans are long-term and aim to "coordinate, organize, and rationalize the delivery of health care services and supports" for people with disabilities.[17]  A few of the principles highlighted in this report are support of self-direction and consumer choice, access to assistive equipment or technology allowing the participant to function independently, and a centralized goal of helping people with disabilities "live full, healthy, participatory lives in the community."[18]

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16. "General Principles of Good Chronic Care," *World Health Organization,* last modified 2004, http://www.who.int/hiv/pub/imai/generalprinciples082004.pdf.

17. National Council on Disability, *Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers,* last modified 2013, http://www.ncd.gov/rawmedia_repository/20ca8222_42d6_45a5_9e85_6bd57788d726?document.pdf. (page 25)

18. Ibid., 14.

The medical model of disability may also influence medical professionalism and ethics. During his time as scholar-in-residence at the Association of American Medical Colleges, Herbert Swick established a useful contemporary definition of medical professionalism. He defined it as "those behaviors by which [physicians] demonstrate that [they] are worthy of the trust bestowed upon [them] by [their] patients and the public."[19] Some of the behaviors that Swick outlines include placing the interests of others before their own, adherence to high ethical and moral standards, response to societal needs, and dealing with high levels of uncertainty.[20] Because disability is derived solely from a physiological basis according to the medical model, this particular understanding of disability may result in health professionals having more power to define, control, and treat people with disabilities.[21] Medical professionals may be more likely to play the role of gatekeeper when it comes to providing care for people with disabilities. One of the key principles in medical ethics is autonomy, allowing and enabling patients to make their own choices.[22] Functioning solely out of the medical model, health care providers may overlook this, and in turn compromise their professionalism. Health care providers may also experience problems when caring for those who are incapable of autonomy. They must ask themselves questions about the value these individuals receive as persons and about how they are to be cared for.

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19. Herbert M. Swick, "Toward a Normative Definition of Medical Professionalism," *Academic Medicine* 75, no. 6 (2000): 614.

20. Ibid., 614-615.

21. Charles E. Drum, "Models and Approaches to Disability," in *Disability and Public Health,* ed. by Charles E. Drum, Gloria L. Krahn, and Hank Bersani (Washington: APHA Press, 2009), 28.

22. Barbara L. Kornblau and Shirley P. Starling, *Ethics in Rehabilitation* (Thorofare: SLACK Incorporated, 2000), 12.

Two notable examples, cochlear implants and autism, illustrate ways in which medical professionals behaving paternalistically can be problematic. Cochlear implants, designed with a medical purpose to improve the hearing of deaf or hard of hearing persons, have received opposition from many members of the Deaf community.[23] Many people who are deaf do not consider themselves as part of a disability group needing to be medically cured.[24] Likewise, Autistic persons do not perceive themselves as individuals needing a medical cure because they see nothing wrong with themselves.[25] The Autistic Self Advocacy Network, run by and for Autistic individuals, was established to "improve public perceptions of autism" and "encourage inclusion and respect for neurodiversity."[26] These two groups challenge the idea that they need to be treated for their physical impairments.

Through the twentieth century, objective and quantifiable approaches to medicine were largely used.[27] Medical professionals often saw just a physiological problem to fix. More recently, however, a combination of both subjective and objective approaches to medicine is being used. However, in 2009, the NCD found that for many health care professional schools and training programs, training and education about disability was not even considered as a core curriculum requirement to receive accreditation or federal funding. In the same report, the NCD also noted that there was a limited amount of

23. Chongmin Lee, "Deafness and Cochlear Implants: A Deaf Scholar's Perspective," *Journal of Child Neurology* 27, no. 6 (2012): 822.

24. Ibid.

25. R. Eric Barnes and Helen McCabe, "Should We Welcome a Cure for Autism? A Survey of the Arguments," *Medicine, Health Care and Philosophy* 15, no. 3 (2012): 255.

26. "About ASAN" *ASAN*, last modified 2014, http://autisticadvocacy.org/about-asan/.

27. Scully, "A Postmodern Disorder", 49.

federal funding for development of competency curriculums on the care of disability for

students in professional health care programs.[28] It is important for healthcare

professionals to be educated in not only the medical positions on disability, but on the

social position as well. One major criticism of the medical model comes from this limited

understanding of disability that many care providers have; a purely medical approach to

disability is incomplete and does not address the subjective experience of disability.[29]

*Social Model*

Although the medical model addresses the unavoidable connection between

health and disability, it misses out on the broader social issues that come with disability

as well. The social model of disability arose out of the disability rights movement in the

1970s and led to the enactment of the ADA in the 1990s as a counter to the medical

model of understanding disability. According to the ADA, a disability results from "a

physical or mental impairment that substantially limits one or more major life activities"

of an individual.[30] Here, a distinction is made between disability and impairment. The

social model understands impairment as "the limitation in a person's physical, mental, or

sensory functioning."[31] An impairment, according to the social model, becomes disabling

depending on how society is or is not set up to receive that particular impairment.

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28. National Council on Disability, *The Current State of Health Care for People with Disabilities,* last modified 2009, http://www.ncd.gov/rawmedia_repository/0d7c848f_3d97_43b3_bea5_36e1d97f973d?document.pdf (accessed November 26, 2013).

29. Drum, "Models and Approaches", 35.

30. "Americans with Disabilities Act of 1990, As Amended," *ADA.gov*, last modified June 2009, http://www.ada.gov/pubs/adastatute08.htm#12102.

31. Deborah Marks, *Disability: Controversial Debates and Psychosocial Perspectives* (New York: Routledge, 1999), 80.

Leading up to the disability rights movement and the ADA, people with

disabilities were dissatisfied with a simple medical explanation for their conditions. They

saw themselves as more than just biological mishaps; they were people who had unique

lives and experiences and could participate and contribute to society if it allowed them to

do so. Under the social model, disability is something that has been socially constructed.

A medical condition or biological problem is not what disables a person. Rather, it is the

way society is organized that prevents somebody with an impairment from fully taking

part in it. The social model is dedicated to "altering social arrangements to make them

more welcoming to biologically anomalous people."[32]

The barriers that society has put up can be physical or attitudinal.[33] For example,

if an individual who uses a wheelchair for mobility cannot access a building because

there are stairs leading up to the entrance, adherents to the social model would say the

building is what leads to the disability, not the wheelchair or the physical impairment that

the individual has. Ideas of normalcy are seen throughout society. In this case, the

architecture assumes that walking is the norm for people. If it were widely held that both

walking and using a wheelchair for mobility were normal, then buildings would probably

be built with accessible ramps both outside and in. As a result, being confined to a

wheelchair would not be disabling. The social model concerns all areas of society that we

have created, from buildings to communication systems to employment opportunities.

Disability, according to the social model, is a deficit of "social assets": the opportunities

32. Anita Silvers, "An Essay on Modeling: The Social Model of Disability," in *Philosophical Reflections on Disability*, ed. D. Christopher Ralston and Justin Ho (Dordrecht: Springer Science+Business Media B.V., 2010), 21.

33. Areheart, "When Disability Isn't 'Just Right'", 187.

to access public spaces, to communicate, or to have a job.[34] Because of the inaccessibility

throughout these areas of society, people with disabilities are excluded and therefore

limited in participation. If society were made accessible to people with impairments, they

could be active and contributing individuals in their communities; they would not be

"disabled". By removing the cause of disability from the individual and placing it on

society, the social model characterizes pathologies as biological variations that just mean

an individual functions in a different way from others.[35]

The social model is not without criticism, though. It may not necessarily take into

account the subjective experience of disability. Every individual with a disability

encounters and interacts with his or her environment in different ways. An impairment

may shape many parts of an individual's life, but according to the social model,

impairments would become irrelevant if society were set up to receive them properly.

This may discredit the personal experience of disability. It is also important to consider

that improving accessibility and social conditions for people with disabilities may help

some but not necessarily all.[36] For example, curb cuts may improve accessibility for

somebody using a wheelchair, but might not be the most helpful for somebody who is

blind. Somebody with a profound intellectual disability will still find him or herself

facing certain stigmas and attitudes even if accessibility to a building is guaranteed or

federal funding is secured for vocational programs. Guaranteeing accessibility and certain

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34. Silvers, "An Essay on Modeling", 27.

35. Ibid.

36. Ibid., 32.

rights is beneficial, but it does not guarantee inclusion and incorporation into communities.

One important development resulting from the disability rights movement was the independent living movement. This movement aimed to help people with disabilities live more independently in their communities. One of the ways in which it did so was by establishing independent living centers (ILCs) in several states. ILCs were established under a "philosophy of independent living", where the individuals with disabilities they serve are encouraged to see and advocate for themselves as consumers of services rather than recipients of care.[37] They are typically nonresidential facilities that people with disabilities can go to for help and advocacy.[38] Some of the help that the nearly five hundred ILCs offer involve assistance with housing, employment, transportation, recreation, and health or social services.[39] ILCs opened in response to institutional care of the nineteenth and twentieth centuries, which aimed to isolate and/or fix people with disabilities. Instead, ILCs aim to change their communities and foster independent living.

Also founded upon the principles of the social model of disability is the network of University Centers for Excellence in Developmental Disabilities (UCEDDs). Currently, there are sixty-seven centers in all fifty states. These programs are affiliated with universities, and serve as connections between academia and the community. They not only serve people with developmental disabilities, but also provide education to

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37. Bonnie O'Day, "Centers for Independent Living: Advocates for Disability Rights," *Community Development* 37, no. 3 (2006): 4.

38. Peter Kopriva, "Independent Living Centers," in *Encyclopedia of Special Education: A Reference for Education of Children, Adolescents, and Adults with Disabilities and Other Exceptional Individuals,* (Hoboken: Wiley, 2007), http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/wileyse/independent_living_centers/0

39. Ibid.

people who may interact on a day-to-day basis with individuals who have disabilities.[40]

UCEDDs promote the independence, productivity, and community inclusion of persons

with developmental disabilities by working on projects that provide training, technical

assistance, service, and research which focus on aiding communities in sustaining all of

their members, disabled or not.[41] They are also involved in improving inclusive

education, transitional services, employment, housing, assistive technology, and

transportation within their communities.[42] State councils on developmental disabilities

also exist and share a similar purpose. The goal of these councils is to develop and

maintain communities that are inclusive of and accessible to people with developmental

disabilities. They also help with and promote self-directed services and supports for

individuals with disabilities.[43]

Transitional services geared towards young adults highlight the social model's

focus on eliminating barriers between an individual with a disability and his or her

community. The transition from adolescence to adulthood can be particularly challenging

for people with disabilities. Transitional care has been established to help smooth this

change. One understanding of transitional care, found in regulations made to the

Individuals with Disabilities Education Act (IDEA) in 2004, says that transitional care is

a "results-oriented process", focused on improving academic and functional achievement

40. "Fact Sheet: University Centers for Excellence in Developmental Disabilities Education, Research, and Service," *Administration for Community Living,* last modified September 19, 2013, http://www.acl.gov/NewsRoom/Publications/docs/UCEDDs_factsheet.pdf.

41. "UCEDDs," *Association of University Centers on Disabilities,* last modified 2011, http://www.aucd.org/template/page.cfm?id=24.

42. Ibid.

43. "Councils on Developmental Disabilities," *National Association of Councils on Developmental Disabilities,* last modified 2014, http://www.nacdd.org/about-nacdd/what-we-do.aspx.

of a child with a disability in order to assist the child's progress and integration from

school to post-school activities.[44] Services are designed to meet individual needs and

prepare adolescents for further education, employment, and independent living.[45]

Transitional care services can extend to many different aspects of life – medical, social,

vocational, or residential – and are aimed at educating and preparing a young adult with a

disability to overcome barriers established by his or her community.[46]

<center>*Combining the Medical and Social Models*</center>

Today, there are increasing efforts to bring the two models of disability together.

Disability cannot fully be discussed and understood without considering both the medical

and social issues that come with it. Opposition to the social and medical models arises

partly because it seems "counterintuitive to always alter the environment or always alter

one's body in order to ameliorate or eliminate disabilities."[47] Presenting disability "as the

product of both one's environment and features of the person" may help to ease tensions

that arise when only one model is subscribed to.[48] One effort to combine the two models

is the World Health Organization's *International Classification of Functioning,*

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44. "Secondary Transition," *Ed.gov*, last modified February 01, 2007, http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C17%2C.

45. Ibid.

46. R. Watson, J.R. Parr, C. Joyce, C. May, and A.S. Le Couteur, "Models of Transitional Care for Young People With Complex Health Needs: A Scoping Review," Child: Care, Health, and Development 37, no. 6 (November 2011): 781.

47. Hans S. Reinders, "Human Vulnerability: A Conversation at L'Arche," in *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* ed. by Hans S. Reinders (Grand Rapids: William B. Erdmans Publishing Co., 2010), 6.

48. Ibid.

*Disability, and Health,* or IFC.[49]  This model seeks to incorporate both the medical and

social models, and it acknowledges that "functioning, activity and participation are

influenced by a myriad of environmental factors, both material and social."[50] This model

understands disability as a limitation in performing an activity or participating in life

situations, resulting from impairment in body function or structure.[51] Rather than solely

focusing on either the medical or social causal conditions of disability, an approach that

considers both of these aspects focuses on the experiences of disability as they relate to

both health and life in society.

An example of the efforts being made to connect the medical and social models is

the increasing use of individualized program planning. This approach to caring for people

with disabilities makes use of whole plans developed for a specific individual, addressing

things such as medical care, social work, therapy and rehabilitation, mental health,

wellness, and independent living. Among numerous programs, I have chosen to highlight

just a few. One program that has been especially successful in providing care for people

with disabilities is the Premier HealthCare program. This patient-centered medical home

center in New York focuses on providing high-quality and well-coordinated health and

human services. The goal is to provide services that will help those it serves "maximize

their potential in every area of life," including school age programs, family support

services, employment training and placement, residential opportunities, and primary and

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49. Boorse, "Disability and Medical Theory," 59.

50. Ibid.

51. Ibid., 60.

specialty healthcare.[52] This program considers both medical and social aspects of an

individual's life. In Minnesota, AXIS Healthcare was designed to "maximize

independence while providing person-centered and person-directed services."[53] The

National Council on Disability found in a 2009 report that this program's focus on

individualized plans has effectively made care more efficient and cost-effective for the

individuals it serves in the Twin Cities.[54] Again, both medical and social aspects of the

individual's life are addressed, and the individual receiving these services is considered

holistically. Another successful program noted in the NCD's report was the Westchester

Institute for Human Development, also in New York. This program helps provide or

secure access to medical care, social workers, and therapists, and also operates as a

resource center "offering information, training, technical assistance, and networking" in

many different social areas, such as special education, transition services, and assistive

technology.[55] These programs are working toward providing services that address all

aspects of life for people with disabilities, from medical to social.

*Medical and Social Models within Contemporary Care*

The tension between medical and social models of disability is played out in

contemporary practices of caring for people with disabilities. Models of disability can

shape the language used in relating a disease or injury to the consequences of the disease

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52. "Mission and Culture," *Young Adult Institute,* last modified 2012,
http://www.yai.org/about/mission-and-culture.html.

53. National Council on Disability, *The Current State of Healthcare.*

54. Ibid.

55. "Mission, Vision & Values," *Westchester Institute for Human Development*, last modified
2013, http://www.wihd.org/page.aspx?pid=675#.Uv4o0UJdUhE.

or injury, so it is important for individuals involved in disability care to be mindful of this.[56] For example, a physician might interpret disability as the physiological impairment an individual has, but the individual might interpret his or her disability as the result of interactions between society and his or her impairment. Thus, the language used by each individual to discuss interventions and progress may differ. When applied to clinical practice and care, models of disability can provide frameworks for organizing patient problems and choosing assessments and interventions for the patient. Models can also provide common language for describing patient statuses or sharing patient information between different medical professions. For example, health care professionals working with an individual who uses a wheelchair for mobility can better communicate about the types of therapeutic interventions being utilized, such as pharmaceuticals, physical therapy, occupational therapy, or assistive technologies.

According to the medical model, care addresses the negative physiological deficit that disability is perceived to be.[57] As a result, care is oriented to ideas of treatment, cure, and prevention, and the goal of care is "freeing individuals from biological dysfunction."[58] These ideas have influenced practices such as injury or disease prevention. For example, the National Highway Traffic Safety Administration promotes a bicycle safety plan to prevent head injuries, and the National Council on Folic Acid was created to educate people about the importance of folic acid in preventing birth defects.[59]

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56. Sandra L. Kaplan, *Outcome Measurement and Management: First Steps for the Practicing Clinician* (Philadelphia: F.A. Davis Company, 2007), 82.

57. Drum, "Models and Approaches to Disability", 28.

58. Ibid. Also quoted is Anita Silvers and her position on the medical model in "An Essay on Modeling", 22.

59. Drum, "Models and Approaches to Disability", 28.

Although these programs were designed to prevent potentially life-threatening injuries

and illnesses, they open up questions of preventing other impairments that are not

necessarily life threatening, such as Down syndrome.  Biotechnologies that allow genetic

screening and prenatal diagnoses are driven by the avoidance of suffering.[60]  They give

women more information when making reproductive decisions.  As a result, over half of

all fetuses prenatally diagnosed with Down syndrome in the United States are aborted.[61]

The medical model also influences access to care. Medical professionals determine the

eligibility of people with disabilities to receive government services by diagnoses and

assessments of physiological conditions.[62] Under the medical model, the primary agent

involved in determining and providing care is the medical professional, and people with

disabilities become more passive receivers of care.

Within the social model, the goal of care is "freeing disabled people from

stigmatization and exclusion."[63]  The concept of disability is shifted from the individual's

physiological impairment to the barriers that people face interacting with the

environment.[64] Vocational, residential, and social services are offered to aid people with

disabilities in overcoming these barriers. Medical care is also organized in such a way

that eliminates these barriers. For example, when implementing a physical activity

60. Christopher Newell, "On the Importance of Suffering," in *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* ed. by Hans S. Reinders (Grand Rapids: William B. Erdmans Publishing Co., 2010), 177.

61. Jaime L. Natoli, Deborah L. Ackerman, Suzanne McDermott, and Janice G. Edwards, "Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995-2011)," Prenatal Diagnosis 32, no. 2 (February 2012): 151.

62. Drum, "Models and Approaches to Disability", 29.

63. Silvers, "An Essay on Modeling", 22.

64. Drum,"Models and Approaches to Disability", 33.

program for an individual with an impairment, an adapted exercise program, equipment, and an accessible facility are all required.[65] The ADA requires full and equal access to medical care services and the facilities where these services are provided.[66] In a US Department of Health and Human Services report on access to medical care for individuals with mobility impairments, accessible examination rooms are described and suggestions are made regarding entry doors, floor space inside the exam rooms, and medical equipment inside the exam rooms as well.[67] Stuart P. Hanson from InfoUse, a group specializing in disability policy research and evaluation, identifies several other principles that should guide analysis of care programs for people with disabilities, all shaped by the social model of disability. One of them is comprehensiveness, or how well the program provides an array of services beyond just health services, because according to the social model, disability results from more than a physical impairment. Another is appropriateness, or how well care is provided on the basis of the individual's needs. Lastly, consumer control, or how involved the individual with a disability was in directing his or her care, is also considered.[68] Through the social model, individuals with disabilities become more active receivers of care via the value placed on providing patients with choices and control in regards to the interventions presented to them.

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65. Ibid., 36.

66. "Americans with Disabilities Act of 1990, As Amended"

67. United States Department of Justice and United States Department of Health and Human Services, *Access to Medical Care for Individuals with Mobility Disabilities,* 2010, http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm.

68. Stuart P. Hanson, "Applying Independent Living Principles to State Health-Care Programs for People with Disabilties," *Journal of Disability Policy Studies* 11, no. 3 (2000): 161-163.

Both the social and the medical models share a common principle in regards to disability care: normalization. Care, as seen through both models, is centered on restoring an individual's capacity to participate in and contribute to his or her community. It seems that the goal of contemporary disability care, through both medical interventions and social interventions, is to bring the individual back to what is generally held to be normal functioning both biologically and socially.

*Shared Account of Personhood*

Both the medical and social models operate out of a particular account of being human. Although specific expressions may vary, there are several qualities that are popularly understood to give somebody his or her personhood and value. In a biological sense, a normal functioning human being has physiological abilities to carry out certain tasks, such as breathing, speaking, hearing, and standing and walking on two feet. Biological normalcy also allows for proper functioning of the body that enables people to participate in the larger community.[69] From this, it is clear why people with disabilities, who may not necessarily fit the mold of what has been decided as normal, are thought of as deviant.[70] Contemporary culture in the United States has also placed value on beauty, youth, and able-bodiedness.[71] Bodily abnormalities are undesirable because they stray from what we hold to be the natural and valuable qualities of the human body.

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69. Reynolds, *Vulnerable Communion,* 25.

70. Lennard Davis, "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century," in *The Disability Studies Reader*, ed. Lennard Davis (New York: Routledge, 1997), 3.

71. Reynolds, *Vulnerable Communion,* 97.

It is also commonly held that human beings are distinct from other living beings due to faculties of reason and will. Reason is popularly understood as something that distinguishes humans as "self-directed individuals, who by independent and self-originating means make assertions and decisions that create and define [themselves]."[72] In fact, many people understand these things to be necessary parts of one's value as a human being.[73] Other abilities and characteristics that are popularly believed to make somebody a human include autonomy and self-determination, participation in social exchanges, and the capability to prescribe meaning, value, and direction to our lives.[74] Other values, such as freedom, equality, productivity, efficiency, and prosperity, are also generally held to contribute to an understanding of what a valuable life is.[75] This contemporary understanding of being human, however, is grounded in our capacities for reasoning, both morally and intellectually.[76] Without these capacities, a person is seen as deviant or abnormal, similar to the way people are seen as atypical if they are biologically or physically different from the bodily norm.

Use of the term "normal" in describing somebody's condition came about much more recently than probably expected – over the period of 1840-1860.[77] However, the values and ideas about what being a normal human means are not novel. As discussed in chapter two, Greek and Roman cultures in the ancient era valued a specific physical and

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72. Ibid., 78.

73. Hans Reinders, *Receiving the Gift of Friendship* (Grand Rapids: William B. Eerdmans Publishing Co., 2008)*,* 52.

74. Reynolds, *Vulnerable Communion,* 79.

75. Ibid., 70.

76. Molly C. Haslam, *A Constructive Theology of Intellectual Disability: Human Being as Mutuality and Response* (New York: Fordham University Press, 2012), 3.

77. Davis, "Constructing Normalcy", 3.

intellectual type. This idea of a normal and valued person has carried forward into contemporary culture. When considering this account of being human in discussing disability, however, it becomes evident that even apparently simple words such as "normal" carry a lot of weight and can be potentially harmful to others.

Thomas Reynolds describes this account as the cult of normalcy.[78] In his book, *Vulnerable Communion,* he effectively outlines a contemporary understanding of normalcy. He begins by discussing the exchange system that society functions out of today. One's body value is measured by his or her ability to participate in and contribute to society. The social context in which one finds him or herself in, such as school, employment, and friendship "involves its own performance expectations and criteria of value measurement."[79] In every life situation, people engage one another in tangible ways, and the value of each person is determined by his or her ability to exhibit these criteria of value measurement. Standards and characteristics that are essential to belonging are assigned from this system of give and take. It also forms ideas of what is normal and what is or is not accepted and valuable.

Reynolds then introduces the idea of "body capital" – value placed on bodies' abilities to participate in and contribute to the communities which they inhabit.[80] Body capital measures a person's exchange value, coming from his or her physical appearance and function. The qualities used to measure body capital, like physical functioning and self-sufficiency, become embedded throughout society. They are passed on into systems

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78. Here, I draw from Thomas Reynold's book, *Vulnerable Communion,* to describe a contemporary account of normalcy. I have cited the book previously in the Medical Model section.

79. Ibid., 57

80. Ibid., 58.

of education and employment, politics, socializing, and even the physical parts of society, including architecture, transportation, and mass media.

From this, a "cult of normalcy" has developed. Bodies that show any deviance in form and/or function threaten this understanding of normalcy. So, measures are taken to restore these bodies to completeness and competence in an effort to preserve and reaffirm "a community's orientation to its sense of the good" and the normal in which many have placed trust.[81] Reynolds critiques the cult of normalcy that contemporary Western culture has developed, saying it hides assumptions that place what is considered good in what is considered normal.  Because of this, negative connotations are invested in anything that is abnormal. According to Reynolds, ideas of normalcy that have developed tell people with disabilities who they are, and it prescribes a negative experience to them.  "The consequence of the cult of normalcy is alienation, both socially and personally," and this is why Reynolds challenges his readers to examine and question these ideas of normalcy, which are often taken for granted and presumed as fact.[82]

In his book, *Receiving the Gift of Friendship,* Hans Reinders critiques the secular accounts of disability found throughout American culture today.[83] According to Reinders, the medical model places disability in an individual's body as biological or physiological defect, and in effect, labels the citizenship of people with disabilities as defective due to their natural limitations. Within the medical model, there is a normal way for the body and mind to function, and if someone's body or mind is functioning abnormally, then that

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81. Ibid., 59.

82. Ibid., 62

83. Here, I draw from Hans Reinders evaluation of secular accounts of disability and personhood in his book, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics*, which I have cited earlier in this section.

person has a disability. This then plays out in medical care for people with disabilities –
the focus of care lies in eliminating abnormalities and restoring normal functioning to the
body and mind.

Reinders finds several problems with the social model's account of disability as
well. "The social model", he writes, "directs our attention to the particularities of society
rather than to the particularities of being human."[84]  Although the social model was
developed to remove the focus from locating disability purely within the body, it actually
perpetuates this view in regards to psychological or intellectual powers, and supports the
idea that "to be free from social marginalization and oppression is a matter of sufficient
will power to get involved and get organized."[85]  In other words, the social model places
value in people's ability to pull themselves up by their bootstraps and overcome the
distress, fatigue, and pain that may come with their impairments. Reinders notes that for
people with profound intellectual disabilities, however, this may not be possible. The
social model assumes that all people have the ability to determine his or her own life
experience, but in reality, not everybody is able to do so. In effect, the social model
"denies the representation of *all* people with disabilities."[86]  According to Reinders, both
models reinforce rather than criticize the traditional way of thinking about humanity –
that we are self-reflective, self-representing, and self-affirming. In order to account for
the individuals who do not fit the mold of what it means to be a person in today's culture,
Reinders argues that this concept of humanity must be changed.

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84. Ibid., 59.

85. Ibid., 66.

86. Ibid., 67.

The medical and social models of disability have emerged as dominant ways of understanding disability in contemporary culture. In the medical model, disability is seen as a physiological abnormality, and care that is shaped by this model is often focused on restoring an individual back to what is considered physiologically normal. The social model, in contrast, locates disability outside of the individual. Disability arises from the interactions between individuals with physical impairments and their societies. If society were organized in ways that would not hinder the participation of individuals with impairments, then they would not be considered disabled. Care that is shaped by the social model often addresses barriers, both structural and political, that lead to disability. A fairly new approach to understanding disability seeks to consider both medical and social aspects of disability, and care models that address both health and life in society are being recognized. The medical and social models, and even this newer approach that takes into consideration both of these models, are shaped by rationalist accounts of personhood, value, and normalcy. As a result, these anthropologies all play out into disability care. Thomas Reynolds and Hans Reinders provide evaluations of these contemporary anthropologies in their works, and suggest that a different understanding of personhood and value is necessary in order to include all persons in it.

CHAPTER FOUR

L'Arche

L'Arche, from the French word for "ark", is an international network of

ecumenical faith communities providing care for individuals with intellectual disabilities.

Founded in 1964 by Jean Vanier, L'Arche has become a unique example of what it looks

like to fully embrace differences between persons and practice life together.  Core

members, the residents who have some form of intellectual disability, and assistants, the

individuals who provide support to the core members, live and work together in

community.  A fundamental attitude that permeates L'Arche communities is that

assistants are there living with, not doing for, the core members.  Members live together

as "fellow human beings who share care and need."[1]  L'Arche promotes seeing the value

and gifts that all people possess, disabled or not, and seeks to provide an environment for

its members that allows these gifts to become known.[2]  L'Arche seeks to offer a

welcoming and loving home for individuals with intellectual disabilities, and more

broadly, seeks to offer an alternative way of thinking about disability and ultimately what

leading a valuable, meaningful life might look like.

I begin this chapter by giving a brief history of L'Arche.  Then, by examining the

history and practices of L'Arche, I identify several key, distinguishing characteristics of

L'Arche that make this organization so unique from other disability care models.  Of

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1. Stanley Hauerwas and Jean Vanier, *Living Gently in a Violent World: The Prophetic Witness of Weakness* (Downers Grove: InterVarsity Press, 2008), 17.

2. "Identity and Mission," *L'Arche USA*, last modified 2014, http://www.larcheusa.org/who-we-are/identity-and-mission/.

special note will be spirituality in L'Arche – why it is important to the communities, and the different ways that it is practiced in L'Arche. To conclude, I will discuss the anthropology of personhood and the notion of what makes a person valuable that are characteristic of L'Arche.

## *History of L'Arche*

L'Arche began as one home, owned by Jean Vanier who was unaware that his single community would eventually expand to more than one hundred forty communities in over thirty-five countries around the world. Born in 1928, Vanier grew up with his four brothers and sister in England and Canada.[3] His family was rooted in the Roman Catholic tradition, and his parents encouraged him in being confirmed, attending mass, and practicing other sacraments.[4] Vanier left his home in 1942 at age thirteen and entered the Royal Naval College in England. He would later go on to join the British Navy and begin his naval career in 1945.[5] In 1950, Vanier resigned his naval commission after spending time "drawn into prayer and reflection on what might be God's call for him."[6] Searching for direction, he went to France to visit with Father Thomas Philippe, a Dominican priest and family friend. Vanier stayed in France to study philosophy, eventually earning his doctorate at the Institut Catholique in Paris.[7] Vanier

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3. "L'Arche Since Its Creation," *L'Arche International,* accessed March 13, 2014, http://www.larche.org/en/discover/larche_since_its_creation.

4. Kathryn Spink, *The Miracle, The Message, The Story: Jean Vanier and L'Arche* (Mahwah: HiddenSpring, 2006), 23.

5. Hauerwas and Vanier, *Living Gently in a Violent World,* 23.

6. "L'Arche Since Its Creation"

7. Ibid.

taught briefly at a university in Canada, but was ultimately dissatisfied with that career and returned to France to join Father Thomas, who had become chaplain at a small institution for people with intellectual disabilities in Trosly.[8] Struck by the poor conditions of the institution and others in Trosly, Vanier noticed that the individuals he encountered there sought connection and relationship with him. He sensed a desire in them for meaningful, personal relationships, and felt deeply the disparity between the gospel message of compassion and mercy that he knew and the dreadful conditions in which these individuals lived.[9] Vanier wanted to do something for the people with disabilities he encountered who were confined to institutions. More specifically, he wanted to give them community.[10]

In 1964, Vanier purchased a home in Trosly, near the institution where Father Thomas served.[11] He invited three men, Philippe, Raphael, and Dany, from the institution to come and live with him. Vanier's goal in starting L'Arche "was to found a family, a community with and for those who are weak and poor because of a mental handicap and who feel alone and abandoned."[12] A welcoming celebration was held when the three men arrived and included others who were involved in establishing this first L'Arche community.[13] The first evening that Vanier spent alone with the three men was

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8. Michael Higgins, "Messy Love: Jean Vanier's L'Arche," *Commonweal,* May 2009, 10.

9. Spink, *The Miracle, The Message, The Story,* 57.

10. Higgins, "Messy Love: Jean Vanier's L'Arche," 10.

11. Spink, *The Miracle, The Message, The Story,* 59.

12. Jean Vanier, *Community and Growth: Our Pilgrimage Together* (Toronto: Griffin Press, 1979), 35.

13. Spink, *The Miracle, The Message, The Story,* 61.

a difficult one for them all.  Vanier recalls feeling helpless and completely lost, especially when it came to interacting with Dany, who could neither hear nor speak.[14]  Vanier soon recognized that it would not be possible for Dany to stay.  After his very first night there, Vanier experienced the mutual suffering – of his own, and of the three men – that nearly all members of L'Arche communities experience.[15]

Vanier, Philippe, and Raphael eventually developed a rhythm living together, and Vanier's friendship with the two men grew more and more each day.[16]  They came to know each other more, learned how to live with one another and care for one another, had fun together, and prayed together.[17]  Vanier was humbled by all that he was learning and receiving from Philippe and Raphael, and came to understand that his role in their small community was not "doing for" but "being with."[18]  L'Arche began with Vanier wanting to give people with disabilities the possibility of living meaningful relationships, but he came to see that he also needed to grow emotionally and in his own capacity for relationships.[19]  Vanier decided to call his home L'Arche, French for "the ark", after Noah's Ark, which he saw as symbolic of a place of refuge, a community of variety, and a community of hope.[20]

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14. Ibid.

15. Ibid.

16. Ibid, 63.

17. Ibid.

18. Ibid, 64.

19. Ibid.

20. Bill Clarke, *Enough Room for Joy: Jean Vanier's L'Arche: A Message for our Time* (Toronto: McClelland and Stewart, 1974), 13.

From Vanier's original home in Trosly, L'Arche expanded globally. Through lectures and spiritual retreats, Vanier shared his vision for L'Arche and sparked interest in others involved in disability care to take part in this vision.[21] The growing interest in L'Arche attracted people who were interested in becoming assistants or being donors to the organization, and it also established credibility amongst the many approaches of caring for people with disabilities that were developing during the deinstitutionalization movement.[22] In 1969, the first L'Arche community in North America was founded in Canada.[23] The following year, a L'Arche community in India was established.[24] In 1972, founders of individual communities gathered together in an attempt to establish unity and better communication with each other.[25] This became the first official meeting of the International Federation of L'Arche communities, and an International Council was established to look after and guide new communities.[26]

Today, L'Arche exists as an international network of communities attracting people of all abilities and all ages, both men and women. Although originally founded in the Roman Catholic tradition, L'Arche has become an ecumenical organization,

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21. Michael Hryniuk, *Theology, Disability, and Spiritual Transformation* (Amherst: Cambria Press, 2010), 99.

22. Ibid.

23. "L'Arche Since Its Creation"

24. Ibid.

25. Spink, *The Miracle, The Message, The Story,* 132.

26. Ibid.

welcoming members from all religions or no religion.[27]  The mission of L'Arche today is

to:

> Make known the gifts of people with intellectual disabilities, revealed through mutually transforming relationships, foster an environment in community that responds to the changing needs of our members, whilst being faithful to the core values of [their] founding story, and engage in [their] diverse cultures, working together toward a more human society.[28]

Through the carrying out of its mission and through its history and development from

Vanier's first home in Trosly, many distinguishing characteristics have developed.

However, many people who have experienced L'Arche first hand claim that it "holds a

message that cannot be adequately translated into words."[29]  To many, L'Arche is more

than an organization – it is their way of living, involving deep community and personal

and spiritual transformation, and each member experiences L'Arche differently from all

others.  Though the L'Arche experience has a certain mystery to it, I will attempt to point

out several qualities and practices of L'Arche that distinguish it.

*Key Characteristics and Practices of L'Arche*

There are many characteristics and practices of L'Arche that make it unique from

other approaches to caring for people with disabilities.  I have identified friendship,

celebration, humility, vulnerability, and patience as being important to the functioning of

L'Arche communities in the way that Jean Vanier envisioned them.

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27. "A L'Arche Community is…," *L'Arche International,* accessed March 13, 2014, http://www.larche.org/en/discover/a_larche_community_is_.

28. "Identity and Mission," *L'Arche USA.*

29. Clarke, *Enough Room for Joy,* 15.

*Friendship*

Friendship is vital to L'Arche communities. Members are called to live in solidarity and mutuality with one another, both giving and receiving from one another in friendship. This is where community is created in L'Arche – within the full and constant investment between members.[30] The relationship between assistants and core members is friendship, rather than a nine-to-five, caregiver-patient relationship.[31] The friendships created in L'Arche are therapeutic both ways, with both core members and assistants benefiting from the relationship.[32] Describing a friendship with a core member in her community, one assistant writes, "He loves me very deeply, and I should love myself the same way. I've learned a lot from [him]. Accepting, forgiving, fun-loving."[33] Assistants come to value core members "less as dependents than as vessels of light."[34]

At L'Arche, communication within these friendships comes in a variety of forms. Storytelling is one form of communication valued among L'Arche members. Stories hold a lot of significance and meaning within L'Arche, as evidenced in their mission statement quoted earlier. It is through storytelling that members come to know one another better and become more open with one another.[35] Physical touch is also used to

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30. Timothy Kearney, "Discovering the Beatitudes at L'Arche," *The Furrow* 35, no. 7 (1984): 463.

31. Ibid.

32. Timothy Kearney, "The Prophetic Cry: Interview with Jean Vanier," *The Crane Bag* 5, no. 1 (1981): 80.

33. Kevin Reimer, *Living L'Arche* (Collegeville: Liturgical Press, 2009), 12.

34. Higgins, "Messy Love: Jean Vanier's L'Arche," 10.

35. Clarke, *Enough Room for Joy,* 43.

communicate amongst friends at L'Arche.[36] Some members may be unable to verbally

communicate with others, so expression of love and respect is commonly seen through

physical gestures such as hugging or handholding. Silence may also be a form of

communication and encountering others in L'Arche.[37] Often times, members can

communicate mutual respect and care through simply being in the presence of one

another, making eye contact, or sharing a smile.[38]

Mutuality in space and time is also important in L'Arche friendships. Vanier

recognized that the physical space in which one finds him or herself "can both reflect

beliefs and affect one's sense of well-being within it."[39] Through living in the same

conditions – physical, emotional, and spiritual – genuine solidarity and relationships are

developed.[40] When planning a celebration or making decisions about what activity to do

or how to decorate a room, both core members and assistants are involved in the

process.[41] Eating areas within the homes are large enough for everyone to gather

together for meals, and living areas are comfortable and welcoming to facilitate events of

coming together and sharing stories or celebrating.[42]

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36. Ibid.

37. Ibid.

38. Ibid., 44

39. Pamela Cushing, "Shaping the Moral Imagination of Caregivers: Disability, Difference & Inequality in L'Arche," (PhD diss., McMaster University, 2003), 191.

40. Catherine Anderson, "Reflecting on Practice in L'Arche: Encountering the Grieving Other," *Compass* 46, no. 1 (2012): 39.

41. Cushing, "Shaping the Moral Imagination of Caregivers," 191.

42. Ibid.

One relationship that illustrates mutuality, solidarity, and communal growth, which are characteristic in L'Arche friendships, is that of Henri Nouwen and Adam Arnett. Nouwen, a Catholic priest and author, spent the last years of his life living in a L'Arche community in Canada. There, he befriended a core member named Adam. To many, Adam was just a client or someone requiring care. Many who worked with him failed to recognize and receive "his beautiful spirit, his enduring patience, and his gentle heart."[43] However, after spending some time in the Daybreak community and getting to know Adam, Nouwen came to see Adam as his friend, teacher, and guide.[44] In fact, their mornings spent together became some of the most reflective and transformative times for Nouwen, during which he learned about patience, love, and identity.[45] Through his time spent at L'Arche and his friendship with Adam, Nouwen saw the importance of seeking out and receiving what others have to offer us. He received Adam as a whole person, with gifts and vulnerabilities just as he had.

*Celebration*

A second defining practice of L'Arche is celebration. Celebrating with one another is vital to creating community in L'Arche. Celebrations in L'Arche entail laughing together, having fun together, and giving thanks for life with each other.[46] Celebrations involve food and wine, song and dance, and lots of laughter. At L'Arche, celebration is a time "when all can rejoice – with their disabilities and abilities – and give

43. Henri Nouwen, *Adam: God's Beloved* (Maryknoll: Orbis Books, 1997), 38.

44. Ibid., 15.

45. Ibid., 48-49

46. Hauerwas and Vanier, *Living Gently in a Violent World,* 37.

thanks to God for having moved [them] from loneliness to togetherness."[47]  Everything is celebrated at L'Arche – life, death, birthdays, holidays, arrivals and departures, and the small, simple things in life.[48]  In the midst of disability and suffering, L'Arche communities recognize that celebration is needed to counter the negative stereotypes that many core members face in society.[49] During birthday celebrations, affirmation and appreciation are given to the honored community member, and he or she is showered with love, prayer, and the affection of all community members.[50]  Even differences amongst members are celebrated and valued in L'Arche. Rather than being rejected or feared, differences "become what make people interesting and distinct" in a supportive environment like L'Arche.[51]  Difference is valued at L'Arche because it "brings together not only people with various gifts but also people from various cultures and religious traditions."[52]  Celebration of the simple things in life and receptivity to enjoy and appreciate the uncommon or unexpected is encouraged at L'Arche.[53]

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47. Hans S. Reinders, "Human Vulnerability: A Conversation at L'Arche," in *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* ed. by Hans S. Reinders (Grand Rapids: William B. Erdmans Publishing Co., 2010), 14.

48. Pamela Cushing, "Disability Attitudes, Cultural Conditions, and the Moral Imagination," in *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* ed. by Hans S. Reinders (Grand Rapids: William B. Erdmans Publishing Co., 2010), 88.

49. Kevin Reimer, "Road to Guadalupe: Hope and Moral Identity in L'Arche Communities for the Developmentally Disabled," *Christian Scholar's Review* 38, no. 3 (2009): 359.

50. Ibid., 361.

51. Cushing, "Disability Attitudes, Cultural Conditions, and the Moral Imagination," 76.

52. Reinders, "Human Vulnerability: A Conversation at L'Arche," 3.

53. Cushing, "Disability Attitudes, Cultural Conditions, and the Moral Imagination," 88.

*Humility*

Another distinctive characteristic of L'Arche is humility. Assistants do not live in L'Arche communities to just take care of the core members. Assistants are called to have responsibility for the safety and care of core members to some extent, but they do so with a deep sense of respect and mutuality, recognizing that they themselves have vulnerabilities and weaknesses. Many come to L'Arche with a desire to help people with disabilities, but soon realize that "it is [the core members] who are helping us."[54] Assistants live out the Beatitudes that have largely shaped L'Arche not by doing good or working for the core members, but by living with them and humbling themselves to receive from them.[55] Assistants come to recognize their own disabilities while living in L'Arche communities.[56] Gestures of community, not of power, are made when assistants acknowledge their own brokenness and limitation in the face of others.[57] In L'Arche communities, power is shared amongst members.[58] L'Arche would not be a place of support and acceptance if assistants took on paternalistic roles and made every decision for the core members. Instead, core members are included in most decision making processes, and are given and encouraged to complete tasks within their communities and homes.

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54. Jean Vanier, *The Heart of L'Arche* (Toronto: Novalis Publishing, 2013), 10.

55. Timothy Kearney, "Discovering the Beatitudes at L'Arche," *The Furrow* 35, no. 7 (1984): 463.

56. Reimer, "Road to Guadalupe," 359.

57. Reinders, "Human Vulnerability: A Conversationg at L'Arche," 6.

58. Cushing, "Shaping the Moral Imagination of Caregivers," 191.

*Vulnerability*

Vulnerability is another defining characteristic of L'Arche communities. Interdependence, not independence, is encouraged within the communities. L'Arche understands the human person as interdependent.[59] People are born into a dependent relationship with their mothers, are dependent on others to learn and grow, and are ultimately dependent on God.[60] Vulnerability is intrinsic to the human condition, and in a particular way to people with disabilities.[61] All members of L'Arche must be prepared to accept the vulnerabilities of one another – such as anger, violence, depression, and insecurity. A new assistant might become angry with him or herself if he or she is having a hard time adapting to community life, or a core member may feel insecure about his or her completion of a household task or project. At L'Arche, these vulnerabilities are accepted and received, rather than disapproved. Members must be vulnerable enough to believe and trust in other people in the community even as they trust and believe in themselves.[62] Rather than being an obstacle to union with others and with God, at L'Arche, vulnerability is seen as fostering these things.[63] Assistants and core members see and experience each other's vulnerabilities, and when friendships continue to grow and strengthen in response to sharing and seeing the truth about each other, healing

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59. Timothy Kearney, "The Transforming Power of Vulnerability," *Irish Theological Quarterly* 78, no. 3 (2013): 245.

60. Ibid.

61. Ibid., 244.

62. Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids: William B. Erdmans Publishing Co., 2008), 336.

63. Kearney, "Discovering the Beatitudes at L'Arche," 463.

relationships in which the strengths and gifts of each person are revealed begin to develop.[64]

*Patience*

Lastly, patience is one of the most distinguishing characteristics of L'Arche communities. L'Arche requires that time be given to others – time to slow down and listen to others, time to touch others and be touched by others.[65] At L'Arche, assistants cannot be in the typical, modern mind-set of being hurried and always task-oriented.[66] Rushing through the day's activities and routines, in spite of what may be habit to them, is not possible for assistants in L'Arche communities. Henri Nouwen recounts an instance when he was helping his friend Adam get ready in the morning before starting his day, and was feeling impatient and preoccupied. In response to Nouwen's impatience, Adam had a seizure that required Nouwen to completely change pace.[67] Nouwen realized he could not rush through his time with Adam, because Adam wanted and needed Nouwen to be with him "unhurriedly and gently."[68] Hurry and impatience are harmful to the relationships and communities of L'Arche.

Routines also shape life in L'Arche communities. These can be morning routines to get ready for the day, household routines, mealtime routines, and so on. There is a rhythm to life in the community that counters the rush of the world outside. Contrary to

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64. Reinders, *Receiving the Gift of Friendship*, 337.

65. Kearney, "Discovering the Beatitudes at L'Arche," 461.

66. Cushing, "Disability Attitudes, Cultural Conditions, and the Moral Imagination," 87.

67. Nouwen, *Adam: God's Beloved,* 47.

68. Ibid.

most people's understanding of them, routines at L'Arche are not seen merely as tasks to be completed, but as opportunities for deeply respectful human interactions to occur.[69] They become vulnerable times of growth for both assistants and core members. Assistants are encouraged not to rush people through routines like an assembly line. Instead, members are encouraged to have the patience to be in the present, to enjoy the present moment without being too preoccupied about the future, and thus gaining a deeper appreciation for what each moment holds.[70]

<div align="center"><em>Spirituality in L'Arche</em></div>

Another reason that L'Arche is unique from other disability care models is that each of its members is called to live together according to the Gospel message. The spirituality of L'Arche shapes the choices that members make, how communities make decisions, and how they order their priorities.[71] It permeates all aspects of L'Arche, and communities are inspired and shaped by the Beatitudes and the spirit of the Gospel.[72] A vision of unity, peace, and acceptance informed by the Gospel has formed L'Arche communities, and assistants and core members alike live by the example of Christ entering into this world to love people as they are.[73] Assistants find a calling to be people of simplicity, gentleness, compassion, justice, and peace in the Beatitudes, as well as an

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69. Cushing, "Shaping the Moral Imagination of Caregivers," 194.

70. Clarke, *Enough Room for Joy,* 42.

71. Vanier, *The Heart of L'Arche,* 11.

72. Kearney, "Discovering the Beatitudes at L'Arche," 460.

73. Hauerwas and Vanier, *Living Gently in a Violent World,* 63.

understanding that "each and every human person, no matter how lowly, sick, poor, or suffering, possesses a unique worth and dignity."[74]

Members of L'Arche experience God's love through mutual relationships within their communities.[75] At L'Arche, the friendships between and the reception and celebration of all members, including all their strengths and weaknesses, is "a practice embodying the love of God."[76] Through this sharing of both gift and brokenness, L'Arche believes its members "discover the reality of God's friendship."[77] L'Arche serves as a reminder that out of God's love, we have been created to love – this is the essential purpose of human life.[78] By celebrating life together, members of L'Arche communities come to know God better.[79]

Among spiritual practices commonly seen in L'Arche communities, prayer is a constant. Most community gatherings are begun with a time of communal prayer for core members and assistants.[80] Time for silent reflection together is also given.[81] This time of silent reflection and prayer is important to the active and lively L'Arche communities because it gives them a time to refocus on "the fundamental spiritual origin

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74. Michael Downey, *A Blessed Weakness: The Spirit of Jean Vanier and L'Arche* (San Francisco: Harper & Row, 1986), 103-104.

75. "A L'Arche Community is…", *L'Arche International*

76. Reinders, "Human Vulnerability; A Conversation at L'Arche," 14.

77. Reinders, *Receiving the Gift of Friendship,* 347.

78. Vanier, *The Heart of L'Arche*, 10.

79. Reinders, "Human Vulnerability: A Conversationg at L'Arche," 14

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80. Cushing, "Shaping the Moral Imagination of Caregivers," 196.

81. Ibid.

and orientation of their [lives]."[82]  Similarly, worship is also at the core of life in

L'Arche. Every moment is seen as an opportunity for worship through singing, giving

thanks, or by prayer.  While visiting a L'Arche community in the United States, one

author experienced a post-mealtime prayer gathering.  Core members and assistants

congregated together and passed a glowing candle around the circle, each recipient being

given "an opportunity to offer prayer, make requests, or spontaneously lead the group in

songs of worship." [83]  For this community, the candle ritual is a time of both communal

and spiritual growth pointing to God's presence.[84]  The Eucharist is regularly received, as

well. One author describes his experience of the Eucharist with a L'Arche community:

> "Candles burn everywhere … The priest is arrayed in a liturgical robe with a
> colorful stole. Handicapped community members sit on either side, ready to
> assist. Chairs encircle a huge, ark-shaped wooden table that was built in the
> community's wood shop … Handicapped members assist with preparing the
> emblems, wafers, and wine, and then help serve."[85]

To members of L'Arche, participation in the Eucharist allows them to "discover more

clearly the presence of God in [their] wounds and others."[86]  Personal presence with one

another and celebration, not just recognition, of the Eucharist both contribute to the deep

sense of unity that manifests from communal participation in this sacrament.  The

Eucharist "is a call away from fear," during which both assistants and core members

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82. Downey, *A Blessed Weakness,* 104.

83. Reimer, *Living L'Arche*, 27.

84. Ibid., 33.

85. Arthur P Boers, "What Henri Nouwen Found at Daybreak: Experiments in Spiritual Living in a Secular World," *Christianity Today* 38, no. 11 (1994): 28-29.

86. Ibid., 105.

"place themselves before God in their place of worship, knowing that God sees them and blesses them just as they are."[87]

*Personhood and Value Understood by L'Arche*

L'Arche's practices are informed by a particular account of personhood. People with disabilities are received in L'Arche as full human persons with unique values and gifts to give others. Rather than being accounted as faulty or broken humans, they are complete human beings who have rights just as every other human to life, care, education, and work.[88]  Common to all human persons is the "need to love and be loved, to know others and to be known, and to live freely and allow others to live freely."[89] Hans S. Reinders offers an insight that encapsulates the understanding of personhood at L'Arche, saying, "The human being exists truthfully in God's friendship, regardless of his or her abilities and disabilities."[90]  Understood this way, the concept of personhood held by L'Arche is "all-inclusive"; nobody is marginalized due to his or her vulnerabilities.[91]

Jean Vanier and L'Arche call into question what contemporary culture judges as success and value.  L'Arche challenges the current value system that "equates human dignity with utility."[92]  Values and perspectives at L'Arche are born out of disability, not

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87. Downey, *A Blessed Weakness,* 88-89.

88. Kearney, "Discvoering the Beatitudes at L'Arche," 460.

89. Downey, *A Blessed Weakness,* 97.

90. Reinders, *Receiving the Gift of Friendship,* 313.

91. Downey, *A Blessed Weakness, 109.*

92. Higgins, "Messy Love: Jean Vanier's L'Arche," 10.

in spite of it, and from this, core members "live with an embodied vulnerability that is essential to being human."[93] They open others up to the shared humanity in which vulnerability and dependence is accepted, even celebrated. "Societal and theological ideals of self-sufficiency and autonomy" are deconstructed, and "ideals of community born in vulnerability, weakness, and dependence" are reconstructed.[94] Community and placing trust in other members are encouraged at L'Arche, and the ideals of self-reliance that permeate contemporary culture are challenged.[95] Often in the larger culture, dependence is alluded to as weakness or failure, but at L'Arche, solidarity and deep community with one another are celebrated.

Similarly, knowing how to give and receive is important to members of L'Arche. Too often, in a culture where "'giving' is a sign of wealth and power; 'receiving' is a sign of dependency and want," this has become difficult.[96] Members of L'Arche learn that before they are able to have anything to give to each other, they first have to receive and be received into deep communion with others.[97] L'Arche also promotes an alternative view from the common contemporary Western understanding of productivity and the value that comes from it. L'Arche places value in fruitfulness and activities that give life to others.[98] Rather than intending to fix or better things and restore people's potential for productivity, L'Arche intends to encourage people to discover and fully be themselves so

93. Tim Basselin, "Why Theology Needs Disability," *Theology Today* 68, no. 1 (2011): 52.

94. Ibid., 47.

95. Ibid., 50.

96. Reinders, *Receiving the Gift of Friendship,* 321.

97. Ibid., 322.

98. Cushing, "Shaping the Moral Imagination of Caregivers," 196.

they are able to give and receive from others in their communities. The aim is for all members to learn to live with difference and limitation in themselves, and likewise to learn to love those in the community for who they are in their differences.[99] People with disabilities can feel accepted for who they are as whole persons with, not in spite of, their disabilities.[100]

Vanier sees the deepest need of a person as a desire to love and to be loved, and understands people as beings created to share life with others.[101] At L'Arche, this deep need that is common among all people is affirmed, and core members and assistants alike are "welcomed and valued for who they are as a person" and are given a place in their community where their gifts can flourish and where growth and transformation become possible.[102]

The desire of L'Arche is to say to all people, "I am glad you exist."[103] Community, celebration, and patience are the customary spirit of L'Arche.[104] Humility and vulnerability are also distinctive of L'Arche communities. In addition to these characteristics, L'Arche communities are deeply rooted in the Gospel message, and express this foundation through spiritual practices such as communal prayer, worship, and the Eucharist. These distinguishing characteristics and conventions, along with the

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99. Reinders, "Human Vulnerability: A Conversation at L'Arche," 5.

100. Cushing, "Shaping the Moral Imagination of Caregivers," 188.

101. Michael Hryniuk, *Theology, Disability, and Spiritual Transformation* (Amherst: Cambria Press, 2010), 245.

102. Kearney, "The Transforming Power of Vulnerability," 245.

103. Hauerwas and Vanier, *Living Gently in a Violent World,* 69.

104. Clarke, *Enough Room for Joy,* 16.

account of personhood that shapes them, make L'Arche show the possibility of the

"freedom of non-autonomy" and all that can be gained when one is willing to be

vulnerable and to need and be needed.[105]

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105. Basselin, "Why Theology Needs Disability," 55.

CHAPTER FIVE

L'Arche and Physical Therapy


L'Arche communities and their defining characteristics and practices have the

potential to shape contemporary disability care practices.  In L'Arche communities,

assistants see their role as members of the community, "being with" core members rather

than "doing for".  The difference between these two roles marks "the distinction between

professional intervention and personal presence."[1]  While health professionals,

specifically physical therapists, may help individuals with disabilities "to overcome

physical and psychological difficulties, to grow to greater autonomy, and to develop their

capacities in various fields," often times these patients "are yearning for meaningful,

authentic, respectful, and committed relationships."[2]  Although physical therapy and

L'Arche both are inherently different institutions, there are certain L'Arche practices and

values that can affirm the work of and perhaps encourage growth in physical therapists.

In this chapter, ways in which these two can perhaps meet will be identified using

L'Arche assistants as examples of certain practices and qualities that physical therapists

can adapt to their existing practices, goals, and theories of disability care.

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1. Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids: William B. Erdmans Publishing Co., 2010), 336.

2. Jean Vanier, "What Have People with Learning Disabilities Taught Me?" in *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* ed. Hans S. Reinders (Grand Rapids: William B. Erdmans Publishing Co., 2010), 21.

*Physical Therapy Theories and Practices*

Traditionally, the goal of physical therapy is to help patients obtain the highest

possible level of personal and physiological functioning and independence. According to

the American Physical Therapy Association's (APTA) Code of Ethics, it is the obligation

of physical therapists "to empower, educate, and enable those with impairments, activity

limitations, participation restrictions, and disabilities to facilitate greater independence,

health, wellness, and enhanced quality of life."[3] Physical therapists pursue improvements

in physical, cognitive, and sensory functions in their patients through physical therapy

interventions, such as exercise plans, adaptive technologies and equipment, or pain

management. These improvements will hopefully allow the patient to function better and

more independently. In addition to promoting independent functioning, physical

therapists also seek "to promote the ability to move, reduce pain, restore function, and

prevent disability."[4]

When physical therapy begins with a patient, therapists perform an initial

assessment to "establish a baseline for intervention."[5] This assessment typically involves

reviewing a patient's skills, abilities, and pathology. After an assessment, physical

therapists develop a rehabilitation plan that may include a variety of interventions.

Baseline progress is measured after these interventions have been given to a patient. If

after a re-examination the goals and expectations of the therapist and patient have not

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3. "Code of Ethics for the Physical Therapst," *American Physical Therapy Association*, last modified October 2013, http://www.apta.org/uploadedFiles/APTAorg/About_Us/Policies/Ethics/CodeofEthics.pdf

4. "Role of a Physical Therapist," *American Physical Therapy Association,* last modified April 2014, http://www.apta.org/PTCareers/RoleofaPT/.

5. Annelisse Barrell, "Assessment," in *Learning Disability: Physical Therapy, Treatment, and Management*, ed. Jeanette Rennie (Philadelphia: Whurr Publishers, 2001), 114.

been met, physical therapists may modify interventions or give new ones to the patient to try.

To evaluate patients and the effects of physical therapy following the rehabilitation plan, physical therapists utilize specific outcome measures. These measures provide "a means to quantify change in patient's functioning" as it relates to body functions and structures, activity, and participation.[6] Two particular outcome measures that are commonly used by physical therapists are functional outcomes and impairment outcomes. Functional outcomes measure a patient's ability to perform tasks of everyday living, including activities of daily living (ADLs), home activities, vocational activities, and goal-directed mobility skills, such as driving a car or walking down a set of stairs.[7] Impairment outcomes measure physiological functioning, such as range of motion or force, and can be compared to other outcomes to relate different intervention approaches.[8] For example, physical therapists may compare the outcome of one leg exercise to another to determine which is most effective at addressing a particular impairment. Physical therapists also often use impairment measures as indicators that interventions are working, with the goal that "minimizing impairments will directly affect improvements in function."[9]

The typical relationship between physical therapist and patient tends to be defined by a one-way transfer of help and information. Therapists have not been expected to

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6. "Outcome Measures in Patient Care," *American Physical Therapy Association*, last modified March 2014, http://www.apta.org/OutcomeMeasures/.

7. Sandra L. Kaplan, *Outcome Measurement & Management: First Steps for the Practicing Clinician* (Philadelphia: F.A. Davis Company, 2007), 43.

8. Ibid., 51.

9. Ibid.

engage in any exchange of emotions or feelings, and are generally accustomed to keeping neutral, objective positions in relation to their patients.[10] The APTA identifies five main roles of the physical therapist: management of patients, consultation, education, research, and administration.[11] Words like management, consultation, and administration do not suggest that physical therapists are expected to fulfill more personal roles such as friend or teacher. More recently, the relationship between not only physical therapists, but healthcare providers in general, and their patients is swinging in the other direction because of the emphasis on patient rights, autonomy, and self-determination.[12] However, despite public policies and legal standards set up to ensure these opportunities for patients, they do not necessarily guarantee good support for patients.[13] For physical therapists, this will depend on a particular kind of moral life that reexamines their role in the patient-therapist relationship.

*Physical Therapy and Interpretation of Disability*

As discussed in chapter three, there have been efforts made to combine the medical and social models of disability. The goal of physical therapy, autonomy and independence, can be an example of the two models coming together. On one hand, physical therapists see a physiological abnormality needing to be addressed via plans of care. On the other, it is recognized that disability results from social causes rather than

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10. Donna Marie Forster, "Jean Vanier and the Transformational Model of Rehabilitation: Principles of Care for Concerned Professionals," (PhD diss, Queen's University, 2007), 23.

11. "Code of Ethics," *American Physical Therapy Association.*

12. Hans S. Reinders, *The Future of the Disabled in Liberal Society* (Notre Dame: University of Notre Dame Press, 2000), 2.

13. Hans S. Reinders, introduction to *The Future of the Disabled in Liberal Society*, by Hans S. Reinders (Notre Dame: University of Notre Dame press, 2000), x.

simply physical causes, and the ultimate goal is to restore social functioning and independence to the patient. Physical functioning, which allows the patient to overcome barriers in society, is restored by eliminating or ameliorating the impairment. The vision statement for physical therapists, as declared by the APTA, is: "Transforming society by optimizing movement to improve the human experience."[14] Physical therapy interventions seek improvements beyond simply curing or eliminating impairment, but also improvements in an individual's ability to participate in and contribute to society.

However, many physical therapists, perhaps unknowingly, make clinical decisions that are dominated by the medical model of disability. The medical model assumes that disability results from physiological abnormalities in individuals. It also states that curing or ameliorating these abnormalities can restore the individual back to normal functioning. This restoration is the "only possible way to bring about social integration of people with disabilities."[15]

Physical therapy and other rehabilitation sciences often come under attack because of their perceived adherence to the medical model. Rehabilitation practices and principles receive criticism because many of them seem to assume that disability is a defect needing a cure or normalization, and in effect, perpetuate a negative view of disability and the marginalization of individuals whose bodies and minds may function differently.[16] Much of this criticism comes from individuals adhering to the social model of disability, who claim that what really needs fixing is not the individual's impairment

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14. "Vision Statement for the Physical Therapy Profession and Guiding Principles to Achieve the Vision," *American Physical Therapy Association*, last modified March 2014, http://www.apta.org/Vision/.

15. Paul K. Longmore, *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple University Press, 2003), 205.

16. Susan Magasi, "Infusing Disability Studies into the Rehabilitation Sciences," *Topics in Stroke Rehabilitation* 15, no. 3 (2008): 283.

but the physical and attitudinal barriers put up by society that are not accommodating to people who have impairments.[17]  It may be argued that "in ignoring the wider social and economic dimensions, the medical perspective fails to do justice to the daily experiences of disabled people and their families."[18]  Still, physical therapists tend to adopt and be more comfortable with models of disability that are based on the impact of impairments on a patient's ability to perform physiologically and pay less attention to the role of society in creating disability.[19]

This criticism can be combated if physical therapists look beyond just a medical explanation of disability.  The meaning of disability to a physical therapist can be shaped by a number of factors, not the least being beliefs, values, and experiences.[20]  Education can also affect change in their understanding of disability.  There have been several studies showing that "education of disability issues develops and deepens knowledge, which enables attitudes to change."[21]  This change in attitude can open up the physical therapist to a deeper understanding of a patient with a disability, his or her experiences of disability, and can ultimately improve the relationship between physical therapist and patient and disability care.

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17. Susan E. Roush and Nancy Sharby, "Disability Reconsidered: The Paradox of Physical Therapy," *Physical Therapy* 91, no. 12 (2011): 1718.

18. Reinders, *The Future of the Disabled in Liberal Society,* 3.

19. Roush and Sharby, "Disability Reconsidered," 1720.

20. Sue Standing and Sue Smith, "First Steps in Getting to Know and Communicating with People Who Have Learning Disabilities," in *Learning Disability: Physical Therapy, Treatment, and Management*, ed. Jeanette Rennie (Philadelphia: Whurr Publishers, 2001), 98.

21. Ibid., 99.

The medical model of disability may foster "an impoverished, one-way relationship of dependence between healer and patient, caregiver and cared-for."[22] Paternalism is still a powerful influence in the relationship between physical therapists and people with disabilities, but does not necessarily always result from bad intentions. Certain practices or behaviors may be well intentioned and grounded in ethical principles of care, but "can lead to ableist care that assumes every patient wants to eliminate his or her impairment to the fullest extent possible."[23] This may not always be true.

Whether subscribing to the medical model, social model, or a combination of the two, physical therapists are influenced by a common account of personhood. This account understands that what gives people value is the ability to be independent, self-sufficient, and contributive to society. Although these things are important, they cannot be the only conditions for worth in people. There are individuals who cannot achieve these things, and physical therapists will encounter patients who may never be able to fully restore their abilities to be self-sustaining and independent in society. Perhaps physical therapists can offer affirmations of value via the acceptance and celebration of their patients and their stories, regardless of how much they achieve in physical therapy. If physical therapists expand their understanding of disability beyond these models and adopt practices and principles similar to those of L'Arche, then maybe their relationships with individuals who have more profound disabilities can become relationships where both therapist and patient will benefit.[24]

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22. Thomas Reynolds, *Vulnerable Communion* (Grand Rapids: Brazos Press, 2008), 25.

23. Roush and Sharby, "Disablity Reconsidered," 1718.

24. Reynolds, *Vulnerable Communion,* 25.

*Physical Therapy and L'Arche*

By looking at the practices and principles of L'Arche, physical therapists have "an extraordinary opportunity to learn that each encounter with another person is an important moment – a moment in which to call the other forth, give him life, or in some way leave him in the death of his loneliness or self-doubt."[25] Jean Vanier emphasizes "there is no way of doing something for other people if you do not first learn how to receive whatever gift they have to offer."[26] The roles of assistants in L'Arche communities can in some ways relate to and inform the role of physical therapists working with individuals who have disabilities, and the distinctive characteristics and qualities of L'Arche can shape those of physical therapists.

There are certainly practices and values physical therapists already have that are similar to those in L'Arche communities. One of these is celebration. Physical therapists celebrate with patients when they make gains in their physical functioning through their care plans. These can be improvements as small as one more degree of flexion, or as big as being able to perform an ADL independently. To some extent, physical therapists practice humility. Practices such as sitting down at the same level as a patient or consulting other healthcare professionals during treatment exhibit a sense of humility. Patience is also an inherent quality of physical therapy. Unlike pharmaceutical therapy or surgical therapy, physical therapy requires time. Physical healing comes from weeks, perhaps months, of therapy.

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25. Bill Clarke, *Enough Room for Joy: Jean Vanier's L'Arche: A Message for Our Time* (Toronto: McClelland and Stewart, 1974), 19.

26. Hans S. Reinders, "Human Vulnerability: A Conversation at L'Arche," in *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* ed. Hans S. Reinders (Grand Rapids: William B. Eerdmans Publishing Co., 2010), 4.

At L'Arche, disability is not viewed as something that makes an individual faulty

or damaged.  Rather, an individual's disability is simply seen as part of who they are.

Personhood, as understood by L'Arche, is also found in dependence, vulnerability, and

giftedness of each person.  Disability becomes a difference that is celebrated, not

obscured.  If physical therapists adopted a similar attitude about disability and considered

their patients as "brothers and sisters in humanity," they might take in to account a fuller

range of their patients' experiences.[27]  Rather than focusing on a single trait, namely, the

bodily impairment that a patient may have, physical therapists informed by this more

holistic understanding of disability may be reminded of their patients' needs and hopes

for things outside of the physical therapy experience.  In turn, goals and activities that are

more meaningful to each patient can be identified and pursued.  These might include

finding a safe and healthy self-image rather than purely the elimination of disease or

injury, or supporting development and growth of life "according to its own natural

rhythm", whatever that may be for a particular patient.[28]

The mutuality and friendship that develops between assistants and core members

can shape the relationship that physical therapists have with patients who live with

impairments.  Characteristic of the friendship between assistants and core members are

the acceptance and receiving of people as they are.  Individuals with disabilities are

people "with strengths and weaknesses, likes and dislikes," and gifts and needs, just like

the physical therapists with whom they may work.[29]  All of these things are part of an

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27. Jean Vanier, *Becoming Human* (Mahwah: Paulist Press, 1998), 59.

28. The former goal noted here is referenced by Roush and Sharby in "Disability Reconsidered," 1720. The latter goal noted is found in Vanier's work, *Becoming Human,* 27.

29. Magasi, "Infusing Disability Studies," 286.

individual's story. Stories, and the sharing of them between friends, are valued at

L'Arche. In contemporary Western culture, impairment or disability seem to be defining

of a person's story. Qualities and aspects of an individual's life beyond his or her

impairment are often failed to be recognized and shared. Impairment might be part of

somebody's story, but it is not defining of he or she. At L'Arche, narratives of a person's

value and being in the world are understood as more than impairment. Even further, each

person's story has gifts to offer those who are willing to hear it and receive it. By getting

to know patients' stories, physical therapists can create an environment where patients

come to know their stories better as well, and where they can feel that their stories carry

value.

       L'Arche can help illustrate what a more balanced relationship between an

individual with a disability and his or her physical therapist may look like via the

mutually beneficial friendships that are formed between assistants and core members.

People with disabilities can potentially spend large amounts of time with physical

therapists. If the physical therapist sees his or her role as superior to the patient's, these

roles may be perpetuated outside of the clinic. Physical therapists may continue to have a

negative view of disability, and the patient will continue to feel inferior and powerless.[30]

By seeing their patients as having as much to offer them as they can offer their patients,

physical therapists would benefit from participation in the physical therapy experience as

well as the patient.[31] Interacting and engaging with patients in personal ways can be part

of a therapeutic environment for both individuals involved.

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30. Susan E. Roush, "Health Professionals as Contributors to Attitudes Towards Persons with Disabilities," *Physical Therapy* 66, no. 10 (1986): 1551.

31. Forster, "Jean Vanier and the Transformational Model of Rehabilitation," 60.

Physical therapists can also apply practices of communication that are characteristic of L'Arche communities to their own practices in the clinic. In L'Arche, assistants get to know and learn how each core member communicates. This is crucial to the development of relationships in which core members feel safe even in their vulnerabilities. Communication is equally as important for physical therapists – it is a means for patients to share their subjective experiences, such as pain or other sensations, with the physical therapist.[32] Physical therapists working with individuals who have physical and intellectual impairments may find themselves in situations where communication may be a bit more challenging. It is important for physical therapists to get to know the ways that these individuals communicate. Just like an assistant learns that a core member may have a word or gesture for expressing a particular feeling or thought through spending time and effort getting to know the core member, physical therapists can give their patients time during which the therapist gets to know the individual's background, abilities, behaviors, and styles of communicating.[33] Each person is unique and responds differently in different situations, so it is important for physical therapists to know their patients and their ways of communicating to accurately identify a patient's needs and desires. People with more profound intellectual disabilities may not be able to communicate their physical symptoms or concerns with their physical therapists, and likewise, physical therapists may not be able to communicate their suggestions for therapy. In these instances, physical therapists may need the help of a relative or caregiver to provide this information. However, similar to the way L'Arche

32. Lena G. Lundström, "Further Arguments in Support of a Social Humanistic Perspective in Physiotherapy Versus the Biomedical Model," *Physiotherapy Theory and Practice* 24, no. 6 (2008): 395.

33. Standing and Smith, "First Steps," 100.

assistants include core members in household decisions, physical therapists should always do their best to include individuals with disabilities in interventions and decision-making. Further, physical therapists could include individuals with disabilities as evaluators of the physical therapy interventions, rather than just performing outcome measurements themselves.

At L'Arche, personal presence is cherished, and patience is valued. Time spent together in community goes by unrushed, and each moment together is significant. Likewise, physical therapists can learn from the unhurried pace and intentional presence found in L'Arche communities. In the APTA's Code of Ethics, physical therapists are called to "respect the inherent dignity and rights of all individuals."[34] This respect goes beyond politeness, courtesy, and welcome, and instead calls for a respect similar to the respect that members of L'Arche communities have for one other. At L'Arche, assistants and core members are respected and celebrated for their inherent value as human beings and for the gifts they bring to the community. Physical therapists can similarly respect the inherent worth in their patients and the gifts as well as the vulnerabilities that they have to share with the therapist. Physical therapists can also show this respect by granting their patients the dignity to choose – goals, interventions, time of appointments, etc. Having a deep respect for individuals with disabilities with whom they work, physical therapists can further enrich the time spent with them. "Any behavior is potentially communicative," even the smallest of them, and by focusing on having a more

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34. "Code of Ethics," *American Physical Therapy Association*.

intentional personal presence with individuals who have disabilities, physical therapists are more likely to pick up on these.[35]

Presence likewise requires patience. Assistants at L'Arche learn to be patient with themselves and with core members through even the daily routines such as cooking or getting ready for the day. Physical therapists can practice patience as well by giving their patients the time they need to complete an activity and by simply being there with the patient throughout the session without rushing through it. It may be difficult at times when schedules get backed up, but just as Henri Nouwen learned with Adam, rushing through things will almost never result in a better outcome.

Another quality of L'Arche communities that can shape how physical therapists practice is the encouragement of humility and vulnerability among its members. Present culture resists the idea of accepting suffering – it seems too passive, patient, and submissive.[36] In L'Arche, suffering is accepted as a part of humanity, and is seen as opportunity to come beside one another in solidarity to walk through a difficult time. Healthcare professionals, including physical therapists, may get too focused on eliminating suffering and disability and overlook the experience of walking through suffering with the individuals with whom they are working. At L'Arche, these times of suffering can be times of deep communion with each other. Also, just as the assistants in L'Arche experience profound personal growth through coming to terms with their own vulnerabilities, physical therapists may experience more development of their self-images by humbling themselves and allowing themselves to be vulnerable with their patients.

35. Standing and Smith, "First Steps," 101.

36. Reinders, *The Future of the Disabled in Liberal Society,* 171.

L'Arche assistants are humble about their roles, as well. Although they have much to do with the successful running of the community, they do not think of themselves as the care providers or leaders, but instead as members of the community with as much to receive as they have to give. Rehabilitation sciences, specifically physical therapy, can be very beneficial to the lives of individuals with disabilities when the physical therapist approaches his or her role and patients openly, humbly, and compassionately.[37] Physical therapists can also humble themselves by recognizing that the patient is the expert on his or her disability. This attitude might open the therapist up to receiving and learning from his or her patient.

*Conclusion*

Although L'Arche and physical therapy serve different purposes in the lives of individuals with disabilities, by looking at L'Arche and applying several of its key characteristics and practices, physical therapy can be a transformational process for both therapist and patient. L'Arche illustrates that "relationships allow us to learn about others, from others, through others and about ourselves."[38] Rehabilitation sciences, specifically physical therapy, can be beneficial to the lives of individuals with disabilities when the physical therapist thinks about disability in a holistic way and approaches his or her patients openly, humbly and compassionately.

To conclude, the focus of this thesis has been on disability care practices and anthropologies in the United States, and on how defining qualities and characteristics of L'Arche may inform and shape contemporary disability care practices via physical

37. Magasi, "Infusing Disability Studies," 283.

38. Standing and Smith, "First Steps," 100.

therapy.  One way that L'Arche differs significantly from contemporary care practices is in the understanding of personhood and value that permeates throughout every practice and characteristic of L'Arche.  In L'Arche communities, every member is treasured – all of their strengths, weaknesses, gifts, and needs are valued and received by others within the community.  Contrary to contemporary values of independence and autonomy, L'Arche finds significance in vulnerability and in sharing it with others.  L'Arche does not aim to cure or eliminate disability from its core members, but rather create an environment where individuals with disabilities are given freedom and the chance to flourish through celebration of humanity in both weakness and strength.  Likewise, physical therapists have the opportunity to promote an environment where patients can find freedom and healing not necessarily through therapy interventions alone, but through being with patients rather than doing for, and through acceptance and value for who their patients are and what they have to offer as gift.

BIBLIOGRAPHY

"1956 Social Security Amendments." *Social Security Administration.* Accessed October 11, 2013. http://www.ssa.gov/history/tally56.html

"A L'Arche Community is…" *L'Arche International.* Accessed March 13, 2014. http://www.larche.org/en/discover/a_larche_community_is_

"About ASAN." *ASAN.* Last modified 2014, http://autisticadvocacy.org/about-asan/.

Anderson, Catherine. "Reflecting on Practice in L'Arche: Encountering the Grieving Other." *Compass* 46, no. 1 (2012): 38-40

Angrosino, Michael V. "L'Arche: The Phenomenology of Christian Counterculturalism." *Qualitative Inquiry* 9, no. 6 (2003): 934-954.

"Americans with Disabilities Act of 1990, As Amended." *ADA.gov.* Last modified June, 2009. http://www.ada.gov/pubs/adastatute08.htm#12102

Areheart, Bradley A. "When Disability Isn't 'Just Right': The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma." *Indiana Law Journal* 83, no. 1 (2008): 181-232.

Barnes, Eric R. and Helen McCabe, "Should We Welcome a Cure for Autism? A Survey of the Arguments," *Medicine, Health Care and Philosophy* 15, no. 3 (2012): 255-269.

Barrell, Anneliese. "Assessment." In *Learning Disability: Physical Therapy, Treatment, and Management,* edited by Jeanette Rennie, 114-133. Philadelphia: Whurr Publishers, 2001.

Basselin, Tim. "Why Theology Needs Disability." *Theology Today* 68, no. 1 (2011): 47-57.

Boers, Arthur P. "What Henri Nouwen Found at Daybreak: Experiments in Spiritual Living in a Secular World." *Christianity Today* 38, no. 11 (1994): 28-31.

Boorse, Christopher. "Disability and Medical Theory." In *Philosophical Reflections on Disability*, edited by D. Christopher Ralston and Justin Ho, 55-87. Dordrecht: Springer Science+Business Media B.V., 2010.

Braddock, David L. and Susan L. Parish. "An Institutional History of Disability." In *Handbook of Disability Studies*. Edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury, 11-68. Thousand Oaks: Sage Publications, 2001.

Buck, Pearl S. *The Child Who Never Grew*. Vineland: The Training School, 1950.

Buck, Pearl S. "The Child Who Never Grew." *Ladies Home Journal*, May 1950.

"Buck v. Bell." *The Oyez Project at IIT Chicago-Kent College of Law.* Accessed August 2, 2013. http://www.oyez.org/cases/1901-1939/1926/1926_292.

Buckingham, Jane "Institutionalization and Segregation." In *Encyclopedia of Disability.* Thousand Oaks: Sage Publications, 2006. http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/sagedisab/institutionalization_and_segregation/0 (accessed October 11, 2014.)

Byrom, Brad. "A Pupil and a Patient: Hospital-Schools in Progressive America." In *The New Disability History*, edited by Paul K. Longmore and Lauri Umansky, 133-157. New York: New York University Press, 2001.

Clarke, Bill. *Enough Room for Joy: Jean Vanier's L'Arche: A Message for Our Time.* Toronto: McClelland and Stewart, 1974.

"Code of Ethics for the Physical Therapist." *American Physical Therapy Association.* Last updated October 2013. http://www.apta.org/uploadedFiles/APTAorg/About_Us/Policies/Ethics/CodeofEthics.pdf

"Councils on Developmental Disabilities." *National Association of Councils on Developmental Disabilities.* Last modified January, 2014. http://www.nacdd.org/about-nacdd/councils-on-developmental-disabilities.aspx.

Creamer, Deborah Beth. "Disability Theology." *Religion Compass* 6, no. 7 (2012): 339-346.

Cushing, Pamela. "Disability Attitudes, Cultural Conditions, and the Moral Imagination." In *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* edited by Hans S. Reinders, 75-93. Grand Rapids: William B. Erdmans Publishing Co., 2010.

Cushing, Pamela J. "Shaping the Moral Imagination of Caregivers: Disability, Difference & Inequality in L'Arche." PhD diss., McMaster University, 2003.

Davis, Lennard. "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the   Disabled Body in the Nineteenth Century." In *The Disability Studies Reader,* edited by Lennard J. Davis, 3-16. New York: Routledge, 1997.

DePoy, Elizabeth G. and Stephen F. Gilson. *Studying Disability: Multiple Theories and Responses.* Thousand Oaks: SAGE Publications, 2010.

"The Developmental Disabilities Assistance and Bill of Rights Act." *The Minnesota Governor's Council on Developmental Disabilities.* Accessed October 11, 2013. http://mn.gov/mnddc/dd_act/documents/FEDREG/90-DDA-LEGLISLATIVEHISTORY.pdf.

Downey, Michael. *A Blessed Weakness: The Spirit of Jean Vanier and L'Arche.* San Francisco: Harper & Row, 1986.

Drum, Charles E. "Models and Approaches to Disability." In *Disability and Public Health*, edited by Charles E. Drum, Gloria L. Krahn, and Hank Bersani, 27-44. Washington: APHA Press, 2009.

"Fact Sheet: University Centers for Excellence in Developmental Disabilities Education, Research, and Service." *Administration for Community Living.* http://www.acl.gov/NewsRoom/Publications/docs/UCEDDs_factsheet.pdf (accessed February 2, 2014).

Fleischer, Doris and Frieda Zames. *The Disability Rights Movement.* Philadelphia: Temple University Press, 2011.

Forster, Donna Marie. "Jean Vanier and the Transformational Model of Rehabilitation: Principles of Care for Concerned Professionals." PhD diss., Queen's University, 2007.

Friedman, Susan Hatters, James Cavney, and Phillip J. Resnick. "Mothers Who Kill: Evolutionary Underpinnings and Infanticide Law." *Behavioral Sciences & the Law* 30, no. 5 (September/October 2012): 585-597.

Goode, David "Willowbrook State School." In *Encyclopedia of Disability*. Thousand Oaks: Sage Publications, 2006. http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/sagedisab/willowbrook_state_school/0 (accessed October 11, 2013.)

Hanson, Stuart P. "Applying Independent Living Principles to State Health-Care Programs for People with Disabilties." *Journal of Disability Policy Studies* 11, no. 3 (2000): 161-170.

Haslam, Molly C.  *A Constructive Theology of Intellectual Disability: Human Being as Mutuality and Response.* New York: Fordham University Press, 2012.

Hauerwas, Stanley and Jean Vanier. *Living Gently in a Violent World: The Prophetic Witness of Weakness.* Downers Grove: InterVarsity Press, 2008.

Higgins, Michael. "Messy Love: Jean Vanier's L'Arche." *Commonweal*, May 2009.

Hryniuk, Michael. *Theology, Disability, and Spiritual Transformation.* Amherst: Cambria Press, 2010.

"Identity and Mission." *L'Arche USA.* Accessed March 13, 2014. http://www.larcheusa.org/who-we-are/identity-and-mission/

Irvine, Paul. "Haüy, Valentin." In *Encyclopedia of Special Education: A Reference for the Education of Children, Adolescents, and Adults with Disabilities and Other Exceptional Individuals.* Hoboken: Wiley, 2007. http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/wileyse/ha%C3%BCy_valentin/0 (accessed October 11, 2013.)

Irvine, Paul "Itard, Jean M. G.." In *Encyclopedia of Special Education: A Reference for the Education of Children, Adolescents, and Adults with Disabilities and Other Exceptional Individuals.* Hoboken: Wiley, 2007. http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/wileyse/itard_jean_m_g/0 (accessed October 22, 2013.)

Jonikas, Jessica A. Cook, Judith A. Hamilton, Marie "Dix, Dorothea (1802-1887)." In *Encyclopedia of Disability*. Thousand Oaks: Sage Publications, 2006. http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/sagedisab/dix_dorothea_1802_1887/0 (accessed October 11, 2013.)

Kaplan, Sandra L. *Outcome Measurement & Management: First Steps for the Practicing Clinician*. Philadelphia: F.A. Davis Company, 2007.

Kaye, H. Stephen, Patricia Yeager, and Myisha Reed. "Disparities in Usage of Assistive Technology Among People With Disabilities." *Assistive Technology* 20, no. 4 (2008): 194-203.

Kearney, Timothy. "Discovering the Beatitudes at L'Arche." *The Furrow* 35, no. 7 (1984): 460-464.

Kearney, Timothy. "The Prophetic Cry: Interview with Jean Vanier." *The Crane Bag* 5, no. 1 (1981): 79-85.

Kearney, Timothy. "The Transforming Power of Vulnerability." *Irish Theological Quarterly* 78, no. 3 (2013): 244-254.

Kopriva, Peter. "Independent Living Centers." In *Encyclopedia of Special Education: A Reference for the Education of Children, Adolescents, and Adults with Disabilities and Other Exceptional Individuals.* Hoboken: Wiley, 2007. http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/wileyse/independent_living_centers/0 (accessed February 1, 2014.)

"L'Arche Since Its Creation." *L'Arche International.* Accessed March 13, 2014. http://www.larche.org/en/discover/larche_since_its_creation.

Lee, Chongmin. "Deafness and Cochlear Implants: A Deaf Scholar's Perspective." *Journal of Child Neurology* 27, no. 6 (2012): 821-823.

Longmore, Paul K. "The Second Phase: From Disability Rights to Disability Culture." In *Disability: The Social, Political, and Ethical Debate,* edited by Robert M. Baird, Stuart E. Rosenbaum, and S. Kay Toombs, 141-151. Amherst: Prometheus Books, 2009.

Longmore, Paul K. *Why I Burned My Book and Other Essays on Disability*. Philadelphia: Temple University Press, 2003.

Longmore, Paul K. and Lauri Umansky. Introduction to *The New Disability History: An American Perspective.* Edited by Paul K. Longmore and Lauri Umansky. New York: New York University Press, 2001.

Lundström, Lena G. "Further Arguments in Support of a Social Humanistic Perspective in Physiotherapy Versus the Biomedical Model." *Physiotherapy Theory and Practice* 24, no. 6 (2008): 393-396.

Magasi, Susan. "Infusing Disability Studies into the Rehabilitation Sciences." *Topics in Stroke Rehabilitation* 15, no. 3 (2008): 283-287.

Magner, Lois N. *A History of Medicine*. New York: Marcel Deeker, Inc., 1992.

Marks, Deborah. *Disability: Controversial Debates and Psychosocial Perspectives.* New York: Routledge, 1999.

"Mission and Culture." *Young Adult Institute*. Last modified 2012. http://www.yai.org/about/mission-and-culture.html (accessed February 3, 2014).

"Mission, Vision & Values" *Westchester Institute for Human Development*. Last modified 2013. http://www.wihd.org/page.aspx?pid=675#.Uv4o0UJdUhE (accessed February 3, 2014).

Moseley, Kathryn L. "The History of Infanticide in Western Society." *Issues in Law & Medicine* 1, no. 5 (1986): 345-361

National Council on Disability. *The Current State of Health Care for People with Disabilities,* 2009. http://www.ncd.gov/rawmedia_repository/0d7c848f_3d97_43b3_bea5_36e1d97f9 73d?document.pdf (accessed November 26, 2013).

National Council on Disability. *Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers,* 2013. http://www.ncd.gov/rawmedia_repository/20ca8222_42d6_45a5_9e85_6bd57788 d726?document.pdf (accessed November 26, 2013).

National Council on Disability. *Toward Independence: An Assessment of Federal Laws and Progams Affecting Persons with Disabilities – With Legislative Recommendations.* Washington D.C.: United States Government Printing Office, 1986.

Natolia, Jaime L., Deborah L. Ackerman, Suzanne McDermott, and Janice G. Edwards. "Prenatal Diagnosis of Down syndrome: A Systematic Review of Termination Rates (1995-2011)." *Prenatal Diagnosis* 32, no. 2 (February 2012): 142-153.

Newell, Christopher. "On the Importance of Suffering." In *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* ed. by Hans S. Reinders. Grand Rapids: William B. Erdmans Publishing Co., 2010, 169-178.

Nielsen, Kim. *A Disability History of the United States.* Boston: Beacon Press, 2012.

Nouwen, Henri. *Adam: God's Beloved.* Maryknoll: Orbis Books, 1997.

O'Day, Bonnie. "Centers for Independent Living: Advocates for Disability Rights." *Community Development* 37, no. 3 (2006): 4-12.

"Outcome Measures in Patient Care." *American Physical Therapy Association.* Last updated March 2014. http://www.apta.org/OutcomeMeasures/.

"Parallels in Time." *The Minnesota Governor's Council on Developmental Disabilities.* July 15, 2013. http://mn.gov/mnddc/parallels/index.html

Parsons, Mikeal C. *Body and Character in Luke and Acts.* Grand Rapids: Bake Academics, 2006.

"Perspectives on the Historical Treatment of People with Disabilities." *Teaching for Diversity and Social Justice,* edited by Maurianne Adams, Lee Anne Bell, and Pat Griffin, 338-354. New York: Routledge, 2007.

"The President's Committee on Mental Retardation." *The Exceptional Parent* 30, no. 8 (August 2000): 86-87.

Prigmore, Charles S. and Paul R. Davis. "Wyatt v. Stickney: Rights of the Committed." *Social Work* 18, no. 4 (July 1973): 10-18.

Reimer, Kevin. *Living L'Arche*. Collegeville: Liturgical Press, 2009.

Reimer, Kevin. "Road to Guadalupe: Hope and Moral Identity in L'Arche Communities for the Developmentally Disabled." *Christian Scholar's Review* 38, no. 3 (2009): 359-373.

Reinders, Hans S. *The Future of the Disabled in Liberal Society*. Notre Dame: University of Notre Dame Press, 2000.

Reinders, Hans S. "Human Vulnerability: A Conversation at L'Arche." In *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* edited by Hans S. Reinders, 3-15. Grand Rapids: William B. Erdmans Publishing Co., 2010.

Reinders, Hans S. *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics*. Grand Rapids: William B. Eerdmans Publishing Co., 2008.

Reynolds, Thomas E. *Vulnerable Communion*. Grand Rapids: Brazos Press, 2008.

Rogers, Dale Evans. *Angel Unaware.* Grand Rapids: Revell, 1953.

"Role of a Physical Therapist." *American Physical Therapy Association*. Last updated April 2014. http://www.apta.org/PTCareers/RoleofaPT/

Roush, Susan E. and Nancy Sharby. "Disability reconsidered: the paradox of physical therapy." *Physical Therapy* 91, no. 12 (2011): 1715-1727.

Schalick, Walton O. "Hippocrates (428-347 bce)." In *Encyclopedia of Disability*. Thousand Oaks: Sage Publications, 2006. http://ezproxy.baylor.edu/login?url=http://literati.credoreference.com.ezproxy.baylor.edu/content/entry/sagedisab/hippocrates_428_347_bce/0 (accessed October 11, 2013).

Scully, Jackie Leach. "A Postmodern Disorder: Moral Encounters with Molecular Models of Disability." In *Disability/Postmodernity*, edited by Mairian Corker and Tom Shakespeare, 48-62. London: Continuum, 2002.

"Secondary Transition." *Ed.gov*. Last modified February 01, 2007. http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C17 %2C.

Silvers, Anita. "An Essay on Modeling: The Social Model of Disability." In *Philosophical Reflections on Disability*, edited by D. Christopher Ralston and Justin Ho, 19-36. Dordrecht: Springer Science+Business Media B.V., 2010.

Siraisi, Nancy G. *Medieval & Early Renaissance Medicine: An Introduction to Knowledge and Practice.* Chicago: The University of Chicago, 1990.

Spink, Kathryn. *The Miracle, The Message, The Story: Jean Vanier and L'Arche.* Mahwah: HiddenSpring, 2006.

Spencer, Herbert. *The Principles of Sociology.* New York: D. Appleton, 1898.

Standing, Sue and Sue Smith. "First Steps in Getting to Know and Communicating With People Who Have Learning Disabilities." In *Learning Disability: Physical Therapy, Treatment, and Management,* edited by Jeanette Rennie, 98-113. Philadelphia: Whurr Publishers, 2001.

Swick, Herbert M. "Toward a Normative Definition of Medical Professionalism." *Academic Medicine* 75, no. 6 (2000): 612-616.

Turkington, Carol and Allen E. Sussman. "Pereira, Jacobo Rodriguez (1715-1780)." In *The Encyclopedia of Deafness and Hearing Disorders.* New York: Facts on File, 2004.

"UCEDDs." *Association of University Centers on Disabilities.* Last modified 2011. http://www.aucd.org/template/page.cfm?id=24 (accessed November 26, 2013).

United States Department of Justice and United States Department of Health and Human Services. *Access to Medical Care for Individuals with Mobility Disabilities,* 2010. http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm (accessed November 26, 2013).

Vanier, Jean. *Becoming Human.* Mahwah: Paulist Press, 1998.

Vanier, Jean. *Community and Growth: Our Pilgrimage Together.* Toronto: Griffin Press, 1979.

Vanier, Jean. *The Heart of L'Arche.* Toronto: Novalis Publishing, 2013.

Vanier, Jean. "What Have People with Learning Disabilities Taught Me?" In *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences,* edited by Hans S. Reinders, 19-24. Grand Rapids: William B. Erdmans Publishing Co., 2010.

"Vision Statement for the Physical Therapy Profession and Guiding Principles to Achieve the Vision" *American Physical Therapy Association.* Last updated March 2014. http://www.apta.org/Vision/

Watson R., J.R. Parr, C. Joyce, C. May, and A.S. Le Couteur. "Models of Transitional Care for Young People With Complex Health Needs: A Scoping Review." *Child: Care, Health, and Development* 37, no. 6 (November 2011): 780-791.

World Health Organization. *General Principles of Good Chronic Care.* World Health Organization, 2004. http://www.who.int/hiv/pub/imai/generalprinciples082004.pdf (accessed November 27, 2013).