PRIMARY CARE:
THE PERSONAL PERSPECTIVE OF ADULTS WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES

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ABSTRACT

Primary Care:

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Doctor of Medical Humanities Dissertation by

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Interaction between primary care physicians and adults with intellectual/developmental disabilities has the potential to influence the quality of the health care experience for both parties. Primary care physicians, as the first and continuing contact for people with health concerns, must be aware of the aspects of care that are important to the person with disability in maintaining a healthy, satisfying quality of life.

Review of the literature regarding primary care for this patient population focuses predominantly on components of service: convenience, timeliness, and physical access, for example. Studies that attempt to ascertain what is most important to the person with intellectual and developmental disabilities, from a personal perspective, are not evident in the literature.

Within the framework of medical humanities, this research will examine the history of disability in society, the arts, and humanities; the place of disability in the evolution of health care; and studies related to the provision of care for those with intellectual/developmental disabilities. The influence of medical humanities in developing the primary care physician's ability to hear, acknowledge, and understand the story of the person with disability will be considered in light of developing effective communication with and care for the person with intellectual/developmental disability. Through interviews with adults with intellectual and

developmental disabilities and health care professionals, the research is designed to collect information on the relative influence of life experience, attitudes, behaviors, and interests important to the person with intellectual/developmental disability, and how those factors relate to developing effective communication and relationship with primary care physicians.

CONTENTS

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I would like to thank the interview participants who agreed to help in developing this personal and professional topic. Your time and input have set a course that has potential to shape health care people with intellectual and developmental disabilities receive in a positive way.

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Introduction

Throughout history people with disabilities have been viewed as anomalies, different when compared to the socially accepted norm. At times they have been viewed as defects of nature, born with inherent deficiencies and possessing little worth. In other eras disability was the product of an imposed social label, influenced by cultural expectations of beauty, health, functional ability, or economic status. Whether the consequence of fate or communal expectation, society has never felt comfortable with what appears deformed, spoiled, or broken. Yet, the perception of disability "is always a question of a given person or of a given society, of a given place, at a given moment."[1]

In times of illness, people with disabilities enter an environment where the milieu is focused on the promotion of cure and wellness. The presence of disability has the potential to skew the manner in which health care providers, including physicians, consider the disabled individual. The existence of physical disability may lead health care providers to assume that the physically disabled person is also limited intellectually. "The distinction between body and person is routinely overlooked in normative judgments with respect to bodily appearance. Negative judgments about someone's physical appearance are, more often than not, accompanied by negative judgments about personhood."[2] The presence of disability, whether physical, intellectual, or multifaceted, should not present a barrier to the provision of appropriate care. Yet, people with

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[1] Henri-Jacques Stiker, *A History of Disability* (Ann Arbor: University of Michigan Press, 1999), 21.

[2] Kay S. Toombs, "What Does it Mean to be Some*body*?," in *Persons and Their Bodies: Rights, Responsibilities, and Relationships,* ed. Mark J. Cherry (Boston: Kluwer Academic Publishers, 1999), 91.

disabilities may not be given the opportunity to explain their needs in a way that is meaningful to them because they are seen first as the disability and secondarily as a person.

Historically, medicine has emphasized a practice based on sound scientific developments and, more recently, cutting edge technology. A knowledge-based disease focus has led to better clinical results, a development that often drives the physician to place great attention on the signs and symptoms of the disease process. The need to diagnose the origin of the complaint, identify the cause of the problem, decide on an effective treatment modality, and develop a prognosis with the goal of positive results tends to mask the existence of the person at the center of the medical activity.[3] The person who presents with the illness is much more than the entity or process that precipitated the need to seek assistance. In reality, the focus of the physician's practice and successful outcome is a person who exists beyond the physical presence.

The physician makes objective decisions based on concrete information. Physical findings, laboratory data, and patient symptoms drive diagnostic determinations. Analytical decision making puts distance between the empirical aspects of medicine and the human qualities of the patient. Such distance establishes a barrier that prevents the physician from recognizing the interpersonal cues that may reveal important components of the patient's story.[4]

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[3] Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine* (New York: Oxford University Press, 2004), 76.

[4] Howard M. Spiro, *Empathy and the Practice of Medicine* (New Haven: Yale University Press, 1993), 134.

Like most individuals, people with disabilities seek medical attention for many reasons. They may experience a disruption in their usual state of being because of chronic health conditions, acute illness, emotional issues, or "existential pains, for the suffering of living in this world, for ailments that no technology can correct. That is where the patient's story comes in, for it can reveal what is important"[5] in the way a presenting condition is experienced and how the story -the symptoms and concerns- are related. The presence of disability does not diminish the stress and difficulty associated with daily living; it may add a degree of complexity to the telling of the story.

The primary care physician "provides both the first contact for a person with an undiagnosed health concern as well as continuing care of varied medical conditions, not limited by cause, organ system, or diagnosis."[6] As the first and continuing contact for people with health concerns, the primary care physician must be aware of the things that are important to the person with disability in maintaining a healthy, satisfying quality of life. It is important that a person's story is heard within the framework of illness, especially in the presence of disability. A person's story is a narrative of what is meaningful and important; it defines the good when a person is well and provides insight into the fullness of the person in times of distress. Disability does not affect the importance of the need to be heard and respected.

The way a primary care physician perceives a person with disabilities has the potential to influence the character of the clinical experience for both the individual with

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[5] Spiro, 4.

[6] Elizabeth H. Morrison, Valerie George, and Laura Mosqueda, "Primary Care for Adults with Physical Disabilities: Perceptions from Consumer and Provider Focus Groups," *Family Medicine* 40, no. 9 (October 2008): 645-651.

disability and the health care provider. "The doctor-patient interaction incorporates aspects both tangible and intangible. The intangible parts -empathy, compassion, good listening, nonverbal behavior, trust, respect- are critical, though notoriously difficult to quantify."[7] Medical humanities, through the use of "methods, concepts, and content from one or more of the humanities disciplines to investigate illness, pain, disability, suffering, healing, therapeutic relationships and other aspects of health care practice"[8] offer the primary care physician an opportunity to explore the intangibles.

A traditional definition of the humanities identifies studies intended to provide general knowledge and intellectual skills rather than occupational or professional skills. Edmund D. Pellegrino, a proponent of medical humanities, expands the traditional definition to emphasize the inherent nature of human value in every aspect of professional activity in the clinical disciplines. "This concern focuses on the respect for freedom, dignity, worth and belief systems of the individual person; and it implies a sensitive, non-humiliating way of helping with some problem or need."[9] The primary care physician can apply Pellegrino's definition to observe, monitor, and listen to adults with disabilities, especially those with intellectual and developmental disabilities, in order to direct care toward their needs, interests, and desires, the things that are most important to them, from a personal perspective.

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[7] Danielle Ofri, *What Patients Say, What Doctors Hear* (Boston: Beacon Press, 2017), 120.

[8] Johanna Shapiro, Jack Coulehan, Delese Wear, and Martha Montello, "Medical Humanities and Their Discontents: Definitions, Critiques, and Implications," *Academic Medicine* 84, Issue 2 (February 2009): 193.

[9] Edmund D. Pellegrino, *Humanism and the Physician* (Knoxville, TN: University of Tennessee Press, 1979) 118.

From ancient times to the present, society in general and medicine in particular have looked at the person with intellectual and developmental disabilities as different than those who appear to meet expected social norms. The assumption of difference has overshadowed the way society and medicine consider the person, often looking solely at the physical, functional, and clinical presence. The feelings, emotions, interests, and desires that represent the whole person are not often taken into account. Ancient cultures considered people with intellectual and developmental disabilities as disposable if unable to fully contribute to the social good. Later societies viewed them as a drain on communal assets, a burden to be carried by their families. In more recent times, people with intellectual and developmental disabilities experienced isolation in institutions overseen by physicians and other medical professionals and were the target of eugenic practices to limit their presence in society.

Through observation and lived experience in the institutions, medical practitioners ultimately determined many people with intellectual and developmental disabilities had the potential to participate in society at a level commensurate with their individual ability. Social and educational agencies, as well as family and community organizations, sought to develop programs and resources to promote their integration into general society.

While physicians recognized that individuals with intellectual and developmental disabilities had the potential to function in society, they continued to struggle with how to address the needs of this population. The clinical presentation was unique to each individual and standardized treatment was difficult. Specific symptoms could be treated from a clinical perspective but multiple barriers to understanding the individual needs of the patient presented challenges. Doctors could identify factors such as communication difficulty or lack of familiarity with physical needs that limited their view of the patient's presentation. They did not look at the patient with intellectual and physical disability as being capable of explaining what bothered them or what was important to them in establishing quality of life.

The medical literature has historically questioned how best to treat patients with intellectual and developmental disability. Much of the literature to the present time describes concerns that focus on factors that influence the provision of care: physical access, adequate appointment time, and clinical data for example. The idea of exploring what is of importance to the patient is relatively absent. The patient's perspective of health and what contributes to wellness may vary significantly from what the physician perceives as relevant in the health care encounter

Individuals with intellectual and developmental disabilities are capable of expressing their concerns and what is important to their health but in a way that may be different from what physicians expect from the general patient population. Likewise, physicians can recognize the clinical and disability-related information they view as necessary to provide effective care for the patient with intellectual and developmental disabilities but may not look to the patient's personal story as essential in developing a positive relationship with the patient. Physicians need to be open to difference and ways of looking at the health care relationship that respond to the personal values and perceptions of the patient.

Information derived through interviews with individuals with intellectual and developmental disabilities highlight what is important to them in the establishing a personal relationship with their primary care physicians and factors that may detract from maintaining positive rapport. Interviews with health care providers, including primary care physicians and a medical school faculty member, define the need to consider social and health determinants, medical knowledge, empathy, and humanistic thinking as well as individual patient needs and concerns in creating a positive personal relationship with the patient with intellectual and developmental disabilities.

The personal perspective of patients with intellectual and developmental disabilities is significant in considering the provision of comprehensive health care for this patient population. The unique character of each patient and the impact of life experience, personal beliefs, and individual interests shape the individual's understanding of health and its relative importance. Medical humanities offer the primary care physician an opportunity to consider different ways of listening to the patient's story, hearing what is said, and focusing on what is important to the patient in developing a plan of care. The circumstances surrounding the perception of health by individuals with intellectual and developmental disabilities are subject to change overtime due to alterations in health status over the lifespan. The patient's story and the ability of the primary care physician to incorporate what is important to patient in a plan of care support the patient's positive personal perspective of the health care relationship.

Chapter One

Intellectual and Developmental Disabilities: A Challenging Journey Through Time

The World Health Organization defines disability in a broad sense.

> Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interactions between features of a person's body and features of the society in which he or she lives.[10]

Society has historically reflected this definition of disability, from the visual perception of the disabled person to the position and impact that person held within the social structure. Depending on the times, disability was equated with mystery, poverty, illness, or dependence. Both physical and intellectual disabilities were viewed as impingements on expected social function and standing, often reflected as such in medicine, science, and the humanities.

Persons with intellectual and developmental disabilities are, by definition, a distinct part of what society considers the disabled in the general population. Intellectual and developmental disabilities are "disorders that are usually present at birth and that uniquely affect the trajectory of the person's physical, intellectual, and/or emotional development."[11] Developmental disabilities can affect a single body part or multiple systems impacting mobility, metabolic processing, sensory ability, or cognitive function.

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[10] International Classification of Functioning, *Disability and Health*. Geneva: World Health Organization 2001 https://who.int/standards/classifications/international-classification-of-functioning-disability-and-health (accessed April 13, 2020)

[11] https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default (accessed June 24, 2021).

The effect of the disability may limit a person's capacity to manage day to day tasks or participate in socially defined roles and life situations.[12] The impact of the disability, whether minor or significantly greater, affects each individual differently. Societies have struggled to define and accept "that difference is not an exception, . . . but something that happens in the natural course of things ."[13]

In ancient societies there was no clear distinction between mental illness and intellectual limitation, referred to as mental retardation, until an Egyptian document of medical knowledge and prescription was discovered and published in 1875. "The earliest written reference to mental retardation appears to have been the Papyrus of Thebes (1552 BC), in which was discussed the treatment of persons whose intellectual abilities were limited."[14] The ancient Egyptians recognized that the brain was the site of all mental functions. They emphasized the importance of memory, concentration, attention, and emotional stability.[15] Human skulls unearthed from that period showed evidence of piercings, presumed to be treatment to allow for escape of spirits from the brain, unexplained entities that caused the limitations in intellectual function and emotional instability.[16]

The Egyptians also recognized physical deformity or disability. Graphic historical evidence in tombs and ruins offers indication that certain disabled persons held

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[12] https://www.cdc.gov/ncbddd/disabilityand health/disability.html (accessed September 8, 2019.)

[13] Stiker, 12.

[14] Diane E.D. Dietz and Alan C. Repp, "Mental Retardation," in *Handbook of Child Psychopathology,* ed. Thomas H. Ollendick and Michael Herson (New York, NY: Springer Science and Business Media, 1983), 75

[15] Mervat Nassar, "Psychiatry in Ancient Egypt," *Bulletin of the Royal College of Psychiatrists* Vol. 11, (December 1987): 420-422.

[16] Dietz and Repp, 76.

a special role in society. They were privileged to serve with people of power, in households of the wealthy and those in government. Dwarves were depicted as receiving honors, seated on altars, or carried in processions. "In ancient Egypt physical disabilities or bodily deformities were considered as divine attributes granted to humans by the gods. This was expressed in representing certain gods with misshapen bodies or as dwarves."[17] The god Bes, for example, represented as a dwarf with facial deformity, was revered as a defender of good. The Egyptians considered human difference, whether intellectual or physical, the result of something other than human wrongdoing. "Far beyond our human conduct there is the hostility of uncontrollable forces."[18] Disability was considered beyond pathologic explanation; an identifiable cause was as much a mystery as the quest to explain and understand the natural world.

Other early societies also sought to explain the world around them, attributing their environment and natural occurrences to uncontrollable circumstances, the work of higher beings or gods they created. Difference in appearance, behavior, or performance was interpreted as a sign of inferiority. Society did not consider ways to accept those with intellectual or physical difference into meaningful membership. Rather, people focused on ideas and actions that would constitute a life of quality. "The Greeks and Romans in particular held a very narrow sense of self image, believing they exemplified the ideal human type."[19] The significant contributions both societies made to the arts,

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[17] Heba Mahran and Samar Mostafa Kamal, "Physical Disability in Old Kingdom Tomb Scenes," *Athens Journal of History* Vol.2, Issue 3 (July 2016): 169.

[18] Stiker, 42.

[19] The Minnesota Governor's Council on Developmental Disabilities, "Parallels in Time: A History of Developmental Disabilities," Part 1, Section 1, 1, https//mn.gov/mnddc/parallels/one/1.html. (accessed September 8, 2019)

philosophy, and science provided a sense of superiority, grounding for a good life. People who didn't conform to such perceived high standards, whether by appearance, ability, or social standing, were considered to be less than acceptable.

Deviation from the expected standards was addressed in specific ways within society. Those born with deformities were considered expendable. The Romans and Greeks both practiced exposure of infants with obvious congenital malformations. The Romans might leave the child out in the elements or toss the infant into the Tiber River. The Greeks would leave the child in the wild, with feet bound as a sign to discourage passersby from attempting rescue.[20] In both instances, the child was meant to return to the gods, the source from which malformation was believed to have originated. Those with mental conditions -insanity or intellectual limitation- might be hidden, housed with family, but social exclusion was rarely considered because these individuals were often able to contribute some level of service to the community. Others who developed impairment through illness or injury were readily treated and cared for[21] with particular attention to those injured during battle. Whether disability was natural in origin or acquired, "people who might be considered neither intelligent nor physically attractive, were not highly valued"[22] in early societies. Social value was based on appearance and accomplishment, the contribution the individual was able to make within the social

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[20] The Minnesota Governor's Council on Developmental Disabilities, Part 1, Section 1, 3.

[21] Stiker, 46.

[22] Ellis M. Craig, "At the Dawn of Civilization: Intellectual Disability in Prehistory and Ancient Times (9000 BCE to 500 CE)" in *The Story of Intellectual Disability: An Evolution of Meaning, Understanding, & Public Perception*, ed. Michael L. Wehmeyer (Baltimore, MD: Paul H. Brookes Publishing Co., 2013). 19-29.

construct. As a result, "the definition of ability and disability, then, shifted according to one's socially prescribed role."[23]

The definition of disability took on new meaning when Hippocrates began to look at physical and mental difference within the natural order of things, with causes of disability emanating from the body itself. Disability might be congenital, the result of heredity or complicated birth that would permanently impact physical or intellectual function. Functional limitations might be the result of injury, illness, or disease. In either case, disability did not necessarily exclude the individual from social participation but it did alter the perception and level of contribution in support of the social structure.[24]

Medical practitioners in Rome embraced the thinking of Hippocrates. Over time, as Rome absorbed Greek territories, the practices of the Greeks were incorporated and and expanded upon to include a concept of those with disabilities as a unique part of society. Those who survived exposure would assume a contributory role commensurate with their functional ability. Some survivors served as slaves. Others with physical deformities or intellectual limitations were taken in by wealthy families, fascinated by strange looking people and behaviors, to serve as jesters or fools for purposes of entertainment and amusement.[25]

Social thought on disability was further influenced as Christianity and biblical teaching were recognized among the Roman populace. Disabilities, both physical and

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[23] Martha L. Edwards, "Constructions of Disability in the Ancient Greek World" in *The Body and Physical Difference: Discourses of Disability*, ed. David T. Mitchell and Sharon L. Snyder (Ann Arbor, MI: University of Michigan Press, 1997). 35.

[24] Edwards, 37.

[25] Christian Leas, *Disabilities and the Disabled in the Roman World: A Social and Cultural History* (New York: Cambridge University Press, 2018), 185-186.

mental, are mentioned throughout the Bible. Traditional themes in both the Old and New Testaments regarding disability focus on three perspectives.[26] First, the presence of disability is related to sin, as punishment for having done something wrong. The wrong may have been committed by the person with disability or inherited through family. In both cases, the disability is linked to circumstances associated with the person, a transgression or lack of faith. Second, disability is suffering that must be endured to bring the disabled individual to acceptance of social and religious barriers. Blindness and deafness may cloak a person's ability to see the physical world or hear the spoken word. Physical disability may result in isolation and rejection of the affected person. Limited by those conditions and without distraction, the afflicted person may come to comprehend what is acceptable in belief and behavior. Finally, charitable actions on behalf of the disabled were intended to bring the disabled to a point of justice, an opportunity to align with society, both religious and secular. Charity in the Old Testament was shown by sharing wealth and speaking in support of the poor and needy, many of whom had disabilities. Charity demonstrated through acts of healing, as in the New Testament, brought relief for those with disabilities and hope to be viewed as equal to the expected norm in society.

With these ideas, the concept of disability as part of the natural order was placed in tension with the belief that the cause was a source beyond the human realm, an act of God for some divine purpose. Disability, like disease, "as natural disorder opens the way

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[26] Pauline A. Otieno, "Biblical and Theological Perspectives on Disability: Implications on the Rights of Persons with Disability in Kenya," *Disability Studies Quarterly* 29, no.4 (2009): https://dsq-sds.org/article/view/988/1164. (accessed May 2, 2020)

to empirical, scientific research on physical and biological rationality that has been disrupted."[27] Conversely, disability as a condition beyond natural control, placed the disabled in "a different order, that of the gods or at least one in which the gods are more proximate."[28]

The decline of the Roman Empire lead to a disintegration of control in government, limited pursuit of intellectual endeavors, and upended social order. Regional leaders across the expansive territory, which encompassed much of Europe, struggled to find stability as Roman control faltered. This period of time, the Middle Ages or Medieval Period (476-1500 AD), was impacted by political and economic challenges that diverted attention away from conditions of the general population.[29] As a result, there is little known about the ordinary people who lived during this time and "if there is little known about the ordinary people, there is even less known about people who had mental problems, and more particularly, what we now call intellectual disability."[30]

Intellectual disability was not recognized as a limiting condition unless an individual was unable to assume self care. "Conditions analogous to intellectual disability were not a problem in the Middle Ages unless a person was unable to care for him- or herself, unable to earn a living, or unable to contribute to a household or community." [31] Willingness to work, if the individual was fit, was key to acceptance in

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[27] Stiker, 43.

[28] Ibid.

[29] Parnel Wickham, "Poverty and the Emergence of Charity: Intellectual Disability in the Middle Ages," in Wehmeyer, 48.

[30] Stiker, 65.

[31] Wickham, 48.

the community. If that was not possible, those with intellectual disability were aligned with the poor, people of lesser means who were unable to secure adequate food and lived in conditions that increased the risk of illness and injury. Individuals with physical or functional limitations were caste in the same group.[32]

Medieval society was aware of difference. "The disabled, the impaired, the chronically ill were spontaneously part of the world and of a society that was accepted as being multifaceted, diversified, disparate."[33] The social fragmentation that resulted from the breakdown of Roman control extinguished the few supports that were available to the disabled. Conditions made the likelihood of difference a common occurrence. The risks associated with childbirth increased the possibility of cognitive and bodily impairment in the child. Illness and disease increased the chances of physical impairment. Malnutrition precipitated disabling deficits in both the young and old, the general population and the nobility.

A child born with disability in the general population would likely have been seen as a burden to the family. In some cases, particularly in Spain and Germany, parents sought to have the child adopted by the nobility. The child would become a member of the court and serve the noble family members as a groom, lady-in-waiting, attendant, or source of entertainment as a natural fool, a person with limited intellectual capacity. When these adopted members of the court accompanied the nobility in public, they served to represent reality, truth, and charity as opposed to the common perception of the upper classes as arrogant and duplicitous. Members of noble families with disabilities

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[32] Wickham, 59.

[33] Stiker, 65.

were treated in various ways. Some were kept home as the family worked around their needs with special assistants and supports. Others were treated by the best doctors at the time in hopes of managing their condition. Some were sent away to monasteries, placed in dungeons, or even murdered.[34]

Physicians at the time were aware of mental disability but "the medical community had little interest in mental disability and especially in the condition they called idiocy, probably because it was thought to be hopelessly incurable and lifelong." [35] Physical disability was viewed differently. "Physical aberrancy was a 'normal anomaly' in the face of which there was neither revulsion, nor terror, nor treatment."[36] It was accepted as a fact of the naturally occurring world. Consequently, individuals with disabilities were assimilated into society unless they defied the accepted social conventions. As with others in society, if they broke the law, exhibited stigmatizing behaviors, or became a burden, they were segregated. People with intellectual disabilities who committed criminal acts, sometimes due to circumstances beyond their understanding, were jailed. Beggars with limited intellectual capacity or physical disabilities were often grouped with criminals and incarcerated.[37] Others with disabilities who were indigent were consigned to almshouses. Individuals who exhibited unusual behaviors were deemed to be in need of support, usually provided by family members. The need to support, assist, or care for disabled individuals during the middle ages proved

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[34] Wolf Wolfensberger, "Idiocy and Madness in Princely European Families," *Intellectual and Developmental Disabilities* 49, no. 2 (February 2011). 46-49.

[35] Wickham, 48.

[36] Stiker, 66.

[37] Ibid, 72.

to be the impetus for development of places of sanctuary and protection when care in the familial or domestic setting was not possible.

The social disparity of the time played on the tension between belief that communal conditions, and disability, were the result of the natural order and Christian thought that they were the result of an act of God. The idea of God's action within the human condition was a common thread among the multiple segments of society. The Catholic Church, recognized within the Roman Empire, served as a stabilizing force for the many Christian believers at this time. As such, it "could not, in justice or in charity, refuse to help a world which was in such desperate need of a more stable social order."[38] The Church established what amounted to the first havens for many people who did not meet expected social criteria: orphanages for abandoned infants, hospitals for the sick, and homes for the disabled and aged. These facilities established the foundation for patterns of care and medical practice for those most in need.

Over the course of the Middle Ages, the practice of care expanded, encompassing a variety of modalities. While the population reacted vigorously against disease in order to maintain their livelihood, they had to choose between secular and religious healers, those who used natural means and those who appealed to the saints or higher powers. Medical practice was limited by social resistance to dissection and related learning, leading to ineffective treatment of various diseases.[39] When a disorder or condition did not respond to care provided through natural means, petition was often made to a

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[38] Rodger Charles, *From Biblical Times to the Late 19th Century*, vol. 1 of *Christian Social Witness and Teaching: The Catholic Tradition from Genesis to Centesimus Annus* (Leominster: Fowler Wright Books, 1998), 103.

[39] Irmo Marini, Noreen M. Graf, and Michael J. Millington, *Psychosocial Aspects of Disability*, 2nd ed. (New York: Springer Publishing Company, 2018) 5.

mystical or saintly resource in hopes of attaining a cure. In the later years of the period, the resources and services provided by the Church proved inadequate to address the needs of the disabled and those who could not care for themselves. To meet the needs of the population, medical care organized around guilds of practice, dedicated institutions for asylum, and even publically supported health services.[40]

Existing facilities became more specialized to provide care for the blind, deaf, those with physical disabilities, including those injured in the multiple battles that took place throughout the former empire, and those who were viewed as mad. The disabled were now less likely to be grouped together with others society viewed as different: people with criminal tendencies, transients, or those whose behaviors went against the social norm.[41] People with developmental disabilities and intellectual limitations were kept with family unless their care became a burden to domestic stability. In those cases, the individuals and whatever assets they might claim were placed in custody of a guardian who had oversight of their health and well-being.[42]

As the Middle Ages came to a close, social and economic change created great challenges for the population as a whole.[43] Persistent wars had disrupted agricultural practices and altered manufacturing, leading to food shortages and deflated wages. The resulting famines increased the incidence of disease and disability and escalated the level of poverty. The families that cared for those with intellectual disability were very often

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[40] Katharine Park, “Medicine and Society in Medieval Europe 500-1500,” *Medicine in Society: Historical Essays,* ed. Andrew Wear (Cambridge: Cambridge University Press, 1998) 60-83.

[41] Stiker, 86.

[42] Stiker, 78.

[43] Parnel Wickham, “Idiocy and Early Modern Law: Intellectual Disability in Early Modern Times (1500 CE to 1799 CE),” in Wehmeyer, 64.

financially strapped, placing the family itself in the category of poor. Providing care for a disabled family member limited the time the able-bodied members could work. These circumstances made it difficult for families to support their members with impairments and they were often left to fend for themselves. Many of the disabled joined the poor in begging or sought shelter through the charity of public or religious facilities. The distinction between those who were able to maintain self-sufficiency and those who could not was evident throughout society.

While this was a trying time for the population with disabilities, society as a whole was experiencing a reawakening of the intellectualism of the past. This period, referred to as Early Modern Times or the Enlightenment (1500 – 1799 AD), saw renewed interest in medicine, science, philosophy, and the arts.

> Many of the ideas related to intellectual disability, which were introduced in the late Middle Ages, emerged in the early modern period, with the condition often called "idiocy", used in reference in early modern Europe to people who were thought to be substantively different in terms of social, vocational, religious, and behavioral competence.[44]

These ideas were set forth by the medical community. Medical practitioners, while grounded in religious and philosophical thought of the past, shifted position from the historical orientation to one that was more naturalistic, influenced by emerging scientific thought.[45] In addition to the religious perspective that defects may be associated with a person's spirit, consideration of difference incorporated ideas related to causes both anatomical and resulting from parentage. Environmental and social conditions were also considered as contributors to limited intellectual ability.

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[44] Ibid.

[45] Wickham, 71.

Philosophers of the time sought to understand the nature of disability as well as the potential and value of disabled individuals in consideration of what the social construct identified as acceptable.

> The moral quality of people with disabilities had previously been greatly doubted in the early years of the Enlightenment, and people with learning disabilities, mental health issues, blind and deaf people were especially thought of as morally uneducable.[46]

As opposed to philosophers early in the period, later thinkers, such as John Locke (1632-1704), "believed that learning comes through association ('ideas derive from experience')".[47] People with intellectual disabilities, like children, were considered to be free of preexisting ideas and open to development through moral education focused on their ability to understand.[48] This way of thinking raised the possibility that individuals with intellectual impairments might learn to function as a productive part of society if exposed to and supported in learning from repeated activities.

The Protestant Reformation which took place in the early 16th century also had an impact on those with disabilities. In areas with "protestant populations, where disciplined work habits earned spiritual and economic benefits, distinctions were drawn between people who were thought capable of work and those who were not."[49] Disability, especially intellectual disability, was not considered a valid limitation to the ability to work or contribute to the benefit of society. As a result, the disabled, if limited in their

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[46] Simon Hayhoe, *Cultural Heritage, Aging, Disability, and Identity: Practice and the Development of Inclusive Capital* https://doi.org/10.4324/9781315149462 (accessed May 15, 2020)

[47] The Minnesota Governor's Council, Part 1, Section 3, 1.

[48] Mihai Androne, "Notes on John Locke's views on education," *Procedia-Social and Behavioral Sciences* Vol. 137 (9 July 2014): 76.

[49] Wickham, 66.

capacity to meet cultural standards related to work and productivity, were placed in the same category as many of the poor. Their fault was not an unwillingness to work; rather, it was an inability to meet the expectations of a culture that viewed them as incompetent and dependent. The shelter that was offered through existing facilities supported by religious or charitable organizations was overwhelmed by the disabled, sick, poor, aged, and others who were disenfranchised. Publically supported workhouses, intended to get the poor capable of working off the streets, and poorhouses, intended to contain those unwilling to work, accommodated the overflow of those in need.[50] The significant number of people who sought shelter and support during this time brought the "first widespread public attention to the problems they posed."[51]

All people considered disadvantaged or poor by social standards had been counted as a single group, despite the small segment of those intellectually limited within the population.[52] A clear definition of what constituted the intellectually limited, referred to as idiots, as opposed to lunatics, those with mental health disorders and behaviors viewed as socially unacceptable, did not exist. Local authorities and overseers were aware of the population with mental disabilities and historically depended on domestic support to meet their material and financial needs. A "crucial conceptual distinction arose from problems of property and title inheritance between idiots and lunatics."[53] Idiots, those with intellectual limitations, were considered to have innate mental

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[50] Wickham, 66.

[51] Peter Rushton, "Lunatics and Idiots: Mental Disability, the Community, and the Poor Law in North-East England, 1600-1800", *Medical History* Vol.32, 1 (January 1988): 34.

[52] Wickham, 66.

[53] Rushton, 36.

incapacity and an inability to perform everyday tasks. Lunatics might be compromised temporarily and eventually recover a state of capacity, able to manage an inheritance and property.[54]

The families of the those with intellectual limitations, as well as those whose family member had a limiting physical disability, generally came to the attention of local authorities because caregiving responsibilities had created financial difficulties. Families sought assistance when no alternate means of domestic or charitable support was available. In England, authorities were forced to consider ways "to support the family if necessary, but not to replace it."[55] As a result, local ordinances, the Poor Laws, were developed to support the domestic setting, establishing a precedent for governing bodies in other territories or locales. The family might be allocated aid from a public or private charity to supplement its resources. An individual with intellectual limitations might be assigned to the care of another relative with available resources from within the extended family. The person might be tabled, their care given over to a willing family for a fee established by local authorities.[56] Lacking other alternatives, the affected individual might be referred to an institutional setting. The institution, whether asylum or hospital, placed the person with intellectual limitations in a congregate setting along with individuals with mental health conditions, "not so much in order to care…. but in order to concentrate their numbers"[57] away from the general society.

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[54] Rushton, 38.
[55] Rushton, 42.
[56] Rushton, 40.
[57] Stiker, 99.

Conditions in Europe, the former territories of the Roman Empire, and conflicts between religious factions helped drive colonization West. The immigrants who arrived in America between 1600 and the mid-1700s found that "the settlement of a vast new rural society meant that early colonists put a premium on physical stamina . . . People with physical or mental disabilities who were potentially dependent could be deported, forced to return to England."[58] Poor laws, similar to those in England, were established to allow local authorities the option of using local taxes to build almshouses for the poor, aged, and disabled; to provide outdoor relief, funding to supply food and other goods to such people to keep them with family in their own homes; or develop ways to put the able-bodied to work.[59]

As settlements expanded and became more urbanized, the population in the almshouses grew to include able-bodied people who were unable or unwilling to find work in the shift from a rural to a more industrialized setting. Local authorities were aware of the impact the crowding, able-bodied commotion, and sometimes scandalous behavior this part of the population had on the poor, aged, and disabled residents. In an effort to relieve crowding in the almshouses and promote a work ethic in this unemployed population, workhouses and poor farms were established.[60]

American thinking about people with disabilities was influenced at this time, the early to mid-1800s, by the science and reason emanating from educators, philosophers, and doctors in Europe. The specialists considered children with intellectual and

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[58] Shapiro, 58.

[59] John E. Hansan, *Poor Relief in Early America* https://socialwelfare.library.vcu.edu/catgory/programs/ (accessed March 18, 2020)

[60] Ibid.

developmental disabilities along a developmental continuum related to their disability and degree of severity.[61] Professionals working with the blind and deaf came to understand that "disabled people could be integrated into society rather than sent away to institutions". [62] Schools were established to educate the blind and deaf by methods similar to those in mainstream education. Intellectual disability, known as mental retardation, feeble-mindedness, or idiocy, continued to be recognized as lifelong and a barrier to education. As a result, state schools created to educate the feeble-minded, children with intellectual and developmental disability, adapted teaching methods based on curriculum for typical children. Treating professionals anticipated that individuals with intellectual disability might attain an ability to contribute to their care, and to some degree, the social construct. People with intellectual limitations now had an alternative to the challenging environment of the almshouse. "If the gap with the mainstream of society was not closed, at least retardation was no longer considered an incurable disease tantamount to insanity."[63]

The state schools, supported in each state through legislative consent and funding, started out small, taking students thought to be able to attain a level of success that would allow them to return to society or family as productive members. By the end of the nineteenth century, medical directors and educators of state schools across America acknowledged that not all students in their schools would achieve the same level of success. This realization was reinforced by the number and nature of applicants to the

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[61] Philip M. Ferguson, "The Development of Systems of Supports: Intellectual Disability in Middle Modern Times (1800-1899)," in Wehmeyer, 82.

[62] Shapiro, 60.

[63] Ibid.

schools. "It was found that more than one-half of the applications for admission, and those by far the most insistent, were in behalf of the 'unimprovables'." [64] The schools, founded to provide education to feeble-minded children with what was thought to be the greatest potential, quickly became institutions to train the feeble-minded across a range of intellectual and physical disability. Many of the students, referred by their families, remained incapable of returning to the community and were soon labeled as inmates. School leadership continued to espouse that "the end aim of all our teaching and training is to make the child helpful to himself and useful to others." [65] In actuality, the children grew to play an integral part in sustaining the institutions.

The services provided within the institutions were driven by the evolving definitions of feeble-mindedness. The emphasis was on a developmental approach based on observation by members of the medical community and the individual's level of functioning.[66] Education became less academic and more a process of training, "as uniform cultivation of the whole being, physically, mentally, and morally." [67] A certain number of individuals benefitted from training in skills that would allow them to be self-sufficient upon return to society. Others with lesser ability and able to be trained were classified as always in need of supervision to perform effectively, whether in the institution or in the community.[68] The individuals with the lowest capacity to benefit

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[64] Walter E. Fernald, M.D., *History of the Treatment of the Feeble-Minded: Reprinted from the Report of the Proceedings of the Twentieth National Conference of Charities and Correction, held at Chicago, June, 1893*, 4th ed. (Boston: Press of Geo. H. Ellis Co., 1912), 9.

[65] Ibid, 13.

[66] Ferguson, 94-95.

[67] Fernald, 13.

[68] Ibid, 15.

from formal training were considered custodial. In some cases, they required care to address even their most basic needs. In others, with "patient habit-teaching, and the well-ordered institution routine, a large portion of these children become much less troublesome and disgusting, so much so that the burden and expense of their care and support are materially and permanently lessened." [69]

Students with the ability to learn skills in a variety of areas contributed to the support of the institutions by reducing the amount of funding required from the state to support their care. Their work provided for the maintenance of the facilities through training in a number of trades and manual labor, food for students and staff through farming and raising livestock, production of clothing, and even care for the lowest functioning children. The medical directors promoted the growth and practices of the schools as beneficial to the state as cost-saving and self-sustaining by using the services of the students, the residents or inmates, of the schools. "The average running expenses of these institutions have been gradually and largely reduced by this utilization of the industrial ability of the trained inmates." [70] The state schools set the precedent for "the large, specialized, congregate care facilities that we now call *institutions* or *developmental centers*." [71] The institutions served to segregate a number of individuals with intellectual and developmental disabilities from society at a time of significant change in America.

As the nineteenth century drew to a close, many people moved from rural to urban areas where growing industrialization offered economic opportunity. At the same

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[69] Ibid, 16.
[70] Ibid, 17.
[71] Ferguson, 79.

time, increased immigration introduced a population whose features and characteristics appeared unfamiliar to general societal expectations. Physicians and other professionals, with growing knowledge to identify and assess individuals with developmental differences, were concerned that the diversity of the incoming immigrants would damage the inherent nature of the existing population. "Many were concerned that, with the influx of Central and Southern European immigrants, and the perceived increase of individuals with IDD, America itself was in a period of decay." [72] People with intellectual and physical disabilities living in the community were included with the immigrants in "what was perceived to be a growing population of unproductive and dependent people." [73]

"One of the fundamental imperatives in the initial formation of American immigration policy at the end of the nineteenth century was the exclusion of disabled people." [74] Initially the law prohibited entry to people with feeble-mindedness, mental illness, "or any person unable to take care of himself or herself without becoming a public charge." [75] The law was loosely interpreted by immigration screeners and physical appearance also became a measure of entry or rejection. Physical characteristics, including body development and overall appearance, lead those in favor of restricted immigration to reject certain ethnicities and those with physical difference, judging them

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[72] Jordan A. Conrad, "On intellectual and developmental disabilities in the United States: A historical perspective," *Journal of Intellectual Disabilities,* Vol. 24, 1 (2020): 89.

[73] Ferguson, 80.

[74] Douglas C. Baynton, "Disability and the Justification of Inequality in American History" in *The New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001). 45.

[75] Ibid.

as unfit. As a result, the disability label was applied "through two main modalities – function and appearance." [76] This interpretation also had an impact on the way individuals with disability were viewed within their communities.

Scientists at the turn of the century claimed heredity and environmental factors influenced the presence of disability. Heredity was believed to be shaped by factors of biological inheritance, the quality of parenting, and conditions related to the social milieu.[77] The theories of genetic inheritance and evolution contributed to development of the idea that society could be changed in a way that promoted the best possible qualities in the population. The term eugenics, first proposed by scientists in England in the mid-1800s, came to be considered by medical and social professionals in America as a way to improve both the functional and aesthetic characteristics of society.[78] "Eugenics, then, was a philosophy - as well as a set of widely accepted beliefs and overt practices- that considered that human progress could be expedited by purposely manipulating the genetic makeup of a society." [79]

The concept of eugenics was acceptable for a number of reasons. Ancient and early cultures believed those with the greatest physical and intellectual attributes were the epitome of society, a belief that carried over to the current time. Individuals who appeared to be less and considered a drain on society, including infants thought to be

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[76] Ibid, 48.

[77] Martin S. Pernick, "Defining the Defective: Eugenics, Aesthetics, and Mass Culture in Early-Twentieth-Century America" in *The Body and Physical Difference: Discourses of Disability*, ed. David T. Mitchell and Sharon L. Snyder (Ann Arbor: University of Michigan Press, 1997): 98.

[78] Ibid, 91.

[79] Ivan Brown, "The New Eugenics and Human Progress," *Journal of Policy and Practice in Intellectual Disabilities,* Vol. 16, No. 2 (June 2019): 138.

defective, were neglected or left to depend on the resources of family or public entities. Common practice lead people to marry and breed within their own social order, maintaining identifiable genetic classes. As urbanization replaced the rural environment, community support deteriorated, poverty and crime became more prevalent, and people with intellectual and physical disabilities were less able to adapt to the culture.[80] Eugenics offered society an option to reduce the challenges that accompanied the changing social milieu with the intent to limit the presence of the feeble-minded and developmentally disabled, as well as others with difference.

Positive eugenics put "the emphasis on 'the fit' having more children so as to offset the proposed fecundity of the unfit." [81] The fit were individuals perceived to meet current social norms and standing. Negative eugenics sought to limit the number of people viewed as socially undesirable. "Limitations on reproduction (negative eugenics) were placed on those considered less desirable through such means as being housed in the many forms of institutions, deportation, segregation, moral and religious persuasion and, later, even sterilization." [82] Impoverished people were often housed in almshouses. Immigrants who were deemed to have limited ability to make a positive social contribution, whether by actual or perceived functional difference, were deported. Institutions for the feebleminded and disabled grew in number and housed increasing populations, segregating those with intellectual and developmental disabilities from mainstream society. "The feebleminded were lumped together as causing societal

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[80] Ibid, 138-139.

[81] Steven Noll, J. David Smith, and Michael L. Wehmeyer, "In Search of a Science: Intellectual Disability in Late Modern Times (1900 CE to 1930 CE)," in Wehmeyer, 139.

[82] Brown, 138.

problems, and they were treated as such." [83] Across the United States, institutionalization addressed a two-fold purpose to "provide protection for and from society".[84] Individuals with intellectual and developmental disabilities were placed in institutions to offer opportunity for care and training while also isolating the population from mainstream society.

Individuals in institutions for the feeble-minded became the target of sterilization laws as the first decade of the twentieth century opened. The application of genetic models, the possibility that feeble-mindedness was hereditary, and the introduction of tools designed to assess intelligence led physicians and psychologists to question the reproductive value of the population. "For the first half of the century, Americans with mental retardation (called 'idiots or feebleminded') . . . were viewed as a menace that threatened to lower the health and intelligence of future generations." [85] Sterilization was intended as a means of social control, a way to limit the reproductive ability of those within the institutions and "stem the ever increasing tide of weak-minded individuals who are demanding more and more room in our charitable institutions by their increase." [86] Superintendents of the institutions, many of whom were physicians, failed to take into consideration the fact that their enhanced scientific understanding of intellectual disability contributed to the increase in the institutional population by supporting segregation of those with intellectual and developmental disabilities.

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[83] Noll, Smith, and Wehmeyer, 139.

[84] Ibid, 142.

[85] Shapiro, 158.

[86] Noll, Smith, and Wehmeyer, 151.

Indiana was the first state to enact a compulsory sterilization law for individuals with intellectual disability in state institutions in 1907. As similar legislation followed in other states, a number of legal challenges on behalf of the targeted population questioned the validity of the laws. [87] In 1927 the Supreme Court upheld the legitimacy of involuntary sterilization of individuals with intellectual and developmental disabilities, labeled as feeble-minded, in its majority opinion to support sterilization of an institutionalized young woman in Virginia.[88] As a result of that opinion, thirty-three states adopted sterilization laws which led to the involuntary sterilization of thousands of men and women with intellectual and developmental disabilities. [89] The practice of sterilizing women with intellectual disability persisted until 1974 when a U.S. District Court ordered that the federal government cease providing funding for the still common practice. [90]

The eugenic mindset of the early twentieth century was embraced by medical, scientific, educational, and social work professionals, as well as politicians and others with an interest in limiting the social differences in society. [91] It continued through the 1930s until a sense of discomfort grew among the general population of the United States, the medical profession, and some religious organizations. [92] The widespread

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[87] Keely, Karen, "Sexuality and Storytelling: Literary Representations of the 'Feebleminded' in the Age of Sterilization" in *Mental Retardation in America: A Historical Reader*, ed. Steven Noll and James W. Trent Jr. (New York: New York University Press, 2004) 208.

[88] Ibid.

[89] Conrad, 90.

[90] Shapiro, 197.

[91] Noll, Smith, and Wehmeyer, 141.

[92] J. David Smith, Steven Noll, and Michael L. Wehmeyer, "Isolation, Enlargement, and Economization: Intellectual Disability in Late Modern Times (1930 CE to 1950 CE)," in Wehmeyer, 176.

application of eugenic ideas in Germany to bring about the eradication of "certain populations from the gene pool" [93] denigrated the eugenic concept of social control.

The early twentieth century also brought a burgeoning awareness that difference was a natural part of society. Physicians recognized that pathological causes were likely the origin of many conditions that caused physical difference and disfigurement. The idea of exhibiting those who appeared different for curiosity or entertainment, something that had been the case since ancient times, began to fall out of favor. People who had been viewed as social anomalies because of their physical appearance or inability to interact in social settings according to accepted norms came to be considered "victims of rare diseases with ten-syllabled names of Greek origin, and that, in all probability, other sufferers, who are unwilling to exhibit their afflictions . . . lose (sic) their fascination." [94] The change in perspective when considering those with difference was viewed as a humane evolution, not as "a sign of weakness, but of sensibilities more intelligently directed."[95]

Despite the recognition that pathology and genetics could well be the cause of difference, ideas about the relationship between difference and heredity continued to affect the way individuals with physical and intellectual disabilities were viewed. Society's interpretation of heredity "was not limited to traits caused by genes"[96] even though doctors, with increasing scientific understanding, were resistant to the idea of

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[93] Conrad, 90.

[94] "Amusement At The Abnormal," *The Nation*, March 19, 1908: 254. Source: http://www.disabilitymuseum.org/dhm/lib/detail.html?id=1913&page=all (accessed July 21, 2019)

[95] Ibid, 255.

[96] Martin S. Pernick, "Defining the Defective: Eugenics, Aesthetics, and Mass Culture in Early-Twentieth-Century America" in Mitchell and Snyder, 90.

social and situational influences.[97] The social interpretation incorporated a practical side, considering the influence family and environment had on the development of those with difference. This interpretation placed the burden for developmental disability on the parents, both medically as related to genetics and heredity, and morally as influenced by the circumstances of family life.[98]

Parents were left with few options to address the needs of a child with intellectual and developmental disability. There were limited resources for support available within communities. In the early 1900s physicians who had been closely connected with their patients in the past were focused on promoting formal medical education, establishing professional standards, and gaining recognition as legitimate practitioners. This focus lead to a situation where "the social distance between doctor and patient increased, while the distance among colleagues diminished as the profession became more cohesive and uniform." [99] This focus moved the practice of medicine to the more formal settings of hospital and clinic rather than in the home or other locations within the community. As a result, it became more difficult for families to access care and maintain a personal relationship with their physician.

Institutions provided the singular source of care for children with intellectual and developmental disabilities when parents and extended family were unable to provide for them in the home. Doctors and psychologists filled the role of superintendent at the

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[97] Leila Zenderlad, "The Parable of the Kallikak Family: Explaining the Meaning of Heredity in 1912," in Noll and Trent, 168.

[98] Pernick, 99.

[99] Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry* (New York: Basic Books, Inc., 1982) 81.

majority of these institutions. Increased scientific knowledge at the start of the twentieth century pushed them to look at intellectual disability "by medical terms that began to dominate how the condition was understood, and referring for the first time to mental processes."[100] They continued the practice that began in the late nineteenth century of grouping individuals by diagnosis, physical disability, and cognitive function. This strategy allowed "the superintendent to have the discretion of demonstrating the power of classification and assessment while focusing treatment"[101] on the individuals most likely to benefit from the treatment provided.

At some institutions psychologists sought to identify the cognitive and functional abilities of the residents in an effort to develop and utilize "the latent possibilities in this group for useful and happy lives."[102] In 1906 at the research laboratory within The Training School, an institution in Vineland, New Jersey, physicians, psychologists, scientists, and educators "confirmed the necessity of conforming the life of the individual child to a level adjusted to his capacity."[103] This research lead to the establishment of specialized training for teachers and staff at schools and community welfare agencies in both public and private settings.

The impact of both World Wars and the Great Depression limited the implementation of new programs for those with intellectual and developmental disabilities. The institutions and welfare agencies responsible for support of this

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[100] Noll, Smith, and Wehmeyer, 132.

[101] Ferguson, 107.

[102] Joseph P. Byers, *The Village of Happiness: The Story of The Training School* (California: University of California, 1934) 44 Source: http://www.disabilitymuseum.org/dhm/lib/detail.html?id=1913&page=all (accessed July 21, 2019)

[103] Ibid, 104.

population were largely funded by state and federal government dollars. Economic, wartime, and social conditions reduced available funding for services and construction of additional facilities, as well as the pool of caregivers. These conditions resulted in a shift from a progressive habilitative training mindset to one of custodial care.[104] The institutions serving people with intellectual and developmental disabilities were specifically intended to house them. The intent was twofold: to protect society from those that might exhibit behaviors outside expected norms and to shelter feebleminded people from an increasingly complex and challenging social milieu.

During World War II a significant number of institutional staff members were either drafted or left to serve in war-related positions. Conscientious objectors filled a number of vacant positions at the institutions through Civilian Public Service units. They provided care, instruction, and other services to support the residents and maintain the facilities. The conscientious objectors also observed the crowded conditions, lack of training programs, recreational and social opportunities, and limited medical care.[105] They brought these observations to the attention of the overseers of the Civilian Public Service and the public soon became aware of conditions in the institutions. Journalists and advocates sought to document and expose the conditions in an effort to bring attention to the need for real training and good care. One journalist reported that leadership at the federal level noted, aside from the need for improvement in the institutional setting, "most of those who are mentally subnormal . . . would get along

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[104] Conrad, 91.

[105] Stephen L. Angell, "Training Schools and CPS," *The Reporter* (July 15, 1944), http://socialwelfare.library.vcu.edu/federal/training-schools-civilian-public-service-1944 Source: http://www.disabilitymuseum.org/dhm/lib/detail.html?id=1913&page=all. (accessed April 25, 2022)

quite well living at home if communities provided special teaching, guidance clinics, recreation centers and supervision."[106]

Multiple factors contributed to society's increased recognition of disability following World War II. Articles in the popular press brought attention to conditions in the institutions serving those with intellectual and developmental disabilities. Veterans of the war were visible reminders that physical and even emotional differences were a part of society as a whole. Scientific and medical advancements led to discoveries that limited some disabling conditions in children and furthered treatment for existing conditions. Educators considered the need to develop educational programs for students with more than mild cognitive limitations. Psychologists began to recognize the stressors associated with caring for a disabled child and advocated for parental guidance as more families made the choice to keep their child at home. Parents realized that, while there may not be a cure for a child's disability, they were essential to improving conditions and services for their children both therapeutically and socially.[107]

As physicians continued to recommend institutionalization for children with intellectual and developmental disabilities, parents advocated to have their disabled child remain part of the family. They sought to have the public recognize "that having retarded children is not a disgrace and that they can be assisted and that they are entitled to aid."[108] Parents sought recognition of their children and their actions were supported in part by

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[106] Edith M. Stern, "Take Them Off the Human Scrap Heap," *Woman's Home Companion* Vol. 75 (August 1948) Source: http://www.disabilitymuseum.org/dhm/lib/detail.html?id=1731&page=all.(accessed July 21, 2019)

[107] Janice Brockley, "Rearing the Child Who Never Grew," in Noll and Trent, 157.

[108] Kathleen W. Jones, "Education for Children with Mental Retardation," in Noll and Trent, 327.

"the rise of medicalization and professionalization of disability, which stressed the importance of treatment and education."[109] Parents felt their children needed and would benefit from the same level of services and opportunities available to children without disability.

During the late 1940s and 1950s parents came together to form local groups of support. The groups sought to bring families together to highlight the needs of their children, raise public awareness of intellectual and developmental disabilities, bring recognition to the need for better options than those currently available, and to inform government officials of the need for financial and legislative support. The actions of these groups, supported by organized professionals in education and psychology, added the legitimacy of everyday experience to professional knowledge and the medical model of disability.

As local parent groups came together, their number brought attention to their shared struggle in seeking greater support than that "offered by doctors or social service agencies."[110] The voice and actions of these groups, lobbying for the needs and rights of their children, in addition to the increasing public presence of individuals with intellectual and developmental disabilities in the community, grasped the interest of politicians at the federal level. Over the course time, lawmakers created and enacted legislation that considered the educational, vocational counseling, and rehabilitation

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[109] Amanda J. Rich, *Standing Together and Finding a Voice Apart: Advocating for Intellectual Disability Rights* (Washington D.C.: American Association on Intellectual and Developmental Disabilities, 2015) 16.

[110] Shapiro, 64.

needs of people with disabilities but they remained "disenfranchised from participating in employment, housing alternatives, and voting, as well as socially."[111]

The Rehabilitation Act of 1973 prohibited discrimination of people with disabilities under programs receiving federal funding, including services delivered under Medicare and Medicaid; established state vocational rehabilitation services; and supported development of independent living centers. The act, as amended in 1978, also included assistance and advocacy to support the legal and human rights of those with disabilities.[112] The Americans with Disabilities Act (ADA) of 1990 was more expansive, allowing protection from discrimination in the areas of employment; areas of public entitlement, including transportation and access to voting sites; public accommodation and commercial facilities; and telecommunication. The ADA also covers all health care and social services programs of public entities.[113]

The protections offered through these acts "require that health care providers provide individuals with disabilities full and equal access to their health care services and facilities."[114] Individuals with disabilities, including those with intellectual and developmental disabilities, may continue to experience barriers to accessible health care through an inaccessible physical environment; lack of accommodation to meet sensory and communication needs; limited staff training regarding the needs of patients with disability; or the health care provider's unfamiliarity with the nature of their disability.

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[111] Marini, 17.

[112] Ibid, 18.

[113] www.https://eeoc.gov/americans-with-disabilities-act-1990-original-text (accessed June 11, 2022)

[114] *Accessible Health Care Fact Sheet* www.nwadacenter.org University of Washington (accessed June 11, 2022)

Interactions with patients with disabilities should occur “without bias, labels, stereotypes or insensitivity.”[115] The focus of care of the individual should not only concern accessibility but the patient’s needs, both clinical and personal, their story.

Medical school education “emphasizes the scientific, technical, and practical. Although patient communication, empathy, and professionalism are given prominent places . . . these are approached in typically pragmatic fashion.”[116] As a medical student, the emphasis is on creating a rapport with the patient through eye contact, body language, and communication style to develop better medical histories with the goal of improving the health status of the individual. The “bigger questions that underlie all this effort to appear caring, to stimulate and sustain genuine interest in the endless stream of people we will meet as patients, let alone why we seek to relieve suffering or value human life at all”[117] are not explored. Medical students are challenged to look beyond the person in front of them, “to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient’s behalf.”[118]

The effort to step away from the scientific, technological, and fact-based aspects of medicine, whether in the context of medical education or practice afterwards, is challenged by the realities of medicine. The need to treat patients, order and interpret

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[115] *Access to care for patients with disabilities: Strategies for ensuring a safe, accessible and ADA compliant practice* American Medical Association 2018 https://ama-assn.org (accessed June 11, 2022)

[116] Stephanie Chapple, “Medical Humanities and Narrative Medicine,” *Australian Medical Student Journal* Vol. 6, Issue 2 (2015): 65 Source: amsj.org/wp-content/uploads/files/issue/amsj_v6_12.pdf#page=68 (accessed July16, 2022)

[117] Ibid.

[118] Rita Charon, “Narrative medicine: A Model for Empathy, Reflection, Profession, and Trust,” *Journal of the American Medical Association* Vol. 286, No.15: 1897-1901 Source: https://jamanetwork.com (accessed June 16, 2022)

tests to establish a clinical baseline, manage time, and ultimately treat a medical condition may mask the physician's ability to see the person and prioritize caregiving. "Listening skills, cultural sensitivity, ethics, empathy, or a commitment to humanism"[119], consideration of basic human needs, can be influenced by the skills attention to the arts and humanities can yield.

Literature asks the reader to consider the content and context from the perspective of another person, to look at the character and the circumstance, to appreciate and share their feelings. Music promotes the skill of active listening, focusing on the nuances of the piece, just as a medical student or physician must center on what the patient is saying and the meaning of what is being said. Art and film task the medical student or physician to interpret something visual, created by an individual who imbued the work with meaning, much like assessing a patient's physical appearance or body language. History and anthropology provide insight into the many aspects of human experience across time, bringing the social, cultural, economic, and political influences to the understanding of disease and illness and their impact on the status of the patient.[120] Thinking about their personal interpretations and perceptions in response to the arts and humanities allows both medical students and physicians to consider aspects of care that go beyond objective scientific data. The humanities ask them to "reflect on their own values, attitudes, and

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[119] David S. Jones, "Medicine and Society: A Complete Medical Education Includes the Arts and Humanities," *American Medical Association Journal of Ethics* Vol. 16, No. 8: 636

[120] Ibid, 636-637

behavior, as well as issues of subjectivity, multiple truths, and ambiguity through the filters of . . . the humanities."[121]

The humanities offer an opportunity to contemplate more than one interpretation, allowing for a certain degree of openness to consideration of the thoughts, feelings, and values of others. The ability to incorporate that consideration moves the interaction between physician and patient away from the strictly scientific and evidence-based to one that "requires the ability to listen to the narrative of the patient, grasp and honor their meaning, and be moved to act on the patient's behalf."[122] The communication between physician and patient becomes an interactive process that establishes the quality of the visit and can "set the tone for the rest of the doctor-patient relationship over years."[123]

Physicians may experience a degree of discomfort and difficulty in establishing communication with individuals with intellectual and developmental disabilities. The nature of disability, whether physical, cognitive, or both, marks the patient as different from the outset, whether the disability is overt or invisible. The social label of difference associated with disability places the physician in a position of uncertainty, compelled to look at the patient as more than the medical issue that precipitated the visit. There is a whole person present beyond the perceived difference and limitations.

The chance to care for the patient with intellectual and developmental disability presents an opportunity for the physician, especially the primary care physician as gatekeeper of medical care, to develop a relationship in recognition that people are much

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[121] Johanna Shapiro, Jack Coulehan, Delese Wear, and Martha Montello, "Medical Humanities and Their Discontents: Definitions, Critiques, and Implications," *Academic Medicine* Vol. 84, Issue 2: 193

[122] Charon, 1897

[123] Ofri, 153

more than their disability and medical issues. "Understanding disability as constituted by an interaction of physiological and intellectual impairments and social factors is a critical first step in addressing disability and in particular the disparities in care that disabled people encounter."[124] The relationship that takes into account issues of personal interest and concern beyond the presenting medical issues can guide the physician in providing access to the quality care envisioned in legislation to support people with disabilities.

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[124] Rebecca Garden, "Disability and Narrative: new directions for medicine and the medical humanities," *Medical Humanities* Vol. 36, Issue 2: 72

Chapter Two

Primary Care of Patients with Intellectual and Developmental Disabilities: The Medical, Personal and Professional Experience

People with intellectual and developmental disabilities routinely experience problems in seeking quality primary health care services. They may encounter health care providers who have poor attitudes about disability and underestimate the patients' cognitive and communicative abilities.[125] These encounters may result in inadequate preventive care, limited care management, and a lesser standard of care. As a result, individuals with intellectual and developmental disabilities are open to high rates of health risks that are regularly monitored in the general population. "In addition, this population is vulnerable to disability-related health conditions that can be severely detrimental to functioning and quality of life."[126]

Despite having a commensurate or even greater need for health care services than the general population, people with intellectual and developmental disabilities have lesser access to needed services.

> Disparities in health care access can be attributed to barriers unique to adults with disability. These barriers include physical inaccessibility of health care facilities and exam rooms, communication difficulties with health care providers, lack of medical information, and lack of knowledge and understanding of disability on the part of health care providers.[127]

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[125] Renee Karl, Denise McGuigan, Matthew L. Withiam-Leitch, Elie A. Akl, and Andrew B. Symons, "Reflective Impressions of a Precepted Clinical Experience Caring for People with Disabilities," *Intellectual and Developmental Disabilities* 51, no. 2 (August 2013):237.

[126] Susan M. Havercamp and Haleigh M. Scott, "National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities," *Disability and Health Journal* 8 (2015): 165.

[127] Ibid, 166.

A number of studies have examined the challenges that result in disparities in the provision of care for adults with intellectual and developmental disabilities. The studies predominately make inquiries of primary care physicians and people with disabilities regarding components of service: convenience, timeliness, and physical parameters. Other studies speak to the need for greater physician education about and exposure to those with disabilities and how to adequately manage their care, whether the disability is physical, intellectual, or a combination of both. Studies that directly attempt to ascertain what is important to the person with a developmental disability in the health care setting and interaction with the physician, from a personal perspective, are not evident in the literature.

Existing studies that indicate adults with intellectual and developmental disabilities report their health and quality of life are good question that determination because, to the outside observer, their lives may look poor.[128] Health care providers often overlook the fact that the presence of an intellectual and developmental disability is the usual state of being for that individual, not necessarily the cause for the health care encounter. The individual's statement that their perception of health is good often limits the primary care physician in further exploration of the individual's story and shifts the focus to the current health concern; the person then becomes a patient in need of medical treatment. The opportunity to communicate with the person regarding things that are important in supporting a healthy, quality life is overlooked as the physician focuses on the current need for care.

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[128] Hailee M. Gibbons, Randall Owen, and Tamar Heller, "Perceptions of Health and Health Care of People with Intellectual and Developmental Disabilities in Medicaid Managed Care," *Intellectual and Developmental Disabilities* 54, no. 2 (April 2016): 95.

The literature identifies the need for enhanced physician education and exposure to people with intellectual and developmental disabilities. Within a framework of medical humanities, the medical school emphasis on concrete learning can be enriched by an understanding of attitudes, knowledge, and behaviors to help medical care move beyond distinct clinical data toward a greater focus on the values and vision inherent to medicine and the perspectives of others.[129] The patient with an intellectual and developmental disability presents an opportunity for the primary care physician to look beyond the present patient concern and consider the patient's collective experience.

Disability is both a medical and social label. The medical aspect, which looks at both the presenting disability and other concomitant clinical conditions, serves to identify physical and functional characteristics that, from a clinical perspective, present barriers to the individual's optimal health. Disability may be seen "as a defect which must be cured or normalized through medical intervention."[130] When primary care physicians are unfamiliar with the presence of intellectual and developmental disability, the "patients can seem so different from doctors that the doctors can have trouble identifying with them."[131] The science-based educational milieu of medical school may modify the humanistic sense and "ambush the empathy that students enter medical school with."[132] The inclusion of both didactic content and actual interaction with patients with intellectual and developmental disabilities would expose the students to the character,

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[129] Shapiro, Coulehan, Wear, and Montello, 198.

[130] *Guidelines: How to Write and Report about People with Disabilities*, 9th ed. (Lawrence, KS:University of Kansa Research and Training Center on Independent Living, 2020).

[131] Danielle Ofri, *What Doctors Feel: How Emotions Affect the Practice of Medicine* (Boston: Beacon Press, 2013), 16.

[132] Ofri, 47.

values, and nature of those perceived as different from the more familiar patient population. This educational model would provide important knowledge and skills to care for those with intellectual and developmental disabilities, as well as "influence attitudes, address unconscious biases, and instill respectful, caring competencies"[133], physician attributes that would be beneficial in the provision of care for all persons.

The social model of disability, "which defines disability as a social construction and asserts that people are disabled by society through environmental and attitudinal barriers"[134] places less importance on the presence of disability and more emphasis on the person's personal perspectives and experiences. The health care experience of those with disabilities is influenced by the availability of needed services, physical accessibility, limited financial resources, and lack of knowledge and discomfort on the part of health care providers.[135] As a result, the quality of care may be limited and differ from that afforded the general population.

People with intellectual and developmental disabilities consider their disability as part of their identity, something that is incorporated in day to day experience and coping within the social structure. The social structure creates a sense of disability as culture where the "persons with disabilities contribute to the values, beliefs, and shared experience that constitute the disability culture."[136] As a result, primary care physicians

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[133] Kerry Boyd, "The Curriculum of Caring: Fostering Compassionate, Person-Centered Health Care," *AMA Journal of Ethics* Vol.18, No.4 (January 2016): 385.

[134] Gibbons, Owen, and Heller, 94.

[135] Tom Shakespeare and Ira Kleine, "Educating Health Professionals about Disability: A Review of Interventions," *Health and Social Care Education* Vol. 2, Issue 2 (October 2013): 20.

[136] Gary E. Eddey and Kenneth L. Robey, "Considering the Culture of Disability in Cultural Competence Education," *Academic Medicine* Vol. 80, Issue 7 (July 2005): 708.

and other health care providers need to be open to the way persons within that socially constructed culture of disability express their needs and concerns.

The presence of disability generates challenges to the physician-patient relationship that necessitate a degree of openness to difference and a level of competence to provide comprehensive, quality care. Developmental disability varies significantly in its impact on cognition and physical presentation, creating the need for an approach to "care that respects an individual's preferences, needs, and values."[137] As patients, people with intellectual and developmental disabilities require consideration related to available and physically accessible services; language and communication needs; patient beliefs and understanding of illness and care; the value of wellness and functional capacity; and appropriate provider practices. The provider should recognize the patient as a key source of clinical information, adjusting the approach to care to support the patient in a way that is understandable and respects the individual's basic autonomy.[138]

The primary care physician, as the most consistently available health care professional involved in caring for people with intellectual and developmental disabilities, is faced with multiple challenges. The physical space in the treating environment may not be sufficient to allow easy access with a wheelchair or other mobility device or the presence of a caregiver or attendant, both of which may be needed to support the visit depending on the needs of the individual. It may be difficult to transfer and position a patient with restricted mobility in the absence of appropriate equipment or a capable assistant. Limited appointment time may prompt the physician to

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[137] Boyd, 384.

[138] Eddey and Robey, Ibid.

forego transferring the patient, reduce the extent of a physical examination, and rely on the patient's verbal report of symptoms and need.[139] The verbal report may lack necessary detail because of the patient's inability to accurately express symptoms or understand the physician's questions. As a result, an incomplete physical examination may leave present and potential health concerns undetected and curtail access to services related to health promotion and preventive care.[140]

"Challenging or ineffective communication in any of its forms is one of the most common barriers to successful health communication . . . between patients with intellectual disabilities and the clinicians who assist them."[141] The physician caring for individuals with intellectual and developmental disability must be open to alternate means of communication. Language may need to simplified to create a level of understanding for those with cognitive limitations. Individuals who are nonverbal or who have difficulty speaking may only respond to questions that require a simple positive or negative response. They may communicate through facial expressions, gestures, or nonverbal utterances, in some cases with the presence of a caregiver or support person to interpret. Communication may be accomplished through the use of augmentative

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[139] Mary Ann McColl, Donna Forster, S.E.D. Shortt, Duncan Hunter, John Dorland, Marshall Godwin, and Walter Rosser, "Physician Experiences Providing Primary Care to People with Disabilities," *Health Policy* (August 2008) Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2645198/ (accessed March 15, 2022) 2.

[140] Lynda Lahti Anderson, Kathy Humphries, Suzanne McDermott, Beth Marks, and Jasmina Siserak, "The State of the Science of Health and Wellness for Adults with Intellectual and Developmental Disabilities," *Intellectual and Developmental Disabilities* Vol. 51, Issue 5 (October 2013): 390.

[141] Marlene Siebert Primeau and Brenda Talley, "Intellectual Disabilities and Health Care Communication: A Continuing Education Program for Providers," *Journal of Continuing Education in Nursing* Vol. 50, Issue 1 (January 2019) 20.

devices. The devices may be as simple as a picture board or as complicated as a complex technology-driven communication system. The fact that a patient may be nonverbal or difficult to understand is not necessarily an indicator of cognitive impairment. Their way of communicating is an adaptation related to their disability. The physician, as well as all health care providers, has an "obligation of involving each individual in his or her own care and in decision making to the fullest capacity." [142] An understanding of the individual patient's way of communicating supports their involvement in developing the most effective plan of care.

Decision making by patients with intellectual and developmental disability can be influenced by how they think about wellness, personal function, and good health. They may define good health as "(a) absence of pain, disease, and symptoms, (b) adherence to or not requiring treatment, (c) physical self-care, (d) mental or spiritual self-care, and (e) ability to perform the activities one wants to do."[143] Patient's definitions or beliefs about what constitutes good health, within the context of their disability, may challenge the physician in providing the best level of care. The patient who feels the absence of pain or overt symptoms demonstrates good health may be resistant to the need for preventive diagnostics and care. Considering adherence to current treatment as an indicator of good health may limit a patient's willingness to accept additional interventions. The ability to manage physical aspects of care, embrace a positive outlook, and participate in chosen activities as indicators of good health may cause the patient to disregard the need for ongoing care or health education.

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[142] Primeau and Talley, Ibid.

[143] Gibbons, Owen, and Heller, 97.

The primary care physician must consider an approach to care of the patient with intellectual and developmental disabilities, and all patients, "in recognition that people are much more than their diseases"[144] or disability. Physician perceptions of disability affect the way appropriate services are provided. "Many health care professionals underestimate the capabilities, health, and quality of life experienced by people with disabilities."[145] Incorrect assumptions about the patient's functional status may restrict their participation in the health care experience. The physician may attribute all presenting medical issues as manifestations of disability or may not fully consider the disability as impacting the overall health status.[146] Both assumptions limit the physician's ability to listen to the patient's personal interpretation of the presenting problem and the impact it has on their usual quality of life.

The patient's interpretation of a health concern provides the physician with information that is "personally significant in the here and now"[147] , information that is presented in the patient's narrative. The narrative is influenced by what is important to the patient seeking care. Intellectual and developmental disability is a life-long, long-term condition but the way a patient views their health may change over time. A primary care physician may look at the presenting health issue as a deviation from what professional experience has labeled normal while "the patient's experience of the same

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[144] Danielle Ofri, *What Patients Say, What Doctors Hear*, 170.

[145] *Core Competencies on Disability for Health Care Education* (Peapack, NJ: Alliance for Disability in Health Care Education, 2018), 3.

[146] McColl, et al., 9.

[147] Trish Greenhalgh, Rosamund Snow, Sara Ryan, Sian Rees, and Helen Salisbury, "Six 'biases against patients and carers in evidence-based medicine," *BMC Medicine* (September 2015) Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4556220/ (accessed August 27, 2019)

condition may not be as an illness at all but as a dimension of being, a fact of life."[148] The patient's narrative may seem ambiguous over the time a primary care physician provides treatment as the story changes relative to how the patient feels and experiences their present state of being. The physician who has been exposed to the humanities and open to reflection and critical thinking may be more responsive to the nuances of the patient's story, able "to shift from more 'automatic thinking' to a critical questioning of approaches, evidence, and interpretations."[149] The integration of clinical evidence and listening to the patient's story provides the primary care physician with the opportunity to see the patient with intellectual and developmental disability from their personal perspective. The patient's personal perspective is the influence that can drive the primary care physician in developing the most effective plan of care

Seven adults with intellectual and developmental disabilities agreed to participate in an interview process to share their experiences during encounters with their primary care physician. The confidential interviews were conducted with participant consent to share their comments and first names only. Participants were given the option to conduct the interview in person or telephonically. The interview questions were open-ended and offered the participants the opportunity to convey their experiences in a way that was most comfortable for them.

The participants are each affected differently by their disability. One individual has both physical and intellectual disabilities, four individuals have physical disabilities only, and two have intellectual disabilities. The participants are high school graduates;

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[148] Greehalgh, et al., 8.

[149] Arno K. Kumagai and Delese Wear, "Making Strange: A Role for the Humanities in Medical Education," *Academic Medicine* Vol. 89, No. 7 (July 2014) 976.

four have attended college, one of whom has a Masters degree. The participants, including those with intellectual disabilities, retain all legal, medical, and decision-making rights, including the ability to give consent.

Andrew has both intellectual and physical disabilities, is non-ambulatory, and uses a power wheelchair for mobility. He is a strong advocate for people with intellectual and developmental disabilities and an active volunteer with a number of community and disability organizations. He speaks clearly and has a vast vocabulary but requires time to process information, sometimes relying on the support of the caregiver present with him at an appointment to provide clarification. He was eager to share his thoughts about the way his primary care physician and the office staff manage his care. By his report, Andrew has experienced challenges related to the office environment, insensitivity of the medical staff in addressing his physical needs, and communicating with staff and his physician/PCP in a way that is best for him to understand.

Andrew’s feeling is that the first contact with office staff sets the tone for the entire visit. He knows his power wheelchair presents a challenge in navigating the environment of the examination room because it is large and requires room to maneuver. Medical assistants don’t always listen when he tries to describe the best way to maneuver the wheelchair, transfer him from the wheelchair to the examination table, or position him properly in the wheelchair when the exam is over. He may have to ask office staff to “talk to me” in order for them to tell him what is being done and why. At times he feels that, despite the fact staff have access to his chart, there has been no record of or information about specifics related to his condition. Andrew feels that because of his apparent difference it may be assumed that he is not interested or capable of processing information related to his care.

Communication with his primary care physician has been difficult for Andrew at times. He has had to remind his primary care physician to speak directly to him and not address comments and questions to the caregiver that accompanies him. Because he requires more time to "allow for decision making", Andrew sometimes feels that his physician doesn't realize he is actually considering what has been said. When he needs to think things over, he will ask the doctor for more information so he can better understand. He may look to his caregiver for an explanation because the caregiver is more familiar with his need for time in processing information. He has to reach a point in the process when he can say "the outcome suits me."

Andrew feels that his primary care physician doesn't consider their interaction "from the individual's perspective." The health care experience would work best if his primary care physician focused on him and what is most important to him as a person with "lower cognition." He "internalizes the lack of acknowledgement" from the primary care physician that he is a person with a different way of processing yet is capable of deciding what he feels is in his best interest in planning his care. He knows how he reacts to pain and what makes him comfortable. The doctor would better understand that if he took the time to ask about those things and how the way he feels affects his daily life. He views the contact with his primary care physician as a process, depicted as a triangle. As the patient he is the most important factor and is positioned at the top. At the base, his caregiver supports him on one side while the doctor and his staff are on the other side to provide care. For Andrew, that care would be offered by a primary care physician who looks at him as “all together”, a person with “a lot of different experiences and feelings”, a doctor “who takes the time” to become familiar with his personal needs and level of comfort.

Tim has a physical disability associated with spina bifida that has moderate impact on his gait. He walks “carefully” without physical support, has no difficulty standing or performing physical tasks, but needs some form of support when stepping up or climbing steps. He works full time in a position that provides information and referral to people with a wide range of disabilities. He has been a patient of his primary care physician, “our family doctor”, for a number of years. He has “a long-time history” with his doctor. They have a shared interest in baseball and the stand-up comedy Tim enjoys. He feels he has a “one to one relationship” with his doctor. The doctor “shows interest” in what is going on in his personal life, is a good listener, makes eye contact, and “makes good use of even a short visit.” Tim reports he only sees his PCP now for regular check-ups or when he is sick. He feels the length of time they have known each other makes their encounters “comfortable.”

Despite the fact that Tim states he has a good relationship with his primary care physician, there are issues that have a negative impact on his visits. The office staff member that takes him to the examination room is “all business” and moves at a pace that “leaves me behind.” Once he’s in the room the office nurse “has a very quick bedside manner”, asking how he is while taking his blood pressure. He may be directed to the scale to weigh in but may not be offered support to step up. Most often he does not have an opportunity to state why he’s there or ask any questions; he feels that the nurse “acts as a gatekeeper” and is not an “interested listener.” Tim states he feels the staff may be "overwhelmed with so many visits scheduled" and "leaves the patient to have a conversation with the doctor."

The work that Tim does has provided him with knowledge of the rights of individuals with disabilities in the health care environment. When he is escorted to the examination room yet left steps behind, he feels accommodation for the slower pace resulting from his physical disability is not taken into account. In the examination room, when he is left to step on the scale without the offer of support he recognizes that the office staff is not "aware of the little things" that are important in providing accommodation for a person with a disability. Tim is able to observe and think beyond his personal experience and consider the things staff might miss. He is aware that for people with disabilities that further limit their mobility, make it difficult for them to communicate or understand what is happening, or aren't able to ask questions or state their concerns, health care may not accurately address their problems or end up being limited.

Harry has had jobs in marketing and, most recently, in administration for a state program assisting individuals with disabilities. He is short in stature and is dependent on crutches to support him in ambulation at all times. The cause of his physical characteristics, "primarily from the waist down", was never discovered but multiple surgeries performed from birth through his teen years made it possible for him to "stand up and get moving." He also has a number of comorbid medical issues that impact his health. Kidney failure resulted in the need for a kidney transplant. Hyperparathyroidism caused high levels of calcium in his blood and loss of bone density. He underwent surgery to remove parathyroid gland tissue and reduce the threat of damage to his kidneys and allow prescribed medications to maintain the remaining strength in his bones.

Routine bloodwork performed by Harry's primary care physician lead to the discovery of the parathyroid condition. Harry scheduled an "as needed" visit to his doctor because he didn't feel well. When he presented with complaints of tiredness, weak muscles, and "brain fog", his primary care physician, aware of the nature of Harry's work and health issues, first focused on stressors related to work, his kidney status, and other recreational and physical activities. Harry reported there were no changes in his "routine days", either at work or outside of work. His doctor "paid attention to the details" he related, asked for additional information, and ordered tests based on what he heard and observed. The primary care physician then ordered bloodwork which revealed the cause of Harry's complaint and he was referred to a specialist. Harry relies on his primary care physician for routine care and to monitor his potential for referral to specialty care.

Harry feels that communication with his primary care physician is both "important and preventive." The doctor listens to what he has to say and is interested not only in his health but other aspects of his life that may have an effect on it. He reports the doctor is aware that because of his physical disability he has the potential to develop additional medical problems. The doctor recognizes the issues underlying his need for regular routine care, will discuss the potential impact of those issues for the long term, and refer him to the specialists that can provide appropriate care when needed. Harry's physical limitations are "respected" by the office staff and the assistance that is offered.

If he perceives any difficulties in the office environment, he feels comfortable asking for help in making his way accessible.

Michelle's physical ability is affected by cerebral palsy. Her hands and gait are unsteady and she fatigues quickly. Her rate of speech is slow and purposeful as she focuses on articulating clearly. She has a seizure disorder generally controlled by medication but experiences unpredictable breakthrough seizures at times. Michelle is employed full-time with accommodations provided by her employer to address her physical needs and sensitivity to light.

Michelle reports she is uncomfortable when she needs to see her primary care physician. She has recorded cerebral palsy as a condition in her medical record and noted her sensitivity to light but has "never been asked" about how those issues affect her. The lighting in the office is bright and "bothers" her eyes. Because of her physical instability, Michelle has to ask for assistance to get onto an examination table that is "just too high" to access without physical support. Her sense is that she is seen as "less than average" because of her rate of speech and "shaky mobility" despite the fact that she is college-educated and has a job. She feels "self-conscious" with the way her primary care physician interacts with her, "so quick and to the point." As a result, she only responds to questions that are asked of her and doesn't share her concerns, ask questions, or mention anything else that might provide the doctor with insight to her interests or feelings. Michelle stated that visits with her primary care physician would be better if the doctor and the staff would "acknowledge my disability, recognize my ability, and see me for who I am." Her experience has made her consider that the only relationship she can have with her primary care physician is professional, based solely on "what he wants to know." She feels that professional relationship is effective because she is always given an appointment when she has an issue related to seizure activity or medication management, is afforded annual testing and regular examinations, and is referred to a neurologist when the primary care physician has concerns.

As a retired educator, Ellen is very willing to share information with her primary care physician. Her feeling is that shared information will be the "foundation for better care." She has had a neurological condition since childhood that progressively limited the movement and sensation in her lower limbs to the degree that she now relies on a manual wheelchair for mobility. Her limited mobility has caused her to develop problems with urinary incontinence and skin integrity.

Ellen's primary care physician, a member of a family practice group, has cared for her "over time". Ellen feels she has a personal relationship with her doctor that has grown by sharing personal information and observations. She has developed a level of trust with her doctor because "she shows interest, listens, considers what is said, and thinks things through with me." Ellen gave an example of a problem that they "solved together" because her primary care physician was able to consider what she was saying and "come up with a plan." The skin on the upper portion of Ellen's right lower leg frequently became irritated. Because she lacks full sensation in the area, the condition often progressed to a state that required significant treatment to promote healing. Her primary care physician was concerned because she was unable to pinpoint a cause and asked Ellen to observe the area and track changes. As she monitored the area, Ellen noticed that because of her position in the wheelchair and lack of sensation in her lower limb, leaking urine often moistened the clothing over the area and went undetected for a period of time. With repeated exposure to the moist conditions, Ellen's skin became irritated. The doctor was unaware of the situation because Ellen always presented with dry clothing during her office visits. Ellen reported her observations to the doctor and together they came up with a care plan to manage the incontinence and address positioning in the wheelchair.

Ellen believes that her primary care physician understands what is important to her in terms of care, comfort, and communication. If the doctor thinks "there is more to my story" she will ask questions until she is satisfied she has the information she needs to provide the best care. Their "interactions" are the basis of a positive and more personal relationship.

Self-advocacy drives the relationships Barb and Josie have with their primary care physicians. When they were very young, their families were advised that institutionalization was the best option for them. Both women became friends as they grew up in a developmental center. Barb, the youngest of four children, didn't develop in the same way as her older siblings, taking more time to achieve early childhood milestones. Her parents were concerned and did all they could to find out what was wrong and do the best for her. She stayed at home with her family until they were forced to make a decision regarding her care. Barb's father was being transferred to Europe for his job and her parents felt the resources to support her needs were not available there. They sought advice from doctors and educators and were advised that the developmental center was the best alternative to meet her needs. Barb was institutionalized when she was four years old but her parents visited often and over time continued to support her progress and goals.

As she grew in the institutional environment, Barb asked questions, spoke up, and learned to advocate for herself. With her sense of determination and the encouragement of her family, she became the first resident of the developmental center to graduate from public high school, transition to independent community living, and maintain full-time employment. Barb currently works with a federally-supported advocacy agency and is a nationally recognized presence in support of people with intellectual and developmental disabilities.

Barb reports that her relationship with her primary care physician is “strong” because she still advocates for what she needs and “feels free” to ask questions and share what is important to her. Her doctor “knows” her because she is “heard” when she reports how she feels and explains what is wrong. She can discuss the things that are important to her and questions the doctor until she feels comfortable when she isn’t sure about making a decision. Barb feels her relationship with her primary care physician is “good” because he is willing to listen, “thinks about what she says and asks her questions”, and explains things in a way she understands; he respects her decisions. She states she “always” has the time she needs during a visit and the doctor understands “the ways” she is “different.”

Josie’s family also struggled to find out what made their child different. She reports she was slow to learn and had “a hard time talking” because the muscles in her face “don’t work right.” Her family was told that she was “slow” and would have to be placed in an institution “to get better.” She believes her family made the best decision at the time, thinking she wouldn’t be able to be her best with their support alone. Like Barb, Josie found she could do more than people at the developmental center originally thought. She was able to graduate from high school, learn to live independently in the community, and maintain a part-time job as a stock person for the local franchise of a national pharmacy chain.

Josie found that the first primary care physician she chose seemed frustrated by the fact that her speech is not clear and she often has to repeat herself to be understood. She reports that after a few visits she had to ask the doctor if he understood what she was trying to say because he “never asked questions or looked me in the eye.” The doctor said he did understand but “only listened once” and then “made his own decisions.” Josie was aware that people with intellectual and developmental disabilities sometimes had a difficult time “getting all the care they need.” She had to ask her primary care physician why he didn’t order mammograms or send her for gynecological care, both of which she understood could help prevent “big problems.” She was not satisfied when the doctor told her “you don’t need it” and didn’t answer her when she asked why not. Josie felt the doctor didn’t look at her as “a regular person” and knew then she needed to leave the practice.

It took Josie “a couple of times” to find a primary care physician she felt comfortable with. She found that some physicians “weren’t patient” with her speech and didn’t acknowledge that she could “understand things.” She states that her primary care doctor now takes time to listen to her and even asks her to repeat herself several times until the doctor understands. The doctor also asks her how she is doing and what she is “up to.” Josie has been able to explain what makes her feel comfortable, what bothers her, and what is important to her. She feels the time the primary care physician spends with her is important and allows her to express herself even when “it’s hard to speak.”

Josie believes a doctor who takes the time to "learn about a patient" is "more interested in keeping them well."

Dr. Theodor Feigelman, board certified in internal medicine, is the Division Director for Developmental Disabilities within a large health system.[150] He serves as the primary care physician for individuals with a wide range of intellectual and developmental disabilities, providing medical care across the lifespan. His practice of more than thirty years is driven by the belief that the care of people with intellectual and developmental disabilities requires a "certain infrastructure." The infrastructure includes the primary care physician, skilled nurses who act as liaisons with the individuals, their families and caregivers, and the providers of health services beyond primary care. Coordinated, comprehensive care establishes a foundation that allows Dr. Feigleman to provide individualized care and "grow older" with his patients.

There are a number of influences that affect the care rendered by the primary care physician to patients with intellectual and developmental disabilities. Dr. Feigleman notes that "changes in medicine, and the medical profession as a whole, over the past thirty years" have allowed physicians to "provide treatment within the ability of the person." The Americans with Disabilities Act (ADA) brought attention to persons with disabilities and the barriers they face, including the barriers that exist in the provision of health care. The ADA considers health care facilities as sites of public accommodation that are required to provide full and equal access to people with disabilities. The requirement directs doctors to provide care to the patient with intellectual and

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[150] Theodor Fiegelman, M.D. Interview by author. Morristown, NJ. November 2018.

developmental disability in a way that best meets their needs. The care should encompass "personal communication in an accessible setting that speaks to personal preferences, goals, and understanding."

The idea of personal communication should direct the primary care physician to look at the patient as a unique individual and acknowledge that there is more to the person than the health concern that brings the label of patient. Dr. Feigelman considers the many ways a patient may provide insight into what is important, from the health and wellness aspect, the expression of interests and goals in life, and the individual's way of expressing understanding. Information can be transmitted verbally, through facial expression, gestures, or with the support of a caregiver familiar with the individual and the way communication is usually conveyed. The interactions between the primary care physician and patient should lead to a fuller understanding of what is important to the individual and whether the patient can comprehend the risks and benefits of care.

Dr. Feigelman presented an example of a patient with intellectual disability whose vision was impaired by cataracts. The patient came to the primary care appointment with a caregiver who knew the patient well and offered support in providing explanation as needed. During the usual examination, Dr. Feigelman noted the cataracts present in the patient's eyes. He asked the patient, who wore glasses, how he felt about his vision. The patient said the glasses helped him see but the eye doctor felt he needed surgery; the patient appeared apprehensive about the procedure. Dr. Feigelman asked the patient why he felt that way. The patient indicated concerns about the procedure, the potential for pain, and how much the surgery would help. Using language appropriate to the patient's level of understanding, Dr. Feigelman described the procedure, what the risks might be, and how the surgery would improve the quality of vision. The patient looked to the caregiver for clarification on some points and ultimately stated he could understand the need for the surgery. Dr. Feigelman noted that, in this example, the time dedicated to addressing the concerns of the patient provided the information that was necessary to gain the patient's assent to the procedure. The idea of assent based on understanding, even when a patient with intellectual disability may need support in giving consent, should drive the eventual decision.

Recognition of persons with intellectual and developmental disabilities as a presence within the whole of society has raised awareness that, as patients, they have both the need of and right to quality, equitable health care. Dr. Feigelman stated that services available and provided appropriately to this population are influenced by multiple factors. The quality of insurance coverage often presents limitations to services beyond primary care. Governmental health care programs offer limited services that may not provide needed specialty care without the necessary clinical recommendation presented by the primary care physician. Preventive care may be limited because some health care providers don't see a disabled person as having the same health-related behaviors and concerns as the general population. The primary care physician may not be familiar with intellectual and developmental disability and the accommodations and supports needed to provide optimal care. Each of these factors can influence the relationship a primary care physician has with the patient and precipitate a lesser quality of care. The quality of the physician-patient relationship among those with intellectual and developmental disability can develop with the patient's expression of what is important with regard to health and the physician's ability to think beyond a strictly clinical picture in hearing what the patient has to say.

Dr. Feigelman noted that people with disabilities are now more present in in the media and current arts. Television and film may include characters with intellectual and developmental disabilities as main characters or characters that promote a social message of inclusion or support. Marketing materials, including television commercials and print advertising, sometimes include people with disabilities. They serve as a reminder that people with visible and invisible disabilities are part of the general population. Visual arts have depicted people with disabilities throughout history and continue to have a contemporary presence.

People with intellectual and developmental disabilities are aware of the arts and media. Dr. Feigleman mentioned patients that regularly watch television and have favorite shows that depict medical scenarios and illustrate social settings as they provide entertainment. Patients may use the social scenarios as a means to express personal ideas about their place in the world. Other patients may read or view graphic materials for enjoyment or distraction from usual activities. Still other patients may view or create art to reduce stress or convey feelings and ideas. In each case, if the patient is given time to tell their story, share their interests, and express their feelings about their present situation the physician has an opportunity to connect with the patient on a more personal level. The patient narrative offers the physician an opportunity to develop the clinical relationship in a way that allows for multiple means of understanding the person and what is most important in the health care milieu.

The importance of looking at all aspects of a person in the social context can support a comprehensive approach to health care. Dr. Dawn Apgar, Ph.D. is an assistant professor, the director of the Department of Sociology, Anthropology, and Social Work, and a member of the faculty at the medical school associated with a leading university and health care system.[151] Previously, she was the Director of the Developmental Disabilities Planning Institute at the New Jersey Institute of Technology. Dr. Apgar also served as Deputy Commissioner within the New Jersey Department of Human Services with oversight of the Division of Developmental Disabilities. Her long-standing experience in looking at the needs of people in wellness and in health, including people with intellectual and developmental disabilities, has brought a broad perspective to building an effective relationship between the patient and physician.

Dr. Apgar states that perception influences the health care experience. It is important to identify the things that influence the perception of health from the patient's point of view. The patient's social, educational, environmental, economic, and personal situation all influence the way a patient defines what is most significant in relation to health and well-being. The effect of these factors on and their relative importance in a patient's life may change over time as the patient faces alterations in life experience and personal health. The changes may affect the way a patient decides what is important to their health but the relative influence of these factors as determinants of health remains in place.

People with intellectual and developmental disabilities are often viewed as different in a socially comparative context. They may be seen as less able and aware than

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[151] Dawn Apgar, Ph.D. Interview by author. South Orange, NJ. April 2019.

the general population because of perceived social and functional norms. As a result of that assigned difference, determinants of health that influence the well-being of the general population may not be considered to have a similar impact on their quality of life. The subsequent social view can limit the opportunity for people with intellectual and developmental disabilities to be heard within the health care experience and express what is most important to them in health and the determinants that influence it. These limitations can lead to a disparity in provision of comprehensive quality health care services. According to Dr. Apgar, key to developing a positive physician-patient relationship with people with intellectual and developmental disabilities is to "listen, hear what they have to say. They deserve to be heard, not talked to."

The manner in which the physician perceives the patient can create barriers to care. Medical students may enter training having had limited contact with people from various ethnic and cultural groups, including the socially defined group of people with disabilities. They may be unfamiliar with individuals with intellectual and developmental disabilities. Lack of exposure to such individuals may limit the students' ability to consider the health care needs of people with intellectual and developmental disabilities within the framework of what impacts the health of the general population.

Dr. Apgar is a proponent of medical education that incorporates an understanding of the relationship of the determinants of health and the health-related circumstances of the patient and family. The Human Dimension Voices Program[152] pairs medical students with families in each of three different communities over the course of three years. The

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[152] *Human Dimensions Voices Program.* Hackensack University School of Medicine at Seton Hall University. 2019.

years long timeframe allows students to build relationships with family members around health issues, looking at all things that impact health including things that are important to them in their daily life and connections within the community. Extended exposure to people with a variety of health issues in diverse settings offers the students an opportunity to look at aspects of health in a number of different ways. Learning derived from the educational experience is shaped by hearing and understanding the things that are important to the patient and family, the goals they have for health and wellness, and the day to day interests that form their place in the family and community. The students are driven to consider different ways of thinking and relating to people across the spectrum of wellness and functional ability. The students' understanding of what is needed to provide comprehensive, quality care and the interpersonal nature of the learning process impacts the perspective of the student in approaching barriers to care that may exist.

Dr. Maria S. Flores is a family practice physician.[153] Her primary care practice serves people with a number of ethnic, cultural, and socioeconomic backgrounds. She reports that the majority of the patients with disabilities she cares for have sustained disability as the result of other medical issues. A stroke, fall, or neuropathy may have resulted in limited physical function. Aging may have brought about cognitive impairment. Dr. Flores sees few patients with intellectual and developmental disabilities. She is affiliated with a large health care system that has specialty physicians dedicated to caring for the population with intellectual and developmental disabilities and will refer patients she feels are in need of services beyond primary care.

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[153] Maria S. Flores, M.D. Interview by author, Edison, NJ. December 2021.

Dr. Flores recognizes that the care requirements of people with disabilities need to be accommodated in the best way possible with the resources that are available to her. She retains a diverse office staff in order to meet the linguistic and cultural needs of the patients. When a patient requires additional space to provide for supportive equipment, staff will assign the patient to the largest examination room with the most accessible equipment. In some cases, Dr. Flores will see a patient in her personal workspace where there is less noise and distraction from general office activity in order to provide a milieu that best suits the patient's needs.

The physical setting appropriate for the patient affords the patient the greatest opportunity to feel at ease. Dr. Flores finds that when the patient is comfortable, it is easier to focus on the patient, listen to what has precipitated the need for care, hear what is important in relation to the issue, and discover how it is affecting the patient's overall well-being. If a caregiver is present, there may be a need to gather additional information, always with the patient's permission. Communication often takes more time than originally scheduled to account for linguistic needs, the patient's way of communicating and level of understanding, and clarification on the doctor's part. Dr. Flores allows additional time within a "fluid" schedule to answer questions, provide explanations, hear from caregivers if necessary, and explore any other concerns that may be important to the patient.

The things that impact a person's life warrant as much attention as what brings a person to the doctor. Dr. Flores considers a number of factors when listening to a patient, "and more so to a patient with a disability." Disability can have a negative impact on the financial concerns of a patient and the family, especially if income is limited or health care benefits are curtailed when a patient is unable to work. The activities that the patient enjoys or must perform can be limited. Usual interpersonal communication can become more difficult if cognition is affected. Personal goals may have to change. If a disability is developmental in nature, the care plan must be projected across the lifespan. In order to provide the best care, Dr. Flores keeps an "open ear and heart" to center care and concern on the patient's individual needs and what is most important to the quality of life.

The experiences of persons with intellectual and developmental and their primary care physicians rest on the idea that an understanding of the patient as a person is key to the provision of comprehensive, quality care. The presence of developmental disability, whether physical, intellectual, or both together presents challenges to building a working, person-centered relationship. The prospect of building a quality relationship lies in a caregiving vision that encompasses both the personhood of the patient and the willingness of the primary care physician to be open to thinking beyond the clinical dimension.

Chapter Three

The Primary Care Encounter: Barriers, Attitudes, and Perceptions through the Lens of Medical Humanities

The adults with intellectual and developmental disabilities who participated in the interview process noted both negative and positive encounters with their primary care physicians. They shared experiences that underscored the challenges that present barriers to fostering a positive relationship with their primary care physicians. Their comments also identified attitudes and circumstances presented by office staff and primary care physicians that have the potential to limit access to individualized, comprehensive, and ongoing quality care. Conversely, they mentioned circumstances related to their care and the treating milieu that provided opportunities to establish a positive relationship with the primary care physician.

The adults with intellectual and developmental disabilities experienced barriers in the health care environment that were analogous to those identified in the literature. Equal access to care may be limited by physical inaccessibility, ineffective communication strategies, the lack of knowledge and understanding of disability on the part of healthcare providers, and limited medical information derived through patient narrative. "Limited patient input . . . power imbalances that suppress the patient's voice, and over-emphasis on the clinical consultation"[154] reduce the possibility of a positive relationship between the patient and the primary care physician.

Physical barriers encountered were related to inadequate space to accommodate the patient's supportive devices, inaccessible examination tables and equipment, and lack of support

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[154] Greenhalgh, Snow, Ryan, Rees, and Salisbury, 1.

in ambulation by medical office staff. The individual who uses a wheelchair for mobility or crutches to support ambulation understands the device is essential to their ability to engage in the world at large. “People with disabilities may consider the devices and equipment they use to be an extension of their person.”[155] Devices to support physical mobility promote social integration and participation in activities that might otherwise be inaccessible. Supportive devices enable the disabled person to physically approach the health care environment in seeking care. Access to care is limited when a health care provider does not recognize the essential nature of the supportive device. Inadequate space to accommodate the device in the treatment setting restricts the patient’s independence in navigating the area and initiating the health care encounter.

Limited understanding by office staff of the patient’s need for supportive devices or human assistance may further limit physical accessibility. The patient’s family member or caregiver may offer physical assistance or support the patient with verbal direction or clarification as needed. A patient with intellectual and developmental disabilities may require hands-on physical assistance to move within the environment when their condition does not mandate use of a supportive device. Physical instability or limited range of movement may cause the patient to move slowly, need more time to navigate the area, or require physical assistance from office staff. An ambulatory patient with intellectual disability may require physical or verbal guidance to manage in a space that is unfamiliar.

The examination area presents additional challenges for patients with intellectual and developmental disabilities. Data essential to address the patient’s health concern and establish a comprehensive care plan can be limited when appropriate equipment is not available. The

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[155] *Core Competencies on Disability for Health Care Education* (Peapack, NJ: Alliance for Disability in Health Care Education, 2018), 6.

patient may be unable to get up on a scale because it requires a step up that cannot be managed independently. Office staff or the primary care physician may have to guess the weight of a person in a wheelchair because the office does not have a wheelchair accessible scale. The examination table may be too high for the patient to access without assistance. The examination table may also be a source of discomfort if the patient has a physical disability or health condition that makes proper positioning difficult. A patient with a longstanding history of interactions with health care providers or an individual with cognitive disability may be uncomfortable with the clinical equipment and examination maneuvers necessary to gather baseline health-related information.[156]

Communication between the patient, office staff, and the primary care physician can affect the way the patient's needs and interests are understood and the care that is offered. The patient with intellectual and developmental disabilities may communicate in a number of ways. Cognitive and physical disabilities both have an impact on the patient's ability to communicate. A patient may use verbal communication in a manner that is clear and informative despite the presence of disability. For others, verbal communication may be challenging for a patient with a disability that causes the muscles associated with speech to be weak or hard to control, resulting in speech that is difficult to understand. A patient with cognitive impairment may need additional time to process information before providing a verbal response. Minimally verbal patients may understand the spoken word but may only respond with simple yes or no answers. Nonverbal patients may communicate through physical gestures or facial signals.[157] In each

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[156] Elizabeth Grier, Dara Abells, Ian Casson, Meg Gemmill, Jessica Ladouceur, Amanda Lepp, Ullanda Niel, Samantha Sacks, and Kyle Sue, "Managing complexity in care of patients with intellectual and developmental disabilities," *Canadian Family Physician* Vol. 64 Suppl 2 (April 2018): S19.

[157] Ibid, S16.

case, the health care provider must use "communication strategies to best meet the needs/abilities of the patient."[158]

Effective communication between the patient with intellectual and developmental disabilities and health care providers serves as a primary source of relevant information for the medical record. Data in the medical record should inform the office staff and primary care physician of the patient's general state of health, existing medical conditions, disability, the particular impact of the disability on the individual patient, and features of the disability related to overall health issues. For patients with decisional capacity, the medical record should also document patient preferences regarding life supporting interventions in the event of terminal illness. Patients with the ability to provide accurate information for the medical record establish a baseline for the primary care physician to plan and provide care. The plan of care should be developed with consideration of that information as well as patient input about the current and presenting health issues. Information in the medical record may be insufficient if the patient has "limited receptive and expressive language skills, motor apraxia affecting speech, or challenges with time concepts and difficulties with abstract language."[159] In that case, the primary care physician may need to evaluate the patient's presenting health concern based on medical history, physical assessment, and observation for changes in behavior in order to develop an appropriate approach to care.

Lack of knowledge and understanding of the patient's disability and associated medical concerns can limit the primary care physician in developing a comprehensive plan of care. "Clinicians and their staff do not need to know about every disability, as long as they do not

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[158] *Core Competencies on Disability for Health Care Education*, 6.

[159] Grier, Abells, Casson, Gemmill, Ladouceur, Lepp, Niel, Sacks, and Sue, S18.

make assumptions about a person's disability and capacity."[160] The patient with intellectual and developmental disabilities may have a perception of health based on a personal interpretation of wellness that encompasses a lack of pain and an ability to manage day to day rather than on the meaning of presenting symptoms. The primary care physician can gain insight into the patient's understanding of their disability and overall capacity to identify health issues by listening to the patient's narrative of what is important to their well-being and how they define their goals of care.

Positive relationships between people with intellectual and developmental disabilities and primary care physicians can develop despite the barriers that may be present. The primary care physician can initiate and establish the relationship by listening to what the patient has to say, taking the time to understand what is important to the patient, and accepting that the patient with intellectual and developmental disabilities is able to contribute in crafting decisions affecting their health and well-being. The adults with intellectual and developmental disabilities who participated in the interview process shared experiences that were both affirming and challenging, depending on their response to barriers and personal interactions in the health care setting. Their collective perspectives highlight the need for primary care physicians to consider the needs and interests of the whole person in all aspects of the health care milieu, aside from the clinical presentation and the physician's preconceived assumptions.

Andrew faced physical barriers in the medical office because limited space made it difficult to maneuver his power wheelchair. He encountered difficulty in having office staff recognize his ability to provide instruction in managing the wheelchair and directing his

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[160] Elizabeth H. Morrison, Valerie George, and Laura Mosqueda, "Primary care for Adults With Physical Disabilities: Perceptions From Consumer and Provider Focus Groups," *Family Medicine* Vol. 40, No. 9 (October 2008): 648.

positioning. Communication with the primary care physician was difficult at times when Andrew had to ask the physician to direct questions and comments to him rather than the caregiver who accompanied him. He thought his physician did not recognize him as someone able to make decisions regarding care despite his apparent physical disability and slower way of processing information. The primary care physician did respond to Andrew's request when he needed additional information and was willing to wait until he reached a decision regarding the care he felt best suited his needs. Andrew felt the primary care physician and his staff were there to provide the care he needed but the care might be rendered in a more appropriate way if the primary care physician took the time to become familiar with his personal experiences, preferences, and level of comfort.

Tim reported that a long-standing history with his "family doctor" contributed to a positive "one to one relationship" and a level of comfort with his primary care physician. His physician is aware of Tim's disability and how it affects his overall health and ability to function in his day to day life. Tim noted that his primary care physician is aware of his personal interests, makes eye contact, is a good listener, and "makes good use of even a short visit" for routine care or when he is sick.

The positive aspects of Tim's relationship with his primary care physician overshadow a notable issue with office staff. Tim feels that office staff members do not always pay attention to specific patient characteristics. Tim's gait is slow because of his physical disability. He is able to ambulate but encounters barriers to access when he is not offered support to access the scale or other office fixtures. While information related to his disability and needs is contained in his medical record, Tim feels that limited time and lack of familiarity with his disability reduce staff attention to details that would enhance the quality of the health care experience.

Harry experiences few issues related to his use of crutches to support ambulation when in the office of his primary care physician. He feels office staff members respect his physical limitations and offer assistance as needed. His relationship with the primary care physician is grounded on the physician's interest in aspects of his life that have the potential to affect his overall health status. Effective communication between Harry and his physician is informed by positive interpersonal communication and an awareness that shared information can have a positive impact on regular health care and prevention of potential complications.

Michelle maintains a "professional" relationship with her primary care physician. She feels she has provided sufficient information in her medical record to inform office staff and her physician about her disability and an accurate account of the impact cerebral palsy has had on her mobility, rate of speech, and response to bright environmental lighting. Despite the content of the medical record, Michelle suspects they do not take into account that she is educated and fully cognizant. She feels she is considered as "less than average" when she has to ask for physical assistance. She states she is "self-conscious" when dealing with office staff and uncomfortable with her primary care physician because they seem to be unaware of her ability and the person she is.

Despite her feelings related to the health care milieu, Michelle is comfortable with the professional relationship she has with the primary care physician. The physician's "quick and to the point" interactions have put the primary care physician in control of her care and caused Michelle to avoid asking questions, raise concerns, or share personal issues. Even with this unfavorable and one-sided communication model, she feels her relationship with the primary care physician is positive because she is able to schedule appointments for regular and preventive care or when feeling unwell, for management of seizure medication, and for referral to her neurologist when needed. She answers the primary care physician’s questions related to her health status when asked and sustains a relationship she considers workable in the “quick and to the point” setting and adequate in the provision of care.

Ellen believes the interactions with her primary care physician are the foundation of a positive and more personal relationship. She believes the relationship developed as she shared personal information and observations related to her disability. The primary care physician listened and worked with her to develop a plan that effectively took into consideration Ellen’s needs related to care, comfort, and communication. Ellen did not report confronting any barriers in accessing the care she requires. She indicated a level of trust associated with the primary care physician’s interest in her personal story and attention to the issues she shared.

Barb and Josie have advocated for themselves in the health care setting. Barb reports a “strong’ relationship with her primary care physician. Her doctor understands the way she is “different”, listens to what she has to say, answers her questions, provides explanations related to care in a way that is understandable, and allows her the time needed to process the information. She feels she is “heard” when interacting with her doctor because he respects her decisions.

Josie faced several barriers when dealing with the first primary care physician she chose. Her speech is difficult to understand as a component of her disability and she often has to repeat herself until she is understood. Josie sensed her doctor became frustrated with her need to repeat herself because he “listened only once”, never asked questions, and made decisions without her input. When she asked about preventive care related to female health she was told she “didn’t need it.” Josie felt that the primary care physician did not consider her a “regular person” and decided it was time to make a change. Her health care was limited by poor patient-physician communication and the physician’s lack of consideration of the needs of women with intellectual and developmental disability. Josie realized she found a primary care physician who made keeping her healthy the focus of care when the physician took the time to listen and understand her, who asked how she was doing, and ordered the preventive services she required.

The adults with intellectual and developmental disabilities who participated in the interview process shared experiences that influenced their relationship with their primary care physicians. Three participants felt their primary care physicians communicated effectively, were interested in their general health and personal concerns, supported them in decision-making, and considered their disability in providing care. The remaining participants confronted barriers to the provision of care in the primary care setting. Ease of entry to areas in the office environment and access to scales and examination tables was limited when the participant used a power wheelchair, was dependent on supportive devices for ambulation, or required physical assistance to navigate in the office environment. Several of the participants felt the office staff and primary care physician did not have an understanding of their disability and how it affects their overall health, abilities, and concerns. Personal information contained in the medical record could offer insight into their medical history and needs with respect to their disability.

Participants with disabilities affecting their speech experienced communication difficulties that impacted the quality of their relationship with the primary care physician. A participant with a disability that makes speech hard to understand felt her primary care physician made determinations about care independently because he didn’t consider her ability to contribute and/or make her own health care decisions. Participants with slow speech or who needed additional time to process information had difficulty relating their needs and personal concerns to the primary care physician. Their ability to establish a personal relationship was limited if the doctor did not offer additional time or support to develop effective communication.

The health care professionals who were interviewed recognize barriers individuals with intellectual and developmental disabilities confront in establishing a positive relationship with their primary care physicians. They also acknowledge the need to look beyond the clinical presentation to provide the care that best meets the needs of the patient with intellectual and developmental disabilities. The impact of disability and experience with illness is unique for each patient whether the patient has a physical disability, intellectual disability, or both disabilities are present. The individual's social, environmental, educational, economic, and personal situation contribute to the way an individual manages with the disability, determine what is important to quality of life, and shape the personal perception and overall value of health. Personal experiences, values, and interests may change over the course of a lifetime but continue to have an ongoing influence on the individual's idea of what constitutes good health and contributes to overall well-being. A positive relationship between the patient with intellectual and developmental disabilities and the primary care physician can develop when potential barriers to care are acknowledged and the patient's personal story is heard.

Changes in medical practice over time have allowed primary care physicians to provide care in a way that considers the ability of the person. The Americans with Disabilities Act (ADA) brought attention to the barriers people with disability face in the health care setting, including individuals with intellectual and developmental disability. The ADA defined health care facilities as sites of public accommodation where patients with disabilities are to be afforded full and equal access to care. Health care for patients with intellectual and developmental disabilities is to be provided in a way that best meets their needs. Appropriate care should take into consideration the patient's overall health, perception of well-being, personal goals and interests, and level of understanding.

Dr. Feigelman, Division Director for Developmental Disabilities within a large health care system, has a primary care practice that serves individuals with intellectual and developmental disabilities within a broad range of physical and cognitive ability across the lifespan. His practice is based on a model that incorporates a health care infrastructure composed of the primary care physician and nurses who develop and maintain a working relationship with the patient, family, caregivers, and other providers who contribute to the patient's health and plan of care. The information used to create the care plan is based on effective communication between the primary care physician and the individual patient.

The patient's story is essential to the physician in order to gain an understanding of the patient's health concerns, interests, and experience with illness. The primary care physician develops a rapport with the patient with intellectual and developmental disability based on effective interpersonal communication. Communication with the patient should occur in a way the patient can understand. Language used to convey or obtain information should be expressed at a level commensurate with the patient's ability to comprehend. Patients may understand verbal communication but may communicate through means other than the spoken word. Facial expressions, physical gestures, nonverbal utterances, or assistive technology may be used by the patient as an alternate means of communication. Caregivers or family members who are familiar with the patient's receptive and expressive language ability may interpret information for the patient in order to promote understanding during the primary care visit. The patient should be provided adequate time to process information and develop a narrative that incorporates what is personally important.

The relationship that develops between a patient with intellectual and developmental disabilities and the primary care physician supports the patient in understanding the rationale for needed care. Procedures that are more complex than those associated with the usual provision of care may create concern for the patient and require an uncomplicated explanation. A primary care physician familiar with the patient's narrative could provide an explanation the patient can comprehend. The patient can gain a better understanding of the care that is needed and consider giving assent.

Dr. Feigelman notes that, while people with intellectual and developmental disability are recognized as a part of society at large, their health care needs are not always considered in the same way as those of the general population. Many individuals with intellectual and developmental disabilities are covered by government health insurance programs.[161] The programs provide for primary care but often limit coverage for preventive care as well as specialty care required to meet the unique needs of this disability population. Primary care physicians unfamiliar with the needs of patients with intellectual and developmental disabilities may not recognize the disparity in care that can result from the limitations of government insurance programs. Understanding the nature and impact of disability on the patient's health is essential to providing the level of care needed and commensurate to that available to the general population. The relationship between the primary care physician and the patient with intellectual and developmental disabilities may be limited by both these factors. Time and attention are needed to hear the patient's story and learn what is important to the patient within the context of health and personal interest. The patient's narrative and recognition of disability-related needs can help the primary care physician look beyond potentially limited health care services and reduce the barriers that lead to disparities in care.

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[161] Gibbons, Owen, and Heller, 100.

The relationship between the patient and primary care physician can be impacted by the patient's exposure to the arts and media. Film, television, graphic creations, print materials, and advertising depict individuals with disability in a variety of social contexts, including medical scenarios. Individuals with intellectual and developmental disability may view the scenarios as a way to consider their place in society and formulate their interests, goals, and personal concept of health and wellness. The influence of media can bring a social perspective to the patient's narrative and offer a wider range of options for communication in the relationship between the patient and primary care physician.

While exposure to the arts and media can influence the way a patient with intellectual and developmental disabilities approaches the health care encounter, media can cause the patient to question the way they are viewed within the relationship with the primary care physician. The way people with disabilities are depicted in the arts and media can be misleading and reflective of social stereotypes. They may be presented as helpless, as individuals with a limited chance at normalcy. They may be shown as inspirational, people with a limitation to overcome rather than live with as part of every day life. "One aspect of good disability representation is that a character's purpose is not solely based on their disability."[162] Characters with disability should be presented as would non-disabled persons. They would have a story, goals, relationships, and interests.[163] The patient with intellectual and developmental disabilities who is exposed to media that shows individuals with disabilities in a way similar to non-disabled individuals may feel

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[162] "Misleading Media: Disabilities in Film and Television," *University of Alabama at Birmingham Institute for Human Rights* November 27, 2019 Source: sites.uab.edu/humanrights/2019/11/27/misleading-media-disabilities-in-film-and-television/ (accessed July 13, 2023)

[163] Ibid.

more confident in developing and sharing a narrative that promotes a positive, personal relationship in the primary care setting.

The place of the patient with intellectual and developmental disability in the social context and consideration of the social determinants of health are essential to provision of comprehensive health services. The effect of these factors and life experience influence the way the patient perceives health and wellness. The relative importance of health in the patient's experience may change over time if alterations in their social, educational, economic, environmental, or personal situation occur. Primary care physicians may disregard the patient's view of health because individuals with intellectual and developmental disabilities are often viewed as different from the general population, less aware of health needs and the ability to consider health care options. The primary care physician who fails to acknowledge the potential capacity of this patient population to provide insight into their health status and the factors that affect it may not provide an adequate, appropriate level of care.

Dr. Apgar, Director of the Department of Sociology, Anthropology, and Social Work and faculty member at a university affiliated medical school, believes that the perception of health by primary care physicians influences the quality of care available to patients with intellectual and developmental disabilities. The primary care physician needs to consider the patient's view of health and the factors that influence its relative importance. The patient's narrative provides the information that explains their interpretation of health and the needs and care they deem necessary to maintain their well-being. Medical students, as potential primary care physicians, need exposure to individuals with intellectual and developmental disabilities to foster a sense of familiarity with the population and gain insight into the circumstances that influence their perception of wellness.

A medical school experience that promotes contact with patients over an extended period of time during the educational process allows the student to become familiar with the multiple social components that affect the patient's life experience and perception of health. Students who interact with individuals with intellectual and developmental disability within the family, community, and broader social context gain a sense of the complexities and nuances that factor into establishing rapport and communication. Students gain an awareness of the role the patient's story plays in establishing a relationship with the patient that is effective in both the clinical and personal sense.

Dr. Maria Flores, the primary care care physician who serves a diverse patient population in the community, may have limited contact with individuals with intellectual and developmental disabilities. The majority of the patients Dr. Flores cares for have disabilities related to underlying medical diagnoses, physical injuries, or age-related cognitive impairment. Accommodations to limit barriers to appropriate care are provided regardless of the nature of the disability. A diverse staff is available to address language and linguistic needs. Patients who require additional space and assistance to accommodate supportive devices are offered examination areas with the greatest available space. Patients with cognitive issues are afforded an extended amount of time to express their needs, allow for input from caregivers who may be present, and conduct an examination in a way that best meets the patient's physical needs. The relationship of the patient with the primary care physician in the practice is considered essential to acknowledging the patient's concerns, addressing the patient's health needs, and developing the most comprehensive plan of care.

The adults with intellectual and developmental disabilities who participated in the interviews identified issues that impacted the patient relationship with the primary care physician and the quality of care provided. Most important was the need for the physician to interact directly with the patient in an appropriate manner. The presence of intellectual and developmental disability does not necessarily imply an inability to question the physician about diagnoses or proposed medical interventions, understand explanations provided at an acceptable linguistic level, or participate in decision-making. Patients wanted physicians to direct questions to them rather than speak around them or to a caregiver who might be present in the examination room. The primary care physician may need to accommodate the patient's request by providing additional time for the patient to process information and formulate a response.

The interview participants reported that relationships with primary care physicians developed in a more positive way if the physician listened to what they had to say about their issues and concerns. Patient narratives tell what is important to the patient not only in maintaining well-being but how life experience, personal interests, and individual goals assist the patient in deciding what is relevant to their health care experience. "The conversation between doctor and patient -the medical interview- is the single most important diagnostic tool in medicine."[164] The primary care physician can refer to clinical data to get a picture of the patient's medical status but hearing how the patient feels and listening to how everyday issues are managed provides the personal and social information that supports a positive relationship. The patient's story can add to the primary care physician's understanding of how intellectual and developmental disabilities shape the ability to function on a daily basis and integrate into the greater community.

In some cases, the adults with intellectual and developmental disabilities felt the office staff and primary care physician did not reference information in their medical record. The

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[164] Ofri, *What Patients Say, What Doctors Hear*, 17.

information may have provided an understanding of their disability and how the disability affected mobility, the need for physical assistance, and the response to environmental conditions such as limited space and lighting. A positive relationship between the patient and primary care physician provides the patient with an opportunity to regularly update and enhance information to support provision of care in a way that best suits patient needs.

The primary care physician encounters a unique patient in each person with intellectual and developmental disabilities "which has its genesis in a health condition (disorder or disease) that gives rise to impairments in body function and structure, activity limitations, and participation restrictions."[165] The impact of intellectual and developmental disabilities varies from person to person and has a significant impact on how the patient presents and functions in the health care setting. The patient visit may be precipitated by "needs arising from their primary impairment as well as general health needs"[166] but the way the patient responds to the condition and conveys symptoms can challenge the primary care practitioner's skill in communication, physical assessment, and diagnosis.

Primary care physicians may make assumptions about the ability of individuals with intellectual and developmental disabilities based on their experience with this population. Attitudes may be shaped by limited exposure to these individuals in medical training and practice as well as social and community settings. Lack of knowledge, experience, or preconceived notions about the character and capacity of individuals with intellectual and developmental disabilities may limit the physician's skill in looking at the patient as a whole. The patient brings a personal perspective to the interaction with the primary care physician that is shaped by

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[165] International Classification of Functioning, *Disability and Health*

[166] Shakespeare and Kleine, 20.

individual life experience, an interpretation of health, and understanding of what constitutes a positive quality of life. The primary care physician must be able to consider the patient and delivery of care in a way that considers the whole person and not just the presenting concern.

Medical education that incorporates clinical training about intellectual and developmental disabilities, professional exposure, and personal interaction can improve the primary care physician's ability "in communicating with individuals who have nonstandard speech, understanding the values and needs of people with disabilities, and encouraging self-advocacy and interdependence."[167] A positive relationship between the patient with intellectual and developmental disabilities and the primary care physician allows the patient to share a narrative that informs the physician of what is important and encourages the delivery of comprehensive care from a humanistic perspective that looks at the person as a whole.

The primary care physician must be open to interpretations of life experience and ways of thinking and observation by patients with intellectual and developmental disabilities that vary significantly from what is thought to be routine in medical practice. Cognitive impairment may make it difficult for the patient to verbally describe the experience of illness in a way that is clear and understandable. A patient with physical limitation may express their health concern through a perspective limited by a perception of space and access. The humanities-related disciplines may open the primary care physician "to enhance empathy, perspective-taking, and openness to different viewpoints, and to prompt reflection on self, others, and the world."[168] The patient

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[167] Joanne Wilkinson, Deborah Dreyfus, Mary Cerreto, and Barbara Bokhour, "Sometimes I Feel Overwhelmed: Educational Needs of Family Physicians Caring for People with Intellectual Disability," *Intellectual and Developmental Disabilities* Vol. 15, Issue 3 (June 2012) Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3708475/ (accessed February 12, 2019)

[168] Kumagai and Wear, 973.

exposed to the arts and humanities through visual, print, or creative modalities may come to the health care encounter with a vision that allows the physician to hear and explore their personal story through a wider frame of reference.

Interactions between individuals with intellectual and developmental disabilities and their primary care physicians that recognize the individual character, ability, and strengths of the patient form a foundation for a personal, positive relationship. The goals of the relationship must embrace the needs and interests of the individual, support comprehensive, appropriate care, and eliminate disparities that occur due to perceptions of difference.

Chapter Four

The Patient's Story and the Physician's Approach: Narrative versus Clinical

The information gathered through the review of literature and interviews with individuals with intellectual and developmental disabilities and medical professionals identified multiple factors that can result in a gap in health care services for this population. Literature related to the provision of health care for individuals with intellectual and developmental disabilities in the primary care setting revealed a number of challenges to the provision of comprehensive, quality health care. A number of studies highlighted issues related to components of service: convenience, timeliness, and physical accessibility. Other studies identified barriers to service that included poor communication between the patient and primary care physician, lack of available medical information to guide health care staff, and poor understanding of disability by health care providers. The literature also noted the need for enhanced medical education in intellectual and developmental disabilities and improved skills in practice to avoid disparities in care for this population.

Medical education related to intellectual and developmental disabilities is limited in many medical school programs, as is exposure to the population. Primary care physicians may approach caring for these patients with little understanding of the inherent abilities that may be masked by overt appearances. The physician's perception of patients with intellectual and developmental disabilities and assumptions about the patient's potential to actively participate in care may limit interpersonal communication. Poor communication may result from the patient's inability to articulate clearly or need to process information slowly. It can also result from the primary care physician's inability to seek patient input about the illness experience and the factors that are important to personal life and wellness.

Adults with intellectual and developmental disabilities indicated a lack of understanding on the part of primary care physicians with respect to their disabilities and how they shaped their personal lives. Adults who felt their primary care physicians had an interest in their disability and how it affected them personally felt the relationship with the primary physician was positive. Patients with intellectual and developmental disabilities did not consider their relationship with the physician personal or positive in cases where the primary care physician appeared uncomfortable with the patient or didn't seek input beyond the presenting health need. Several participants indicated that the primary care physician failed to recognize their ability to comprehend health concerns related to their disabilities, understand their presenting and preventive health needs, and participate in making decisions related to care. Communication difficulties associated with verbal articulation, rate of speech, and time needed to process information limited effective interaction between the patient and primary care physician. The presence of a caregiver, whether for physical support or assistance in conveying information, sometimes made it necessary for the patient to ask the physician to direct questions and comments to the patient. The need for supportive devices or physical assistance to achieve mobility made it difficult to navigate and access equipment in the office setting. The barriers in the health care milieu and the primary care physician's limited ability to acknowledge the personal characteristics of the patient with intellectual and developmental disabilities can impede the opportunity to create a relationship that meets the patient's personal needs, interests, and goals.

Information derived from interviews with health care professionals who provide care for people with disabilities, including individuals with intellectual and developmental disabilities, confirmed an awareness of barriers that present the potential for disparities in care. The primary care physician with a practice that provides care dedicated to individuals with intellectual and developmental disabilities across the lifespan emphasized the need to consider the individual patient from aspects of personal ability, interests, social influences, and level of understanding. The primary care physician needs to hear what the patient has to say in order to gain an awareness of their perception of health and wellness and the capacity to comprehend information related to the provision of care. The patient's story and attentive communication between the primary care physician and the patient with intellectual and developmental disabilities can yield a positive personal relationship and a comprehensive plan of care.

The primary care physician with a diverse community practice sees few patients with intellectual and developmental disabilities. The majority of patients with disabilities in the practice have disabilities associated with underlying health conditions, injuries, or age-related cognitive limitations. Despite the nature of the disability, the primary care physician recognizes barriers that may limit effective interactions in the health care setting. Barriers to communication, accessibility, and adequate medical information can affect the physician's capacity to develop an individualized plan of care. The narrative the patient provides regarding the ability to address everyday activities, express and understand health needs, and identify life circumstances and experiences that drive personal interests helps to establish a positive relationship focused on the whole person.

The medical school faculty member acknowledged that it is essential to recognize the way the patient with intellectual and developmental disabilities perceives the importance of health and well-being as well as the primary care physician's perception of the patient's capacity to understand and consider care options. The patient's perception is influenced by social, educational, environmental, economic, and personal factors that shape the patient's subjective experience and life circumstances. The primary care physician may have had limited training in disabilities and little exposure to patients with intellectual and developmental disabilities. The physician may form a perception based on inexperience with this patient population as well as social thinking that individuals with intellectual and developmental disability are less able than the general population. The physician's perception can limit the opportunity to accurately assess the patient and develop a comprehensive plan of care. The patient's story as it relates to issues of personal importance and health needs to be heard. The story can provide the primary care physician with a better understanding of the patient's needs within the context of intellectual and developmental disabilities and offer the foundation for a positive personal relationship.

Medical education that provides experiential learning can improve the capacity of primary care physicians "to deliver person/family-centered care to people who live with intellectual and/or developmental disabilities."[169] Experiential learning exposes the medical student and primary care physician to an array of disabilities and associated

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[169] Kerry Boyd, Erica Bridge, Meghan McConnell, Nick Kates, and Karl Stobbe, "A Curriculum of Caring for People With Developmental Disabilities in Medical Education," *Journal on Developmental Disabilities* Vol.24, No.2 Source: oadd.org/wp-content/uploads/2019/12/41028-JoDD-24-2-v11f-10-18-Boyd-et-al.pdf (accessed June 23, 2023)

health conditions. The primary care physician is challenged to provide treatment to the patient with intellectual and developmental disabilities in a way that addresses characteristics unique to the individual patient, presenting disability, and concomitant health conditions.

The presence of illness can modify the patient's usual presentation and way of communicating, sensory processing, and general behavior.[170] The patient's current experience of illness may change the way feelings are expressed, the personal story of health and wellness is told, and challenge the relationship with the primary care physician. As a result, an alteration in health status within the framework of intellectual and developmental disabilities creates a sense of ambiguity. The primary care physician must consider other approaches to thinking about the patient's current illness scenario when the illness challenges the patient's usual means of expression and communication.

The medical humanities provide ways to reconsider familiar ideas, situations, and relationships that have supported the existing plan of care for the patient with intellectual and developmental disabilities. Alternate ways of thinking about the patient's medical story and the factors that influence it allow the primary care physician "to pursue entirely new avenues of questioning and discovery"[171] in looking at the patient within the context of the present illness. The arts and humanities guide the physician toward other ways of interpreting the effect of the patient's clinical picture and personal narrative and allow the

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[170] Clarissa Kripke, "Adults with Developmental Disabilities: A Comprehensive Approach to Medical Care," *American Family Physician* 2018 May 15;97 (10): 649-656 Source: https://www.aafp.org/afp/2018/0515/p649.html (accessed August 8, 2021)

[171] Kumagai and Wear, 976.

opportunity to "reexamine relationships in health care as interactions between individuals - *qua human beings* - in all their individuality, fallibility, and strength."[172]

The humanities allow the health care professional to consider the inconsistencies in the patient's state of health and view of illness. "The role of science is to reduce the mysterious to the known."[173] The humanities promote critical thinking that looks beyond the clinical -scientific- presentation to seek meaning in the patient's telling of their story. Open mindedness and appreciation of the patient's message allow the primary care physician to look at the patient with intellectual and developmental disabilities in a way that respects the patient's current feelings, ideas, preferences, and concerns about the illness experience. The relationship between the patient and physician is strengthened by the physician's empathetic approach, the "effort to appreciate the patient's experience from his or her perspective."[174]

Empathy permits the primary care physician to build a personal relationship with the patient with intellectual and developmental disabilities that looks at the patient as a whole. The humanistic approach to care considers the patient with respect to interests, feelings, needs, expectations, and circumstances that affect the overall health care condition. The knowledge, attitudes, and experiences of the primary care physician are integrated into the way the physician thinks about the patient and the way they influence the physician's ability to become a partner in the patient's story.[175]

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[172] Ibid, 977.

[173] *Why Humanities in Medicine?* Source: https://med.uottawa.ca/faculty-medicine/department-innovation/medicine-humanities/why-humanities-medicine (accessed June 25, 2022)

[174] Grier, Abells, Casson, Gemmill, Ladouceur, Lepp, Niel, Sacks, and Sue, S21.

[175] Amanda Lee Roze des Ordons, Janet Margaret de Groot, Tom Rosenal, Nazia Viceer, and Lara Nixon, "How clinicians integrate humanism into their clinical workplace-

The primary care physician "can help patients with intellectual and developmental disabilities maximize their potential by presuming they have an ability to learn"[176] and communicating with them in a way that best meets their level of comprehension. Understanding the patient's health care narrative and cognitive ability guides effective communication. The physician should address the patient directly even in cases where the patient relies on a family member, caregiver, gestures, vocalizations, or device to facilitate communication. Patients may be able to absorb information that supports both their health and goals if the physician takes the time to explain and ensure the patient understands. The role of the primary care physician "is to help the patient and caregivers to clarify and discuss the patient's values in relation to possible medically appropriate interventions."[177] The patient should be encouraged to ask questions and contribute as much as possible in reaching a decision. A patient may require support to understand the nature of an intervention, share decision making with the provider, or assent to understanding to make an independent decision.

The adults with intellectual and developmental disabilities who participated in the interview process reported a positive relationship with the primary care physician when they were able to share personal information and advocate on their own behalf. Their subjective experiences about health and wellness included aspects of everyday life that,

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'Just trying to put myself in their human being shoes'," *Perspectives on Medical Education* October 8, 2018 7(5): 318-342 Source: ncbi.mln.nih.gove/pmc/articles/PMC6191400 (accessed June 16, 2023)

[176] Kripke.

[177] William F. Sullivan and John Heng, "Supporting adults with intellectual and developmental disabilities to participate in health care decision making," *Canadian Family Physician* 2018 April; 64(Suppl 2): S32-36 Source: https://ncbi.nlm.nih.gov/pmc/articles/PMC5906782/ (accessed May 4, 2023)

when shared with the primary care physician, helped to generate care to maintain well-being, address current health issues, or attend to new areas of concern. Self-advocacy helped to support them in developing their story, directing the physician to keep the focus of communication patient-centered, seeking care appropriate to disability-related limitations, requesting preventative care, and making informed and supported decisions. "Through self-advocacy, people with intellectual and developmental disabilities have more impact on their own situations and public policies that affect them."[178]

The way individuals with intellectual and developmental disabilities view themselves and perceive health and quality of life can be impacted by their awareness of media and the arts. The media may sway the thinking of individuals with intellectual and developmental disabilities as patients by the way they are depicted in society, social interactions, and medical scenarios. "Images and stories in the media can deeply influence public opinion and societal norms."[179] The depictions presented in the media may influence the patient's health care narrative in a way that casts doubt on the things that are individually important in developing a personal relationship with the primary care physician.

Individuals with intellectual and developmental disabilities may use the arts as a means of expressing their concerns, negative and positive feelings, and emotions. Film, graphic arts, and literature provide patients with various means to consider situations and

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[178] *Self-advocacy*: *Joint Position Statement of AAIDD and the Arc* Adopted February 12, 2020 Source: https:/www.aaidd.org/news-policy/policy/position-statements/self-advocay (accessed march 18, 2020)

[179] "Disability in the Media," *United Nations Department of Economic and Social Concerns, Convention on the Rights of People with Disabilities (CRPD)* Adopted 2016 Source: un.org/development/desa/disabilities/resources/disability-and-the-media.html (accessed May 26, 2023)

experiences in ways different from their personal perspective. Creative modalities allow the patient to develop active methods of viewing life experiences that impact health and wellness. The arts allow patients an opportunity to relate to their primary care physicians and the health care milieu in ways that expand the mutual frame of reference for wellness and healing. "But how can the arts be healing? To heal is to restore, and that activity is shared by the arts and every kind of health care. Indeed, there is a case for saying that health care is itself an art with a scientific basis."[180]

The personal perspective of adults with intellectual and developmental disabilities concerning their relationship with their primary care physician is influenced by a number of factors. The physician's attitude toward people with disabilities, experience with a patient population that embodies cognitive and physical challenges, and limited knowledge of disabilities has an impact on the way the patient views the physician and potential for positive interaction. The patient brings a history of illness experience that frames a unique health care narrative influenced by the quality of the physician's ability and willingness to engage in and understand the need for recognition as an individual aside from the presence of disability.

"The goal of health care for patients with developmental disabilities is to improve their well-being, function, and participation in family and the community"[181] and all aspects of the lived experience. Positive personal relationships between the patient with intellectual and developmental disabilities and the primary care physician bring respect

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[180] R.S. Downie, ed., *The Healing Arts: An Oxford Illustrated Anthology* (New York: Oxford University Press, 2000), preface.

[181] Kripke.

and understanding that supports the personhood of the patient and relevance and meaning to the role of the physician.

Chapter Five

The Personal Perspective: The Influence of Medical Humanities on the Primary Care Physician's Ability to Hear, Acknowledge, and Understand the Story of the Patient with Intellectual and Developmental Disabilities

The provision of primary care for individuals with intellectual and developmental disabilities is dependent on humanistic consideration of the person as patient. Attitudes and behaviors that show respect and interest for the patient's social situation and medical status provide an opportunity for the primary care physician to enter into a positive personal relationship with the patient. The social determinants of health help shape the patient's life experience and perception of health and well-being. The patient's experience and perception impact the personal narrative that provides a source of insight for the primary care physician in developing a relationship with the patient and creating an effective, person-centered plan of care.

The patient with intellectual and developmental disabilities brings a history of illness experience to the primary care setting that may be concomitant with the disabilities present or in addition to the preexisting condition. The patient's illness experience is influenced by barriers in the health care milieu, as evidenced in the literature reviewed, that may be physical in nature or associated with a lack of patient-specific health history, ineffective communication, and limited knowledge of intellectual and developmental disabilities on the part of health care providers.

The primary care physician may view the patient with intellectual and developmental disabilities as less able than patients who are members of what society considers the general population. A patient with a physical disability may be seen as having a cognitive limitation because the primary care physician views "disability as implying cognitive impairment."[182] The patient who appears to respond slowly when presented with information may need additional time to process what is heard, clarification of information in nonclinical language, or support from a caregiver who is familiar with the patient's way of understanding and expression. The patient's rate of response may be due to a feature of their disability that is physical in nature and not associated with intellectual disability.

The primary care physician may have an uncertain perception of intellectual and developmental disability due to limited knowledge of and exposure to the population in need of primary care. Training in medical school and schools of the health professions have historically provided limited training in disabilities, including intellectual and developmental disabilities. As a result, patients with disabilities "experience barriers to routine clinical and preventive services and public health and wellness initiatives."[183] Primary care physicians who are in a position to provide care to patients with intellectual and developmental disabilities may create a disparity in health services due to a limited understanding of the need for services that are generally considered routine as well as the necessity for coordinated specialty services associated with the patient's disability. Additional limitations to appropriate care may be related to limited accessibility in the health care environment, insufficient appointment time to allow the patient to

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[182] Elizabeth A. Morrison, Valerie George, and Laura Mosqueda, "Primary Care for Adults With Physical Disabilities: Perceptions From Consumer and Provider Focus Groups," *Family Medicine* Vol.40 (9) (2008) 649.

[183] *Core Competencies for* Health *Care Education*, 3.

communicate their concerns, and the physician's focus on the patient's disability rather than the presenting need.[184]

The patient with intellectual and developmental disabilities may express the need for health care in any number of ways, depending on the way they communicate. A patient may be able to state symptoms verbally, as part of a descriptive narrative. The patient may have difficulty answering questions about their condition if the presenting health issue is uncomfortable or causes generalized distress. "Problems that would normally present as a specific complaint or symptom might instead present as an undifferentiated change in behavior."[185] The patient may describe their need through vocalizations, gestures, or a state of agitation. The patient may rely on a caregiver who accompanies them to provide detail about the presenting concern. When the patient communicates in non-verbal ways or strays from the usual pattern of communication, the primary care physician must be able to look at the situation and hear the patient's story in alternate ways.

The medical humanities can help the primary care physician consider the patient's narrative from different standpoints. The arts, and especially literature, provide the physician with interpretive resources to reflect on the patient's story in ways that convey empathy for the patient's experience.[186] Listening to the patient's narrative while considering the clinical evidence can support the primary care physician in developing a plan of care that effectively addresses the patient's concern and sets the groundwork for a

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[184] Morrison, George, and Mosqueda, 648.
[185] Grier, Abells, Casson, Gemmill, Ladoucer, Lepp, Niel, Sacks, and Sue, S18.
[186] Charon, 1899.

relationship that is therapeutic from a clinical viewpoint and positive from the personal perspective.

The patient's story is a narrative of life experience, health, and illness. The presence of intellectual and developmental disability adds another dimension to the health care milieu that can inhibit the primary care physician in the approach to care. The physician must make "a determined effort to see the other person as a unique individual" and "envision that person's perspective"[187] in order to hear their story. The adults with intellectual and developmental disabilities who participated in the interview process noted the most positive relationships with their primary care physicians developed when the physician listened to what they had to say, communicated in a way that best met their needs, worked with them to review concerns, and explained the nature of care needed to address identified needs in a way that was clear and understandable.

The health care professionals interviewed acknowledged the presence of barriers that present the potential for limitations to the provision of comprehensive care for individuals with intellectual and developmental disabilities. The primary care physicians recognized that barriers, primarily those related to effective communication and awareness of intellectual and developmental disabilities, also had an impact on the quality of the personal relationship between the patient and primary care physician. The primary care physicians indicated the need to be open to the patient's questions and concerns and demonstrate a willingness to address them in a way the patient understands and within the context of the patient's story. In the community setting, patients with

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[187] Ofri, *What Patient's Say, What Doctors Hear*, 186.

disabilities, whether intellectual and developmental, congenital, or acquired, must receive care appropriate to their needs and with respect to their overall health and well-being.

The medical school faculty member identified the need for medical students to have exposure to patients, including those with intellectual and developmental disabilities, over the course of their education. The students' perceptions of patients with and without disabilities are shaped by exposure to the patient in the day to day context and the stresses that contribute to their general state of being. Ongoing contact with a patient allows a student to develop an appreciation of the effect social determinants of health have on the patient's story as it relates to their health and illness experience. The medical student and future physician benefits from consistent exposure to patients in conjunction with the clinical knowledge medical school offers. Student experience guides a model for care in future practice that incorporates the scientific with the personal patient narrative in striving to maintain patient health and address illness.

Review of the literature and information derived from interviews with individuals with intellectual and developmental disabilities and health care professionals demonstrated a consistency in recognizing the factors that have the potential to impact the quality and provision of primary care. The primary care physician's perception of individuals with intellectual and developmental disabilities may be affected by "societal attitudes toward people with disabilities and . . . shape values, language, personal attitudes, and how people with disabilities feel." [188]

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[188] Paula M. Minihan, Kenneth L. Robey, Linda M. Long-Bellil, Catherine L. Graham, Joan Earle Hahn, Laurie Woodward, and Gary E. Eddey, "Desired Educational Outcomes of Disability-Related Training for the Generalist Physician: Knowledge, Attitudes, and Skills," *Academic Medicine* Vol.86 No.9 (2011): 1173.

The literature cites the need for medical students to experience enhanced contact with individuals with intellectual and developmental disabilities and didactic training that incorporates content that recognizes "patients' disabilities are only one of many dimensions of their health."[189] Medical education that includes content in the area of disabilities can provide the primary care physician with the knowledge and skills to interact empathetically with the patient with intellectual and developmental disabilities, develop an effective relationship, and deliver quality care.

"Most students enter medical school with strong humanistic and empathetic tendencies."[190] During the course of their education, the students' focus may shift from a strong interest for human values, welfare, and dignity to a more scientific concentration. The need to retain and understand a large body of medical information and clinical data may mask the person-centered tendencies that motivated the students to study medicine. Medical school programs do not need to teach empathy but rather develop an educational program with a focus that extends beyond the scientific. Medical education that provides students "with humanities, long-term patient contact, and one-on-one mentoring can help minimize ethical erosion"[191] and shift the focus to the person who exists beyond the physical presence.

Medical schools have employed a variety of approaches to incorporate content about disabilities, including intellectual and developmental disabilities, into the curriculum. Lectures and seminars provide didactic content, providing knowledge about disabilities but lack the opportunity for interactive experiences between patients and

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[189] Ibid.

[190] Ofri, *What Doctors Feel,*52.

[191] Ibid, 52.

students. One-time experiences in community or clinical settings that engage medical students with individuals with intellectual and developmental disabilities provide exposure to the potential patient population. The experience may leave a lasting impression on the students but additional training is required to establish a degree of confidence in interacting effectively with people with disabilities of all types. Engaging with individuals with intellectual and developmental disabilities within the context of an ongoing clinical rotation affords medical students the opportunity to explore the patient's personal reaction to the illness experience, develop the most effective way of communicating, and expand an understanding of the things that are important to the patient's comfort and ease. Teaching and learning by individuals with disabilities and, in some cases their caregivers, offers students insight into living with a disability, the challenges that arise, and the things that give value to the life experience.[192]

Patients with intellectual and developmental disabilities acquire a perception of the quality of primary care associated with the barriers that affect access to care and the relationship that develops with the treating physician. The patient's personal relationship with the primary care physician is formed by positive patient-physician communication that includes focusing on the patient during verbal interactions, directing physician questions directly to the patient, taking the time to listen and explain clinical information in a way that is understandable, and avoid rushing through an appointment.[193]

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[192] Shakespeare and Kleine, 22.

[193] Morrison, George, and Mosqueda, 648.

The health care professionals emphasized the need to recognize and address barriers to the provision of comprehensive health care for patients with intellectual and developmental disabilities. In order to provide effective and appropriate care, the primary care physician must have knowledge of the patient's disabilities and associated health conditions, the impact social determinants of health have on the patient's perception of health, and the effect both life experience and the experience of illness have on the patient narrative. The story the patient with intellectual and developmental disabilities relates provides the primary care physician with information that identifies personal concerns, issues of interest, and circumstances that shape their personal perception of health and wellness. The physician must be open to different ways of hearing and interpreting the patient narrative. "What patients say and what doctors hear can be two very dissimilar things."[194] A primary care physician exposed to the arts and humanities can consider the patient's story in ways that expand the frame of reference to better understand the patient's meaning.

The way the patient with intellectual and developmental disabilities develops their narrative can also be influenced by the arts and the media. Patients are exposed to social depictions of disability in television, film, graphic arts, and the printed word. "On a social level, the question of disability has to do with how people with disability are seen and why."[195] Situations that incorporate images or descriptions of disability can affect the way the patient crafts their story. The patient may develop a narrative based on a

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[194] Ofri, *What Patients Say, What Doctors Hear, 108.*

[195] Lennard J. Davis, "Nude Venuses, Medusa's Body, and Phantom Limbs: Disability and Visuality," *The Body and Physical Difference: Discourses of Disability*, ed. David T. Mitchell and Sharon L. Snyder (Ann Arbor: University of Michigan Press, 2000) 52.

perception of social expectations rather than the way health is experienced in the presence of intellectual and developmental disabilities.

Research into the topic of the personal perception of primary care by adults with intellectual and developmental disabilities revealed commonalities in the way the adults as patients and health care professionals as providers perceive barriers to developing a positive personal patient-physician relationship. Communication between the patient and physician is affected by the way the patient relates their story and the way the physician hears and interprets what is said. The patient's narrative may be reflective of their experience and vision of health but the physician may instead look for clinical substance in the way it is told. "The clinical method is an interpretive act which draws on narrative skills to integrate overlapping stories told by patients, clinicians, and test results."[196] The communicative interactions between the patient and the primary care physician set the tone of the shared narrative that leads to a positive relationship and delivery of care. In the case of patients with intellectual and developmental disabilities, the things that are of personal significance to them add a dimension to their individual story, a narrative that allows the physician to develop a more individualized approach to care and relationship.

The patient with intellectual and developmental disability brings a range of feelings, experiences, and expectations to the health care encounter. The patient's story develops "with factors much more complex and multifaceted"[197] than the issues of health and wellness. The patient may be apprehensive over the current illness or simply the fact that a visit with the primary care physician is necessary. The patient with sensory issues

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[196] Trisha Greenhalgh, "Narrative based medicine in an evidence based world," *The BMJ* (January 1999): https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1114786/.

[197] Ofri, *What Patients Say, What Doctors Hear*, 58.

may be upset by the bright lights in the examination room, the touch of people and feel of medical equipment they are unaccustomed to, or the voices and sounds in the environment. The illness may add another layer of stress to preexisting life situations. As with all people, issues with family, friends, work, and finances may be of concern. The current health concern may limit the patient's participation in activities or personal interactions that would normally bring them a sense of comfort, satisfaction, or happiness.

The primary care physician can promote a positive experience with the patient with intellectual and developmental disabilities when the things that are important to the patient are taken into consideration. The physician can develop a personal narrative with the patient by exploring the things that create an aura of discomfort as well as the things that bring the patient a sense of ease and joy. The physician may accommodate the patient with auditory sensitivity by allowing the patient to wear headphones while waiting for the examination. Sensitivity to light can be acknowledged by dimming the lighting in the room during the visit. Tactile sensitivity may diminish if the physician explains the need for touch during each step of the examination.

The patient's story can also inform the physician of the things that bring the patient with intellectual and developmental disabilities a sense of ease and joy. The positive aspects of the patient's narrative may provide the primary care physician with the means to focus on interactions that bring personal meaning to the relationship with the patient. A patient's interest in graphic art, music, movies, or television may offer the physician a means to enter into a dialog that will ease the patient into the health care encounter. Discussion of family and friendship can offer the physician an opportunity to discover the positive aspects of the patient's personal relationships and the feelings of support and security that allow the patient to share their story and build a personal connection with the primary care physician. The primary care physician can help the patient discover a sense of well-being that is associated with the physician's understanding of what is important to the patient in their everyday life experience.

Effective patient-physician relationships and the quality of care that comes as a result of the relationship are affected by the knowledge, attitudes, and skills[198] of the primary care physician. When these attributes are incorporated into practice, the primary care physician can effectively listen to the narrative of the patient with intellectual and developmental disabilities, assess their needs and concerns, and develop a relationship that supports an empathetic and comprehensive plan of care.

The personal perspective of adults with intellectual and developmental with regard to primary care is influenced by factors that relate to respect of the individual. Participants in the interview process cited the need for the primary care physician and staff in the health care milieu to recognize their individual needs and abilities. Needs for physical supports and human assistance, adequate time to process information, and recognition of personal information in the medical record were viewed as components necessary to support a positive relationship. As patients, the interview participants valued primary care physicians who listened to the concerns and issues that affected everyday life and circumstances. Effective communication between the patient and physician resulted in care aimed to address disability-related needs, newly identified health care concerns, and preventive care. The adults with intellectual and developmental

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[198] Minihan, Robey, Long-Bellil, Graham, Hahn, Woodward, and Eddey, 1174.

disabilities felt validated when physicians considered patient reports of presenting conditions and issues of concern in prescribing care.

Interview participants also noted interactions with primary care physicians that limited their participation in the health care relationship. In several instances the primary care physician conducted the health care encounter without regard for patient needs associated with their disabilities. The patient with speech that was difficult to understand and the patients who needed more time to process information felt the physician did not take their individual attributes into account during the health care encounter. As a result, they did not have the opportunity to actively participate in the encounter and contribute to the plan of care. As a result, the patient-physician relationship was limited and did not contribute to a positive perspective of care on the part of the patient.

The information obtained through the literature review and interviews with health care professionals support the need for more comprehensive medical education in the area of disabilities in general and in intellectual and developmental disabilities in particular. Disabilities impact the quality of life and health care across the lifespan. Physician knowledge, skills, and attitudes toward patients with intellectual and developmental impact the quality and comprehensive nature of care provided to this patient population. An integrated curriculum in medical schools offers future physicians the opportunity to develop the body of knowledge and skills to address the health care needs of this population. At this time, medical schools are developing integrative curriculums that consider the needs of multiple populations in an effort to eliminate disparities and provide equitable care. The National Curriculum Initiative in

Developmental Medicine[199] is expanding programs into medical schools to promote knowledge and increase medical student awareness through personal contact with individuals with intellectual disabilities throughout the course of their education.

Patients with intellectual and developmental disabilities benefit from effective communication, collaboration with the primary care physician in developing the plan of care, and receiving coordinated services that address their health care needs in a comprehensive manner. Patient centered care involves health care providers who are aware of intellectual and developmental disabilities as well as the supports that are necessary to maintain the optimal state of health. Patients may be able to navigate the health care milieu independent of additional support or may require family or caregivers to assist in establishing a positive relationship with the primary care provider.[200]

The adults with intellectual and developmental disabilities who consented to participate in the interview process were a sample capable of providing clear input and giving consent to health care services. A significant part of the adult population with intellectual and developmental disabilities requires support in making decisions for health care and other services essential to quality of life. Data derived from interviews of that segment of the population and the people who support them for medical decisions would generate additional material and provide more insight into the way adults with intellectual and developmental disabilities perceive and receive primary care services.

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[199] *Medical Schools Adding Focus on Developmental Disabilities*, disabilityscoop.com/2018/03/12/medical-schools-focus-dd/24838.

[200] Karen McNeil, Meg Gemmill, Dara Abells, Samatha Sacks. Terry Broda, Catherine R, Morris, and Cynthia Foster-Gibson, "Circles of care for prople with intellectual and developmental disabilities," *Canadian Family Physician* April 2018, 64 (Supp 2) Source: https://www.cfp.ca/content/64/Suppl_2/S51.full (accessed May 3,2023)

Patients with intellectual and developmental disabilities who require support in health care decision making may not have the capacity to express their concerns, ask questions regarding care, or indicate preferences for care and treatment. Their ability to participate in the decision making process may be influenced by factors "beyond their intellectual and adaptive functioning -factors such as their previous experience with health care decisions, the degree and quality of interaction between health care professionals and the patient, and the method of communication used."[201] The patient must rely on the assistance of family, caregivers, or others whom they trust to help in processing information, understanding what is communicated, and encouraging the patient to contribute as much as possible to the decision making process. The patient's vulnerability in the health care setting may increase when the primary care physician is unaware of their personal values and preferences. The personal components of the patient's health care narrative are essential to the primary care physician in supporting the patient to the fullest extent in supporting a positive relationship and developing an approach to the provision of care.

There are many additional factors that have the potential to impact the way individuals with intellectual and developmental disabilities perceive primary care and receive appropriate services. Available health insurance coverage, financial resources, available supports from family, agencies, and community resources, groups that support self-advocacy, and organizations specific to certain disabilities offer additional potential means to navigate the health care system and secure services.

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[201] Sullivan and Heng.

The primary care physician, as the gatekeeper for health care services for individuals with intellectual and developmental disabilities, needs to consider the person seeking care as an individual, with needs that go beyond those associated with with their disabilities. The individual has a story to tell that provides a greater clinical picture than the presenting symptoms or complaint. In the case of patients with intellectual and developmental disabilities, the things that are of personal significance to them add a dimension to their particular story, an essential narrative that allows the primary care physician to develop a more individualized approach to care and wellness. The patient's story often directs the physician to look beyond what is evident and consider alternate ways to interact with the patient in order to gain a better understanding of what needs to addressed. The influence on personal attitudes and values derived from incorporation of medical humanities in medical education, as well as greater familiarity with people with intellectual and developmental disabilities, can provide a foundation to improve access to comprehensive care and support development of an effective personal patient-physician relationship.

"'Disability' is a word that often polarizes. It is a concept that assumes classification: once a person is disabled, he or she is conveniently tucked into that slot, as though disability were a single thing."[202] Adults with intellectual and developmental disabilities, as all people with disabilities, are unique in their abilities, perceptions, and relationships. The primary care physician, in cultivating a personal relationship with adults with intellectual and developmental disabilities, must approach the patient with

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[202] Danielle Ofri, "Abilities and Disabilities: The Range of Human Function," *Bellevue Literary Review* Issue 15 (June 29, 2020) Forward Source: https://blreview.org/table-of-contents/issue15 (accessed January 6, 2023)

respect as a person of worth first and provide care with “empathy and human connection, along with all the medical technologies and therapeutic modalities that a doctor can offer.”[203]

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[203] Ofri, *What Doctors Feel,* 212.

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Appendix A

Primary Care: The Personal Perspective of Adults with Intellectual/Developmental Disabilities

Interview Questions

1. When do you see your primary care physician (regular doctor, not a specialist)? Is it only when you are sick? Do you visit the doctor for regular check ups?
2. When you visit, does the doctor ask you what is wrong? Does he or she speak to you to find out how you are? Does he or she ask about other things that affect your well-being: work or activities, friends, things that interest you, or things that affect how you feel?
3. Do you feel comfortable speaking with the doctor? Do you feel he or she listens to what you have to say?
4. What is good about your visits to the doctor?
5. What would make your visits better?
6. What is most important to you during your visit?
7. Is there anything else you would like to say, discuss, or ask me?

Appendix B

DREW UNIVERSITY IRB SUBMISSION INSTRUCTIONS

All materials should be submitted electronically in a single file. All questions should be answered, and answers must appear on this form. Materials in an incorrect format (e.g., directing the committee to a different document, multiple documents) will be returned to the investigator without review. *Please do not submit as a Google Document*

Materials to be submitted:

- A completed copy of the Human Participants Research Review Form;
- A copy of your consent and debriefing forms;
- All surveys, interview protocols, instructions, stimuli, and tests.

If your research is being conducted at another institution (e.g., a school, a church, a medical facility), a letter of institutional approval should be submitted to the Drew IRB along with your other materials.

Only Drew faculty members may submit research for IRB review. If the principal investigator is a student, the faculty advisor should review and approve the student's work before submitting the research for IRB review.

Projects Originating In:	**Should Be Submitted To:**
College of Liberal Arts	Marc Boglioli, Associate Professor of Anthropology, mbogliol@drew.edu
Caspersen School of Graduate Study	TBD – Until a new member is assigned, G. Scott Morgan, Associate Professor of Psychology; smorgan@drew.edu
Doctor of Ministries Program or Theological School	Susan Kendall, Director of Doctoral Studies, skendall@drew.edu

HUMAN PARTICIPANTS RESEARCH REVIEW FORM[204]

1. Project Title:

Primary Care: The Personal Perspective of Adults with Intellectual/Developmental Disabilities

2. Principal Investigator(s):

Janet A. Gwiazda

If student research, name of faculty sponsor: Dr. Kate Ott

Name of anyone else involved in the study administration/data collection:

N/A

3. Email address of Principal Investigator(s):

jgwiazda@drew.edu

4. Duration of the Project (approximate starting date and completion date of data collection):

February 11-March 11, 2019

5. Describe how the requirement to obtain training in the responsible conduct of research involving human subjects was met:

Review of the Belmont Report and completion of Responsible Conduct of Research: Basic

RCR and Human Subjects

6. Electronic Signature(s):

Principal Investigator: Janet A. Gwiazda Date: ____________________

Faculty Supervisor: Dr. Kate Ott, PhD Date: ____________________

Revised June 2018

7. Provide a brief description of the purpose and goals of the proposed research, including in what form the research is potentially to be published (e.g. thesis, dissertation, article, book).

   The research is intended to ascertain what is of personal importance to the participant in developing an effective relationship with the primary care physician. Within the framework of medical humanities, the intended dissertation will look at the influence the humanities have on the lives of the participants in society and in seeking health care and the perspective of primary care physicians in addressing the needs of adults with intellectual/developmental disabilities.

8. Describe your participants. Indicate the total number of participants and whether any of the participants will be minors or will be from other protected populations (e.g., pregnant women, mentally disabled, etc.).
   Seven individuals with intellectual/developmental disabilities will be interviewed. Four individuals have physical disabilities only, two have intellectual disabilities, and one individual has both physical and intellectual disabilities. All potential participants are high school graduates; five have attended college, one of whom has a Masters degree. The potential participants, including those with intellectual disabilities, are high-functioning and retain all legal, medical, and decision-making rights, including the ability to give consent.

9. How will participants be recruited? Are there any specific selection criteria? Will participants be compensated in any way for their participation?

All participants will be identified by the investigator through past advocacy, community, or employment activities. Participants identified through past employment will be former coworkers, never involved in any care-related activities. Participants will be contacted individually and recruited based on their willingness to participate. All participants will be their own guardians and have the ability to state an understanding of the research as explained. Participants will not be compensated for participation.

10. How will you obtain consent from participants (and legal guardians, if minors are involved)?

Participants will be provided with a consent form, prepared according to the guidelines provided by Drew University. The investigator will read through the consent document with the participants on an individual basis, as needed. The purpose of the research will be explained to the participants who will then be asked to state their understanding or ask for clarification. A printed copy of questions to be asked will be available to the participants in advance, if requested.

11. Describe the study's procedures and all activities that participants will be asked to perform. Remember that copies of ALL materials should be submitted as part of this completed form.

Once participants have been recruited and the parameters of the interview established, the investigator will meet with them on an individual basis in the setting of choice. The interview will be conducted at a pace dictated by the response of the participant; the timeframe will be open. Participants will be informed that the investigator has no association with any primary care physicians; their responses to the interview questions will be held strictly confidential. Participants may, at any time, defer from responding to any question they feel uncomfortable with. When the interview has been completed the participant will be asked if there are any outstanding comments or concerns. Participants will be provided with the investigator's contact information in the event questions arise. The investigator will also ask the participants for permission to contact them if clarification is needed.

12. Where will this research be conducted?

The research will be conducted via telephone or in face-to-face meetings at the place of the participant's choice.

13. Are any aspects of your research kept secret from participants? If yes, indicate what will be hidden and why it is necessary to hide this information.

No aspects of the research will be kept secret from the participants. The topic of and rationale for the research will be fully explained to the individuals. The participants will be informed that all participants have a developmental disability that is physical and/or intellectual in nature. Any participant questions will be answered, including an explanation of medical humanities and how they can help bring perspective to the things that are important to the individual with an intellectual/developmental disability.

14. Describe any potential benefits of your research to participants and/or society.

The research may raise the awareness of participants to bring up things that are important to them in developing a rapport with the primary care physician. The information gained from the interviews will be summarized and used to suggest strategies to assist primary care physicians and other health care providers in caring for adults with intellectual/developmental disabilities.

15. Consider the risks that your study may pose to participants, including physical, psychological, social, economic, or other types of risks or harms. Explain these risks even if minimal or routine to daily life.

Risks to the participants will be minimal. Participants will be contacted and made aware of the intent of the research in order to seek agreement for participation and reduce any potential anxiety that may be related to the planned interview process. The time associated with the interviews will be flexible, scheduled in a way that has minimal impact on participants' routines. They will be able to ask questions for clarification and, if needed, choose to have a companion or caregiver present during the process.

16. If applicable, explain the procedures that you will use to minimize the risks to participants that you identified in your answer to question 15.

As stated in response to question 15, participants will be approached prior to the interview process to introduce the project, seek their willingness to participate, and inform them that consent will be required for participation. They will be encouraged to seek clarification related to the interview questions at any point during the interview process and have human support at their discretion.

17. Discuss the procedures you will utilize to protect the anonymity or confidentiality of your participants and your data.

Participant names will not be included in any documentation of the interviews. The investigator will take notes during the process and ask for permission to utilize a direct quote. The participants will be informed that their comments may be quoted in the research without mention of any identifying individual information. Data will be compiled and assessed to determine themes and concerns. All written materials generated during interaction with the participants will be input into a dedicated file on the investigator's password protected personal computer and the materials will then be destroyed. The data will ultimately be stored in the investigator's password protected personal computer.

18. For the majority of research projects, participants should be provided with a debriefing form that contains further information about the study and contact information for the principal investigator(s). Will you provide a debriefing form? If not, indicate why.

At the conclusion of the interview, all participants will be provided with the investigator's contact information as well as a brief statement of the intent of the research and the participants' role in the process. The document will include an acknowledgement of the participant's willingness to engage in the activity.

Appendix C

Interview Process

Explain project and ask if the explanation is understood.

- Dissertation: what it means

- Topic and research

    1. Define medical humanities: personal narrative, what is important to the participant for quality of life, influence of the arts in how people - including the participant- look at disabilities, thinking about what is right for the individual.

    2. Explain that the investigator is looking to identify what is important to the participant when seeing their primary care physician and receiving care to meet their personal needs.

    3. Ask the participant to review the above information and answer any questions the participant may have. If the process is understood, ask for agreement to participate.

- Interview questions

    As a participant, you may, at any time, decide not to answer any question you do not feel comfortable with.

    1. When do you see your primary care physician (regular doctor, not a specialist)? Is it only when you are sick? Do you visit the doctor for regular check ups?

    2. When you visit, does the doctor ask you what is wrong? Does he or she speak to you to find out how you are? Does he or she ask about other things that affect your well-being: work or activities, friends, things that affect how you feel?

    3. Do you feel comfortable speaking with the doctor? Do you feel he or she listens to what you have to say?

    4. What is good about your visits to the doctor?

    5. What would make your visits better?

    6. What is most important to you during your visit?

    7. Is there anything else you would like to say, discuss, or ask me?

Participants will be advised that hearing their personal stories will provide detailed information that will help in identifying what is important to them in communicating with their primary care physician to improve the quality of care for them as individuals. In addition, the information will assist in developing strategies to guide primary care physicians in how to listen and communicate more effectively with people with intellectual/developmental disabilities.

Appendix D

Consent Form

Primary Care: The Personal Perspective of Adults with Intellectual/Developmental Disabilities

Dear (Participant's Name):

You are invited to participate in a research study to determine how patients with intellectual/developmental disabilities can receive better care from their primary care physicians. You were selected as a possible participant because you have a developmental disability and have experience with your primary care physician. As part of this study, you will be asked to take part in an interview with this investigator. During the interview you will be asked questions about your visits with your primary care physician. The questions will try to find out what you feel is the most personal and important information the doctor needs to know about you to give you the best care. Your participation will give the investigator information that will help in developing ways to guide primary care physicians in how to listen and communicate with people with intellectual/developmental disabilities to provide the best individual, personal care possible.

Please read this document and ask any questions before you agree to be in the study.

Background: Studies have been done that ask primary care physicians and people with disabilities what is important to them during a visit. The studies show that getting an appointment with the doctor, the time the doctor spends with the person, and speaking with the doctor are important. This study is intended to determine what people with intellectual/developmental disabilities feel is most important to them in their lives that would help their primary care physician in providing them the best care to meet their needs.

Duration: You will be asked to participate in a one-time interview. The interview will last between 1-2 hours. You may take a break or stop at any time if needed.

Procedures: If you agree to be in this study, you will be asked to meet with the researcher at a time and place that is convenient for you. You may also choose to conduct the interview by phone. You will be able to review the questions to be asked before you agree to meet. You may stop your participation at any time without any problem or consequence.

Risks and Benefits: This study has the following risks:

- The interview time may interfere with your routine. You may choose the time and place for the interview.
- You may feel uncomfortable sharing your feelings about your visits with your primary care physician. You will be allowed to answer the questions in a way

that is most comfortable for you or you may not answer a question that makes you feel uncomfortable. You will not need to share the name of your doctor or any medical information.

- Your personal identity will not be shared. All information you provide will be kept only by the researcher.
- The information you provide will help in thinking about ways to make communication between people with intellectual/developmental disabilities and primary care physicians more personal.

Confidentiality: Your personal identity will not be shared. Written records of the information you provide during the interview will be kept only by the researcher in a secure file. No information that would make it possible to identify you will be used when the research is included in writing a dissertation.

Taking Part is Voluntary: Taking part in this study is completely voluntary, up to you. You may skip any questions that you do not want to answer. If you decide not to take part or skip questions, it will not affect your relationship with the researcher or Drew University. If you agree to take part, you may withdraw at any time.

Contacts and Questions: The researcher conducting this study is Janet Gwiazda. You may ask any questions you have right now. If you have questions later, you may contact the researcher at jgwiazda@drew.edu or (908) 642-0255. If you have questions or concerns about this study and would like to speak with someone other than the researcher, you may contact Dr. Scott Morgan, Chair of the Drew Institutional Review Board, at smorgan@drew.edu or (973) 408-3970.

Statement of Consent: The procedures of this study have been explained to me and my questions have been addressed. I understand that my participation is voluntary and I may withdraw at any time without a negative consequences or any problem. If I have any concerns about my experience with this study, I may contact the Chair of the Drew Institutional Review Board regarding my concerns.

Participant Signature: ________________________**Date**: __________________

Appendix E

Debriefing Form

Dear (Participant's Name);

The study in which you just participated was designed to determine what is important to the person with an intellectual/developmental disability that a primary care physician should be aware of to help in supporting a healthy, satisfying quality of life.

In this study you were asked to answer questions about the care you receive and what would make your experience with the primary care physician more effective for you.

For more information on the topic of research you may go to the website for the National Institutes of Health, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC.

If you are interested in learning more about the research being conducted, or the results of the research of which you were a part, please do not hesitate to contact Janet Gwiazda, principal investigator at jgwiazda@drew.edu or 908-642-0255. In addition, you may contact the faculty advisor, Dr. Kate Ott, at kott@drew.edu or 973-408-3298.

Thank you for your help and participation in this study.

Janet Gwiazda

VITA

Full name: Janet Ann Gwiazda

Place and date of birth: Perth Amboy, New Jersey; 08/28/1949

Parents Name: William and Anne Kazakewitz

Educational Institutions:

	School	Place	Degree	Date
Secondary:	Rahway High School	Rahway, NJ	High School	June, 1967
	St. Vincent's Hospital and Medical Center School of Nursing	New York, NY	Diploma	May 1970
Collegiate:	Rutgers, College of Nursing	Newark, NJ	Bachelor of Science	May, 1982
Graduate:	Bernard Baruch College and The Mount Sinai School of Medicine	New York, NY	Master of Business Administration in Health Care Administration	May, 1991
	Drew University, Caspersen School for Graduate Studies	Madison, NJ	Doctor of Medical Humanities	August, 2023