

“NO, I’M NOT TOO YOUNG TO BE DISABLED”: THE INTERSECTION OF
AGE AND INVISIBILITY IN THE DELEGITIMIZING EXPERIENCES
OF DISABLED YOUNG ADULTS

by

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DEDICATION

I would like to dedicate this work to my brother, Stephen. It seems like fate that it be published ten years after his passing. He is my northern star.

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ABSTRACT

Sixty-one million adults in the United States are living with a disability. Of those, 10% are conditions that are “invisible.” Invisible disability is not as easily seen as the outwardly expressed, highly visible disabilities that most people think of, and consequently may be overlooked in an able-bodied society. Young adulthood is commonly thought to be the healthiest time in a person’s life, as well as a developmental stage where independence, social relationships, and identity are expanded. Experiences of invisible disability during young adulthood contradict the social expectations and stereotypes about disability. My research steps into the various spheres of invisibly disabled young adults’ lives to understand how the intersection of age and visibility come together to produce experiences of delegitimization—the questioning, judging, and challenging of claims to disability by others—in the negotiations of identity and experiences in education, employment, and medical care. Through interviewing participants about their experiences with disability, and my own experiences as an invisibly disabled young adult, I have found that the interplay of age and visibility produce unique experiences of delegitimization in all aspects of life, increases the barriers for invisibly disabled young adults to achieve adulthood, and suspends invisibly disabled young adults into liminal spaces in multiple areas of their lives, from identity to independence.

I. INTRODUCTION

When I go to the doctor, they run their tests, their bloodwork, their x-rays and MRIs. Then they say there is nothing wrong with me. They say that what I'm feeling is only in my head, that I must be making it up or exaggerating, they say that I'm "too young." Then they send me home, but it is not in my head, I am not exaggerating. It is real. I had to do my own research and I had to find my own answers, but there is an explanation: I am disabled. Eventually I found a doctor that confirmed it with a specific diagnosis. Yet, everywhere I go, people still tell me that I am too young to be disabled, or that I don't look disabled. People on bus give me dirty looks for sitting in the disabled seats. Old people at the grocery store yell at me for using the mobility carts, or reprimand me when I park in handicap parking. Everyone thinks that being young automatically means being healthy, or that disability only looks like the little person in the wheelchair on the handicap sign. Why does no one see what I experience?¹

In the United States, the Center for Disease Control (C.D.C.) and the Americans with Disabilities Act (A.D.A.) define disability as a physical or mental condition that impedes on a person's ability to perform major life activities. Major life activities are the actions that people need to do every day, such as eating, sleeping, walking, standing, thinking, concentrating, reading, learning, communicating, seeing, and hearing. Disability is thus a broad category that can present in various ways. In many cases, disability may be obvious—it may be outwardly expressed through physical abnormalities, such as amputation, or the use of mobility aids, such as wheelchairs— but in other cases, disability has no outward display. These "invisible disabilities" are not easily seen or measured and consequently may be overlooked by able bodied society (Lipson 2004). While potentially unnoticeable through outside observation, invisible disabilities often include debilitating symptoms of pain, fatigue, cognitive dysfunctions, and irregularity of nonvoluntary bodily systems. Autoimmune disorders, neurological disorders, chronic fatigue and pain, and neurodevelopmental disorders such as autism are just a fraction of the diagnoses that fall into this category. While the CDC estimates that 26.7% of adults in the United States—61 million people—are living with a

¹ This is a composite quotation inspired by Coleman's life history composite, "The Life of a Free Software Hacker" (2013). While every story I collected was unique, there were consistent threads and expressions throughout. This quotation is a fictional composite of 23 interviews highlighting these consistencies amid their diverse experiences.

disability, 10% have “invisible” conditions (CDC 2019, Disabled World 2021). Disability is both a medical and a social category that describes a bodily condition as well as a social experience, particularly experiences with ableism—the discrimination against disabled people; the tendency to regard people with a disability as incomplete, diminished, or damaged, and to measure the quality of life with a disability against a nondisabled standard; the social prejudice against people with disabilities based on the belief that typical abilities are superior; and harmful stereotypes, misconceptions, and generalizations of people with disabilities— and barriers from a society that is not designed inclusively and equitably.

While both invisibly disabled and visibly disabled people can experience ableism in the form of discrimination and misconceptions, it is an increased burden for those living with less visible disabilities as their experiences are often delegitimized by individuals and social and institutional systems. This experience is exacerbated when their invisible disability intersects with their identity as a young adult, a stage of life that is commonly viewed as the healthiest in a person's life. With the stories shared from eighteen participants, this thesis explores how visibility and age intersect to shape the experiences that individuals have with disability in their identity, education, employment, and independence. Additionally, it explores how experiences of disability impact the young adult life stage, and the transition from childhood to adulthood.

This project is in part a self-reflection and autoethnographic. I began identifying as disabled around the age of 19, after several years of debilitating pain that interrupted my life. The stereotypes and misconceptions I had been taught about disability up to this point, prevented me from seeing it in myself for several years, but once I embraced that identity for myself, I started to see the world differently. Many misconceptions fell away and the everyday ableism in our society become more apparent. I started to be more accommodating of my limits and aware of ways the society I lived in

would not accommodate them. Thus, this project was shaped by the experiences that I had as a young, invisibly disabled person.

At 17 and recovering from my first knee surgery, I was denied the rental of a wheelchair while visiting a zoo because I did not have an adult present. That was one of the first experiences I had that showed me people did not accept me as disabled because of my age. A couple of years later, I was stopped by a university police officer on my campus and questioned for parking in handicap parking. He went as far as to accuse me of stealing the car that I was driving. That was my first taste of the ways that invisible disabilities are not accepted. Those experiences led me to question how those two elements—age and visibility—acted together to shape the way I, and others, embodied disability.

Living with similar symptoms, feelings, and limitations as many of the participants in this study, I was able to gain immediate rapport. While many of the participants are actively working within their own fields and daily lives to challenge the narratives surrounding disability, and specifically invisible disability, the academic setting that I am part of is not a place that offers equitable opportunities for all of the participants to be heard. This work serves as a conduit for young invisibly disabled individuals in particular, collecting and sharing their stories within a field that has real potential to bring the kinds of changes they hope to see in our society in the future.

The next chapter, Methods, will describe the project's design, detail some of the writing procedures, and introduce the participants. Chapter 3, Anthropological and Disability Literature and Theory, will discuss the literature and theory that have shaped my understanding and framing of this research. The following three chapters portray the life experiences of the eighteen participants. Chapter 4, Experiencing Disability in the Medical System, details the experiences of invisible disability in the U.S. medical system and the processes of obtaining diagnosis. Chapter 5, Negotiations of a Disability Identity, analyzes the challenges and influences acting on the formation

of disabled identities. Chapter 6, *Young Adulthood and the Inaccessibility of Life*, looks at the experiences of disability from a life stage lens, focusing on the experiences that influence young adults transitioning from childhood to adulthood. Lastly, Chapter 7, *Conclusion*, will overview how invisible disability and age shape the disability experience and identity for invisibly disabled young adults, and will conclude with the final take away participants wish readers to have. By the end of this thesis, I hope that all readers come away with an enriched understanding and appreciation of what it means to be invisibly disabled as a young adult.

II. METHODS

As mentioned in the introduction, this research was largely inspired by my personal experiences with invisible disability at a young age. My symptoms began at the age of 15, progressed slowly for a few years, then significantly worsened. The more limitations I began experiencing and the more doctors could offer me no explanation, the more I began to identify with disability. It was four years later that I finally adopted the identity of being disabled, though I was still undiagnosed. I was 19, in my first semester of college, and all the ways in which I was not like my peers became apparent to me. It was around that time that I finally started making accommodations for myself: I got a handicap placard, I got a wheelchair, I started setting harder boundaries with my friends and family, and most importantly I stopped fumbling over how to explain my limits. I am disabled, and that was explanation enough. Embracing disability was a major turning point in my life. In the last three years, especially thanks to this research project, I have become well-versed in disability culture, laws, rights, and unfortunately, ableism. Witnessing all the ways that disability, especially the disability I experienced, was misunderstood fueled me to understand why and to seek ways to change people's perceptions. But as I delved into the literature on disability across multiple disciplines, I was unsatisfied. I did not see experiences like mine represented. This research was designed to fill the gaps I identified: how visibility and young adulthood effected experiences of ableism and disability.

Population and Recruitment

As the focus of this study is on how participants are perceived by others during delegitimizing experiences, I chose to approach age as a social rather than biological category. The life stage of young adulthood is defined as a period of transition from childhood to adulthood. Colloquially, the milestones of adulthood may look like living independently, achieving higher education, settling down at a full-time job, getting married, or having kids. While the actual

characteristics of adulthood may vary from individual to individual based on the complex intersections of identity and upbringing, societally in the United States, there are three generally accepted criteria of adulthood: acceptance of self-responsibility, autonomously made decisions, and financial independence (Konstam 2015.) Disabled young adults may experience barriers that prevent these criteria from being accomplished at the ages abled bodied people do or they may not be viewed by others as having accomplished them because of disability. For today's young adults, this is further exacerbated by generational hardships, such as student loan burdens, growing wealth disparity, and changes in social welfare and financial security. For these reasons, participants were selected based on how they identify or feel they are identified by others. The ages of participants that identified themselves as young adults ranged from 20-33 years old.

It was important to me when designing this research that disability also be approached as a social rather than biological category. Conceptual models of disability, the authority of medical science, and the inaccessibility of health care will be further explored in this thesis to demonstrate the importance of approaching disability through less restrictive definitions. As such, this study was open to all young adults who identify as having an invisible disability, regardless of medical diagnosis.

The original intent was to recruit within my home state of Texas, so recruitment materials were first shared with three local disability organizations — the Easter Seals of Texas Austin, the Coalition of Texans with Disabilities, and DisAbilitySa — who distributed materials on my behalf in their communities via newsletters and social media. Flyers were made and posted at a handful of locations around San Marcos, Texas, including some physical therapy locations, local businesses providing medical equipment, and various locations on the Texas State University campus. However, due to low recruitment rates, I also provided recruitment material to two nationwide disability organizations — Patients Rising and the Invisible Disabilities Association — as well as

within multiple online support groups created for individuals with invisible disabilities that I was an active member of prior to research using my personal social media accounts. Within a day of the materials being posted on these platforms, I had overwhelming interest in the project that spanned 11 states, and even multiple countries. The goal was to recruit 20 individuals interested in participating in a single, one-hour long interview. As participants living outside the United States live under different social and legal circumstances that substantially impact their experiences, international participants were excluded from the study. Recruitment resulted in substantial interest, however, due to time constraints of the thesis project, only 23 participants were interviewed.

Interviews

I conducted one-hour interviews over the virtual meeting platform Zoom. Interviews were semi-structured, with topics broadly covering participants' experiences with disability in school, work, health care, and their feelings about disability identity, invisible disability terminology, and the public perceptions of invisible disability. Examples of questions asked include:

- “What kind of experiences have you had in the medical care system? How do you feel these experiences have impacted your pursuit for diagnoses and/or treatment?”
- “How do you think your disability has impacted your employment, if at all?”
- “Do you feel any less disabled because your disability is less visible? Why?”

The interviews flowed with ease due to my identity as an invisibly disabled young adult, which allowed me to quickly establish rapport. In past projects, I found it difficult to spontaneously generate follow-up questions, transition between questions seamlessly, and to find a natural progression of questions that fit individuals' stories and diverse experiences. However, due to the personal nature of this topic, I found that I was able to approach the interviews more conversationally and was better prepared to respond with follow-up questions. This allowed conversations to flow more naturally and led to participants and myself acting more comfortably.

This comfort combined with the semi-structured format allowed me to better adapt to the diversity of participants' experiences. While some had a lot to say about one topic, other participants found experiences in another area more important to them. This methodology allowed participants to focus the conversation around the topics that were most salient and important to them. My own experiences were advantageous in gaining rapport, and my familiarity with how vast conditions, symptoms, and experiences are prevented any of my personal experiences and opinions from shaping or coloring the interviews. While some experiences were shared or similar among participants, I approached each interview with the understanding that every single participant's condition and experiences are uniquely embodied.

Virtual participation in interviews increased the accessibility for many of those that participated due to physical limitations that would make in-person interviews more difficult, and the Zoom platform allowed for accommodations to be made in the form of closed captioning and text format rather than strictly verbal interactions.

Journaling Exercise

At the end of the interview, each respondent was invited to continue their participation with a six-week journaling activity. Journaling participants were provided with a set of prompts in which they were asked to observe different feelings and/or interactions during the course of the week, and then spend five to ten minutes responding to the week's prompt. Examples of prompts include:

- Observe your interactions with others this week. Did your interactions feel more validating or invalidating? Describe the interactions that stand out most to you and how they shaped the way you felt about and performed your identity as disabled young adult this week.
- Observe how you feel and behave outside of your home—that is, at school, at work, or at places of entertainment this week. How do different environments shape the way you feel about and perform your identity as disabled young adult?

- Observe yourself this week and reflect on your experiences participating in this study. What do you think are the most important observations you've made about yourself and how you navigate social life and your identity as a young disabled adult? Why?

Responses were welcomed to be handwritten, typed, or recorded and sent back to me using secure methods at the end of the six-week exercise. This was a new methodology for me, so I took a very hands-off approach out of concern that too much pressure would discourage participation. At the end of the six-week period, I had not received any journals. I waited a week or so before reaching out to gently remind respondents to send them in if they had completed any of the prompts, to which I then received two journals. Due to low response rate, the data from this method was not utilized in analysis, but trying this method was a valuable learning experience for me. If I utilize this method again in the future, I will try a slightly more hands-on approach, perhaps sending out the prompt weekly rather than providing respondents with all the prompts at once. I still believe low-pressure is most encouraging for participation, but I think now that slightly more guidance is best for keeping participants engaged.

Demographics and Representation in the Study

Rather than having a set questionnaire for demographic questions, I took an inductive approach that allowed participants to self-identify and determine the salience of their demographic information. As demographic questions are frequently used to delegitimize the experiences of and to discriminate against young adults with invisible disabilities, I choose not to directly ask for this information in order to create a comfortable and safe setting for the interview. Demographics that emerged naturally during the interview were recorded. While this method does not result in consistent demographics collected from each participant and cannot be generalized to represent certain populations, it allowed participants to independently identify the pieces of information they felt were important about themselves and relevant to their stories. Age was shared by 16

participants, with participants' ages ranging from 20 to 33. Gender identities were mentioned by 15 participants, either as an influence in their experience or as important to their identity: 10 participants identified as women, two identified with flexible gender identities, one as a man, one as nonbinary, and one specifically identified as Two-Spirit. Including the diversity in gender identities, a total of six participants identified as members of the LGBTQ+ community in regard to their sexuality, gender, or both: two participants identify as transgender; two identified with flexible gender identities; one as nonbinary; one participant identified as lesbian; one participant identified themselves as queer; and one participant identified as aro-ace (aromantic and asexual.) Only two participants specifically mentioned their ethnicity impacting their experiences: one Indigenous individual and one Mexican American individual. Relationship status was mentioned by 15 participants when discussing how relationships impact their experience with disability and vice versa: 7 noted being single, 5 described living with domestic partners, 2 are currently engaged, and 1 commented on being married. Level of education and employment came up naturally as a result of the focus on experiences in school and work, but socioeconomic status arose as an important aspect of lower-income participants' experiences.

Privacy and Anonymity of Participants

For privacy reasons, participants were informed before the interview, as well as at the start of the interview, that I would never ask for specifics about their diagnosis or condition, but they were welcome to share details at their comfort level. Diagnoses that were volunteered are mentioned only if I deemed that sharing is not a risk to the participant's anonymity, and only when relevant to understanding the particular story. A total of 25 different conditions were voluntarily mentioned by the participants in this study, myself included. A glossary of conditions, their commonly used abbreviations, and brief descriptions is provided in the appendix.

Participants' names have been anonymized with the use of pseudonyms. To reflect their identities as closely as possible, pseudonyms were chosen from a list of popular names from roughly the same year the participants were born using the same first letter of either the participant's first or last name. For example, a popular name from my birth year, 2000, with the same first letter as my name, B, would be Brianna. I did my best to choose pseudonyms that were reflective of any ethnic or gender identities. For example, gender fluid or nonbinary participants were given gender neutral pseudonyms or pseudonyms that were close to the feel of their chosen names. Participants in this study are always referred to by their preferred pronouns if they were specified. For participants with fluid pronoun preference, such as she/they, 'they' is invariably used for consistency.

Language choice is widely debated when writing on the topic of disability. There are various terminologies, such as special needs, differently abled, handicapable, disAbled, etc. While some individuals might prefer terminologies or language such as these to describe themselves, this paper will use the widely supported preference to avoid euphemisms and use the term disabled (Andrews and Forber-Pratt 2022, Carter-Long #SayTheWord, King 2016.) This terminology is most widely accepted as it is felt that other terminologies imply that disability is a 'dirty word,' or that it is something negative. Preference towards identity-first language, such as 'a disabled person,' or person-first language, such as 'a person with a disability,' is less conclusive. Person-first language arose from the "People First" movement in the U.S. during the 1970s which aimed to correct the dehumanizing and medicalized language, but identity-first language is growing in popularity in tandem with the growing popularity of the social model— a conceptual model to understand disability— with the goal of framing disability not as a characteristic, but as a form of diversity that people can take pride in (Andrews and Dunn 2015, Andrews and Forber-Pratt 2022, Best et. al. 2022.) As preference for one or the other is highly individualized based on factors of disability acquisition, identity development, diagnosis, and treatment in society, both person-first and identity-

first are used throughout this thesis. Though, not equally. This thesis will lean towards a preference for identity-first language, as that was the preference observed among most participants, as well as the observed preference in the disability communities I am part of.

Meet the Participants

Ashley is 33 years old and living in Indiana with her significant other. She was diagnosed with postural orthostatic tachycardia syndrome (P.O.T.S.), a blood circulation disorder, in 2018. Her favorite things to do are garden, hike, and Pilates, even though heat and physical exertion are known to exacerbate the symptoms of her condition. Ashley's education background is in anthropology (same as me!) and she currently works full-time with a non-profit research organization.

Ava, pronouns she/they/he, is a 21-year-old from the Midwest. She has been officially diagnosed with P.T.S.D. for two years now, though they have been experiencing the condition since their early teens. Ava identifies as a disabled, queer, Mexican American who makes a mean cup of coffee, aka they work full-time as a barista.

Cameron is 21 years old and has lived in many places. She used to live just down the road from me here in Texas, but she's currently living in Montana, and she has plans to move to Washington next year. She's a current student and plans to attend university to study plant-based medicine with her girlfriend. She was diagnosed with celiac disease as a young child but has recently been diagnosed with Chron's disease as well. Last month, she hosted a birthday party for her cat (who definitely wasn't trying to eat Cameron's laptop during the interview).

Devyn is a 24-year-old woman from Texas. Her journey with disability began in middle school, and over the last 11 years, she has been diagnosed with chronic fatigue syndrome and Ehlers-Danlos syndrome. She recently underwent an intense operation with the hope of improving her symptoms and is doing really well. Devyn has a passion for women's soccer and enjoys writing and directing campaigns of Dungeon's and Dragons and home movies made with her cousins.

Victor is a 20-year-old man from Minnesota. He identifies as an “AutiHDER,” a fun colloquial term for someone that is A.D.H.D. and Autistic and is currently seeking diagnosis for his physical pain symptoms as well.

Flor, pronouns she/they, identifies as Two Spirit—a distinct gender and social role in Indigenous communities. Important to Flor’s identity is her Native American and Norse heritage, which she believes places reverence and respect on the idea of a wounded healer. Flor is 25 years old and has been medically diagnosed with arthritis in the spine and self-diagnosed with autism and dissociative identity disorder (D.I.D.) Flor likes to read and collects Tamagotchis.

Gwen is a 22-year-old college student from Ohio. She’s in the senior year of her psychology degree and plans to continue with a graduate program in California. Gwen first got sick with Lyme disease when she was 16, with chronic symptoms persisting since then. Her experiences have made her passionate about advocacy. She leads support groups for people with chronic Lyme disease, has done multiple interviews with congressional committees about disability and prescription costs, and is currently writing a book.

Heather is 26 years old and works as a professional speech language pathologist, though she will be a student again soon. In the fall, Heather is returning to university to earn her PhD. She started seeking diagnosis for fibromyalgia when she was 12, but wasn’t medically diagnosed until six years later. Her hobbies are of the creative and crafty variety; she enjoys cross-stitch and sewing, as well as reading and writing.

Lacie is a 30-year-old jack of all trades. She weightlifts, cooks, bakes, and is an avid skier on the water and in the snow. Though she’s mostly skiing on snow now that she lives in Massachusetts. On top of being a current student in nursing school, she is also working with COVID-19 testing and vaccinations and as a nursing assistant in a transplant unit. To top it off, at the time of the interview,

she was two months away from being married. In 2012, Lacie was diagnosed with Ehlers-Danlos Syndrome, then undiagnosed, and re-diagnosed after five years.

Maggie is 21 years old and a full-time teacher's assistant at a school for autistic students. She's currently taking time off from school because of COVID-19 but is planning to finish her degree and get her bachelor's in special education. She has been diagnosed with Hashimoto's disease since she was a teenager and is currently seeking a diagnosis for some kind of joint disorder. She enjoys writing, playing games, attending church events, going to rock concerts, and visiting Universal Studios, where her boyfriend works.

Morgan is 24, married, and living in Ohio. She was diagnosed at 17 years old with Chiari malformation, a deformity in the skull that forces the brain into the spinal canal. She enjoys playing video games, especially on her Nintendo Switch, doing puzzles, and reading.

Rachel is 24, and lives in Virginia with her two cats, Deville and Binks. Rachel has no diagnosis; her main symptoms arose after complications from a surgery that she describes as having nearly killed her. In addition, she is also hard of hearing. She paints, reads, writes, and carries a sparkly, rhinestoned cane.

Rane, pronouns they/them, is 29 years old and lives in Maine. They studied social work and psychology in college and worked for several years as a social worker in residential programs and case management. Rane got their first diagnosis for mental health when they were 20, but they are still trying to obtain a medical diagnosis for their physical disability symptoms. For fun, Rane plays video games and writes poetry about their experiences with disability, queerness, and transgender identity.

Raven is 30 and lives in Minnesota with her fiancé. She was diagnosed with cyclical vomiting syndrome when she was 19, and experiences some related comorbidities of anxiety, depression, and hypermobility. Raven has two cats, a chameleon, and a snake. She loves Halloween, collects dead

things, and holds a grudge for all the organs that have been removed in her pursuit of treatment.

Oh, and her favorite sushi is an eel and avocado roll. Yes, all of this came up naturally during our interview.

Ryan, pronouns he/they, is a 29-year-old from Colorado. His experiences within the health care system for mental health inspired him to major in counseling psychology, earn his master's degree, and become a therapist. Ryan has been diagnosed with autism, dissociative identity disorder, and fibromyalgia. He lives with his husband, and their two dogs, Echo and Storm. Echo was originally trained to be a service dog for Ryan, but then was diagnosed with an invisible disability of their own. Echo has epilepsy.

Shelby is 22 years old and studying communications at a university in Pennsylvania. She has a passion for music, both singing and listening. Taylor Swift and Lindsay Sterling are two of her favorite artists. She reads a lot, mostly fantasy and fiction, including more fanfiction than she "wants to admit." Her symptoms first caught the attention of her parents at the age of 8 or 9, but it took nine years to finally get a diagnosis.

Stella is a 30-year-old woman from Indiana. She self-identifies with chronic fatigue, anxiety and O.C.D., and a learning disability. In 2015, Stella was also diagnosed with a rare autoimmune disorder called Addison's disease. Despite fatigue being her main symptom, Stella is passionate about her work as an early educator. She currently teaches toddlers aged 12 months to two years old. Her dog, Dusty, is her "baby," and her favorite thing to do is hunt for good shopping deals.

Wendy has been diagnosed with A.D.H.D., irritable bowel syndrome, polycystic ovary syndrome, and experiences symptoms of chronic pain. She has chosen to take a break from school due to the risk COVID-19 poses to her and her family, but plans to return in the future to finish her psychology degree. In the meantime, she works as a veterinarian assistant and enjoys crafty hobbies like crocheting.

Then, of course, there is me. My name is Britney, I'm 22 years old and I live in Texas. I lived with unexplainable and debilitating pain in my knee since I was 15, and after nearly seven years, I was finally diagnosed with Ehlers-Danlos syndrome. I was also diagnosed with A.D.H.D. in my second year of college. My favorite things are coffee, books, and cats. I live with my significant other of almost seven years and our kitty, Sophie-Mai. This project has been my baby for the last two years, and I'm very excited to share it with all of you.

III. ANTHROPOLOGICAL AND DISABILITY LITERATURE AND THEORY

Epistemics, Legitimation, and Expertise

Knowledge and facts are intertwined in systems of power, and those who hold the power in society, control the knowledge that shapes how the world is understood and experienced (Dumit 2006). In disability literature, Dumit (2006) argues that the dominant powers controlling knowledge in the field of medicine are, “insurance companies, industry, and the state” (pg. 587). Patients presenting illnesses that insurance companies have not legitimated with a billing code are denied diagnosis or treatment, as well as medical recognition of the illness, and the funding granted for research has extensive influence over the production of knowledge by controlling which questions get asked in the first place.

Liotard (1985) posits that before knowledge becomes widely available as a way to negotiate understanding, it must first go through a process of legitimation—an authority declaring something as rule. Lack of legitimacy that comes from a medical diagnosis can be grounds for refusal of access to the rights and protections under the Americans with Disabilities Act (A.D.A.), access to financial assistance, and recognition or embodiment of a role in society that has different expectations than able-bodied citizens. Dumit (2006) argues that insurance companies and the United States government may purposefully restrict the kinds of disability experiences that are legitimated in order to systematically deny coverage and welfare.

Authorities who dominate knowledge and fact are motivated to control knowledge legitimation in ways that maintain the status quo from which they benefit, according to Foucault’s theories on biopolitics (2008). Biopolitics are the practices of control and transformations of human life by political and social authorities. Medical experts—such as doctors, nurses, professors of medicine, and other medical professionals—are given disproportionate power as experts of disability

due to their training and affiliation with powerful institutions that benefit from the medicalization of disability.

Medicalization refers to the process of expanding the social control or jurisdiction of the medical domain by defining human or social problems using medical terms and frameworks to shape understanding of the problem, and using medical intervention to correct, treat, or cure it (Conrad 1992). The medicalization of disability has professionalized and gatekept expertise on disability so that the expertise of specific professionals is seen as more valid and authoritative than the expertise of people who are themselves disabled.

But Lyotard (1985) also argues that two kinds of knowledge that exist, compete, and conflict with each other: scientific and narrative. Disability scholarship and the anthropology of expertise reason that expertise is more than professionalization and institutional legitimacy (Boyer 2008, Ginsburg and Rapp 2020, Kasnitz 2020). Boyer (2008) challenges us to engage expertise more broadly as a non-professional, human category that is achieved through the processes of life. Living with disability produces a particular knowledge that disabled people, “develop and enact about unorthodox configurations of agency, cultural norms, and relationships between selves, bodies, and the designed world,” which Cassandra Hartblay defines as disability expertise (2020, pg. 1). Hartblay compares this type of expertise to “situated knowledge” a phrase used by feminist science and technology studies’ author Donna Harraway. Harraway (1988) adds to the argument that objective knowledge is unattainable because the production of knowledge is a reflection of the knower’s personal perspective, their history, their interactions, their senses. Disabled people have a perspective of the world that is different than abled people. The way we experience the world, understand it, and adapt to it generates expertise that challenges the medicalization of disability by contextualizing it within the needs, desires, values, and experiences of those who are most affected.

Despite the expertise that disabled people acquire through negotiating their existence in a world designed for the able-bodied, their knowledge is devalued by the medicalization of disability. The slogan, “Nothing About Us Without Us,” was popularized within disability activism by activist and author James Charlton to represent the empowering sentiments of no longer tolerating the so-called experts—doctors, social workers, even parents—to dictate disability without the input of disabled people (2000).

Conceptual Models of Disability

What is recognized as fact changes and develops over time alongside changes in society, because knowledge and society are shaped by one another. The knowledge that receives legitimation may influence society, but society also shapes what questions are asked, how answers are understood, how knowledge is situated in culture, the way accepted knowledge affects experiences, and how that knowledge is reproduced and taught in society. Emily Martin’s work (1991, 2001) explores how cultural gender stereotypes present themselves in biological descriptions of human anatomy and reproduction in the medical field, demonstrating how what is considered fact is shaped by its positioning in society. Knowledge surrounding disability has long been dominated by biomedical professionals and the narrative, or experiential, expertise of disabled people disregarded. Changes in the way disability has been understood have occurred over time. This section will explain a few of the prominent conceptual models that have been used to make sense of disability.

The long-dominating medical model of disability has shaped the cultural understanding of disability as a biomedical category. Disabilities are viewed strictly as biological abnormalities or flaws that are visible medically and require medical treatment to be cured and eradicated (Kumar 2016, Mehrotra 2012). In the 1950s, Talcott Parsons, an American sociologist, published his theory that society is structured, and its function is shaped by the roles that individuals adopt to support it (Parsons 1951). Parsons’ “sick role” outlined the role of the disabled in the structure of society: the

ill were absolved from social expectations while seeking medical treatment, but only until they could recover and become productive members of society again. The medical model of disability and Parsons' sick role individualizes and medicalizes the perceived deficits of disability (Cheshire et. al. 2021). Society is then structured based on the idea that being able bodied is the natural standard that everything be designed around, and disability is the unnatural anomaly. If a person in a wheelchair could not climb a set of stairs, the medical model would seek to solve the problem of the individual rather than the stairs, creating ambiguity in the model for those whose conditions are not terminal but not curable. Where do they fit into society?

In the late 1960s in the United States, it became apparent to disabled communities that their experiences were oftentimes not a direct result of their physical symptoms or impairments, but rather from the way they were treated or excluded because of their disability. Mike Oliver pioneered a new model, the social model, that perceived disability not as a biological failure that limits individuals, but as a socially produced phenomenon resulting from a societal failure to remove barriers that limit individuals with biological differences (1996). Through this lens, disability is not understood as just a biomedical description or category, but as an experience. Challenging the individualization the medical model perpetuates, the social model treats disability as an experience that comes from lack of society-scaled adaptations and accommodations for people with disabilities both socially and structurally to make full participation accessible (Kumar 2016, Shuttleworth and Kasnitz 2004).

Critics of the social model argue that it underestimates the magnitude in which biological impairments impact experiences of disability. Critical disability theory incorporates the body and physical impairment into the discourse while also considering the ways in which institutions, cities, and societies systematically and socially disable people (Ginsburg and Rapp 2020). In other words, critical disability theory is where aspects of the medical model and social model meet. In many ways,

a society can impose limitations where limits need not exist, but it is undeniable that some experiences and some limits are simply unavoidable truths of the condition that is impacting the body or mind. Critical disability theory's important implication is the need for a conceptual model of being disabled that encourages inclusive society and accepts the existence of biological difference without devaluation.

In addition to conceptual models that seek to answer what disables people, biology or society, there are also models that describe how disability is coped with, both by the individual and by society. Hays (2010) argues that cultural expectations of productivity inform judgements of value in society, which in turn influence strategies of coping with disability and agency. He identifies two models, the John Wayne Model and the Suffering Response. Hay describes the John Wayne Model as, "a purposeful indexing of the image of disease as something to be wrestled into submission" (p. 260). Individuals that assert their social value by continuing to meet societal expectations of productivity, not allowing disability to impede them, are recognized and applauded for these efforts. The Suffering Response then is descriptive of those unable to overcome disability to continue meeting societal expectations of productivity. He argues that these expectations of productivity are a structure of power that values those who can meet them and devalues those who cannot. Like critical disability theory, Hay also comments on the lack of cultural models for "living sick," (2010, p. 270), in other words, a model of value, productivity, and agency that is not rooted in able-bodied standards.

Visibility, Stigma and Performance Theory, and Delegitimization

In the United States, Hay's "social expectations of productivity" are fashioned by neoliberalism, an economic ideology of market-based productivism. Productivism, as described by Mladenov (2017), is an ethos that imbues work with moral meaning, rendering those unable to work as culturally devalued. Culturally devalued individuals who cannot meet expectations fall into Hay's

Suffering Response, while those who can meet these expectations despite disability are recognized and applauded. However, Hay's notes that this recognition is not equal among all disabled people. Hay introduces the important concept of visibility. Those adhering to the John Wayne model are only recognized and applauded for their efforts if their disability is visible to others. Those with invisible disabilities, who are still "overcoming" their disabilities to meet expectations, are not recognized for being disabled or applauded for their efforts, they are viewed as "normal." Hay (2010) places both of these words in quotation marks throughout the work because they are words that were frequently used by their participants, but the position of the argument is to disagree that disability is something to be overcome or that disability is not normal. Those with visible disabilities are devalued as not useful members of society and pitied, but those with invisible disabilities are devalued as being lazy and do not receive pity (Hay 2010).

Invisibility in disability literature can refer to the social erasure, or lack of recognition, some citizens experience in society or to the inability of others to see symptoms of a disability. Both can be explored with Erving Goffman's theories on stigma and performance. In his book "Stigma: Notes on the Management of Spoiled Identity" (1963), Goffman describes how society classifies people into categories of natural and unnatural, so that assumptions about the social identity of a person can be made based on stereotypes created by this classification. Stigma comes from the possession of an attribute that has been deemed different than the stereotype of natural in society and is therefore considered undesirable. In disability literature, these theories on stigma are used to explain invisibility in the sense of social erasure. Disability is deemed unnatural and stigmatized because able-bodied attributes are considered the stereotype of natural. Hay (2010) uses this theory to argue a further type of stigma within disability, between those whose symptoms are visible to others and those whose symptoms are not, based on stereotypes of what disability looks like.

Stereotypes of natural and unnatural in society come to define, “what a given type of individual should be,” (Goffman 1963, p. 3). Stereotypes of what disability looks like or what it means to be disabled exclude individuals whose disability are not visible from being recognized as disabled, as seen in Hay’s models (2010). Assumptions about a person’s social identity are made through first impression, leading Goffman to argue that all social interactions are performance (1959). Depending on the social situation, people perform in a way that is expected so that they might be accepted, so that they match the preconceived set of attributes that are deemed normal and desirable. This performance reinforces the identity of the performer, but it also acts as a means of assessment for others in society.

As a stigma, disability is viewed in society as an abnormality and is expected to leave a physical trace that marks the disabled as different. When disability does not leave this physical mark, it is not performed in a way that matches what others in the society envision disability to be. The result of those with invisible disabilities not performing the way that is expected for socially accepted perceptions of disability is what Hay (2010) calls “delegitimization.” He defines delegitimization as, “local social interactions in which others judge the validity of experience, often basing those judgments on assumptions about real disease as something physically apparent or visible” (Hays 2010, p. 260).

Anthropology of Disability / Disability Anthropology

Anthropological research on the topic of disability represents a smaller portion of the literature on disadvantaged communities – such as race, gender, sexuality, and indigeneity – despite disability affecting a similar proportion of human experience. Additionally, disabled researchers are underrepresented in anthropology and experience discrimination. There is an expectation that disabled individuals who enter the field of anthropology, for example, will research on disability. The questionable ethicality of disability being studied by able-bodied researchers also discourages

disability research be conducted by able bodied researchers (Nilika 2012). These expectations create methodological issues and gaps in research, enforcing the notion of an abled/disabled binary and perpetuating exclusionary categories. When disability is researched, it typically falls into one of three categories (Kasnitz and Shuttleworth 2001): a focus on a specific impairment (Bagatell 2010, Lipson 2004), a cross-cultural analysis (Holleman 2019, Zoanni 2019), or a self-reflection by a disabled anthropologist (Griffiths 2020, Kasnitz 2020). Exclusionary categories and overly narrow scopes limit the full reach of anthropology in the study of disability.

Anthropology's theoretical history has accounted for gaps in the populations and themes studied in disability research. Laura Nader's "Up the Anthropologist: Perspectives Gained from Studying UP" (1969) and Michael-Rolph Trouillot's "Anthropology and the Savage Slot" (2003) are influential critiques of colonial trajectories in anthropology that focused on the other, populations and cultures that were unlike themselves—considered to be less developed, less educated, or less evolved. The critiques by Nader and Trouillot shifted anthropology's gaze upwards to the systems of power that are responsible for social injustices. However, alongside critiques of systems of power, particularly neoliberalism and colonialism, "savage" subjects became suffering ones (Ortner 2016; Robbins 2013).

Prior to the Independent Living Movement, the movement for equal rights for disabled people in the 1970s, ableism in disability research was rampant as disabled people were often slotted into this suffering slot by non-disabled researchers and activists. Common themes of disability research included remediation, disadvantage, deficiency, defect, and separation from the public. The following titles exemplify the ableism that persisted in this literature over time: "When Should the School Refer the Mental Defective to the Specialized Agency or Institution?" (Engel 1940), "The Cultural Dilemma and Spiritual Crisis of the Family with a Handicapped Child" (Zuk 1962), "Learning Disability or Error of Growth?" (Ames and Gillespie 1973), "On Disabling the Normal:

‘The Implications of Physical Disability for Other People’ (Hilbourne 1973). Since the social model became more widely embraced and began changing the perception of disability, research has begun to improve by humanizing and giving agency to disabled individuals that research under the medical model did not. There are, of course, gaps in this research still.

A weakness of studies on disability is over-specificity in some respects, such as research limited to specific conditions, and under-specificity in others, such as research disregarding the impact of life stage on disability experiences. The gap in life stage-specific disability research is significant. Disability research is most commonly split into childhood disability versus adult disability, disregarding that adulthood is often divided into four stages: Early Adulthood, Early Middle Age, Late Middle Age, and Late Adulthood (Medley 1980). Studies of disability experiences in adults typically encompass an overly wide range of ages, or no range at all that lumps together all disabled people over the age of 18, instead of focusing attention on the experiences that take place in different life stages. For example, the experiences of chronic fatigue would be completely different for a single 23-year-old who is enrolled in university and working part-time than those of a married 66-year-old who is retired. Life stages are social categories that are defined by the social experiences that are generally unique to that stage. Research that utilizes too large of age-ranges is unable to consider the differences in these experiences.

Disability research has gaps medically and socially. One social aspect of disability that sees little focus as a study is social disablement, the experiences of exclusion that is external to the medical symptoms of a condition. In Bhutan, Schuelka (2018) concluded that schools produced disablement with built environment, teaching styles, curriculum, and language. Psychological impacts were witnessed in students labeled disabled due to the treatment they experienced as a result of the label. Hay (2020) and Ware (1992) identify delegitimization as another socially disabling experience. Delegitimization is an experience of suffering that results from having one’s claim to disability

questioned, judged, or disbelieved. While not widely explored in disability research, delegitimization has major ramifications spanning from effects on internal self-image to denial of medical treatment.

While similar sounding, Hartblay distinguishes a difference between an “anthropology of disability” and “disability anthropology.” Anthropology of disability is a subfield of medical anthropology that studies disability as the subject matter, whereas disability anthropology is a distinctively conversational exchange between the disciplines of anthropology and disability studies and “starts from, and maintain focus on, the point of view of people with disabilities themselves,” (2020, p. S27). Disability anthropology would benefit from greater understanding of the way disabled people experience judgement and questioning of their claim to disability, and how they feel these experiences of social disablement affect their access needs, relationships, health, wellbeing, and most notably, their identities as disabled people.

At its core, this thesis relies on the understanding that disability is more than just a category based on bodily limitations, but a social experience that is constructed by both internal and external forces. The social model and critical disability theory form the foundation for evaluating delegitimization as an experience of socially produced disablement. Through application of stigma and performance theory, the social model is bolstered with the understanding of how delegitimization comes from a socially constructed category where some fit the preconceived description, and some don't. Beyond the ways that invisibility is defined here, this thesis explores the way physical recognition and social erasure are intertwined and investigates multiple spheres of invisibility: the internal self, the external self (physical), the social, and the medical. This thesis blends together theories on the epistemics of medicine, the medicalization and individualization of the medical model, the societal barriers of the social model, productivism and self-worth, stigma, visibility, and delegitimization to examine experiences of disability.

IV. EXPERIENCING DISABILITY IN THE MEDICAL SYSTEM

Disability has historically been understood through the lens of medical knowledge and biological fact. Under the medical model of disability, the category of disability includes individuals with a disease, injury, diagnosis, or abnormality, regardless of any experienced limitations (Kumar 2016). The medical model reflects biological systems rather than experiences, therefore a person with a disease that does not cause any limiting experiences would be considered disabled, but a person without any recognized disease that does experience limitations would not. While the medical model is slowly being replaced by other conceptual models, such as the social model or the World Health Organization's International Classification of Functioning (ICF) model, medical professionals are still the dominate experts on disability.

The treatment of medical knowledge as exhaustive and unchanging fact governs how health care is provided and to whom, allowing for people whose experiences do not align with these accepted facts to slip through the cracks. Medical knowledge is not exhaustive or absolute; the questions being asked and the knowledge being produced are, like all knowledge, rooted in systems of power, social institutions, and culture (Dumit 2006, Foucault 2008, Lyotard 1985, and Martin 1991). Medical facts in the U.S. are skewed towards what is already accepted as fact, what is provable, and what insurance will acknowledge (Dumit 2006). Therefore, experiences that are not explained by existing medical facts; that are unprovable with tests, imaging, and bloodwork; or that are unrecognized by insurance providers render the individual invisible to medical institutions and are denied legitimacy.

Lyotard argues, "Scientific knowledge is not the totality of knowledge," (1985, p. 7). Lyotard's narrative knowledge is built on the basis of experience. The particular knowledge that disabled people create and utilize to negotiate their identities, their abilities, their limitations, and their experiences in the world around them is disability expertise (Hartblay 2020, Kasnitz 2020). Yet,

the expertise that disabled people have over their own bodies and experiences are often disregarded as inferior to that of medical professionals. Disability expertise that challenges the authority of accepted medical facts can make existing within the medical system challenging for those with disabilities; obstructing their access to health care, preventing diagnosis, withholding legitimation, and complicating the identities of those struggling to have their experiences realized. Those rendered invisible in the medical system create alternative narratives, including alternative forms of diagnosis, that exist outside of the accepted medical fact to survive and find support.

Achieving medical visibility, diagnosis, and treatment is further complicated by intersecting influences on the patient's identity. Treatment within the medical system is shaped by these intersections of social and cultural categories or characteristics (Crenshaw 1991, Goethals et. al. 2015). This chapter will explore where different branches of power or marginalization overlap and how the unique experiences, perspectives, and treatment of the disabled within the medical system constitutes how individuals are diagnosed and treated, which narratives they seek, and how they perceive the medical system.

Barriers to Health Care

Achieving visibility in the medical system in the form of medical diagnosis or treatment is not always easy, or even possible, for everyone who identifies as disabled. The various intersecting aspects of a patient's identity and real or perceived social or cultural characteristics interact with the systems of knowledge that define medical fact. Factors that shape the legitimacy found in health care can include visible characteristics of condition, age, biological sex versus gender identity, socioeconomic status, race and/or ethnicity, and previous medical history.

From structural to systemic, various barriers also obstruct access to medical diagnosis, treatment, and legitimacy. The individuals represented in this study spent anywhere from months to years, some near decades, attempting to obtain a medical diagnosis and/or treatment for their

conditions, if they managed to obtain any at all. Interactions within the medical system have been described here by participants as lengthy, costly, extremely frustrating, and has resulted in negative impacts to mental health and personal identity. For invisibly disabled young adults, a medical diagnosis can be the difference between being believed by others or being discredited, the difference between accepting themselves as disabled or not, and the difference between getting the accommodations or treatments they need to thrive or struggling through life without them.

Structural Barriers of Medical Systems, Affordability, and Insurance

Where does diagnosis begin? It starts with symptoms, and in the digital age, maybe it starts with Google searches. It starts with a need to see a doctor, but which doctor? How do those seeking care know which doctor to see? They might start at a primary care physician and be referred to the right specialist. They might start by searching for doctors in their insurance network or in their area and looking at reviews posted online. They might start by searching for doctors who treat certain conditions. Patients may be able to locate a doctor and find reviews left by patients, but they are less likely to find information regarding whether or not a doctor has experience with the conditions or symptoms they have and how they approach treatment of that condition.

Morgan describes finding doctors as a trial-and-error process. She was diagnosed with Chiari malformation, a rare deformity of the skull that causes brain tissue to be pushed into the spinal canal, at 17 years old. She has a difficult time locating doctors with any knowledge of her rare condition. Morgan said,

For the last two neurologists I've seen, I was their only patient that had Chiari. They had never heard about it before. It's a lot harder [to find doctors]. Especially because I want to find a Chiari specialist, but it's so hard. I feel like I have to do a lot of research about a doctor before I make an appointment [...] Really the only thing I can get on them is reviews and 9 times out of 10, it's mostly stupid shit. I definitely wish there was more info available to check doctors out because I feel like it's not good right now, I can't find much.

Researching doctors can yield little more than their credentials, affiliations, awards, possibly their history of malpractice claims, and reviews. Reviews left by patients on insurance websites,

physician or health center webpages, or Google are typically centered around either complaints or praises of the doctor's bedside manner, the front desk staff's demeanor, wait times, and/or feelings during appointments. Reviews of this caliber can offer insight into how a patient might be welcomed but fail to reveal anything specific about the doctor's beliefs or experience. Some websites, such as MediFind.com or Healthgrades.com, sometimes include a list of conditions the doctor has experience treating, but it is not transparent to the user where that data comes from, nor does it indicate how the doctor treats or manages those conditions. There is essentially no way to know if a doctor has familiarity treating a particular disability or what their methods of treatment consist of without visiting them, and that rarely works out on the first try.

Shelby had to try dozens of doctors before finding one that could diagnose her. She said, "It took me about nine years to finally be officially diagnosed. I've seen, I want to say, over 25 different medical professionals, in multiple states." Several participants discussed having to travel long distances, even across state lines, to get the care they needed. Devyn, a northern Texas native, has spent the last year flying back and forth to South Carolina to see one of a handful of doctors in the country who specializes in a procedure for symptoms related to Ehlers-Danlos syndrome. Devyn and her family had to pay for airfare, rental cars, hotel stays, and meals for multiple visits, one being a three-week stay after her surgery. The cost of seeking specialized medical care can be more than many can afford.

Medical care in the United States is extremely expensive. Diagnosis for the invisibly disabled often means several emergency room visits, numerous appointments, referrals to specialists, various tests and blood work, and sometimes even exploratory surgeries. Studies show those with chronic conditions are burdened by greater use of physician services, greater prescription medication use, greater hospital admissions, greater emergency room visits, and greater out-of-pocket costs than

peers without chronic conditions (McPhail 2016). At 21 and working full-time, Maggie's diagnosis has been delayed by the expense. She said,

Currently, I'm waiting on a diagnosis for a joint disability, it's either lupus or some form of arthritis, but it has taken over a year to get to this point because I haven't been able to afford doctor's appointments. It took a year to get the bloodwork done, and 4 months to get an appointment to look at the results of the bloodwork, because money and insurance, which is ugh.

Insurance is its own distinct issue when considering the barriers to medical care. Health care in the United States is a privilege that many do not have. In the U.S., one in three young adults are uninsured and a reported 23.6% of disabled people aged 18-44 do not have access to health care (Kenney and Holahan 2008, CDC 2019). Even still, access to insurance does not guarantee care. Gwen said, "I'm very fortunate to have insurance, however a lot of my treatment hasn't been covered by insurance, so sometimes it just doesn't help. That kind puts a barrier in your care."

Even when an individual has access to insurance coverage, additional barriers rise to the surface: deductibles, co-pays, referrals, coverage limits, visit limits, hour limits, uncovered tests, fail-first policies—insurance policies that require patients to fail on the insurer's preferred prescription or treatment option, before they will cover the prescription or treatment originally prescribed, prescription coverage, exclusions, age caps, and waiting periods. Gwen's diagnosis was delayed by several years due to the expense of a test her insurance did not cover. She said, "The actual test to confirm that I had Lyme disease was not covered by my insurance. It cost upwards of \$1500. It was pretty difficult to obtain for several years, so I was really just getting worse." Typically, formal diagnoses are required before treatments and certain accommodations and/or resources can be accessed, resulting in people like Gwen getting worse due to waiting because of the burden of cost.

The burden of cost can also prevent diagnosis entirely. Victor and Ryan found themselves facing a high out-of-pocket price tag for a test their insurance did not cover for adults. Insurance coverage for autism testing and services in most states is restricted by age. Ryan said, "Usually the

testing is about \$3000, and my insurance doesn't cover it if you're over 18.” Forty two out of 50 states limit coverage for autism testing and services to the age of 21 or younger, some states limit coverage to ages as young as six years old (Applied Behavioral Analysis 2017, National Conference of State Legislatures 2021). Fortunately, Ryan was able to receive funding from a vocational rehabilitation organization in order to obtain the diagnosis that finally gave him access to accommodations at his university. However, the lack of insurance coverage and cost of out-of-pocket expenses are just a few reasons why Victor is not actively pursuing a medical diagnosis for autism. He is still seeking diagnosis for another condition, though, and says, “Now that I can do everything myself, I've been making sure to ask people who are very well versed in insurance and such for help. My mom didn't teach me anything about it, so I just had to do this all on my own.” Insurance coverage can be complex and intimidating, especially for young adults who are new to having control over their insurance. Lack of fluency with insurance acts as a barrier too.

Wait lists for specialists can be another detrimental setback for those seeking diagnostic services or follow-up care. Especially since the emergence of COVID-19, the invisibly disabled are witnessing higher demand for the doctors they regularly see, translating to longer waits. Rane said, “I'm struggling with wait lists because a lot of this coincided with COVID and getting pushed back and people trying to see the same specialists I am as a result of long COVID.” Long Covid has significant overlap with multiple chronic conditions, such as myalgic encephalomyelitis/chronic fatigue syndrome (M.E./C.F.S.), Lyme disease, and fibromyalgia, and patients utilize the same kinds of specialists, such as rheumatologists, immunologists, and neurologists. The result is wait lists that are months long (Ducharme 2022, The Washington Post 2022). The heightened demand caused by COVID-19worsening this problem, but lengthy wait lists have been a barrier for certain specialists long before the pandemic began. Several years ago, following her clinical diagnosis in 2012, Lacie

spent years on a wait list to see a geneticist, the only kind of doctor that could narrow her clinical diagnosis down from a family of conditions to a specific type within that family. She said,

I called like every geneticist in the country, and there are not many, I'm sure you know. I got on a bunch of wait lists, and I was on a wait list for two years for one in Boston... a state we didn't even live in. The next closest geneticist was in Utah, and they actually died while I was on the list.

Waiting months to years for a diagnosis prolongs the wait for treatment, advances conditions, worsens symptoms, delays acceptance, and postpones access to resources and accommodations.

Medical Invisibility and Invalidation

The medical system's treatment of rare conditions and contested conditions is a barrier that stops many seeking diagnoses. Cameron said, "I've had doctors who have flat out looked at me and told me that conditions like fibromyalgia just don't exist. I think it's fascinating that there can be disagreement on whether or not something exists like that." Conditions like chronic fatigue syndrome (C.F.S), fibromyalgia (F.M.), and multiple chemical sensitivities (M.C.S.) have been contested medically and often diagnosed and treated as psychosomatic, due to the lack of known medical explanation for the symptoms. Patients seeking help for chronic conditions without a traceable cause may feel minimized, blamed, and/or dismissed by medical professionals, resulting in feelings of frustration, shame, guilt, craziness, or weakness (Stone 2014).

Participants in this study often described an endless cycle of negative tests. Devyn spent years as an early tween feeling chronically fatigued, though no test medically explained why. She said,

I was sick, I was fatigued, but they just wanted to throw antidepressants at me. It was like that for years. Doctors doing all these tests, not finding a single thing wrong, and I did do like all the tests. When they can't see an easy answer, they just think you're exaggerating or lying. I honestly diagnosed myself a few years into it because of the Internet.

Devyn turned to the internet for answers and found groups of people with similar experiences in chronic fatigue syndrome communities, all experiencing the frustrations of having a condition that was not recognized medically. These online communities exemplify disability

expertise; here, the experiences of the individual carry more authority than the medically accepted facts, verifiable evidence, and insurance billing codes that doctors are bound by. When a patient presents symptoms with no explanation identifiable using the acceptable tests and textbooks, doctors treat the experience as inconceivable or are limited in their treatment options and deny medical visibility to those whose realities disagree with the accepted medical facts (Dumit 2006).

The same dismissal or discrediting of symptoms occurs for patients seeking diagnoses for conditions that are considered rare. Despite their known existence, doctors often treat rare conditions as too rare to be realistic possibilities. Stella was symptomatic for approximately ten years before accurately diagnosed. She told me of her diagnostic journey,

My first symptoms showed up back when I was 13. They were so small that I was treated for menstrual problems, for anxiety, for thyroid. All these little things that weren't terribly uncommon. I was treated for allergies and anemia, and as it turns out, I don't really have issues with either of those once I was accurately diagnosed and treated for the proper thing... Even the endocrinologist in 2013/2014 couldn't figure it out, he just kept testing my thyroid and kept changing that dosage. Even though Addison's disease should fall into the expert category of an endocrinologist, it's just so rare, he didn't think to test for it.

Stella was repeatedly misdiagnosed, despite having a "textbook," as she described it, combination of symptoms that indicated Addison's disease. Stella felt the doctors went for simple explanations and solutions for her symptoms rather than looking harder for the cause of them. Rare conditions are not treated as viable explanations despite the reality that an estimated 25-30 million people in the U.S. alone live with a condition that is labeled rare, an estimate that is considered low by the director of The National Institute for Health and Medical Research, Ana Rath (Templeton 2019). In Stella's case, Addison's disease was not considered and completely overlooked due to its rarity.

In comparison, for Lacie the rarity of her condition caused her doctor to backtrack and revoke another doctor's diagnosis, leaving her without a diagnosis again for five years. She told me,

Initially, I was diagnosed while unconscious by the surgeon doing my shoulder repair in 2012. I took that diagnosis back to my primary doctor and they went, 'oh honey, that's too

rare, you can't have that. It must be something else.' I spent another five years searching for another diagnosis... So, I was diagnosed, undiagnosed, and then re-diagnosed. It just wasted so much time.

Even though the diagnosis had been brought to their attention, her primary doctor invalidated the possibility due to the condition's rarity. Lacie spent another five years without the functional uses of a medical diagnosis, such as accessing accommodations at school or work, as well as the emotional validation and visibility that comes with having experiences recognized and supported by medical experts.

Ironically, Lacie and I share the same condition, despite its being considered rare: Ehlers-Danlos Syndrome (E.D.S.) It is a condition that tends to run in families because it is passed genetically. It is quite common for genetic conditions, such as E.D.S., to require a familial history for diagnosis, but what happens when an individual does not have access to their family's medical history? As an adoptee, Rane shared their experience with diagnosis and treatment without this history. They said,

Trying to get listened to for something rare is incredibly hard. I'm adopted, I don't know any of my first-degree relatives, so I don't have any family to point to, to say that they're experiencing this too. I have my medical history for my biological parents, but it stops at my birth, so I know nothing of the last almost 30 years.

Without familial history to bolster their claims, Rane has a difficult time convincing doctors to look harder at their symptoms despite negative tests.

The medical visibility of a condition is not the only way patients' medical care can be obstructed. Characteristics such as age, gender, weight, ethnicity or race, and previous diagnoses impede how a doctor treats a patient. Young adults seeking disability diagnoses or treatments are too often told that they are too young to be disabled. Maggie was told she was too young to have a specific condition. She said,

It took 2 or 3 years to get the diagnosis, because at 16, all the doctors said I was too young. It usually shows up in people 40 or older [...] A lot of doctors said I was too young; I

couldn't have it. It took until I found my current doctor, who was also diagnosed with Hashi's at a very young age, to get that diagnosis.

Treating conditions as if they have firm age limits, such as with autism, or age minimums, such as Maggie's experience with Hashimoto's Disease, invalidates the claims of the people actually living with those experiences. Gwen referred to the invalidation, dismissal, and refusal of diagnosis as medical gaslighting, which is defined in sociological and health science spheres as the discourses operating in medicine to dismiss and invalidate patient experiences (Sebring 2021). About her experiences with gaslighting in medicine, she said, "I was told a lot, 'You're too young to be having these issues,' and I didn't know what that meant, because I am having these issues." When doctors set limits on who can experience a condition and when, they are directly challenging the expertise individuals have over their own body and life. This challenge results in patients being denied adequate care, including diagnosis and treatment.

Devyn felt that being both young and a women affected her treatment during the early years of her condition, she said, "I was 12/13 years old. As a 13-year-old girl, it's the puberty years you know, when you say you're tired, you really just do not get taken seriously at all." Studies show that women, especially women of reproductive age, have a substantially higher prevalence of chronic illness, yet studies also show that across 770 diagnoses, women are diagnosed on average four year later than their male counterparts for the same conditions (Harris et. al. 2021, Brunak et al. 2019).

Cameron witnessed this firsthand, she said,

I don't want to necessarily immediately pull the gender card, but after watching my male friend/coworker go through his expediated process at the exact same clinic that treats my Chron's, I thought it was interesting. I'm very glad this is how it worked for him, but in less than two weeks he went from getting his potential diagnosis, to getting the confirming procedure and diagnosis three days later. Then he was getting an infusion of the medication that I had to fight for, for five months, three days after that. That's how it should work, and I'm not mad that it worked out for him like that, but I'm definitely jealous. I'm still not even there and it's been over a year.

Following the trend seen in the Brunak et. al. study (2019), Cameron's diagnosis required months of tests, bloodwork, and exploratory surgeries to confirm while her male counterpart's took weeks. Obtaining a diagnosis or treatment for chronic or invisible conditions is trickier as a woman, necessitating the employment various strategies in order to be believed, understood, and viewed as credible patients (Werner and Malterud 2003).

Weight was a significant barrier for those participating in this study. Flor, Heather, Cameron, Victor, and Gwen are just a few of the participants that had doctors blame their symptoms on their weight. Victor has not been able to obtain a medical diagnosis due to barriers he experiences due to his weight, identity as a trans man, and the cost of medical care. He suspects P.O.T.S. for the symptoms related to his heart rate and fibromyalgia as a possible explanation for his pain, but says,

It's just been very difficult to get diagnosed in general because the previous doctor I had didn't agree that anything was wrong with me, particularly because I'm chubbier [...] The two or three years of me seeing a doctor and trying to figure everything out, all I was told was that it was just my weight; my blood work was fine; my X-rays were fine; all these tests came back fine; I was OK, there was nothing actually wrong with me; the pain was probably because I'm overweight.

Invisibly disabled people that are considered overweight have their symptoms dismissed and are treated as if their weight is a personal failure that has caused their poor health. This "responsibilization" (Manderson and Warren 2016) places blame on the individual for failing to maintain their health, in this case through their weight, and places the responsibility on them to make themselves healthier. Flor told me, "I went to a lot of doctors, and finally they thought it kind of seemed like arthritis, so they sent me to a rheumatologist. The rheumatologist did one test, told me to lose some weight and come back in six months, then charged me \$600 for it."

Disparities in medical care as a result of ethnicity and/or race are well-documented and undeniable, with provider interactions listed as one of the leading causes of disparities (For examples see Kim et. al. 2018, Ryn 2002, Mayberry et. al. 2000). Provider bias influences quality of care, communication and trust between provider and patient, understanding of differing symptom

presentation, and prescribed treatment, especially pain treatment (Klonoff 2009). As an Indigenous person, Flor faces a lot of bias, stereotypes, and discrimination when seeking medical care and they believe that it has affected the diagnostic and treatment options available to them. They said,

I would notice that people would listen to me more if I brought my white partner to the appointment. Being Native American, there is that stigma about being a substance abuser. Even if I was very clear about not wanting a lot of pain medication because of my history with it... even wanting to work with them about that, there would be a lot of hesitation about giving me any sort of pain management... I just deal with it using my own methods. Even if that means I have a low level of pain all the time, at least I'm not trying to jump through hoops to convince people I'm not just looking for drugs.

Ethnic discrimination obstructs diagnosis, treatment, and visibility for invisibly disabled individuals belonging to marginalized communities.

Discrimination can also arise from a previous diagnosis— particularly if that diagnosis is a psychological disorder. Doctors may dismiss symptoms they view as an extension of an existing condition, such as the case with Cameron's Chron's disease symptoms. She said, "I do have a mental health history. I'm a very anxious person, so I feel like it's really easy for doctors to just look at my chart and see my anxiety diagnosis and say that's why my stomach hurts all the time." Victor and Lacie also had their symptoms blamed on their anxiety, Heather and Devyn's symptoms were blamed on depression.

Previous psychological diagnoses can also obstruct medical care as a result of the stigma surrounding mental health. Ryan is currently in school for counseling psychology with plans to be a therapist when he completes his degree. His treatment by that field when seeking his own diagnosis is what inspires his career choice. He said, "I think stigma and ableism is a huge problem in the psych field. Even people who you'd expect to be knowledgeable and understanding just aren't. Sometimes I don't even know why they chose that career. It's one of the biggest driving forces behind me getting through my own education."

Lacie, Raven, and Rane have had doctors make assumptions about drug or alcohol abuse, blaming their symptoms on that, with or without cause. Rane was seeking a diagnosis at a psychiatric hospital when their symptoms were written off as substance abuse. They said, “The very first psychiatrist I talked to was terrible. I told her what had been going on, and she just told me I had a drug and alcohol problem. I left pissed [...] I knew the symptoms came before the substance coping.” Rane’s educational background in psychology provided them with a warning that this psychologist was wrongfully assuming the substances were the cause rather than a symptom.

Likewise, Lacie has been treated poorly as a result of her prescription records. She regularly carries Narcan, a drug that reverses the effects of overdose, ever since her dog located someone who was overdosing. Even though Lacie is a registered nurse, she has been treated by medical professionals as an opioid addict, coloring the care she receives as a result. Unfortunately, chronic pain patients are often labeled as being drug seekers and their pain is written off entirely. Individualizing the problem of drug dependence and/or abuse, similar to putting the responsibility of health on the patient, puts blames on the individual rather than the systemic issues that create the problem in the first place: pharmaceutical companies profiting off of over-prescription and addiction (Schwab 2019).

Similarly, Heather expressed frustration with the conclusions that medical professionals jump to about chronic pain patients. She said,

There’s this aura of people with chronic pain in medical fields, where they seem to think that we're drug seekers. I walk in with a chronic pain disease, and they think I just wants meds, which is ridiculous because I don't want them, and I won't take them, even if they're prescribed. That's just the gut reaction for them, to disbelieve me on a dime so that they can save the drug addicts or whatever they think they're doing.

As Heather said, she is not looking for medications, she is looking for answers. She needs help, but she is not being treated as a valid patient because of these stereotypes. Heather is denied any kind of legitimacy before even being listened to because doctors too often assume anyone complaining of

pain is seeking drugs. Among these participants, it opposite was often expressed: they don't want drugs, they are tired of doctors just shoving medications at them and sending them away. They want to be listened to. They want a doctor to validate that their pain is real, and they want to find the cause of pain so that it can be effectively treated, whether that includes medication or not. In my personal experiences, I have had many doctors prescribe various pain medications, muscle relaxers, even steroids, but I have always refused to take them because I did not want to rely on medication the rest of my life and feared becoming addicted. It felt like those doctors were just treating symptoms without actually seeking to discover what was causing the pain in the first place.

Even the possibility of abuse is not sufficient reason to refuse to listen to someone in pain, or to deny orders from other doctors who include these medications in treatment plans. Raven's cyclical vomiting syndrome (C.V.S) treatment regime includes medications that label her a chronic pain patient, so she wants people to know, "Not everyone is drug seeking. There's a lot of people who really, truly need the medications that they're given. I've tried different preventative medications, I've tried a bunch of different abort medications, and it just seems that there's one regimen for me that seems to work."

The barriers discussed here are by no means exhaustive of the barriers that make medical systems inaccessible to many, but they represent the experiences of myself and those who took the time to share their stories with me.

Diagnostic Routes

Diagnosis is the legitimization of disability that unlocks a range of emotional endorsements, such as validation, recognition, acknowledgement; societal allowances, such as occupation of Parsons' sick role that absolves the sick from social responsibilities; offers A.D.A. protections and accommodations; and provides institutional opportunities, such as medical treatments, medications, insurance coverage, and government financial aid. The Americans with Disabilities Act (A.D.A.) is a

law that protects the civil rights of disabled Americans by prohibiting discrimination, ensuring equal opportunities, and affording the right to accommodations in the workplace, educational institutions, and in public. The protection of these rights, however, may be inaccessible without documentation of disability by a medical professional.

The A.D.A. defines disability as an impairment that substantially limits major life activities and Section 1630.2(j)(1)(v) specifies that limitations of major life activities should be judged based on the comparison to most people in the general population, not by scientific or medical analysis. Yet, in Section 1630.9 the A.D.A. gives employers and educational institutions the ability to require documentation of disability when accommodations are requested, and they can require this documentation to come from a medical professional (A.D.A. 1990).

Emotional endorsements, societal allowances, and institutional opportunities are not guaranteed without the authority that medical diagnosis brings, but due to the barriers discussed that prevent everyone from having equitable access to health care systems and the disparity between recognized medical fact and the reality of individuals' experiences, there is a need for alternative methods of claiming disability and achieving visibility. Alternative diagnostic routes include self-diagnosis and the route that is humorously referred to as "peer reviewed" diagnosis. These routes prioritize the expertise of disabled people over the medical establishment, and act as anything from aids in achieving or total substitutes for medical diagnosis. Each route comes with its own advantages, disadvantages, and difficulties. Disabled people choose the route that is most appropriate for them based on their needs, resources, and available options.

Medical Diagnosis

Medical diagnosis for invisible conditions often starts with a suspicion or self-diagnosis by the patient that a medical professional then confirms. Confirmation brings the patient validation in their experience and confidence in their claims. Ava suspected her diagnosis for many years before

she was able to access diagnostic services but was reluctant to self-diagnose something she viewed as serious as P.T.S.D. When her suspicions were confirmed, she said,

It felt very validating. I always felt very shy saying it before, I was always like, 'I think I have this thing,' but I never had the confidence to just be like yes, I have it. Now I can very confidently say it. It's not quite the same as saying I have a broken leg, and everyone can look and see that you have a broken leg, so it felt really good to be able to get that formal diagnosis.

The invisibility of the condition made self-diagnosis feel less valid to Ava, so getting a medical diagnosis helped her realize visibility.

Likewise, Ryan's professional diagnosis of autism confirmed his own diagnosis, validated his experiences, and allowed him access to resources he needed to succeed. He said,

It was overall extremely positive and validating for me. I suspected autism before the formal diagnosis, so it just reaffirmed that I was correct and that there was a label for the things I experienced my whole life, plus it gave me the necessary paperwork to have accommodations. It felt like finally having the key to go back to college.

Medical diagnosis for the invisibly disabled can be disadvantageous for all the reasons discussed previously: it is costly, time consuming, frustrating, invalidating, *and* it places a hefty burden on the person seeking care. Ashely has been medically diagnosed with P.O.T.S., and even though she feels she was diagnosed faster than most, she really had to advocate and be insistent with her doctors to be heard. She said,

I felt like I had to prove my condition, through documentation of my triggers, my symptoms, and everything that happens. I have like a little diary of when something happened; what did I eat that day, and what did I do to potentially trigger my illness. It caused me to document things. Then I got very serious about at-home monitoring of my blood pressure and my heart rate too, to figure out what was happening with my body. I feel like I got a little bit more scientific just so I could educate doctors what was happening to me, and in some cases, in a sense prove that something was happening.

For invisibly disabled people dealing with the medical system, a paradox exists: they have to be experts—they have to research conditions, document and collect evidence, and know exactly what is happening to them and how to explain it—yet they are treated as if they know nothing.

Devyn says, “So many doctors just look at you like you don't know what you're talking about. I get it, I'm not a doctor and you are, but no one knows me better than me, and things are not right.” Having the expertise of your own body, symptoms, and lifestyle invalidated is a disadvantage that is seen often by those with invisible or chronic conditions.

The disadvantage of delegitimization and the burden that comes with paradoxical expertise is exasperated by gaps in the medical system. As seen in the previous section, invisibly disabled and chronically ill individuals get an intimate understanding of how medical care works. Ashley says,

It's frustrating because you really start to get an understanding of under the hood of the medical system. Medical science is not as mature, or as well developed as you think it is. There is there's a lot of unknowns in medicine and I don't think people recognize just how much is unknown.

Professional understanding of chronic illness is growing, but there is still significant ableism, misinformation, and lack of education that leaves much to be desired. Wendy said,

The education for doctors needs to improve. They need to be taught more about things that are chronic; about pain management and about believing people when they say they're in pain... they shouldn't have to prove the amount of pain they're in. They tend to like only what they can explain and fix. Sometimes they can't explain it, and a lot of times, they can't fix it. They do what they can to pretend they can fix it.... that makes it harder on you as a disabled person if they're still trying to just fix it instead of finding ways to make it easier or help you deal with it.

Lack of education on chronic conditions specifically may make the medical diagnosis route impractical for some.

Self-Diagnosis

These participants described the most significant disadvantage of self-diagnosis as the possibility of not being able to access the rights and resources for disabled people. Though neither the A.D.A. nor the Equal Employment Opportunity Commission (E.E.O.C.) specifies the requirement of medical diagnosis in its definition of those protected, employers are entitled to require medical documentation to authenticate accommodation requests, but only if the disability or need is not “obvious,” as stipulated by the E.E.O.C. (A.D.A. Rehabilitation Act). An invisibly

disabled person's right to accommodations and equitable employment can therefore be denied without the advantage of a medical diagnosis.

Despite their best efforts, Flor has been unable to obtain a medical diagnosis as of yet. They had no choice but to diagnose their own needs, in this case a cane for their chronic pain, but Flor's employer denied their request to use their personal mobility aid at work. About the experience, Flor said,

At the moment, I am unemployed. I was working for a large coffee company... I just wanted to use a cane on the floor— that's all I wanted, I didn't want a stool or anything— but because I didn't have an official diagnosis, they wouldn't let me... so I had to quit.

Under the E.E.O.C.'s regulations, Flor's employer has the right to require a medical diagnosis, but it leaves those unable to obtain one without protections in the workplace.

Some individuals intentionally avoid the medical diagnosis route, either because they perceive a professional diagnosis would offer no advantage or because having a diagnosis recorded would create barriers in other areas of their lives. An advantage of self-diagnosis is the same validation that comes with having an explanation for experiences without the hassle of the medical system if the documentation would not offer any benefit. Victor is not seeking medical diagnosis for autism, in part because of the expense mentioned previously, and the lack of foreseeable advantage of documentation. He said, "It is not worth it for the lack of accommodations that we get. The best positive I see is if I get to go to Disney ever again, front of the line! Other than that, I can't think of anything else." The accommodations, if any, offered or needed in school or workplaces do not always justify a need for a medical diagnosis.

In Flor's case, having official medical documentation of their dissociative identity disorder (D.I.D.) or autism would open them up to ableism and discrimination that could obstruct them from their desire to be a parent. They said,

I haven't been officially diagnosed with either [condition]. Part of it is due to the fact that I do want to become a foster parent when I'm older, so I haven't pursued those diagnoses

because I know that they would impact my ability to do that. Sometimes self-diagnosis is this is the only way that you're able to get those answers for yourself.

Flor noted that understanding, even professionally, of D.I.D. is very limited and could be used as a basis to discriminate. Flor protected their options for the future by choosing to self-diagnose.

Doctors themselves often choose not to seek out professional help in fear of negative impacts to or total loss of their medical licenses (Dyrbye et. al. 2017, Samuel 2017, Shanafelt et. al. 2011).

Self-diagnosing is sometimes the only option some have. Rachel has a handful of seemingly unconnected symptoms that doctors have not been able to piece together for a diagnosis. She said,

I had gastric bypass surgery in 2018, and I almost died shortly afterwards because of starvation... it then caused a whole bunch of neurological problems in me because my body was shutting down [...] No doctor is looking at this and saying, 'oh we've got this event that's a pretty big deal, maybe we should try and go with something based off of that.' It's just, 'oh, this is really weird. You started having seizures? That's very strange, yeah, we don't know what that is.' And the same basically for all of my singular problems. Instead of thinking it's probably all connected to this one event, because that's when it all started [...] No diagnosis for you. Which I know they're not doing it to be mean, they just don't want to say anything and then later be wrong or try and get me on the wrong medicine and it doesn't help. Whatever. So, I've been having to just self-diagnose for certain things, that way I can put words to it and get help.

Likewise, Rachel has self-diagnosed some of her symptoms into medical terminology, such as aphasia, to better communicate the symptoms she experiences to her doctors, but she has also self-diagnosed herself as disabled as a way to reflect her experiences when doctors have been unable to provide her with any answers.

Peer Reviewed (Community) Diagnosis

Individuals looking for answers or help might seek out communities or spaces for disabled people, communities specifically for invisibly disabled people, or even communities for people with a certain condition. In these spaces, individuals can find advice, support, and guidance for their diagnostic journey. They may find advice that leads them to a medical diagnosis, or they may find enough validation through their peers that a medical diagnosis seems unnecessary.

The disadvantages and advantages of “peer reviewed” diagnosis generally mirror those of self-diagnosis. Without formal documentation, there is the potential of being denied the accommodations, rights, and protections afforded to those with medical diagnoses. However, the feelings of confirmation, validation, and confidence that come from a peer reviewed diagnosis are amplified by knowing that others who share your experience have come to the same conclusion, or that those who have been medically diagnosed agree with your assessment.

The expertise found in disability communities can act bridge people seeking diagnosis to the resources they need to obtain a medical diagnosis. After years of trying different doctors, Devyn turned to the internet. She said,

I honestly diagnosed myself a few years into it because of the Internet. If the Internet didn't exist, I probably would still be wondering. I talked to other people who've had the same exact experience that I've had, I learned about chronic fatigue and other chronic illnesses. I don't think I got an actual diagnosis until I was like 20.

Devyn found information about her symptoms and related conditions through the experiences of others first, self-diagnosed herself with their expertise, then was able to take what she learned to find a doctor with that experience and get diagnosed professionally. She was medically diagnosed over five years after self-diagnosing through the expertise she found in disabled communities.

Multiple Routes

My own diagnostic journey mirrors Devyn's. I spent nearly seven years going in circles within the medical system. I would see a specialist, they would send me to a another specialist, they would do an MRI and send me back to physical therapy, I would go to physical therapy and it would make the problem worse, so I would end up back at the doctor and be told that there was nothing wrong, it was in my head, it was normal for young girls to experience pain like that and I would grow out of it.

One day I saw a post on a social media platform that described my experience, so I delved into research. I found communities for people with conditions that sounded like my own and learned from their experiences, they led me to medical journals and other online resources, and many shared their advice on how to talk to doctors about my suspicions. When I went to the next doctor, I came armed with expertise from the communities I found and was diagnosed that day.

The route that someone takes to diagnosis is not necessarily static. Someone may start with a self-diagnosis and be perfectly content with remaining there. Another might start with a self-diagnosis in hopes that they can seek medical confirmation later down the road when other circumstances are right, such as affordability. Someone else might start with attempting medical diagnosis first but struggle, like me, so they turn to self or community diagnosis. From there, they can be satisfied with their self or community diagnosis, or they can learn from others' expertise and return to the medical system to try again. The social model of disability encourages disability expertise to have equal footing with medical expertise. With this perception of disability, every route is valid for claiming disability, and every person's journey may look different. It is the supremacy of medical knowledge and the inaccessibility of health care that forces alternative routes to emerge, to fill the gaps in what medical facts fail to legitimize and offer validation to those who slip through them. No route is entirely perfect or without disadvantage, but the routes that disabled individuals take reflect their needs, opportunities, and their negotiations of disability expertise in the world around them.

V. NEGOTIATIONS OF A DISABILITY IDENTITY

Development of a distinct disability identity can be turbulent, especially for the invisibly disabled whose identities are not so clear-cut. The first step is to recognize oneself as disabled. Various factors can play into recognition or not: visibility or appearance; the level of support or accommodation needed; personal perceptions of the meaning of disability and disabled; and employment, education, and social status (Andrews and Forber-Pratt 2022, Valeras 2010). The identity development models created by Gill (1997) and Forber-Pratt and Zape (2017) agree that challenging the oppressing perceptions of disability, of the types of people that are valuable and deserving of rights, is one of the first steps in integrating disability into identity. Even though the social model of disability has grown in status, the medical model for understanding disability has been dominant for hundreds of years. Those culturally embedded views are still instrumental in shaping how disability is perceived, compounding the societal tendency to divide and label people by adding biological rules to the disability category. Identity is not static though, and neither is disability. Identities and disabilities are both multiple and malleable, meaning they can change and fluctuate depending on context or person (Valeras 2010, Vandebroek 2010).

As the models of development from Gill and Forber-Pratt and Zape outline, the development of a disability identity is roughly the same as other minority identities; it is embedded in a group identity and requires establishing a place for oneself in the world as a member of a marginalized group. Identifying as a member of a marginalized groups invites the individual to be a participant within the community, which for Gill's model, is necessary for a completely integrated identity (1997). Connecting with disability communities provides the opportunity to challenge the learned views of disability, to appreciate personal experiences as expertise, to learn from knowledge shared among peers, and to find support. Barriers such as accessibility, segregation, stigma, and poverty have long been obstructions in the ability of those in disability communities to connect, but

with the rise of legal protections and the internet, connecting with community is easier now than ever before (Andrews and Forber-Pratt 2022).

Between point A and point B of developing any identity is a stage of transition, a liminal period where someone is becoming something new, but is not yet one or the other (Turner 1967). During this time, disabled individuals cope with who they used to be compared to who they are now, what they used to be able to do and what they can do now. The liminal space of identity development is often full of growing pains, exploration and discovery, and self-growth, that eventually culminates in a stronger, more integrated identity (Gill 1997, Willet and Deegan 2001). Though, disability creates a form of sustained or permanent sense of liminality because those who are disabled are neither sick nor well, neither incorporated into society nor existing outside of it (Jackson 2005, Willet and Deegan 2001). Invisible disability specifically sustains this liminality even further by challenging all the binaries used in society to classify and sort people into their expected roles (Goffman 1959, Jackson 2005, Valeras 2010). Further, when negotiating disability identity, those with invisible disability negotiate multiple identities at once and,

Make daily decisions about which identity to embody. They are constantly negotiating when, where, why, and how to disclose and adopt the disability identity, or [...] to give society the impression of 'able-bodiedness.' These decisions have reverberating implications for one's whole self-concept and social relationships. (Valeras 2010).

These decisions have to be strategic, because claiming disability often results in delegitimization, the suffering caused by disbelief, invalidation, and questioning from others, but is necessary at certain times, such as accessing accommodations.

Here I will elaborate on the intricacies of negotiating disability identity with the lived experiences of the participants and myself, including the process of development, from the point of realizing disability to the integration within disabled communities; the specific impact of invisibility on identity development and negotiation, and the felt impacts of sustained liminality.

Delayed Identities

When I asked the participants of this study, “At what point did you start identifying as disabled?” it came as no surprise to me that for many, it was several years after the onset of their symptoms, because that was my experience too. Raven said, “I was a little nervous, when I was first getting sick, with the term disabled because I didn't really understand what that meant for me at the time.” Personal perceptions of what disability is and what being disabled means are just one of the many factors in recognition of disability described by Andrews and Forber-Pratt (2022), and Valeras (2010). Other causes for delays in recognition among these participants included: lack of medical diagnosis, having their symptoms ignored by family or doctors, imposter syndrome, and terminology that matched their experience, internalized ableism, misconceptions, and a combination of hope and denial. Regardless of the cause of delay, participants described feelings and events they had to work through in order to recognize their disability and begin developing an identity that integrated it, a process that ranged from one to eleven years among these participants.

Lack of Diagnosis and Dismissal of Symptoms

Oftentimes, invisibly disabled individuals have trouble recognizing that their experiences are indicative of a condition or diagnosis. Some of the participants in this study, such as Lacie, thought their pain was a normal thing that everyone experienced. Lacie said, “I was probably in my mid-20s before I realized that not everyone had pain every day. I thought it was normal, I thought everyone had it.” Others blamed themselves for their symptoms, attributing symptoms to results of their lifestyle, their weight, their lack of regular exercise, their diet, etc. Stella said, “I just thought that if you didn't exercise and ate nacho cheese, you just felt like that. I just thought it was my own fault.”

Without recognizing their symptoms as cause to seek out diagnosis, participants went on living with symptoms deprived of treatment, accommodation, or explanation, and continued trying to fit themselves into a world designed for the able body and mind. Disability visibility begins with the

self. Disability can be invisible internally, resulting in the same perceptions modeled in Hay (2010): either overlooked or criticized and devalued. Ryan told me about the long-term impact of his self-image that resulted from being unaware that the way he felt was indicative of his condition(s). He said,

Before diagnosis, I thought I was just genuinely less competent in life and blamed myself. I thought something was wrong with me as a person but didn't know how to fix it. It takes a huge toll on your self-esteem too, even after learning why you struggle and having that label.

It was not until the participants realized that their experiences were not the same as their peers that they started to seek out an identity that explained their experiences. For Ava, this happened in their late teens. They said,

I was definitely at an age to understand that not everyone actually exists like this. That's kind of when I started to adopt the term disabled, just to put a word to these things I was experiencing and the way I was existing in the world compared to other peers.

Due to the longstanding tradition of medicalization, disabled individuals, especially invisibly disabled, often need a medical diagnosis to feel comfortable adopting the label of disabled. Though, as seen in the previous chapter, a medical diagnosis can be difficult, or even impossible, to obtain and may take years after the onset of symptoms. The process is often challenging, long, and emotionally draining. After years of searching for answers, some participants described feeling frustrated, crazy, and even depressed. Without a diagnosis to explain and validate their experience, invisibly disabled individuals may not know how to identify themselves. Rachel, who is still working towards a diagnosis after many years, expressed to me the struggle of identifying as disabled without one, "If doctors can't say, 'This is a diagnosis and this is what we can do to help you,' it's hard to know where to go from there. So, there was definitely a huge struggle and a huge shift at first, but it's been more positive recently." Rachel had a difficult time integrating the disabled label into her identity due to the invalidating experiences she has faced while seeking diagnosis, but she has become more accepting of the label recently as a result of the validation she found as a member of

disabled communities. Her integration in disabled communities has provided the necessary validation she needed to progress in integrating disability on the internal level (Gill 1997).

Before and/or during the diagnosis process, indivisibly disabled individuals may have their symptoms dismissed by doctors, family, friends, and even by themselves. Flor, started seeking diagnosis in their early young adulthood, described the realization that their symptoms had been present since childhood, they had just been ignored by family members. Flor said,

I thought that everything was fine up until then. Then, I started realizing that when I was growing up, we would be walking and I would say my joints hurt, or like something hurt, and they would just say suck it up, keep walking, or they would make fun of me for it.

The invalidation of Flor's symptoms in childhood prevented them from seeking medical care until adulthood, when the severity of their symptoms could no longer be ignored. Repeated dismissal of symptoms by medical professionals impacted the way Morgan felt about her experiences and identity. She said, "It really made me feel for a long time like I wasn't disabled. That's why I didn't call myself disabled, why I didn't label myself as disabled." The invalidation of her symptoms prevented Morgan from making sense of her experiences—which included fatigue, migraines, dizziness, and black outs in her teenage years—and delayed the development of her identity as a disabled person. Flor, Morgan, and Heather all shared similar experiences of repeated invalidation leading to internalized doubt, but that doubt occurred in different ways for each of them. Flor's childhood invalidation led to doubt that delayed seeking care, Morgan's medical invalidation led to doubt that delayed her identity development, and the invalidation from doctors that Heather experienced led to doubt that manifested in internal invalidation. She said, "Being sort of brushed aside, especially when it's an invisible disability, it sort of makes you feel like what if they're right? What if I have been just making it up, or I'm not as bad as I think I am?" That kind of internalized doubt is a contributor to feelings among the invisibly disabled commonly called imposter syndrome.

Imposter Syndrome, Liminality, and the Right Word

Imposter syndrome is used here outside its original context of unfounded feelings of fraudulency or doubt in one's success or achievements to instead describe unwarranted feelings of fraudulency or doubt in one's authenticity as a member of a community (Eldridge 2023). Many participants in this study harbored these feelings for identifying with a condition without a medical diagnosis, or for even identifying with disability at all if they did not feel "disabled enough," as Ryan described it. He told me, "For a long time I felt like I wasn't even allowed to call myself disabled because it would invalidate or offend others with 'real' disabilities." Invisibility contributes significantly to how individuals perceive their disability, potentially feeling less disabled due to a lack of visibility either physically, medically, or socially (Hazel 2022). While some of these participants did not feel any less disabled due to their invisibility, they described being treated as such. Others admitted to feeling less disabled than those who were more visibly disabled at the beginning of their identity development, but are currently challenging or have successfully overcome those feelings since. Others still feel less disabled, either because their condition is "mild," as Ashley said, in comparison to other they know, or because they struggle to receive recognition of their disability in both abled society and in disabled communities.

In this way, imposter syndrome contributes to the sustained liminality disabled individuals may experience, as invisibly disabled individuals may feel an inability to fit in as a member of the able-bodied communities they physically resemble, but are not immediately recognized as a member of the disabled communities their experiences resemble. Instead, they are stuck somewhere in between. When asked about the intracommunity feelings, participants described tension and even resentment between visibly and invisibly disabled members. Heather said, "I think intracommunity issues for people with disabilities based on whether they're visible or invisible get extremely fraught. I don't like the term, but like oppression Olympics." Some of the tension comes from the idea that

because invisible disability is not immediately obvious, the limitations or the struggles are less than those of people with more apparent disabilities or that invisibly disabled people get to “pass” as abled and circumvent discrimination (Gill 1997, Valeras 2010). Flor says, “I do think that there may be a kind of resentment I suppose. If you had to use a wheelchair every single day, that's just how people are going to see you. Whereas the people that can ‘choose’ to not have that be very visible, there’s the resentment of them not being able you have that leeway.”

Despite having some choice or ability to be perceived as abled, the invisibly disabled must instead contend with different challenges, including the challenge of not being perceived as disabled. Being abled passing and struggling to be recognized as disabled makes it difficult to access accommodations. Maggie said,

It’s kind of a double-edged sword. If I want to appear ‘normal’ and not feel like people are judging me, I can get away with it; but there are also times where I need accommodations and express that out loud, and someone says they don’t see why I need it. That’s the point, it’s an invisible disability. You can’t see it. I can appear normal, but really, I’m not. Really, I’m disabled, and really, I need those accommodations.

Visibly disabled and invisibly disabled share many struggles, and the struggles that differ are like two sides of the same coin. Stella described it like this: “I feel like people with invisible disabilities and people with visible disabilities almost have opposite problems. People with invisible disabilities have to prove that they CAN’T do something, and people with visible disabilities have to prove that they CAN.” These problems may manifest differently, but both problems are really rooted in the stereotypes and misconceptions people have of what it means to be disabled.

While difficulties and struggles should not be compared within the community, it is appropriate to note that the experiences of visibly disabled and invisibly disabled people are often very different. As a member of queer communities and identifying as a nonbinary trans individual, making room for different experiences is important to Rane, so they appreciate the role that the term “invisibly disabled” serves. They said,

It creates a necessary distinction in experiences. Like trans men and women have very different experiences, visibly disabled and invisibly disabled people have different experiences in the way society interacts with them [...] Using the term invisible disabilities makes the space to talk about those distinctions that you might not otherwise be able to make that space for.

Because of the distinct experiences that come with invisible disability, some participants did not feel comfortable with their identity until they found the right term to portray their experience.

Morgan said,

Honestly, I never really heard of that term [invisibly disabled] until like last year. It made so much sense to me, I was like, 'Oh my God, that's exactly me, I don't look disabled, but I am.' [...] It's really hard to cope with because of having to explain and having to convince people almost that I am disabled.

Many participants expressed approval of the term “invisibly disabled,” because it made presenting themselves as disabled easier. It raised fewer questions, it was easier to explain, and it encompassed a variety of conditions that are not externally visible, such as mental health, autoimmune disorders, brain injuries, connective tissue disorders, etc.

Internalized Ableism, Misconceptions, Hope and Denial

Several participants shared how their eyes had been opened to the ableist ideologies they were guilty of having before they experienced disability personally. Rachel said, “Before, I definitely had some viewpoints that were problematic to say the least, just because of the way I was raised, and it's made me question those beliefs for sure.” Participants spoke about their previous ideas of what disability looks like, which prevented them from seeing themselves as disabled earlier in their journey and delayed their identity development. Some participants grew up around others who are disabled, such as parents or grandparents, and their perceptions of disability reflected those individuals rather than themselves. Cameron’s father is a disabled veteran. Asked how that impacted her identity, Cameron said, “That's kind of the picture in my head of what a disabled person looks like, my dad [...] I do think that's part of why it took me so long to call myself disabled [...] I think that had an impact on my perception of my own level of sickness.”

Perceptions of disability are often overly narrow. What people often think of are very physical manifestations or things that are very socially visible, such as congenital deformities, amputations, paralysis, cancer, and blindness. Overly narrow ideas of disability minimize the vast array of disabling conditions that are experienced. Wendy had an experience similar to Cameron's growing up with disabled parents. She said,

My parents both have disabilities, my mom especially is very visibly disabled. So, I also compared myself to her and thought, she's disabled, I'm not; she has to use mobility aids, I don't. So, it took me a while and it took meeting others with invisible disabilities to accept that just because I don't use mobility aids, doesn't mean I'm not disabled.

Wendy's idea of what disability looks like included the use of mobility aids, because that was the version of disability she had been exposed to. Integrating into disability communities and forming relationships with other disabled people in college exposed Wendy to diverse disabilities, allowing her to recognize her own disability and integrate it into her identity (Gill 1997, Forber-Pratt and Zape 2017).

Some misconceptions about disability are less concerned with visibility, and more concerned with ability. These misconceptions are narrow and limiting as well. A few participants talked about how their experiences did not align with the ideas they previously had about disability; they were straight A students, athletes, held full-time jobs, and so on. Rane said, "I didn't see any of my mental health as such because I was still going to school full time, still working full time, all that stuff." In fact, multiple participants who described their primary diagnosis as a mental health condition said that for a long time, they did not recognize their mental illness as a disability, and therefore did not recognize themselves as disabled. Victor identifies with both mental and physical disabilities that are hidden, or less visible. While seeking a diagnosis for his physical disabilities, he learned that neurological stress, such as the stress associated with undiagnosed autism, can eventually lead to physical symptoms. This discovery led him to note the tendency to disregard disabilities as long as they are not manifesting physically. He said, "Societally, most people put more emphasis on physical

disability than mental disability. So, that's usually around the time I've noticed most people go seeking help, when it's affecting them physically.”

Disability is often understood as being a very static, very permanent, medical category, rather than of a state of being, or a set of experiences, that can fluctuate and change. If disability is seen as a permanent category, identifying as disabled is equivalent to giving up hope for recovery. Gwen said,

It's been something I've had to really come to terms with. It feels very permanent, it's not something that feels like it's going to go away. When I first got sick, it was a lot of feeling like we're going to figure out what's wrong with me, and we're going to fix it, it's going to be fine.

Giving up on the potential for recovery means entering that liminal space of identity development where you are no longer the person you used to be, but you do not yet know who you will be. In my experience, it is a scary feeling. I used to be a very athletic person. I played soccer, I danced competitively with a studio team, and I did gymnastics; I liked to run, and exercise, and was very fit (yes, I had abs). So, when my pain started and was hardly noticeable at first, I thought I must have strained a muscle, it would get better. But it did not get better, it got worse. As it did, I just thought I was continuing to aggravate an injury that had not fully healed, so I took time off from sports. It continued to worsen while I was inactive and that is when I started seeing doctors. They sent me to physical therapy, they prescribed muscle relaxers and steroids, they gave me braces, they taped my knee, but nothing helped. I saw doctor after doctor, convinced that the real problem just had not been found yet, but once it was, I would stop having pain and be able to return to sports. I did not want to close the door on recovering, because that would mean accepting that my pain and the limitations because of it was permanent, and that fear that I would never be the person I was prevented me from recognizing my disability for what it was. As the Forber-Pratt and Zape development model clarifies, acceptance is not all positive. Within the process of acceptance is frustration. Within the process of acceptance is grief.

Grief

For some, identifying as disabled comes as a great relief because there is finally a label that validates their experiences, and adopting it comes easily. For others, accepting the disabled identity comes with a period of grieving. Rane's education and employment background as a social worker positioned them to understand grief, and they explained it like this, "I'm kind of glad that a lot of my early work was in death and grieving, specifically. Western society doesn't do that very well when it comes to actual death and end-of-life, but also when it comes to acknowledging that grief comes from things changing." Grief is a process that attempts to find meaning in loss. Existential grief is a process that attempts to find the meaning of loss in life and the meaning of life after loss.

Stephenson and Murphey (1986) argue that chronically ill and disabled experience ongoing loss, loss that forces us to confront undeniable realities of loss related to disability. This ongoing type of loss and grief makes typical, linear models of grief unsuitable for disabled people. Linear models operate on three assumptions: the end point is knowable, the cause of grief is singular and can be adjusted to, and source of grief will eventually be removed physically (Worthington 1994). The chronically ill and disabled must face changes in ability and self-image, alienation from former self, death of the imagined future self, loss of social status or acceptance, and continuous events that initiate grief in cycles rather than linear progressions (Stephenson and Murphey 1986, Worthington 1994). These participants grieve the lives they once had and the lives they imagined before disability, such as their education goals, dream careers, social lives. They grieve the abilities that have been lost, the life they missed out on, and the ways their life could have been different if their disability had been recognized sooner. Participants face these losses and forge new meanings constantly. Grief is not simply the first step in acceptance of disability, it is a continuous process that disabled people must work through to produce meanings of life and identity.

Loss of Former Self

Integrating the disabled identity means accepting a different version of yourself, a version that can range from being slightly altered to profoundly different than before. Participants described feeling disjointed from things they used to do. They used to be athletes, they used to run miles, they used to like going to the movies, they used to like music, they used to travel. They used to be able to do things that they no longer can. Ashley said,

People don't realize that I've had to go through a grieving process. I used to be a very extroverted person, I would go out way more and just be much more social with my friends. I just can't do those things [...] It's a little bit weird having lived this whole other life where I was very physically able for a long period of time, and then I transitioned into being less physically able to do things and having to understand what my limits are and how to control those limits.

The contradiction between the old self and the new self is an internal conflict that Gill (1997) would note as a barrier to psychological wholeness, resulting in painful disintegration and feelings of anger, frustration, shame, and guilt. Among chronic illness and disability, guilt takes on a less standard shape. By accepting responsibility or blame for illness, symptoms, or loss of ability, guilt is used to cope with existential grief (Stephenson and Murphey 1986). Rachel's identity transformed with the loss of abilities and former identities. She said, "I used to identify as an academic, I used to identify as a traveler [...] and because I can't necessarily do those things or do them well anymore, I prefer to just say I am disabled." Rather than disability being integrated into identity, it replaced the identities that were lost. Control is asserted over the condition and loss experienced by accepting responsibility for it, avoiding a painful confrontation with existential grief and new meaning making.

Loss of Future Self

Ashley said, "I had to go through this process of grieving because I can't live that life, but I also can't let myself be sad about the life I'm not able to live." Many participants had expectations of what their lives were going to look like, the goals they were going to achieve, the places they were

going to live, the work they were going to do, and many of those expectations had to change. Linear models of grief are generally completed in 6-12 months (Worthington 1994), but the continuous reminders of lost abilities, lost identities, and lost dreams keep chronically ill and disabled people stuck in loops of grieving and accepting.

Some participants in this study had to grieve the aspirations they had for themselves. Some wanted to be pilots, firefighters, doctors, film directors, travel photographers, and parents, but due to the unavoidable constraints of some conditions, participants found themselves no longer capable of the careers they had once dreamed of. Morgan said, “I wanted to do a lot of things that I now can't do because of my disability. I wanted to go into the Air Force and be a firefighter, but none of that's possible now because my disability.” Morgan’s seizures and the impact of her condition on her motor skills would make careers such as these not only difficult to sustain, but also very dangerous for her health and safety. Raven was already working her dream job— a production manager on ghost tours and leading a maintenance crew—when her condition came out of remission and forced her to quit. The physical stress Raven’s work put on her body aggravated symptoms, which if not properly managed, could lead to dehydration, fainting, and malnutrition. About having to quit working she said,

I liked to build things, fix things, and paint things. I just can't do that line of work anymore. I was very proud of my work, and it was something I loved, then I lost it all. Really it took probably a year of going through stages of grief. I can't do it anymore, yet I want to.

Unlike in models of linear grief, where the source of grief eventually is no longer present, the loss of ability is a continuous source of grief.

Continuous sources of grief negate the first assumption of linear grief: known end point (Worthington 1994). The significant loss to who Rachel saw herself as and the future she had planned for that person is a grief that does not follow linear models with a start and an end. Rachel saw herself as an academic, she had lofty ambitions of achieving multiple degrees, even PhDs, but

had to withdraw from college in her second year due to complications that arose from a surgery. She said,

I still go through it all the time. When I actually really sit down and think about what I wanted, you know? I try to think, 'Well even if I can't get a degree at this time, who knows what the future looks like,' even though I really, truly, honestly doubt that I will ever get even an associates level degree. There is a huge, huge well of grief about that.

Rachel's grief has no knowable end point. The future of her condition and the future of her ability is suspended in a cloud of unknowns.

What was Missed and What Could Have Been

Many of those I spoke to started experiencing their symptoms in middle or high school, missing out on a lot of the significant milestones of the teenage and young adult years. Some participants talked about missing out on important high school and college milestones and experiences like extra-curriculars and clubs, sports, prom, graduation, living in college dorms, getting their first job, moving out of their childhood home, and so on. Though Gwen has been able to attend college as she anticipated, it has not been the experience she hoped for. She said, "I haven't really had the traditional college experience at all. I always saw myself living on campus, being involved, things like that. Because of my illness, most of my experience has been alone in my room with my laptop." Living in the dorms on campus, having a roommate, joining clubs, and going to campus events are all part of the idealized college experience.

Gwen felt robbed of that experience because of the danger being immunocompromised during the COVID-19 pandemic has posed for her. She has had to make choices to prioritize her safety that result in feelings of additional loss. Devyn also did not get to have a lot of the experiences she thought she would. She started experiencing increasingly severe symptoms of chronic fatigue in middle school, and looking back at her high school years, she said,

I didn't get to grow up the same way my peers did [...] By the time I was 16, I was just so separated from other people my age. I was talking to and seeing more doctors than people my own age, and I didn't get to do all those experiences that teenagers got to do.

Devyn missed out on all the experiences she associated with that stage of life: attending traditional high school, playing high school and collegiate sports, getting her driver's license, getting her first job, going to college. The lack of a lot of these experiences contribute to why Devyn, at 24, says she still has a hard time seeing herself as an adult.

Like Devyn, others spent years of their young adult lives focused on getting a diagnosis or treatment. Some participants, like Victor and myself, wonder what life could have been like if we had been diagnosed sooner. Victor said, "It's definitely been a period of mourning. I think of all the help that I could have gotten if people were to listen to me, but sadly nobody did, so now I think it's a lot worse than what it could have been." Victor was unable to access accommodations that could have improved his quality of life until recently. Knowing that you could have been helped, knowing that you experienced more pain and hardship than you had to, is profoundly difficult. I have been misdiagnosed more times than I can count, resulting in treatments and surgeries that have created more problems and more pain over the last five years. Even as I write this, I am recovering from my third knee surgery. I have a three-inch incision, 15 stitches, a minimum of six months of physical therapy ahead of me, and five years' worth of atrophy, or muscle death, all because a misdiagnosis led to a detrimental surgery being performed. I was 16. I have to think, what would the last five years have been like if I was properly diagnosed and treated from the beginning? What would I have been capable of, what would I not have had to give up? I have to grieve the meaningless of loss that was preventable.

Multiple Identities and Moving Forward

Loss of ability and loss of former identity can elicit feelings of liminality during development of new identity. Lacie felt conflicted by the contradicting aspects of her identity, feeling as if she must be one or the other due to societal dichotomy, the expected roles that people can play (Goffman 1959, Valeras 2010). She said,

Choosing to identify with one facet of who I am is weird. There's also the conflicting fact that I'm a healthcare professional, but I'm also a healthcare consumer. That butts heads. Yes, I weightlift, yes, I'm disabled. You know? There's a wheelchair user at my gym that has really given me the confidence to screw it and use my cane. Seeing other people embrace that part of their identity has helped. It used to be that if I was having a bad walking day, I wouldn't go to the gym. Now, I think maybe I still can, I just need to make it work a different way.

Lacie is suspended in a form of sustained liminality (Jackson 2005), unable to fit into one societal box, but she is becoming accepting of that fact. Lacie is learning and accepting that the disabled identity does not have to contradict the other pieces of her identity, it can be integrated as one of the many facets of herself.

When accepting disability, participants expressed that sometimes you have to let go of the life you had, and sometimes the life you imagined, and metamorphize into something new. That, of course, does not always happen without growing pains, but I think Gwen had the most beautiful explanation of the grief that comes with disability,

I think living with an invisible disability is all about confronting your own identity all the time, and that's hard. I always use the word soul, because I know not everybody believes in something spiritual, but there's a separate thing from the mind and the body about you as a person, and that's the part that chronic illness or disability touches that people don't talk about. That's been the hardest part for me: changing as a person. It's been good change, but it's difficult. You are constantly changing when you have an invisible disability, probably more than other people. You don't have the ability to stay stagnant, because you're always trying new things to try to keep your body safe. It means that you have to leave a lot of things behind, and a lot of people behind, and keep shedding your skin and growing and transforming.

Growth, Community, and Engagement

Despite all the loss and change that participants are grieving, several described the positive aspects and personal growth that have resulted from experiencing disability. Participation within disabled communities and interests in activism were positive changes for many, and some found life paths previously unexplored that allow them to engage with disability. Participants describe both interpersonal and intrapersonal changes, more patience, kindness, and acceptance for themselves and others. Some described changes in how they perceive disability and having pride in disability as a

form of diversity. But mostly, participants described coming out the other end of identity development with a better understanding of themselves. Stephenson and Murphey said, “It is an irony that the victims of chronic illness or disability are forced to confront a more authentic existence than society as a whole,” (1986, p. 144).

Butterflies

As Gwen said, invisible disability means changing, growing, and transforming as a person constantly. The participants here discussed how identifying with and experiencing disability changed the way they thought about disability, their own abilities, and their treatment of others. Victor described how experiencing disability himself made him confront the ableist perceptions he learned. He said,

I just started being a lot nicer to myself [...] Identifying as disabled has helped me work through a lot of internalized ableism. I feel like I treat people a lot nicer and I'm a lot more understanding, instead of that toxic mindset of, 'well I go through this, and I can do just fine.' I'm really happy about that. It's very unfair to hear, regardless of being disabled or not. Everybody has different pain thresholds.

Many participants noticed that identifying and accepting disability positively impacted the way they treated themselves and others: kinder, more patient, and more forgiving. It was expressed often in interviews that invisibly disabled people know, probably better than anyone, that you never know what someone might be struggling with that you cannot see, so grace should be given to everyone.

Gill said, “In order to affirm the disability experience as a positive and important feature of our identities, people with disabilities have had to separate and individuate from a parent culture that fears and devalues disability,” (1997, p. 44). Wendy elaborated on how accepting disability impacted how she views and understands her limitations, saying, “Identifying as disabled has allowed me to accept myself more, what I can and can't do [...] I'm not sure really if my behaviors changed, it was really just recognizing them for what they were. It's still tough, but it's a little freeing at the same

time.” Limitations are not failures. The social model encourages a shift towards viewing disability as diversity, a neutral human trait rather than a medicalized problem, or even as a unique culture to be celebrated. Stella, Gwyn, and Rane talked about their feelings towards disability identity becoming something that was neutral or positive for them. Stella said, “For me, I don’t really think of the word disabled as a bad thing or a negative connotation. I just feel like we are all unique and different and weird. I just am who I am, and I like it. I accept who I am.” The disabled are the largest minority group in the United States, and the only minority classification anyone may become a member of at any point in life. Disability is an innate part of humanity. Reflecting on the way disability is treated in society, Ava said,

Disability is part of who we, as humans, are and always have been. It's hard, but it can be such a beautiful thing when we're able to accommodate and make room for people [...] The way we treat our disabled people is a really good reflection of who we as humans and a society are [...] When we are able to accommodate people that are in need, it shows the best of us.

Community

Disabled communities, and communities specifically for those with invisible disabilities or rare conditions, were vital to the participants in this study. Disabled communities offered them a space to exist without question, without challenge, and be with others who have similar experiences. Disabled people can find support, validation, advice, ideas, doctor recommendations, they can learn from others’ diagnostic journeys, get clues that can help lead them to diagnosis, and find information on a range of conditions, especially those that are less well-known. Discovering the term ‘invisible disability’ opened doors for Ava to find communities specifically for conditions like hers. She said, “Once I found that vocabulary, I found my people. I found a group of people I could identify with, that understood. Even though our disabilities aren’t the same, we are all kind of going through something similar. It’s so validating and comforting, and a community feeling for me.”

In these spaces, the experiences of disabled people are appreciated as valuable knowledge, oftentimes more valuable than that of doctors. Flor says, “People’s firsthand experiences are more important than what the doctors have to say... Doctors aren’t as aware of it as the people who actually experience it are.” The participants exhibited a strong sense of trust towards other disabled people in their communities. The expertise that disability communities represent are something that the participants have relied on for knowledge and support. Shelby said,

I think identifying as disabled has definitely given me a safety net and a network. Obviously, it's not just me, there's a ton of other people out there. If I have questions, or an issue that I need advice on related to my disability, I can ask and there will usually be people who are able to answer... Sharing these tips and tricks, sharing things that help, whether they be products or methods or whatever. Just having that sort of community to reach out to.

Multiple participants, through recommendation of others in the community, have found ways to manage their conditions and symptoms: purchasing their own mobility aids, such as wheelchairs and canes, and other medical-grade equipment for home use, such as transcutaneous electrical nerve stimulation (TENS) machines or shower chairs; employing herbal medicines, cannabidiol (CBD), and marijuana; managing diets and exercise; utilizing headphones or earplug, sensory swings, electrolyte powders, and more.

The shared expertise on management strategies in disabled communities provides more than just suggestions, it provides emotional encouragement. When a doctor would not validate Flor’s need for a mobility aid, they found that disabled communities did. Flor said,

I remember looking at different websites with all these different people using canes and using their mobility aids and saying, ‘It's OK to use these things, and to identify as disabled even if you feel like it could be worse.’ [...] So, I finally bought myself cane one day. On the way there, it was just this horrible struggle, and on the way back, I was noticing just how much easier it was, how good it provided.

Flor found validation from peers to replace the invalidation from medical professionals and encouragement to be their own expert in what they needed.

Gwen felt grief over what she lost, but also an appreciation for what she gained. Disability is a positive element in her life, and she feels a sense of duty in spreading that positivity with her community and with others. She said,

It is weird to think about adulthood without this [disability] because it's all I've ever known. That does make me a little sad. When I see my best friend, [...] it's hard to watch her do things that I thought I was going to do and didn't get to. But I am also doing things now that nobody thought I was going to do. I had an interview earlier this year with a congressional committee talking about my experience with Lyme disease. I would have never put myself out there like that before, especially with the government. I had another interview earlier this month with a congressional committee about costs of drugs. I'm writing a book. So, I've done a lot of things that, as a young person, I never thought I could do. Even in disability, there's a lot of things that I found that have pushed me to a different level of appreciating life that I am grateful for.

VI. YOUNG ADULTHOOD AND THE INACCESSIBILITY OF LIFE

Young adulthood is the stage in an individual's life when they are transitioning from life as a child to life as an independent adult. This life stage is marked by characteristics of identity exploration, instability, liminality, and opportunities to transform. During this stage, young adults explore new possibilities for defining their life. The markers of adulthood may vary individually based on the complex intersections of identity and upbringing, but societally in the United States, there are three generally accepted criteria of adulthood: acceptance of self-responsibility, independently made decisions, and financial independence (Konstam 2015). Though Konstam argues for trends that adulthood is being accomplished later for young adults in the United States due to an increasingly complex and different world than generations before, the inaccessibility of life in the United States for disabled young adults increases the struggle of finding their place in society.

The role of disabled people in society has long been a topic of discussion, notably since Talcott Parsons' theory of social roles in the 1950s. Parsons introduced the sick role to absolve the ill from social expectations as long as they were seeking medical care to recover and become productive members of society again (Cheshire et. al. 2021). Hay (2010) argues there is no model that meets the reality of living with chronic illness and that social response to illness is directly linked to visibility and ability to be productive in society: Those with visible illness are met with either praise or pity, while those with invisible conditions are viewed as normal or lazy (2010). However, the ability to be productive is narrowly defined in neoliberal capitalist systems in the United States. The social model of disability argues that ableist and inaccessible structures in place by the neoliberal system are really to blame for limiting the full participation of disabled individuals in society, not disability (Gannicott 2018, Mladenov 2020, Ware 1992).

Invisibly disabled adults in the United States face a problem that is twofold. First, they live in a system that disables them because it is inaccessible and ableist. Second, their disability is not

recognized because it does not fit into the narrow confines of the sick role that is accepted. The inaccessibility of life hits young adults the hardest due to the transitional nature of the life stage, where their education, professions, independence, and social relationships are in the beginning stages of expansion, creating difficulties and delays in their transition into adulthood. In this chapter, the participants share their experiences with school, work, money, family and friends, and life in the public eye and the meaning these experiences have for them as invisibly disabled young adults.

Education

The educational experiences for those represented in this study vary widely based on the age in which they began experiencing symptoms, what those symptoms were, and when they were able to begin seeking medical care. The participants here identified some of the additional hardships that come with their disability in school settings, such as the impacts of symptoms on their schooling and their schooling on symptoms, medication, being out sick or hospitalized, and COVID-19. Barriers and limitations in education act to delay and restrict the level of education obtained, forcing some students to continue their education at slower paces, drop-out or take medical leaves, or forgo higher education altogether. Those who continued on to post-secondary education faced barriers accessing accommodations, and subpar accommodations when these were accessed. The experiences with disability in all levels of education, from primary to post-secondary, shaped the opportunities participants felt were available to them as young adults— educationally and professionally.

Symptoms and School

Common symptoms associated with the conditions represented in this study are pain, weakness, fatigue, poor concentration, headaches, memory loss or black outs, fainting, seizures, dizziness, and balance issues. Experiencing symptoms in the classroom can negatively impact the way a student is able to function, comprehend, participate, and succeed in their education. Shelby is

currently enrolled in a local university where she is seeking her degree in communications. Though she has had positive experiences with her university's accommodations, she identified pain, focus, and energy as significant struggles in school. She said,

My disability mainly affects my time at school in two main ways. I'd say the first way, which is one of the biggest, is writing. I have some issues with strength and my joints that prevent me from handwriting a bunch, so I do have some accommodations [...] The other one that I've had issues a lot with is energy and focus. Sometimes I just run out of energy and then I end up getting behind in my schoolwork [...] Last semester was horrible for that. I turned in a couple of my final papers a couple of weeks late, and that really affected my grades.

Multiple participants, including Heather and myself, share Shelby's experience with hand pain. Hand pain, including pain in the fingers and wrists, can prevent handwriting, note taking, and typing. Unfortunately for me, I experience pain when writing and typing, as well as difficulty concentrating because of A.D.H.D. Writing this thesis requires hours of dedicated writing time per day, hours that I have to divide up as much as possible because typing too long makes my fingers and wrists ache for days on end. However, only working in short bursts is not conducive to the way I experience A.D.H.D.; I need longer to get really focused and productive. My pain, concentration issues, and the way those two problems interact, have been a significant difficulty for completing this thesis on time.

Focus is a problem that affected many of the participants in school, especially those with A.D.H.D. diagnoses like me. When Wendy transitioned from high school to college, she noted an increased difficulty in managing her A.D.H.D. symptoms with medication. She said,

In high school, I used to do all my homework at school because I knew I couldn't do it once I got home [...] because during the school day, my meds would help. Then, in college, the classes are more separated. It's nice to have time in between, but with the way medication works, it's hard when you don't know if it's going to wear off before your next class.

Trying to align class and medication schedules can be difficult with the little control that students have over class options and times, leaving open the possibility that they will be unable to manage their symptoms in class. Medications are used to manage more symptoms than just focus,

they can also manage pain, seizures, headaches, etc. Timing medication can be one difficulty, but the medication themselves can be another. Medications have side effects, creating even more incompatible symptoms in the classroom.

Medication side effects and physical pain share a negative effect on students' cognition.

Heather noted the impact that pain and medication had on her memory and concentration in school,

It was just sort of draining, the school environment. Then being expected to be on top of things mentally when you're physically in pain is hard, to say the least. There are some pretty significant cognitive issues that come with not only having chronic pain, but also being on medications that affected my memory and my ability to focus in class.

Heather demonstrated the inequity of having equal, rather than equitable, expectations for chronically ill and disabled students as those who are able-bodied and neurotypical. Pain is proven to negatively affect attention span, working memory, and long-term memory, making constant pain inconducive to learning (Moore et. al. 2012). In high school, Morgan's symptoms consisted of severe headaches, dizziness, and even black outs. Those symptoms caused her to miss a lot of school, but she told me, "The days I was at school, I wasn't really at school. I would lay with my head down, not really paying attention [...] I couldn't absorb information that well because I was focused on my pain the whole time." Like Morgan, I often experienced days at school where I would leave class having not heard a word of what was said. My pain tends to make my brain go on autopilot; I would be there, but I would be counting the seconds until class ended so that I could go home and try anything to alleviate my pain. I tried countless things in attempt to manage my pain in class—topical creams, TENS units (a device that delivers mild electrical stimulation to reduce pain signals and relax muscles), medications, I even brought ice packs to school—but some days, nothing in the world would block out the pain enough to allow me to comprehend the material. I always tried to tough it out, because I wanted to be a good student, but some days I had no choice but to leave class.

Pain, lack of energy, and inability to focus not only impact the ability to learn but result in negative feelings about oneself as a student. Despite loving school, Heather had some unfavorable

experiences prior to being diagnosed where she was made to feel bad about her inability to participate. She said,

Starting from the beginning of when I got sick, I was 12 years old and I was in middle school, which is hell for everyone whether you're disabled or not. I had gym class and I had to deal with not only being disabled, but undiagnosed. It's not like I could get a doctor's note or even explain it to a gym teacher, who was like, 'OK, now go run a mile' and I'm like, 'Oh my God I can't do that'. It was just sort of having to deal with that and being 'bad' and non-participatory in gym class because I knew I couldn't do it.

Feeling bad, difficult, or non-participatory, or repeatedly receiving low grades can stunt how one sees their self-efficacy, their potential for academic success, and negatively shape their self-image overall (Bergen 2013). They may think they are not cut out for school, such as how Ryan felt about life in general before being diagnosed, and give up advancing their education altogether.

Symptoms have an impact on students in school, but school also has an impact on the student's symptoms. The stress and exertion associated with schooling can trigger crashes or flares, a sudden worsening of symptoms that eventually subside. Raven's dream degree and career had to be reconsidered due to the high-stress nature of the degree and profession. Stress in any form can exacerbate her condition, causing a flare. She said,

The schooling is high demand, and so is the job. Stress can be a trigger, whether it be excitement, like good stress, or bad stress. I have to try and chill out as much as possible, and that's not really the profession for that [veterinarian]. I guess I just kind of gave up on that one.

A flare of Raven's condition almost always results in severe dehydration and even hospitalization, so it is no surprise that she was forced to make significant changes to her lifestyle in order to manage those triggers. Difficult content, assignments, exams, grades, etc. are sources of stress for many students. All of those stressors were intensified by Devyn's frequent absences when she first began experiencing her symptoms of fatigue. She said,

It was stressful because I missed so many days and I would have so much stuff to catch up on. I was always missing what was going on. It was like definitely one of the most stressful periods in my life [...] I would find out later that stress and anxiety is exertion in its own right, and when you're spending all your time anxious over something, you're spending all

your energy on it. It can easily cause like a crash for me. And I think that definitely happened in high school multiple times.

Despite being out for an illness, Devyn was still responsible for the material she missed. The stress of having so much work to catch up on exacerbated her symptoms of fatigue, creating a vicious cycle of worsening symptoms, missing school, and getting behind.

“Out Sick”

Missing school was stressful for Devyn, and unfortunately, when she was first beginning to experience her symptoms, she missed a lot of school. The absences raised difficult questions among her parents, teachers, principals, and peers without a diagnosis yet to point to as an explanation. She said,

Even for half a second, my dad was questioning it. I know that if he did, there had to have been a lot of other people who thought I was just skipping school [...] I know that my mom had so many problems with my principles and my teachers, trying to explain to them about why I was missing so much school. It was 7th grade when I first got sick, and I missed like two months that first time. I missed all of 8th grade practically. I had to do all these tests to try to get back in the 9th grade the next year [...] then when I came back in 9th grade, by that time when I was missing like a week or two.

At first, Devyn’s father suspected that she was faking illness to avoid school, and worried that she was being bullied. Her mom had to fight with principals and teachers to make them understand that she was missing school as a result of an unknown illness they were seeking diagnosis for. Her peers did not believe that she was really sick when she was gone or would become annoyed with her constant absences. To this day, Devyn still worries about what her friends, classmates, and teammates thought about her during this time. Around the time of her diagnosis, Morgan also missed a significant amount of school. She said, “I was diagnosed when I was 17, it was my senior year of high school. I missed about two months that year.” Since most doctors only see patients on weekdays during business hours, therefore school hours, emerging and young adults have no choice but to miss school in order to seek care for diagnosis.

Despite the absences and difficulties of their symptoms, Devyn and Morgan had the opportunities to return to school and graduate. In high school, Flor's education was complicated by symptoms related to their mental disabilities, autism and D.I.D. Flor said, "When I was 17, I was halfway through my senior year of high school when I had to be hospitalized due to my mental health and mental disabilities. That meant that I couldn't graduate, even after almost making it." The symptoms that Flor was experiencing at the time was a significant disruption that prevented them from being able to graduate, but their health and well-being had to come first.

COVID-19

With the COVID-19 pandemic being a monumental health risk for those with autoimmune disorders and/or those with symptoms of a compromised immune system, these individuals often have to make choices to prioritize their health and safety. With increasing inattention towards COVID-19 by people eager to return to their normal lives, those who COVID-19 still poses a significant risk to are often stuck between a rock and a hard place when it comes to making decisions to prioritize their health. The attendance policies and COVID-19 policies at Wendy's university put her in a difficult position, making her choose between her education and the safety of herself and those around her. She said,

More people act like it's over, even though it's definitely not. For my one in-person class that I had that semester, it was a philosophy class. It wasn't the kind of class you could just not go and be able to catch up [...] That class in particular was very crowded for Fall 2021. It scared me a lot to go in the middle of a pandemic. People were coming sick because they would count participation once a week, so if you weren't there you wouldn't get points for that. My school had decided at one point that if somebody in a class got COVID, they didn't have to report it to the class. It's very much bullshit. My whole family is immunocompromised, my P.C.O.S. is a condition that makes me immunocompromised, my roommate at the time had a similar condition so they were also immunocompromised, and their girlfriend was also immunocompromised. Most of the people I came into contact with were immunocompromised, so I was scared to potentially get anyone infected.

The inconsequential treatment of a wide-spread, highly infectious pandemic like COVID-19 is a serious threat to the lives of immunocompromised people. As Wendy's case demonstrates, even

something as mundane as attending class cannot be taken lightly when it could mean endangering the lives of themselves and others. She wished that her professors were still making more of an effort to offer hybrid options for attending classes. The combination of COVID-19 and her symptoms urged Wendy to take a medical leave from school for the year, but she hopes to continue her education when she is well enough. In addition to fear, the treatment of COVID-19 as minor and its disregard also brings forth loneliness and isolation for the immunocompromised. Gwen did not get to have the college experience she imagined, because of COVID-19's emergence. She describes herself as being very extroverted and feels the isolation during COVID-19 has been detrimental to her education and happiness. She said,

I haven't really had the traditional college experience at all. I always saw myself living on campus, being involved, things like that. Because of my illness, most of my experience has been alone in my room with my laptop. I'm a pretty extroverted person, so I think that social isolation effected my education as well. It's difficult, it's been really difficult. I don't want to sound insensitive, but it was a little easier when we were all doing it remotely. It felt a lot less lonely, I guess, because we're all going through this horrible thing together. Then people started going back to their lives, and it's been hard to feel left behind again.

Despite many people getting to resume their lives in the wake of COVID-19, those living with compromised immune systems feel left behind, like their lives are worth less than the normalcy that some wish to relive (Morris and Astor 2022). In January 2022, a public health official offended many in the disabled communities after sharing “encouraging news” (Scheier 2022). about the studies showing that more than three-quarters of the omicron variant fatalities were among people with pre-existing medical conditions. Later the same year, President Biden announced the pandemic was over, intensifying the danger, fear, and isolation of disabled people invisible.

Accessing Accommodations

The Postsecondary National Policy Institute (PNPI 2021) reports the challenges on campuses that disabled students have identified include physical accessibility of campus, negative interactions with students, stigma, added work of seeking accommodations and support, inadequate

accommodations, and having accommodations ignored by faculty. For the participants who have pursued a post-secondary education, recognition of their disability through the university's disability center and accommodations such as the ability to record lectures, test in quiet environments, and priority seating, have been crucial to their success. However, accommodation also proved a burden to obtain. Participants dealt with internalized ableism that prevented them from thinking they qualified for accommodations, difficulty understanding the process to apply for accommodations, problems with their university's disability center, trouble knowing what accommodations were available, issues getting the accommodations they requested approved, and accommodation sufficiency.

After high school, Gwen went straight to community college. There she struggled with managing multiple conditions and maintaining her grades, which resulted in her withdrawing and returning to school multiple times before completing her degree. It was not until she sought a four-year degree that she considered requesting accommodations. She previously did not think she qualified for assistance due to the invisibility of her disability, and she told me,

I wish I would have figured out that process earlier in my education. I didn't think that they were meant for me, I guess. I know that sounds kind of silly, but I guess when I thought of accommodations, I thought of people who you can physically see their disability. That is probably some internalized ableism that I didn't realize I had as an early teenager. I just thought I'll tough this out, I'll figure it out.

Multiple participants struggled to recognize the ways their condition impacted their education, or the ways that accommodations could help alleviate those difficulties. Cameron is currently obtaining credits through Straighter Line, a self-paced program that awards college credit, as well as working through some other credits online with a university before transferring to a medical program. The full impact of her condition was brought to her attention by her therapist, who persuaded her out of the mindset that she was not qualified for accommodations. Cameron said,

My therapist was the one who was blunt enough that when I was complaining about how my motivation has just been completely downhill over the last year, she's like, 'well yeah, but you've gotten diagnosed with Crohn's disease and you're disabled, and this and this.' She was kind of urging me into looking at disability services at my school and stuff. I kind of had the mindset that I don't like need that, I'm not sick enough to need that kind of accommodation or anything.

In some cases, not understanding how to get accommodations or what kind of accommodations are even offered can prevent students from seeking assistance. Rane went their entire college career without formal accommodations that might have helped them. They said, "I never tried to get accommodations because I didn't understand how the process worked or that a lot of the accommodations that people think of aren't the only ones that you can ask for." Disability centers are often not explicit about the full range of accommodations available prior to a student beginning the process with them, opting instead to list the more obvious accommodations, such as interpreters and captioning, note takers, and assistive technologies, such as access to screen reading software (A California University, A Colorado University, A Pennsylvania University, A Texas University). If these are the only kinds of accommodations visible to students seeking this service, they may shy away from attempting to access accommodations at all, like Cameron and Rane, due to internalized feelings of not being disabled enough to ask for help

Once participants decide that accommodations are something they needed, they begin the process of working with their university's center or office for disabled students. For Ryan, Gwen, and Shelby these experiences were mostly positive. Once Ryan was able to obtain a diagnosis, working with the disability services at his university was a pleasant experience. He said, "When I started off, I had no idea what I could even ask for. They were able to make suggestions to fit my needs and help communicate them to all of my professors, so the burden wasn't on me alone to explain myself." Taking the burden off communicating with professors was the support that Gwen appreciated most. She said,

It's just been a nice to have that safety net to not have to explain my condition to them either. That was something I kind of struggled with a lot. I have a condition that is not universally understood, and it can be kind of exhausting and traumatic to try to explain it to people all the time.

Shelby was pleasantly surprised with her university's disability coordinator because they already had experience working with other students that had Shelby's same diagnosis. Having someone with knowledge of her rare condition drastically improved her experience. Not all university disability services, or disability coordinators, are created equal. Heather had positive experiences with accommodations, but they came directly from her instructors. She said,

I had great professors who were willing to accommodate me, but I did not get any real accommodations through the school. The support for students with disabilities was not great at my school and didn't really do much. I had a policy where every new class, the first day of classes I stayed late and went to the professor told them the situation: I have chronic pain disorder, it's going to affect my ability to come to class some days, I have a hard time with handwritten essays in class, I might need some extended time or the ability to use a computer, this is just the facts of the matter. I had really remarkable professors who were almost always OK with that, but it was sort of like that was up to me to take care of. Not the university.

While Heather's educational experience was still positive because her professors were understanding and helpful, the lack of support from the university's disability center placed the burden of explaining her disability and communicating her needs on her and would leave her without any formal backing if her requests had been denied.

Others had less than positive experiences with both their university's disability centers, the process of obtaining accommodations, and the adequacy of their accommodations. In nursing school, Lacie received accommodations that allow her to wear ring splints, devices that support hypermobile joints, to minimize pain in her finger joints and priority seating near an outlet for her TENS machine. However, obtaining those accommodations was not easy. Lacie said,

They make it seem easy to get accommodations. In theory it's simple, but in reality, there's so many obstacles. I have to get my crippled ass into my car, go drive an hour to the doctor, pay for parking, hobble up their steps, all just to fill out a form. The doctor doesn't know what I need, I don't even know what I need, I don't know what the options are. The

disability office will meet with you, and they can try and recommend things, but figuring out what would actually be beneficial is difficult.

Despite the accommodations that Lacie has, she still feels they are inadequate to fully support her education. This is in part because of the field she is in. Lacie talked about the harsh realities of nursing school, saying,

I definitely just push through [...] I'm sure there are other accommodations that would help, I'm sure they exist. I don't even know how to go about approaching those kinds of accommodations. I don't know if I can request those accommodations and still be seen as competent [...] I don't want to feel like that, but I do. That's the environment I'm in, nursing is notorious for eating their young. Can I really show up to a clinical with a cane and expect to be treated just like everyone else? No.

Though notoriously difficult, nursing is not the only program to offer inadequate accommodations. Maggie is currently in school for her Associate's degree and has plans to follow up with a Bachelor's in special education, but is still trying to figure out how to get accommodations that actually help her. Her university uses a system with levels for accommodations, and students are assigned a level that includes access to only certain accommodations. With only level 1 accommodations, Maggie explained,

Even with the accommodations... It's not great. The recording really helps. The extra time on tests is basically useless. But I can't redo anything unless the teacher specifically allows me to. I can't turn in anything a day late [...] I tried to get extended time on due dates, and they said that's a level 4 accommodation, and I was only given level 1. I didn't understand why there were levels [...] I don't even know what to ask for... I don't know where to start. Nobody talks about it! Nobody talks about the options; nobody shows them to you. They ask you to bring in your ideas of what you need, and you tell them what you need, and then they say that's a level 4, they can't do that, so here's a level 1. It sucks! It sucks because everyone is like, 'no, no, no, we know you, you need this.' It's frustrating

A level system is an inadequate way to offer accommodations, as it attempts to measure disability against a linear scale where conditions, symptoms, and needs all increase together. Instead, disability is an experience that varies from person to person, condition to condition, even day to day. What helps one person, may not help another. Two people with the same diagnosis may experience completely different sets of symptoms and require assistance in different areas. Only the disabled

person themselves is qualified to know their experience and their needs. Gwen said, “I don't understand how they [university disability office] can reject somebody's accommodations; they don't know what it's like to live in our bodies.” Even with all the accommodations in the world, the educational experience is not the same for disabled students as their peers. Gwen continued,

Dealing with an educational institution, which is a wonderful thing, is also a really burdensome thing for a student with a disability. There are a lot of extra things that I feel like we have to do just to get through the day. School feels pretty inaccessible [...] Even if you're signed up for accommodations and they try their best to be accommodating, you don't have that traditional experience of being with an instructor, being around your peers, and getting that experience that higher education is supposedly about.

Discontinuation of Education

A combination of symptoms, medications, absences, COVID, and inaccessibility is responsible for the discontinuation of education for the participants of this study, whether temporarily or, seemingly, permanently. Ryan, Cameron, Maggie, and Stella all had to withdraw from school at some point as a result of their symptoms but have since returned to complete their degrees with proper support. Ryan said,

I tried to go to college right after graduating but dropped out after just a year. It was a lot of stress and burnout, and because at the time I was undiagnosed with anything I had no help. Then in 2019 [...] I got my autism diagnosis, and other things followed, so it was all documented. Now the university knows about the autism and fibro, and I have the necessary accommodations to do well in my classes!

Now Ryan is about to graduate, and plans to continue on to earn his Master's degree.

Flor, Devyn, Morgan, Rachel, and Raven had different experiences. Their conditions and the inaccessibility of school caused them to withdraw for good. The barriers that obstructed Flor's completion of school were man-made, rather than directly caused by their condition. While Flor's symptoms resulted in hospitalization that prevented their graduation, inaccessible institutions kept Flor from returning to school. When I asked if they had attempted to obtain their GED, they told me,

I would love to have my GED. I would love to have had graduated, and I almost did, but it just wasn't an option for me, and it continues to not be an option. The tricky thing about it [getting a GED] is that when you've been outside of the school system for a long time, they basically want you to retake some classes [...] Unfortunately, that usually requires going into an office environment for a set period of time. That just was never really a good option for me, because I wasn't physically able to go to those things.

Even if the physical barriers could be alleviated with accommodations, it is unlikely they would be able to access such accommodations without a medical diagnosis. Without a GED, Flor's employment options are limited, and they have had to lie to find work, an action they feel is a direct result of the barriers that prevented their graduation. Flor said,

It has impacted some of the opportunities... some of the jobs that I've applied to, but honestly not a lot of people actually check [...] A little fibbing here and there isn't that big of a deal. This system isn't working for me, I might as well work this system to my advantage.

Graduating high school was a major accomplishment for Devyn, but since then, all her energy has been devoted to finding ways to improve her quality of life and diminish her symptoms. The expectations she had for her future were completely altered. Before getting sick, though, Devyn was a star soccer player with a future of playing at the collegiate level. When she got sick that she became bedridden, those dreams were reduced. She said, "At that age, I was really serious about soccer and was dreaming of going to Texas Tech and playing for their soccer team. Even after I got sick and had to quit sports, I still thought I'd at least be able to go to a local college." Devyn has not been able to attend a local college either. The educational path she imagined for herself was truncated by the incompatibility of her symptoms and higher education. She is hopeful though that her upcoming surgery will result in significant improvements to her symptoms that will potentially allow her to return to school in the future.

Morgan, Raven, and Rachel were all enrolled in university already when their conditions caused them to withdraw, and they have unable to return. Morgan initially had to withdraw because of a scheduled surgery, but following the surgery, her pain prevented her from returning. Morgan

would not have been able to achieve the level of learning she desired with the severity of the pain she was experiencing. She said,

I graduated May of 2016, and the following fall I was going to go to a local university [...] I actually had to withdraw from the semester before classes started because I had to have surgery. At first, I was planning to go back after I healed up and everything, but it didn't happen that way, I ended up not going back. It was frustrating because I really wanted to go to school and do something, but at the time, my pain and everything was just too bad, there was no way I could focus on my classes.

Morgan's symptoms affected her schooling, but Raven's schooling would have impacted her symptoms. Raven had already completed a year of her degree and was prepared for her second when she began experiencing symptoms of her condition. She had to withdraw because the stresses of university would be a constant trigger, risking her health and safety if her symptoms were out of control. She said,

I was enrolled to go into my second year of college at a local 4-year university. I had everything ready, all my books bought, all that stuff. I was going to be in the dorms again. I had to have everything pulled. I had to drop out and I haven't actually been back to college since [...] Stress can be a trigger, whether it be excitement, like good stress, or bad stress. I have to try and chill out as much as possible, and that's not really the profession for that. I guess I just kind of gave up on that one.

Like many others, Raven had to make significant lifestyle changes to manage the realities of her disability. Rachel was also in her second year of university, with dreams of earning multiple degrees, when those dreams were cut short by symptoms that arose after the surgery that nearly killed her. The neurological side effects forced her to withdraw. She told me,

I was in school, I had to drop out because of all this. With the whole almost dying thing, I was so out of it for, God I want to say, two months. I was completely not there. I honestly don't remember a lot of that time, just what people told me later. I was taking classes online, and I thought even with the surgery it would be fine because I'm online, not expecting any of that [nearly dying]. I just went on and I was like no, I need to drop out. Mostly because I can't remember anything anymore, like new info is whew, it's gone. I was in my second year of college.

Rachel has been unable to return to school after that medical event due to the persistent symptoms that affect her memory. Symptoms are just a fact of living with a condition; they are not always

manageable, or avoidable, or curable. While some limitations are the result of external, man-made causes, some limitations are just the reality of the diagnosis (Barnartt 2010, Shuttleworth and Kasnitz 2004).

Educational and Professional Opportunities

The educational experiences of disabled students are different than their non-disabled peers (Brown and Leigh 2020, Wood 2017). Regardless of the symptoms they experience, or the medications or accommodations they are able to access, the expectation is for disabled students to rise to meet the expectations set for their abled peers. Ryan says, “I feel I have to push myself harder than most to succeed though [...] and pushing myself to kind of meet abled standards has caused me to crash multiple times. Taking on challenging things like earning a degree have definitely highlighted for me just how disabled I am compared to my peers.” The experiences that disabled people have with education shape the opportunities participants have educationally and professionally. Disabled students may face barriers as a result of symptoms, medications and side effects, absences, safety, and accommodations that impact their ability to attend, learn, participate, graduate, and continue their educational careers. As demonstrated by Flor, the level of education achieved certainly has a significant impact on employment options available. Konstam argues that employment for young adults is complicated by demands for higher education, citing a prediction from labor economists that by 2018, 62% of jobs in the United States would require a post-secondary degree. If these predictions hold, the inaccessibility of higher education endangers the professional opportunities of disabled young adults who cannot equitably access that level of education. Flor pointed out the dilemma between accessing education and employment, “The fact that because I'm disabled, I can't really seek higher education, but because I can't seek higher education, I can't find jobs that would work with my disability.”

Employment

According to Bureau of Labor Statistics, approximately 46.1% of disabled people aged 20-35 are employed, compared to the 76.6% of their same aged, abled peers (Bureau of Labor Statistics 2023). The participants in this study shared the highs and lows they face when seeking employment as disabled young adults: incompatibility of jobs with their symptoms, structural barriers and accommodations, discrimination, wages, and careers that bring joy and fulfillment.

Symptoms on the Job

Symptoms common among people who have chronic and invisible conditions are often discordant with the demands of employment, especially in jobs that are typical for young adults. Fifty percent of food service employees and 39% of retail service employees are 20-30 years old (Zippia 2021). Cameron has tried, but she has found it difficult to find any work that meets her needs as a disabled person, and as a full-time student, without having an advanced degree. Without being able to stand for long periods of time and being sensitive to heat, she finds most retail and service industry jobs are not a good fit. She said, “Not having a college degree, the job market is kind of limited. I just cannot be doing cashier or retail jobs, like fast food [...] I do pretty good when I'm allowed to sit down and work at my own pace... but I get beyond exhausted if I'm standing for more than an hour consecutively. So, jobs like the fast-food place where I was manning the grills or the fryers for 6-to-8-hour shifts. I could usually push through all shift, but then I would have to call out of work for the next two days [...] it was so hot in that restaurant all the time, and that doesn't do well for me either. My medication makes me practically allergic to the sun.”

Trying to juggle her needs as a disabled person, a student, and a young adult makes finding suitable employment difficult. She needs employment that does not cause her harm, but she is trying to save up to move out-of-state for school. She continued, “The problem that I'm running into with the job market is that all the jobs that I could do physically, don't pay well; and all of the jobs that

pay enough [...] I just don't have the physical capability for.” There is a discrepancy between what works for Cameron’s disability and what she needs to live on.

Another discrepancy emerged for Flor: one between the jobs that are suitable for her physical disability and jobs that are suitable for her mental disabilities. They said,

Either I'm physically being worked to the bone, honestly, I just can't stand for 8 hours a day, it's not possible for me, or I am able to sit every day but I'm having to deal with high-stress situations constantly. It's actually heartbreaking because right when COVID hit, I was working at a call center, and we were able to work from home. It was kind of the best or ideal situation I could have been in at the time, but having to talk to people all day, every day, and in very high stress situations, the amount of burnout that caused with my autism was so bad that I had to quit.

Condition flaring as a result of stress has been discussed in previous section but triggers vary widely depending on the symptoms, condition, and the individual. Even people with identical diagnoses may experience completely different symptoms, and what triggers one person’s condition may not be a problem for another. Common triggers include environmental, physical, and psychological stress; “pushing through” or exceeding pain limits; loud noises; changes in temperatures; even changes in the weather.

Rane tried working for many years, continuing to worsen their condition by continuing to strain their body with working. Finally, they had to stop and realize their limits. They said,

My body just kind of collapsed and said no. It didn't give me an option other than to deal with it. Prior to that, I just worked through it, mostly out of necessity [...] I grew up poor and that sticks with you. It took until my body just stopped and said no for me to reckon with working and my disabilities [...] Sometimes I still think I can do something kind of regular, and then I'll get hit with a flare because a thunderstorm rolls through, and I'm like, oh no, no I can't

Irregularity or unreliability when it comes to being at work or completing tasks by a deadline was a concern for multiple participants. The fluctuation with invisible and chronic conditions means that some days are better than others, and some days are much worse. They do not know what they are going to feel like tomorrow, so how can they promise to be at work? This is the problem that Devyn faces. She has a lot of skills, she is a talented writer and artist, but for years her fatigue has

been severe. Without being able to work on a consistent timeline, she feels there are no employment options available to her. She said, “There's just nothing, there's just no job I could do because with my type of illness, there's no being reliable. There's no way that I could promise anyone that I can work even just an hour tomorrow, there's no promising anything.” Symptoms that prevent reliability to employers gives invisibly disabled people little to no options for employment, even if they desire to work somehow.

Morgan feels the same way, she feels there are not any employment options that are manageable with her conditions. Morgan, and many others in this study, continued working despite detrimental effects on their health due to the pressures of affording necessities such as food, housing, medications; contributing to their households; being financially independent; paying for education; etc. Since high school, Morgan has bounced from job to job, pushing through her pain and prioritizing work over health. She said,

It's just been job after job after job because I have to call off all the time, or go in late, or get sent home early. After surgery, my body can't cope with stress the same way, so I have non-epileptic seizures. There were a lot of times that I would see have a seizure at work. I would literally have a seizure, get back up, and go back to work like nothing happened [...] A lot of the time, I would have a seizure and have to go home. If I go to work, I'm going to have a seizure, or I'm going to be in so much pain that I can't go into work, or I get sent home early. I couldn't even I can't even hold like a part time job as a cashier, I've tried that. There's just nothing that works for me, unfortunately... I really wish that there were more options for people that are disabled the way that I am. I feel like there should be something, but there's not.

Despite strong desires to support themselves, to be productive, or to have fulfilling careers, it has been difficult for participants to find careers that maintain a balance between disability and work. The employment needs of the chronically ill and invisibly disabled do not coincide with the current structure of employment.

Employment in the US

In the United States, our society is controlled through the economic ideology of neoliberal capitalism that has seeped into our education, policy, labor practices, and identities. This ideology

reverses self-improvement, competition, and hard work, creating a meritocracy that values only the most optimized and efficient in producing, laboring, and consuming (Mladenov 2020, Scharff 2016, Srnicek and Williams 2015). Disability may impact the ability to work in certain ways, but they do not negate the intelligence, skills, and desire to work that disabled people have to offer. The structure of labor practices under the neoliberal capitalist ideology is responsible for limiting the ways in which people are viewed as productive in society (Hay 2010, Mladenov 2020). Cameron, Flor, Rane, Devyn, and Morgan all displayed desires to work, but found it impossible to find employment that was flexible enough to utilize their skill while managing their symptoms. The retail and service industry jobs often held by young adults often list the ability to stand for long shifts (6-8 hours), lift 50lbs, as well as strong verbal communication skills, a valid driver's license, etc. as physical requirements whether all of those abilities are actually necessary or not.

Shelby comes across this problem when looking for jobs that accommodate her symptoms of fatigue and weakness. She said,

Pretty much any type of office job is going to fit that criterion, more or less, but otherwise it can be tricky... when you're looking around for jobs, you can't always tell what's going to work best just from job description. Sometimes they'll say things like you have to be able to lift 25 pounds, and then you never end up lifting anything.

The requirements listed on job applications are considered evidence of the "essential functions" (A.D.A. 1990) of the job and are not required to be accommodated under Title 1, Section 12111 of the A.D.A. This can act as a legal way to discriminate against disabled people and exclude them from employment, intentionally or not.

With the hypercompetitive nature of neoliberalism shaping labor practices, employers want easy, quick, one-size-fits all employees to get the job done. As a disabled person in this environment, it feels like employers do not want to slow down enough to find out what you need and make accommodations that would allow you to be the best worker you can be.

Victor's mobility issues mean that he has to find employment that allows him to sit or utilize his mobility aids to accommodate periods of walking or standing. In his pursuit of employment, Victor has experienced blatant discrimination from employers unwilling to accommodate his needs.

He told me,

I interviewed at a hotel for a front desk clerk thinking that would mean I would probably be sitting at a desk, but no. They stopped the interview after about 30 seconds of asking me questions because I said that I was disabled, and I would need to use a wheelchair. They said I needed to be able to walk from the front end of the building to the back end of the building for the two different desks... She said that if I was not able to walk or stand for this amount of time, they cannot hire me.

Victor would have been able to complete the tasks required with the use of his wheelchair, a reasonable accommodation, but even if the solution was simple, essential functions are not required to be accommodated under Title 1, Section 12111 of the A.D.A.

Accommodations have the potential to be very simple and effective, allowing disabled individuals to shine in the workplace while working around their symptoms. Ava works full-time in a coffee shop where her P.T.S.D. is sometimes triggered by customers. Ava said,

Very often there will be times where there's very drunk or rowdy patrons after things like Saint Patrick's Day, New Year's, any of those big drinking holidays. That has occasionally made me very uncomfortable. I was very grateful to have my coworkers there to stand up for me or deal with customers themselves and let me just go do dishes in the back.

The support of her employers and coworkers allows Ava to remove herself from these situations and be productive in another way.

For Stella, her autoimmune disorder results in a lot of fatigue and issues with her blood pressure. Accommodations as simple as having a structured time for her to take her lunch and redistribution of tasks on days with flaring allow her to work full-time in a job that makes her happy.

Stella said,

I've been blessed that both of my jobs have been accommodating. When you work in early childhood, with toddlers or preschoolers, your lunch break might be at 11, or it might be at 2; it's just whenever it works out. For me that is not realistic or possible, because I do have to take my medication and eat my blood pressure with drop. I don't just hangry, I will

pass out if I don't eat. One of my accommodations on file is that I have to have a consistent time every day to take a lunch, instead of very sporadically like the other teachers do... I also have a very understanding co-teacher. She can tell when I'm off my game or not feeling well. I can tell her that I can't do that task today and ask if she can do that today and I'll do a different task.

Maggie loves her job as a teaching assistant at a local school that focuses on special education, and she hopes to finish her Bachelor's in special education and become a full-time teacher there. The administration has been wonderful to Maggie, very understanding and very accommodating. When Maggie was injured at work due to an underlying condition, the school paid for the medical care she needed and ensured she had accommodations in the classroom to help her while she recovered. Despite the overwhelmingly positive experiences Maggie has had at this job, she says, "The anxiety still kicks in when you have to sit down and say you're disabled and that you need help."

Disclosing disability and making the need for accommodations known is frightening, due to fear of discrimination, not getting hired, getting fired, or being treated differently. When applying for jobs, it is common for disabled people to feel unsure of whether or not they should disclose their disability. Some believe they must disclose if they wish to request accommodations, others think disclosing is the reason they never get hired.

Wendy disclosed in case she needed to access accommodations but worries what impact this will have on her employment. She said, "On the application where it asks if you identify as disabled, I did say yes just in case I needed accommodations. I was struggling to decide whether I would put that or not. I didn't want it to change how people perceived me, or if I was allowed to do the job."

Voluntary disclosure of disability on job applications is a way for employers to circumvent the anti-discrimination laws that prevent them from asking about disability when hiring. Rane believes these voluntary disclosures allow employers to discriminate against them when hiring, and said,

Jobs take a look at my application and say no because I put that I'm disabled. I've thought about stopping that and just letting them know once I'm hired that I'm disabled, because after that, they can't fire me or else it would be discrimination. It makes me really upset, but I've just been denied so many jobs because of being disabled.

The laws that are supposed to protect equal employment are weak; loopholes exist for employers to exploit in order to discriminate when hiring, fire when disclosures are made, and refuse requests for accommodations (A.D.A. 1990, A.D.A. Rehabilitation Act 2002, and Keck 1994). Lacie knows that, technically, she should be protected from discriminatory firing. However, without explicit protections for her use of mobility aids, she fears that the use of her cane at work would get her fired. She said,

I've never used my cane at work. I feel like there's such stigma... Am I just going to get fired if I show up to work with a mobility device one day? [...] I don't try it. You know, even though legally in my job description there's nothing that says you can't use a mobility device, it does say you have to be able to do the demands of the job. But the demands of the jobs are... you know, like all this gray area that you're trying to navigate.

“No Pain, No Gain”

Without her mobility aids, Lacie has to just “push through” her pain at work. She says her training as a nurse, her identity as a woman, and her experience with invisible disability primes her to be able to ignore her symptoms to do what needs to be done. Lacie says,

I tend to kind of suck it up and just deal. Which is not great for my health, I know, but nurses are expected to do that, women are socialized that way, and people with invisible disabilities are just accustomed to making do [...] I'm trying to figure out how I can make it work as well as not coming home absolutely destroyed [...] Right now, it's a lot of pushing through it and suffering at home, which I do not want long term, but I've got about 16 weeks of classes and 14 of clinical maybe. I'm kind of just trying to keep the eye on the prize.

Participants in this study demonstrated a tendency to “push through,” as Lacie terms it, and live with the consequences of exceeding their limits, in order to do their jobs. The ability to work was very important to some participants, and the inability to do so took a toll on their identities.

Being unable to work has been difficult for Gwen to come to terms with and has required her to think critically about the feelings of being devalued. She said,

I have had to quit jobs because of my disability, it made my symptoms pretty bad. That was pretty devastating because I see myself as a very productivity-driven person. I've had to kind of challenge that within myself, which is probably internalized ableism. Like, if I'm not able to do certain things so I'm worthless, or because I can't do all the things that I used to, in the way that used to do them.

In neoliberal systems, self-worth becomes indistinguishable from the ability to perform under capitalism. Parsons' sick role only excuses people from their duty to perform temporarily, but when illness is not temporary, ideals of self-worth can become complicated or even diminished (Hay 2010).

About their inability to work, Rane says, "There is a lot of the shame, it's rooted in the general societal, 'you need to be productive for capitalism to be a worthwhile human,' kind of stuff." Disability conflicts with neoliberal labor practices in the United States. Symptoms and job requirements clash, discrimination persists, and self-worth is tangled up in the need to produce optimally. However, since COVID-19, changes have been emerging in the way the workforce is imagined and constituted.

Employment Evolution

Despite all the abysmal consequences the of COVID-19 pandemic, it forced the country, and the world, to adapt in some ways that have increased accessibility. These include telemedicine, online learning, mental health awareness, and remote employment. My favorite part was the increased popularity of curbside food pickup. It was a convenient and painless way for me to get food without having to go inside. But Ashley was more than just inconvenienced by changes that came with the COVID-19 pandemic. Her move to remote employment not only allowed her to maintain gainful employment but let her to work from a carefully controlled environment where she could better manage her symptoms, improving her quality of life. She said,

I am very lucky to work from home, at least for now, permanently. I transitioned into a new role during COVID, and at the time they were starting to hire people kind of outside their geographic range [...] making a commitment to be hybrid/virtual environment and that really helps me. It helps me a lot because again, I can control my environment a lot more if

I'm just at home. It also gives me the flexibility to do things that I need to do [...] to really maintain my improved condition [...] I call it having to behave, so having a schedule that allows me to do that on a regular basis really benefits me.

COVID-19 forced the ways of working to be reimagined, resulting in an increase of flexibility when it comes to environment and hours. Ashley commented on the changes she is witnessing in her workplace because of COVID,

I would say that on the whole, my employer is very thoughtful about different kinds of diversity, and they recognize that there are talented people that are maybe neurodiverse or have able-diversity, and I think they recognize that a hybrid/virtual environment improves people's ability to show up in whatever way works best for them [...] I feel very lucky that happened and I think that's in large part due to covid, and just more broadly that changing environment of the current workforce.

Futures in Fulfilling Careers

As young adults negotiate their identities, they seek to discover their passions and find employment that is meaningful and fulfilling. Stella found her passion teaching young children, and despite its demand on her energy each day, she loves her work. She said, “While some people don’t understand why I choose to have such an active job, that is my choice. It gives me fulfillment, and purpose, and joy. All of that is worth the fatigue it brings me.” The fulfillment Stella gets from her job is enough to offset how the fatigue affects the rest of her life. She says, “I use up 90% of my energy in the eight-hour workday, so I don’t have the energy to do things at home or recreational activities on the weekends. That is probably how it impacts my life the most.” The choice to give everything to work comes at a cost elsewhere. Education, jobs, relationships, and the responsibilities that come with adulthood— shopping for groceries, cooking, cleaning, etc. – have to be negotiated to fit alongside the realities of disability.

Heather works full-time as a speech pathologist, and when I asked her if her disability impacted her work at all, she told me,

I don't think it does, and the reason why is because I won't let it. I know that I can get through a day at my job. I often times will not be able to do anything else, I come home and then I am done. It causes other problems in my life, I don't cook because I can't stand in the

kitchen after a day of work, I can only clean on the weekends. All of my energy has to go to my job on the weekdays, but that's the priorities that I have given myself. I refuse to let being sick impact what I want from my career.

Finding equilibrium in life with disability can be a point of stress, but young adult brings stresses all on its own. Gwen desires to find a job that allows her to achieve that equilibrium and make her happy, but in addition to the fears and challenges that come with disability, being a young adult in the world right now is daunting. She said,

I am worried about having a job that will support me financially, as well as support me mentally as a person. It's not just sickness, it's also just, I'm sure you understand, being a young person right now. It's kind of scary because we have no idea what the world is going to look like. You know?

Independence

Achieving financial independence, one of Konstam's criteria for reaching adulthood, is complicated by the inaccessibility of higher education and employment. Financial independence during young adulthood is the key to other forms of adult independence, such as living independently and forming an identity autonomous of parental figures. The inability to work enough, or at all, to support oneself creates a dependence on external support, either from government benefits or from personal relationships. The emotional impact of dependence can stunt feelings of adulthood and suspend disabled young adults in that life stage of in-between.

Disability Benefits Explained

Government support in the form of disability benefits is further complicated for young adults that are in-between childhood and adulthood due to how financial benefits are awarded. There are two types of assistance: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Supplemental Security Income is federally paid support to those with limited income and limited resources. To be eligible for SSI, an individual beneficiary must earn less than \$1,913 per month, before taxes, and own less than \$2,000 in resources— including cash, bank accounts, and life insurance, and deemed resources— a portion of the resources belonging to a

spouse or parent—and be over 65 years old or disabled. Under SSI, disability is defined as a “medically determinable” impairment that results in an inability for gainful employment and has lasted a continuous year (Social Security Administration “How You Qualify”). Social Security Disability Insurance is a benefits program that is earned through employment and is based on work history and taxed earnings. To qualify for SSDI, you must be deemed disabled and have enough work credits. SSDI uses a five-step process to determine if a disability is qualifying based on income, duration, condition, and ability to work (See Figure 1).

Deciding Qualifying Disability

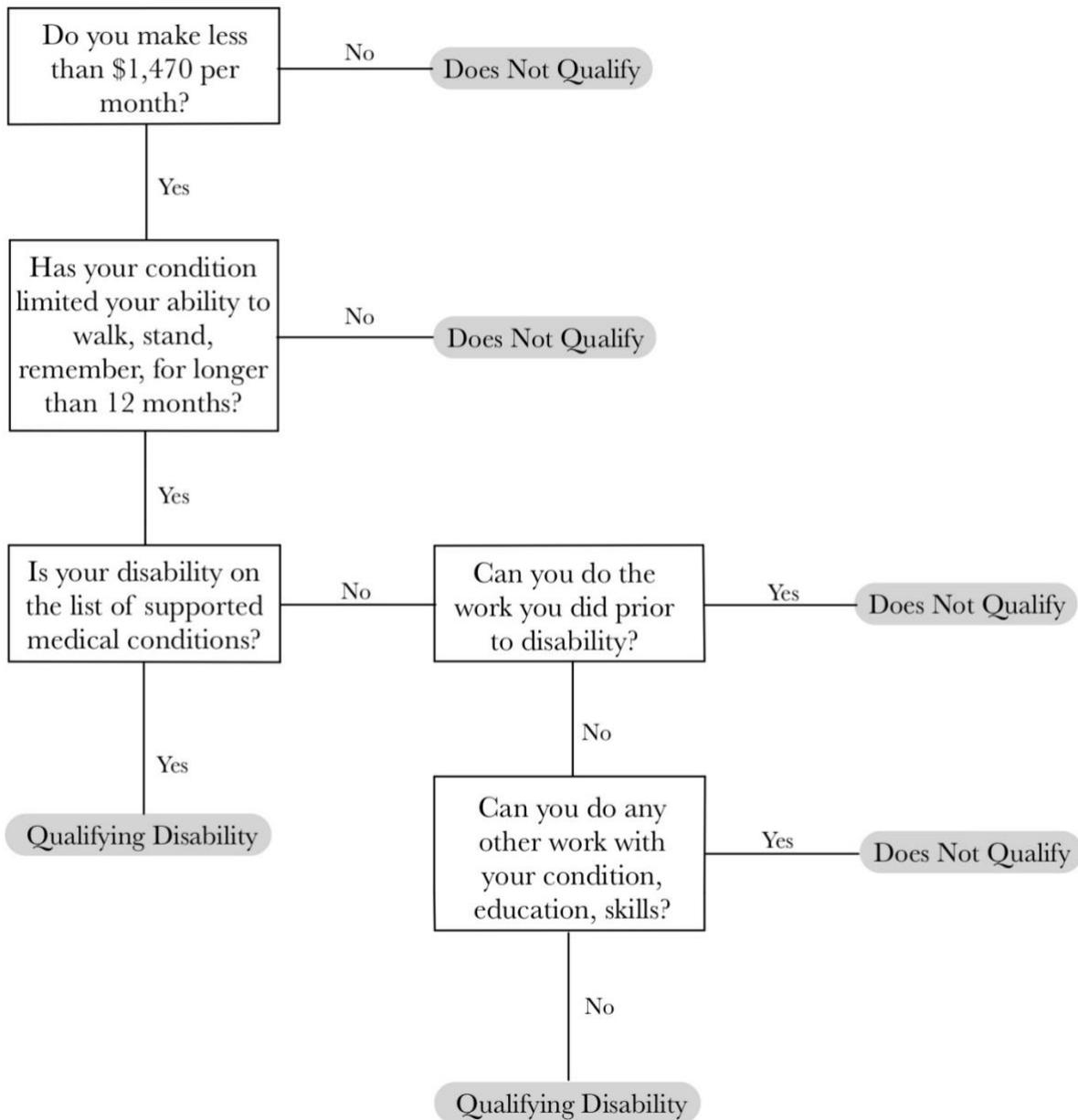


Figure 1. The Social Security Administrations Steps for Determining a Qualifying Disability.
Figure by Author.

Work credits represent total yearly wages. One credit in 2023 is the equivalent of \$1,640 earned, with a total of four credits being earnable per year. The number of work credits needed to qualify for disability benefits is a complicated system that depends on the age at which disability

began, current age, duration of work (credits earned), and time passed since work. For example, if disabled before turning 24, you only need to have earned 6 credits, or \$9,840 earned, within the 3 years before disability began. If disabled between the ages of 24 and 31, the work credits must reflect working half of the time between age 21 and the time your disability began. If you were disabled at age 27, working half that time would be three years; three years of work equals 12 credits, representing \$19,680 earned. Unfortunately, the complexity does not end there. If disability began prior to the age of 22, beneficiaries may use their parents' work credits to be qualify, with stipulations. A "Disabled Adult Child" that uses their parents' work history must remain unmarried and must not have substantial earnings, in 2023, this is \$1,470 per month. A disabled adult child that gets married or earns more than the allotted amount will automatically lose their benefits (Social Security Administration "How You Qualify").

The Not-So Benefits of Disability Benefits

Disability benefits can make incredible differences in the lives of the disabled people they support, but in many ways, the system fails to be accessible and adequate. Of the nine participants that discussed government assistance with me: one has considered applying but found it to be an unrealistic option, two have thought about looking into benefits but have not due to the negative experiences of others, one is planning to apply, two have applied and been denied, and only three have applied and been approved. The application process is difficult, lengthy, can be costly as lawyers are sometimes necessary to win an approval. People must often go to court to appeal negative decisions. The limitations set in order to qualify are unfair and obstructive to living equitable lives; and once again, the lives of disabled individuals are suspended in uncertainty and fear.

The process of applying, getting approved or making appeals, and receiving benefits is a lengthy endeavor. The average processing time of an application for SSDI is three to six months. Nationwide, only 38.9% of approvals are awarded at the level of initial application (Citizens

Disability 2023, Social Security Administration 2022). Requesting a reconsideration, the lowest level of an appeal, can take an additional three to five months. If denied again, the wait time to appeal the decision before a judge has a national average of 10 months, with the judge's decision taking up to three months after that. Nationwide, over 50% of approvals take place after appealing before a judge (Citizens Disability 2023, Social Security Administration 2022).

Raven is unemployed due to the stress of employment causing dangerous flares of her condition, C.V.S. She and her fiancé make ends meet with his income and her SSDI based on her own work credit. Raven was initially denied and had to appeal the decision. From start to finish, she fought for her benefits for a year and a half. She said,

I started applying for it when I was younger, but I had a little bit of a remission. It was just enough where they didn't want to pursue the disability anymore. So, when it came back with a vengeance in 2020, I lawyered up, because I knew better from previous experiences. If you don't get a disability lawyer, it's a lot harder to get disability for something like this [invisible and chronic], especially at such a young age. It took a year and a half, with one denial and an appeal, and then I went before the judge with my lawyer. January of this last year, of 2022, I finally won my case. We had started that back in June of 2020, so that's about the time frame that it took with a lawyer. It can be even harder without one.

Like Raven, Rachel and Devyn also had very lengthy experiences obtaining disability, approximately two years of denials and appeals.

Even after approval, the wait is not over. There is a 5 month wait period for SSDI payouts once approved. The lengthy process of obtaining government assistance is the reason Flor has not attempted to apply. Flor said,

In order to apply, I need to be below a certain income level, but that income level is not a livable wage at all, and the process could take years to actually get approved. So, I need the help so that I can live below this income level, but I have to be below this income level in order to receive help. It just wasn't an option for very catch 22 reasons. In order to be able to live, I wasn't able to get the assistance that I need.

The income level required to qualify for SSI and/or SSDI is so low, \$1913 and \$1470 respectively, that living at that wage without other assistance while waiting for SSI or SSDI approval and payouts would be impossible in many areas in the U.S.

The ability to retain a lawyer is certainly a privilege that can make a big difference in obtaining benefits or not and speeding the process along. Applicants who retain professional representation for their appeals are up to three times more likely to be approved than a person attempting without (Citizens Disability 2023). Lawyers can be expensive though, that is why Victor is hoping to hire a lawyer to help his case who operates on contingency fee, so he will not have to pay for their services unless his case is won, and he receives benefits. Being young and invisibly disabled, Raven and Rachel were both fortunate to have lawyers help argue their cases. Without a diagnosis, Rachel struggled to have her disability realized, even with a lawyer arguing her case. She said,

I was denied for I want to say two years after I became disabled, and I had to do the whole lawyer and go before the judge thing... It was a huge deal having to try and get the doctors to agree that I was disabled. That was a nightmare for a while.

Disabled individuals have to argue the reality of their condition and limitations. They must demonstrate that they are not too young, they are not faking, their condition is real, their limitations are real. Doing so without legal representation can be tough, but Devyn's mother put in the work when no lawyer would take their case, and after two years, they won.

Proving disability in the courts requires a lot of paperwork—medical records, doctors' reports, test results. Without access to medical care and these documents, disability applications may be denied on the basis of lack of evidence. Rane was denied for this reason. They said,

I got denied in March. Partially because I don't have a lot of long-term medical documentation because I have always been underinsured or uninsured and if I didn't absolutely have to go or if I did the calculations and couldn't afford going, I wouldn't. Then also, I have rare issues and none of them are actually on paper because I'm stuck in waitlist hell.

Cost and wait lists obstructed Rane's diagnosis and documentation, and the lack of diagnosis and documentation obstructed their access to benefits.

There is a common misconception that welfare for disability in the United States is a system that is abused or taken advantage of for profit, when in reality, disability benefits are unlivable. In

2023, the average monthly payout for SSDI is \$1,340 for adults and only \$904 for disabled adult children, and the average monthly payout for SSI is \$718 (Social Security Administration 2015). For comparison, the average monthly rent for apartments in the states where participants lived ranged from \$825 to \$2,900 (World Population Review 2023).

About the amount she was awarded, Devyn said,

Originally it was tiny. Laughable. They were going to give me like \$530 month. Who in the world could live off of that? I'm lucky, I've got my family so I'm not desperate, but if there's someone out there who's alone and needs that money to live off of, they'd never be able to live off of it. But they had made a mistake... I got the lowest amount because I have no work history, but because I was a minor when I originally filed... that means that they base it off of my parents' work history, specifically my dad who had like a 60-year work history. So, I moved up to like \$1200 a month or something, which is much better but still barely livable for most places in the US.

At first, Devyn's SSDI payout was calculated using her work history, or rather lack thereof, but when it was corrected and calculated as a disabled adult child, her payout increased because of her parents' work credits. Devyn notes that neither amount is truly a livable amount for someone in the U.S. if they were not receiving additional help besides their benefits, such as their parents.

Raven is unable to work as a result of the dangerous flares that employment would cause, so she and her fiancé live off of her benefits and his income. Even then, money is tight. Raven is trying to get compensation for her fiancé's role as a caregiver and receives assistance from her parents. She said, "I only get \$945 a month.... As of right now, I'm working on trying to get my fiancé counted as a paid caregiver for me so that he's able to get paid and help our income... I rely on my parents as well for some things sometimes." Raven's SSDI payout is not enough for her to live independently, or even enough to act as a second income to contribute to her relationship without still needing assistance from her parents. It causes strain on her relationships with her fiancé and parents.

Rachel takes offense to the misconceptions towards disability benefits, because her SSDI is significantly below the national average. She said, "I get \$299 a month. That is what I get from my

SSDI. I'm just rolling in it, clearly. My disability is giving me so much free money. I always hate when they say that.”

It is not just the dollar amount of the payout that makes living on disability benefits arduous, it is the conditions that limit the equity of life. Rachel continued on to say, “You can only have \$2,000 in your savings account, so you can't save for anything. That's not even including if you have a car or if you own a house. Things like that count against you too. They really want you to be in poverty.”

Rachel asked that I share information regarding a special savings account, called an ABLE account, where up to \$10,000 may be saved and used for disability-related expenses that SSI cannot count against you. This type of account is not available everywhere, but where it is available, it is a great opportunity for those who qualify for SSI to have a greater sense of financial security.

Wendy pointed out the same limitation regarding savings, but also pointed out an additional limitation that feels unfair to her, “It is incredibly hard [to get benefits] and then you can't live off it. You can't get married and have disability [benefits], or you can't have more than \$2000 to your name. It's bullshit.” If an individual has SSDI based on their own work credits, their eligibility and benefit amount is not affected by marriage. However, if an individual has SSDI benefits as a disabled adult child and gets married, benefits are immediately revoked. An individual receiving SSI benefits may see a reduction in benefit amount or completely lose their benefits if they get married, because their spouse's income is counted as their own.

Morgan is unable to receive benefits because she is married. She said,

I tried to apply for disability but when I called Social Security, I was informed that... I wasn't eligible for the first one [SSDI] because I didn't have enough work credits because I couldn't work a stable job, and then I was denied for the other [SSI] because of my husband's income. They literally told me on the phone at Social Security that if I were to split from my husband, then it would be completely different, and I would be able to get on the second type... They basically told me it's because my husband has a good income. So, we just have to rely on one income, and I don't think that's fair.

Without enough work credits to qualify for SSDI on her own and a spouse's income that makes her ineligible for SSI, Morgan is left unable to contribute to her household. Unless, of course, she divorces her husband and remains unmarried; then she is eligible for benefits as a disabled adult child.

Multiple participants felt similarly about the inequity of marriage rights; their sentiments can be summed up into feeling that marriage should not affect benefits because if it does, it robs the disabled individual of their autonomy. They are forced to be dependent, with no money of their own, in an economy that proves difficult for even two-income households to make do. Morgan said, "It's really stressful not having your own income, and even just not having that second income period."

The dependence that receiving disability benefits forces creates fear, uncertainty, and insecurity. The unlivable amount that Rachel receives in SSDI leaves her completely dependent on her parents. When I asked her how that felt, she told me, "I'm terrified... what if my parents die and I'm left destitute? They are completely supporting me and if anything were to happen, if they lost a job, or if they died, I'm screwed. I can't support myself financially at all, especially with \$300 a month."

Government assistance comes with so many stipulations and conditions, it can feel like your life is being micromanaged. Beneficiaries must report if they get a job, no matter what is earned or how many hours are worked, if they file for any other type of benefits, such as SSI or worker's comp, if they move, if they get married or divorced, if they change their name, if they become a parent, if they have an outstanding warrant for a felony, if they are convicted of a crime, if they violate parole or probation, if they plan to leave the US for more than 30 days, if their citizenship status changes, if there are any changes in their condition, and more. Once approved for disability benefits, beneficiaries are subject to periodic reviews of their condition (Social Security Administration 2021).

If the beneficiary's condition is deemed to have improved, they will lose benefits. Reviews can happen as often as every six months, or as few as every seven years, depending on how much improvement is expected. Devyn will have her condition reviewed in roughly a year. After fighting so hard and appealing multiple times to get her benefits, she is worried that the next time they assess, her benefits will be taken away and she will have to repeat the entire two-year process. She said,

'It's pretty scary because... when they approved me for it, it was just for the next 24 months, so two years. That started I think this past October, so it's getting close to a year since I've got it and it's scary because I have to go through the process again... to get it extended and get more. Like I said, I'm lucky because I have my family, but if something happened to them, I'd be totally reliant on that. You just feel so vulnerable I guess, to be at the will of someone else and not being able to protect or help yourself at all in that in that regard. It means that my life is so in the air.'

Strain of Dependence

With or without government assistance, the overwhelming majority of participants in this study do not feel capable of being financially independent. Only two participants feel confidently in their financial independence, three feel they are in a position to be financially independent but are worried about the future, and the remaining ten participants are not currently or do not feel capable of being financially independent.

When Heather was enrolled in university before, she was largely independent and even working multiple jobs, but did still receive help from her parents when necessary. Heather works full-time now and currently feels financially independent, but as she heads back to school in the fall for her PhD, she worries that transitioning from having a full-time job to being a full-time student will change how she feels about being independent.

Ashley also experiences concern about future changes to her financial independence. Currently, Ashley not only feels financially independent, but she is the primary income for her

household. This role leaves her feeling responsible for supporting her and her partner and worried about the future of her condition. She said,

I actually got very serious about financial independence, in part because of my fear of my condition getting worse. Being the breadwinner among myself and my partner... I feel a heavy sense of responsibility to make sure that if I can't work, that my life doesn't just crumble and that we are not suddenly beholden to other people to take care of us or to make sure that our needs are met. I've gotten very serious about saving money... that way if I have to take some time off work, or if for whatever reason, I'm permanently unable to work, then financially we have a little bit of a buffer.

Heather and Ashley are worried about feeling dependent on others again and the feelings that come with it.

The majority of participants discussed some degree of reliance on parents, roommates, and domestic partners in their day-to-lives. The inability to financially support themselves or to contribute to their households resulted in feelings of stress, vulnerability, fear, guilt, shame, tension, and negative impacts towards self-worth. Devyn and Rachel demonstrated the fear and vulnerability of having benefits taken away or the possibility of having to solely rely on the unlivable benefits provided. When I asked Maggie how she feels to not be financially independent despite working full-time, she said,

Very scared. My boyfriend and I eventually plan to get married and move in together. There are times that I worry that we aren't going to be able to make ends meet, which is a scary thought. I rely on my parents a lot for stuff, I know not a lot of people are able to rely on their parents... Not everyone else has that. I'm very grateful, but I'm still also very worried.

Parents were discussed at length as being big sources of financial support, but participants did not want to be forced to rely on their parents forever, and some feel guilty needing support at their age. Raven's disability benefits are not enough to financially support her, so she relies on her fiancé's income and her parents' help. For someone who used to work, and was very passionate about their work, Raven said,

It's kind of a blow to the ego, for sure... I'd love to be financially stable and be able to make sure that all the bills are paid, and not have to pick and choose what can be done here or there, that kind of thing. So, it does make it really difficult. I rely on my parents as well for

some things sometimes... But there's a little bit of guilt in there. They're in their retirement years and they're still trying to help keep their 30-year-old afloat.

In addition to guilt, there is also shame associated with being financially dependent. For young adults in a productivist society, where employment becomes the marker of social worth and value, the inability to attain financial independence feels like a failure (Mladenov 2017). The disparity between what was expected of him and what he has accepted he is capable of has negative effects on Victor's mental health. He said,

I feel very helpless... It hurts knowing that I'm not financially independent. Especially since growing up, I was the perfect oldest child. My parents put a lot of expectations upon me. Around the time I was figuring out that I am disabled, my mom told me that she thought I would already have my own house by then, thought I'd already be financially independent, but I was still mooching off my family... I still have a lot of that trauma to work through. While I'm becoming more accepting of the fact that I may never be financially stable in this economy, it still hurts, and it gives me a lot of anxiety.

The unstable economic conditions the U.S. is experiencing currently only exacerbate feelings of fear, uncertainty, and vulnerability. Young adults in general are being forced to accept that things like home ownership or children may not be realistic expectations, at least not as soon as they would like, and their financial options are severely limited (Konstam 2015). The economic climate makes Flor even more worried about relying on their family for help. They said,

I'm extremely scared. Luckily, I have a very large family and my younger sister is very caring, but it's stressful to have to take care of me, to have another mouth to feed. When we're barreling towards a recession already, and prices are going higher and higher, I can see the strain on her and the strain on a lot of my other family members... I know I'll never be able to own a home, I might not be able to get like the nicest car. I'm super grateful but it also just makes me feel super guilty to have to rely on the people around me when I know that it's already causing that much more struggle.

Financial dependence puts strain on relationships, including but not limited to familial and romantic. Rachel's financial situation causes tension between her and her brother. They are both supposed to be paying their parents rent while they live at home, but without being able to work and getting less than what she is supposed to be paying them from her benefits, she is unable to contribute. She said, "I'm living with my parents and currently don't have a way to pay them back.

My brother is paying rent, and I'm supposed to be paying the same amount, but there's definitely a bit of tension in the house with me being the one that is not contributing."

Before his diagnosis and proper understanding of his needs and limits, Ryan was unable to maintain a job. It had a negative impact on his self-esteem and the relationship between him and his domestic partner. He said, "I felt a lot of guilt about not contributing to our household the way I wanted to, and it was rough having so little income for two people. I also worried that if we split up, I would have nothing to support myself with and no security." Since finding a part-time job that allows him to reduce those concerns, things have improved for Ryan and his partner. He continued,

It's a lot better now that I've been able to find a job that lets me work around my disabilities. Even though I do feel secure about the relationship itself, it just feels better and helps my self-esteem a lot to know I could take care of myself if I needed to, too. It's also a relief to take on my share of responsibility because I can see how much less overwhelmed my spouse is now that he's not the only one having to pay our bills.

Financial dependence is not the only dependence that disabled young adults struggle with in their relationships. In addition to financial dependence, Devyn also relies on her parents for help with daily tasks due to the severity of limitations she experiences. She said,

Nowadays, in the last like five years that my health really has deteriorated, I'm so dependent on my parents. You feel like a kid whenever your parents are taking care of you, they have to cook for me and everything. It's embarrassing and you feel a little pathetic and yeah... it sucks.

Devyn's need for help, and her parents filling that role of caregiver, makes her feel as if she has no independence. It makes her feel as though she is not an adult. Unfortunately, I cannot report that the feeling is much better when that primary role of care giving is bestowed on a romantic partner. While not financially dependent, I do rely on my (amazing) partner for all the things I cannot do in our shared home: the grocery shopping, the cooking, the sweeping, the dishes, taking out the trash, and so on. He does all of these things because they cause me pain, but I still feel guilt and shame for not contributing equally to our home. I feel as if that makes me less worthy to be his partner, and I worry that the burden of taking care of the both of us, our home, and our pet will

eventually cause strain in our relationship. He has never once caused me to feel that way, it is a deeply rooted fear that is a product of the society we live in that pushes the message that we must be productive all the time.

VII. CONCLUSION

In our society, perception of disability lies somewhere between the social model medical and the model of disability. The social model of disability conceptualizes disability not as biological failure, but as a social experience produced through exclusion and barriers at a societal level that restricts full participation. Since the passing of the Americans with Disabilities Act, we can see how treatment of disability has broadened to more than an individual level problem. Exclusion and barriers are being treated at the societal level with rights, protections, and guidelines for inclusion. However, the perceptions of what disability is, what it looks like, and who it affects is still predominately influenced by the medical model. Disability is still largely assumed to be a strictly biological category that is either externally or medically apparent, giving the authority to define disability to medical institutions. In tune with the medical model, medical institutions define disability through known medical knowledge and facts. Validation and support from an institution with authority produces legitimacy, further shaping which experiences of disability are real, acknowledged, and visible to others.

The long history of dominance of the medical model has created a set of expectations and stereotypes for what disability looks like and who it affects. Generally, the perception is that disability is visible, oftentimes severely limiting, and mostly affects the elderly, victims of accidents like car wrecks, veterans, or are congenital— defects from birth. Expectations such as these are used societally to make assumptions of the social identity, but the experiences and appearances of invisibly disabled young adults does not match this set of expectations for disability, so they are often viewed as able-bodied until otherwise corrected. When disability is claimed, these mismatched expectations and experiences result in delegitimization—interaction in which the validity of claims to disability is judged, questioned, and challenged. For invisibly disabled young adults, delegitimizing interactions can emerge in several areas of life, creating distinctive experiences of disability.

In medical care, the perception of real disability being a biological category that is visible and provable with medical knowledge, facts, and tests creates invisibility for those whose experiences are not measurable or determinable and for experiences that contradict accepted medical facts. The reality is that medical knowledge is not exhaustive or infallible. Science is an iterative process of asking questions, testing, and retesting, but not all questions are asked or given the same attention. The treatment of all medical knowledge as absolute results in the denial and erasure of experiences that fall outside the parameters of this knowledge. For invisibly disabled young adults, this invisibility in the medical system and lack of legitimacy can delay or prevent medical diagnosis; result in poor treatment and neglect from practitioners; cause patients to feel crazy, depressed, even suicidal; and restrict access to treatment, insurance coverage, disability benefits, accommodations in school and work, societal recognition, and all the rights and protections afforded by the A.D.A.

Recognizing disability and negotiating a disability identity forces individuals to face a society that stigmatizes, devalues, and dehumanizes disability, but also a society that does not easily accept the validity of invisible disability. Invisibly disabled individuals have to challenge those expected perceptions of disability and combat the delegitimization experienced in order to have their disability recognized, both by themselves and by others. The perceptions of disability, the struggles to be made visible medically, and the invalidation of others are so pervasive that among participants their delays in recognition and acceptance of disability spanned from one to eleven years—suspending the invisibly disabled somewhere between healthy and unhealthy, visible and invisible, abled and disabled. However, it was notable that among many of these participants, experiencing and identifying with disability had positive impacts on their perceptions of disability, their treatment of themselves and others, and their participation in disabled communities. These positive changes reflect a realignment in perception of disability with the social model rather than the medical model

as disability is experienced. With this realignment, disability becomes a neutral or positive aspect of human diversity.

Invisibly disabled young adults face a world that is not built for them, limiting the participation of disabled young adults and complicating their movements to adulthood. The neoliberal capitalist and productivist systems that shapes education and labor practices creates narrow definitions of productivity and participation. These systems value efficiency, translating to heavy workloads, fast timelines, long hours, multiplicity of roles and responsibilities, and high physical and/or mental demands. Social worth and value get intermingled with employment, forcing invisibly disabled young adults to either push through at the potential detriment to their health in attempt to meet the expectations set according to the abilities of able-bodied people, or to face being devalued in society and treated as lazy. In addition, the inaccessible structures of education and employment can act as a barrier for achieving the level of independence, financially or otherwise, that allows young adults to graduate into fully fledged adults. Instead, the expected progression through life stages is stunted for invisibly disabled young adults, once again suspending them somewhere in the middle, as neither child nor adult. Accommodations in these systems are often restricted to those with medical legitimacy, excluding those who have already been rendered invisible in those systems. Even for participants with accommodations, achieving independence felt like an impossibility, regardless of being unemployed or working full-time. The inability to achieve value in society through employment and the inability to achieve independence resulted in feelings of shame, guilt, vulnerability, and negative self-image.

Delegitimization of experiences that clash with the medicalized expectations of disability produces invisibility in several spheres: medicine, identity, social expectations, and even culturally within disabled communities. The voices and experiences of the invisibly disabled are often overshadowed by more visible experiences of disability in research, but invisibility creates its own

unique experiences of disability that should receive greater attention. Better understanding of these experiences and increased understanding of disability through social or critical lenses can lead to social change. The perception of disability can grow to include all the diversity that it includes, reducing the harmful effects within identity, health care, education, employment, and public interactions that results from delegitimization. In medical care specifically, doctors can improve their treatment of patients with symptoms that lack medical visibility by listening without invalidating and by leaning away from the medical model to instead embrace ways to help patients manage symptoms when the answers to cure and fix are not available. Lastly, in all areas of life, accessibility and equity would improve with the creation of a model of disability for what Hay calls, “living sick,” (2010, pg. 210), a model of value, productivity, and agency that is not rooted in able-bodied standards.

Hitchhiker’s Guide to the Invisibly Disabled

This project has been an incredibly wonderful, even if physically painful, experience for me. I truly appreciate having the opportunity to meet all of these wonderful people and getting to talk to them about their lives. I learned so much about my community through them, and hopefully I shared some useful tidbits as well. Every single one of them has faced difficulties, but still showed up to tell their stories so that it might help others. Their fire for wanting to change the world, their drive to air out the dirty laundry and fix what’s wrong, is what inspired me to end every interview with this exact question: “What is the number one thing you wish people would understand about invisible disability?” Apart from wanting to share a glimpse into the realities of invisible disability in young adulthood, I wanted to create a collection of real, implementable advice for readers to take away from this. Maggie joked that I should call it a “Hitchhiker’s Guide to the Invisibly Disabled,” so here are the final words of wisdom from these wonderful participants.

Disability is not A Dirty Word

- Disability is part of who we, as humans, are and always have been.

- Life can be incredibly difficult with invisible disability, but our lives still have value.
- Not everybody that is disabled, looks disabled.
- Just because you can't see it, or fathom it, or understand it, doesn't mean that it's not real. We're not crazy.
- No matter what you think of someone, everyone deserves to be treated like a human being and be believed.

Keep an open mind and listen.

- If somebody isn't fitting in the box that you are putting them in, then there's probably a reason.
- Be open to listening. That's all anyone asks for.
- Try to confront your own biases. There's a lot of misinformation, a lot of fear, a lot of assumptions about disabilities. So just take a step back and recognize where you might be misconstruing something and be open to other people's experiences.
- If you know one person with an invisible disability, you know ONE person with an invisible disability. We are all different, we have different stories, different experiences. If someone is comfortable answering questions, ask for *their* experience, because it's different than the one you've already heard about from someone else.

Chronic means chronic.

- It's all the time. There may be times where it is not as bad and times where it is worse, but it doesn't go away. It's forever. Even if you can forget because it's invisible, we can't forget.
- Most days are going to look different. Some days are great, some days are just not good days.

We're not faking, we're not seeking special treatment.

- No one does it for attention. No one enjoys having people stare at them for using mobility devices or enjoys needing extra support, so the thought that people would be faking it for attention is harmful.
- Having a physical disability that nobody can really see feels like you're on a stage, trying to put on a performance of able bodied-ness, and people are just throwing tomatoes at you. And in this analogy, you are allergic to tomatoes.
- Accommodations only level the playing field, they do not give an unfair advantage.
- Quit with the savior complex of trying to catch people faking. Trying to "help" us may be hurting a lot of people in the process.

Be Kind.

- You are not going to know that someone is invisibly disabled. Be patient with people, have compassion, and cut people some slack.
- We don't *owe* you an explanation, or proof, or personal details of our condition.
- We are people too. We are not robots, we are not dolls, we are not toys. Don't talk to us as if we are stupid, or defective, or children, or like we can't understand you. Be kind.

If you can't be kind, be quiet.

- Keep judgments, snide comments, rude remarks, and accusations to yourself.
- Either have an open mind or mind your own damn business.

APPENDIX SECTION

Disorder Types

Autoimmune Disorders

Types of disorders where the body's natural defense system, the immune system, can't tell the difference between healthy cells and foreign cells, causing the body to mistakenly attack normal cells.

Dysautonomia or Autonomic Nervous System Disorders

Types of disorders where the nerves that control nonvoluntary bodily functions, such as the regulation of blood pressure, temperature control, digestion, etc., are damaged and not performing properly.

Endocrine/Hormone Disorders

Types of disorders where glands in the body produce too much or too little of one or more hormones, resulting in insufficiencies, imbalances, or overproduction.

Neurodevelopmental Disorders

Types of disorders that influence how the brain functions and alters neurological development, causing difficulties in social, cognitive, and emotional functioning.

Mental Health Disorders

Types of disorders characterized as clinically significant disturbances in a cognition, emotional regulation, and behavior.

Congenital Disorder

Types of disorders that are present at or before birth, either inherited or caused by environmental factors.

Neurological/ Central Nervous System Disorders

Types of disorders that affect the brain as well as the nerves found throughout the human body and the spinal cord.

Musculoskeletal Disorders

Types of injuries or disorders that effect the muscles, nerves, tendons, joints, cartilage, and spinal discs and are characterized by pain and limitations in mobility and dexterity.

Connective Tissue Disorders

Types of disorders that affect the parts of the body that connect the structures of the body together.

Conditions

Addison's Disease

An autoimmune disorder that attacks the outer portion of the adrenal glands, causing insufficiency of cortisol and aldosterone. Cortisol is the hormone responsible for responding to stress and maintaining blood pressure, heart function, the immune system, and blood glucose levels. Aldosterone is responsible for balancing sodium and potassium in the blood, which affects blood volume and blood pressure. Symptoms of this insufficiency include fatigue, abdominal pain and nausea, muscle and joint pain, loss of appetite and weight loss, dehydration, dizziness, low blood sugar, and life-threateningly low blood pressure.

Anxiety Disorder

A mental health disorder characterized by an excessive and persistent sense of apprehension, anxiety, dread, and/or stress and can be accompanied with physical symptoms of increased heart rate, fatigue, headaches, pain, difficulty concentrating and/or sleeping. Anxiety disorder is not the same as occasional worry or experiencing anxiety due to stressful life events.

Arthritis

A disease that comprises of more than 100 types of arthritis and related conditions that cause inflammation or swelling of the joints, tissues around the joint, and other connective tissues. Specific symptoms vary depending on the type of arthritis, but common symptoms are swelling,

pain, stiffness and diminished range of motion. Arthritis can be caused by an autoimmune response, an infection, age, genetics, etc.

Attention Deficit / Hyperactivity Disorder (A.D.H.D.)

A neurodevelopmental disorder characterized by developmentally inappropriate levels of inattention, impulsivity and hyperactivity. Symptoms can include poor concentration, easily distracted, failure or inability to complete tasks, disorganization, poor time management, low frustration tolerance, emotional dysregulation, trouble coping with stress, etc.

Autism Spectrum Disorder (A.S.D.)

A neurodevelopmental disorder caused by differences in the brain. Autistic people may behave, communicate, interact, and learn in ways that are different than others. The experiences and needs of Autistic individuals can vary significantly, but some indicators can include difficulty understanding what others are feeling or thinking; having sensitivities to certain sensory inputs, such as noise or light; repetitive behaviors; feelings of distress when routines are interrupted; etc. Expressions of autism are vast, vary between children and adults, and vary between men and women. There is no singular cause, rather includes biological, genetic, and environmental factors.

Chiari Malformation

A congenital, structural defect of the skull which presses the lower part of the brain on and through an opening in the base of the skull and brain tissue extends into the spinal canal. This can put pressure on the brain stem and spinal cord and block the flow of cerebrospinal fluid (C.S.F.)—the clear liquid that surrounds and cushions the brain and spinal cord. Symptoms include headaches, neck pain, balance issues, vertigo and dizziness, hearing problems or ringing in ears, muscle weakness, etc.

Celiac Disease

A digestive disorder where an immune response is triggered by the consumption of gluten. Inflammation of the small intestine causes damage to the lining, leading to complications, such as malabsorption of nutrients, anemia, early osteoporosis, and infertility. Symptoms include diarrhea, constipation, weight loss, numb feeling in legs, joint and bone pain, muscle cramps and abdominal pain, and rashes. Celiac is genetic and the only known treatment is a strict adherence to a gluten-free diet.

Chron's Disease

An autoimmune disorder that is part of the inflammatory bowel disease family and causes swelling of the tissues anywhere along the gastrointestinal (G.I.) tract, but most commonly the small intestine. Chron's symptoms in the G.I. tract include abdominal pain, constipation, severe diarrhea, tears, fistulas, and bleeding. Outside the G.I. tract, Chron's can also cause fatigue, changes in appetite, weight loss, malnutrition, rashes, joint pain, osteoporosis, and liver complications.

Chronic Pain Syndrome (C.P.S.)

A long-lasting pain that is generally caused by a miscommunication between the brain and nervous system, causing nerves to become hypersensitive to pain messages. Chronic Pain Syndrome may be related to other conditions— such as forms of arthritis, fibromyalgia, inflammatory bowel disease, etc. —but may also occur when there's no known trigger for the pain. C.P.S. symptoms can include joint pain, muscle aches, burning pain, fatigue, sleep problems, loss of stamina and flexibility, depression, anxiety, and irritability.

Cyclical Vomiting Syndrome (C.V.S.)

A disorder of unknown cause that induces spontaneous and repeated episodes of vomiting and nausea. Side effect symptoms can include abdominal pain, dehydration, dizziness, fatigue, sensitivity to light, headaches, weight loss, etc. Symptoms can be triggered by emotional stress or

excitement, certain foods and drinks, hot weather, physical exertion, and menstruation. Episodes are not caused by any infection or other illness and the exact cause of C.V.S. is not fully understood, but it is possible that it is linked to genetics, digestive disorders, hormone imbalances, and/or nervous system problems, such as mitochondrial mutations that impact the body's functions.

Deaf and Hard of Hearing (D/H.H.)

Deafness is the lack of auditory perception or severe hearing loss that results in very little or no functional hearing. "Hard of hearing" refers to reduced or deficient hearing or partial hearing loss. Deafness and hearing loss may be caused by congenital defect, injury, disease, medications side effects, or general loss with age.

Depression (also referred to as: Major Depressive Disorder or Clinical Depression)

A mental health disorder that causes persistent feelings of sadness, loss of interest, and worthlessness; sleep disturbances; lack of energy; changes in appetite or weight; trouble concentrating and remembering; suicidal ideations; and unexplained physical pains, such as headaches.

Dissociative Identity Disorder (D.I.D.)

A mental health disorder that presents as multiple, distinct personalities. The various identities can control a person's behavior at different times, and can have their own personal history, traits, likes and dislikes. Switching between personalities can result in a disconnection between thoughts, memories, surroundings, actions and identity. The condition can cause memory loss, varying levels of awareness, delusions, poor sleep, and depression. Trauma is not part of the diagnostic criteria, though it is the most common cause.

Ehlers-Danlos Syndrome (E.D.S.)

A group of 13 rare, inherited connective tissue disorders that support the skin, tendons, ligaments, blood vessels, internal organs and bones. Each type of E.D.S. has its own set of features

with distinct diagnostic criteria. Some features are seen across all types of E.D.S., including joint hypermobility, skin hyperextensibility, and tissue fragility. Other symptoms can include chronic pain; muscle weakness; joint instability; frequent dislocations; organ fragility, prolapse, and rupture; digestive issues; extensive bruising; heart valve insufficiency; etc.

Endometriosis

An endocrine/hormonal and musculoskeletal disorder in which the tissues that line the inside of the uterus is present outside of the uterus. Endometrial tissue can be found in the ovaries, fallopian tubes, uterosacral ligaments, gastrointestinal tract, etc. Symptoms can include pain in the lower abdominal, back, vagina, or rectum; constipation and nausea; fatigue; pain with menstrual periods, sexual intercourse, or bowel movements; heavy or painful menstrual periods; and difficulty getting pregnant or infertility.

Epilepsy

A central nervous system, or neurological, disorder characterized by abnormal brain activity that causes seizures, periods of unusual behavior, sensations, and sometimes loss of awareness. There are eight types of seizures and symptoms vary by type. Seizures can either take place in one area of the brain, called focal seizures, or in all areas of the brain, called generalized seizures.

Fibromyalgia

A musculoskeletal disorder that causes pain throughout the body, accompanied by fatigue, sleep, memory, and mood issues. Researchers believe that fibromyalgia affects the way the brain and the spinal cord process painful and nonpainful signals, amplifying painful sensations.

Hashimoto's Disease

An autoimmune disorder that attacks the thyroid, leading to the death of the thyroid's hormone-producing cells and declines hormone production (hypothyroidism.) Resulting symptoms

include fatigue, muscle weakness, joint pain and stiffness, sensitivity to cold, problems with memory and concentration, brittle nails, hair loss, depression, etc.

Lupus

An autoimmune disorder that causes the immune system to attack healthy tissue, causing inflammation throughout the body. Inflammation can occur in the skin, joints, lungs, kidneys, blood, and heart. It can cause a wide range of symptoms throughout the body including fatigue, muscle and joint pain, fever, chest pain, sensitivity to sunlight, rashes, memory problems, headaches, etc.

Lyme Disease

An autoimmune disorder that is caused by bacteria passed to humans through the bite of infected ticks. Typical symptoms include fever, headache, fatigue, and rashes. Although most cases of Lyme disease can be cured with a course of oral antibiotics, patients can sometimes have symptoms of pain, fatigue, or difficulty thinking that lasts for more than 6 months after they finish treatment. Some experts believe the bacteria can trigger an autoimmune response, causing symptoms that last well after the infection itself is gone. If left untreated, infection can spread to joints, the heart, and the nervous system.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (M.E./C.F.S.)

A chronic, long-term illness characterized by extreme fatigue that lasts for at least six months, symptoms worsened by physical or mental activity but not improved with rest, problems with memory or thinking skills, muscle or joint pain. Little is known or agreed upon regarding M.E./C.F.S., but studies suggest four possible causes: genetics, individuals may be born with a predisposition of developing the disorder; Infections, some people have developed symptoms after recovering from a viral or bacterial infection; trauma, some cases report significant emotional or physical stress shortly before becoming symptomatic; and problems converting energy, some people have problems converting the body's fuel, primarily fats and sugars, into energy.

Obsessive Compulsive Disorder (O.C.D.)

A mental health disorder that features a cycle of obsessions— unwanted and intrusive thoughts, images, or urges that trigger intensely distressing feelings—and compulsions—behaviors that individuals repeat in attempt to get rid of the obsessions and/or decrease their distress.

Polycystic Ovary Syndrome (P.C.O.S.)

An endocrine/hormone disorder that produces an abnormal number of androgens, a male sex hormone that is usually present in small amounts in women, causing enlarged ovaries with small cysts. The cause is not well understood but can have genetic and environmental causes.

Post-Traumatic Stress Disorder (P.T.S.D.)

A mental health condition that is triggered by a terrifying event — either experiencing it or witnessing it. P.T.S.D. symptoms are generally grouped into four types: intrusive memories, like flashbacks or nightmares; avoidance, such as avoiding places or people that trigger memories of the traumatic event; negative changes in thinking and mood, such as memory problems or difficulty maintaining relationships; and changes in physical and emotional reactions, like self-destructive behavior, trouble sleeping, or being easily startled.

Postural Orthostatic Tachycardia Syndrome (P.O.T.S.)

An autonomic nervous system and blood circulation disorder where the body cannot regulate blood pressure and heart rate. Blood is not circulated properly from the lower extremities to the head, resulting in low blood pressure and increased heart rate. Symptoms include dizziness and light headedness, fainting, fatigue, chest pain, etc. and can be exacerbated by heat, long periods of standing, and strenuous exercise.

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