Disability and Self:

Critical Factors in Positive Adjustment After the Onset of Disability in Emerging Adulthood

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ABSTRACT

Resiliency, self-efficacy, and social support are key factors influencing adjustment following the onset of chronic disability. The presence or absence of these factors influences the affected person's perceptions of self, perceptions by others, and overall life satisfaction and confidence in their ability to achieve goals. This article assesses data collected from an open-ended interview with a single participant, D, organized by thematic analysis. It finds that D's resiliency, self-efficacy, and social support system significantly influenced her mindset and attitude toward life after being diagnosed with Multiple Sclerosis (MS). The author explores how these factors were influenced by the micro-, meso-, and macro-contexts in which D existed, focusing particularly on the context of her relationships with others. The paper concludes with recommendations for future research.

Over 1 billion people live with some form of disability and that number is increasing (World Health Organization, 2021). Some reports suggest that 15% of adults ages 60 and older report at least one functional limitation (Infurna & Wiest, 2016), while an estimated 5% of working Americans experience a short-term disability each year (Council for Disability Awareness, 2021). Research indicates the life stage in which one develops a disability may influence their developmental trajectory, since individuals face different responsibilities and priorities throughout the life course. As discussed by Lachman (2004), in emerging adulthood, individuals are generally healthy and therefore focused on milestones related to their career and personal life. Emerging adulthood is characterized as a time when young adults explore their newfound freedom and solidify their identities (Arnett, 2000). Developing a physical disability during emerging adulthood disrupts normative developmental trajectories and creates a stark contrast between life experiences gathered as an able-bodied person and life experiences following the onset of disability.

The development of a disability not only influences how a person views themselves, but also impacts their interactions with others and with society at large. Ableism is a tangible experience for many people with disabilities who may experience judgment and marginalization. Experiences of ableism can vary depending on the severity of symptoms, the individual's own attitudes and perceptions, and the visibility of an individual's disability. People with visible disability symptoms may be more likely to experience overt ableism, as their conditions are difficult or impossible to hide. Conditions characterized by recurring-remitting symptomatology, such as Multiple Sclerosis (MS), are unique in that they have a spectrum of symptom severity. MS is an incurable neurodegenerative disease in which the body's immune system attacks the myelin sheath, resulting in diverse and unpredictable manifestations of symptoms. An individual may be able to pass as able-bodied at times, depending on where they happen to be on the spectrum at that time. The choice to disclose or conceal disability

can have practical and psychological consequences that influence a person's daily experiences (Nario-Redmond, 2020).

Studies by Fong et al. (2006) and Dalmonte et al. (2004) found that a "positive outlook, maintenance of social relationships, and an ability to adapt to the environment are critical to maintaining well-being" (Ploughman et al., 2012, p. 7). The purpose of this study is to demonstrate how a person's resiliency, self-efficacy, and social support system influence both how they view themselves and their ability to thrive and achieve their goals after the onset of a physical disability.

LITERATURE REVIEW
ABLEISM

Ableism is defined as prejudice and discrimination based on physical and mental disability classification (Nario-Redmond, 2020). Nario-Redmond (2020) identifies ableism as affective emotions or attitudinal reactions, behavioral actions or practices, and cognitive beliefs and stereotypes that go beyond general negativity. There are nuances and degrees to which these three forms can manifest, and ableism exists at the internal, interpersonal, and institutional levels.

Internalized ableism incorporates ableist attitudes, beliefs, and practices in the minds of individuals who identify as disabled. This form of internalized oppression has been found to contribute to mental health concerns, including anxiety, depression, isolation, and feelings of inferiority (Jóhannsdóttir et al., 2022).

RESILIENCY AND MULTIPLE SCLEROSIS

After experiencing stress or trauma, some people adjust positively and establish a stable developmental trajectory; others respond maladaptively (Herrman et al., 2011). An individual's ability to recover from stress can affect development and influence health outcomes. Ploughman et al. define resilience as "the ability to achieve, retain, or regain a level of physical or emotional health after illness or loss, which is associated with successful coping and 'bouncing back' in spite of

substantial adversity" (2020, p. 2769). Studies on the ability to maintain independence, adaptive lifestyle habits, social participation, and overall health-related quality of life through symptom management suggest that resilience promotes healthy aging with MS (Ploughman et al., 2020).

Higher psychological resilience is associated with better physical function in people with MS and with fewer neurological symptoms (Jakimovksi et al., 2022). Studies report a lifetime prevalence of depression in people with MS of up to 50%, and the development of depression is closely linked to coping style, positive adjustment, and resilience factors (Ploughman et al., 2020). Social connection closely intertwines with the concept of resiliency: greater social support is associated with greater resiliency and more adaptive coping strategies in people with MS (Jakimovksi et al., 2022).

SELF-EFFICACY

Self-efficacy refers to an individual's sense of control over their achievements and their capacity to respond to challenges and meet goals. Disability self-efficacy is a person's belief that they can manage their disability to achieve their goals (Amtmann et al., 2012). There are several ways in which self-efficacy beliefs impact behavior, including the actions an individual chooses to take, as most opt for behaviors that result in feelings of competency and accomplishment. These beliefs also influence perseverance and perceived stress levels (Amtmann et al., 2012). Individuals with higher levels of self-efficacy often demonstrate lower levels of anxiety and depression, which can positively influence their outlook and adjustment to life following a diagnosis (Tan-Kristanto & Kiropoulos, 2015).

Additionally, an individual's locus of control influences how they perceive life events. People with an external locus of control attribute events and consequences to forces outside of themselves, such as others' actions, while those with an internal locus of control feel that their actions are the catalysts for events. A health locus of control (HLC) refers to the perception individuals have of their options for symptom management

and disease control (Wilski et al., 2019). The degree to which an individual feels responsible for their disability can affect how they choose to cope with the limitations they experience.

SOCIAL SUPPORT

Social support is associated with better psychological well-being, reduced stress levels, and improved emotional well-being and perception of happiness and success (King et al., 2000). Jensen et al. (2014) found that perceived social support is associated with subjective well-being in people with physical disabilities. The corollary is that there is a strong association between lack of social support and depression. Individuals with physical disabilities are at a higher risk of lacking perceived social support, as their mobility may be impaired and, as a result, their ability to engage with a broader community is limited. The type of social support people receive, whether from friends, family, or significant others, has a differential impact on depression levels; friend support plays the largest role (Jensen et al., 2014). The importance of friend support indicates the influence of the broader social environment on perceptions of self and happiness, demonstrating how essential having a diverse support system is to positive adjustment after an adverse life event.

METHODS

D is a 56-year-old heterosexual, cisgender, white female from New York who developed MS at 24. This study aims to explore the influence that developing a disability in emerging adulthood has on an individual's perception of themselves and their ability to live a fully-realized life and achieve their goals. Having lived without this disability for a significant portion of her early life, as well as having experienced periods of remission and flare-ups, D has unique insight into the spectrum of MS. This research focuses on the influence of resiliency, social support, and self-efficacy on D's perception of her abilities before and after her diagnosis and into middle adulthood.

The student researcher arranged to interview D in person at her home. The student researcher made it clear before and throughout the interview that the participant could stop at any time and that D was under no obligation to answer questions with which she did not feel comfortable. The interview lasted approximately two hours and was recorded and transcribed via the Otter app on the researcher's phone. To protect D's confidentiality, these recordings were deleted upon completion of the research paper. She was informed of her rights and signed an informed consent document indicating that she understood the interview's context, requirements, and outcome. Quotes from the interview were organized using thematic analysis into topics related to self-perception, perception by others, resiliency, and social support. This study received IRB approval prior to publication.

RESULTS
IMPACT OF DISABILITY ON SOCIAL SUPPORT

Numerous protective factors were present in D's childhood, including a strong sense of community, growing up in a middle-class family, having access to quality education, and being white in a homogenous, conservative town. Concurrently, she experienced certain risk factors, particularly within her family dynamics. D shared that her role in the family, even as a child, was the peacemaker and "perfect child" who made her parents proud and helped to mitigate the consequences of her sibling's maladaptive behaviors. Growing up with a brother who struggled with substance abuse and undiagnosed bipolar disorder, she became familiar with the disabling effects of mental and physical illness.

When discussing her parents' devastation over her diagnosis, she expressed feelings of guilt: "I felt awful. I'm not the one that brings heartache into their life." She experienced a transition from being an independent emerging adult to an emerging adult who relied heavily on the support of others. This sense of guilt carried over to other important relationships in D's life, including that with her husband. She recalled her fears of becoming dependent on her husband at only 24, thinking at the time, "Oh no, he's going to have to take care of me, like I'm an old

woman." Despite fears of being a burden, D shared that her husband and marriage adapted quickly to life after her diagnosis: "My husband became even more devoted. He looked out for every detail, every detail that would make my life better and easier."

Relocating far from home as an emerging adult, D found herself away from family and friends. However, she quickly established connections through her husband's work, finding a cohort of young adults in similar situations as transplants to the area.

> I had just gotten married here in New York and immediately moved out to Los Angeles. So I didn't have a whole group of good friends or any family. But everyone from my husband's company were kind of misfits being out there, having no family. So we had a good social support system.

She explained that her friends in California became skilled at adapting to her needs to the point that she experienced very few perceived limitations during that period. Her disability became integrated into the backdrop of her social relationships without defining her. This was made especially clear as she described how her friends responded to her new limitations.

> They're just like, oh, we'll carry you up the hill. Well, you know, there's no handicapped access here. I'll throw you over my shoulder. So yeah, in that respect, it wasn't a stigma…They'd say don't worry. We'll get you there.

Despite acknowledging the crucial role social support played in D's perception of her limitations, she was highly resistant to becoming involved with the broader MS/disability community. She explained that she felt the disability community represented a "pity party" she could not afford to get involved in. In her own words, "Out of sight, out of mind." D expressed that she felt no need to be involved with the community because she could get any information about her condition from her doctor or online, without hearing about other people's problems. Coming from a family that believed highly in taking

responsibility for one's problems without outside help may have helped shape this attitude toward her disability.

SELF-PERCEPTION AND DISABILITY

D's priorities at different stages in her life evolved with how she perceived herself and her abilities, roles, and goals. Due to the relapsing-remitting nature of her MS, there were periods when she could live life essentially as an abled person and disconnect from her diagnosis. However, during symptom flare-ups, she could not ignore the very real limitations that she was experiencing. She was also frustrated with herself for not having the capacity to do everything she wanted. Initially, and for quite some time, flare-ups were characterized by spikes in internalized ableist thoughts; D felt she was being denied the full experience of emerging adulthood. However, these attitudes would shift as she developed adaptive coping mechanisms and began to accept life as it was. D expressed that as a young adult, she struggled with comparing her experiences with those of her peers. Watching her cohort advance their careers was difficult, especially in conjunction with her health challenges. When D lost her job due to her symptoms, it significantly impacted her self-perception: "I was incredibly disappointed with myself because I worked so hard to get where I was, and I had to leave it because of this stupid disease… I felt badly about myself because of that."

D expressed that she was also forced to confront the reality of her condition when her doctor presented an ultimatum: be a lawyer or be a mom. At this point, she had to reassess her goals and aspirations and recognize that she could not do everything. She cited this as another turning point in her acceptance that the real limitations imposed upon her by MS restricted some life paths. However, D took this as an opportunity to reevaluate her priorities and recognize that she valued starting a family over having a career. After the birth of her daughter, D had to again come to terms with her capabilities as she initially struggled to reconcile her new role as a mother with her physical limitations.

> There were things I couldn't do with my daughter when she was a baby. Like I could never give her a bath by myself. Those kinds of things…got to me, but then I hired a nurse to come and take her for a couple hours here and there. And she did all the things I couldn't do, and I just had to be okay with that because then I could do other things… So that made it not so bad. It was just part of how we lived.

The experience of aging also influences a person's perception of themselves. While D's chronological age is 56, it is important to consider her biological age when discussing her perception of self. As a neurodegenerative disease, MS strongly affects biological aging and physical deterioration, and D expressed concerns over both physical and cognitive decline as she ages and the disease progresses. When asked about considerations when planning for the future, she explained that she is much more practical about her capabilities now.

> Well, now I have to absolutely face that if I stay in the physical condition I am in right now, there are things I won't be able to do. For example, we are most likely taking the retirement cruise of our lifetime long before my husband is retiring…It's nothing we planned on doing, but you know what? I might not be able to do it next year. Or ever, right? So I'm just realistic about it.

These concerns have affected how D approaches life and perceives the opportunities afforded to her. Developing a pragmatic view of her situation has been an empowering coping mechanism from the onset of her MS.

SELF-EFFICACY

D's experiences and decisions since she developed MS are characterized by a strong sense of self-efficacy and an internal locus of control, which greatly influenced how she perceived herself and her opportunities. She expressed that she frequently faced the decision to either give into despair or forge ahead. D shared that after her mother

received a cancer diagnosis, her mother essentially decided life was over.

> From the day they gave her her diagnosis, not a positive word passed her lips. Everything was miserable. Everything was terrible. Everything was awful. Even good things that happened…I never wanted that, and I thought, 'I got through all these years with the disease without becoming bitter.'

At a critical turning point in her life, D adopted a mindset that deliberately looked for the positive aspects of life because she viewed it as a decision within her control, demonstrating her strong sense of self-efficacy. This mindset of perseverance through adversity, modeled by her father as he managed her brother's struggles and family responsibilities, came to play a crucial role in how she tackled the challenges she faced as an emerging adult.

RESILIENCY AND DISABILITY

"I think that's probably the best thing you can do. Just make it a part of how you live." This simple statement by D reflects a profound strength and resiliency that characterizes her experience with MS from her diagnosis up to the present day. Throughout the interview, D made many comments about refusing to let her diagnosis "ruin [her] attitude."

> I saw when my mother was so depressed and negative, what it did to the people around her, and I never wanted to do that to my family and friends. And truthfully, it's better to have a good attitude, and people want to make themselves miserable by seeing only the negative.

D's experience watching her mother battle cancer strengthened her already existing resiliency. Some of D's response may be rooted in the interpersonal role that she took on within her family from a young age, that of the dependable child who rose to meet challenges head-on. When asked to identify her strengths, D reflected on some of the characteristics that informed her perspective on disability and adversity.

> I think I'm very pragmatic. And I think that helps a lot. You have to be practical. How can I make this better? You try it. Does it make it better? Maybe, maybe not. But you tried to make it better. And if it simply can't be done, you move on.

D's resilience manifests through a strong sense of practicality. Her ability to bounce back after setbacks and challenges is integral to who she is, shaped in part by her self-determination.

HISTORICAL CHANGES AND SOCIAL INSTITUTIONS

D also reflected on the broader social changes she witnessed over the past three decades. When D was first diagnosed, there were limited treatment options for MS, and she jumped on the opportunity to be a "guinea pig" for experimental medications. While reflecting on disability accommodations and treatments for MS now, compared to when she was diagnosed, D expressed gratitude for the changes over the past decades.

> I think in the last 20 or 30 years it has been an amazing period of time for disabled people, with the ADA rules being enforced and people becoming more aware. So I think it's a better world than 30 years ago when I was first diagnosed…if I had been 25 and living in this kind of world, maybe I wouldn't have had to make that decision of 'I'm disabled,' or 'I'm not disabled.' So I think it's really wonderful.

It is evident that societal perceptions of people with disabilities have shifted positively since D's diagnosis, as have the accommodations and opportunities afforded to them. The accessibility of public spaces was also identified as a way in which things have become "exponentially better" since her diagnosis. The increasing accommodations provided to her through her urban environment and the development of accessibility tools, such as her electronic gait stimulator and her portable wheelchair, have made it easier to maintain her current mobility and allow her more freedom.

EXPERIENCES WITH ABLEISM

The complex interactions between achievement and disability perception are reflected in D's thoughts on how others' opinions have influenced her life. People judge D as either abled or disabled based on the severity and visibility of her symptoms, meaning that at times she could "pass" as able-bodied even if it took a physical or mental toll to do so. Overall, D expressed that she is far less concerned with the perception of others than when she was younger and still coming to terms with her new reality. Having to constantly decide between disclosing her condition or maintaining an abled persona characterized much of D's early period with MS.

After her diagnosis, D continued working at a California law firm, hiding her diagnosis from her bosses and coworkers as she recognized there were potential repercussions to disclosing her disability status. D recounted how she was forced to share her diagnosis after deteriorating to the point that her symptoms became visible. When her MS caused her to require a cane and wear an eyepatch, she was asked to leave her position. In this instance, the ableist perception of others directly resulted in limited career opportunities.

D shared that as she has gotten older and her disease has progressed, she has noticed acute differences in interactions with acquaintances and strangers. D described feeling largely unbothered by the thought of how people see her, despite recognizing that others' perceptions influence how they interact with her. Now, the choice to disclose her condition is no longer an option; symptoms such as a persistent limp provide visual indicators. Responses to her disability are often characterized by ableist attitudes, whether they manifest as pity, discomfort, or dismissal. She emphasized how frustrating it can be when someone reduces her to her disability. D also reflected on how she responds to other people's reactions now compared to when she was younger.

> The younger me probably would have cared. But now, I don't care if someone says, 'Oh, what is that,' and they kind of push it, and

> I tell them, 'Oh, you know, Multiple Sclerosis.' It really doesn't matter to me what they say. What are you gonna do?

Rather than shying away from increasing visible indication of impairment over the years, D has embraced the realities of life with MS. Not only did she share her gratitude for mobility aids such as her walker and wheelchair, she also described her assortment of "fabulous canes, one for every outfit." D reflected that while she cannot control whether people are aware of her disability, it is up to her to decide how she responds to them.

DISCUSSION

Study of the factors that contribute to positive adjustment after the onset of disability is a crucial area of research that is only becoming more relevant, as more and more people are experiencing disability and living with their conditions for many years. As people with MS age, their expectations and priorities evolve with the progression of the disease. According to Ploughman et al. (2012), many people diagnosed with MS feel that physical limitations influence their quality of life less than they affect social and emotional functioning. We can conclude that resiliency, self-efficacy, and social support all contribute to an individual's sense of agency and control over their condition and promote positive adjustment.

D's inner strength and belief in her ability to live a fully realized life helped her positively adjust to life with a disability and maintain an adaptive developmental trajectory. Informed by her parents' beliefs and behaviors and her loved ones' support, her mindset characterized her self-perception and her efforts to reach her goals. Throughout the interview, D expressed beliefs in resilience and resistance to despair. Without this sense of control over how she responded to adversity, D may have found it more difficult to cope with her diagnosis, particularly in the early stages. As Ploughman et al. (2012) proposed, D experienced a transition from denial to acceptance to self-advocacy. This transition was not always linear, as MS's relapsing-remitting nature caused her

to vacillate between denial and acceptance even as she learned to advocate for herself.

Individuals do not exist within a vacuum, and it is essential to look at the broader social contexts in which they exist. The development of disability affects an individual's life trajectory through the interdependent lives of that individual and the people with whom they have relationships. D's diagnosis of MS had a profound impact on herself and on dynamics with her parents, husband, and larger social network. D relied on the support of friends and family members while navigating life with MS. Social support positively influences one's selection of coping skills, social life, sense of empowerment, and reduction in loneliness (Forouzan et al., 2013). The importance of this support is underscored by the numerous references D made throughout the interview to the network of friends and family that emerged to help her manage MS.

D's experiences with MS were also influenced by the intersection of her identities and positionality. Multidisciplinary research has consistently indicated significant health disparities between whites and racial/ethnic minorities, with minority and socioeconomically disadvantaged populations up to three times as likely as other groups to experience disability at older ages (Schoeni et al., 2005). However, research has indicated that many of these differences are linked to disparities in income and education rather than biological distinctions (Fuller-Thomson et al., 2009). As a middle-class woman, D had access to early care. Although she experienced financial concerns relating to her inability to work, she was at a lower risk of falling into poverty. She was fortunate enough to understand the healthcare options available to her and to connect with pioneers in the MS field who facilitated her involvement with novel treatments as they became available.

LIMITATIONS

It must be noted that the data provided through this interview represent a single person's experience. The resulting interpretations may not accurately describe the experiences of other persons with

disabilities, even those who also developed MS at a young age. Due to the subjective nature of disability, caution must be exercised when attempting to extrapolate one individual's experience to a broader population. There is a possibility that the phrasing of some questions may have led D in a particular direction, even though open-ended questions were used. Additionally, data analysis was carried out by a single individual without collaboration with others. However, every effort was made to ensure that conclusions regarding the roles of resiliency, self-efficacy, and social support in D's experience of disability were rooted in evidence drawn from relevant, peer-reviewed research.

FUTURE RESEARCH DIRECTIONS

Future research directions may explore the influence of different types of social support on an individual's experience, investigating whether there are differential effects based on the source of support. Additionally, researchers may be interested in studying how positive internal traits, such as resiliency and self-efficacy, can be cultivated through interventions. Developing programs that encourage the adoption of health-promoting attitudes and behaviors may allow healthcare professionals to provide important scaffolding for coping mechanisms moving forward. These interventions could significantly impact how people with MS view themselves, their capabilities, and their life trajectory.

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