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A Mixed Methods Approach to Exploring Disability Identity in Adults with Acquired Brain
Injury

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Abstract

A Mixed Methods Approach to Exploring Disability Identity in Adults with Acquired Brain
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Background: Disability identity is the extent to which a person incorporates disability into their sense of self and connects with the disability community. The construct has been associated with increased psychological well-being, resilience, and engagement in disability advocacy, but remains understudied in rehabilitation. Adults with acquired brain injury (ABI) experience significant disruptions to their sense of self, but little is known about their disability identity development or how rehabilitation professionals can support this process. No prior research has examined the construct in this population through the lens of a disability identity framework.

Objective: The aims were to describe disability identity in adults with ABI, explore key influencing factors associated with disability identity in this population, and identify strategies for rehabilitation professionals to support disability identity development.

Methods: Guided by Forber-Pratt and Zape's (2017) Disability Identity Development Model, an explanatory sequential mixed-methods design was used. In the quantitative phase, 107 adults with ABI completed an online survey assessing disability identity along with personal, impairment-related and environmental factors, and occupational identity. Data from the survey were analyzed using multiple linear regression to identify potential relationships between disability identity and the various factors. Following quantitative data analysis, purposive sampling of survey participants was used to recruit 17 participants for four focus groups. Focus group data were recorded, transcribed, and analyzed using a hybrid approach thematic analysis. Two coders used an iterative coding process to collaboratively develop codes and subsequent themes. Integrated analysis compared the results and focused on how and to what extent the qualitative results helped to explain the quantitative results.

Results: Disability identity scores varied widely and clustered in the "low" range. In the full regression model, younger age, racially marginalized status, greater impairment visibility, and greater impairment severity were significantly associated with higher disability identity; self-reported environmental barriers did not account for additional variance in the model.

Occupational identity was also positively associated with disability identity. Qualitative findings characterized disability identity as a dynamic process that often begins with grief and the processing of difficult emotions and is strengthened through connection with the disability community. Participants described that impairment influences disability identity through interactions with social and built environments, that other marginalized identities shape how disability is understood, and that re-engagement in meaningful occupation supports identity development. Focus group participants also identified two main priorities for rehabilitation:

improving disability-affirming care and greater disability education amongst rehabilitation professionals.

Limitations: The cross-sectional design cannot assess change over time or support causal inferences about the relationships between disability identity and the factors examined. The sampling method for the survey and sample demographic background may limit generalizability of quantitative findings. Focus group participants had underrepresentation of individuals with lower disability identity which limit the transferability of qualitative findings. Findings should be interpreted with consideration of measurement limitations, including the four-item assessment of environmental factors and the need for further validation of the Disability Identity Development Scale cut scores.

Conclusions: Disability identity after ABI is a dynamic process that often begins with grief over the pre-injury self and the renegotiation of internalized ableism, takes shape through the interaction of impairment-related, personal, and environmental factors, and is strengthened through community connection. These findings extend Forber-Pratt and Zape's (2017) model to the context of acquired disability and suggest that rehabilitation can support disability identity through disability-affirming care delivered by a more disability-educated workforce.

Recognizing disability identity as a meaningful rehabilitation outcome beyond functional recovery has the potential to improve well-being and participation for adults with ABI.

Plain Language Summary

The term “disability identity” means how much a person sees disability as a part of who they are and how connected they feel to a community of other disabled people. Research has shown that people with a strong disability identity tend to have better mental health, more resilience, and more involvement in their communities. We know very little about how people develop a disability identity after an acquired brain injury (ABI) – such as a stroke or a traumatic brain injury – or how rehabilitation professionals who work with them can help.

To learn more, this study looked at disability identity using a survey, then focus groups. First, 107 adults with ABI filled out an online survey about their disability identity and other things that might be connected, like their age and race, the severity of their impairments, challenges faced in their environment, and their sense of connectedness with the activities that matter to them. After we looked for patterns in how these things might affect disability identity, we ran focus groups with 17 of the people who took the survey to talk more about their experiences and what rehabilitation professionals could do to help.

This study found that disability identity after ABI changes over time and often starts with grief over who the person used to be. Several things were linked to a stronger disability identity, including being younger, being a person of a marginalized race, having a more visible or more severe impairment, and having a strong sense of self related to their meaningful activities. Focus group participants shared more details about how these things all work together with their day-to-day encounters with getting around and interacting with people to shape their disability identity. They shared how important it is to connect with other disabled people to feel less alone and more understood, which also helped strengthen their disability identity. Participants shared that rehabilitation professionals should be disability-affirming by listening, treating their

experiences as expertise, avoiding treating disability as only a problem to be fixed, and connecting them to the disability community. They also want healthcare professionals to learn more about disability to better prepare them to work with disabled people.

Overall, the findings from this study suggest that disability identity is a meaningful part of life after ABI that changes and shifts throughout time. Rehabilitation can do more than restoring physical function by helping people build a positive disability identity and find community as they navigate life after ABI.

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Chapter 1: Introduction

Disability identity is a critical yet understudied construct in rehabilitation. While existing models of rehabilitation often focus on functional recovery, disability identity aligns with critical disability models that emphasize empowerment, participation, and self-advocacy. People with strong disability identity report lower psychological distress and decreased risk of depression and anxiety, are more resilient in the face of systemic barriers, and more engaged with disability rights efforts. Adults with acquired brain injury (ABI) face complex disruptions to their sense of self, but little research has examined how they develop a disability identity or how rehabilitation can support this process. Understanding disability identity development in this population is essential for informing ways rehabilitation professionals can support the process.

However, literature exploring disability identity development in adults with acquired brain injury is scarce. Although some work has been done to understand the shifts in identity that occur after acquired disability, none have been guided by disability identity frameworks, leading to gaps in knowledge about this specific construct and the potential factors involved. It is also unclear if rehabilitation professionals address disability identity in this population, although the need for interventions related to environmental barriers is apparent. Therefore, this study aims to use a mixed methods design to fill that gap by exploring disability identity in adults with acquired brain injury, and identifying factors that may be related to disability identity development and ways rehabilitation professionals can support the process. Forber-Pratt and Zape's Disability Identity Development Model (2017) was used as the guiding framework for the proposed study, providing additional insight into the construct in this population, and ultimately informing ways in which development of a strong disability identity can be supported after acquiring a brain injury. The aims of this study are threefold:

Aim 1: Describe disability identity in adults with acquired brain injury.

Aim 2: Explore associations between disability identity and key influencing factors in this population.

Aim 2a: Explore the relationship between impairment, personal, and environmental factors and disability identity.

Aim 2b: Explore the relationship between the constructs of occupational identity and disability identity.

Aim 3: Identify strategies for rehabilitation professionals to support disability identity development.

By examining disability identity in adults with ABI through an established disability identity framework, this study addresses a gap in current knowledge. It advances understanding of how disability identity develops in a population for whom the construct has not previously been examined and offers rehabilitation professionals direction on how to support it as a meaningful outcome beyond functional recovery. Because a strong disability identity is associated with better psychological well-being, greater resilience, and increased engagement, supporting its development has the potential to improve the lives of adults with ABI as they navigate life after injury.

Chapter 2: Literature Review

This chapter reviews the literature relevant to understanding disability identity in adults with ABI. It begins by defining disability identity as a construct and examining the frameworks used to conceptualize its development, which provides the theoretical foundation for this study. The chapter then addresses what is and is not known about disability identity specifically in adults with ABI. Next, it reviews the impairment-related, personal, and environmental factors that may be associated with disability identity development, establishing justification for the key factors this study examines. Finally, the chapter considers the role of rehabilitation in supporting disability identity and the limited guidance currently available to rehabilitation professionals, establishing the need to understand how rehabilitation professionals can support disability identity development after ABI.

Disability Identity

Disability identity has been defined as “a sense of self that includes one’s disability and feelings of connection to, or solidarity with, the disability community” (Dunn & Burcaw, 2013, p. 148). In contrast to the medical model of disability that focuses on minimizing or overcoming individual impairments, disability identity is rooted in social, political, and diversity models of disability (Adamson, 2018; Forber-Pratt et al., 2019). Shakespeare (1996) describes self-identity for people with disabilities not as an outcome of personal impairment, but rather the outcome of oppressive societal forces and attitudes towards the impairment. Many scholars have conceptualized the relationship between personal and communal experiences in shaping disability identity. Siebers (2017, 2019) calls for understanding the experience of disability as complexly embodied, meaning it is based on the dynamic interactions between personal experiences, environmental factors, and interactions with other disabled people and society at

large. In this way, disability identity involves the individual and the collective (Evans, 2017). Similarly, Kafer (2013) recommends a political relational framework for understanding disability, arguing for a more flexible and collective understanding of disability that includes varying levels of personal and/or societal identification with disability. Theories of social identity also consist of both the understanding that a person belongs to a group (e.g. the disability community) and the meaning a person derives from being part of the group (Forber-Pratt et al., 2019).

These conceptualizations of the disability experience provide a richer understanding of disability identity. Expanding on the above definition, Forber-Pratt et al. (2019) define disability identity as “the extent to which one feels shame or takes pride in disability; the degree to which one has integrated disability into one’s sense of self; and the type of contact, camaraderie, and engagement one has with the larger disability community” (p. 120). This definition will be used to describe disability identity for the purposes of this study.

Disability Identity Frameworks and Measurements

Over the last several decades, many models of disability identity have been put forth from rehabilitation and disability studies fields. One of the earlier models of disability identity was proposed by Gill (1997) in her work titled *Four Types of Integration in Disability Identity Development*. Also called the Disability Identity Model, Gill’s framework suggests there are four phases in which people may find themselves when developing a disability identity: “coming to feel we belong (integrating into society), coming home (integrating with the disability community), coming together (internally integrating our sameness and differentness), and coming out (integrating how we feel with how we present ourselves)” (Gill, 1997, p. 39). These four phases are presented as stages, described in such a way that highlights a journey of self-

discovery moving from initial desire to find a place in society to a feeling of wholeness with disability. Although she provides examples based on her professional work with disabled people, Gill's model is theoretical and lacks empirical evidence to support the proposed framework. Similarly, Gibson (2006) proposed a three-stage theoretical model of disability identity development, moving from passive awareness, to realization, and finally acceptance of disability. These early models lacked evidence gathered formally through observation and experience with disabled people and failed to recognize the dynamic relationship between phases of identity development (Forber-Pratt et al., 2017).

The first formal measure assessing disability identity was the Disability Identity Scale, known to be developed based on Gill's model of disability identity development (Forber-Pratt et al., 2017). The scale includes 17 items aimed at assessing attitudes that the participant has about disability or perceives others to have. Although this scale has been used in disability literature (Valeras, 2010; Whitney & Whitney, 2006), Forber-Pratt and colleagues have been unable to identify studies of the scale's psychometric properties or samples used to develop the scale (2017, 2022). Lack of information about development or psychometric properties is a notable concern when considering its use in research or practice.

In an effort to empirically investigate the development of disability identity, Hahn and Belt (2004) surveyed 156 people with disabilities attending civil demonstrations in order to understand their attitudes towards disability. Unlike Gill's (1997) model that focused on identity as a primarily personal phenomenon, Hahn and Belt sought to understand external factors that influence disability identity development. They used "communal attachments", (e.g., thinking that people with disabilities have things in common, prioritizing friendships with other disabled people), along with "personal identity" (e.g., being glad or proud to be a person with a disability,

having a personal meaning of disability) to illuminate the shared importance of individual feelings and connection to community in shaping disability identity. While the emphasis on external factors shaping disability identity is an important contribution of this model, the personal/intrinsic component has been criticized. In the model, the personal factors are primarily related to desire for a cure, rather than providing a more comprehensive perspective as is provided in relation to external factors (Forber-Pratt & Zape, 2017).

Hahn and Belt's (2004) study of disabled activists utilized a scale developed by the authors, called the Personal Identity Scale. This scale includes eight items using Likert-style responses to evaluate one's personal affiliation with disability as well as their sense of belonging within the broader disability community. When scoring this measure, items are summed, and a higher score indicates higher disability identity. Hahn and Belt reported preliminary evidence of construct validity of this scale based on their finding that people with higher disability identity were less likely to desire a cure for their disability (2004). The Personal Identity Scale has subsequently been used in other studies of disability identity (Bogart, 2014, 2015). However, it is important to consider that this scale was developed and tested on only one group of participants, who were primarily white males with mobility impairments, which raises concerns about its validity amongst other populations.

Darling and Heckert (2010) also aimed to empirically describe disability identity development using a sample of 388 disabled adults. Their model included three interrelated components of disability orientation: identity, including pride versus shame about disability; model for understanding one's disability, including either a social or personal model; and role in disability community, including activism or passivity. While the overall model of disability orientation provides a well-rounded picture of factors involved, the conception of identity is

limited to personal experiences (Forber-Pratt & Zape, 2017). This suggests that an individual must undergo a strictly personal development of their disability identity prior to fully engaging with social environments.

Along with their framework, Darling and Heckert (2010) developed the Questionnaire on Disability Identity and Opportunity as a way to evaluate the constructs of participation and orientation. In this measure, 30 items are used to assess an individual's disability orientation, which includes their identity, model, and role. Their psychometric analysis of this measure with a sample of 388 disabled participants found it has potential to be valuable for use in practical and research settings. However, only one component of the scale (identity) is related to disability identity, while the other components (model and role) are related to the person's perceptions of disability in society more broadly (Forber-Pratt et al., 2019), which may complicate the assessment of disability identity alone.

In response to the shortcomings of previous frameworks for disability identity development, Forber-Pratt and Zape (2017) proposed a model that is empirically developed, considers both internal and external factors, and describes the dynamic nature of identity through statuses rather than stages. The four statuses in this model describe the process by which people develop their disability identity but emphasize that some statuses may be more salient at different points in time or someone may resonate with multiple statuses simultaneously, highlighting the fluid nature of disability identity. The four statuses include: 1) acceptance, when a person and those closest to them become accepting of their disability; 2) relationship, when a person becomes connected with other disabled people and learns about the disability community; 3) adoption, when a person embraces the shared values of their community; and 4) engagement,

when a person decides to help others within the disability community and act as a role model (Table 1).

Table 1

Forber-Pratt and Zape's Model of Disability Identity Development (2017)

Acceptance status	• Become disabled and/or born with a disability • Person accepts own disability • Close friends and family are accepting of the disability
Relationship status	• Person meets others like themselves • Engages in conversation with these individuals • Learns about the ways of the group
Adoption status	• Adopts the shared values of the group
Engagement status	• Become a role model for others • Help those who may be in other statuses • Give back to the disability community

Based on their proposed model of disability identity status, Forber-Pratt et al. (2020, 2021, 2022) developed the Disability Identity Development Scale to understand an individual's disability identity (Forber-Pratt & Zape, 2017). The Disability Identity Development Scale includes 35 statements that an individual rates on a 5-point Likert scale from "not at all like" them to "definitely like" them. The scale is comprised of four components, that when taken together, represent a person's disability identity at a given point in time, with a higher total score indicating stronger disability identity. The four components include: "internal beliefs about one's own disability and the disability community, anger and frustration with disability experiences, adoption of disability community values, and contribution to the disability community" (Forber-Pratt et al., 2022, p. 126). An initial factor analysis supported the four factors mapping to their

established disability identity model (Forber-Pratt & Zape, 2020). An additional psychometric study was completed with 1,124 adults with diverse disabilities including physical disability, mental health conditions, and other health impairments (Forber-Pratt et al., 2022). This study, using confirmatory factor analytics, confirmed the scale was unidimensional and that the use of a single sum score of disability identity was merited, rather than parsing it into separate sub-scores. This analysis demonstrated reasonable psychometric properties of the measure amongst a diverse sample.

Understandings of disability identity have evolved in recent history, shifting from highly personal, stage-based processes to more comprehensive understandings that include one's relationship to their environment and the disability community and the recognition that people's disability identity is not static and may fluctuate throughout life. This evolution highlights the complexity of disability identity as a construct and underscores the value of a framework for understanding it. Forber-Pratt & Zape's Disability Identity Development Model (2017) combines both internal and external influences on disability identity development and highlights the fluidity of identity. Using this framework to explore disability identity amongst specific population groups will provide additional insight into the construct, ultimately informing ways in which development of a strong disability identity can be supported.

Understanding Disability Identity in Acquired Brain Injury

The Brain Injury Association of America (2025) defines an ABI as one that has occurred after birth, and can be traumatic (e.g., falls, motor vehicle accidents) or non-traumatic (e.g., stroke, anoxia). Acquired brain injuries are common – a yearly average of 2.8 million traumatic brain injuries and 800,000 strokes have been reported in the United States (Goldman et al., 2022) – and can lead to a unique experience of disability. These conditions have a sudden onset and

often result in a variety of residual functional impairments in physical (e.g., weakness, gait changes, sensory impairment), cognitive (e.g., executive functioning impairment, memory loss), and psychological domains (e.g., increased anxiety, depression) (Goldman et al., 2022). In addition to these complex personal presentations of impairment, people with ABI may face environmental and societal barriers that further affect their experience of disability, often resulting in reduced participation compared to people without ABI in required and meaningful life activities (Shrivastav et al., 2022; Silva et al., 2025; Wong et al., 2017). These experiences potentially influence the development of a sense of self related to disability after acquired brain injury. Therefore, it is important to understand the potentially unique process of disability identity development in this population.

Forber-Pratt et al. (2017) conducted a systematic review of disability identity literature, which found few results related to disability identity development specifically in people with ABI, some of which also include participants with other neurological conditions. One article sought to understand the experiences of individuals with paraplegia related to community participation (O'Connor et al., 2004). The participants in this study identified four challenges that emerged when redefining a sense of self after spinal cord injury – maintaining a non-medicalized identity, grappling with new differences, adjusting to the work required in daily life, and finding a balance between autonomy and reliance. While this study was not guided by any disability identity models, the overarching challenge for participants to redefine their sense of self in a holistic way, “inclusive of the injury but not defined by it” (p. 215), is similar to Forber-Pratt and Zape’s (2017) acceptance status, wherein the individuals were making sense of their disability and accepting the changes to their life. Another article by France et al. (2013) analyzed interviews to uncover the narrative genres used by people after stroke to describe their illness.

This study utilized Frank's (1995) illness narratives that reflect personal, cultural, and societal influences on one's description of their illness and sense of identity. In results similar to the O'Connor et al. (2004) study, participants after stroke often presented with the "quest memoir" narrative, in which they accept their illness and try to either incorporate it into their life or "move on" from it. Participants in both studies emphasized the reconstruction of self-identity after acquiring a neurological condition, but generally did not describe connection to a broader community as a part of their overall journey to acceptance of disability status.

Additional searches for disability identity literature yielded few results specific to people with ABI or neurological conditions more generally, and available literature was primarily framed more broadly in social identity theory. Gendreau and de la Sablonnière (2014) interviewed 10 people with either traumatic brain injury or spinal cord injury to understand their identity reconstruction post-injury. Using the Cognitive-Developmental Model of Social Identity Integration as a guiding framework, they found that participants underwent a process of identity reconstruction consisting of three stages: categorizing their experiences of pre- and post-injury life while placing higher value on pre-injury characteristics, compartmentalizing various aspects of their identity and struggling to find wholeness, and integrating new components of their identity into their overall sense of self. Using perspectives from the social model of disability and social identity theory, Hutchinson et al. (2018) sought to understand the impact of social processes on the identity of 14 individuals living with a variety of neurological conditions (e.g., stroke, MS, spinal cord lesion). They found that personal factors such as new physical or cognitive impairments, along with encounters of socially constructed disablement contributed to changing identity after an acquired neurological condition.

This body of work highlights the importance of changing identities and life restructuring that occur after an acquired disability. While some studies have sought to explore aspects of identity after ABI (France et al., 2013; Gendreau & de la Sablonnière, 2014; Hutchinson et al., 2018), none have been guided explicitly by disability identity frameworks. While participants in these studies emphasized the reconstruction of self-identity after acquiring a brain injury, they generally did not describe connection to a broader disability community as a part of their overall journey to acceptance of disability status. Participants aimed to rebuild their identities in order to fit in with their previously established social categories; disability identity models would encourage embracing the new category of disability and connection to the disability community. More work is needed to understand if these factors might minimize the sense of loss or help individuals accept and integrate their new identity status with ABI. More recent models such as the disability identity development model by Forber-Pratt and Zape (2017) can guide exploration of disability identity in adults with ABI and will provide additional insight into the construct in this population, ultimately informing ways in which development of a strong disability identity can be supported after acquiring a brain injury.

Factors Associated with Disability Identity Development

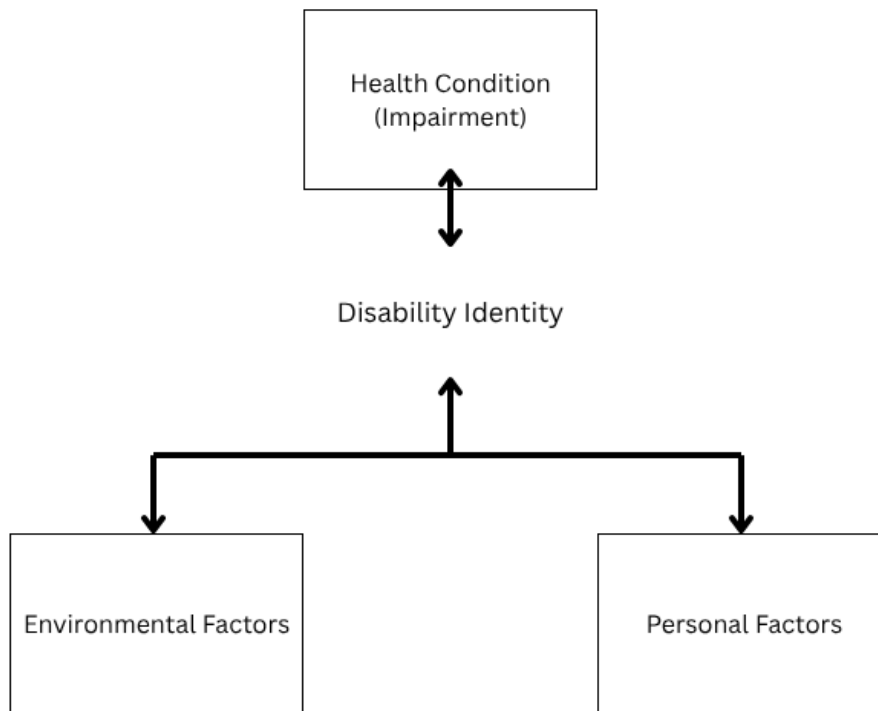
Previous conceptual and empirical understandings of disability identity focused primarily on intrinsic factors related to identity development. However, contemporary models urge consideration of other factors contributing to disability identity development including social and environmental constructs (Forber-Pratt & Zape, 2017). While limited, existing literature available from samples of adults with disabilities describes a variety of factors that may contribute to development of disability identity.

Using the ICF as a Framework

Forber-Pratt and Zape (2017) emphasize the contributions of both internal and external factors in development of a disability identity. In the field of rehabilitation, biopsychosocial models have been developed to understand disability as the interaction between various factors. The International Classification of Functioning, Disability, and Health (ICF; WHO, 2001) identifies impairment, personal, and environmental factors that may contribute to a person's experience of disability (Figure 1). While a new impairment likely serves as the entry point to experiencing disability for people with ABI, personal and environmental factors may significantly affect development of a disability identity. One of the major criticisms of the ICF is its lack of inclusion of subjective experience and personal meaning as contributors to a person's participation (Hemmingsson & Jonsson, 2005), which makes a full understanding of an individual's health difficult. However, the ICF has been a helpful framework in exploring the relationships between various factors in identification with disability and disability pride (seeing disability as an affirming source of group solidarity), which are distinct but similar constructs to disability identity (Bogart et al., 2017, 2018). Following the framework of previous work (Bogart et al., 2017, 2018), pairing the ICF's biopsychosocial approach with complementary perspectives that center subjective experiences can help to illuminate the factors that influence personal meanings about disability and disability identity development. The following sections describe impairment, personal, and environmental factors that may affect disability identity development among adults with ABI.

Figure 1

ICF Factors Mapped to Disability Identity



Note. Adapted from WHO, 2001.

Impairment Factors

Literature related to disability identity development has uncovered potential differences in people with acquired versus congenital disabilities. Charmaz (1994, 1995) studied people with acquired chronic illness and their adjustment to a new disability status. The studies revealed the impact of experiencing a time of loss and/or change that is unique to people acquiring disability later in life, after previously establishing a sense of self without disability. Similarly, Hahn and Belt (2004) found an early age of disability onset to be associated with stronger disability identity in their sample of disabled activists. Bogart (2014) expanded on this concept by comparing the disability identity of people with congenital disabilities to those with acquired

disabilities. In this study, people with acquired disabilities had lower disability identity than people with congenital disabilities, and earlier **time of onset** was associated with an individual's higher overall satisfaction with life. Bogart (2014) therefore suggested that the relationship between onset of acquired disability and disability identity may be less about the amount of time one has to adapt, and more about the life one has lived before becoming disabled. Importantly, the participant samples included in these studies had physical and mobility-related disabilities, so it is unclear how the presence of other impairments common with ABI, such as cognitive and psychological, may further complicate the development of disability identity.

Impairments such as cognitive, psychological, or communication-based are often non-apparent to the general population. These have been described as **“invisible” impairments**, and their presence may uniquely impact development of disability identity. Evans (2019) sought to understand the process of disability disclosure in adults with acquired non-apparent impairment, which revealed that decisions about and acts of disclosure were an important part of disability identity development. In some situations, participants described disclosure as a way to separate oneself from the identity of disability; in others, it was a way to validate their identity and connect with others. Similarly to Forber-Pratt and Zape's (2017) model, people with acquired non-apparent impairment did not seem to follow a linear trajectory of types of disclosure that led to identity development; they instead used different types of disclosure intermittently depending on the context. However, the “validating” forms of disclosure, or instances where disclosure “signals a political identity that resists systems of oppression against a shared, minority status”, appeared to most significantly impact disability identity development (Evans, 2019, p. 727). Some participants in Evans' study did have ABI and other neurological conditions (e.g. TBI, MS), and their overall experiences were similar to those with non-neurological conditions (e.g.

Crohn's disease). However, some participants with MS described additional physical impairments that complicated the disclosure process, such as using a wheelchair or other mobility aid in certain environments. Given that people with ABI may also have varying levels of apparent and non-apparent disability, it would be important to understand if these variations lead to different experiences with disability identity development.

In addition to type of impairment, the **severity** of impairments may also affect disability identity development in people with ABI, though this relationship is under-explored in the literature. In a sample of 710 adults with a variety of reported impairments, perceived severity of their impairments was a strong predictor of whether they identified themselves as a person with a disability – people with higher perceived severity were more likely to identify with disability, a distinct but related concept to disability identity (Bogart et al., 2017). Similarly, in adults with spinal cord injury, less perceived impairment severity was associated with lower overall disability identity (Lee et al., 2008). Given the scarcity of literature understanding the impact of severity on disability identity status, exploring this connection amongst people with potentially complex impairments is warranted.

Personal Factors

In addition to impairment-related factors, personal factors may also contribute to the development of disability identity. Defined as individual characteristics that are not directly related to a health condition (WHO, 2001), personal factors may include age, gender, sexual orientation, and race. These factors are particularly important in disability identity development as they are separate but related facets of an individual's identity that, taken together, contribute to an intersectional experience. Coined by Kimberlé Crenshaw to draw attention to the "conceptual limitations of ... single issue analyses" (1989, p. 149), intersectionality as an analytic

approach has come to signify the idea that the characteristics of a person intertwine and overlap with each other to shape a person's unique experience in the world. When conceptualizing and studying disability, it has often been considered as a separate or singular experience, rather than an understanding situated in the complexities of intersecting identities (Peña et al., 2016). As Siebers (2017) reminds us, it is not possible for people to “peel off” their various identities because they constitute one another. Therefore, exploring the intersecting identities of adults with ABI is crucial for a full understanding of their disability experience.

The likelihood of acquiring traumatic and non-traumatic brain injury increases with **age** (Ma et al., 2024; Yousufuddin & Young, 2019). However, the intersections of aging and disability identity in these populations have yet to be sufficiently explored. In Darling and Heckert's exploration of disability identity, they found that older adults with disabilities had fewer opportunities to engage with disability communities or empowering perspectives of disability (2010). Older people also experience medicalized approaches to aging services, which often perpetuate the ‘successful aging’ discourses that describe disability in aging as a personal failure (Katz & Calasanti, 2015). Taken together, this medicalized notion of disability in aging and lack of access to empowering disability discourses likely negatively impacts disability identity development in older adulthood.

In a study with adults first experiencing disability in older age, Leahy (2023) found that interaction with other older adults experiencing disability or engaging in disability activism did foster disability identity development. Hutchinson et al. (2018) found that, specifically for older adults with acquired neurological disability, societal attitudes around disability, including experiences of social stigma, led to increased resistance to identify as disabled. However, the process of rethinking their disability in terms of an “experience” rather than a “loss” was

important for identity development, and in some cases could be achieved in part through social engagement with others with shared experiences. These studies suggest there is value in sharing experiences with other disabled older adults, but more work is needed to better understand the intersectionality of aging and disability in people with ABI.

Gender can intersect with disability in various ways that may ultimately affect identity development. For adult women, disability status can lead to infantilization and perpetuation of the idea of women as “helpless victims” (Mohamed & Shefer, 2015). In a study of women with different types of disability, physical disabilities lead to perceptions of asexuality, while intellectual or emotional disabilities led to perceptions of hypersexuality (Shuttleworth et al., 2012). For men, the status of disability conflicts with stereotypical ideas of masculinity (e.g., strength, independence, vigor) (Mohamed & Shefer, 2015), and it is unclear how this conflict affects disability identity status in men. In a study of transgender disabled youth, there was a reported “cumulative effect between transness and disability” (Baril et al., 2020); again, highlighting the inseparability of identities. Given the paucity of literature exploring the intersection of gender and disability in adults with ABI, exploring this factor is warranted.

The intersections of **sexual orientation** and disability identity have not been sufficiently explored in those who acquire disability later in life. In literature investigating the development of sexual identity amongst disabled people, it seems that the act of coming out can be complicated by simultaneous experiences of ableism and heteronormativity, leading to additional isolation and feelings of insecurity (Goulden & Kattari, 2023; Stoffelen et al., 2018; Toft, 2020). Disability and queer studies scholar McRuer describes similar societal pressures of “compulsory heterosexuality” and “compulsory able-bodiedness” – systems that work to reproduce an “ideal” or “normal” body – that are intertwined and together impact the experiences of those at the

intersections of these identities (2006). Evidence has indicated that lesbian, gay, and bisexual people face physical and mental health disparities that are related to their experiences with stigma and violence; but those who choose to conceal their sexual identity can also experience these negative health outcomes (Forber-Pratt & Zape, 2017; Lick et al., 2013). In order to identify potential opportunities to reduce negative outcomes, more work is needed to understand how disability identity intersects with sexual orientation.

An individual's **race** also contributes to their sense of identity, and people with marginalized racial identities may also have unique experiences with disability identity development. Literature has indicated that racial minority groups experience a variety of health disparities, and for those with disabilities, these disparities are influenced by the systemic racism and ableism combined (Dorsey Holliman et al., 2023). Although these disparities also exist for non-disabled racial minorities, it has been reported that a healthy racial identity can contribute to positive health outcomes such as lower stress and anxiety, indicating that it may serve as a protective mechanism for people with disabilities (Forber-Pratt & Zape, 2017). The connection between racial identity and disability identity is underexplored and warrants further investigation.

Environmental Factors

Societal attitudes towards disability can play a role in disability identity development. Marginalized groups (including people with disabilities) often face stigma, a social construct that involves labelling and negative stereotyping of groups with less power by those with more power (Link & Phelan, 2001). In people with ABI, stigma has been demonstrated to negatively affect adaptation to life after injury (Mukherjee et al., 2006) and can result in delayed medical treatment (Ge et al., 2021). In a study of disability identification in people with self-reported

impairments, stigma was a strong predictor of identification as disabled, more so than impairment and personal factors (Bogart et al., 2017). The authors suggest that disability identity may therefore be a protective factor against stigma, enabling a person to externalize rather than internalize their negative experiences.

For people with disabilities, **social support** has been found to be a coping resource and can act as a buffer against stigma (Bogart et al., 2017). Social support specifically from other people with shared disability experience is important in disability identity development. Forber-Pratt and Zape (2017) highlighted the importance of disability community in their sample of disabled college students and veterans, reporting the benefits of being around people who could fully understand them and did not require additional explanation related to experiences of discrimination or environmental barriers. More work is needed to understand general and disability-specific social support in relation to disability identity in adults with ABI.

Physical and structural environmental barriers may also affect disability identity development by limiting valuable social interactions and perpetuating stigma. Research has indicated that people with acquired brain injury face many environmental barriers (e.g., inaccessible buildings, fluctuations in natural surroundings) that negatively impact community participation (Hammel et al., 2006; Whiteneck et al., 2004a). Similarly, in Forber-Pratt & Zape's study of disabled college students and veterans, some participants noted that barriers in the built environment limited their opportunities for social participation, which in turn hindered the external connections needed for their disability identity development (2017). In a study of young adults with disabilities, those with stronger disability identification were also more likely to be involved in disability rights advocacy efforts, indicating that disability identity may be important in shifting the focus from internalized stigma to self-advocacy related to environmental barriers

(Nario-Redmond & Oleson, 2016). Given the overall paucity of literature, more research is needed to explore this relationship.

Disability Identity and Occupational Identity

In the field of occupational therapy, the construct of occupational identity has been studied in adults with ABI. Occupational identity has been defined as “a composite sense of who one is and wished to become as an occupational being generated from one’s history of occupational participation” and is described as a component of an individual’s overall self-identity (Kielhofner, 2008, p. 106). A systematic review of the literature related to occupational identity post-stroke identified a three-stage model for development of occupational identity, involving the factors contributing to initial disruption of occupational identity, the individual’s experience of occupational identity disruption, and their strategies for coping with the disruption (Martin-Saez & James, 2021). An autoethnography of occupational identity after traumatic brain injury uncovered similar themes of disruption and “occupation-specific grief” related to new difficulty performing valued life activities (Brown et al., 2024). Similarities between these discourses of occupational identity development and disability identity development include the process of accepting one’s disability, but do not account for the importance of community highlighted in disability identity models (e.g., Forber-Pratt & Zape, 2017).

Gaps in Rehabilitation Support for Disability Identity

Amongst marginalized minority groups (including disability communities), social identities have been associated with health outcomes and can significantly influence the way people understand and respond to the structures and systems they are a part of (Haslam et al., 2009). Compared to people who reject or deny their disability status, people with a strong disability identity have lower psychological distress and decreased risk of depression and anxiety

(Bogart, 2014, 2015). Additionally, people who integrate disability into their identity are more resilient in the face of structural and systemic challenges in the workplace and in society more broadly, and are more politically engaged with disability rights efforts (Forber-Pratt et al., 2019; Nario-Redmond & Oleson, 2016; Santuzzi & Waltz, 2016). Therefore, disability identity is an important outcome with connections to rehabilitation. Rehabilitation professionals (e.g., occupational, physical, and speech therapy practitioners, psychologists, social workers, etc.) can play a role in understanding the disability identity of an individual, and choosing intervention approaches and strategies that foster increased disability identity when appropriate.

Many general rehabilitation approaches could be used to facilitate the disability identity process. Bogart et al. (2018) found that personal (e.g. age, gender) and environmental (e.g. social support, stigma) factors, but not impairment (e.g. number of impairments, pain), predicted disability pride in people with self-reported impairments. This finding highlights the need for rehabilitation interventions that focus on modifiable environmental factors rather than only impairment-related factors, such as facilitating access to social support and community engagement, which are environmental factors that can be negatively impacted after acquired brain injury (Northcott et al., 2016; Semanision et al., 2024). Community engagement and self-advocacy have been established as meaningful occupations within the occupational therapy scope of practice (American Occupational Therapy Association, 2020), meaning occupational therapy practitioners may have distinct value in facilitating disability identity development after acquired disability by emphasizing its relationship to re-establishing meaningful occupations. Given its impact on well-being and participation, disability identity should be recognized as a relevant outcome in rehabilitation; however, further research is needed to guide how rehabilitation professionals can effectively support its development in practice.

Opportunities for interventions that directly target disability identity are limited. Forber-Pratt et al. (2019) provide suggestions for framing initial discussions around disability identity in the rehabilitation setting and follow-up worksheet-based intersections to strengthen a person's connection to their disability, however, it is unclear if these interventions are being used in routine care amongst rehabilitation professionals or if they are effective. This limited existing guidance around supporting disability identity is not specific to ABI, and no research has examined how rehabilitation professionals might support disability identity development from the perspective of adults with ABI themselves. Disability identity after ABI may develop through a unique process, so there is a need to learn directly from adults with ABI how rehabilitation can support their disability identity development.

Taken together, this body of literature establishes the significance of disability identity and what is currently known about the construct, and also highlights the gaps in knowledge about disability identity in adults with ABI. Addressing these gaps requires an approach that can both characterize disability identity and its associated factors and illuminate the contextual processes that quantitative data alone cannot capture. A mixed-methods design is therefore well suited to this inquiry, using quantitative methods to describe disability identity and identify associated factors, and qualitative methods to explain how and why those factors matter for adults with ABI as well as how rehabilitation professionals can support a strong disability identity.

Chapter 3: Methods

This chapter outlines the methods used to examine disability identity in adults with ABI. It begins by describing the purpose and structure of the explanatory mixed methods design. It then describes the quantitative methods, including recruitment, survey development, data collection, and data analysis procedures used to describe disability identity and examine its association with personal, impairment-related, and environmental factors (Aims 1 and 2). Finally, the qualitative methods are described, including focus group recruitment, data collection, and data analysis procedures used to explain the quantitative findings (Aims 1 and 2) and explore how rehabilitation professionals can support disability identity development after ABI (Aim 3).

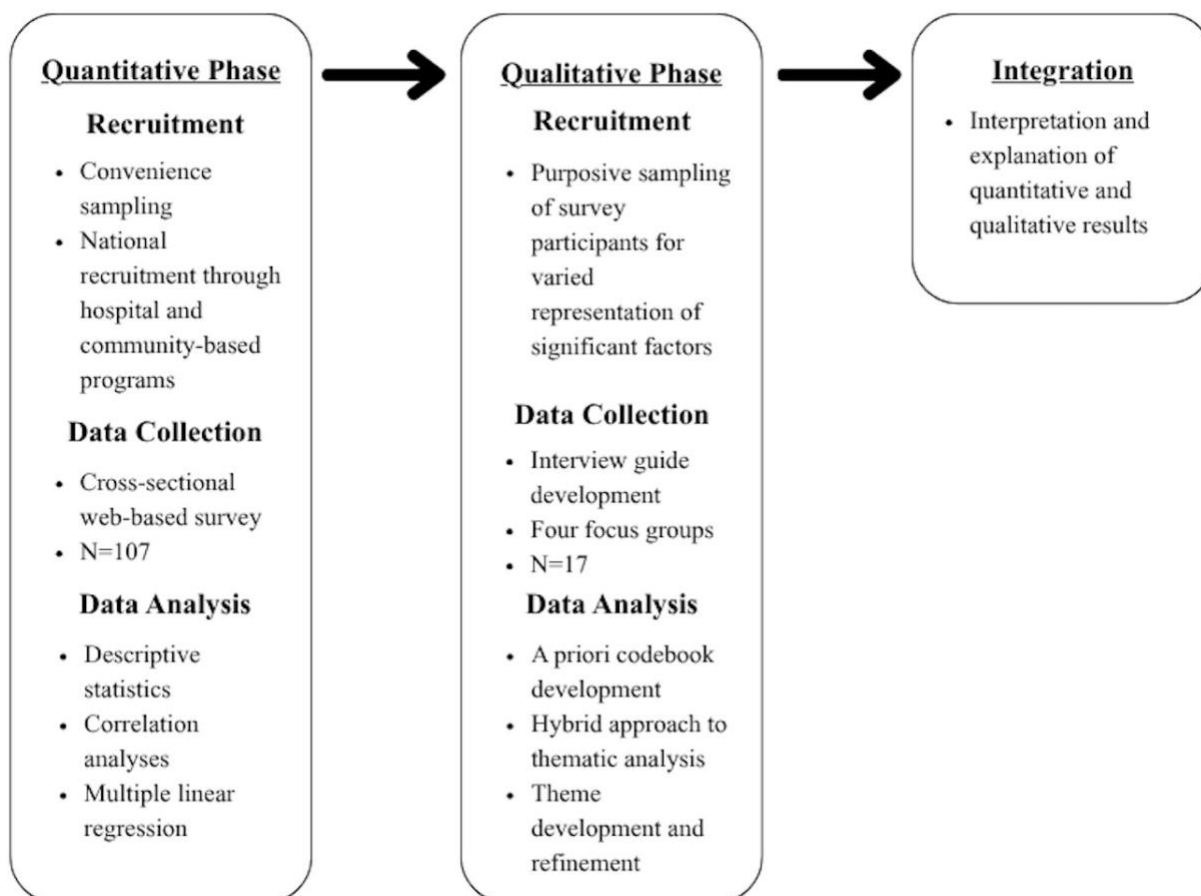
Design

Guided by Forber-Pratt and Zape's Disability Identity Development Model (2017), an explanatory mixed methods design was used, involving collecting quantitative data first and then explaining the quantitative results with in-depth qualitative data. Combining quantitative and qualitative methods provides a more in-depth and complete picture of research problems (Creswell & Plano Clark, 2018). In this study, a mixed methods approach allowed for an in-depth exploration of disability identity after ABI. Quantitative data examined disability identity among adults with ABI (Aim 1), identified significant impairment, personal, and/or environmental factors that may contribute to disability identity development (Aim 2a) and explored a potential relationship between the constructs of occupational identity and disability identity (Aim 2b). Qualitative results then explored why and how certain factors contribute to disability identity development in this population (Aims 1 and 2) and explored how rehabilitation professionals can support disability identity development (Aim 3). See Figure 2 for a visual

diagram of the research process. All research activities were approved with exempt status by the University of Washington Institutional Review Board (#00023616).

Figure 2

Visual Model of Mixed Methods Design



Note. Adapted from Creswell and Plano Clark, 2018.

Quantitative Methods

The quantitative portion of the study employed a cross-sectional survey design to explore the status of disability identity development (Aim 1) and associated impairment, personal, and environmental factors among adults with ABI (Aim 2).

Participants

Recruitment. Convenience sampling was used to recruit adults with ABI. A recruitment flyer (Appendix A) was created that described the study and included a link to take the survey as well as a link to contact the primary researcher if interested in learning more or to access support for participation. Flyers were distributed via email to 36 community-based support groups for ABI survivors, eight university TBI Model Systems Centers, two inpatient rehabilitation systems, and four outpatient rehabilitation systems across the western, midwestern, southern, and eastern regions of the United States. Flyers were also distributed in person at a local fundraising event for stroke survivors and to the local inpatient and outpatient rehabilitation systems. Inclusion criteria included adults age 18 years or older, self-report of acquired brain injury, ability to complete an online survey with or without accessibility-related assistance, and ability to take a survey in English. Individuals were excluded if they identified as disabled prior to their acquired brain injury or if they have a comorbid progressive neurological condition (e.g. Multiple sclerosis, Parkinson's disease, dementia).

Sample size and power analysis. The study aimed to recruit 125 adults with acquired brain injury. Power analysis using G*Power was conducted based on the analysis plan described below. The analysis requiring the highest sample size was the multivariable linear regression examining environmental factors while controlling for the other variables (Aim 2a). In order to detect a small-to-moderate effect ($f^2 = 0.1$) at the .05 significance level with 80% power, a minimum of 100 participants was required. At $n=100$, the remaining analyses were powered above 80% to detect similar effect sizes. A target sample size of 125 participants was chosen to reflect a 25% inflation, accounting for potential missing data (Dillman et al., 2014).

Data Collection

Procedure. Data were collected through an electronic survey using the Research Electronic Data Capture (REDCap) platform (Harris et al., 2009; Harris et al., 2019). Participants were asked to complete the survey online but were informed that assistance was available to complete the survey via phone or videoconference, and the primary researcher was available to read questions, but not to assist with understanding. Participants had the opportunity to enter a drawing for two \$25 gift cards for participating in the survey. Participants who were interested in taking the survey accessed it directly. Informed consent was obtained virtually prior to the survey loading. Two participants requested support and completed the survey over the phone. Their informed consent was obtained by the primary researcher when providing assistance.

Survey development. The survey included questions from established questionnaires/measures, standard demographic questions, and additional impairment-related questions created for the study (see Appendix B for survey questions). After completing a final draft of the survey, three people with acquired brain injury who met the inclusion criteria above were identified for a brief interview to ensure the survey was understandable and acceptable (Dillman et al., 2014). Because the survey consisted primarily of previously developed questionnaires, the interviews focused primarily on overall readability, formatting, and accessibility. See Table 2 for the interview guide.

Table 2*Survey Development Interview Guide*

Topic Area	Questions
Readability	- What do you think of the order of the questions?
	- Is more detail needed as an introduction to the survey?
Length	- How long did the survey take you to complete?
	- Do you think the length is acceptable?
Accessibility	- What did you think of the format and font?
	- Do you think the survey should be presented on one long page or multiple pages?
	- If you took the survey on a phone/tablet, was the formatting acceptable?
Sensitivity	- Did you think any of the topics were particularly sensitive?
	- Do you think a content warning should be included?
General	- What was your overall impression of the survey?
	- Do you think anything should be added/removed/revised?

Based on the interview results, the survey was revised to improve accessibility and clarity. Overall, the people interviewed found the initial draft of the survey to be acceptable in length, readability, and accessibility. One person suggested improving accessibility by allowing survey participants to save and return to the survey, and all three agreed that breaking up the survey into multiple pages improved accessibility by decreasing the visual and cognitive stimulus. One impairment-related question had the option to choose from visible and/or invisible impairments and gave a few examples of each category. For the invisible category one participant suggested adding a psychosocial/emotional-related example to the invisible category to expand participants' understanding of invisible impairment. With the person's input the example was adjusted to include "difficulty managing emotions, depression, anxiety" in addition to "difficulty remembering things" and "difficulty with speaking".

Dependent Variable

Disability identity. Disability identity was measured using the Disability Identity Development Scale (Forber-Pratt et al., 2021). The Disability Identity Development Scale includes 35 statements that an individual rates on a 5-point Likert scale from “0=not at all like” them to “5=definitely like” them. The scale is comprised of four components: internal beliefs about own disability and the disability community, anger and frustration with disability experiences, adoption of disability community values, and contribution to the disability community. When taken together, these components represent a person’s disability identity at a given point in time, with a higher total score indicating stronger disability identity (score range = 0-140). The cut score for the “low” category is 57, “low-moderate” is 84, “high-moderate” is 111, and “high” is above 111 (Forber-Pratt et al., 2022).

Although the scale is newly developed and therefore not yet widely used in research, initial factor analysis confirmed that the four factors identified by the scale map onto the Model of Disability Identity that is used to frame the proposed study (Forber-Pratt & Zape, 2017; Forber-Pratt et al., 2020). An additional psychometric study revealed the scale to be a reasonable assessment of disability identity amongst a larger and more diverse sample size of 1,126 adults with a self-reported disability (Forber-Pratt et al., 2022). This study used confirmatory factor analyses to determine the use of a single sum score of disability identity, highlighting that disability identity should not be parsed into separate factors, but understood as the combination of these factors together. The study also provided initial descriptive cut score data using the calculated percentiles of participant responses, though authors note these categories should be interpreted with caution as additional work is needed to establish validity of the cut scores (Forber-Pratt et al., 2022).

Independent Variables

Impairment factors. Participants were asked for their *age of acquiring brain injury* (via free text numerical input) based on previous literature suggesting a connection between time of onset and disability identity (Bogart, 2014). To explore the relationship between type of impairment and identity (Evans, 2019), participants were asked to categorize their *type of impairment* as “no impairment, visible impairments only (i.e. difficulty walking, difficulty using my arm), invisible impairments only (i.e. difficulty remembering things, difficulty with speaking, difficulty managing emotions, depression, anxiety), or both visible and invisible impairments”. This variable was coded into four categories for analysis with “no impairment” as the reference category, “invisible impairments only” as a category, and “visible impairments only” and “both visible and invisible impairments” as a category. They were also asked to rate the *severity* of their impairments using a 5-point Likert scale-style question previously used by Bogart (2017) that found connections between severity and identification with disability. Participants were asked to rate their response to the question, “my condition is severe (it significantly affects my daily life)”; 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree.

Personal factors. Participants were asked for their *current age* (via free text numerical input) to explore relationships between aging and disability identity (Leahy, 2023). Participants were asked for their *gender* (“man, woman, non-binary, or prefer to self-describe”) and *sexual orientation* (“asexual, bisexual, gay, heterosexual or straight, lesbian, pansexual, queer, or prefer self-describe”) as well as their *race* (“American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Middle Eastern or North African, Native Hawaiian or Pacific Islander, and White”) following previously documented guidance about survey questions related to these demographics (Matsumo, n.d.; United States Census Bureau, 2024). Gender was

dummy-coded as “man” = 0 and all others = 1, sexual orientation was dummy-coded as “heterosexual or straight” = 0 and all others = 1, and race was dummy-coded as “white” = 0 and all others = 1. These categories were dichotomized because the small number of participants in individual gender, sexual orientation, and racial subgroups precluded their separate inclusion in the regression models. Categorization was guided by a shared distinction between historically marginalized identities and the reference group in each case.

Environmental factors. Four questions from the Craig Hospital Inventory of Environmental Factors Short Form (CHIEF-SF) were used to ask about *physical and structural barriers* as well as *attitude and support* in participant’s environments. The CHIEF-SF is comprised of subscales that can be scored separately, so the subscales related to physical and structural barriers and attitude and support were chosen. Each of these subscales contains two questions where participants were asked to rate the frequency (daily=4, weekly=3, monthly=2, less than monthly=1, never=0) with which environmental factors are encountered as well as the magnitude of the problem (big problem=2, little problem=1) if the problem occurred over the past 12 months. The questions for the physical and structural barriers subscale include, “how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do?” and, “how often have other aspects of your surroundings – lighting, noise, crowds, etc. – made it difficult to do what you want or need to do?”. The questions for the attitude and support subscale include, “how often have other people’s attitudes toward you been a problem?” and “how often did you experience prejudice or discrimination?”. When multiplied together, the frequency and magnitudes scores provide an overall impact score (0-8) of that environmental factor, with a higher score indicating higher impact of the barrier on daily life (Whiteneck et al., 2004b). The CHIEF has good discriminant validity amongst a variety of

conditions including brain injury, and scores from the short form are consistent with long form scores in these populations (Whiteneck et al., 2004b).

Occupational identity. The Occupational Identity Questionnaire (OIQ) was used to assess participant's *occupational identity*. The questionnaire consists of 14 items that are summed to achieve a final score of level of occupational identity, with higher scores indicating stronger sense of self in relation to occupational roles. The scale is comprised of three factors: sense of past self, satisfaction with current circumstances, and sense of present self and future expectations. Taken together, these factors represent a composite picture of a person's sense of self as an occupational being (Shikata et al., 2021).

The psychometric properties of this newly developed assessment have been investigated with older adults living in the community as well as those in the hospital and residing in nursing homes. An initial study involving 135 community-dwelling older adults determined reasonable structural validity using exploratory and confirmatory factor analyses, adequate internal consistency using the Person separation index and reliability coefficient, and a significant but weak correlation between the OIQ and the occupational identity subscale of the Occupational Performance History Interview Version II, indicating reasonable criterion validity (Shikata et al., 2021). A follow-up study conducted with 126 hospitalized older adults used confirmatory factor analysis to confirm the structural validity of the OIQ with a different population and Person separation index and reliability coefficient to demonstrate high reliability (Shikata et al., 2025). See Table 3 for a review of all variables included in quantitative analyses.

Table 3*Independent and Dependent Variables*

	Measures/Questions	Scales	Categorization
Dependent variable			
Disability identity (aim 1 and 2)	DIDS 35 questions related to internal beliefs about own disability and the disability community, anger and frustration with disability experiences, adoption of community values, and contribution to the disability community.	5-point Likert scale: not like me at all, a little bit like me, somewhat like me, a lot like me, very much like me (0-140 total score)	
Independent variables			
Time since injury (aim 2a)	Age of injury onset - current age	Number of years	
Type of impairment (aim 2a)	“How would you describe the impairment(s) related to your brain injury?”	No impairment, invisible impairments, visible impairments, both visible and invisible impairment	
Severity of impairment (aim 2a)	“Please rate your response to the following question: My condition is severe (it significantly affects my daily life).”	5-point Likert agreement scale: strongly disagree, disagree, neutral, agree, strongly agree	
Current age (aim 2a)	“What is your age?”	Numerical free text box	
Gender (aim 2a)	“How would you describe your gender?”	Man, woman, non-binary, prefer to self-describe	Man = 0, all others = 1
Sexual orientation (aim 2a)	“How would you describe your sexual orientation?”	Asexual, bisexual, gay, heterosexual or straight, lesbian, pansexual, queer, prefer to self-describe	Heterosexual or straight = 0, all others = 1

Race (aim 2a)	“How would you describe your race? Choose all that apply.”	American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Middle Eastern or North African, Native Hawaiian or Pacific Islander, White	White = 0, all others = 1
Physical and structural environment (aim 2a)	CHIEF-SF 2 questions related to the frequency and magnitude of physical and structural barriers.	Frequency score (daily=5, weekly=3, monthly=2, less than monthly=1, never=0), multiplied by magnitude score (big problem=2, little problem=1) to achieve barrier impact score (0-8)	
Attitudinal environment and support (aim 2a)	CHIEF-SF 2 questions related to the frequency and magnitude of attitude and support barriers.	Frequency score (daily=5, weekly=3, monthly=2, less than monthly=1, never=0), multiplied by magnitude score (big problem=2, little problem=1) to achieve barrier impact score (0-8)	
Occupational identity (aim 2b)	OIQ 14 questions related to sense of past self, satisfaction with current circumstances, and sense of present self and future expectations.	4-point Likert agreement scale: strongly disagree, disagree, agree, strongly agree (21-84 total score)	

Note. DIDS = Disability Identity Development Scale; CHIEF-SF = Craig Hospital Inventory of Environmental Factors–Short Form; OIQ = Occupational Identity Questionnaire.

Data Analysis

Data were analyzed using R (R Core Team, 2025). Descriptive statistics were calculated to summarize sample characteristics and distributional properties of all study variables, including means, standard deviations, and ranges for continuous variables, and frequencies and percentages for categorical variables. Variables were also screened for normality through examination of skewness and kurtosis, with all values below 2 for skewness and below 7 for kurtosis, indicating appropriateness for the use of parametric procedures (West et al., 1995).

To examine bivariate relationships among study variables and to screen for multicollinearity prior to regression, correlation analyses were conducted. Pearson product-moment correlations were calculated among all study variables; these are equivalent to point-biserial correlations for associations between a continuous and a dichotomous variable and to phi coefficients for associations between two dichotomous variables. A bivariate correlation of .70 or greater was treated as an indicator of multicollinearity concern. A strong correlation was identified between current age and age of brain injury onset ($r = .80$). To address the high collinearity between current age and age of injury onset, a derived variable representing time since brain injury was calculated as the difference between current age and age of injury onset. This variable was conceptually aligned with some research emphasizing duration of lived experience with disability (Hahn & Belt, 2004). Correlation analysis of the derived variable confirmed that time since injury was only weakly correlated with current age ($r = .20$), indicating that the multicollinearity issue had been resolved and the variables were suitable for regression analyses. The invisible and visible impairment indicators were also strongly correlated ($r = -.86$). Because these are mutually exclusive indicators derived from a single four-category impairment type variable (no impairment, invisible impairment, visible impairment, or both

visible and invisible impairment, with no impairment as the reference), this correlation reflects the coding structure rather than multicollinearity, and both indicators were retained to represent the levels of the impairment type variable in the regression models.

Following correlation analyses, a multiple linear regression was conducted in which all 10 independent variables were entered into the model at once to assess their unique contributions to disability identity score, while controlling for the effects of other variables (Aim 2a). Model fit was evaluated using the F-statistic and R^2 , and individual unstandardized (b) and standardized regression coefficients (β), and p -values were examined to assess the significance and strength of the association for each variable with disability identity score. An assumption of this analysis was that participants identifying as women and other gender identities shared sufficiently similar marginalization to be grouped for analysis. To assess this assumption, a sensitivity analysis was completed, excluding the two participants who did not identify as a man or woman.

To further explore the contribution of environmental factors as a group beyond impairment and personal characteristics, the full model was then compared to a reduced model in which the physical/structural barriers variable and the attitudinal/support barriers variable were removed. Comparing the change in R^2 of the full model to this reduced model tested whether the environmental factors together accounted for variance in disability identity beyond impairment-related and personal factors. This comparison was motivated by prior literature highlighting the importance of environmental factors in disability identity development (Bogart et al., 2017, 2018; Forber-Pratt et al., 2017).

Finally, to explore a potential relationship between the constructs of occupational identity and disability identity (Aim 2b), a linear regression analysis was conducted with disability identity total score as the dependent variable and occupational identity score (as measured by the

Occupational Identity Questionnaire) as the independent variable. Correlation was calculated to assess the strength and direction of the linear association between occupational identity and disability identity, then linear regression was conducted to estimate the amount of change in disability identity scores per unit increase in occupational identity. This exploratory analysis assessed the extent to which participants' sense of occupational identity may explain their disability identity.

For all regression analyses, regression assumptions (linearity, normality of residuals, homoscedasticity, and independence of errors) were evaluated. Normality was assessed through visual inspection of histograms and examination of skewness and kurtosis values. Linearity and homoscedasticity were assessed through visual inspection of residual-versus-fitted plot. Independence of errors was supported by the study design, as each participant submitted one response and participants were not sampled in clusters.

Qualitative Methods

Following the explanatory mixed methods approach, the results of the quantitative analysis guided further qualitative exploration of disability identity and the factors that may influence disability identity development in adults with ABI (Aims 1 and 2) and identification of strategies for rehabilitation professionals to support disability identity development in this population (Aim 3).

Participants

Participants were recruited from a pool of survey participants who indicated willingness to participate in a follow-up focus group. Purposive sampling was used to identify up to 20 participants by ensuring adequate diversity amongst disability identity status based on the total

score of Disability Identity Development Scale and adequate representation of the significant factors associated with disability identity during the quantitative phase (e.g. race, age, impairment severity, impairment visibility). Individuals were required to have access to Zoom and participate in the focus group in English. Participants were encouraged to use supports as needed for participation in the focus group, including augmentative communication devices and/or care partner support for communication and technology. Individual interviews were offered to participants who were interested in sharing their perspectives but uncomfortable with a group setting.

Data Collection

Four focus groups were formed with a target focus group size of four to six participants, in order to balance an inclusive environment while also facilitating thematic saturation (Namey et al., 2016; Trevisan, 2021). Focus groups were chosen to emphasize a sense of community amongst participants and to facilitate group brainstorming and sharing of ideas (Acocella, 2012). Virtual focus groups were conducted to maximize accessibility – virtual focus groups promote ease of access for people who have difficulty with travel, provide discreet opportunities for people to take breaks from the conversation by reducing the volume and muting the microphone and/or turning off the video, and allow text-based communication as an alternative to speech-based communication (Fischbein et al., 2024). Focus group sessions lasted 70-95 minutes, beginning with a brief review of the construct of disability identity to establish a shared operational definition for the group and additional information throughout about the results of the quantitative data analysis to provide context for the questions and factors discussed. A simple PowerPoint presentation was used intermittently throughout the session to visually display the information given. All participants were compensated for their time with a \$25 gift card.

Using the Forber-Pratt and Zape's Disability Identity Development Model (2017) as a guiding framework, a semi-structured interview guide was created to further explore the associations found during the quantitative analysis (Table 4). Participants were asked generally about their disability identity and the process of disability identity development after brain injury, followed by questions that more specifically targeted the significant factors associated with disability identity development identified in the quantitative analysis. Questions were aimed at identifying factors that positively and negatively impact development. Finally, participants were asked about the role of rehabilitation professionals in developing a strong disability identity.

Table 4

Interview Guide

Question 1	How would you describe your disability identity? <i>Probes: How do you see disability as part of who you are? What connection do you feel to people with shared experiences? Do you think it's high or low? Has it changed since your initial injury?</i>
Question 2	How have certain factors affected your identity with disability? <i>Factors: race, current age, impairment severity, impairment visibility, connection to others with shared experiences, built and/or social environments, participation in roles and/or activities that are meaningful.</i>
Question 3	What other factors have helped you embrace your disability, or made it difficult to accept?
Question 4	How could rehabilitation professionals support people in developing a strong disability identity after a brain injury? <i>Probes: What has OR would help you in developing a strong disability identity? Which factors we discussed would be important to focus on?</i>
Question 5	Is there anything else you'd like to share that we haven't already discussed?

Data Analysis

Focus groups were transcribed verbatim using a transcription service. A hybrid inductive and deductive approach thematic analysis was used to analyze focus group data. Guided by the work of Proudfoot (2023), the hybrid approach involved establishing a set of a priori codes to explore disability identity guided by Forber Pratt and Zape's model (2017), while also allowing generation of additional codes from the data itself. This iterative process allowed for expanding on the model of disability identity development while also identifying gaps or alternate explanations of disability identity development in adults with ABI. A second student researcher with experience in qualitative research was recruited to assist with data analysis and was paid \$100 for their assistance.

The researchers first identified a set of a priori codes. They then independently coded one focus group transcript and reconvened to develop the codebook including the a priori codes and inductively developed codes. The remaining three transcripts were coded with the primary researcher as the primary coder and the second researcher as the secondary coder. Any code disagreements were addressed through discussion, and a third researcher (from the primary researcher's committee) was available to address any discrepancies. Coding was an iterative process, with codes being added and revised throughout based on the data. To ensure consistency across the data, the primary researcher conducted a final review of all transcripts after coding. After all transcripts were coded and reviewed, the researchers collaboratively reviewed the codes and determined themes.

Multiple strategies were used to ensure trustworthiness during the qualitative phase. To ensure confirmability, the researchers regularly engaged in peer debriefing and practiced

reflexivity. The primary researcher identifies as someone with a chronic health condition and has a personal and professional connection to ABI, and it was important to reflect on that positionality throughout the process. An audit trail was kept and made available when disseminating findings, which also supports confirmability. To ensure credibility, one to two participants from each focus group who made significant contributions were contacted for member checking and asked to provide feedback about the initial themes developed after analysis. Triangulation of the qualitative data with the quantitative data and at the researcher level (with two coders) also supports credibility of the results. Dependability was enhanced through the process of independent coding by the two coders during codebook development. Finally, transferability was enhanced through the process of thematic saturation. Qualitative sample size was chosen to support thematic saturation (Namey et al., 2016), and no new codes were generated during analysis of the final focus group, which also supports saturation.

Integrated Analysis

During the study, integration occurred through connecting the data through the sampling frame by using survey participants for the follow-up focus groups. Following quantitative and qualitative data collection and analysis, additional integrated analysis was conducted. In this step, quantitative and qualitative results for aims 1 and 2 were merged together for direct comparison. Analysis focused on the “fit” of the integrated data by assessing how and to what extent the qualitative confirmed, expanded on, or were discordant with the quantitative results (Fetters et al., 2013).

Chapter 4: Results

This chapter presents the results of the study. The chapter first describes the characteristics of the survey and focus group participants. Findings are then organized by aim: describing disability identity in adults with ABI (Aim 1), presenting the quantitative associations between disability and personal, impairment-related, and environmental factors and the qualitative findings that help explain them (Aim 2), then identifying how rehabilitation professionals can support disability identity development in this population (Aim 3).

Participants

A total of 120 survey responses were captured in REDCap between September through December of 2025. Survey data were reviewed by the principal investigator for completeness, duplicate responses, and bot response activity (i.e., spending less time on each page than it would reasonably take to read and response to the questions, answering the “honey trap” question that was hidden to participants but would be detected by a computer). After review, 12 responses were removed for any level incompleteness and one response was removed for bot response activity, resulting in a final participant count of 107. Table 5 shows survey participants’ characteristics.

Table 5

Survey Participant Characteristics (n=107)

Categories	Count	Percentage
Race		
White	80	74.8
American Indian or Alaska Native	2	1.8
Asian	13	12.2
Black or African American	9	8.4
Hispanic or Latino	2	1.8
Middle Eastern or North African	1	0.9

Gender			
Man	57	53.3	
Woman	48	44.9	
Non-binary or other gender identity	2	1.8	
Sexual orientation			
Heterosexual or straight	88	82.2	
Asexual	1	0.9	
Bisexual	9	8.5	
Gay	3	2.8	
Pansexual	1	0.9	
Queer	3	2.8	
Other	2	1.8	
Impairment type			
No impairment	8	7.5	
Invisible impairment	43	40.2	
Visible impairment	12	11.2	
Both visible and invisible impairment	44	41.1	
Categories	<i>M (SD)</i>	Median	Range
Impairment severity	3.53 (1.30)	4	1–5
Current age	53.12 (16.35)	55	18-84
Time since ABI (years)	10.27 (10.73)	7	0–55
Disability identity (DIDS total)	56.93 (30.47)	52	12–138
Physical/structural barriers (CHIEF-SF)	5.33 (4.15)	4	0–16
Attitudinal/support barriers (CHIEF-SF)	3.23 (3.96)	2	0–16
Occupational identity (OIQ total)	42.45 (5.20)	43	31–52

Note. DIDS = Disability Identity Development Scale; ABI = Acquired brain injury; CHIEF-SF = Craig Hospital Inventory of Environmental Factors–Short Form; OIQ = Occupational Identity Questionnaire; M = Mean; SD = Standard Deviation.

After quantitative data analysis, a total of 35 survey participants were contacted via email and 17 agreed to participate in one of four follow-up focus groups. Participants represented all categories of disability identity – low ($n=2$), low-moderate ($n=4$), high-moderate ($n=7$), and high ($n=4$) – but were mostly situated in the low-moderate and high-moderate categories (65%).

Participants were mostly White (65%), with Black or African American (12%) and Asian (23%)

racess also represented. Most participants agreed to some degree that their condition was severe (88%), and just over half reported both visible and invisible impairment (53%). Table 6 describes participants' demographic information related to these factors.

Table 6

Focus Group Participant Characteristics

Participant ID	DIDS score	Age	Race	Impairment severity	Impairment visibility
Group 1					
P1	34	77	White	Agree	Invisible
P2	114	37	White	Agree	Both
P3	94	71	White	Strongly agree	Both
P4	60	36	Asian	Agree	Invisible
Group 2					
P5	105	29	White	Agree	Both
P6	116	59	Black or African American	Disagree	Visible
P7	71	51	Asian	Agree	Both
P8	95	23	Asian	Strongly agree	Both
Group 3					
P9	91	60	White	Strongly agree	Invisible
P10	105	51	White	Agree	Both
P11	103	55	White	Strongly agree	Invisible
P12	79	45	Black or African American	Strongly agree	Both
P13	102	69	White	Strongly agree	Invisible
P14	112	40	White	Strongly agree	Invisible
Group 4					
P15	67	44	Asian	Neutral	Both
P16	138	37	White	Strongly agree	Both
P17	56	54	White	Agree	Invisible

Note. DIDS score 0-57=low; 58-84=low-moderate; 85-111=high-moderate; 111+=high.

Impairment severity question: "Rate your response to the following question: My condition is severe (it significantly affects my daily life)".

Findings

Aim 1 Results: Describing Disability Identity

This aim used quantitative and qualitative findings to describe disability identity in adults with ABI. While quantitative results showed substantial variability in DIDS scores across the

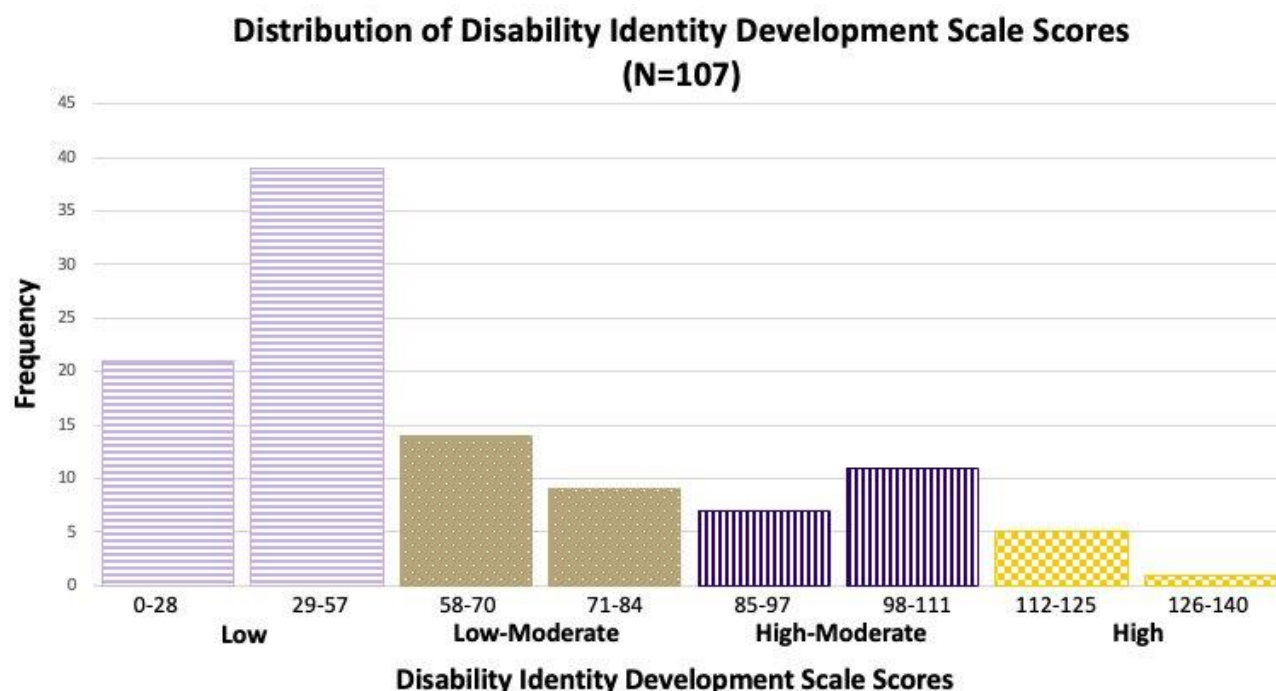
sample, qualitative findings demonstrated that disability identity is an ever-evolving process often shaped by initial grief, adjustment and acceptance, and community connection.

Quantitative Results

Figure 2 displays the distribution of DIDS scores for the sample. Scores were spread across the scale, ranging from 12-126 ($M = 56.93$, $SD = 30.47$), with a median of 52 ($Q1 = 34$, $Q3 = 80$). Scores clustered most heavily in the lower score ranges, with the highest frequency observed in the “low” category ($n=60$, 567%). Frequencies decreased across the higher score categories, with a smaller number of participants scoring in the “low-moderate” ($n=23$, 21%), “high-moderate” ($n=18$, 17%) and “high” ($n=6$, 6%) categories. Results indicate that disability identity varied considerably among participants. This distribution provides an initial descriptive picture of disability identity in adults with ABI.

Figure 2

Distribution of Disability Identity Development Scale Scores



Qualitative Results

Theme 1: Initial Integration of Disability into Sense of Self Requires Processing

Difficult Emotions. Participants often described disability identity as emerging through a process involving grieving the pre-injury self.

Subtheme 1a: Early Identity Disruption is Marked by Grief and Loss. Participants described a period of time early after ABI that was emotionally overwhelming, with grief playing an important part in their life. P15 shared, *“especially in the first few years of any kind of traumatic medical experience there’s gonna be a lot of grief, a lot of anger, and that is shaping how we view ourselves”*. For many, this grief was directly connected to a stark rupture of their pre- and post-injury sense of self. P13 described the experience of grieving the loss of their former self, stating, *“I was not allowed to grieve my passing. I was not allowed to remember the good times... I’m just remembering that I used to be an awesome techie, you know?”*. Similarly, P10 shared feeling that *“who I was no longer existed, and it was true. But I liked who I was. I hated who I was now. I wanted to go back.”* Together, these accounts highlight the importance of grief and loss of pre-injury self after ABI.

Subtheme 1b: Internalized Ableism can Delay Identification with Disability.

Participants also described resistance to identifying as disabled, which was often linked to negative beliefs about disability. P12 described rejecting the label of disability because of what they felt it represented, stating, *“I used to hate that label, that I was disabled. I didn't want to, you know, didn't want that to be a part of my life, because I felt like there was something wrong with me if I labeled myself as disabled”*. P2 shared a similar experience and explicitly named the feeling as internalized ableism, stating, *“early on, it was the result of internalized ableism. I was like, I do not want to identify as disabled. I don’t want this to be part of who I am”*. For some,

understanding of disability as a label carrying negative implications delayed willingness to incorporate disability into their sense of self.

Theme 2: Disability Identity is Dynamic Rather Than Fixed. After initial acceptance of disability, participants described disability identity as something that continues to change over time and across contexts, rather than as a stable category. P17 described disability identity as “*an ever-evolving kind of concept for me. It’s always changing, and it’s so hard to pinpoint a static identity.*” Similarly, P14 described their disability identity as “*a roller coaster*”, with “*ups and downs in all the places*”, including different stages of life and overall goals. Even those who described a strong connection with disability noted that the feeling was not constant. P5 shared:

I think I have a relatively high identity with disability. But I wouldn’t say I’m always gung-ho about it, like, I’m not always for it... Sometimes I like being known for something other than my disability and surviving brain bleeds. I do feel this sense of camaraderie and sense of understanding that maybe the other parts of society don’t connect with... It’s not that I’m ashamed of it, but sometimes I like being able to be seen as more than just someone who survived strokes, I guess.

For participants, disability identity was an iterative and ongoing process.

Theme 3: Disability Community Connection Transforms Disability from an Individual Problem into A Shared Identity. Connection with other disabled people helped participants move from isolation toward belonging and stronger disability identity. Rather than experiencing disability in isolation, participants shared that being with others with shared experiences helped them feel less alone and better understood. P16 stated, “*It’s nice to be around people with neurological difficulties. So, I’m not alone. It’s always nice to be around someone who understands how it is to be different.*” P8 described a similar sense of belonging that was

harder to find elsewhere, sharing, *“I really like brain injury support groups and meetups, because everyone is also different there, and understanding.”* Participants also described community spaces as places to work through challenges related to disability identity. P6 shared:

It’s been real helpful for me to join a lot of things like this, and just listen to other people share their stories, and I talk about my story. So, it’s been helpful for me mentally to get over some of those hurdles with my identity that I had from a mental standpoint.

P9 reflected on their experience of a week-long retreat hosted by the Love Your Brain Foundation for people with ABI as shaping their identity with disability, sharing, *“I think that’s the part that made me feel okay. It has made me feel more confident about, yes, I am a disability person, and other people should know that”*. Connection to others in the disability community helped participants understand disability as a shared identity grounded in belonging.

Integrated Results

Quantitative and qualitative findings were integrated to provide a more comprehensive description of disability identity in adults with ABI. Quantitatively, the greatest concentration of participants scored in the “low” category, but scores amongst all categories represent substantial variability in the sample. Qualitative results expanded this descriptive picture by demonstrating that initial disability identity development requires processing of grief and loss, with community connection as an important avenue towards a stronger disability identity. Qualitative results also highlighted the dynamic nature of disability identity, further explaining the variability of DIDS scores.

Aim 2 Results: Exploring Relationships Between Disability Identity and Associated Factors

Aim 2 used quantitative and qualitative findings to examine factors associated with disability identity in adults with ABI. The quantitative findings identified several variables with

significant associations with disability identity, and the qualitative findings further explored how those factors were experienced in daily life.

Aim 2a Quantitative Results

Disability identity showed moderate positive associations with impairment severity ($r = .33$) and racially marginalized identity ($r = .36$), and moderate negative associations with current age ($r = -.30$). Positive associations were observed for impairment type ($r = .27$), physical/environmental barriers ($r = .12$), and attitudinal barriers ($r = .16$). Gender ($r = .07$) and sexual orientation ($r = .13$) showed negligible associations with disability identity. Time since injury was not strongly associated with disability identity at the bivariate level ($r = .01$); however, it remained in multivariable regression models as an a priori impairment-related factor. See Table 7 for a display of the correlations.

Table 7

Correlations Among Study Variables

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Disability identity	—										
2. Age	-.30	—									
3. Time since ABI	.01	.20	—								
4. Severity	.33	-.09	.20	—							
5. Invisible impairment	-.05	-.30	.02	-.04	—						
6. Visible impairment	.18	.27	-.02	.18	-.86	—					
7. Gender	.07	-.04	.00	.12	-.04	.11	—				
8. Sexual orientation	.13	-.25	.02	.15	.17	-.19	.10	—			
9. Race	.36	-.25	-.09	.13	-.13	.17	.10	.12	—		
10. Physical/structural barriers	.12	-.16	.03	.17	.00	.08	.19	.13	.20	—	
11. Attitudinal/support barriers	.16	-.12	.05	.23	.15	-.14	.14	.05	.13	.55	—

Note. Coefficients are Pearson correlations for pairs of continuous variables, point-biserial correlations for pairs of one continuous and one dichotomous variable, and phi coefficients for pairs of dichotomous variables. Invisible and visible impairment are indicator variables (reference = no impairment).

A multiple linear regression was conducted to examine whether personal, impairment-related, and environmental factors were associated with disability identity scores (Table 8). The

full model was significant, $F(10, 96) = 4.05, p < .001$, explaining 29.7% of the variance in disability identity scores ($R^2 = .297$, adjusted $R^2 = .223$). Younger age, racially marginalized status (relative to White race), visible impairment (relative to no impairment), and greater impairment severity were significantly associated with disability identity. Time since ABI, invisible impairment only (relative to no impairment), gender, sexual orientation, and the two environmental barrier variables were not significantly associated with disability identity. The results of the sensitivity analysis excluding the two participants who did not identify as a man or woman were not meaningfully changed, providing no evidence to refute grouping these participants together.

To examine the potential additional joint contribution of the environmental factors, the full model was compared to a reduced model that excluded the physical/structural and attitudinal/support barrier variables. The reduced model, containing only impairment-related and personal factors, explained 28.4% of the variance in disability identity ($R^2 = .284$). Adding the environmental factors did not significantly improve model fit, $F(2, 96) = 0.87, p = .423$, change in $R^2 = .013$, indicating that the environmental barriers did not account for additional variance in disability identity above and beyond impairment-related and personal factors.

Table 8

Aim 2a Multivariable Linear Regression

Independent Variable	<i>b</i>	<i>SE b</i>	β	<i>t</i>	<i>p</i>	R^2
Impairment and personal factors						.284
Current age	-0.47	0.18	-0.25	-2.55	.012*	
Time since BI	0.11	0.26	0.04	0.44	.663	
Visible impairment	21.45	10.83	0.70	1.98	.040*	
Invisible impairment	12.74	10.70	0.42	1.19	.236	
Severity	4.98	2.20	0.21	2.26	.026*	
Gender	-1.26	5.31	-0.02	-0.24	.813	
Sexual orientation	3.34	7.26	0.04	0.46	.646	

Race	16.38	6.43	0.23	2.55	.012*	
Environmental factors					.423	.297
Physical/structural barriers	-0.84	0.79	-0.11	-1.05	.294	
Attitudinal/support barriers	1.04	0.84	0.13	1.24	.219	

Note. $*p < .05$; Unstandardized (b) and standardized (β) coefficients are from the full model, in which all factors were entered simultaneously. R^2 values reflect model fit for the impairment and personal factors alone (.284) and for the full model including environmental factors (.297).

Aim 2a Qualitative Results

Theme 1: Disability Identity is Shaped by the *Interaction* Between Impairment and Environment. Participants did not describe impairment as influential on its own; rather, impairment became meaningful through encounters with inaccessible spaces, systems, and social responses.

Subtheme 1a: Visibility and Severity Matter Because They Shape Daily Experiences.

Participants described the visibility and severity of their impairments as important in their identity because they affected everyday interactions. P16 described how the use of a wheelchair changed public perceptions:

I'm in a wheelchair, and so I can't really walk. So, one thing, my disability identity is like... I'm a real person, thank you. When I go out in public places in my chair, people just, they either ignore people in chairs, or they think of you as children. Or less than. And so, it's like, uhm, excuse me, I'm here.

P10 shared a similar sentiment about being perceived by others after ABI, stating “*the hardest part about having a disability is that people see it before they see me. And it sucks*”. Others shared how public perceptions of their visible impairments also affected their own self-awareness. P12 shared:

I think the factor that contributed the most to my identity is the visibility factor. Because with my stroke came the right side paralysis, so it made it hard for me to walk, for me to

use my right side at all. And so, people noticed that a lot. And so, that made me aware that people were noticing that I didn't have the same gait or walk that I had before, you know, and I didn't, you know, that made me feel insecure a little bit. I think that helped me determine that, you know, okay, I am disabled. I have decided that I am disabled, I need to embrace it and figure out what I can do to make my life easier.

Visibility and severity of impairments were meaningful not only because of functional changes, but because they shaped how participants were perceived and treated in their daily life.

Subtheme 1b: Built and Institutional Environments Make Disability Concrete. For many participants, disability identity was reinforced through navigation of built environments that were not designed with disability in mind. P8 described how the heightened awareness of their environment after ABI led to increased self-awareness, stating, *“I rely on a wheelchair or a walker, so I can't do many sidewalks that are broken. I never really noticed them before my injury, and now I do, because I need them to be paved and flat, or an elevator. So, I'm very aware of myself”*. Along with the built environment, participants also shared about the effects of navigating institutional environments on their identity with disability. P15 reflected on their post-ABI experiences within the healthcare system, noting the lack of accessibility for fine-motor tasks like completing paperwork and paying for services. They shared:

I think that reinforces some of my identity as well. Like, well, I'm a person with a disability, and you're not making this easy for me, and so it's just, like, really frustrating... And we have technology to make things more accessible for people to get those things done, but it's not everywhere.

P1 shared similar challenges related to the invisible impairments they experienced after ABI including cognitive fatigue and sensory sensitivity, stating *“I think I was just too busy figuring*

out how to fit into a world that isn't really set up to accommodate those of us who are, I like to think as 'differently abled'". For participants, built and institutional environments made disability tangible in everyday life, therefore contributing to how they understood themselves as disabled.

Subtheme 1c: Social Environments can Reinforce Stigma and Ableism. Participants also described social environments as shaping disability identity through experiences of misunderstanding and stigma. P8 described difficulty assimilating into what they referred to as the "typical" community, "*because many people don't know what's wrong, or what's normal for me. Mine is definitely not normal for typical people, so it is hard to fit in*". Other participants shared more explicit examples of stigma and ableism. P17 shared:

If I tell somebody that I have a head injury here in Oklahoma, 9 times out of 10, they turn the other way and leave. They will not talk to me anymore. They think that it's so... there's real big stigma...whatever, and that I'm gonna turn psychotic, or whatever, and it's like, come on, people! So, my brain got hurt a little bit, that's all.

P1 also shared about explicit discrimination in the workplace, saying "*I came very close to filing a complaint under the ADA against my employer because of the attitude and subsequent actions of a coworker who basically dismissed my injury as not being valid*". Social responses that communicated stigma and ableism reinforced the idea of disability as a negative attribute, which led to difficulty embracing an identity with disability.

Theme 2: Personal Identities Shape How Disability is Understood. Participants' other identities influenced how they interpreted disability and where it fit within their broader sense of self.

Subtheme 2a: Other Marginalized Identities Provided a Framework for Understanding Disability. Some participants described disability as one part of a broader experience of living with multiple marginalized identities. For these participants, disability was understood in relation to those previously held identities. P12 explained:

Being an African American man, and also being a gay man, it kind of helped me identify with those minority cases... so I can already identify with that, you know, it [disability] is just one more layer of that.

Similarly, P11 connected disability identity to a longer history of queer identity and activism, stating, “*I’m queer. I was in ACT UP, and I think social justice has always been a core part of my identity*”. Some participants also shared how previously held identities specifically shaped experiences of disability within the healthcare system. P6 shared:

There's a lot of stigmas out there that need to be erased. One, especially in the African American community, I noticed, was that some healthcare professionals either talk down to folks or don't give them the attention that they give others, or less eye contact, or less, just less overall care.

For some participants, other marginalized identities provided a framework through which disability identity could be interpreted.

Subtheme 2b: Age of Injury Shaped How Disability was Experienced and Interpreted. Participants described their age at the time of their injury as something that influenced how others interpreted their ABI and recovery, therefore influencing their identity with disability. P3 shared about being older at the time of their ABI:

I was 68 when I had it, and I was viable, I was active, I didn't look really old yet. And I tell you what, my clinicians, several of the doctors kept saying 'well, you're an older

patient, you're an older patient', as if I was inept because of that... that was really disturbing to me.

For this participant, impairment was framed in relation to assumptions about older age. P2 described the inverse experience of being younger at the time of injury, stating, “*because I was 28, I kept getting the feedback of, you're so lucky your brain is going to recover so well, like you're so lucky you were so young when your brain exploded, and that was not a helpful comment to hear*”. Age shaped disability identity through the meaning others attached to age of injury, influencing how participants saw themselves after injury. When the perception of others was at odds with participant self-perceptions, disability was seen as the driver of these unwanted perceptions.

Theme 3: Acceptance of Disability Often Required Time, Reflection, and a Broader Sense of Meaning. Although participants described difficult early experiences after ABI, many also shared how disability became more integrated into their identity over time. P7 described the process of disability identity development since their injury:

It's been one and a half years since my stroke. At first, I don't know what's going on with me. And then... I feel sad. And then... I get more acceptance for who I am. And I begin to see, my disability is here to stay. Eventually, I'm feeling better.

Similarly, P11 emphasized the ongoing process of understanding one's identity, stating, “*I've worked for years to help myself understand and accept my new identity, and understand what my identity is, and what does that word mean, and I feel better about it*”. Reflecting back on their initial period of grief, P15 shared how developing a disability identity can change the significance of grief over time:

I think of this image of the grief and loss as a big circle, that is really engulfing your whole life at first. But it doesn't shrink over time, it's your life around it that gets bigger, and so it feels smaller because your identity and everything else is getting bigger and more expansive.

Acceptance of disability after ABI was not immediate for participants but developed gradually as they made space for disability within an expanding sense of self, and the concept of time and time needed for this development varied.

Aim 2b Quantitative Results

An exploratory regression analysis was used to examine a potential relationship between occupational identity and disability identity. Occupational identity was positively correlated with disability identity, $r = .22$, $p = .02$, indicating a small but statistically significant association. In the regression analysis (Table 9), occupational identity significantly predicted disability identity scores ($b = 1.29$, $\beta = .22$, $p = .022$). This model explained approximately 5% of the variance in disability identity ($R^2 = .05$). The standardized coefficient indicated that higher occupational identity was associated with higher disability identity with a modest effect size.

Table 9

Aim 2b Simple Linear Regression

Independent Variable	b	$SE\ b$	β	t	p	R^2
Occupational identity score	1.29	0.56	0.22	2.32	.022*	
Model summary						.05

Note. * $p < .05$.

Aim 2b Qualitative Results

Theme 1: Occupational Loss Disrupts Both Occupational Identity and Integration of Disability into Identity. Participants described loss of meaningful roles and activities as central to the disruption of self after ABI. P3 shared the effect of their injury on valued family

roles, sharing, *“it took away my ability to be a grandmother. I used to drive every week to see my grandkids, and I can’t do that anymore”*. Similarly, P7 shared how their role as a parent has changed: *“My teenager feels me as being not helpful in her homework. Even though I know how to do math. She stopped asking me questions. She’s thinking about whether I know my stuff”*. For P13, loss of their professional role shaped their identity with disability after ABI. They stated, *“The biggest problem as a professional was running into suddenly being a non-entity. Because in my era, you are your achievements. Your identity is your job... so, everything was gone”*.

Participants also felt loss related to leisure and avocational occupations. P6 reflected on their previous hobby of running, sharing, *“I wasn’t able to run anymore, or, for as long as I was, so I went to a bit of depression. Because I felt like a part of my identity got stripped away in that regard”*. Occupational loss after ABI disrupted how participants understood themselves in their family, work, and leisure roles. Because the disruption was attributed to their ABI, occupational loss was seen as another negative consequence of disability.

Theme 2: Re-engagement in Meaningful Occupations Supports Embracing Identity with Disability. Returning to meaningful occupations, even in adapted ways, helped participants rebuild sense of self in relation to disability. P6 explained how work remained central to their identity and recovery, stating, *“I was able to bring work to my speech therapy sessions. I would say, ‘this is how I would communicate everyday with this certain customer or vendor’, something like that”*. Some participants described the importance of returning to meaningful activities through regaining skills and/or adapting activities. P15 shared:

A lot of my identity was also impacted by the things I got to do with my hands. I was really into gardening, and doing yoga, and cooking, and making things for friends and family, and hosting people at my house, and I’ve done less of that. But I’ve been working

really hard to not only build back up those skills, but adapt things to where I am now... I want to do these things again because they gave me so much joy.

Similarly, P4 described meaningful occupation as a source of emotional regulation. They shared, *“playing the trumpet, that's really relaxing for me... And so that's like a pressure valve, a positive pressure valve, where, if I have a bad day, I can play my trumpet”*. For some participants, re-engagement involved adjusting expectations and focusing on what was possible. P9 shared, *“I think that being in the moment, and finding that thing that you can do is probably the thing that spends more time than anything else I do. So, I limit myself to 3 things a day, things that are meaningful to do, that's it”*. Returning to meaningful roles and occupations supported participants in building a sense of self that included disability.

Integrated Results

Quantitative and qualitative findings were integrated to more thoroughly examine how associated factors relate to disability identity in adults with ABI (Table 10). Overall, the integrated findings suggest that disability identity is shaped not by a single factor alone, but through the interaction of personal, impairment-related, environmental, and occupational contexts.

Quantitative findings showed that racially marginalized status, greater impairment visibility and severity, and higher occupational identity were significantly associated with higher disability identity. Qualitative findings expanded these results by illustrating how personal identities shape the way disability is understood and diverge from the quantitative results by showing how impairment-related factors became meaningful in participants' daily interactions with their built and social environments. Quantitative findings also showed that younger current age was associated with higher disability identity. Although discussion about current age was

prompted during the focus groups, participants diverged from current age and instead shared about how their age at the time of their ABI contributed more towards their disability identity development.

Although quantitative findings did not demonstrate a significant relationship between time since ABI, qualitative findings diverged by emphasizing the importance of time to adjust to disability and integrate disability into one's overall sense of self. Participants qualitatively shared multiple conceptualizations of time and time periods for their adjustment to disability, suggesting that understandings of time are personal and may not be captured well by quantitative data.

Integrated results also show how occupation is an important context for disability identity. Quantitative results indicated that higher occupational identity was significantly associated with higher disability identity. Qualitative findings expanded on these results by demonstrating how loss of meaningful roles and activities disrupted sense of self, and how re-engagement in meaningful occupations supported disability identity development.

Table 10

Aim 2 Joint Display of Integrated Results

Factors	Quantitative result	Qualitative result
Age	Younger age significantly associated with higher DI ($\beta = -.25, p = .012$)	Personal identities shape how disability is understood. - P12: <i>"Being an African American man, and a gay man, it helped me identify with those minority cases... so disability is just one more layer of that".</i> - P11: <i>"I'm queer. I was in ACT UP, so I think social justice has always been a core part of my identity".</i> - P3: <i>"I was 68...several clinicians kept saying, 'well you're an older patient', as if I was inept because of that. That was disturbing to me".</i>
Race	Racially marginalized status significantly associated with higher DI ($\beta = .23, p = .012$)	- P2: <i>"Because I was 28, I kept getting the feedback of, 'you're so lucky your brain is going to recover so well', or 'you're lucky you were so young when your brain exploded', and that was not a helpful comment to hear".</i>
Sexual orientation	Not significantly associated with DI ($\beta = .04, p = .646$)	

Impairment severity	Greater reported severity significantly associated with higher DI ($\beta = .21, p = .026$)	Disability identity is shaped by the interaction between impairment and environment. - P12: <i>"My impairment made it hard for me to walk or use my right side at all. People noticed that a lot.... That made me feel insecure a little bit, but helped me determine that, okay, I am disabled, I need to embrace it"</i> . - P15: <i>"When I was navigating healthcare systems post-stroke, it was really apparent, what we would consider small things to people who don't have disabilities, how for granted that is taken, and that reinforces my identity as well. I'm a person with a disability, and you're not making this easy for me. I couldn't write very well after my stroke, and so signing my name and filling out paperwork was really frustrating. We have the technology to make things more accessible for people, but it's not everywhere"</i> . - P16: <i>I'm in a wheelchair, so, my disability identity is like... I'm a real person, thank you. When I go out in public places, people just, they either ignore people in chairs, or they think of you as children. Or less than. And so, it's like, uhm, excuse me, I'm here.</i>
Impairment visibility	Impairment visibility significantly associated with higher DI compared to no impairment ($\beta = .70, p = .040$)	
Structural barriers	Not significantly associated with DI ($\beta = -0.11, p = .294$)	
Attitudinal barriers	Not significantly associated with DI ($\beta = 0.13, p = .219$)	
Time since ABI	Not significantly associated with DI ($\beta = 0.04, p = .663$)	Acceptance of disability often required time, reflection, and a broader sense of meaning. - P7: <i>"It's been one and a half years since my stroke. At first, I don't know what's going on... I feel sad. And then... I get more acceptance for who I am. And I begin to see, my disability is here to stay. Eventually, I'm feeling better"</i> . - P11: <i>"I've worked for years to help myself understand and accept my new identity, and what my identity is, and what does that word mean, and I feel better about it"</i> .
Occupational identity	Higher occupational identity significantly associated with higher DI ($\beta = 0.22, p = .022$)	Occupation shapes how disability is understood and integrated into disability identity. - P6: <i>"I wasn't able to run anymore, or, for as long as I was, so I went to a bit of depression. Because I felt like a part of my identity got stripped away in that regard"</i> . - P15: <i>"A lot of my identity was also impacted by the things I got to do with my hands. I was really into gardening, and doing yoga, and cooking, and making things for friends and family, and hosting people at</i>

my house, and I've done less of that. But I've been working really hard to not only build back up those skills, but adapt things to where I am now... I want to do these things again because they gave me so much joy".

Note. DI=Disability identity.

Aim 3 Results: Implications for Rehabilitation Professionals

This aim used qualitative data to explore implications for rehabilitation professionals to support disability identity development after ABI. Participant findings centered on two themes: the need for disability-affirming rehabilitation and the need for more education about disability in the healthcare system.

Qualitative Results

Theme 1: The Rehabilitation Experience Should be Disability-Affirming.

Participants described disability-affirming rehabilitation as care that moves beyond a medicalized approach by normalizing disability, respecting lived expertise, listening without dismissal, validating loss, and facilitating connection to disability-related supports.

Subtheme 1a: Rehabilitation Professionals Should Normalize Disability. Participants described the need for rehabilitation professionals to move away from framing recovery solely in terms of returning to “normal”, emphasizing the power in acknowledging disability as part of a meaningful life. P15 shared:

It's so ingrained in us to always want to try to achieve back to this “normal” functioning. And I think that is so destructive to our psyche and our identity of accepting where we are... I think what rehab professionals can do is kind of counter that language and message to be more, not just positive, but really to be present to where that person is... We want to be seen as perfectly fine who we are.

Similarly, P5 shared the importance of hearing that life is worthwhile when a full recovery of impairment does not occur:

Just needing to hear that reassurance that, even if you don't get where you need to get, there are ways to still make things work to enjoy life and to do the things you want to do. And I don't think that's verbally said enough from, at least in my experience with rehab professionals. It's always, alright, let's go in, let's crank out your exercises, and get to work, which is fine, that's what I'm there for, but it's also the fix-it mentality of, this is the only way life is gonna be enjoyable, is if you can pick up all these balls and marbles and pegs and things that are really hard to do.

Participants shared desire for a rehabilitation experience that supported adjustment to life with disability, not just restoration of prior functioning.

Subtheme 1b: Lived Experience of Disability Should be Treated as Credible Expertise.

Participants emphasized that disability-affirming care requires rehabilitation professionals to recognize their clients as knowledgeable about their own bodies and experiences. P5 shared the positive impact of providers “*knowing that their clients or patients are intelligent, and that our experiences, like, we know what we know. We know how our bodies are functioning, and what we're experiencing*”. P2 similarly highlighted the skills involved in adjusting to disability:

Do not underestimate people with disabilities. We have to learn to adapt to a world that is not made for us. We can be incredibly creative. I might do things a little bit differently.

I'm definitely going to be slower, but that doesn't mean that I can't get it done.

For participants, part of disability identity development involves having their lived experience treated as a legitimate source of expertise.

Subtheme 1c: Providers Should Listen Rather Than Redirect or Ignore. When sharing experiences with rehabilitation professionals, participants highlighted the importance of being listened to and taken seriously. P12 reflected on the hospital stay immediately after their stroke and the medical professionals who ignored their request for services:

When I was in the hospital after my stroke, I had no voice. I was horrified, scared, I didn't know what I was gonna do. And I remember letting the therapists know that, hey, I think I need a speech therapist. And they declined those services to me. And I felt very unheard. It hurt a lot. I cried a lot in the hospital, because I just was like, I just want someone to listen to me, because I'm concerned about this. This is my livelihood, this is my passion. I never got a speech therapist that entire time I was at the hospital. I just felt like I wasn't being heard, I wasn't being listened to.

P3 also emphasized the importance of listening, stating, “*this is what my body is communicating to you. I understand your equations, rules, and they’re not working. It’s like sometimes I feel like I’m talking to a wall*”. Participants viewed listening as a distinct and necessary component of disability-affirming rehabilitation. Disability became hard to embrace when ignored by others.

Subtheme 1d: Validation is More Helpful Than Dismissal or Forced Positivity. In addition to being heard, participants described a need for responses that did not minimize their experiences. P11 reflected on a frustrating encounter with a rehabilitation professional, where in response to a comment about feeling bothered that they aren’t doing what they used to do, the provider responded with forced positivity, saying, “*oh, but look at how much better you’re doing every day*”. P11 shared, “*that was not the response I was asking for. He didn’t understand there was a struggle I was having in accepting my identity*”. Other participants reported being dismissed by providers when sharing the realities of adjustment to disability. P13 shared, “*Every*

single professional I dealt with was telling me, this is your new you. Stop focusing on your old one... It felt very dismissing". P3 shared a similar experience of dismissal:

One day when I was having trouble walking, I made a comment that I feel so lame, and my physical therapist said, "you're not lame". I'm like, I just told you I felt lame. And you know, it made it sound like I was complaining or doing something wrong. Like I was saying something that wasn't true. But it was true to me at that time.

Participants want rehabilitation providers to validate their emotions and experiences of identity disruption without minimizing them, allowing space for the processing needed in development of an identity with disability.

Subtheme 1e: Providers Should Connect People with Peer Support and Disability

Resources. Participants also described disability-affirming rehabilitation as including connection to practical disability-related services and resources. P15 noticed the absence of this kind of support after ABI:

I don't remember anyone ever recommending me to connect to other stroke survivors post-stroke. And I had to be the one. I researched... I was able to find the support groups. But nobody, not my doctors, neurologists, OT, PT, none of them had any kind of information or suggestion for, like, if you're struggling, or just want to connect to other survivors, there's this support group... I was really surprised.

In contrast, P1 described the positive impact of a provider addressing urgent social and financial barriers by connecting them with resources, stating, *"There was someone who, not only listened, but saw me as a whole person.... He saw that there was something much more urgent that needed to be dealt with, and that's what he dealt with"*. P5 emphasized the value of resource-sharing between disability-informed professionals and disability communities:

I think being aware of the social support groups and adaptive support groups in your local area, as well as psychotherapists who specialize in disability, can be really helpful for people navigating this new life of being disabled. Or even people who are not new to it and have been dealing with it for a long time. It can be refreshing and reinvigorating to be connected with other people and professionals who can get what you're going through.

For participants, disability-affirming rehabilitation must include connection to communities and resources that support life with ABI, which in turn fosters disability identity.

Theme 2: Professionals Need More Education About Disability. In order to provide disability-affirming care, rehabilitation professionals need more education about the lived experience of disability and non-medicalized disability frameworks. P5 emphasized the lack of formal disability education across healthcare professions:

I don't know the course requirements for rehab professionals. I know, even in the medical world, for many doctors, they never take a single course solely on disability. And I think that is so valuable to have in any profession... Then, we could really have better care for clients, and impact the way someone views and accepts their disability.

P14 described a need for broader disability awareness within healthcare, stating, “*I think there’s a lot more awareness that need to be brought to the medical society, to explain to people, like with research, so people cannot just brush it off*”. Participants also emphasized the need for education to include listening to disabled people themselves. P12 shared, “*I think having more things like this is fantastic, where professionals are listening and just trying to get more information from us as survivors and people who are experiencing this day in and day out*”.

Although not directly related to disability identity, participants viewed education about disability more broadly as a critical step towards improving the rehabilitation experience.

Chapter 5: Discussion and Conclusion

Discussion

The purpose of this study was to describe disability identity in adults with ABI, to identify factors associated with disability identity in this population, and to explore how rehabilitation professionals can support disability identity development after ABI. This chapter interprets the quantitative, qualitative, and integrated findings in relation to Forber-Pratt and Zape's (2017) Disability Identity Development Model and the broader disability identity literature. The following discussion posits that disability identity after ABI is a dynamic process shaped by the interaction of personal, impairment-related, and environmental factors, and that this understanding carries direct implications for the role of rehabilitation professionals in disability identity development. It considers what these findings contribute to disability identity theory, including how they expand on Forber-Pratt and Zape's (2017) model in the context of ABI, and what they imply for rehabilitation practice.

The Dynamic Nature of Disability Identity

To the author's knowledge, this is the first study to describe disability identity patterns amongst adults with ABI using the DIDS. The DIDS scores in this sample of adults with ABI were varied but did cluster more in the "low" (0-57) range with a mean score falling at the top of low range (56.93, $SD = 30.47$). While the scoring categories should be used with caution, in general the finding indicates that participants in this study had a wide range of disability identity levels at the time of the survey but were more likely to report lower disability identity, meaning many people with ABI did not think of disability as a strong part of their sense of self. A previous study by Bogart (2015) utilized the Personal Identity Scale (Hahn & Belt, 2004), a scale similar to DIDS but shorter (only eight questions) to understand disability identity in people with

MS. They reported the mean Personal Identity Scale score was 22.65 ($SD = 4.97$) with ranges from 12–39 (total score ranges from 8–40). Although Bogart (2015) only describes the mean and range of scores of the Personal Identity Scale score and therefore comparison is limited, the ABI group in this study showed a lower mean disability identity (in relation to the total score) but also larger variability (based on the SD in relation to the total score range). While there is limited literature to directly compare the ABI group in this study to others, this finding suggests that people with ABI may, on average, have a lower disability identity than people with other acquired neurological conditions, but may have a wider range of experiences with disability identity.

The qualitative findings provide some insight to this result. Many participants in the focus group presented with higher identity levels, and they described an early period after ABI dominated by grief for their pre-injury self and resistance to disability, often rooted in internalized ableism. Grief was described as an emotional reaction to injury tied to a rupture between one's pre- and post-injury sense of self. At the same time, identification as disabled was often resisted because the label was perceived as negative. Working through the grief associated with mourning the former self while also working to re-examine disability against previously held beliefs were important components of initial integration of disability into participants' identities. The clustering of scores in the "low" range may be interpreted as an indication that many people in this sample are still grappling with grief and internalized ableism, and therefore, may not have reached this initial acceptance of disability that the qualitative participants (with higher identity levels) were able to reflect on.

The distribution of scores may be also understood in context of the fluctuating and dynamic nature of disability identity. The focus group participants often described disability

identity as fluctuating across time and contexts rather than as a stable category. Therefore, it is also possible that people in the “low” category may have had higher disability identity at other points in time, but were experiencing lower identity with disability at the time of the survey. Forber-Pratt et al. (2022) cautioned against treating a given DIDS score as a stable trait of that individual and highlighted that individuals move among disability identity statuses, rather than progressing through fixed stages, as previously conceptualized (Gill, 1997; Gibson, 2006). A more explicit longitudinal study examining the nature and pattern of disability identity development as well as influencing factors over time could provide better evidence for supporting this population through the fluctuations of identity with disability.

Current findings from this study add an important perspective to disability identity that Forber-Pratt and Zape’s (2017) model does not adequately capture. Their model describes four statuses of disability identity, including an “acceptance” state, where a person and those close to them come to accept their disability. While Forber-Pratt and Zape briefly acknowledge that the “traditional stages of grief” may be part of this status for people with acquired disability, the model does not adequately account for a potential “pre-acceptance” state. For this sample of adults with ABI, it appears the initial process of working through grief and loss is necessary to arrive at acceptance of disability. This interpretation is similar to past literature highlighting the reconstruction process of sense of self with acquired disability, including emphasis on attempts to integrate pieces of new identity into sense of self while still placing higher value on pre-injury traits (France et al., 2013; Gendreau & de la Sablonnière, 2014). This study adds to the body of disability identity knowledge by demonstrating how this process of mourning and reconstruction is an important part of disability identity development for adults with ABI. This work bridges the gap between identity models focused only on personal identity reconstruction (France et al.,

2013; Gendreau & de la Sablonnière, 2014; Hutchinson et al., 2018; O'Connor et al., 2004) and Forber-Pratt and Zape's model, which requires an entry point of acceptance.

The “pre-acceptance” period appears to be a meaningful and perhaps necessary step towards disability identity development for people with ABI. It may be important to acknowledge and notice it as a separate step, allowing providers to potentially identify and support someone in that phase. Additional insights from the focus groups regarding the specific ways in which participants felt unheard (having their feelings redirected, their requests for services denied, and their expressions of loss met with forced positivity) reveal how encounters with rehabilitation professionals can negatively impact disability identity. They also frequently described a broader rehabilitation culture oriented toward restoring function and characterized by a “fix-it” mentality, and they identified this orientation as unhelpful to identity development. These responses share a common trend of provider discomfort with disability, therefore treating it as a negative to be corrected or reduced. By minimizing or ignoring participant's experiences, such responses can reinforce the internalized ableism that participants described struggling to overcome. By insisting participants stop focusing on their former selves or reframing their concerns as complaints, responses from professionals can also shut down the grief processing needed for disability identity development for people after ABI. When recovery is framed solely as a return to a pre-injury baseline, the implicit message is that a life with disability is a lesser outcome.

Disability-affirming rehabilitation instead normalizes disability and supports adjustment to a changed life rather than restoration alone. By validating emotions and treating lived experience with disability as credible expertise, rehabilitation providers can work against ableist assumptions and make space for all emotions and experiences involved in disability identity

development. Because the rehabilitation environment is part of the broader environment that shapes disability identity, rehabilitation providers' framing of and language about disability matter. This aligns with the acceptance status of Forber-Pratt and Zape's (2017) model, in which a person and those around them come to accept disability. In the context of rehabilitation, the provider's framing and language conveying acceptance may foster personal acceptance of disability. How rehabilitation professionals speak to their clients about disability shapes how they come to understand it.

This shift is consistent with the increasing recognition of experiential knowledge as a legitimate form of expertise in healthcare (Castro et al., 2019). Engaged and person-centered listening is a critical and teachable communication skill (King, 2022) that may be an accessible entry point for rehabilitation professionals making the shift towards disability-affirming rehabilitation. Rehabilitation professionals can normalize grief as an expected component of adjustment to disability and more explicitly make space for clients to share their experiences with loss without redirection or deflection. As Forber-Pratt et al. (2019) recommends, providers also must look inward to examine their own assumptions about disability as the necessary first step to counteracting the ableism people after ABI are working to overcome.

Disability Identity is a Complex Web of Factors

Aim 2 explored how personal, impairment-related, and environmental factors relate to disability identity in adults with ABI. The integrated findings suggest that disability identity is not the product of any single factor in this population. Instead, it emerges through the interaction amongst these various factors. This pattern is consistent with Forber-Pratt and Zape's (2017) Disability Identity Development Model and the ICF framework (WHO, 2001), which both highlight the importance of both internal and external influences on disability. Quantitatively,

younger age, racially marginalized status, and greater impairment visibility and severity emerged as significant factors related to stronger disability identity, whereas time since injury, gender, sexual orientation, invisible impairments, and self-reported environmental barriers did not. The qualitative findings clarified why and how certain factors mattered for disability identity and diverged from the quantitative findings to highlight factors that were not significant quantitatively.

Impairment and Environment Interactions. Among the impairment-related variables, greater severity and visible impairment (relative to no impairment) had significant associations with stronger disability identity. This aligns with prior work in which perceived severity predicted whether people with self-reported impairment identified as disabled (Bogart et al., 2017), and that less perceived severity was associated with lower disability identity after spinal cord injury (Lee et al., 2008). For participants in this study, perceiving their condition as severe (significantly impacting their daily life) potentially meant increased engagement with the realities of disability while navigating daily life. In the qualitative findings, participants did not describe impairment only as influencing disability identity; rather, impairment became relevant through encounters with inaccessible spaces, institutions, and social responses. Visibility and severity of impairment mattered because they shaped how participants were perceived and treated and experienced the environment, which may explain why invisible impairment alone does not significantly influence disability identity development. Similar to Bogart et al.'s (2017) discussion that severity operates partially through more encounters with social and environmental barriers, visible and severe impairments were identity-shaping in part because barriers were more frequently encountered, interpreted, and responded to in participants' daily environments. This dynamic interplay of body, environment, and social response is described as

complex embodiment by Siebers (2017). Complex embodiment underscores the reciprocal nature of the relationship between one's body and the social/environmental representations of their body, arguing the equal importance of disabling experiences that come from the body and from the environment. Participants in this study supported the theory of complex embodiment quantitatively through the impairment-related variables, then expanded through their qualitative examples of daily disabling interactions between impairment and environment.

Despite the emphasis on environmental factors in qualitative data, participant self-reported environmental barriers captured by the CHIEF-SF subscales were not uniquely significant factors and adding them to the model together did not meaningfully improve model fit. This finding diverges from Bogart et al.'s (2018) study of people with any reported health condition, who found that environmental factors were significant predictors of the similar construct of disability pride. In that study, environmental factors were assessed using larger scales related specifically to perceived social support (12 items) and stigma (eight items). The insignificant findings in the current study may therefore be a result of measurement related limitations. Environmental barriers were assessed quantitatively with only four items from two CHIEF-SF subscales, which capture the frequency and magnitude of specific physical, structural, and attitudinal obstacles. This limited operationalization may not have been sensitive enough to capture more diffuse, accumulated experience of being perceived as lesser throughout environmental contexts like in Bogart et al.'s (2018) interpretation of their findings, where stigma and social support were measured in more detail. In the qualitative data, participants described that they may encounter relatively few discrete barriers that may not be captured using CHIEF-SF, while still absorbing messages about disability that shape their identity. Therefore, the environmental influence that matters for disability identity may be less about the documented

impact of an obstacle and more about the impact of being perceived as less than because of it. The qualitative findings offer empirical support for the emphasis of external dimensions of Forber-Pratt and Zape's (2017) Disability Identity Development Model and the need to understand their relationship with disability identity better. Future work with a greater emphasis on the impact of stigma in one's environment may better capture this relationship.

The Subjective Meaning of Time Since Injury. The impairment-related variable regarding time since ABI was not significantly associated with disability identity. This finding may be partially explained by Bogart's (2014) findings that people with congenital disabilities had a higher disability identity than those with acquired disabilities, and amongst those with acquired disabilities, younger age of onset was associated with higher life satisfaction. Although their study focused on age of onset, not time since injury, they highlighted that embracing disability may be less about the amount of time to adapt to disability and more about the life one has lived before becoming disabled. The qualitative findings of the current study may expand on this explanation as they provide additional unique insight into the importance of time since injury among people with ABI.

Participants did consistently describe time since their injury as an important component of disability identity development, as that time allowed them to integrate grief and loss as well as going through the process of acceptance to their new selves. However, the time each person needed was varied and was highly individual. Participants shared differing increments of time (e.g., 1.5 years, several years) and varied ways in which they perceived the amount of time involved in disability identity development after ABI (e.g., related to grief, being a journey). Kafer (2013) similarly describes a shift in thinking about time when living with disability, describing the term "crip time" as a call for understanding the ways in which disabled people

experience time in non-traditional ways. Although not directly tied to disability identity by Kafer, she posits that crip time challenges the normative expectations of the length of time things should take and also the pace at which disabled people do them. Samuels (2017) further describes this idea in relation to accepting life with acquired disability, reflecting on the tension between the focus on linear time and illness stages in the medical institution and her bodily experience of non-linear time, including navigating grief of past and future self. Therefore, time since injury, as a linear and chronological data point, may have failed to capture the subjective and variable meaning of time in relation to disability identity development that the qualitative data revealed. The participants in this study described their varied and flexible perceptions of time in relation to accepting their disability, which serves as a preliminary example of how crip time extends to identity development. This is an important reminder that, rather than rigid adherence to the linear expectations of recovery, honoring crip time throughout the rehabilitation process may better support disability identity development after ABI by allowing people space and time to grieve and explore their identity with disability at their own pace.

Disability is a Layer of a Broader Experience with Marginalization. Among the personal factors, race had a strong quantitative relationship with disability identity. Although the non-White subgroup sizes were small, participants of marginalized racial status reported higher identity than White participants. Sexual orientation was not significantly associated with disability identity quantitatively and was again a small subset of the sample size but arose as an important factor amongst focus group participants who did not identify as heterosexual/straight. In both instances, the qualitative data provided additional insight into these relationships.

The combined findings suggest that people with marginalized identities such as a non-White racial background and non-heterosexual/straight experience disability identity

development in relation to their other identities. The contextualization of disability identity in relation to other marginalized identities by the focus group participants underscore the importance of understanding disability identity within its intersectionality with different identities. Intersectionality supports the idea that identities are important parts of a whole self and cannot be “peeled off” from one another (Crenshaw, 1989; Siebers, 2017). Interestingly, focus group participants who already held other marginalized identities described disability as “one more layer” of an existing experience of difference and also connected their disability identity to prior histories of social justice engagement.

This finding also supports the conceptions of disability as a minority identity tied to social status and rooted in collective experiences, or as a political identity that facilitates collective action, rather than a purely medical or personal condition (Adamson, 2018; Forber-Pratt et al., 2019; Kafer, 2013; Shakespeare, 1996). One plausible interpretation is that prior experience navigating a politicized, minoritized identity provides a framework through which disability can be taken up as a shared, social and political identity rather than internalized as an individual deficit (Kafer, 2013). A strong minority identity can operate as a protective and transferable resource to navigating identity with disability (Forber-Pratt and Zape, 2017). This understanding provides an important framework for rehabilitation professionals on how to discuss disability identity by highlighting the value of attending to clients’ intersecting identities rather than treating disability in isolation. Providers should recognize that clients arrive with existing identity-related experiences and can connect them with communities and resources that reflect the full range of who they are.

Age Shapes How Disability is Interpreted by Others, and Therefore Self. Another personal factor, younger current age, had a significant quantitative relationship with higher

disability identity for this sample. This finding is consistent with literature among people with acquired versus congenital disabilities, where earlier age of injury was associated with higher disability identity (Bogart, 2014). Although all participants in this study have an acquired disability, it is possible that the perceptions of younger people towards disability are different given the more recent societal shift in disability recognition and rights. Forber-Pratt and Zape (2017) describe this group as the “ADA-generation”, positing that people who have grown up with increased disability inclusion may perceive disability differently. Also confirming this finding is literature that older adults may be more resistant to identify as disabled, particularly because of societal attitudes and stigma around disability (Hutchinson et al., 2018). As older adults already face social stigma related to ageism, disability may be viewed as a compounding negative attribute.

In qualitative data, participants did not focus on their current age, but instead discussed the impact of age in relation to their age of injury because of the meanings other people attached to their age of acquiring a brain injury. Older participants encountered ageist assumptions of ineptitude, while younger participants felt similarly minimized by being told they were “lucky” at their time of injury. Age shaped disability identity through the ways that recovery and capability were interpreted by those around the person after ABI. Recent literature also demonstrates that both older and younger adults face stigma following acquired neurological disability. Older adults with acquired disability grapple with the need to overcome age-related stereotypes of what is possible at a certain age, such as ability to work (Hutchinson et al., 2018); similarly, younger adults after stroke also face stigma related to ability to participate in what may be considered “traditional” milestones in higher education, work, and family life (Zheng et al., 2023). Therefore, additional qualitative exploration is warranted into the ways in which age

shapes disability identity after ABI. While preliminary, for rehabilitation providers, this finding underscores the importance of critical reflection of one's own biases related to age, including who is "too old" or "too young" for disability.

Disability Identity is Strengthened Through Community Connection

In the qualitative focus groups, participants described connection with other disabled people as important for transforming disability from an individually experienced problem to a shared identity. This finding is in accordance with Forber-Pratt and Zape's (2017) model, in which the relationship, adoption, and engagement statuses rely on connection to and participation in the disability community. While the quantitative data did not capture the impact of positive social support and networks (possibly because the environmental factors were measured as barriers), this qualitative finding is consistent with evidence that social support from the disability community is strongly associated with disability pride, possibly because it acts as a buffer against stigma by prompting people to reject negative societal attitudes in favor of pride about their group status (Bogart et al., 2017). Because social networks are frequently disrupted after ABI (Northcott et al., 2016), connecting people to shared communities can fill a critical gap in post-ABI care.

Peer support is a central tenet of the disability rights movement, grounded in the premise that experiential knowledge and shared experience offers both emotional and practical support for people with disabilities (Magasi & Papadimitriou, 2022). There is a growing body of evidence of peer support programming for people with ABI. A community-based peer mentor program focused on higher education access has been implemented with young adults with neurological disorders (including TBI) and demonstrated increased access to post-secondary education and an overall sense of increased belonging (Kolakowsky-Hayner et al., 2012).

Another example is the Improving Participation After Stroke Self-Management (IPASS) program, which provides small group-based interventions by a trained facilitator and a peer stroke survivor and addresses community reintegration and participation rather than impairment alone (Wolf et al., 2016). The IPASS self-management programming has improved participants' sense of empowerment through interactions with peers (Lee et al., 2017). A systematic review of 13 self-management programs (including IPASS) highlighted the value of peer support in group-based programming, particularly because it facilitated social participation and sharing of experiences (Clark et al., 2020). Recent evidence also links peer support to disability identity in those who serve in the peer support roles. A qualitative analysis of peer support workers with physical disabilities (including TBI and stroke) found that peer support work fostered an increase in positive disability identity for those with recently acquired and long-term disability, and participants highlighted the “reciprocal empowerment” felt by both peer and mentor through reciprocal knowledge sharing and community building (Magasi et al., 2026).

Translated into practice, facilitating disability-community connection in rehabilitation could take multiple forms. One strategy could be implementation of a referral system to peer-led organizations and condition-specific groups, so that connection becomes a standard element of discharge planning rather than something clients must request or discover on their own. Embedding trained peer mentors or navigators within rehabilitation teams could also more systematically ensure peer support is identified, and offering group-based programming (like described above) could focus on building community relationships alongside functional skills. As the interest in peer support interventions for people with acquired disability grows, Magasi and Papadimitriou (2022) have proposed an evidence-based framework for implementing peer support interventions in rehabilitation contexts. It is important to note that the programs

described above were designed to improve participation, self-efficacy, self-management, or healthcare access, and their effect on disability identity has not been directly tested.

Understanding the role of peer support and community connection in disability identity development after ABI could offer additional benefit of these programs. A possible future direction is to adapt peer and community-based interventions to explicitly support disability identity development and to measure disability identity as an outcome.

Disability and Occupational Identity: Related but Distinct

Disability and occupational identity have not previously been examined together. Although modest, this study's findings suggest a relationship between these two constructs, which is informative in two ways. First, the significant but modest association suggests that occupational identity and disability identity are related but distinct constructs for adults with ABI. They overlap in the process of reconstructing a coherent sense of self after ABI, a process documented in the literature about occupational identity and more broad identity (Brown et al., 2024; France et al., 2013; Gendreau & de la Sablonnière, 2014; Hutchinson et al., 2018; Martin-Saez & James, 2021; O'Connor et al., 2004), yet they are not redundant. Occupational identity focuses on one's sense of self as an occupational being generated through a history of participation (Kielhofner, 2008), whereas disability identity concerns the integration of disability into one's sense of self and connection to the disability community (Forber-Pratt et al., 2019). The small amount of shared variance is consistent with this conceptual distinctness.

Second, the qualitative findings suggest that meaningful occupation may serve as a pathway toward disability identity. Participants described the loss of valued roles as a central disruption of self after ABI, and because that loss was attributed to the injury, it was experienced as another negative consequence of disability. Re-engagement in meaningful occupations, even

in adapted forms, supported a sense of self that could include disability. These findings resonate with the occupation-specific grief described by Brown et al. (2018) as the unique type of grief after acquired disability related to decreased participation in meaningful life activities. The findings also echo their call for occupational therapy practitioners to uncover a client's "keystone" occupation – an occupation so central to one's sense of self that reconstruction is not possible without return to the occupation in some form. In their qualitative study of how people with disabilities (including people with stroke and TBI) define life participation, Hammel et al. (2008) found that participation was not only about the activity itself, but was connected to identity and sense of self, such that participating in personally meaningful activities was a way disabled people expressed and affirmed who they were. The present findings expand this concept for participants with ABI. Re-engaging in meaningful occupation was a means of reconstructing a sense of self that could incorporate disability rather than viewing it as a negative, suggesting that meaningful participation may be an avenue through which disability identity is strengthened.

The occupational dimension represents a distinct contribution of this study. The present findings suggest that re-establishing meaningful occupation may simultaneously rebuild occupational identity and support disability identity development. This relationship is not currently represented in existing disability identity frameworks, which emphasize community connection and internal acceptance but not occupational engagement. Because the design of this study is cross-sectional, the effect is small, and the direction of influence cannot be established, these initial findings may be interpreted in several ways: Disability identity may support occupational re-engagement, occupational re-engagement may support disability identity, or the two may reinforce one another. While this finding is promising, this relationship is preliminary, which requires further exploration.

The Need for a Disability-Informed Workforce

Taken together, the implications woven through this discussion describe the need for a shift away from a medicalized, restoration-focused model of care towards practice that treats disability as a meaningful identity grounded in community. Participants shared disability-affirming rehabilitation strategies and the need for greater disability knowledge amongst healthcare professionals as priorities for facilitating this shift, and their priorities expand on the little existing guidance for addressing disability identity in rehabilitation (Forber-Pratt et al., 2019). As described throughout this discussion, these strategies include making space for grief and the renegotiation of internalized ableism, using framing and language that affirm rather than devalue disability, honoring non-linear timeframes and intersecting identities, and connecting clients to disability community and to support resources.

Delivery of effective, disability-affirming care relies on a more disability-informed workforce. However, participants noted that clinicians across health professions often receive little or no formal education devoted to disability, which has also been raised as a concern for decades in healthcare education literature (Ankam et al., 2019; Harrison et al., 2021; Kielhofner, 2005; Linton, 1998; Shakespeare et al., 2009). Participants suggested training be informed by non-medicalized frameworks and, crucially, by listening to the lived experience of disabled people themselves. Without disability-specific knowledge and exposure to critical disability frameworks, the affirming, validating, and community-connecting practices participants valued are less likely to be delivered reliably. This finding points toward integrating expanded disability content into entry-level and continuing rehabilitation education using approaches that position disabled people as educators and partners rather than only as patients.

The Alliance for Disability in Healthcare Education, a national organization of disabled people, disability advocates, and interprofessional health educators, recently established a set of core competencies on disability for healthcare education (Alliance for Disability in Healthcare Education, 2018). The competencies include six domains (contextual and conceptual frameworks on disability, professionalism and patient-centered care, legal obligations and responsibilities, teams and systems-based practice, clinical assessment, and clinical care over the lifespan and during transitions) and guiding principles for each. These domains and principles echo the disability-affirming practices identified in this study; that disability is a rich part of human diversity, not only a negative health status, that people with disabilities are experts in their lived experience, and that quality of life must be understood from the disabled persons' perspective. These competencies offer rehabilitation educators a strong framework to improve disability knowledge amongst learners. How this information is taught is also important. Havercamp et al. (2021) provide several, more effective alternatives to standalone disability courses in rehabilitation education. They recommend weaving disability content into topics already present in the curricula, so disability is treated as another aspect of human diversity. They also highlight the importance of direct contact with disabled people, including recruiting people with disabilities as lecturers and curriculum partners. These practices are consistent with the community-engaged, justice-oriented agenda advanced in disability-focused rehabilitation scholarship (Harrison et al., 2021). As participants acknowledged, education about disability is not in itself a disability identity intervention; rather, it is an upstream investment that makes disability-affirming, identity-supportive care possible across the workforce.

The Benefit of Mixed Methods Research

The explanatory mixed-methods design was a key strength of this study as it enabled a more comprehensive understanding of disability identity development among people with ABI than either quantitative or qualitative methods could provide alone. Combining quantitative and qualitative data allows researchers to draw on the strengths and offset the limits of each method, generating findings that integrate statistical data with lived experience related to a complex health phenomenon (Fiorini et al., 2016). While the survey findings offered important information about disability identity trends and relationships with other factors, the qualitative data added critical depth and context to understanding these constructs. Specifically, qualitative findings added depth to both significant and insignificant relationships. For example, the qualitative findings helped to extend the relationship between personal factors, impairment-related factors, and environmental factors that the quantitative data did not capture. These findings illustrate the value of a mixed methods design, where an insignificant quantitative finding is reinterpreted by qualitative findings that may be better suited to capturing disability identity in people after ABI. Overall, the mixed-methods approach offered a fuller and more contextualized account of the relatively new construct of disability identity and improved the rigor of the study.

The value of the mixed-methods approach demonstrated in this study reflects its broader importance in rehabilitation and health research. Populations involved in rehabilitation research (including adults with ABI) are highly heterogeneous, which can limit the external validity of quantitative methods and their relevance to everyday lives of participants. In addition, the complex interaction between personal, impairment-related, and environmental factors, described in biopsychosocial frameworks used by rehabilitation researchers, can be difficult to capture

through quantitative methods alone. Mixed methods have been proposed as a way to produce findings that are more ecologically valid and meaningful to disability communities (Kroll & Morris, 2009). The findings illustrate how knowledge that is both scientifically rigorous and meaningful to the community can advance and inform rehabilitation research and practice. A well-rounded understanding of the complex, dynamic, and contextual nature of disability identity after ABI provides foundational evidence for developing rehabilitation practices and interventions that are responsive to the lived experiences and diverse needs of individuals with ABI.

Limitations

Several limitations should be considered when interpreting these findings. One limitation is the cross-sectional design of the study. Although the qualitative findings characterize disability identity as a dynamic process, the quantitative data were collected at a single point in time and therefore cannot capture change over time or support causal inferences about the relationships between the factors examined and disability identity. Participants in the qualitative focus groups described disability identity as fluctuating across time and context, but this fluctuation could not be examined quantitatively. Longitudinal designs are needed to trace how disability identity unfolds after ABI and to clarify the direction of the relationships identified here.

Limitations related to sampling should also be noted. Convenience sampling, conducted primarily through brain-injury support groups, model systems centers, and rehabilitation settings, may have over-represented individuals already connected to disability communities. The requirement to complete the survey without cognitive-related assistance, as well as the exclusion of individuals who identified as disabled prior to their ABI or who had a comorbid progressive neurological condition, may have excluded people with more significant impairments and limits

the populations to which the findings apply. The sample was also predominantly White, so the findings may not generalize across cultural or linguistic contexts. Dichotomizing gender, sexual orientation, and race also assumes a degree of homogeneity within the grouped categories. This was necessary given the subgroup sizes but may obscure meaningful differences between groups that could be examined in larger, more diverse samples. In the qualitative phase, individuals with lower disability identity were underrepresented; although they were contacted, most did not respond. The focus group findings therefore reflect the perspectives of participants who had a higher level of disability identity compared to the quantitative sample. While these participants offered valuable insight into the process and the supports that aided disability identity development, the perspectives of those with lower disability identity are less well represented.

Measurement limitations also warrant caution. Environmental factors were assessed using only four items from two CHIEF-SF subscales, a narrow operationalization that may not have captured the breadth of environmental influence that the qualitative findings revealed and may have contributed to the non-significant environmental associations in the quantitative analysis. The DIDS is a relatively new instrument whose category cut scores require further validation (Forber-Pratt et al., 2022), so categorical interpretations of scores should be treated as provisional.

Reliance on self-report and self-categorization for survey completion introduces the potential for recall and social-desirability biases. However, most constructs measured in this study are inherently subjective and cannot be objectively assessed, making self-report the most appropriate method for data collection. In addition, triangulation of the quantitative findings with the qualitative data increases credibility of the results and confidence in the areas where the two converged.

Taken together, these limitations highlight the need for caution in interpreting the findings and underscore important directions for future research. Despite these limitations, the study employed a mixed-methods design that combined the breadth of quantitative data with the depth of qualitative perspectives, providing a more comprehensive understanding of disability identity after ABI. The convergence of findings across methods strengthens confidence in the overall conclusions, while the identified limitations offer guidance for future longitudinal and methodologically robust investigations of disability identity development with a larger and more diverse sample of this population.

Conclusion

This study used an explanatory sequential mixed methods design to describe disability identity in adults with ABI, to identify factors associated with disability identity in this population, and to explore how rehabilitation professionals can support disability identity development after ABI. Taken together, the findings characterize disability identity after ABI as a dynamic process that often begins with grief over the pre-injury self and renegotiation of internalized ableism, takes shape through the interaction between impairment-related, personal, and environmental contexts, and is strengthened through connection to people with shared experience. Quantitatively, younger age, racially marginalized status, greater impairment visibility and severity, and higher occupational identity were associated with higher disability identity. Qualitative findings clarified how these factors became meaningful through participants' everyday experiences.

This study extends Forber-Pratt and Zape's (2017) Disability Identity Development Model in two ways: by identifying an initial, grief-laden "pre-acceptance" process that precedes the model's acceptance status, and by situating occupational identity and meaningful occupation

as relevant to disability identity development. These contributions carry practical significance for rehabilitation. Participants called for care that is disability-affirming, that treats their lived experience as credible expertise, that actively connects them to the disability community, and that is delivered by a workforce educated about disability. Ultimately, this study positions disability identity after ABI as a dynamic process that continues to evolve over time and is shaped by many factors. By shifting from a medicalized to a disability-affirming model of care, rehabilitation professionals have a meaningful opportunity to support this process.

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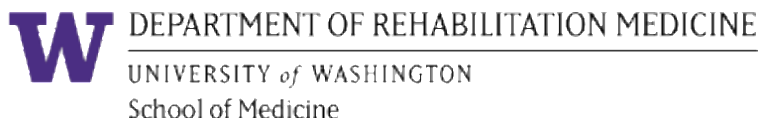
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Appendix A: Survey Recruitment Flyer

Virtual Recruitment Version



PARTICIPANTS NEEDED FOR ONE-TIME SURVEY:
Are you a stroke or brain injury survivor?
We want to hear from you!

WHAT IS THE RESEARCH STUDY ABOUT?

We want to understand how adults with a brain injury think about their condition as part of who they are. We also want to know if certain factors and life experiences shape someone's sense of identity. Ultimately, we want to identify ways to support positive sense of self after brain injury.

WHAT DOES THE STUDY INVOLVE?

- Taking a one-time online survey (about 45 minutes to complete).
- Option to participate in a follow-up focus group.
- Help can be provided to participate!
- *This study is approved with exempt status by the UW IRB.*

BENEFITS FROM THE STUDY

- **No in-person requirements!** We are recruiting people from anywhere within the United States.
- Enter in a raffle to win **\$25** for completing the survey.
- Receive **\$25** for participating in an optional follow-up focus group.

YOU MAY BE ELIGIBLE TO PARTICIPATE IF YOU:

- Are 18 years of age or older.
- Have had a brain injury – examples include stroke, traumatic brain injury (TBI), or anoxia.
- Are able to take an online survey in English – technical help is available for completing the survey!

FOR MORE INFORMATION, CONTACT:

Emma Gregg, OTD, OTR/L



ergregg@uw.edu



360-562-0549

In-Person Recruitment Version



PARTICIPANTS NEEDED FOR ONE-TIME SURVEY: Are you a stroke or brain injury survivor? We want to hear from you!

WHAT IS THE STUDY ABOUT?

We want to understand how adults with a brain injury think about their condition as part of who they are. We also want to know if certain factors and life experiences shape someone's sense of identity. Ultimately, we want to identify ways to support positive sense of self after brain injury.

INTERESTED? CONTACT US!

 ergregg@uw.edu

 360-562-0549



WHAT DOES THE RESEARCH STUDY INVOLVE?

- Taking a one-time online survey (about 30-45 minutes to complete).
- Option to participate in a follow-up focus group.
- Help can be provided to participate!
- *This study is approved with exempt status by the UW IRB.*

BENEFITS FROM THE STUDY

- **No in-person requirements!** We are recruiting people from anywhere within the United States.
- Enter in a raffle to win **\$25** for completing the survey.
- Receive **\$25** for participating in an optional follow-up focus group.

YOU MAY BE ELIGIBLE TO PARTICIPATE IF YOU:

- Are 18 years of age or older.
- Have had a brain injury – examples include stroke, traumatic brain injury (TBI), or anoxia.
- Are able to take an online survey in English – technical help is available for completing the survey!

BRAIN INJURY SURVEY
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Appendix B: Survey Questions

Demographic Questions

1. What is your age?
2. How old were you when you had a brain injury?
3. How would you describe the impairment(s) related to your brain injury?
 - a. No impairments
 - b. Visible impairments only (i.e. difficulty walking, using a wheelchair or other aid for mobility, difficulty using my arm)
 - c. Invisible impairments only (i.e. difficulty remembering things, difficulty with speaking, difficulty managing emotions, depression, anxiety)
 - d. Both visible and invisible impairments
4. Please rate your response to the following question: My condition is severe (it significantly affects my daily life).
 - a. Strongly disagree – Disagree – Neutral – Agree – Strongly agree
5. How would you describe your gender?
 - a. Man
 - b. Woman
 - c. Non-binary
 - d. Prefer to self-describe: _____
6. How would you describe your sexual orientation?
 - a. Asexual
 - b. Bisexual
 - c. Gay

- d. Heterosexual or straight
 - e. Lesbian
 - f. Pansexual
 - g. Queer
 - h. Prefer to self-describe: _____
7. How would you describe your race? (Choose all that apply).
- a. American Indian or Alaska Native
 - b. Asian
 - c. Black or African American
 - d. Hispanic or Latino
 - e. Middle Eastern or North African
 - f. Native Hawaiian or Pacific Islander
 - g. White

Disability Identity Development Scale (Forber-Pratt et al., 2021)

Not like me at all – A little bit like me – Somewhat like me – A lot like me – Very much like me

1. If I witness someone else facing discrimination on the basis of ANY disability, I do something about it.
2. I am proud to identify as a person with a disability.
3. I serve on disability-related panels, Boards or committees.
4. I organize events for the disability community (i.e., support group meetings, sporting events, advocacy events, lectures).
5. I have a strong sense of belonging to people with disabilities.
6. I learn about disability culture by reading books/articles/blogs/websites.

7. I believe there is a disability community.
8. I am a mentor to other people with disabilities.
9. I identify with disability culture.
10. I give advice to other people with disabilities.
11. I am a mentor to other people with MY disability.
12. I advocate for accessibility.
13. I identify as a person with a disability.
14. I advocate for inclusion.
15. I wish that I was not disabled.
16. I like (or would like) attending disability community events.
17. I embrace the core values of disability culture as my own.
18. I view myself as a disability expert.
19. There are some days that I wish I did not have a disability.
20. I believe there is a disability culture.
21. I connect people with disabilities to the disability community.
22. I fundraise for disability-related causes.
23. I seek out friends who have disabilities.
24. I identify with a disability community.
25. I speak publicly about disability (in person or online).
26. Being a person with a disability is an important reflection of me.
27. I am able to contribute to the disability community.
28. I engage with the disability community.
29. I think of my disability as a core part of who I am.

30. I like (or would like) attending disability-related advocacy events (i.e., rallies, protests, policy townhalls).
31. If there was a "magic pill" that would take away my disability with no side effects, I would take it.
32. I like (or would like) attending events hosted by disability-related organizations.
33. I have a strong sense of belonging to the disability community.
34. If I witness someone else facing an access barrier, I do something about it.
35. I like (or would like) attending disability-related talks or lectures.

Craig Hospital Inventory of Environmental Factors Short Form (Whiteneck et al., 2004)

Daily – Weekly – Monthly – Less than monthly – Never – Not applicable

Big problem – Little Problem

1. In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?
2. In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc. – made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?
3. In the past 12 months, how often have other people's attitudes toward you been a problem? When this occurs has it been a big problem or little problem?
4. In the past 12 months, how often did you experience prejudice or discrimination? When this problem occurs has it been a big problem or a little problem?

Occupational Identity Questionnaire (Shikata et al., 2025)

Strongly disagree – Disagree – Agree – Strongly agree

1. Previously, I felt a rewarding sense of satisfaction about work and homemaking.
2. Previously, I lived with a sound mind and body.
3. Previously, I felt that I was helpful to others.
4. Previously, I did well despite difficulties.
5. Previously, I did well with other people.
6. I cannot do as I did when I was young, but I think that I am doing well.
7. I have fun in my life.
8. Rather than having nothing to do, it is better to have something to do.
9. From now on as well, I want to meet the expectations around me.
10. I want to live happily in the future.
11. From now on as well, I want to do what I can do.
12. I would like to challenge myself to do what I do not do now.
13. I think that there is a person who understands my feelings and I am satisfied with that.
14. I think that I live as I expected I would.

Follow-up Questions

1. Thank you for completing this survey! You are eligible to enter a drawing for two \$25 gift cards for participating. Please share your email address if you are interested in being entered into the drawing. *Your email address will not be connected with your survey responses.*
 - a. Email address: _____
2. We would like to follow up with participants to get more in-depth information about your experiences with disability identity. Please share your contact information if you would

be interested in participating in a 60-90 minute virtual focus group. All focus group participants will be compensated with a \$25 gift card for their time. *Your contact information will not be connected with your survey responses.*

a. Email address: _____

b. Phone number: _____