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## STORIES OF ME: DISABILITY IDENTITY DEVELOPMENT IN PERSONS WITH ADHD

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**STORIES OF ME: DISABILITY IDENTITY DEVELOPMENT IN PERSONS WITH  
ADHD**

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Disability and Equity in Education

Submitted in partial fulfillment

of the requirements of

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National Louis University

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## ABSTRACT

Theoretically, developing a strong sense of ADHD identity, adolescents can combat anxiety and stigma. Combatting anxiety and stigma can support student's postsecondary success. How can teachers help? The study aims to explore the narratives of disability identity from the adult reflective perspective to identify potential recommendations for teachers. This mixed-methods study collected data through two semi-structured interviews of adults with ADHD, a focus group, and survey data from social media communities. The stories were analyzed for evidence of a sense of identity, pride, and self-esteem. The emerging themes provided recommendations for educators which included the need to foster relationships (teachers with students and peer-to-peer in ADHD communities), teach explicit skills and strategies, and support the needs of families and students to understand and access resources. The implications of the data also included the need to capitalize on the power of community, equip educators to teach disability history, foster disability pride, and build relationships with students.

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## CH. 1

### “The Backstory and Catalyst”

#### INTRODUCTION

*Faith pulls back the glass and steel doors of her public high school as she takes in the familiar hustle and bustle of teens and adults in droves intermingling while they walk the halls with different destinations and motivations. Faith's neatly styled raven-black curly hair brushes against her mahogany brown skin as she lifts her head slightly to acknowledge an acquaintance. She double-checks her backpack while standing in front of her locker and proceeds to head to her first class of the day, English. As she enters the room, a familiar knot grows in the pit of her stomach because, unbeknownst to her peers (but known to her teachers), Faith has a secret. No one would have guessed that this quiet pleasant, hard-working student had ADHD and a learning disability. In the back of her head, Faith knew that her ADHD and learning disability was nothing to be ashamed of, but in the forefront of her mind, she was self-conscious of her differences and her needs. English class happened to be a minefield of opportunities for exposure to her weaknesses: Discussions, reading aloud, extended listening, group work, and so many details to remember. Faith settled into her seat and worked to settle her nerves. On the other side of the room, her teacher scans the faces of the young adults she has grown to care for so much. The teacher's gaze lingers for a moment on Faith and knowing her diagnoses and struggles she mentally prepares for the tightrope walk.*

#### ***The Tightrope Walk***

*What is the best way to help you?*

*Do I shout out your strengths for the world to see?*

*But then you might shrink back, not wanting them to see “little ole’ me”*

*Do I act like your diverse needs are no big deal?*

*But then you might not get the support needed to achieve the ideal.*

*I am sensitive to your compilation of adolescent needs*

*This time in your life is confusing, all men would agree*

*I'll walk the tightrope for you, not too obvious but not too distant*

*Until you can stand on your own, confident, and resilient*

*It's complicated!*

*-Andrea Johnson (2019)*

The poem is the voice of the teacher, the tightrope walker, passionate to help their student but conflicted as to the best approach. This teacher's quandary is a side plot to the life story of her student, Faith. The tightrope walk is the complex and precarious set of decisions adults make when deciding how to meet adolescent needs. Adolescence can be complicated but a teacher's core desire is to support students in their growth academically and socially. When I was a special education case manager, I would often tell parents and colleagues that high school is only part of the path that leads to a student's future. It is not an ending point. Our job was to support students' movement along that path and prepare them for the next stop. In light of the brief time that they are within our school walls, we must do all that we can to support students during this period of development called adolescence. Adolescence is the stage where teenagers start to establish their ideas about their identity. Everything that they choose to do, be involved in, how they choose to express themselves, and who they align themselves with is all part of the tapestry of identity possibilities. Students are developing a framework for understanding who they are socially, academically, racially, sexually, cognitively, religiously, physically, etc., and situating that understanding internally and outwardly in their interactions with others. For my students with

disabilities, the identity journey is the same but also includes an understanding and positioning of their personal view on their disability. Disability is any difference/impairment/illness that might have a degree of impact on an individual's functioning physically, academically, functionally, or socially in the context of one's environment (Leonardi et al, 2006). The impact is not rooted in the individual but is contextual and environmental. This view of disability being centered on external/environmental barriers is based on the social model of disability and not the medical model of disability (Medical and Social Models of Disability, 2018). Many people have a medical model understanding of disability which is where disability lies solely within the individual who is expected to conform, adapt, be treated, fixed, or be stigmatized. Despite that understanding of disability, some of my students accept disability as part of their identity and readily/publicly accept support as needed. They have a positive disability identity. These students are more confident and comfortable as they navigate their high school careers and transition to college. They are ready to seek the resources they need on their college campus. For other students, I found that the desire to "fit in" and avoid stigma presented a challenge to accepting educational support, particularly for students with invisible disabilities (eg. mental health impairments, Specific Learning Disabilities, and ADHD) which are considered high-incidence disabilities. In the UK, "it is estimated that 70-80% of disabilities are invisible (Invisible Disabilities in Education and Employment, 2023, p. 1). To be able to provide specific disability-related resources, adults supporting these students have to be sensitive to the student's expression of identity but also sensitive to the avoidance of stigma. Because educators want to develop confident students who have positive self-concepts, the question is whether adults can positively impact disability identity and if so, what is the best approach. I've witnessed students

reaping the benefits of having a positive self-concept of disability which led me to want to learn more so I could help others do the same.

According to Dunn and Burcaw (2013), Positive Disability Identity (PDI) is the affirmation and acceptance of disability as a positive aspect of self-worth, pride, and community. PDI is what I've identified in students who displayed more self-advocacy than their peers in high school. What I've seen in my students also aligns with the research on the psychological benefits of a well-developed concept of identity. Having a positive disability identity is found to have "psychological health benefits such as increased self-confidence, self-esteem and increased protective factors when facing discrimination" (Forber-Pratt & Zape, 2016, p. 5). In light of the benefits, Shmulsky et al (2021) agree that supporting disability identity can lead to better experiences for students in college and lead to more equity in society (p. 53). Student resilience in the face of discrimination and stigma is an ideal goal for developing PDI.

With the desire and responsibility of educators to support students in their personal development, the differences between students' acceptance of disability make me wonder how teachers and other adults in students' lives can support the development of a positive identity that will lead to the benefits of self-confidence and postsecondary success. As expressed in the poem, it can feel like a tightrope walk trying to balance giving students what they need and deserve in a general education setting while also respecting the student's desire to not appear different to their peers. The desire is to support and not stigmatize. This led to my desire to explore the narratives of disability identity from the adult reflective perspective, those who have passed through the adolescent stage and have matriculated from college. Adults can be retrospective, introspective, and share stories and insights about their course of academic achievement and their development

of identity along the way. From adult narratives, themes, and ideas can be captured that will inform actions educators can take to support positive disability identity (PDI).

This chapter will define the problem being addressed in this study, previous studies, connected theoretical concepts, key vocabulary, the overview of my research questions, goals, proposed methods, and my role and positionality in the research.

## **THE PROBLEM**

### **“What creates the tightrope?”**

The tightrope is a metaphor for the line adults must walk balancing students’ needs and sensitivities during adolescence as they develop their identities. This tightrope act is caused by both the negative impacts of identity crisis during adolescence and the impact of potential stigma. When discussing mental health in classrooms, educators in the United Kingdom describe recognizing the needs of students as pressing but also feeling that students needed to be sheltered from certain terms or issues that could be interpreted as a deficit or illness. For example, mental health, a disability, was the “elephant in the room” avoided in school to minimize stigma (Danby & Hamilton, 2016, p. 95). An elephant in the room could be addressed through a shared understanding of disability identity, and positive disability identity could bring positivity to students’ perception of themselves. A well-respected and influential developmental psychologist who theorized the stages of human development, which includes the development of identity, is Erik Erikson. Erikson defined eight stages of psychosocial development with the fifth stage being adolescence. The stage of adolescence is characterized by identity and identity confusion. It is a period where an “individual weighs out their previous experiences, societal expectations, and their aspirations in establishing values and ‘finding themselves’” (Orenstein & Lewis, 2021). The development of disability identity both in theory and in practical ways creates a struggle

within one's self (Titchkosky, 2006, p. 4). If the adolescent can develop a strong sense of identity during this period, then any outside perceptions of the individual that doesn't match their sense of identity will be rejected which reduces levels of anxiety (Orenstein & Lewis, 2021). In other words, the stronger the sense of a positive identity, the more the individual can reject stigmas. The opposite is also true. Adolescents with a maladapted or weak sense of identity reject aspects of themselves and therefore stigmas cannot be rejected. Marcia adds to Erikson's understanding of the importance of the process of developing identity by explaining:

The better developed this structure is, the more aware individuals appear to be of their uniqueness and similarity to others and of their strengths and weaknesses in making their way in the world. The less developed this structure is, the more confused individuals seem about their distinctiveness from others and the more they have to rely on external sources to evaluate themselves. (Marcia, 1980, p. 109)

The myriad of aspects of identity is vast and most are beyond the scope of this study. The focus of this study is an inquiry into how educators and adults can support the development of an initial framework of academic and social aspects of identity which will allow our students to fight against any stigmas which could impede their access to needed support and services.

Based on Erikson's theories, the process of developing identity is important but why might developing a disability identity be important? Disability is an aspect of identity that is rejected because of stigmas attached to the words and perception of disability. Disability identity is important because it requires a personal meaning-making of what a diagnosis or disability label means to the individual in relation to the world (Johnstone, 2004, para. 10). Developing an understanding of self, the world, and oneself in relation to disability is an ongoing part of the development of identity that occurs during adolescence.

Dunn and Burcaw expand on the idea of developing a personal understanding of disability. In the article, *Thinking about disability identity*:

Disability identity refers to possessing a positive sense of self and feelings of connection to, or solidarity with, the disability community. A coherent disability identity is believed to help individuals adapt to a disability, including navigating related social stresses and daily hassles. (Dunn and Burcaw, 2013)

Unfortunately, growing that understanding and acceptance of a disability can be a challenge for teenagers. Developing a disability identity becomes challenging because of the lingering effects of disability history where over the years persons with disabilities were described as infirm, wretch, deviant, and imbecile. In addition, media, and societal stigmas have created spaces where persons with disabilities have been viewed negatively, shunned, taken pity on, or on the opposite spectrum, are viewed as the unattainable virtuous hero. For example, many villains in classic tales and movies have some disability (e.g. Captain Hook, Richard III, Freddy Kruger, The Joker), or in contrast, the person with a disability is the virtuous hero to take pity upon or be inspired by (e.g. Tiny Tim, Hunchback of Notre Dame, Forrest Gump, Professor X). It is a weighty decision that one has to make to consider being identified as part of the disabled community. I have had students without visible disabilities like a Specific Learning Disability (SLD) or Attention Deficit Hyperactive Disorder (ADHD) who dissociate with a disability because they define it by the visible disabilities that they may see in their peers. Johnstone explains, “Disabled people, for example, were often viewed as the disability itself, placing the disabled person in the position of either taking exaggerated steps to hide the disability or to join with other similarly stigmatized individuals in groups of support or solidarity” (2004, para. 3). The exaggerated steps I’ve seen in high school are the students who intentionally come to class



late so they are not seen in a classroom with less than the typical number of students. I have also seen students in inclusion classes who ignore the diverse learner teacher and only allow the general education teacher to help them. These exaggerated steps are made to avoid stigma. Moving past the stigmas is a societal challenge but a move toward a positive identity can be encouraged and supported by teachers. Positive disability identity should be encouraged for not only those with visible disabilities but especially those with invisible disabilities. Having an invisible disability creates more opportunities to reject connections to negative stereotypes of disability instead of being able to reframe or redefine their differences positively. Because teachers can have so much influence, discovering the ways that they can support disability identity in students with invisible disabilities is paramount. This study's focus is on addressing the problem of teachers not knowing where to begin to encourage positive disability identity in students with invisible disabilities.

## **THEORETICAL AND CONCEPTUAL CONTEXT**

### **“Framing the tightrope walking picture”**

I identified the problem informally from my experiences in professional educational settings (high school classes), informal surveys of my colleagues, and a semi-structured interview with the high school social worker at my school. These informal interactions confirmed that general education teachers were not feeling prepared to talk about disabilities with their students. The social worker shared experiences of challenges trying to help students access postsecondary resources and that the students didn't know how to advocate for their disability-related needs. In my initial literature review, I found that most studies on disability identity focus on younger children and not adolescents and adults so this study will further the body of work available to understand more about identity and ADHD from a different

perspective (Cabral, Liu, & Soares, 2020, p. 106). The literature review on disability identity completed by Forber-Pratt, Lyew, Mueller, & Samples (2017) did not identify a study that included persons diagnosed with ADHD. There is also a gap in research connecting disability identity and academic outcomes for students particularly with invisible disabilities - notably, ADHD. Therefore, this study is framed by several theories and definitions:

The first theory is the psycho-social development of humans developed by Erik Erikson. “...Erik Erikson (1956) brought identity formation to the forefront of human development by highlighting identity formation as a necessary step in reaching healthy human maturity and potential” (Arnold, 2017, p. 2). The developmental theory claims that developing humans go through a crisis at each stage of development. Each stage brings a dilemma that must be resolved positively so that the human can progress in life successfully. Arnold (2017) explains:

As an infant, we must develop trust in the world around us; as toddlers, we begin to develop autonomy; as young children, we learn to take initiative and begin to exert some control over our lives; and as childhood draws to a close, we develop a sense of industry and accomplishment, often through social and academic success... the primary task of adolescence is the development of identity, the ability to know one’s self, to develop stability in how one sees oneself, and to be true to that self, based on personal agency, which Erikson called fidelity. (p. 3)

Erikson’s theory of human development provides the grounding for understanding the importance of identity development.

The second theory important to this study expands on the understanding of “how” identity is formed. James Marcia’s Identity Status theory, explained by Arnold (2017), provides a model for how identity is formed. Arnold (2017) explains that Marcia “conceptualized identity

formation through the dimensions of exploration and commitment” (p. 5) Exploration is defined as the process of discovering the role one is to play. It is being open to new ideas and values. It is a time to try new things to determine what fits. Commitment is when an individual makes choices and acts upon their understanding of who they are. It is a solidifying of:

...values, expectations, personal parameters, goals, and beliefs, as well as educational and vocational decisions. A key component of healthy identity commitments is that they are made based on one’s self-definition, and driven by emerging self-understanding, not on the expectations, values, or goals of others, such as parents, peers, or social organizations. Differentiating self from others, and acting on self-knowledge is critical to authentic identity formation. (Arnold, 2017, p. 5)

This theory helps frame the conceptualizing of themes and lessons gathered from the disability narratives that will be captured in this research study.

Another theory providing context to this study is the social identity theory developed by psychologist Henri Tajfel (1974). The social identity theory is a framework for understanding how belonging to a group brings a sense of identity, pride, and self-esteem. Though the disability community is multi-faceted, multicultural, intersectional, and sometimes segregated by disability, understanding social identity is key to understanding the relationship between the individuals and the disability groups for which they might claim membership. Tajfel (1974) defines social identity when he states “For our purposes, we shall understand social identity as that part of an individual’s self-concept which derives from his knowledge of his membership of a social group (or groups) together with the emotional significance attached to that membership” (Tajfel, 1974, p. 69). Social identity theory and disability identity both inform the framework from which I approach this research. I seek to know more about the effects of identifying with a

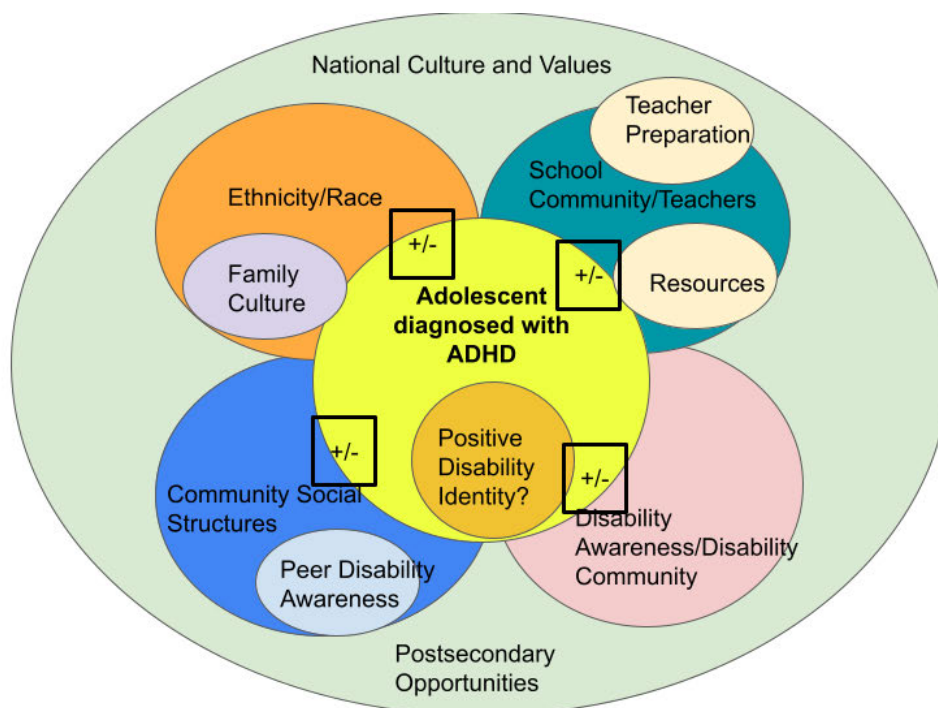
social group (social identity theory) and how that identification (disability identity) affects academic and social outcomes and access to resources.

Finally, the concept of positive disability identity is defined in this study as having a positive self-concept and feeling connected to or an affinity for the disability community (Developing a Positive Disability Identity, n.d.). Disability in this sense is not defined in the medicalized view. Disability is being used as a term that defines how an individual makes sense of what is different or distinct about themselves that does not fit congruently with societal norms and expectations physically, functionally, or mentally. Whatever the “disability,” accepting differences as part of the natural diversity of humanity and as a positive part of one’s self-concept is part of positive disability identity. Connecting with others with similar differences is another level of acceptance and affinity. In a review of the literature, this phenomenon of disability identity was found to be an important factor in developing interventions by persons who can support individuals along their journey (Forber-Pratt et al, 2017, p. 198).

The theories of identity formation, identity status, social identity theory, and disability identity create a conceptual framework for questioning how to support PDI in students. In addition, the context of the student (nationally, racially, ethnically, familially, socio-economically) creates a picture of the complexity of an adolescent student developing their identity in the center. An important context to note for developing identity is the current age of relatively easy access to information and social media. Various disability social groups have formed on social media. This form of community building may inform or influence disability identity as disability communities and other historically oppressed groups have been more visible in the context of social media (Sweet, LeBlanc, Stough, & Sweeney, 2020). Technology and social media are interwoven in all the overlapping contexts of identity development.

**Figure 1**

*Context of Adolescents with Disability*



*Note.* This figure demonstrates the intersecting and overlapping contexts and influences on an adolescent with ADHD. These contexts impact the possibility of a positive disability identity.

Other key concepts that also provide theoretical context are defined:

**Social-Emotional Learning** - Social-Emotional learning describes the development of social and emotional skills that are important factors in being successful academically (Elias, 2004, p. 54)

**Disability resources** - accommodations, modifications, services, and supports available to persons with disabilities to provide equity in education.

**Invisible Disabilities** - Disability not easily or immediately perceived by others.

**ADHD** - medically characterized as a condition with traits of inattention, hyperactivity, and/or impulsivity that impacts individuals' functioning across different environments.

## **PREVIOUS RESEARCH**

### **“What do we already know about walking the tightrope?”**

Previous research highlights the shared experience of adolescent students with disabilities navigating the formation of identity as well as the tightrope act of their educator in respecting students' need to avoid stigma. One of the students with learning disabilities in Peters' (2010) study shared his musings by saying “Let's say what if they found out (I was in special ed)? Would they still be my friends? Would they still go to the park with me? Or would they just blow my cover and tell everyone I was in special ed?” (Peters, 2010, p. 595). Peters goes on to describe how this student and many of his peers developed strategies to hide their “status markers.” Peters also shared how their special education teacher “became an accomplice in managing their secret. She covered the window in her classroom and excused students from class before the scheduled time so that her students would not be seen leaving the 'special ed room” (Peters, 2010, p. 595). While the tightrope walk is still a reality, research has shown that some changes in the perception and acceptance of disability are growing. The disability rights movement in the 70's and 80's shed light on the need to remove the stigma from disability. This led to the development and promotion of disability pride and the increase in recognition of disability in the social model:

The National Organization of Disability/Harris Survey of Americans with Disabilities (National 2000) documents the growth of a sense of common identity among people with disabilities. In 1986, 40% of the people with disabilities in their national sample identified somewhat or strongly with the disabled population, and in 2000, 47 percent

shared a sense of common identity with people with disabilities. As the data suggests, however, more than half of those surveyed did not share this identity. (Darling, 2013, p. 73)

Despite the growth in positive self-identities among individuals with disabilities, the understanding of the social model of disability is not as well-known and adopted by society (Darling, 2013, p. 4). This lack of awareness leaves room for further research on how to promote disability identity. Though there is research on identity and disability, much of the research done has been on individuals with physical and cognitive disabilities. More research is needed to understand the phenomena of the disability identity of persons with invisible disabilities. Pfeifer & Berkman (2018) conclude “Given that developing positive personal and social identities, as well as balancing autonomy and connectedness, are core tasks of adolescence, these self-related and social sources of value are worth prioritizing in investigations and translational efforts” (p. 162). Studying the narratives of adults with ADHD will help educators understand the potential role that they can play in developing PDI through the analysis of themes and trends in the qualitative and quantitative data.

## **RESEARCH PURPOSE AND QUESTIONS**

### **“How can we be better tightrope walkers?”**

Adolescence is a time of self-discovery and the development of one’s identity is key to understanding the purpose and urgency of this research. Through daily interactions, high school educators are positioned so that they can help students be aware of their uniqueness and prepare them for navigating the world. Forber-Pratt et al (2017) explains “A major source for processing one’s disability identity, then comes in interactions with rehabilitation professionals, educators, and caregivers...” (p. 204). This study will help to illuminate the “how” for teachers to address

this phenomenon in adolescents with ADHD. This is why it is important to understand the stories of disability identity development in adults to understand how to better prepare teachers for this challenge.

The following questions will guide this mixed methods study:

1. How do adults with ADHD reflect on and share their experiences and understandings of ADHD?
2. What do adults with ADHD and postsecondary degrees attribute to their development of a disability/ADHD identity and postsecondary academic achievement?
3. How did identity influence how participants accessed disability support and resources? What were those resources? What are those stories?
4. From the perspective of adults with ADHD, what can educators do to support positive disability/ADHD identity?

### **Goal and Methods of the study**

The goal of the study is to gather the stories of adults with ADHD to gain insight into the way they perceive their disability/ADHD and disability identity. The stories will also help to identify the actions of teachers and other adults that impacted their disability identity development. The significance of the goals of this study is not only in the potential for increasing student-initiated access to secondary and postsecondary disability resources but there is potential for increasing students' social-emotional learning (SEL) and social-emotional skills during adolescence through teacher intervention. SEL impacts the ability of a student to successfully transition to adulthood. Studies show that "..., children and youth who do not possess these skills are more likely to be rejected, experience school difficulty, drop out of school, and suffer mental health problems and be under- or unemployed during adulthood" (Elksnin & Elksnin, 2004, p.



6). The goal of school is to prepare for adulthood. If our students do not have appropriate and well-developed social-emotional skills, we have missed the mark. For students with disabilities, a personal understanding of their identity as a diverse learner and its relation to their world is an important SEL skill needed for adolescents that teachers can better support by understanding the development of PDI.

The methods for data collection for this mixed-methods study is to conduct semi-structured interviews of adults with ADHD, host a focus group, and collect survey data from social media communities to gather stories that will expose the role of adults in the development of their sense of identity related to ADHD. Identity is the narrative one tells themselves about who they are. A narrative design for this study will capture stories so we can learn more about the phenomena of identity development.

## **REFLECTIVE RESEARCHER**

### **“A Tightrope Walker”**

Every day I work with teenagers who are in the midst of the adolescent stage of development. It is the stage where teenagers are trying to establish their identity, grapple with peer pressure, and navigate their understanding of their strengths and weaknesses. From the choices of clothing that they wear, the activities they choose, and the increased value of maintaining high status with peers. Adolescent life is complicated. As an educator, I strive to be very sensitive to my students with disabilities and the possibility of stigmatizing them at this sensitive time in life. It can feel like a tightrope walk trying to balance giving students what they need and deserve in the general education setting while also respecting the student’s desire to not appear different from their peers. Like my students, I can identify with trying to navigate a world not set up to celebrate your difference. Part of identity is personality and the personality I most

closely relate to is being an introvert. An introvert is naturally more reflective and introspective versus gregarious and social with large groups. In a world where extroversion and social navigation are valued and celebrated, it is my challenge to decide how much I want to conform to extroverted norms and expectations to avoid stigma. I have grown to appreciate the strengths of being an introvert and the path that it takes me but it is with this understanding and acceptance of my difference that I approach my diverse learners with compassion. This compassion led to my wonderings about how best to support my students.

Aside from being an introvert, I also identify as a black woman, daughter, sister, wife, and mother of two children, one of which is diagnosed with ADHD. I identify with many stigmatized identities and my child's diagnosis positions me close to, but not a part of, the invisible disability community. My identity as a mother, black woman, and educator have the greatest influence on how I perceive having a positive disability can be beneficial despite living in a society full of stigma. My identities motivate me to want to know more.

## **CONCLUSION**

This chapter defined the phenomena of disability identity and the problem of the lack of understanding of how adults can support the development of PDI in adolescents. I also explained the connected theoretical concepts that frame this research study, provided key vocabulary, an overview of my research questions, goals, and proposed methods, and explained my positionality to the research. The stage is set and now it is time for the exposition of our research story as Faith's story continues in her English class.

## CH. 2

### “The Exposition”

#### LITERATURE REVIEW

*Faith sat in the back of the classroom rhythmically jostling her leg while looking at the back of her classmate’s heads wondering if they too were as nervous as she was as the teacher explained the upcoming group project. Faith shifted in her seat because she felt she wasn’t the best student. She knew she had a learning disability and ADHD and group work was always an opportunity where her secret could be exposed. Despite the positive vibes she felt from her peers during Disability Awareness Week, Faith didn’t feel like it would matter when it counted. What if she misread or missed a detail in the directions? What if they thought she was lazy? Would she be holding her group back? “Faith? Time to get into your group” Mrs. Smith calls. Thoughts interrupted, Faith takes a deep breath, lifts her cheeks into a half smile, and turns to face her peers.*

Faith’s trepidation is the effect of grappling with the reality of disability identity versus the need for peer acceptance. Faith is actively undercover or “passing” which can be mentally exhausting. She is not confident that the effects of the stigmas surrounding disability were mitigated by the efforts of the adults in her school life (Disability Awareness week). What more can be done to help Faith? What should her teacher do? To learn more, the following literature review will explore the topics of identity, stigma, disability identity, ADHD, postsecondary achievement, and social-emotional learning. The search was performed using Library One Search which included databases such as EBSCO, ERIC, and PsychINFO. Searches and articles were also gathered from Google Scholar. Search terms included “identity,” “adolescence,” “stigma,” “disability,” “disability identity,” “ADHD,” “Postsecondary success,” “Postsecondary

achievement,” and “Social-emotional learning.” The results were restricted to peer-reviewed articles, books, book chapters, and nonacademic articles written in English articles. The review of the literature will provide context for my research and highlight the gaps that the research aims to fill.

## **Identity**

French philosopher, Rene Descartes, famously said “I think, therefore I am.” Identity is a complex idea that is not defined by any one aspect of one’s perception of themselves, outward appearance, or character. Identity is defined by the Merriam Webster Online dictionary as “the distinguishing character or personality of an individual,” “the condition of being the same with something described or asserted,” and “sameness of essential or generic character in different instances” (Identity Definition & Meaning - Merriam-Webster, n.d). Identifying the sameness and distinguishing characteristics as they relate to others is the process of forming an identity. There are multiple human characteristics to consider, so identity is multifaceted and different identities intersect. McLean & Syed (2015) describe identity as:

...the anchoring concept for thinking about difference and sameness in our time. It is not a concept confined to the jargon of social sciences or the humanities; it permeates our everyday conversations, our moment-to-moment cognitive processes of sense-making in a world increasingly characterized by human diversity. (p. 11)

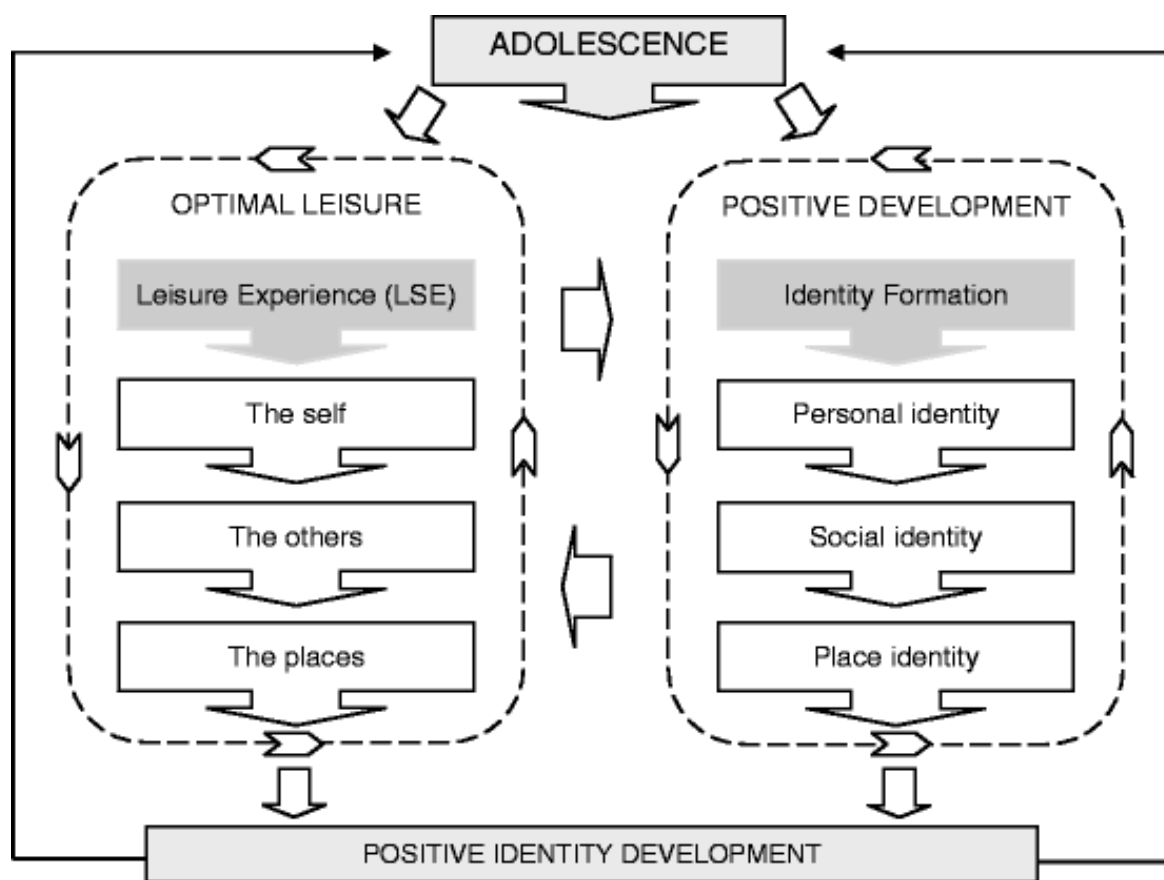
Identity is how one starts to categorize themselves in relationship to others similar or different to themselves.

Adolescence is a time of self-discovery and the development of one’s identity. It is “... a time of identity flux” (Altschul, Oyserman, & Bybee, 2006, p.1163). Erik Erikson is considered an “identity architect” who viewed the process of identity development as part of human

development across a lifetime but most prominently formed during adolescence where adolescents are more concerned with their social roles and how they connect their roles and skills to the “ideal” (McLean & Syed, 2015, p. 17). Although it is recognized that adolescence is an important stage of identity development, the literature is “relatively uninformative about the micro-processes by which identity is obstructed in that age period and does not capture the way in which people construct a sense of themselves as continuous across time” (Pasupathi & Hoyt, 2009, p. 559). In other words, the current research leaves opportunities for more understanding of the phenomena of identity development over time.

**Figure 2**

*Positive Identity Development*



(Freire, 2013)

The value of developing an understanding of identity, particularly a positive one, is seen in the studies of racial identity and academic achievement by Altschul, Oyserman, & Bybee (2006). They hypothesized that adolescent students with high racial-ethnic identity (REI) would find more success academically. Their study confirmed that there is a relationship between Latin and African American students with high REI particularly in the areas of awareness of racism, being connected with the community, positive views of achievement for their racial group, and attaining better grades (p. 1165). In the literature review and study, positively connecting with aspects of one's identity garners positive academic benefits. Race is just one of the various personal and social identities that youth grapple with but it can be theorized that positive connections to other aspects of identity, such as disability, could garner similar benefits.

### **Stigma**

Stigma is when a stereotype negatively impacts the thoughts and actions toward a person, place, or thing. Stigma interprets different aspects of human practices and appearances as not quite human. Often stigma is connected to visible and non-visible disabilities, physical abnormalities, unusual body shape or makes, interactional quirks, mental illness, and depending on the context, gender, sexuality, race, and class (Titchkosky, 2006, p. 151-152). Stereotypes, and therefore stigmas, develop from public images, experiences, and the hegemonic narrative of society on what is and is not the "norm" and highlight or exaggerate characteristics that do not fit the norm. Stereotypes of persons with disabilities in media have created stigmas that "... have been so internalized by an oppressive society and in particular by the medical profession (which objectifies our bodies through the gaze of deficits and deviance) to the extent that our self-perceptions become our psychological monsters" (Peters, 2010, p. 584). This is the reality of stigma that many adolescents avoid by not revealing their differences. Instead of difference,

stigma creates an idea of deviance. Goffman argued that an individual with a stigmatized identity engages in identity management during social interaction. Identity management is the attempt to control the impressions of others by controlling what aspects of identity are revealed (McLean & Syed, 2015, p. 14). This is the same concept as passing or covering. "Passing and covering involves a process of information control. In passing, the individual attempts to prevent others from becoming aware of a potentially stigmatizing attribute" (Darling, 2013, p. 17). This identity management, passing, or covering is the rejection of stigma related to identity. Managing your identity (masking) has been shown to pose mental health impact (Shmulsky et al., 2021, p.54). However, studies show that identifying with other members of a stigmatized group rather than a majority culture rejects stigma and increases self-esteem (Bogart, Lund, & Rottenstien, 2018, p. 155). Identifying with members of a stigmatized group is a disability identity.

### **Disability Identity**

Of the many characteristics and qualities that amalgamate identity, disability identity specifically recognizes self-awareness of the characteristics that are related to disability. Disability identity is a self-concept that includes a cognitive recognition of disability "I am a person with a disability" and an evaluation of that recognition "I am proud to be a person with a disability" (Darling & Heckert, 2010, p. 132). In a study completed on disability development in college students, a student identified with a positive disability identity said, "I'm not broken and I don't need to be fixed or cured. If I were to become NT [neuro-typical], I would not be me anymore and a lot of my good qualities would disappear" (Shmulsky et. al, 2021, p. 55). Developing self-concept and self-awareness is key to understanding identity and how it relates to disability. Self-awareness about one's identity (defined internally or externally) is essential to understanding oneself. Disability identity can be described 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). Defining disability identity goes beyond how an individual feels about themselves but also moves to an individual making connections to the disability community.

Noted in a comprehensive literature review of disability, including Dunn and Burcaw’s scholarly writing, Forber-Pratt, Merrin, Mueller, Price, & Kettrey (2020) created the Disability Identity Development Scale to capture a collective understanding of disability identity. In creating the scale, the team categorized disability into four areas: 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 (p. 6).

Internal beliefs about one’s disability and the disability community are the development of a personal meaning of disability. Acceptance of one’s self and situation can solidify the personal meaning of disability “while promoting a favorable disability identity” (Developing a Positive Disability Identity, n.d). Internal beliefs are foundational to one’s disability identity.

Acceptance of oneself concerning disability can also lead to shared anger and frustration with disability experiences caused internally, socially, educationally, or politically. All shared experiences connect people and disability experiences do the same. Self-concepts come from interactions with society and disability identity (positive or negative) comes from one’s processing of how they are perceived, received, and treated (Darling, 2013, p. 6). According to de Beer et al (2022) invisible disabilities are often considered more questionable and therefore misunderstood, misperceived and stigmatized. Students with invisible disabilities have a significant drop out rate in post-secondary institutions (p. 2). The dropout rate is evidence of the negative experiences shared by persons with invisible disabilities. Research shows that “these experiences may negatively affect individuals’ identity and self-esteem (Invisible Disabilities in



Education and Employment, 2023, p. 14). Sharing the positive and negative experiences of disability connects individuals to a shared culture and promotes self-understanding (Titchkosky, 2006, p. 42). Anger and frustration with the disability experience continue to solidify disability identity.

Adoption of any disability community values is evidence of fully adopting a disability identity. Common lived experiences can create cultural understandings, an individual's understanding of their disability, understanding of societal expectations and their impacts and intentions (Titchkosky, 2006, p. 39). Whether or not explicitly named, disability communities and their values are based on shared experiences. The disability community or cultural group is a social and cultural construction shaped by the experience of living with a physical or mental impairment (Putnam, 2005, p. 189).

Adopting community values based on shared experiences can lead to community pride. This pride is “feeling empowered to claim rather than deny or mask one’s disability” (Developing a Positive Disability Identity, n.d). Pride can lead to contributions to the disability community - politically, socially, educationally, etc.

Some persons with a diagnosis that would be medically or educationally considered a disability do not self-identify with a disability but Putnam’s qualitative study showed that a positive self-identity still occurs without an identity based on disability status (Putnam, 2005, p. 189). In other words, whether or not the word “disability” is accepted, claiming to be a part of a community of persons who have the same diagnosis (Blind, Deaf, Autistic, ADHD, etc) is still inclusive of having a disability identity.

Whether or not to accept and/or express a disability identity is not supported by all scholars or disability communities. Ahktar discusses disability in terms of embedded and

non-embedded disability and makes a distinction by considering one's attitude toward their disability based on their disability; understanding how one's disability interacts with the many other traits they simultaneously have; and how disability is embodied in individuals (2016, p.368). Responses to these considerations determine how/if disability identity is expressed. Ahktar explains, "...it may emerge most clearly with disability since disabilities are embodied identities, and the way in which they're embodied can vary greatly across individuals, largely because of differences in a disability's causes, degree, and nature" (2016, p. 369). The individualized experience of disability means that for some persons with disabilities, disability is an embedded disability that is subjectively valuable and essential to their personhood.

The individualized experience also means that disability identity is influenced by the associated disability community and the disability experience of the person. Ahktar gives the example of the deaf community vs. persons with cancer:

For instance, the organization and cohesion of the deaf community (sometimes called the 'deaf culture') suggests that many deaf or partially deaf people consider deafness a significant element of their sense of self (even if they don't regard deafness as a disability). In contrast, the same cannot be said of most illnesses. Consider cancer. Those who have cancer typically diminish the importance it has in defining their lives and sense of self, and we don't see the emergence of 'cancer cultures' in anything like the sense we see with certain disabilities. If anything, we've seen the emergence of 'cancer-survivor cultures', indicating that those with cancer view it as an alien intrusion on themselves and as therefore something to overcome. (2016, p. 366-367)

Invisible disabilities like learning disabilities and ADHD have supportive communities supported by associations like Children and Adults with Attention-Deficit/Hyperactivity

Disorder (CHADD) and Attention Deficit Disorder Association (ADDA), social media sites like Facebook groups, and resource websites like understood.org. However, as Dunn and Burcaw explained, individuals with invisible disabilities who can “pass” (not easily perceived as having a disability) may not identify with a disability community.

Research currently shows that many adolescents and young adults are reluctant to self-identify as having a disability. Raver, Murchake, and Chalk (2018) explain:

Research on young adults with disabilities has suggested that many do not self-identify as a person with a disability. Despite using recruitment materials mentioning disability, Nario-Redmond, Noel, and Fern (2013) found that 7 to 18% of their samples identified as “nondisabled or able-bodied.” Researchers using recruitment methods with no mention of disability found that 73% of emerging adults with a disability did not self-identify as ‘disabled.’ (Raver, Murchake, & Chalk, 2018, p. 157-158)

Aligned with that type of thinking is sociologist Erving Goffman who in 1963 believed in spoiled identity for individuals with disabilities and that individuals with disabilities should learn to minimize their differences to be able to be accepted into society (Darling, 2013, p. 2).

However, research now shows that a positive disability identification predicts a positive sense of belonging. Raver, Murchake, & Chalk (2018) go on to say, “Our findings extend the literature by demonstrating that developing a positive disability identity, a favorable view of oneself as a person with a disability, is related to one’s sense of belonging in emerging adults with disabilities” (Raver, Murchake, Chalk, 2018, p. 163). With acceptance comes positive opportunities for self-help and advocacy, necessary characteristics for adulthood. This research study affirms the need for persons with disabilities to have a positive self-identity.

The significance of having a positive disability identity (or not) is the gain or loss of physical and psychological benefits that could be afforded to those who adopt a positive view of their disability. Studies find that there are physical and psychological health benefits that lead to strong self-worth and the ability to face ableism which is needed to achieve personal goals like postsecondary education (Forber-Pratt et al, 2020, p. 3). Without the acceptance of self-defining characteristics, like disability, achieving goals like postsecondary success can be more of a challenge. “A well-developed identity allows individuals to have a better understanding of their strengths, weaknesses, and unique attributes (Marcia, 1966, p. 551). It is with this understanding of the benefits of disability identity that research on adult narratives can be used to further explore how having a disability identity develops and explore the impact of adults on that development.

### **ADHD - an invisible disability**

In 2019, the Centers for Disease Control and Prevention (CDC) estimated “ 6.1 million American children (9.4%) between the ages of 2–17 years had ever been diagnosed with ADHD, with approximately half belonging to ages 12–17 years” (Cabral, Liu, & Soares, 2020, p. 106). This is an increase from the CDC data just 5 years prior where there were 7.2% diagnoses in children. ADHD has not only grown in the prevalence of diagnosis but has evolved in definition and diagnosis criteria which contribute to the changes in numbers. ADHD was first described in a 1775 publication named *Mangel der Aufmerksamkeit/Attentio Volubilis* written by the German physician Melchior Adam Weikard (Morris-Rosendahl & Crocq, 2020, p. 67). His idea of attention deficit was connected to sensory stimuli capturing an individual’s attention and distracting them from their thoughts, most often occurring with hearing and sight. “Volubilis,” one of the terms he used to describe this phenomenon, means “easily rotating” which is to

illustrate the movement of attention (Morris-Rosendahl & Crocq, 2020, p. 67). Though not named ADHD, inattention was recognized in the publication as having an impact on functioning at an early age. Changes in diagnostic criteria and understanding of inattention's impact on daily functioning have increased the prevalence of an ADHD diagnosis. One change included an increase in the criteria for the age of onset from 7 to 12 years. This change recognized that though a neurodevelopmental disorder, how it presents in early ages may impact the ability to make a clear diagnosis. Currently, "Inattentiveness, hyperactivity, and impulsiveness are core symptoms of attention deficit hyperactivity disorder (ADHD), a neurodevelopmental disorder" (Lohre, 2020, p. 1). ADHD is diagnosed when an individual has 5 or more symptoms in the attention or inattention domains, symptoms present in more than 1 setting, and symptoms that clearly impact functioning (Cabral, Liu, & Soares, 2020, p. 105). Symptoms are described as mild, moderate, or severe based on the functional impact. The presentation of ADHD is further described as predominantly hyperactive, predominantly inattentive, or combined. Nothing in the Diagnostic Statistical Manual for Mental Disorders, 5th edition (DSM-5) diagnostic criteria includes anything of the traits and symptomatology of ADHD that can be easily seen when looking at a picture of a person with this diagnosis. This is why ADHD is considered one of the invisible disabilities, if it is defined socially and individually as a disability at all. Some call ADHD a learning or functional "difference," "neurodiversity," or a "superpower." While this study refers to ADHD as a disability due to medical and educational context and classifications, negative connotations are not intended with the term "disability." It is important that this is clarified because, unfortunately, neurodiversity and ADHD have been associated with a lot of stigma. It is "... associated with high levels of stigma, which may lead to treatment barriers, self-fulfilling prophecies, and social rejection" (Bell, Long, Garvan, Bussing, 2011, p. 184).

Stigma can lead to individuals not seeking help as needed. This is a barrier to health and success. Because of the academic, social, and medical impacts of this invisible disability, understanding the positioning of a teacher to be an influential adult in developing positive disability identity in a student's life should be explored.

### **Postsecondary Achievement**

Postsecondary success is measured by achieving academic attainment (training, 2yr or 4 year college) and/or economic stability (career). For this study, I focused on academic attainment. In K-12 schools, students are identified with a disability through the school processes of individualized evaluations when referrals are made. When matriculating to a postsecondary institution, students now have to self-identify as a person with a disability in order to receive accommodations and support. According to national statistics, less than a third of students who were identified with a disability in K-12 self-identified as having a disability in postsecondary education (Students with Disabilities at Maryland Colleges and University, 2022, p. 2). The decrease in self-disclosure could be theorized as attributed to a student's lack of education about their own disability, rejection of their disability, or lack of advocacy skills. Whatever the cause, lack of access to accommodations and support is concerning, particularly related to students with disabilities achieving postsecondary success.

The goal of all students attending postsecondary institutions is to graduate. Students with disabilities have the same goal but are not meeting that goal at the same rate as their non-disabled peers. According to the National Center for Education Statistics, 64% of students who started their bachelor degree in 2014 completed it in 6 years (Irwin et al, 2022, p. 27). Connor explains that:

...30% of students with attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD) enroll in 2-year college programs, and 6% attend 4-year institutions (Wagner et al., 2005). However, the transition to a postsecondary education environment can make students with LD and/or ADD/ADHD feel anxious and overwhelmed (Cohen, 2004; Cohn, 1998; Lee & Jackson, 1992; Sandier, 2008). Only 28% of these students manage to graduate, which is approximately half of the graduation rate for students without disabilities. (Connor, 2012, p. 16).

More currently, according to the Postsecondary National Policy Institute, “Among the 38 million people who are 25 or older and report having a disability, 6.7 million (18%) held a bachelor’s degree or higher in 2019, up from 13% in 2010. However, this is considerably lower than the 36% of the population who do not report a disability in 2019” (Students with Disabilities in Higher Education, 2022). With such a low graduation rate (lack of postsecondary success) many factors can be linked to the influence of disability on persistence, self-advocacy, and classroom functioning on a college campus. Many college campuses offer some disability support for students. Students with invisible disabilities may not access the same level of support as their peers with visible disabilities for a variety of reasons. Many college support services are created to support physical and sensory disabilities (de Beer et al, 2022, p. 7). It is important that “flexible and visible avenues of support and accommodation are normalized so that students are aware of their availability (de Beer et al, 2022, p. 2). With the unique challenges of having an invisible disability in mind, students should be better prepared for navigating disability in their post-secondary experience while in high school. During a table talk, Professor Torres explains how she opens a space in her classroom for students to share about their disabilities and she said,

A lot of them were grateful and appreciative. And they felt pride, I think for the first time a lot of them were willing to go out on campus and start mobilizing around disability identity that they always had but that was so stigmatized and not talked about, that they really didn't come to an understanding of it until college... I want them to be strong and happy and comfortable with their identities earlier.

(Li, et. al, 2021, p.368)

The American Institutes for Research completed research for the College and Career Readiness and Success Center. They identified “High School Correlates of Secondary and Postsecondary Success” and one of the potential factors includes participation in SEL intervention (Hein, Sambolt, & Smerdon, 2013). SEL intervention is where disability identity and other noncognitive skills would be supported.

### **Disability Identity's impact on Postsecondary Achievement**

Social Emotional Learning (SEL) can lead to the development of identity and a sense of belonging. SEL is described as gaining and using cognitive, affective, and behavioral skills that undergird learning, relationships, and physical and psychological health (Everleigh et al, 2022, p. 28). This is relevant to the ongoing discussion of postsecondary outcomes for students with disabilities. Elias considers “SEL, as the missing piece, helps bridge a gap in theory and practice with regard to improving outcomes for students with learning disabilities” (Elias, 2004, p. 56). The postsecondary outcomes are impacted by students' ability to connect with peers and navigate the development of their identity. This is particularly difficult for students with learning disabilities. Elias found that students with learning disabilities have had more difficulty with these skills which impact peer relationships (2004, p. 53). Elksnin & Elksnin agree and purport “The body of research that followed supported Bryan's conclusions that youth with LD are less



well accepted by peers” (Elksnin & Elksnin, 2004, p. 3). The education field’s interest in social-emotional learning is growing because research has shown positive impacts on postsecondary success academically, socially, and emotionally (Elksnin & Elksnin, 2004, p. 6). On the contrary, the effects of not meeting social-emotional and academic needs will translate to negative postsecondary outcomes for students. Because of the noted difficulty of students with learning difficulties with social-emotional skills, actively working to further development of these skills is warranted. I find that working in the school setting I can see how social-emotional skills are overlooked because the primary focus is academics and learning that can be readily quantified. Behaviors that students may exhibit are more attributed to task avoidance, attention-seeking, etc. versus the possibility that there are social skill deficits that need to be addressed. I’ve seen students with learning disabilities and ADHD that are just deemed “annoying” by peers and sometimes teachers but research is showing that these behaviors can be reflective of social skill deficits. Further supporting the need for social-emotional learning with students with learning disabilities, Bryan, Burstein, & Ergul conclude that “Children's "reading" of their social environment may be the dominant factor that shapes their selection of responses.” (Bryan, Burstein, & Ergul, 2004, p. 47). How a student perceives or “reads” their role in the ecology of their classroom will shape their response in that community. Students with learning disabilities can benefit from improved social-emotional skills which impact how they respond in their school community and postsecondary outcomes. The gap in outcomes exists between students with disabilities and their general education peers. Bryan, Burstein, & Ergul (2004) makes a solid case for increased SEL for students with disabilities to help bridge the gap.

### **Social-Emotional Learning**

Positive self-identity can be developed through social-emotional learning (SEL) in school. The significance of developing social-emotional skills through SEL is that it impacts the ability of a student to successfully transition to adulthood. Studies show that “..., children and youth who do not possess these skills are more likely to be rejected, experience school difficulty, drop out of school, and suffer mental health problems and be under- or unemployed during adulthood” (Elksnin & Elksnin, 2004, p. 6). If our students do not have appropriate and well-developed social-emotional skills to accompany academic skills, we have not accomplished our goals as high school educators. For students with disabilities, a personal understanding of their identity as a diverse learner and their disability’s relationship to their world is an important but sometimes poorly supported SEL need for adolescents. Unfortunately, research currently shows that many adolescents and young adults are reluctant to self-identify as having a disability. Positive disability identification predicts a positive sense of belonging. Raver, Murchake, and Chalk (2018) explain, “Our findings extend the literature by demonstrating that developing a positive disability identity, a favorable view of oneself as a person with a disability, is related to one’s sense of belonging in emerging adults with disabilities” (p. 163). Because this positive self-identity begins to develop in the adolescent years of middle and high school, Teachers who can support PDI by incorporating SEL into their classroom can help to develop this positive self-identity. Building community and social-emotional skills can also take place through Disability Awareness Programs (DAP) or other disability-affirming programs. These programs might be interventions to help to build a positive disability identity. However, more research is needed to understand the micro-processes and interactions needed to support disability identity in adolescence.

## **CONCLUSION**

This chapter was an exposition of the literature and ideas of identity, stigma, disability identity, ADHD, postsecondary achievement, and social-emotional learning. These ideas frame Faith and any adolescent's disability identity journey. The literature has shown the need for more understanding of what role adults can play in supporting students like Faith on their journey. My research questions and literature review lead me to action through narrative inquiry.

### CH. 3

#### “Rising to Action”

#### METHODOLOGY

*Faith sat in the comfy chair and leaned forward listening intently to her counselor, Mr. Herring, explain more about ADHD and learning disabilities to Faith. During their weekly meeting, Faith shared about her anxious feelings in her classes and Mr. Herring knew that she needed to understand more about herself and her disability. “ADHD creates a different way of thinking, not better or worse, just different...” he explained as he talked about how thinking about our differences is how we start to form our beliefs about ourselves and others. Faith let this information wash through her and over her. It was comforting and yet renewed questions she had about what all this would mean for her each day. She was still so unsure of how much ADHD was a part of who she was. She needed to know more.*

#### **Next steps: Qualitative-Quantitative Research**

The pursuit of knowing more is where research rises to action. Research starts with epistemology, the theories behind different ways of “knowing” (Steup and Ram, 2020). Research is a pursuit of knowledge and when a researcher wants to know more, explore, describe, or explain phenomena, particularly human phenomena that cannot be quantified, a researcher should use a qualitative research method. Qualitative research is described as a way to induce meaning from social phenomena or build a deeper understanding of social life (Leavy, 2017, p. 9). Qualitative research design is a process that acknowledges the complexity of life as needing an approach that is dynamic and recursively builds upon itself.

Characteristics of qualitative research include exploring a problem as well as:

collecting data that is based on words (e.g., from an interview) or images from a small number of individuals so that the participant's views are obtained; analyzing the data from description and themes using text analysis and interpreting the larger meaning of the interpretations; writing the report using flexible, emerging structures and evaluative criteria and including the researchers' subjective reflexivity and bias. (Creswell & Guetterman, 2019, p. 16)

These characteristics center the researcher as an instrument of research. The researcher is the one conducting the interview, developing descriptions and themes, and interpreting meaning while acknowledging the inherent subjectivity throughout the process. The researcher, as an instrument of research, is one of the key components of qualitative research. The components also include fieldwork and naturalistic engagement (being present with people to gather information); contextualizing lived experiences; paying attention to the impact or influence of the research process; maintaining fidelity to participants (Ravitch & Carl, 2021, p.9).

Quantitative research designs include experimental studies and pretest-posttest designs where there are controls and variables with the goal of generalizability from the sample population (Newman & Benz, 1998, p. 10). The researcher is positioned as being as objective as possible using standardized definitions and operations to discover knowledge about a phenomenon.

Quantitative research is not necessarily an opposite approach to qualitative research but can be viewed as complementary or used for a different purpose. Quantitative research "is used when one begins with a theory (or hypothesis) and tests for confirmation or disconfirmation of that hypothesis" (Newman & Benz, 1998, p. 3). Using both approaches reflects the multiple

ways a researcher can view the world and acquire knowledge. Using both research approaches is considered a mixed-methods research design.

### **Why use Mixed-Methods Research Design for this study?**

Choosing the research design of a study should align with the goals and purpose of the study. The purpose of my study is to understand the multi-faceted phenomenon of disability identity development. Both qualitative and quantitative designs inform my research on the development of disability identity from different points of reference. The identity development phenomenon is complex and mixed-methods research design seeks to understand the complexity. My goal was to provide insight into the development of disability identity from the perspective of the participants and use both methods to allow for recursive cycles that will deepen the interpretation of themes and meanings. Recursive cycles included returning to the data, theories, and previous research for additional analysis and discovery as I seek to answer my research questions. Qualitative research is flexible enough to allow the researcher to illuminate the participant's story and express their journey which is integral to a study about personal identity. The quantitative aspect of this research was the survey given to be able to gather standardized data from, not only my interview participants but also a larger group of persons in the disability community. This quantitative data provided an additional perspective and framing for the narratives that were shared through qualitative data.

### **Research Methodology - Narrative Inquiry**

Research methodology is “how” the theory, questions, and goals of the study will be accomplished within the chosen research design. The research methodology I chose to use is a narrative inquiry. Narrative inquiry is a method of studying human lives by valuing individuals' lived experiences as a source of important knowledge and understanding (Clandinin, 2013, p.

17). This methodology is most appropriate for my study because narrative inquiry “...allows for a rich description of these experiences and an exploration of the meanings that the participants derive from their experiences” (Chunfeng Wang & Geale, 2015, p. 195). This design and methodology are integral to my research questions and conceptual framework because I want to discover and learn from the stories of disability identity through the descriptions of the experiences of my participants. Stories are integral to identity. Our identity is built on the stories that we tell ourselves about who we are. It is “... the ancient yet timeless ways in which we humans have and continue to draw on stories as a way to share and to understand, who we are, who we have been, and who we are becoming” (Huber, Caine, Huber, & Steeves, 2013, p. 213-214). Narrative inquiry is seeking stories and inquiring about experiences (Clandinin, 2013, p. 13). It is both the content and structure of the story that will provide insights into individual experiences. By seeking the stories of persons who are living the experience of ADHD and grappling with that identity, I will be able to understand more about the contextual impacts and concepts impacting positive disability identity. Memories are the stories that will primarily inform the study. As an adult storyteller “... self-defining memories should be prime candidates for reflection because such memories theoretically lie at the heart of the self-concept, and are important for constructing identity to oneself and others” (Thorne, McLean & Lawrence. 2004, p. 515). By surveying and interviewing adults with ADHD, I will see the uniqueness and similarities in their memories and stories.

My approach with participants was to take the position of learner and be a collaborative partner in creating a narrative. I engaged participants by asking open questions that led to narratives that exposed themes that resulted in recommendations that can inform teacher preparation. Through this process, I challenged myself to examine the influence of my position

as an educator and mother of a child with ADHD on my identification of themes and implications. A constructivist approach to the narrative inquiry helped to shape my interpretations by using multiple perspectives and beliefs to provide a multifaceted analysis.

### **Research Questions**

Research questions and goals are a key part of a research design. They should guide the methods, data collection, analysis, and implications of the research. For this study, a key understanding to the urgency of this study is that adolescence is a time of self-discovery and the development of one's identity. Marcia (1980) explains that the more developed the structures of identity, the stronger sense a person has of their relationships with others and their unique abilities and weaknesses as they navigate the world (Marcia, 1980, p. 159). Through daily interactions, educators are positioned so that they can help students be aware of their uniqueness and prepare them for navigating the world. This is why it is important to understand the stories of disability identity development to understand how to better prepare teachers for this challenge.

My research questions are:

1. How do adults with ADHD reflect on and share their experiences and understandings of ADHD?
2. What do adults with ADHD and postsecondary degrees attribute to their development of disability identity and postsecondary achievement?
3. How did identity influence how participants accessed support and resources in secondary and postsecondary education? What were those resources? What are those stories?
4. From the perspective of adults with ADHD, what can educators do to support positive disability identity?

### **Goal Of The Study**



The goal of the study is to gather the stories of adults with ADHD to gain insight into the way they perceive their ADHD and ADHD identity and also to identify the actions of teachers and other adults in the lives of adults with ADHD that impacted their disability identity development. The significance of the goal is not only to identify how educators and other supportive adults can increase student-initiated access to secondary and postsecondary disability resources. There is potential for teachers to learn to support an increase in students' social-emotional skills which will bolster student success in secondary and postsecondary institutions. SEL impacts the ability of a student to successfully transition to adulthood. Studies show that "..., children and youth who do not possess these skills are more likely to be rejected, experience school difficulty, drop out of school, and suffer mental health problems and be under- or unemployed during adulthood" (Elksnin & Elksnin, 2004, p. 6). The goal of school is to prepare for adulthood. If our students do not have appropriate and well-developed social-emotional skills, we have missed the mark. For students with disabilities, a personal understanding of their identity as a diverse learner and its relation to their world is an important and poorly supported SEL need for adolescents. The goal is for teachers to understand disability identity development so they can better support social-emotional skills such as self-awareness, self-advocacy, and self-confidence.

### **The Significance Of The Study**

The significance of the study lies in the potential for educators to activate the psychological benefits of a well-developed concept of identity. Students with a well-developed sense of self have increased confidence, and self-esteem and are better equipped to advocate for themselves. Equipping educators to support positive disability identity will help students be

resilient in the face of stigma and more willing to access needed postsecondary disability-related resources.

### **Data Sources**

My data was gathered through a survey, focus group, and interviews. A survey is a set of questions sent to participants that provide a general idea of the beliefs/ideas/experience of a target group. I distributed a survey to members of the ADHD educator community which allowed me to gather various standardized responses to views related to my research questions. My survey was sent electronically to educators with ADHD via social media groups (ADHD adult groups on Facebook, Reddit, Instagram, and Twitter). I reached out to a couple of Instagram influencers with over 1, 000 followers who circulated the survey as well. Outside of social media, the survey was also sent to the American Education Research Association (AERA) special interest group (sig) for disability studies and ADD.org. Some snowballing occurred as some educators were solicited through participants forwarding the survey to others who fit the participant criteria. The survey asked quantifiable questions about the diagnosis of ADHD, access to disability/ADHD-related resources, and the impact of adults in developing positive ideas about ADHD. The questions were closed questions to gather ratings of experiences and understanding of ADHD identity development. At the end of the anonymous survey was a question to recruit participants for an interview or a focus group where participants could share stories to illustrate their experiences and reflections. All participants were informed of the measures taken to maintain their privacy and anonymity (the survey was anonymous and pseudonyms were used in the focus group data).

My second data source was a focus group of volunteers. These volunteers completed the survey and indicated a willingness to also participate in a focus group. A focus group is a data

collection tool that allows the researcher to facilitate a semi-structured discussion and time of sharing with participants in a study. The focus group was one of my opportunities to gather the stories that would be analyzed for answers to my research questions. Volunteers met with me virtually and answered open-ended questions that also allowed other participants to affirm and contrast their stories about the research topic.

Finally, a semi-structured interview is data collected by the researcher posing predetermined questions that leave room for open-ended responses and follow-up questions based on the participant's response. The semi-structured interviews allowed me to probe for depth and context within the interviews even while providing some structure to make sure to answer my research questions. I used a digital recorder (phone, Google Meets recording) and a transcription service (Otter.ai) to capture the data.

### **Participant Selection**

My participants were a geographically diverse group of educators with a minimum completion of a bachelor's degree and also diagnosed with ADHD.

#### **Rationale:**

**Educator/Adult** - An educator has the unique perspective of not only being a past high school student but also being a current person of influence in a school setting. Adult participants can be reflective of their adolescent and postsecondary experiences.

**Minimum Education** - The focus of the study is to identify the influences that lead to postsecondary achievement. In this specific case, success is defined as the completion of a bachelor's degree which is required for teacher certification.

**ADHD** - The focus population of the study is persons who have been diagnosed

with ADHD. Connecting to a community where receiving a medical diagnosis or self-identifying as an adult with ADHD is required would logically mean that the participant has accepted the diagnosis and has had at least one conversation as to what ADHD is.

**Race and Gender** - I wanted diverse perspectives because I understand that culture will impact participants' perspectives and experiences. The diversity of respondents relied heavily on the diversity represented on social media platforms. These platforms determined the demographics of my participants despite the goal being for a variety of races and genders to be represented.

**Locality (region of the US or World)** - Social media allows the opportunity to engage participants from anywhere in the world. Where my participants live could impact their perspectives on my research questions. My analysis and conclusions include this perspective on the data. Ultimately the voluntary respondents influenced the actual diversity of participants.

### **Context of Participants and Research**

There was not a central site for my participant selection, but there is a similar context that impacts the participants:

#### **1. IDEA**

In 1975 the Education for All Handicapped Children Act was put into place in the United States. It was reauthorized in 2004 and is known as the Individuals with Disabilities Education Act. This law allowed more children with disabilities to be educated in public school settings. The law provided rights and responsibilities for the public education to be “appropriate” for individual students. My American

participants experienced public education after this law was enacted and may have benefited from its provisions of rights for students with disabilities so it is part of the larger cultural context for these interviews.

## 2. ADHD in the DSM

ADHD is defined medically as a neurodevelopmental disorder. It appeared in the 1968 Diagnostic and Statistical Manual of Mental Disorders (DSM) as a “hyperkinetic reaction of childhood.” The name was changed to Attention Deficit Disorder (ADD) in 1980 and then became ADHD (Attention Deficit Hyperactivity Disorder) with 3 subtypes (predominantly inattentive, predominantly hyperactive-impulsive, combination) (Holland, 2021). My participants were impacted by the evolving history of diagnosis and treatment of ADHD. Some may have been diagnosed with ADD and others with ADHD as it is medically defined now. This history is part of the context for my participants.

## 3. Development of social media disability communities

Social media platforms have provided an opportunity for individuals to connect with people around the world and down the street. Members of online groups and communities can share resources, experiences, and advice. My participants were recruited from various social media communities of adults with ADHD.

### ***Data Management and Security***

I acknowledge that my data could have been compromised during transcription either with an inaccurate transcription or a violation of privacy. Accuracy was addressed with multiple listenings, post-transcription, to make sure the transcript is accurate. I made sure to only use pseudonyms and not send any other identifying information to the transcription service so that

my participants were not fully identified.

I assigned pseudonyms and not numbers to my participants so that the humanity of the study is maintained while the privacy of the participants is also maintained. Names are part of one's identity. I made sure that I kept the pseudonyms straight throughout the process so that data is not compromised.

### **Data Analysis**

My research questions are asking the “what” and “how” about disability identity for adults with ADHD. To answer my research questions I analyzed the data I received which was in the form of responses to surveys, transcripts from the focus group, and semi-structured interviews. My quantitative data analysis will be meaning-making from the survey data. I used various tables and charts to determine the frequency of similar responses, the average response from the participant pool, and overall trends in the descriptor ratios and correlations based on the responses to questions. A variety of statistical analyses were used to discover the stories behind the standardized data.

My qualitative data analysis was the process of meaning-making from the focus group and semi-structured interviews. The analysis of the data occurred through various means including coding, interpretation, summarization, making connections to theory, identifying themes, and triangulation within the study. Because of the iterative nature of coding, there is an opportunity for discovering more and more about the research questions through interpretation and analysis. Interpretation is the researcher making meaning shown through the explanation and summary of the data. Analysis also describes the meaning but includes reflections on the process of data gathering and insights gained from the data. Analysis more intentionally sticks closely to

the data and the methodology to support any insights claimed. The analysis of my qualitative data includes both interpretive and analytical looks at the data.

My methodology is a narrative study. My analysis includes a look at the structure and tone of the stories that I collect as data because the structure will reveal how the narrator frames their experience. I also looked for insights from content through coding which led me to a thematic analysis to answer my research questions. The themes that I used to label my data show my analysis of the data gathered. I used my conceptual framework, existing theories, and survey questions to be able to have a rich understanding of my research questions. The themes and structures of the answers (narratives) describe the experiences and thoughts of my participants regarding ADHD and disability identity.

To increase the rigor and validity of my study it is important that I was intentional about examining any assumptions that I brought to my methodological approach and data collection methods. My interview questions did not assume a deficit or a medicalized interpretation of ADHD. I made sure I was being flexible to all the outcomes of the data I collect while still focusing on answering my research questions. My summative data analysis required continuous reflection, and engagement with participants, colleagues, and peers to vet my interpretations (codes) and emerging analysis. I triangulated my data with existing theory, previous studies, and supplemental data collected before and after the study through surveys. Subjectivity is inevitable throughout the process but was acknowledged throughout the study for transparency.

**Validity**

Validity in a mixed-methods research design is the implementing and assessing a study's rigor by gathering complex data that deepen insight into the phenomena and is supported by gathering multiple perspectives (triangulation). It is also about accurately sharing participants' experiences. A mix of surveys and interviews will be used to get more detailed and complex

information about the phenomenon from adults with ADHD. Validity is ensured by using previous research and theory to guide my interview and survey questions. I also used “member checks” (employing the use of participants and/or members of the focus population) in providing feedback on my implications and interpretations of the data.

The survey for educators with ADHD is based on my research questions and theoretical themes and was used to help with triangulation with the results of the interviews and focus group. Triangulation and validity were also achieved by interviewing at least two participants and gathering data from the focus group. Outside readers, my chair, and committee members helped to challenge my assumptions and help to focus my interpretation.

My study is contextualized by describing the participants' demographics because I believe that any study on identity is very individualized and identity is heavily influenced by demographics. The interpretations of my study provide insight and perspective for teachers but are not intended for use in a standardized or generalized way. The interpretations should inform but not dictate future teacher responses.

### **Ethical Considerations**

There are several ethical considerations for this study. It was important that my participants were well-informed, respected, and protected. This started with my development of a clear and concise explanation of my research goals, questions, data collection, and protection methods that used language that is friendly to my participants. My participants were provided with a detailed explanation of how data will be used, the use of pseudonyms, storage of data, etc. Participants were also given the opportunity to receive the outcomes of the study. My explanation of the study was part of the informed consent letter that participants reviewed and electronically signed before participating in this minimal-risk study. The tone of the explanation



as well as the tone of the data collection process (interviews and survey) was positive. The way I set a positive tone was to situate the understanding of disability in the social model of understanding vs the medicalized understanding. I stayed away from a deficit understanding of ADHD and posed ADHD as a difference that is sometimes a superpower and sometimes creates challenges in an ableist society. During the virtual interviews, it was important to monitor my participants and my body language (on camera) to ensure participants felt comfortable and I provided assurances of their opportunity to exit the interview at any time, turn the camera off, take a break, and/or express feelings about the interview.

Identity is very cultural and contextual. This is why I was intentional about gathering demographic information and information on the context of identity development for my participants. The contextual and cultural influences could impact the recollection and reflection on participants' stories. Contextual influences would also include any power dynamics that could influence data. I was aware of the power dynamics of researcher and participant and planned my study to take a learning, listening, and collaborative stance. Although the participants were largely unknown to me I assured them that the interview would not influence any social relationships online and that they are in no way being coerced into participation. During analysis, I provided a thick rich description of the interview so that the participants' narratives and my analysis are well contextualized.

### **Plan for Researcher Reflexivity**

I recognize that I inherently hold some assumptions and biases that impact my understanding and approach to this research. One assumption could be the understanding and agreement on defining ADHD as a disability and what a disability identity entails or means to an

individual. As I interact with adults diagnosed with ADHD I will not assume that all aspects of disability or ADHD identity labels are accepted and embraced.

I also needed to identify and address any power asymmetries that could impact the interviews and possible interpretations. Because I am the researcher and not a member of the community, I was aware of the potential for power asymmetry and ableist positioning that could come across in recruiting, surveying, and interviewing. I reached out to potential participants through educators with ADHD communities through social media. Because the participants will largely not be previously known to me I worked to establish a relationship where they can be open with me about vulnerable aspects of their experience. Through my transparency about why I was doing this study and sharing with the participants how the information will be used, I attempted to mitigate the potential power dynamics of researcher and participant.

### **Conclusion**

“How” new knowledge will be obtained through research is the research design and methodology. In my narrative study my “rise to action” is to learn more about disability identity through the lens of adults with ADHD. This led me to a mixed-methods research design with a narrative inquiry methodology to answer my research questions. I gathered stories through a focus group, interviews, and a survey to delve deeper into the phenomenon of disability/ADHD identity to provide insight for educators about supporting the phenomenon through the adolescent years. As Faith, and students like her, pursue an understanding of self through the input received from peers and the adults in their life, my pursuit of knowledge will continue through the collection of qualitative and quantitative data from the stories of adults with ADHD.

## CH. 4

### “Uncovering the Dilemma and the Falling Action ”

#### DATA ANALYSIS AND RESULTS

*Faith continually processed all that she was learning about ADHD. Mr. Herring’s conversation with her helped allay some of her anxiety and spur her curiosity and research online. Faith chuckled at a meme that describes exactly how she feels when she becomes hyper-focused on a task. She shook her head at a peer’s post about how his father keeps hinting at his “laziness.” She clicked “Join” when she found an online community for girls with ADHD. She saw glimmers and reflections of herself in the various ADHD communities that she found which were igniting an ember of confidence in Faith. Not enough to yet fuel a conversation about her ADHD with her peers or teachers, but enough to allow Faith to, for the first time, accept her accommodation of small group testing with extended time for her upcoming science test. Peeking through the glass of the testing room door, Faith was surprised to see classmates that she hadn’t suspected had accommodations. As she took her seat, her brown eyes made a brief connection with a pair of blue curious eyes, and with a nod, there was an unspoken confirmation of understanding and connection between peers.*

#### **From Theory to Action: Data Collection**

A narrative progresses when there is an understanding of the problem and potential solutions are exposed. Faith’s story continues as she starts to do her research in her pursuit of knowledge. The pursuit of knowledge in research leads to a collection of data. The collection of data, in its various forms, is where research moves from theory to action. The data collected for this study was accomplished through both quantitative (survey) and qualitative methods (focus group and interview) while simultaneously recognizing that the identity and perspective of the

researcher and participants are as much a part of the research outcomes as the words, phrases, ideas, and statistics collected. The demographics of the research influence how coding is applied. The demographics of the participants affect how ADHD is experienced. The problem that my research is addressing is the need for understanding how to support adolescents in their development of a positive identity particularly related to ADHD identity. High school educators are positioned so that they can positively impact identity development. My research questions were:

1. How do adults with ADHD reflect on and share their experiences and understandings of ADHD?
2. What do adults with ADHD and postsecondary degrees attribute to their development of disability identity and postsecondary achievement?
3. How did identity influence how participants accessed support and resources in secondary and postsecondary education? What were those resources? What are those stories?
4. From the perspective of adults with ADHD, what can educators do to support positive disability identity?

My goal was to gather the stories of adults with ADHD to gain insight into the way they perceive their ADHD and ADHD identity and also to identify the actions of teachers and other adults in the lives of adults with ADHD that impacted their disability identity development. This chapter will provide the results of the data collected to answer the research questions.

### **Data Collection**

My data collection started with the distribution of the survey “Stories of Me: ADHD Identity.” The survey was sent to potential participants via various ADHD communities on social

media and other online communities. These included: Teachers with ADD/ADHD [Facebook group] (posted four times), The ADHD Life [Facebook Group], Adult ADHD Support Group [Facebook Group], r/adhdwomen [Reddit Group], r/ADHD [Reddit Group], Twitter (posted two times) and LinkedIn (posted and shared two times). The survey was also sent to American Education Research Association (AERA) Disabilities Studies Special Interest Group and ADD.org. The survey received 25 responses.

Survey participants were also invited to volunteer for a virtual focus group called “Sip and Share.” Volunteers could drink a beverage of their choice during the group and were offered a gift card for some coffee as a token of appreciation for their time. There were nine volunteer responses to participate in the focus group. As the day approached, some sent regrets for no longer being able to participate. On the day of the group meeting, there were four participants in the group. Pseudonyms were chosen: Emma, Anna, Eveylyn, and Alice. As participants entered the Google meet there was a brightly colored slide and upbeat music playing to welcome them to the “Sip and Share.” I welcomed each participant as they joined the group and thanked them in advance for their time. The participants were directed to electronically sign the consent form for participating in the focus group. After confirming consent I shared a slide with all the questions for the focus group discussion. This was done to allow participants to prepare responses and to provide some structure to the discussion. All camera’s were turned on as each participant smiled and introduced themselves. As the discussion started the energy was laid back and yet enthusiastic with the participants excited to share their stories. One participant shared how they had not been in a group discussion with other educators with ADHD and how it was affirming. As heads nodded with the sharing of stories that sparked memories of similar experiences the

group ended with my gratitude for participation and confirmation that a gift card for Starbucks was on the way.

The interviews were held similarly. There were six responses to the interview opportunity with two persons who were ultimately available to participate in interviews via Google Meet. Pseudonyms chosen for the interviewees were Olivia and Emily. Interviewees signed electronic consents and a rapport was easily established while participants answered the projected interview questions.

## **Descriptive Findings**

### **Demographics: Surveys**

Participants in the survey were adults with ADHD who all completed postsecondary degrees - bachelor's (44%) and Master's degrees (40%). Most participants identified as White (96%) and female (100%). The participants live and work across the United States Midwest (36%), Northeast (20%), and Western states (12%), along with two participants from Canada, two participants from the United Kingdom, and one participant from each of the following countries: Australia, Mexico, Germany, and New Zealand. Most participants were between 40-49 years old (48%) and between 30-39 years old (32%). Experience working in education ranged from 0-25 years with most having 0-5 years of experience (48%). Most respondents worked in elementary (24%) and middle schools (20%).

### **Demographics: Interviews**

Interviewees, Emily, and Olivia were adults with ADHD who completed bachelor's degrees. They were in the 30-49 age range. Emily identified as white and Olivia as White and Asian (Filipina). Both participants live in the US Midwest. Their experience in education

ranged from 10-25 years, and they work in elementary and middle school sites.

### **Data Analysis Procedures**

The data analysis centered around answering my research questions by asking about the “what” and “how” of disability identity development. The quantitative data (surveys) were analyzed through the frequency charts generated through Google forms and Descriptor Ratios generated in Dedoose. Responses to survey questions were then aligned with a corresponding research question. The survey questions asked participants to share how and when the ADHD diagnosis was given, rank ADHD as part of their overall identity, rate their positive perceptions of ADHD, share if they disclosed their diagnosis, share whether or not the participant accessed resources, rate the impact of educators on their view of ADHD, and select recommendations for other educators to support positive ADHD identity.

The qualitative data was analyzed through an analysis of the coding input by the researcher into the Dedoose program. Codes were created based on the themes of research questions and research methodology (deductive codes), but codes were also added based on the themes found in the responses from the participants (inductive codes).

### **Codes**

The following codes and child codes with their corresponding guiding definitions and examples were applied to the transcripts of the focus group and interviews.

**ADHD Reflection - Negative** (Child codes include disorganization, lack of follow-through, lack of timeliness, and forgetfulness): Stories, anecdotes, and words used during participant’s reflection that positioned ADHD as restricting or negatively impacting daily functioning.

*Disorganization Code example “like my room was always a mess. Like I did every single, like assignment, I ever had at the absolute last minute.”*

**ADHD Reflection - Neutral:** Stories, anecdotes, and words used during the participant’s reflection that positioned ADHD as neither positive nor negative in impacting daily functioning.

*Code example “Um, and growing up, there probably wouldn’t have been any flags for any of my parents, my parents, or anybody.”*

**ADHD Reflection - Positive** (Child codes include Creativity, Strength, Advantage): Stories, anecdotes, and words used during the participant’s reflection that positioned ADHD as enhancing and positively impacting daily functioning.

*Strength Code example “ I didn’t really, actually realize that a lot of my core strengths were from it as well.”*

**Access to Supports and Resources:** Description of the type and frequency of access to ADHD or disability-related supports and resources available in high school, college, or workplace.

*Code example “So as soon as I could I applied for accommodations, but it’s I still have this guilt when I have to use them because I went so long like all through undergrad anytime I needed and a deadline extended I would have to like swallow my pride like Oh, I couldn’t do another assignment, and now I have to get this extended, and it feels really bad and why can’t I do this so now I have like these medical reasons that and these explanations for why would need extensions on assignments, these accommodations but it still is kind of hard to use them”*

**Adult Impact - Negative** (Child codes include lack of follow-through, lack of support, and



jokes): Adult interaction in the participant's life negatively impacted their perception of ADHD and access to diagnosis or resources.

*Code example: "And I guess that the school psychologist had suggested to my teacher, oh, maybe it's ADHD. And she said, No, she's not hyper. So I just wish the results of that test would have been taken a little more seriously. Because if I would have gotten any sort of accommodations from it, I could have been, school would have been so much easier for me. It would have just been so in college too"*

**Adult Impact - Positive** (Child codes include no judgment and support provided): Adult interaction in the participant's life positively impacted their perception of ADHD, access to diagnosis, or resources.

*Code example: "But I had a teacher in seventh grade who was just like, invaluable to me, she was my math teacher, and I didn't have any, like 504 accommodations, but she would just let me come in and do stuff with her anyway, just because she saw that I was a student who needed help and clearly hadn't gotten it and a lot of other classes. So she would I could go in after school and take tests with her for as long as I needed to when I would get frustrated and cry about not understanding something, she wouldn't make me feel bad, she would give me a hug and comfort me and just provided all these things for me that were really helpful"*

**Advice for Teachers/Educator Support:** Upon reflection, participants' shared what helpful approach or strategy they "wished" an adult in school would have done for them, made recommendations of educator support, or shared what helpful approach or strategy the participant now does for their students.

*Code example: "But like, when I said that to her, and she was like, I think you have this*

*[ADHD] like why I wish there would have been like, follow up then like, Hey, you could go talk to this person about this, or you could talk to this person about it, it would have saved a lot of stress, anxiety, heartache, etc.”*

**Advice to Teens:** Participants shared a helpful approach or strategy for an adolescent

*Code example: “They're just on social media. I don't even know if they actually realize the depths of, like how you can actually find communities of like-minded or similar situations people are like, even if they know how to navigate that either.”*

**Diagnosis:** Participants shared their story of diagnosis

*Code example: “So I wasn't officially, officially diagnosed until last year.”*

**Helpful Strategy/Resource:** Participants shared a current strategy or resource that they find helpful.

*Code example: “And so like for me to get stuff done, I need to, like, read stuff all over.”*

**Narrative Characteristic:** How the participant told the story is noted (word choice and chronology).

*Code example: “I took the scenic route through college. I quit after seven semesters and a major change in music is, like, a huge thing. changing majors was basically starting over, took seven years off, and then went back and took another three years to finish my degree and then went on to my master's. And I always joke, oh, I've got ADHD. That's how I did college.”*

**Negative ADHD Identity/Stigma:** Participants shared a current negative perception, action, or connection to ADHD (including the ADHD community).

*Code example: “And so all those little faults that I now can label as ADHD. I mean, it was a lot of internalizing, just like, yeah, you messed up hardcore, and you need to figure this out.”*

**Neutral or not part of Identity:** Participants shared neither a negative nor positive perception, action, or connection to ADHD (including the ADHD community).

*Code example: “it's that weird little label that you get for your identity. It's, I feel like, it's hard for me to say that it's like, the diagnosis is part of my identity, I feel like all the symptoms are often what I always think about, and I'm still trying to be like, merging those two things together with such a late diagnosis.”*

**Positive ADHD Identity:** Participants shared a currently positive perception, action, or connection to ADHD (including the ADHD community).

*Code example: “And I think I think some of it's just nice to know that other people share the experience. And then seeing what other people's tips are like someone was posting about QR codes the other day. I was like, Oh, that would be super convenient if I could get myself organized enough to like, get the QR codes up”*

**Disclosure:** Participants shared whether or not they have or would disclose their ADHD diagnosis within a personal or professional setting.

*Code example: “And I disclose with my employers now because it is what it is. I haven't needed to ask for accommodations. But if I ever felt that it would make a difference. With my employment, I wouldn't hesitate to do so.”*

The analysis of the qualitative data includes an examination of code co-occurrence and code case count.

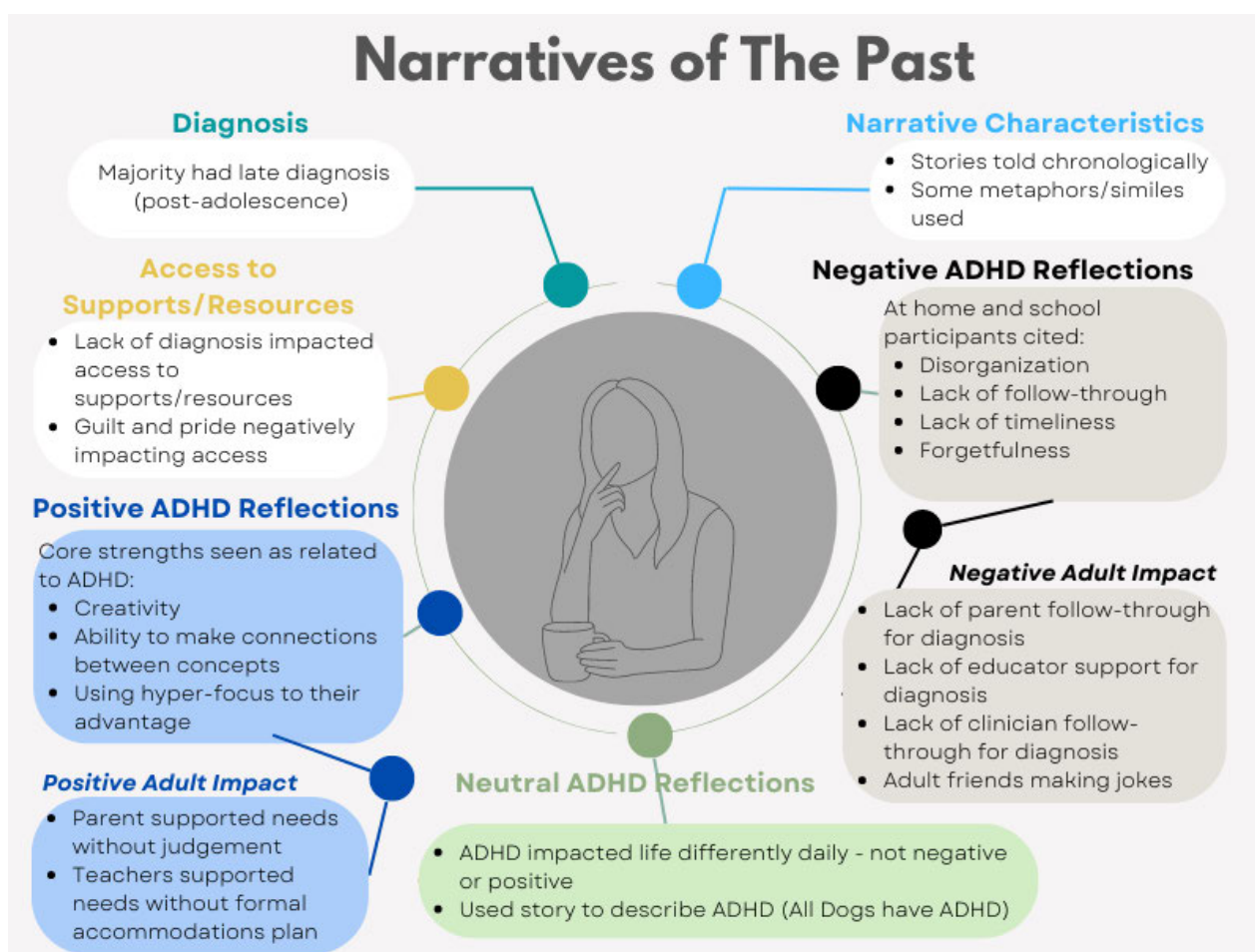
## Results

### Visual Overview of Results

The “Narratives of the Past” visual is a summary of the analysis of the codes and themes revealed in the data collection process when the participants were reflecting on their past experiences recognizing and developing their understanding of ADHD. The summary visually shows the connections between the codes and themes.

**Figure 3**

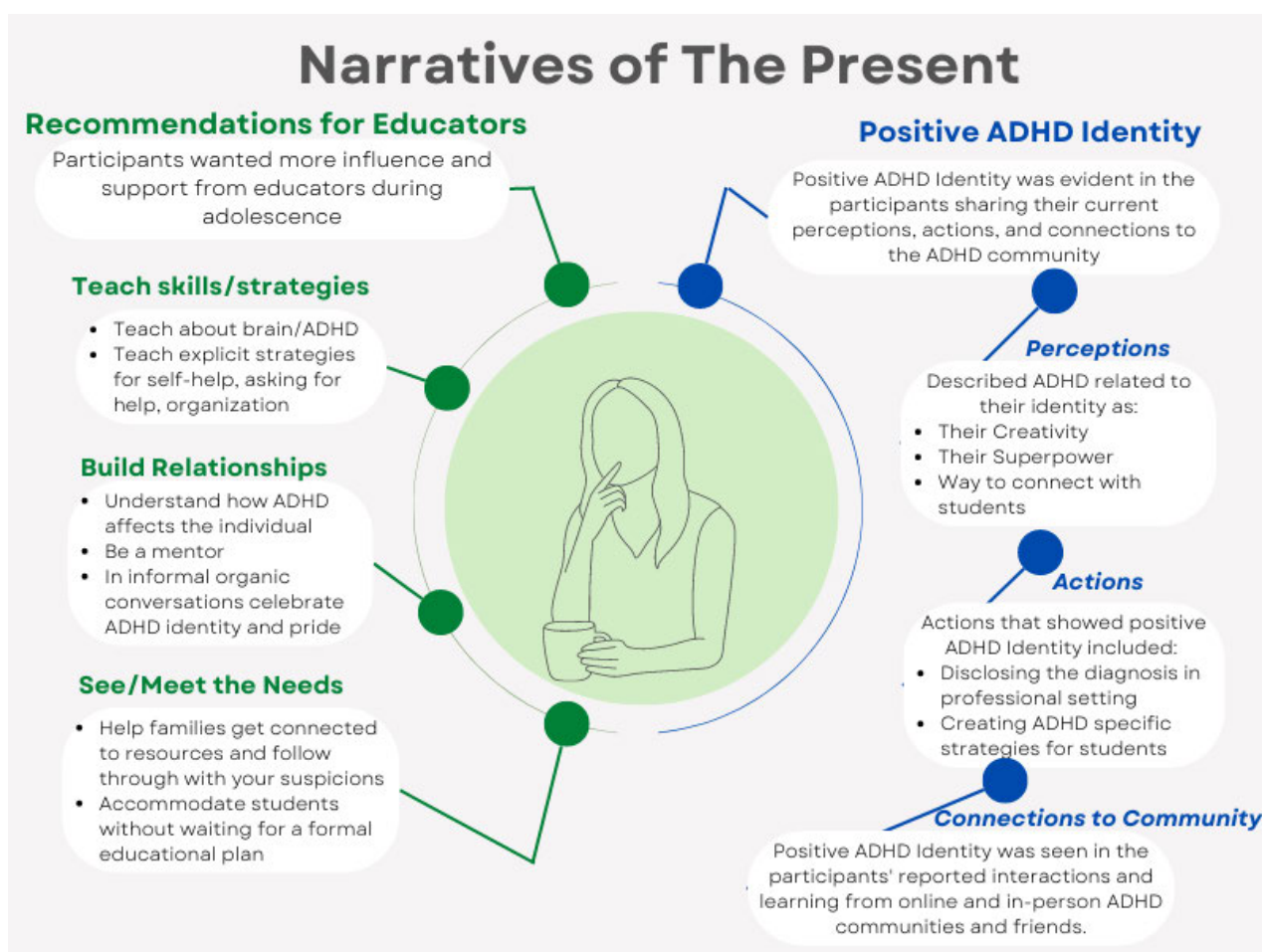
*Narratives of the Past*



The “Narratives of the Present” visual is a summary of the analysis of codes and themes revealed when participants shared their current understanding and recognition of ADHD in their life. It also summarizes the recommendations for educators from the participants.

**Figure 4**

*Narratives of the Present*



**Research Question 1:** How Do Adults with ADHD Reflect On and Share Their Experiences and Understandings of ADHD?

***Participants Had A Negative Reflective Perspective of ADHD***

The participants' reflective perspectives of ADHD were told chronologically from the oldest memories to the newest memories and the reflections were largely negative. In the focus

group, the participants had four times as many negative reflections as positive ones. The interviewees' reflections on ADHD in childhood were 100% negative. Participants shared various memories of how ADHD negatively impacted their daily functioning in their childhood. Evelyn recalled how her symptoms of ADHD ruined something good that she created. She said "And I just remember this one art project, I drew this in freshman art. It was, I was really good. I was like, this is a really good drawing. You did shading and everything. But it got shoved into everything and crumbled." Emma shared a missed opportunity based on her ADHD symptom of doing things at the last minute. She explained,

Yeah, I'm just being last minute. Like, saying stuff at the last minute, telling people about stuff at the last minute. And it's not a part of me, that's like, oh, I want to, of course, I want to wait till the last minute to tell my mother that I have a field trip, or I need her to sign something, or I have this project. It wasn't that. That's just how it always ended up. It was last minute. I think about the fifth grade, fourth or fifth grade, fourth grade or something. I was supposed to turn in a permission slip to join band, and I was like, I'm gonna play the French horn. And then I just never turned it in. And fifth grade, you know, late elementary school means just like, Okay, well, I guess that was it. You missed it. But, um, that really stands out to me, it's just like, you just totally just missed out on an opportunity, because you didn't turn in a permission slip, and then you just never followed up.

Alice shared how her high school experience with her parents was an example of how the symptoms of ADHD were often confused for willfully negative behavior. She said,

My high school experience was pretty much the same way my parents would, you know, tell me, Well, your room is not clean. So how can we trust you to take care

of this or other things, if you're not taking care of your own stuff? You forget to turn in your homework? How can we expect that you're going to remember to do, you know, to put gas in the car? Okay, maybe there were reasons for that. But it was the assumption was, I was being willful, or being defiant or doing, like intentionally making choices that led to those oops, moments, or that I shouldn't have done that kind of thing, as opposed to taking a step back and going, how can we prevent this from happening again, or what skills are missing that we need to develop?

Overall, the reflections of the educators on their childhood as related to ADHD's past impact were negative.

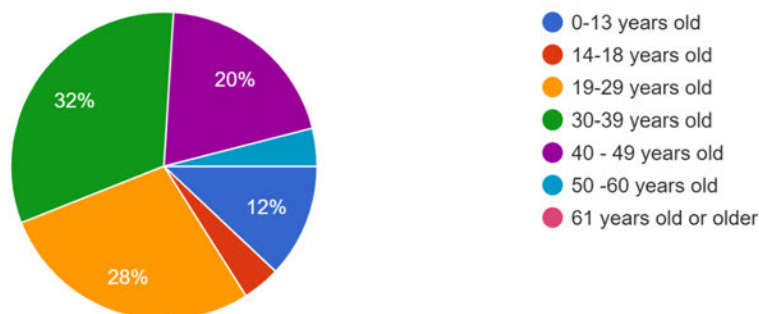
### ***Most Participants Had Late Diagnoses***

The survey data, focus data, and interview data all showed a high prevalence of late diagnoses. Only three participants were diagnosed with ADHD before the age of 13 years old.

**Table 1**

### ***Age of Diagnosis***

At what age were you diagnosed or did you realize that you had ADHD or likely had ADHD?  
25 responses



The prevalence of late diagnoses impacted participants' perspectives of their behaviors in childhood. Emma, a focus group member said, "...and so for most of my life, I had no real understanding of some of my behaviors or things that I was doing for most of my, well, all of my childhood and a huge chunk of my adult life." While some adults and peers in the participants' lives may have considered or joked about the participant having ADHD during childhood, the diagnosis didn't come until the symptomatology was taken seriously or the participant reached out individually for help. Alice felt gaslighted after sharing her concerns with her advisor in college. She laments "But he denied my lived experiences, because ADHD, to people who don't know, it just kind of seems like normal person disorder, like everybody is forgetful sometimes, and everybody is disorganized sometimes. But people who don't know don't know that it really affects your life in a major way." Reported late diagnoses were very common amongst this group of participants.

### ***Current Perception of ADHD Is Predominantly Positive***

While none of the participants provided an absolute ranking of 5 on a scale of 1-5; 5 indicating a 100% positivity ranking of ADHD as a superpower, the majority of participants perceived ADHD as neutral to positive.

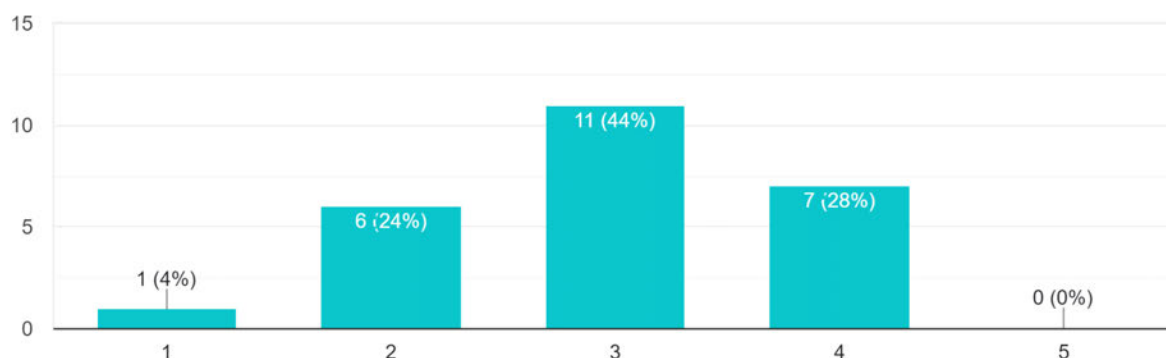
### **Table 2**

#### *ADHD Positive Aspect of Identity*



How would you rank your view of ADHD related to being a positive aspect of your identity?

25 responses



### ***ADHD Identity Was a Leading Marker of Participant Identity***

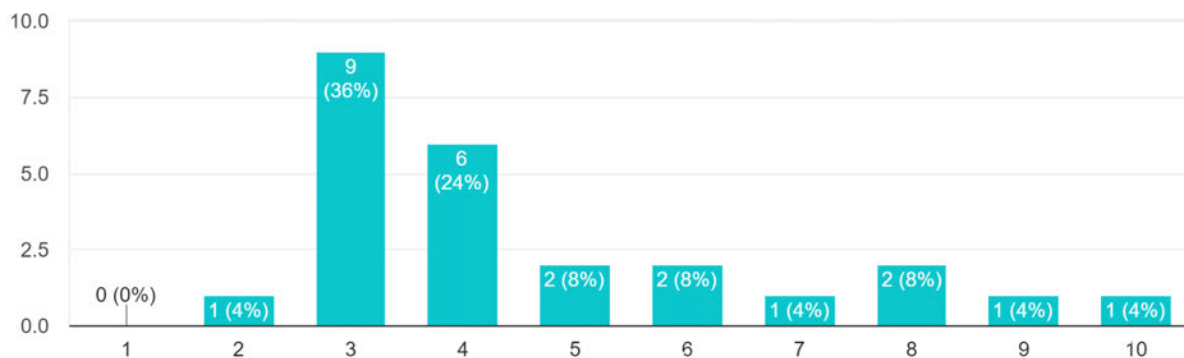
Survey participants were asked to rate how ADHD would fit into their identity markers based on what they would share with others. While answers varied, most participants indicated that ADHD ranked as a 3 on a 1-10 scale with 1 being “It is the first thing I would share” and 10 being “It is the last thing I would share.”

### **Table 3**

#### *Ranking Identity*

Identity can be defined by a lot of different categories, gender, sexuality, ethnicity, ability/disability, talents, religion, nationality, family dynamics, edu...ld ADHD rank on the list of things you would share?

25 responses



### ***ADHD Impacts Educator's Professional Practice***

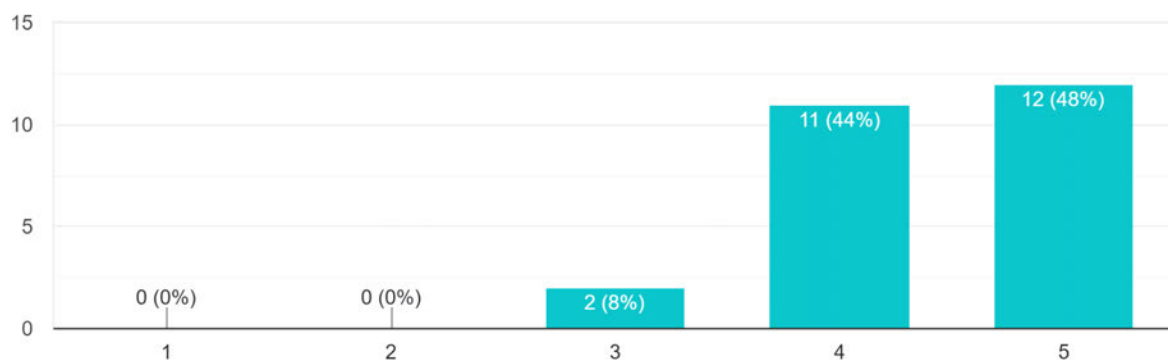
The participant's experience with ADHD was largely ranked as having quite a lot of impact on an educator's work (48% rated it as a 5 on a 1-5 scale and 44% rated it as a 4).

**Table 4**

### ***ADHD Impact on Work***

How much does ADHD impact your work as an educator?

25 responses



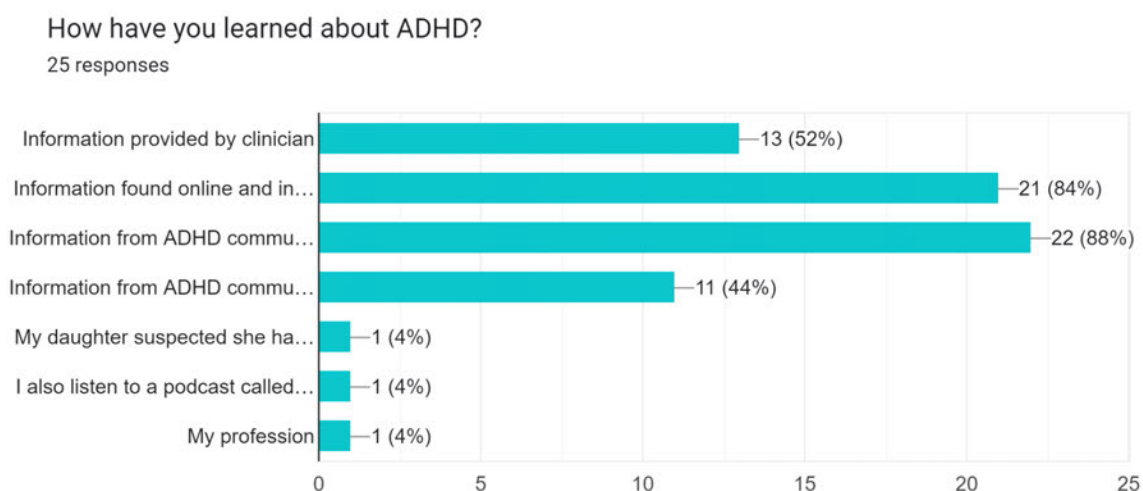
**Research Question 2:** What do adults with ADHD and postsecondary degrees attribute to their development of a disability identity and postsecondary achievement?

***The ADHD Community Is the Strongest Source of Learning About ADHD***

Sharing the experiences with ADHD is part of learning about ADHD and developing an ADHD Identity. 88% of respondents indicated that they learned about ADHD from an online community. Secondly, participants learned about ADHD from their personal online research (84%). Thirdly, participants learned about ADHD from information provided by a clinician (52%). 44% of participants indicated that they learned about ADHD from an in-person ADHD community.

**Table 5**

*Learning about ADHD*



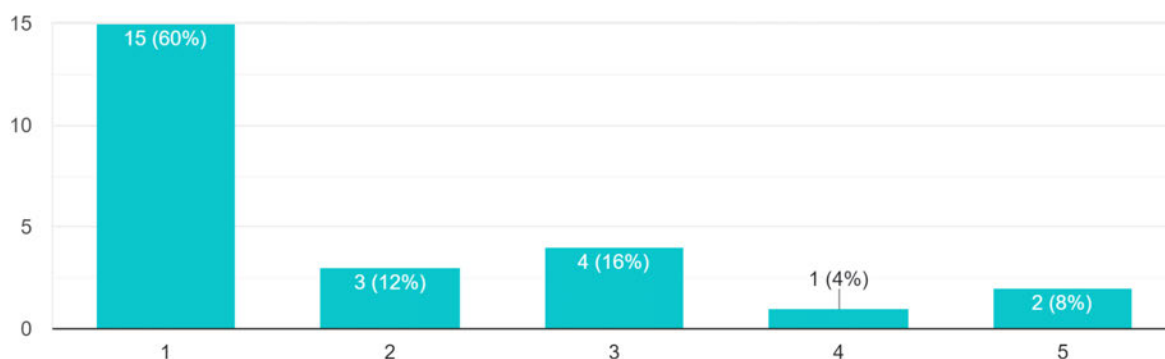
***Educators Did Not Shape Future Educators' Understanding of ADHD***

While not completely absent from shaping the views of ADHD, participants did not find educators as being very influential in their understanding of ADHD. 15 of 25 educators rated educator's influence as a 1 on a 1-5 scale (5 being very influential).

**Table 6***Educator Influence on Understanding*

As you reflect on your understanding of your ADHD, how much did an educator help shape your views?

25 responses

*Desire for Educator Support of ADHD Understanding is High*

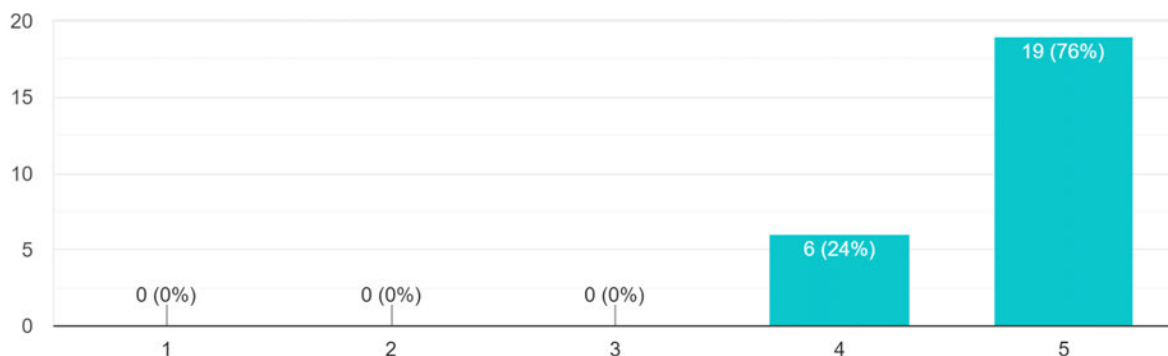
While educators were not found to have been influential on the participants' understanding of ADHD, there was a strong desire for educators to be more supportive of the understanding of ADHD. 19 of 25 participants rated their desire for educator involvement as a 5 and the remaining 6 survey participants rated it as a 4 (on a scale from 1-5; 5 is the strongest desire).

**Table 7**

## Desire for Educator Support

As you reflect on your experience with ADHD, how much would you have wanted an educator to support your understanding of ADHD?

25 responses



### ***Adults Did Have Predominantly Positive Impact***

While negative adult impacts were noted, as the participants reflected on the impact of adults in their lives, the predominant sentiment was that there was a positive impact made by parents, teachers, mentors, friends, colleagues, and administration. This positive impact helped the participant's positive ADHD identity in their home, educational and workplace settings. Across the focus group and interviews, there were 22 excerpts coded with Adult Impact - Positive vs. 13 Adult Impact Negative. An example of the positive adult impact included a mother who reserved judgment and focused on helping their child through their needs. Anna shared:

...and she [Anna's mother] every morning when she got home from work, and she'd be like, Okay, well, what homework did you have? Show it to me. Like, show me your homework. Show me that you finished it. It wasn't like, did you do your homework? And I would say yes, because I would be lying. It was like, Okay, well, what was your

homework tonight? Show me your homework. Let's get it out. Show me. And it wasn't ever like it was like if it wasn't done. Okay, let's sit down and work on it. Let's get it done

***Participants Largely Indicated Personal Traits of Positive ADHD Identity***

Through the learning that these participants did through online platforms, communities, and clinicians, the majority of participants cited positive ADHD Identity traits that also support their current work in education. The code case count for positive ADHD Identity totaled 39 excerpts compared to negative ADHD Identity (26 case count) and Neutral or not part of identity (7 case count). Emma states “And so I think, my creative side, my like, my, you know, inquisitive side, a lot of things that I find as strengths about me, I think, is part of my identity, but it's linked to ADHD.” Anna related her positivity with ADHD to how she interacts with her students. She shared “But I think I can, like, it feels positive in the way that it, like I interact with others, like the depth that I'm interested in things that I like will hyperfocus on are just the amount of things that I'm interested in, because my brain just goes and goes and goes that I can talk to students about and then those students can feel special.” While the participants shared traits of negative ADHD Identity, the responses about how ADHD is viewed as part of their identity currently were positive.

**Research Question 3:** How did identity influence how participants accessed support and resources in secondary and postsecondary education? What were those resources? What are those stories?

***The Majority of Participants Did Not Disclose ADHD***

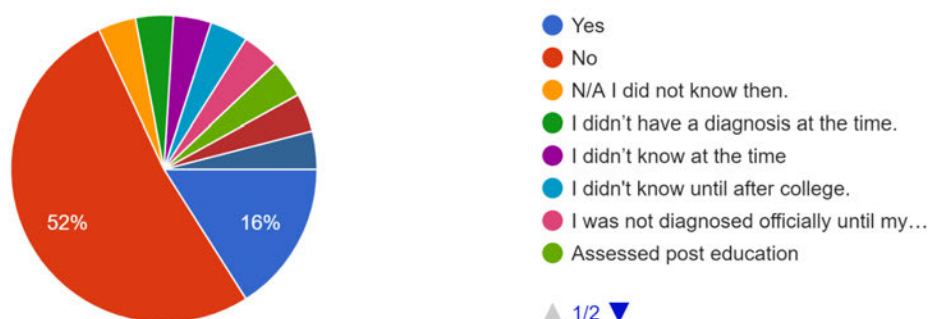
With the late diagnosis of the majority of the participants, most did not disclose that they had ADHD in their secondary or postsecondary education. Only 16% said that they made the disclosure.

**Table 8**

*Disclosure of ADHD*

Did you disclose that you had ADHD to any of your educators? (High School - College)

25 responses



***Being Undiagnosed Led to a Lack of Access to Resources during High School and College***

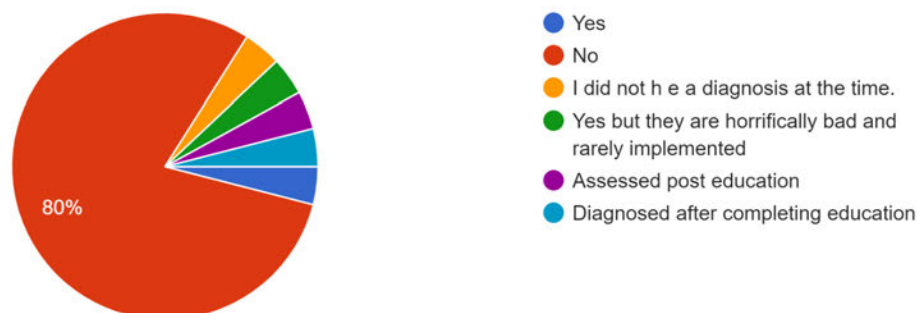
Only 8% of participants affirmed that they accessed ADHD or disability resources in high school or college. As indicated by the participants, the high percentage of late diagnoses impacted the ability of participants to be able to take advantage of possible resources.

**Table 9**

*Accessing Resources*

Did you access any ADHD or disability related resources during your education? (High School - College)

25 responses



### ***Need Access to Informal and Formal Support and Resources***

The code co-occurrence chart indicated an overlap with the participants' discussion of access to supports and resources and advice for teachers (four overlapping excerpts). Though the majority of participants did not access support and resources during their education the advice they had for fellow educators supports the use of informal and formal supports. Participants cited the need for the teaching of study skills, a check on their work, help with organization, extra time, and prompting to turn in homework. Olivia explained, “Like if I had been able to have extra time for assignments or frequent reminders to turn things in even that would have been really helpful especially in like high school I had a few teachers that were like like I literally would just it was a it was a come in, put your homework in the basket and sit down kind of thing and I never put my homework in the basket and it was in the folder it was done.”

**Research Question 4:** From the perspective of adults with ADHD, what can educators do to support positive disability identity?



***Educators can make Positive Impacts through Relationships, Skill building, and Supporting families with access to Help***

The co-occurrence chart had eight overlapping excerpts related to advice for teachers and positive adult impact. This is the highest number of co-occurrences found in the study.

Participants recommended that adults in education learned more about ADHD because it would benefit all students. They recommended that educators with ADHD be forthcoming with their needs and strategies to build a culture that supports ADHD. Building relationships with students, and patiently providing what individual students may need regardless of any accommodations plan were also recommended. Alice said “But we really, I was able to develop really close relationships with those teachers. And they were not just teaching me music, but also life skills and executive functioning skills. And I think if I hadn't had that, I wouldn't be where I am today.” Participants would like to see adults educate parents about available accommodations and how their child could be diagnosed.

***Organic and Informal Conversations Were The Most Recommended Approaches for Educators***

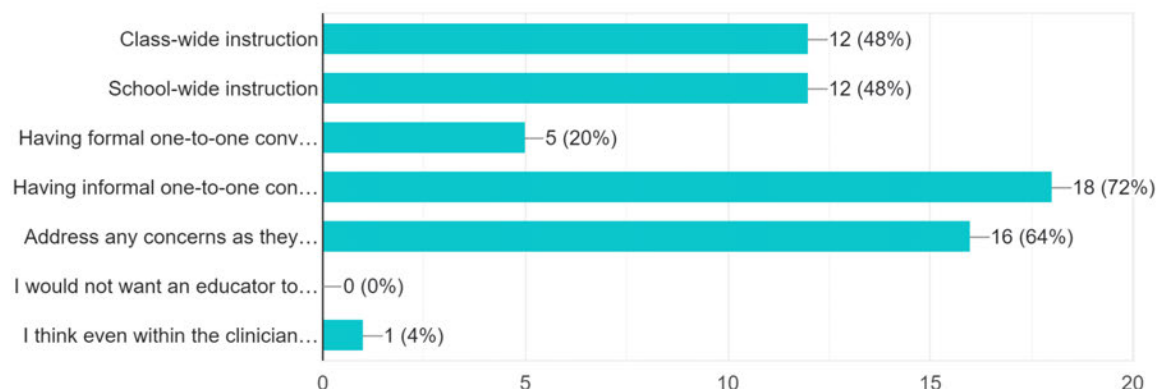
The highest chosen answer to explicitly asking educators to share the best way to support ADHD identity development was “Having informal one-to-one conversations” with students (72%). Second, was to “Address any concerns as they arise” (64%). The third response chosen is to provide both school-wide and class-wide instruction about ADHD (48%).

**Table 10**

*How Educators Can Support*

What would be the best way for an educator to support an understanding of ADHD (definition, history, rights, notable people, supports, etc.)?

25 responses



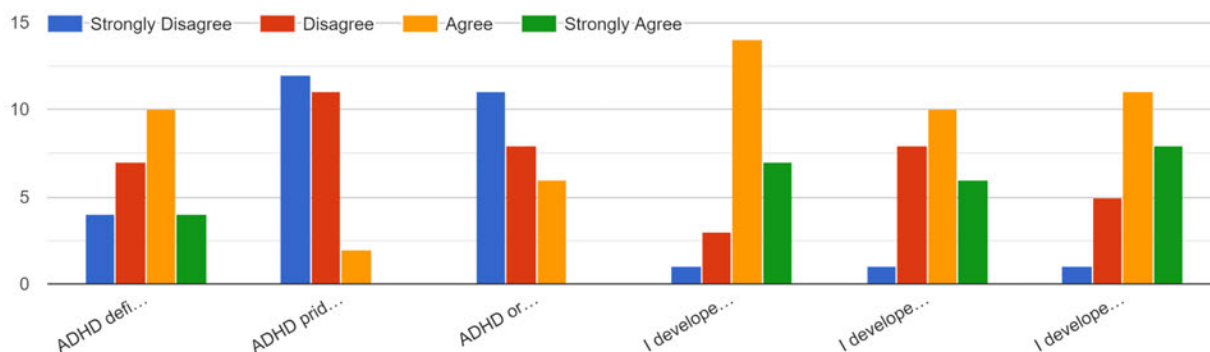
### ***ADHD Pride and Disability History are Not Present in Education Profession***

Participants' responses were “disagree” to “strongly disagree” as to whether or not ADHD pride and/or support were highlighted in one or more collegial conversations or professional development. However, the participants responded with “agree” to “strongly agree” when asked if they developed strategies specifically for students with ADHD (21 of 25 participants). 16 of 25 participants had strategies to promote positive ADHD identity and 19 of 25 indicated that they use their strategies regularly.

**Table 11**

*Preparation and Strategies*

Based on your experiences in education (what you learned from students, parents, colleagues, on your own), to what extent do you agree or disagree with the following statements?



### ***Educators Should Teach Explicit strategies, Help Students Learn about their Brains, and Foster Community***

Participants shared several ideas about educator support for adolescents with ADHD. The themes that emerged were focused on strategies and skills, students understanding how they think, and providing an opportunity for students to help each other. Evelyn reflected on her need for explicit prompting and said “I think some of the help that I needed was like actual, like, explicit, like, can you do this right now? Because my brain just wouldn't be telling me this is something you need to do now...It's like, Well, I'm just going to shove this here and then somehow future me will take care of it.” Emily added, “Yeah, or like even, like learning skills, right? Like getting your desk done does not help you learn how to clean it.”

Despite the hesitation of teachers to stigmatize students, Olivia stated “if there were teachers, who would have, like, pulled me aside and, like, helped me in an inconspicuous, inconspicuous isn't the right word, but inconspicuous way. You know, like, I think it would have been helpful. And I think if I understood how my brain worked earlier, like I think I might have not liked it then, but I would have been thankful for it now.”

Fostering a community would include facilitating a:

Gathering for them, and also to talk about strategies in school because like, you told me, you asked me like, What do you need? What would you need in high school or elementary school? And I'm like I was, like, someone just told me what to do. But like, actually having kids come together and talk about Well, in this class, my teacher has me do this, or reminds me of this, or in this class, you know, actually coming together and talking about what works for them. Because I think about, you know, the 504 IEP meetings, the only person with ADHD in that meeting is the student if the parent doesn't have it, or whatever. And so, thinking about a community of students where they're able to talk about what works like what works for you in school, maybe it'll work for me, what worked? What is the teacher doing for you? What do you struggle with? Oh, I struggle with the same thing. What can we come up with?

***Encourage Adolescents to ask for help and build skills***

Alice found that for one of her students with ADHD, she had to assure the student that it was okay to ask for help or accommodations. Alice said, “ if there's a test, I'm like, girl, like, it's fine, whatever you need, whatever you need, don't freak out.” Emily agreed and added “And so I think they would be, like, better about self-advocating, I could be wrong. But like, I feel like, my advice would be to like, build skills now. That will help you in the future. Like, don't wait till you're 40 to try to learn how to like, organize papers and how to organize like, your, your life, essentially.”

**Summary/Conclusion**

Gathering data is part of the process of understanding the problem and seeking new knowledge. The new knowledge needed in this study was to better understand the experience of

developing an ADHD identity and find out what would be beneficial to develop a positive identity in adolescents with ADHD. The quantitative and qualitative data provide insights into answers to the research questions. From the negative perception of the experiences of ADHD in childhood to the positive ADHD identity of the participants, the data provides some direction for educators. Faith has gained new knowledge from her counselor. Like Faith, the next steps are to consider what the new knowledge means for our future as we end this story.

## CH. 5

### “The Resolution”

#### SUMMARY, FINDINGS, IMPLICATIONS, RECOMMENDATIONS

*Faith looked around the auditorium taking in and savoring the moment as her fellow graduates adjusted their caps and gowns. There was an energy and tension in the room like a dam holding back the celebration that was about to burst. The graduates listened to the commencement speaker patiently waiting for their moment to let loose. As Faith listened, she smiled to herself as she also reflected on her journey through high school and college. She remembered how shy and unsure of herself she was. She was grateful to the counselors, teachers, professors, and her social media ADHD communities for helping to illuminate her ADHD identity, teaching her how to advocate for her needs, and developing confidence in who she was as a learner with ADHD. She knew that as she was preparing to lead her own classroom in the fall, she too would help students discover and celebrate the uniqueness within themselves.*

#### Summary of Study

While Faith is a fictional character, Faith’s story is representative of the potential opportunities for empowerment in adolescents with ADHD. The desire for a resolution like Faith’s is what led to my desire to explore the narratives of disability identity from the adult reflective perspective. Adult participants were chosen because adults can be retrospective and introspective as they share stories and insights about their course of academic achievement and their sense of identity along the way. From adult narratives, I hoped to be able to capture themes that can inform actions educators can take to support positive disability identity (PDI), particularly a positive ADHD Identity.

The importance of a positive ADHD identity is found in the fact that if an adolescent can develop a strong sense of identity during this period in life, then any outside perceptions of the individual that doesn't match their sense of identity will be rejected which reduces levels of anxiety (Orenstein & Lewis, 2021). With a strong sense of identity, adolescents can combat the anxiety and stigma related to their identity as neurodiverse persons. My study focused on gaining insights designed to address the problem of teachers not knowing how to develop PDI in their students. The phenomenon of developing a disability identity was found to be an important factor in developing interventions by persons who can support individuals along their identity developing journey (Forber-Pratt et al, 2017, p. 198). Teachers have the potential to be a factor in supporting adolescents on their journey.

The conceptual framework for this study includes James Marcia's Identity Status theory which provides a model for how identity is formed. Marcia "conceptualized identity formation through the dimensions of exploration and commitment" (Arnold, 2017, p. 5). Commitment is when an individual makes choices and acts upon their understanding of who they are. Through the stories of educators with ADHD, I was looking for evidence of commitment that showed their identity formation. Psychologist Henri Tajfel Social Identity Theory was also a part of the conceptual framework for understanding how belonging to a group brings a sense of identity, pride, and self-esteem. The stories gathered in the study were analyzed for evidence of this sense of identity, pride, and self-esteem in the participants from ADHD-affirming communities.

In my initial literature review, I found that most studies on disability identity focused on younger children and not adolescents and adults. This study furthered the body of work available to understand more about identity and ADHD (Cabral, Liu, & Soares, 2020, p. 106). The literature review on disability identity completed by Forber-Pratt, Lyew, Mueller, & Samples

(2017) did not identify a study that included persons diagnosed with ADHD. The literature has also shown the need for more understanding of what role adults can play in supporting students, like Faith, on their identity-affirming journey. This is where this study contributes to the field of education, specific areas of social-emotional learning, and identity development.

My study is centered around four research questions to explore the participants' development of an ADHD identity and extrapolate interventions for educators to support the adolescent development of PDI.

1. How do adults with ADHD reflect on and share their experiences and understandings of ADHD?
2. What do adults with ADHD and postsecondary degrees attribute to their development of disability identity and postsecondary achievement?
3. How did identity influence how participants accessed support and resources in secondary and postsecondary education? What were those resources? What are those stories?
4. From the perspective of adults with ADHD, what can educators do to support positive disability identity?

The data collection methods chosen for this mixed-methods study were two semi-structured interviews of adults with ADHD, a focus group, and collected survey data from social media communities to gather stories that were designed to expose the role of adults in the development of their sense of identity related to ADHD. Identity is the narrative one tells themselves about who they are. The narrative design for this study captured stories to learn more about the phenomena of identity development and will answer the research questions.



This chapter will explore the conclusions and implications based on the study's findings, as well as provide recommendations for further studies.

### **Summary of Findings**

My goal was to answer my research questions, and I accomplished that goal with insights that emerged from the research data. A combination of inductive and deductive coding and analysis were used and the data also provided insights beyond my research questions. The educators who responded to the survey, focus group, and interview opportunities were all volunteers and predominantly white females with a late diagnosis of ADHD. Acknowledging the demographics of the respondents is important to contextualize the findings and conclusions found through this study. If I do not consider the intersectionality of gender and race in ADHD, then I risk sharing findings that can lead to further inequities (Eliot, 2021, p. 124). Although I theorized that a more diverse participant group would be found via social media, historically, symptomology of ADHD and diagnostic criteria were based on male-stereotypical ADHD. This has led to “more females and gender non-binary individuals seeking a diagnosis of ADHD later in adolescence or early adulthood, which partially explains why individuals diagnosed with late-onset ADHD are ‘more likely to be female’” (Eliot, 2021, p. 135). My participants fit the research findings of more late diagnoses for females with ADHD. The lack of diversity of my participants also fits the research supporting the underdiagnosis of black children with ADHD. According to Healy’s research, “The odds of being diagnosed with ADHD were almost 70 % lower for Black children, 50 % for Latino children, and 46 % lower for children of other races and ethnicities” (Moody, 2016, p. 155). Also affecting the demographics of my participant pool are the typical demographics of online platforms. According to the Pew Research Center report on social media use, women report using Facebook and Instagram more than men (Auxier &

Anderson, 2022). With the demographics and context of my participants in mind, the following are the findings of my study.

### **Research Question 1: How Do Adults with ADHD Reflect On and Share Their Experiences and Understandings of ADHD?**

Educators with ADHD told chronological accounts of their experiences and understanding of ADHD. They reflected on and shared their experiences with ADHD by telling their memories of ADHD's impact, recalling their diagnosis journey, and identifying the continued impact of ADHD as part of their identity. When reflecting on past experiences, most participants shared reflections predominantly categorized as negative (disorganization, lack of follow-through, lack of timeliness, and forgetfulness). An individual's strongest memories are the ones that often hold the most emotional or physical impact. In this case, the memories shared in the study reflected the negative emotional impact of experiences related to deficits in daily functioning at home and at school. Researchers found "Negative information often is remembered with a greater sense of vividness than positive information" (Kensinger, 2009, p. 8). The predominantly negative reflections do not mean that there were no positive memories during childhood and adolescence, but that for this group of participants, the negative memories were more vividly connected to reflections on ADHD.

The experience and understanding of ADHD were also negatively impacted by receiving a late diagnosis. The survey data, focus data, and interview data all showed a high prevalence of late diagnoses. Only three of twenty-five participants were diagnosed with ADHD before the age of 13 years old. Late diagnoses impacted the participant's self-perception related to ADHD characteristics. Participants with late diagnoses shared how it would have been helpful to have

known about the diagnosis to be able to access resources and have a better understanding of themselves in a positive light instead of internalizing that something was “wrong” with them. Late diagnoses also impacted access to resources during the participants’ adolescence and along their educational path.

Despite the prevalence of the late diagnosis, the majority of participants currently perceive ADHD as neutral to a positive part of their identity (creativity, superpower, and advantages). This shows that a positive ADHD identity can be developed post-adolescence. Survey participants acknowledged that ADHD was currently in the top three identity markers when describing themselves which indicates a level of importance and impact.

**Research Question 2: What do adults with ADHD and postsecondary degrees attribute to their development of a disability identity and postsecondary achievement?**

Adults with ADHD attributed their development of an ADHD identity most strongly to connections to the ADHD community. The community includes access to online educational resources, connections to friends, colleagues, or administrators with ADHD, and/or participation in online ADHD communities found through social media. Access to the community provides connections to others with similar experiences, pride in the distinction, understanding more about the experience and diagnosis, and sharing of resources. Sharing of lived experiences with others with ADHD was part of participants’ overall learning about ADHD and their development of an ADHD Identity. 84.6% of respondents indicated that they learned about ADHD from an online community. Secondly, participants learned about ADHD from their online research (69.2%). Thirdly, participants learned about ADHD from information provided by a clinician (46.2%).

This shows the power of an ADHD community to develop a positive ADHD identity and the need for continued access to supportive information online and through clinicians.

The majority of participants cited positive ADHD identity traits that also created an advantage for the participants' current work in education. Educators connected positivity with ADHD in their beliefs about their creativity, ability to successfully manage multiple concepts or inputs (Eg. organizing a band), and ability to interact and build deep relationships with students.

Participants did not find educators along their journey very influential in their understanding of ADHD. These findings show the need for growth in this area because participants shared a strong desire for educators to be more supportive. 19 of 25 participants rated their desire for educator involvement as a five and the remaining six survey participants rated it as a four (on a scale from 1-5; 5 is the strongest desire).

While educator impact was not noted as strong in the journey of developing a positive ADHD identity, as the participants reflected on the impact of adults in their lives, the predominant sentiment was that there was some positive impact made by parents, teachers, mentors, friends, colleagues, and administration. This positive impact helped the participant's positive ADHD identity development in their home as well as in their educational and workplace settings.

**Research Question 3: How did identity influence how participants accessed support and resources in secondary and postsecondary education? What were those resources? What are those stories?**

The access to support and resources in secondary and postsecondary education was largely impacted by the reported late diagnosis of the majority of participants. Some shared that

they wished they had been diagnosed earlier so that they could have access to support and resources. Another participant, diagnosed before college, confessed her feelings of guilt and pride getting in the way of seeking the available support and resources.

Impacted by the late diagnosis of the majority of the participants, most did not disclose that they had ADHD in their secondary or postsecondary education. This leads to only 7.7% of participants who affirmed that they accessed ADHD or disability resources in high school or college. While late diagnosis impacted access, the lack of disclosure is more widely considered a concern in postsecondary institutions. It is suspected that the size of students with disabilities at universities is different from what is reported because students are not “disclosing their disability for a variety of reasons including stigma, fear of discrimination, past negative experiences, and gaps in knowledge about available institutional support and accommodations” (Grimes et al, 2017, p. 425). Based on those reasons for not disclosing, whether or not to disclose one’s diagnosis relies on the perception of disability and perception of self, essentially having a positive disability identity.

Though the majority of participants did not access support and resources during their education, the advice they had for fellow educators is for educators to be a resource and use informal and formal accommodations and support for students based on their needs, not just their educational plan. Participants cited the need for educators to teach study skills, check the progress of student work, help students with organization, allow extra time for the completion of assignments and assessments, and prompt students to turn in homework.

**Research Question 4: From the perspective of adults with ADHD, what can educators do to support positive disability identity?**

Participants recommended that educators foster relationships (teachers with students and peer-to-peer in ADHD communities), teach explicit skills and strategies, and support the needs of families and students to understand and access resources. Educators should patiently provide whatever individual students may need regardless of any official accommodations plan that may or may not be in place. Participants believed that it was important for students to understand how they think (how their brain works and how they learn), how to advocate for themselves, and know the accommodations they need. Educators should provide opportunities for students to help each other and develop a supportive community.

While acknowledging that knowledge of ADHD pride and/or support were not often available or referenced in pre-service training, collegial conversations, or professional developments, participants recommended that adults in education learn more about ADHD and develop strategies that would benefit all students.

To support students in developing their ADHD identity, participants recommended that educators have informal one-to-one conversations with students and address any individual concerns as they arise. The third recommendation related to teaching about ADHD pride and community through school-wide instruction. This reflects the need for a better individual and collective understanding of ADHD. This also supports the need for explicit social-emotional teaching of skills that will support student self-awareness and advocacy.

### **Implications**

Based on the findings of the study that answered my research questions, several (contextualized) implications can be made to inform educator preparation and educator practice.

#### **The Power of Community**

The findings of this study have reinforced Henri Tajfel Social Identity Theory by

illustrating how belonging to a group or community can bring a sense of identity, pride, and self-esteem. While identity development is most prevalent during the adolescent years, the development of a positive ADHD or disability identity can be supported post-adolescence and throughout adulthood. The ADHD community is a strong source of learning and development of pride, whether in a formal group like ADD.org, an informal social media group, or access to a friend, colleague, or administrator who has ADHD. In the Boston Law Review Eyer (2021) explains, “...social media offers tremendous opportunities for the types of moments of self-disclosure that scholars, people with disabilities, and those who are both have recognized are constitutive of disability identity, especially for those with hidden disabilities” (p. 576). These groups could be promoted, created, and used more intentionally in education to break down stigmas and connect adolescents to ADHD communities.

Understanding the power of community, educators should actively support avenues for developing ADHD communities in schools. For example, communities can be developed by providing opportunities for ADHD to be discussed in classrooms (incorporating disability history or highlighting the perspective of a known person with ADHD in the curriculum) allowing students to voluntarily share their perspectives. Educators can also create groups to support specific common characteristics of people with ADHD and allow students to develop and share strategies that work for them (eg. The Executive Club where students work on executive functioning skills).

### **Equip Educators with More Education on Disability History and Pride**

To be able to support disability and ADHD identity, educators need to be equipped with the knowledge to do so. The educators in this study indicated that there was little preparation or professional development during undergraduate study or once in the field that prepared teachers to have conversations beyond the definition of disability. Pre-service and current teachers need

more education and strategies to support not only learning about students with ADHD but also how to support their positive outlook on ADHD identity.

Considering the lack of diversity in this study's respondents, underdiagnosed individuals need to be seen and heard in disability history. This is crucial for underdiagnosis and late diagnosis of black and brown individuals. The experience and perspective of ADHD for black and brown students are different from their counterparts. Highlighting diversity in disability history will build not only a positive ADHD identity for our students but may be a catalyst for earlier diagnosis for traditionally underdiagnosed individuals because it will increase ADHD awareness and pride across a school.

### **Advice to the “Tightrope Walkers” (Educators): Build Relationships and Think Big**

An educator who desires to know what approach is best to support an adolescent with ADHD can start by building relationships with students. Building relationships with students is needed so informal conversations can include positive affirmations and acknowledgment of the student's ADHD. The study suggests that the teacher who gets to know their students beyond what is in their educational plan and accommodates beyond what is required creates a lasting impact on students whether or not they have been diagnosed (yet). Educators who have ADHD can also consider mentorship roles for students with ADHD. The stigma of disability is real, but the findings show that balancing stigma with helping a student is best addressed through the individual relationships built with students. There isn't a one-size fits all approach.

Educators should also think big and strive to build a school culture that affirms identities, including a positive ADHD identity. This can be achieved through targeted disability awareness days, weeks, and specific school programming, but disability awareness should be part of ongoing school culture building. School leaders can prioritize having a student or staff disability advocate on each school committee. This will help to keep the voice of persons with disabilities



at the table for school decision-making. Disability and ADHD identity can also be included in any identity-affirming discussions and learning. Social-emotional learning includes the understanding of self. For all students, “Self” should explicitly include consideration of disability and how to navigate social interactions with a diverse group of people of many identities and abilities with respect, kindness, and understanding.

### **Added Benefit of the Study**

This study had the added benefit of facilitating an opportunity for participants to connect with other educators about their unique experiences with ADHD. The focus group created a temporary ADHD community which, in turn, reinforced positive ADHD identity. The study also garnered participants from different regions of the US, Canada, Mexico, Australia, and the UK. While limitations exist, the benefit of using social media and virtual meetings was allowing multi-state and international participation in the study. The variety of geographically diverse participants highlighted the differences and commonalities in the stories.

### **Limitations of the Study**

A limitation of this study was the use of social media to recruit participants. The use of social media inherently shaped the pool of participants to those who are technologically savvy, self-identify as having ADHD, and are interested in participating in social media which impacted the demographics of the respondents. Findings in this study must be contextualized with this limitation in mind.

The participants' age of diagnosis also created a limitation to the study. Most participants were categorized as having a late diagnosis (post-adolescence) which impacted the ability of participants to fully answer some of the preset survey and interview questions. This includes the limited ability to explore the experience of ADHD identity during high school and postsecondary (eg. accessing resources and supports). Late-diagnosis participants also provided a unique

perspective on developing a positive ADHD identity. The study confirmed the presence of a positive identity and focused on the adult impact on the process but could not provide the participant's perspectives on how development occurred during adolescence.

Another limitation of the study was the lack of the volume of survey responses to further strengthen the validity of the survey data. The survey had a very targeted population of adults with ADHD that excluded non-educators. In addition to the limited participant pool, online survey fatigue may have been a factor in the lack of response. Educators receive multiple surveys (especially post-quarantine). It is possible that "Respondent fatigue, also known as survey fatigue, is a common problem in the collection of survey data" (O'Reilly-Shah, 2017, p. 2). A limited participant pool shaped the possible statistical findings.

A significant limitation is that the study didn't garner a variety in the racial and gender demographic of participants. While it is unknown if the demographics of the participants were reflective of the totality of demographics of online ADHD communities, the study findings are impacted by the lack of voice and perspective from the BIPOC participants. The lack of racial diversity in the study is reflective of both the disparities seen in the diagnoses of children with ADHD "Studies also describe racial/ethnic disparities in diagnosis and medical treatment of ADHD, indicating that African-American and Latino children may have lower rates of receiving a diagnosis and medication compared with white children" (Coker et al, 2016, p.2). This disparity creates a limitation and needed contextualization of the findings of this study.

### **Recommendations for Future Research**

This study was a mixed method study with a narrative design that analyzed the stories of adults with ADHD to garner themes to answer questions surrounding the development of a positive ADHD Identity. The survey, focus group, interviews, and analysis of the coding and frequencies lead to actionable outcomes for educators to consider. Future research could

consider completing a study from a teen perspective on their identity development. Instead of a reflective look at identity development in adolescence, a study from a teen perspective would bring a different sense of relevancy to the recommendations that a teacher could use to implement change in their classroom. A comparative study with this current study would allow a cross reference of outcomes to see if the recommendations remain the same across targeted participants.

Another recommendation for future research would be to focus on the intersectionality of identities by identifying adult and teen participants in black and brown communities who could share stories of the development. Not only stories of their ADHD identity development but the development of their racial identity and how the two identities intersect and interact. This approach could shed some light on the experience of identity development and garner further recommendations for teachers who serve traditionally underdiagnosed individuals. Reaching this specific participant group may take some partnership with clinical and educational institutions who could help to identify willing BIPOC participants as well as targeting social media groups designed specifically to support those communities. The use of social media influencers would also be beneficial. This would further expand and balance the body of research on identity development for individuals with ADHD.

### ***The Tightrope Walk (updated)***

*What is the best way to help you?*

*Do I shout out your strengths for the world to see?*

*But then you might shrink back, not wanting them to see “little ole’ me”*

*Do I act like your diverse needs are no big deal?*

*But then you might not get the support needed to achieve the ideal.*

*I will be sensitive to your compilation of adolescent needs*

*Building a relationship with you, teaching you skills you need to achieve*

*I will walk the tightrope for you, while striving to shape your self-view*

*Someday you will stand on your own, confident, and uniquely you.*

*It's my honor!*

*-Andrea Johnson (2022)*

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## Appendix A: Survey

### Stories of Me: ADHD Identity

Thank you for participating in this approximately 10 - 15 minute survey.

I am a doctoral student at National Louis University. I'm also a mom, an educator of over 20 years, and passionate about the growth and development of all adolescents, particularly those who are "different." As I contemplated the topic for my doctoral research, I found myself drawn to the idea of identity and its impact on individuals. I've had students with ADHD who were very aware of their needs and were able to advocate for themselves confidently. I've also had students who refused essential help in the efforts they made to conceal their differences.

This survey is aimed at collecting the perspective of educators with ADHD learning about the impact that adults had in their lives which may have shaped their understanding and adoption of ADHD as part of their identity. The goal is to be able to learn how educators may be able to positively impact identity development.

Thank you for your willingness to participate and share your perspective.

Please contact Andrea Johnson at [REDACTED] if you have questions about the survey.

#### **PARTICIPATION**

Your participation in this survey is voluntary. You may refuse to take part in the research or exit the survey at any time without penalty. You may skip any question you do not wish to answer for any reason.

#### **BENEFITS & RISKS**

Your responses will help me learn more about the experience of adults with ADHD. There are minimal risks to your participation. The minimal risks are similar to that of a conversation or discussion in a public educational setting.

#### **CONFIDENTIALITY**

Your survey answers will be stored in a password protected cloud-based file. The only identifying information I will receive is demographic information. No names or personally identifying information will be included in any reports or presentations based on this data. Your responses to this survey will remain anonymous.

#### **CONTACT**

If you are interested in the culminating results of the research, or you have further questions or concerns about your rights as a participant in this survey, contact Andrea R Johnson, MA, M.Ed at [REDACTED]. Additionally, if you have questions about your rights as a research subject, you may contact Dr. Angela Elkody, Chair of this study ([aelkordy@nl.edu](mailto:aelkordy@nl.edu)) or the National Louis University IRB Chairs Dr. Shaunti Knauth ([shaunti.knauth@nl.edu](mailto:shaunti.knauth@nl.edu)) or Dr. Christopher Rector ([CRector@nl.edu](mailto:CRector@nl.edu)).

#### **WITHDRAWAL**

If at any point, you would like to withdraw from participating in the survey, you are able to do so.

#### **ELECTRONIC CONSENT:**

Please select your choice below. You may print a copy of this consent form for your records.  
Clicking on the "Agree" button indicates that:

- You have read the above information and understand the benefits and risks
- You voluntarily agree to participate
- You are 18 years of age or older

Clicking on the 'Disagree' button will end the survey.

**\* Required**

**1. ELECTRONIC Consent \***

*Mark only one oval.*

I AGREE to the statements above (*Skip to end*)

I DISAGREE with the statements above

**LET ME KNOW A LITTLE ABOUT YOU: YOUR DEMOGRAPHICS**

**2. What is your highest level of education? \* *Mark only one oval.***

High school degree

Associate degree

Bachelor's degree

Master's degree

Doctoral degree

Other:

**3. With which of the following do you identify? *Mark only one oval.***

Asian

Indigenous American

White/Caucasian

Latinx

Black/African American

Hawaiian/Pacific Islander

Multi-racial

Other:

**4. What is your age? \* *Mark only one oval.***

0-13 years old

14-18 years old

19-29 years old

30-39 years old

40 - 49 years old

50 - 60 years old

61 years old or older

**5. How many years have you been teaching? \* *Mark only one oval.***

0-5 years

6-10 years

11-15 years

16-20 years

21-25 years

26-30 years

31-35 years

36 or more years

6. By which gender do you identify? *Mark only one oval.*

Male

Female

Prefer not to say

Other:

7. What is your role (s) in education? (check all that apply)

*Check all that apply.*

Early Childhood Teacher (Prek-K)

Elementary Teacher(1 - 5th grade)

Middle School Teacher (6th - 8th grade)

Elementary Fine and Performing Arts Teacher (Art, Music, Dance)

Elementary school Special Education Teacher

High School English Teacher

High School Social Science/STEM Teacher

High School Math Teacher

High School Science Teacher

High School World Language Teacher

High School Fine and Performing Arts Teacher (Art, Music, Dance)

High School Special Education Teacher

Postsecondary Educator (college or graduate level)

Student Support Personnel/Clinician (Counselor, Social Work, Psychologist, Speech Pathologist, etc)

Other:

8. Have you been diagnosed (clinically or self-diagnosed) with ADHD? \* *Mark only one oval.*

Yes

No

Other:

9. How were you diagnosed? \*

*Mark only one oval.*

By a clinician (Neuropsychologist, Licensed clinical Social worker, psychologist, other)

Self-diagnosed

Other:

10. At what age were you diagnosed or did you realize that you had ADHD or likely had ADHD?

*Mark only one oval.*

0-13 years old

14-18 years old

19-29 years old

30-39 years old

40 - 49 years old

50 -60 years old

61 years old or older



11. Where do you currently live and work? \*

*Mark only one oval.*

- US Midwest State ( Minnesota, Illinois, Indiana, Michigan, Missouri, Iowa, Kansas, Nebraska, North Dakota, South Dakota, Ohio, and Wisconsin)
- US Northeast (Massachusetts, Maine, New Hampshire, Vermont, Rhode Island, Pennsylvania, New Jersey, New York, and Connecticut)
- US Southeast (Georgia, North Carolina, South Carolina, Washington D.C., New York, Kentucky, Delaware, Maryland, Florida, Tennessee, Mississippi, Alabama, Virginia, and West Virginia)
- US Southwest (Texas, New Mexico, Arizona, and Oklahoma)
- US West (California, Nevada, Colorado, Hawaii, Oregon, Utah, Idaho, Montana, Wyoming, and Washington)
- Canada
- Mexico
- Other:

## YOUR REFLECTIONS

12. Identity can be defined by a lot of different categories, gender, sexuality, ethnicity, ability/disability, talents, religion, nationality, family dynamics, educational skills, etc. If you were to write about your identity, where would ADHD rank on the list of things you would share? *Mark only one oval.* 1 2 3 4 5 6 7 8 9 10

It is the first thing I would share

It is the last thing I would share

13. How would you rank your view of ADHD related to being a positive aspect of your identity?

*Mark only one oval.* 1 2 3 4 5

Negative/ My greatest weakness

Positive/My superpower

14. Prior to your diagnosis, how much did you know about ADHD? \* *Mark only one oval.*

Not much at all

A little

I had some information

I knew quite a bit

I was an expert

15. How much did you now know about ADHD? \* *Mark only one oval.*

Not much at all

A little

I know some information

I know a lot

I am an expert

16. How have you learned about ADHD? \* *Check all that apply.*

Information provided by clinician

Information found online and in texts (personal research)

Information from ADHD community online

Information from ADHD community in-person

Other:

17. Did you disclose that you had ADHD to any of your educators? (High School - College) *Mark only one oval.*

Yes

No

Other:

18. Did you access any ADHD or disability related resources during your education? (High School - College) *Mark only one oval.*

Yes

No

Other:

19. How much does ADHD impact your work as an educator? \* *Mark only one oval.* 1 2 3 4 5

Not much

Quite a lot

20. How much do you find yourself seeking out students with ADHD as an educator? \*

*Mark only one oval.* 1 2 3 4 5

Not much

Quite a lot

21. As you reflect on your understanding of your ADHD, how much did an educator help shape your views? *Mark only one oval.* 1 2 3 4 5

Very little

Very much

22. As you reflect on your experience with ADHD, how much would you have wanted an educator to support your understanding of ADHD? *Mark only one oval.* 1 2 3 4 5

Very little

Very much

23. What would be the best way for an educator to support an understanding of ADHD (definition, history, rights, notable people, supports, etc.)?

*Check all that apply.*

Class-wide instruction

School-wide instruction

Having formal one-to-one conversations

Having informal one-to-one conversations

Address any concerns as they arise

I would not want an educator to be involved in ADHD identity development

Other:

24. Based on your experiences in education (what you learned from students, parents, colleagues, on your own), to what extent do you agree or disagree with the following statements?

*Mark only one oval per row.* Strongly Disagree Disagree Agree Strongly Agree

- ADHD definitions and diagnoses were covered in at least one professional development opportunity, collegial conversation, etc.
- ADHD pride and/or support were highlighted in one or more professional development opportunities, collegial conversations, etc.
- ADHD or Disability history was highlighted in one or more than one professional development opportunity, collegial conversation, etc.
- I developed strategies for teaching students specifically with ADHD I developed

practical methods for supporting students with ADHD feel positively about ADHD

- I developed methods for teaching students with ADHD that that I use regularly

### **THANK YOU FOR YOUR PARTICIPATION!**

I'd like to get more information to better serve our students by learning from your stories. I am seeking persons willing to meet with me virtually to participate in a Sip and Share which is a focus group to share stories about their experience. The group will meet once virtually and will take no more than an hour of your time. If you are willing to participate in the Sip and Share, please click this link:

[REDACTED]

I would also love to extend the invitation to do an individual interview. The interview will take no more than an hour of your time. If you are willing to be interviewed (one to-one virtually) please click on this link: [REDACTED]

If you are interested in the results of this research, feel free to email me at [REDACTED].  
Thanks again!

## Appendix B: Focus Group Questions

### **SIP and SHARE FOCUS GROUP Stories of Me: ADHD Identity**

Thank you for participating in this approximately 1 hour focus group.

#### **PARTICIPATION**

Your participation in this group is voluntary. You may refuse to take part in the research or exit the group at any time without penalty. You may skip any question you do not wish to answer for any reason.

#### **BENEFITS & RISKS**

Your responses will help me learn more about the experience of adults with ADHD as they reflect on their adolescence and identity and will help to shed some light on how adults in students' lives can positively impact identity development. There are minimal risks to your participation. The minimal risks are similar to that of a conversation or discussion in a public educational setting.

#### **CONFIDENTIALITY**

A recording of this group discussion will be stored in a password protected cloud-based file. Name will be changed to pseudonyms. No names or personally identifying information will be included in any reports or presentations based on this data. Your responses in this group will remain anonymous.

#### **CONTACT**

If you are interested in the culminating results of the research, or you have further questions or concerns about your rights as a participant in this survey, contact Andrea R Johnson, MA, M.Ed at [REDACTED]. Additionally, if you have questions about your rights as a research subject, you may contact Dr. Angela Elkordy, Chair of this study ([aelkordy@nl.edu](mailto:aelkordy@nl.edu)) or the National Louis University IRB Chairs at (630) 874-4117 or [IRBMailbox@nl.edu](mailto:IRBMailbox@nl.edu).

#### **WITHDRAWAL**

If at any point, you would like to withdraw from participating in the focus group, you are able to do so.

Introduction of myself and my why

#### **Questions:**

Let's Introduce ourselves (first name, current role in education, region that you live). Remember first names only and names may be changed to pseudonyms for the research.

1. What is your ADHD diagnosis journey?

2. Identity can be defined by a lot of different categories, gender, sexuality, ethnicity, ability/disability, talents, religion, nationality, family dynamics, educational skills, etc. Identity is essentially how people define themselves. How is your identity connected to ADHD?
3. How do you define/describe ADHD and what it means in your life? Are there any metaphors or similes that you could use?
4. Did you disclose your disability in college? Why? Or Why not?
5. Do you or did you use any resources (at school, at work, Medical, or community) to support your navigation and success in institutions like school? college? work? If so, Which ones? How did you get connected? Why use the resource? If not, why not?
6. Do you feel positively about ADHD? Why or Why Not? Give examples.
7. What do you wish an adult would have done for you while you were in school that would have helped you? Tell me about a time that sticks out to you where an adult helped.

## Appendix C: Interview Questions

### **INTERVIEW QUESTIONS** \*presented orally and visually via Google slides

1. Just to get a little background information about you, please tell me a little about yourself (who you are, what type of work you do, where you went to school?).
2. Identity can be defined by a lot of different categories, gender, sexuality, ethnicity, ability/disability, talents, religion, nationality, family dynamics, etc. Identity is essentially how people define themselves. Is your identity connected to ADHD? How?
3. Talk to me about your diagnosis journey.
4. Please tell me a story of how ADHD was/is evident in your life.
5. Do you feel positively about ADHD? Why or Why Not? Give examples.
6. Do you or did you use any resources (at school, at work, Medical, or community) to support your navigation and success in institutions like school? college? work? If so, Which ones? How did you get connected? Why use the resource? If not ,why not?
7. What do you wish an adult would have done for you while you were in school that would have helped you? Tell me about a time that sticks out to you where an adult helped.

## Appendix D: Consent for Focus Group and Interview Participants

### **CONSENT FOR PARTICIPATION IN THE STUDY**

I am a doctoral student at National Louis University. I'm also a mom, an educator of over 20 years, and passionate about the growth and development of all adolescents, particularly those who are "different." As I contemplated the topic for my doctoral research, I found myself drawn to the idea of identity and its impact on individuals. I've had students with ADHD who were very aware of their needs and were able to advocate for themselves confidently. I've also had students who refused essential help in the efforts they made to conceal their differences.

This study is aimed at collecting the perspective of educators with ADHD learning about the impact that adults had in their lives which may have shaped their understanding and adoption of ADHD as part of their identity. The goal is to be able to learn how educators may be able to positively impact identity development.

Thank you for your willingness to participate and share your perspective.

Please contact Andrea Johnson at [REDACTED] if you have questions about the survey.

### **PARTICIPATION**

Your participation in this study is voluntary. You may refuse to take part in the research or exit the study at any time without penalty. You may skip any question you do not wish to answer for any reason.

### **BENEFITS & RISKS**

Your responses will help me learn more about the experience of adults with ADHD. There are minimal risks to your participation. The minimal risks are similar to that of a conversation or discussion in a public educational setting.

### **CONFIDENTIALITY**

The recording of today's discussion will be stored in a password protected cloud-based file. Pseudonyms will be used during the analysis and sharing of the data. Only the researcher and the dissertation chair will have access to the original recordings. Your responses in session will remain anonymous and the data will be destroyed upon the conclusion of the study.

### **CONTACT**

If you are interested in the culminating results of the research, or you have further questions or concerns about your rights as a participant in this survey, contact Andrea R Johnson, MA, M.Ed

at [REDACTED]. Additionally, if you have questions about your rights as a research subject, you may contact Dr. Angela Elkody, Chair of this study (aelkordy@nl.edu) or the National Louis University IRB Chairs Dr. Shaunti Knauth (shaunti.knauth@nl.edu) or Dr. Christopher Rector (CRector@nl.edu).

## **WITHDRAWAL**

If at any point, you would like to withdraw from participating in the study, you are able to do so.

## **ELECTRONIC CONSENT:**

Please select your choice below. You may print a copy of this consent form for your records. Clicking on the "Agree" button indicates that:

- You have read the above information and understand the benefits and risks
- You voluntarily agree to participate
- You are 18 years of age or older

Clicking on the 'Disagree' button will end your participation in the study.

☐ I agree with the statements above

☐ I disagree with the statements above



## POST for SOCIAL MEDIA

# YOUR ADHD Story

As an educator with ADHD you have a unique perspective that can help other educators.

**PLEASE HELP!**

**PLEASE COMPLETE THIS  
BRIEF SURVEY THAT WILL  
SHARE YOUR STORY AND  
YOUR STRATEGIES**

