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Transitional Experiences of Post-Secondary Students with Non-Disclosed Disabilities

Sierra E. Headrick

Eastern Illinois University

## ABSTRACT

The purpose of this study was to examine the transitional experiences of undergraduate students with non-disclosed disabilities and gain insight on the intentions of students choosing the route of non-disclosure in higher education. It was found that students with non-disclosed disabilities have significant challenges with managing their workloads and stress in their transition into college. Additionally, changes in support from high school to college have a significant influence on self-disclosure of disabilities. With parental guidance lacking from the participants' support systems in post-secondary education, it was found that changes in support among the group's transition into college may be a present factor in the participants' decision not to disclose their disabilities. It was also found that awareness of negative stigma towards disabilities can influence disclosure and disability identity in students with invisible disabilities. For these reasons, it is important for professionals in higher education to encourage positive conversations about disability and encourage students to disclose disabilities early in their transition.

## ACKNOWLEDGEMENTS

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## CHAPTER I

### Introduction

In the United States, 11% of undergraduate students in a post-secondary educational setting report having at least one disability (National Center for Education Statistics, 2016). Additionally, the number of college students with learning disabilities has doubled since the early 2000's (Vickers, 2010). Disability is defined as a “physical or mental impairment that substantially limits one or more major life activity” (ADA, 2017, para. 3). Many of the physical impairments recognized as disabilities effect mobility and movement, such as cerebral palsy, paraplegia, and multiple sclerosis (MS). However, “the universal symbol of disability—found on parking spaces, restrooms, and doors of public buildings—is the wheelchair, yet most college students with disabilities do not have physical disorders" (Lee, 2014, p. 40).

The majority of disabled students in post-secondary education have learning disabilities, such as Attention Deficit Disorder (ADD), or mental disabilities, such as psychological and mental health disorders (Raue & Lewis, 2011). Most individuals with these kinds of disabilities can easily ‘pass’ as non-disabled and do so in order to avoid social stigma (Davidson & Henderson, 2010). Unfortunately, it is more likely for students with hidden or invisible disabilities to fall behind educationally if they have not self-disclosed their disability to their institution (Leake & Stodden, 2014). Current federal accommodation laws require self-disclosure of disability to the institution in order to gain access to accommodations and appropriate support services (O’Shea & Kaplan, 2017). Therefore, disclosure of disability plays a large role in transitional success and retention rates for this group of students.

Individuals with disabilities have been historically excluded, marginalized, abused, and neglected by society. Along with the Civil Rights Movement in the 1960’s, the Disabilities

Rights Movement fought for equal rights and opportunities for individuals with disabilities (Shyman, 2013). Soon after, federal laws and regulations began to reflect the demands of the movement by giving individuals with disabilities equal access to opportunities as their non-disabled counterparts. The new legislation included mandates for educational accommodations and transitional planning services for students in public K-12 school systems (Eckes & Ochoa, 2005). Institutions of higher education are also mandated by law to provide accommodation services; however, gaining access to these accommodations is dependent on self-disclosure of disability to the institution (O'Shea & Kaplan, 2017).

The likelihood of an individual self-identifying as disabled can depend on a number of factors including level of impairment, demographic (age, gender, race, etc.), and environmental factors such as perceived stigma or social support (Bogart, Bouchard, Lund, & Rottenstein, 2017). Additionally, new college students need to successfully transition to their new environment, which can be even more difficult for those who have additional barriers such as those with disabilities (Davidson & Henderson, 2010). Students who do not self-identify their disability could have significantly more barriers to successful transition due to lack of support. Therefore, the experiences of students with non-disclosed disabilities are important to understand in order to better support this group of students (Longtin, 2014).

### **Purpose of the Study**

The purpose of this study is to examine the transitional experiences of undergraduate students with non-disclosed disabilities in a post-secondary educational setting at a mid-sized, four-year institution located in the rural Midwestern United States. The goal is to gain insight on the intentions of students choosing the route of non-disclosure in higher education. The narratives of students with non-disclosed disabilities are important in analyzing the reason why

this group of students choose non-disclosure and how we, as student affairs professionals, may be able to encourage these students to disclose early on, in an effort to improve retention rates and assist with significant transitional barriers. This study was accomplished by utilizing a qualitative methodology to gain in-depth knowledge about the experiences and perceptions of four undergraduate students with non-disclosed disabilities.

### **Research Questions**

The primary research questions used to guide this study were:

- What are the perceptions of students with non-disclosed disabilities on why they do not disclose?
- What is the high school to college transitional experience of students with non-disclosed disabilities?
- What insights do participants offer to future students who choose not to disclose their disability to their college or university?

### **Significance of the Study**

Obtaining in-depth information about the transitional experiences of students with non-disclosed disabilities could be significant in improving support services for this group of students and increasing their retention rates. The implications of this research has provided useful information about the support systems of this particular group of students in which they may utilize instead of accommodation services. Anderson, Carter and Stephenson (2018) suggested that schools should place a stronger emphasis on providing additional support services outside of the classroom for students with disabilities. Understanding how students with non-disclosed disabilities would like to be supported by their college could be potentially significant in the development and structuring of support services and outreach programming.

## **Limitations of the Study**

Students who feel uncomfortable disclosing their disability to the university may feel similar about disclosing to the researcher. Due to this issue, there was difficulty accessing participants who fit the researcher's criteria and the sample size in this study was small with four participants. Additionally, experiences of this study's participants may not be consistent due to the variance of cognitive functioning among participants. Another limitation of this study is the location and size of the research site. The research site is located in a rural area and may not be reflective of institutional environments located in urban areas. Furthermore, the research site is a mid-sized institution and may not be reflective of larger or smaller institutions.

## **Definition of Terms**

**Accommodations.** Students with disabilities are entitled to request reasonable accommodations be made for their disability. Accommodations can be physical/structural, academic, and instructional. Common accommodations for students at post-secondary institutions include setting alterations, time/schedule changes, and test format changes (Longtin, 2014). These accommodations should provide an inclusive environment for individuals with disabilities.

**Disability.** Disability is defined as a "physical or mental impairment that substantially limits one or more major life activity" (ADA, 2017, para. 3). Disabilities can be physical, hearing-visual, speech-language, intellectual, developmental, and emotional.

**Individualized Education Plan (IEP).** A planning service mandated through the Individuals with Disabilities Education Act (IDEA) which consists of students, educators, guardians, and health professionals to coming together to devise a plan which will best help the student thrive (Hart, Grigal, & Weir, 2010).

**Invisible Disability.** An invisible or hidden disability is a “physical, mental or neurological condition that is not visible from the outside, yet can limit or challenge a person’s movements, senses, or activities” (IDA, 2019).

## CHAPTER II

### Review of Literature

In this section, the legislative history of disability law, the impact of the 20<sup>th</sup> century disability rights movement, evidence of transitional success and access to accommodations for students with disabilities, and relevant theories about development of students with disabilities will be analyzed.

#### Legislative History

Throughout the course of U.S. history and prior to the Disability Rights Movement of the 20<sup>th</sup> century, individuals with disabilities were often excluded, marginalized, abused, and neglected by society (Shyman, 2013). The Disability Rights Movement set forth a plethora of legislative, social, and educational change for individuals with disabilities and the movement laid the groundwork for society to empower, individualize, and liberate individuals with disabilities (Shyman, 2013). The first major piece of legislation for the Disability Rights Movement was the Architectural Barriers Act of 1968, which mandated that all public, government-owned/funded buildings be handicap assessable (Shyman, 2013).

The Architectural Barriers Act of 1968 set the groundwork for the Rehabilitation Act of 1973, which is to this day one of the most notable legislatures in support of the Disability Rights Movement. Specifically, Section 504 of the Rehabilitation Act outlawed overt exclusion of individuals with disabilities and promoted inclusion in educational settings and the workplace (Shyman, 2013). Section 504 specifically mandated that students with disabilities be given the same educational privileges as any other student (Hart et al., 2010). Additionally, in 1972, *Pennsylvania Association for Retarded Citizens v. the Commonwealth of Pennsylvania* became a landmark case for individuals with disabilities. In this case, the argument was made that students

with developmental disabilities were not being given access to appropriate educational services. In response, the court declared it was unconstitutional for public schools to refuse to give accommodations to individuals with intellectual disabilities (Shyman, 2013). Soon after, The Education for All Handicapped Children Act was signed into law in November 29, 1975 by President Ford (IDEA, 2004). For the first time, individuals with all kinds of disabilities were recognized by anti-discrimination and accommodation laws (Lee, 2014). After centuries of exclusion, segregation, and discrimination, children with disabilities were finally given the opportunity to develop and learn in integrated and inclusive atmospheres (IDEA, 2004).

The next major legislature for individuals with disabilities was the Americans with Disabilities Act (ADA), which was signed into law by President George W. Bush in 1990. The new law required that individuals with disabilities are given reasonable accommodations where needed (Hart et al., 2010) and was created to model the Civil Rights Act of 1964 and Section 504 of the Rehabilitation Act, in response to the historical discrimination against individuals with disabilities (ADA, 2009). The legislation recognized that over the course of history, disabled people have been deeply affected by the effects of the exclusion, isolation and segregation from the rest of society. In an effort to alleviate some of these effects, ADA strived to serve as a national recognition that individuals with disabilities can freely participate in all aspects of society free of discrimination due to institutional and social barriers (ADA, 2009).

Title I of ADA covers employment and mandates that individuals with disabilities are given equal opportunity to participate in employment with the “full range” of opportunities which are available to others (ADA, 2009). Title II covers state and local government opportunities and requires equal opportunity to benefit from government programs, services and activities, which include education, employment, and transportation, among many others. Title

II of ADA also mandates that state and local government facilities take reasonable measures to accommodate for individuals with disabilities (as long as it does not cause financial burdens to the institution), in an effort to avoid discrimination (ADA, 2009). Title II covers public transportation, as well, stating that individuals with disabilities shall not be discriminated against by public transportation authorities and shall be given proper accommodations where necessary, such as paratransit services (ADA, 2009). Title III of ADA covers public accommodations, which are all privately owned entities which are open to public use, such as restaurants, private schools, retail stores, and recreational facilities, among many others. These entities, labeled as “public accommodations” by the ADA, must comply with the basic nondiscrimination legal mandates which ban unequal treatment and exclusion of individuals with disabilities (ADA, 2009). Public accommodations must also accommodate individuals with disabilities as long as said accommodation does not cause undue financial burden for the business (ADA, 2009). Title IV of ADA covers telecommunication relay services and mandates telephone companies to provide special services to individuals with hearing and speech disabilities. Typically, this mandate can be achieved by providing telecommunication relay services (TRS), which provides a third party communication assistant to relay messages to and from callers with hearing or speech disabilities (ADA, 2009).

With the passing of ADA, the Education for All Handicapped Children Act was transformed into the Individuals with Disabilities Education Act (IDEA), which further mandated that students with disabilities be given access to public education with appropriate accommodations and in non-restrictive environment (Shyman, 2013). Since the law has been amended, children now have access to individually focused education plans and transitional planning in public K-12 education (IDEA, 2004). Specifically, children and adolescents covered

under IDEA now have access to an Individualized Education Plan (IEP) and are provided with needed transportation, therapy, and parental guidance consultation at no cost to the student's family (Shyman, 2013). The current stated purpose of IDEA is to ensure an appropriate, individualized, and free education is available to all children with disabilities, to prepare students for the future by giving them the tools to successfully develop skills for furthering their education, going into the workforce, and living independently, to protect the rights of children with disabilities and their guardians and to implement and provide early intervention services for small children (IDEA, 2004).

Overall, the main objective of IDEA is to set children up for success in adulthood by providing them the tools to success in K-12 education (Leake & Stodden, 2014) and providing early intervention services for young children and toddlers (IDEA, 2004). As IDEA has evolved and been amended, there has been a larger emphasis placed on transitional services to better prepare high school students for their transition into post-secondary endeavors (Madaus & Shaw, 2006). And although students with disabilities are still enrolling in college at a lower rate than the general population of students without disabilities, the transitional emphases of IDEA is one of the primary factors influencing the steady increase of enrollment of students with disabilities (Madaus & Shaw, 2006).

IEP transitional plans are focused around creating obtainable and realistic goals for the future and creating a plan which will help the student successfully meet those goals (Eckes & Ochoa, 2005). The IEP and transitional planning is special in the sense that it allows for students, educators, guardians, and health professionals to come together to devise a plan which will best help the student thrive (Hart, et al., 2010). However, there will always be various kinds of barriers for students during transitional periods, no matter how prepared they are. The goal is

not to perfect the transitional experience; instead, it is to minimize significant obstacles along the way (Eckes & Ochoa, 2005). Self-advocacy plays a large part in this process, as the goals are centered on the student's personal goals and interests, meaning the student serve as the primary director during the entire process (Eckes & Ochoa, 2005).

**Accommodations in higher education.** As previously discussed, there were many laws put into place during the Disability Rights Movement to ensure appropriate accommodations are made for individuals with disabilities (Hart et al., 2010). Requests for these accommodations have steadily increased as the number of students with disabilities entering post-secondary institutions continues to grow (Eckes & Ochoa, 2005). However, the same laws that mandate accommodations in institutions of higher education also prohibit colleges and universities from seeking out students with disabilities. Instead, the responsibility of disclosing disability is up to the student (Hart et al., 2010; O'Shea & Kaplan, 2017). For many students, accommodations in an academic environment allow them to learn in an inclusive atmosphere and excel along with their peers (Vickers, 2010). Improved academic experience is one of the many reasons why self-disclosure is essential for students with disabilities in order to access proper accommodations in a post-secondary setting (Hart et al., 2010).

If a student chooses to self-disclose their disability to a college or university in order to gain access to the appropriate accommodations, the following services may be available to them: instructional accommodations, academic accommodations, setting alterations, time/schedule changes, and test format changes (Longtin, 2014). None of the listed accommodations change anything about the academic rigor of the student's education. Instead, the services allow for the student to process the information in an individualized way while also allowing them to actively and successfully participate in class discussion and coursework in an inclusive environment

(Longtin, 2014). Due to the multiple benefits of academic accommodations, self-advocacy serves as one of the most critical assets students with disabilities need to have in order to succeed in a college atmosphere. It is essential for students with disabilities to have the ability speak up for themselves in order to access the aforementioned individualized services and accommodations (Longtin, 2014). This process requires quite a bit of self-awareness and self-advocacy on the behalf of the student (Hart et al., 2010). To build skills in self-advocacy and comfortability in discussing their disability, it is important for students to build a rapport with professors and support staff on campus (Hadley, 2006).

To request the previously mentioned accommodations, students must visit their disability resource office on campus and provide the university with documentation of their disability. Many students use IEPs, 504 plans, and summary of performance plans (IEP transition plans) as evidence to request accommodations. However, providing evidence of an Individualized Education Plan is not always sufficient enough for the university to provide accommodations, in which case, the university will typically request an evaluation of the student in order for them to gain eligibility to receive special services under legal mandate (Vickers, 2010).

Some students may find that their disability does not warrant accommodations in post-secondary education as it did in their K-12 education, which is due to the separate laws and mandates colleges and universities run on. The services offered in K-12 are vastly different from the accommodations available in post-secondary education (Eckes & Ochoa, 2005). The laws that govern post-secondary institutions (i.e. ADA and Section 504) are civil rights statutes, not educational statutes, and are more focused on preventing discrimination (Vickers, 2010). Understanding these differences can better prepare students for their transitional experience into college (Eckes & Ochoa, 2005).

## **High School to College Transition**

There is a lack of research on the successful transition of students with disabilities into post-secondary settings. However, it is important, as student affairs professionals, to know what kind of services this group of students may need in order to set them up for a successful transition (Longtin, 2014). Due to the consistent increase in enrollment of this particular group of students, it is more important now than ever before for students, educators, support staff, and parents to understand the significant differences in mandated student support services for students with disabilities in high school in comparison to an institution of higher education (Eckes & Ochoa, 2005). This transitional period intensifies the significance of self-advocacy, as the student no longer has a team of professionals advocating for them when they transition to college (Hadley, 2006).

Over 80% of high-school IEP transition plans list furthering education as a goal (Newman & Madaus, 2015). However, individuals with disabilities in higher education face significant barriers in comparison to their counterparts, especially when it comes to academic success and graduation rates (Abreu, Hillier, Frye, & Goldstein, 2016). Recent research has suggested that in a post-secondary educational setting, students with disabilities have a much lower retention rate, are more likely to attend junior college than four-year institutions (Leake & Stodden, 2014), are less likely to enroll in post-secondary education in general, and take more time to complete their desired degree program in comparison to their counterparts (Kim & Lee, 2016). In regards to retention rate of students with disabilities, research shows that many of these students choose to opt out of living in residential communities on campus, lack preparedness for academic rigor in higher education, and delay the start of their post-secondary

education after high school (Kim & Kee, 2016). Each one of these factors has been linked to lower retention rates of students in post-secondary institutions (Kim & Lee, 2016).

Research has also suggested disclosure of disabilities in order to receive appropriate accommodations may enhance experiences some of these areas, such as academic achievement (O'Shea & Kaplan, 2017). Many students with disabilities experience significant academic challenges, specifically those who have learning disorders. As previously discussed, institutions are federally mandated to be equipped to provide accommodations for these students. However, there can be significant barriers in accessing these resources, which are often related to disclosure of disability, navigation of the process to request accommodations, and understanding the substantial differences between accessing similar resources in high school compared to college (Abreu et al., 2016).

Researchers have also found when students with learning disorders are faced with significant challenges in the classroom, they often do not feel comfortable discussing it with their professors, as they do not wish to disclose their disability. This self-disclosure can be a significant challenge for students with disabilities and can make the adjustment period during their transition feel overwhelming (Hadley, 2006). Research has suggested utilization of Disability Services and accommodations can significantly impact a student's grade point average (GPA), as a positive correlation between frequency of visits to the Disability Services office and GPA was found in a recent study (Abreu et al., 2016). Outside of the classroom, traditional factors are also significant for students with disabilities to consider when transitioning to an institution of higher education. Examples of traditional factors are enrollment status (full-time or part-time), living arrangement, grade point average, and cost of attendance (Kim & Lee, 2016).

**Barriers to disclosing disability.** Individuals with disabilities are a part of a minority group which is often stigmatized through labeling, stereotyping, separation, loss of status, and discrimination (Daley & Rappolt-Schlichtmann, 2018). Many individuals are aware of the negative societal perceptions associated with their minority group. This awareness is characterized by the person understanding or believing that they are seen as a stereotype more than an individual person (Daley & Rappolt-Schlichtmann, 2018). Often, individuals within minority groups will band together to support one another, lift self-esteem and build pride within their community. However, this unity is a phenomenon which is not common for individuals with disabilities (Bogart, Lund, & Rottenstein, 2018). Instead of gravitating towards other people with disabilities, individuals that are conscious of the stigma associated with their disability often feel pressure to assimilate and isolate themselves from other disabled individuals (Bogart, Lund, & Rottenstein, 2018). Furthermore, research has suggested that students may be avoiding disclosure of disability in college due to societal perceptions and influences (Hong, 2015).

In a recent study, four major themes of barriers in which college students with disabilities face were found. These barriers are faculty perception, fit of advisors, college stressors, and quality support services (Hong, 2015). It seems that although students with disabilities are continuing to enroll in college at increasing rates, the institutions may be struggling with accommodating and supporting these students beyond what is legally obligated. Additionally, the study found that individuals with disabilities are less likely to self-advocate, self-regulate, develop an effective locus of control, and be self-aware. These struggles, combined with the lack of supportive resources, can lead to unsuccessful assimilation and transition into a new environment. That, coupled with the fear of being perceived as less capable or being treated

differently than other students often holds students back from discussing accommodation needs with their professors (Hong, 2015).

On the other hand, research suggests that when the correct social conditions exist and individuals with disabilities are properly accommodated for, they are more likely to self-identify their disability. The likelihood of an individual self-identifying as disabled can depend on a number of factors including level of impairment, demographic (age, gender, race, etc.), and environmental factors such as perceived stigma or social support (Bogart, Bouchard, Lund, & Rottenstein, 2017). Recent studies show that self-identification of an individual's disability is linked to higher reported self-esteem and sense of pride in his/herself (Bogart, Lund, & Rottenstein, 2018).

### **Theoretical Framework**

Transitional experiences of students with disabilities are unique due to the significant barriers they experience. Not only are they going through a major transition into a new atmosphere along with the multiple barriers outlined by Schlossberg (1984), but they also are faced with significant barriers to successfully transitioning due to their disability. These barriers are especially significant for those who choose the route of non-disclosure or who do not self-identify themselves as being disabled, as outlined by Davidson and Henderson (2010). As previously stated, there is a lack of research on the successful transition of students with disabilities into post-secondary settings. However, the lack of research does not negate from the fact that transitional experiences of students with disabilities are important to understand in order to offer valuable and successful support services to this group of students (Longtin, 2014). In order to gain better understanding of the intersection of transition and disability, this study will use a combination of transition theory and disability theory as a framework.

**Transition theory.** Schlossberg's 1984 theory of transition is a psychosocial model of development which examines experiences and major life events that effect many aspects of a person's life, also known as transitions. This theory is focused heavily on perceptions of transition and encourages assessment and reflection to work through coping strategies. The first step in this assessment of transition is identifying the type of transition. Schlossberg (1984) classifies transitions as anticipated, unanticipated, event, non-event, or chronic. Anticipated transitions are predicted based off normal life cycles, such as puberty, moving out of parents' house, etc. The unanticipated transitions, however, are the opposite and not predicted or expected at all. An event transition is expected and counted on by the individual, as is a non-event. However, the difference between an event and a non-event is that the non-event never actually happens, while the event does. The last type of transition, the chronic transition, is actually a response to disruptions in the person's life due to other types of transition (Schlossberg, 1984).

The second step in transitional examination as outlined by Schlossberg (1984) is evaluating the context of transition. It is essential to determine whether the transition personal, interpersonal or community related. The last step is to assess how much of the persons daily life has been altered. During transition, the role of perception also plays a large part. First, there is primary appraisal, which is how the individual feels about the transition in general. Then secondary appraisal, which is how the individual feels about their resources helping them through their transition. Once the examination of transition is complete, the individual must move on to coping resources. These resources are *situation, self, support, and strategies* (Schlossberg, 1984).

*Situation* refers to: the timing of the transition, the person's control over the situation, if the transition is going to cause a significant role change for the individual, duration of the transitional period, if the individual has previous experience with significant transitions, stress of the individual in transition, and at last, reflection of transition. Once there is reasonable understanding of the situation, there is a shift to one's *self*. This shift involves assessment of the way which the individual's personal and demographic characteristics are affecting how he/she views life. Reflection on this aspect can help the individual in coping with their transition.

*Support* refers to the type, function & measurement of support one is receiving through intimate relationships, family units, networks of friends, institutions and communities. The last coping resource as outlined by Schlossberg (1984) is *strategies* through transition, which can involve modification of the situation, controlling or changing the meaning of the dilemma or issue, and managing stress.

**Disability theory.** New college students with disabilities will face extended and additional barriers during their transitional experience and beyond. These barriers are especially significant for the students who chose the route of non-disclosure during their transition into higher education. Despite the implication that utilizing support services enhances the college experience for student with disabilities, many students with invisible or hidden impairments (i.e. intellectual and developmental disorders) are less likely to disclose their disability to their college or university, as they often do not see themselves, or "self-identify", as being disabled (O'Shea & Kaplan, 2017) and can easily *pass* as being without disabilities (Davidson & Henderson, 2010). Failure to self-identify with disability can likely be attributed to a number of various factors. To this day, there is a persistent negative societal stigma on disabilities, which can be impactful on self-esteem of individuals who have any kind of disability, especially during

young adulthood (Hong, 2015). Society typically paints an image of individuals with disabilities (intellectual disabilities, specifically) as socially incompetent and bizarre. In response to these negative social stigma's many individuals with invisible impairments will make the choice to disassociate themselves with that image by denying their disabilities (Bogart, Lund, & Rottenstein, 2018). While individuals with physical, visual, or hearing disabilities are less likely to 'pass' as a non-disabled, individuals with invisible disabilities can often times blend themselves in without their disability being noticed. Disassociation is often an attractive option for these students due to the fear as being labeled and placed in a negative category by their peers, educators, and family (Davidson & Henderson, 2010).

A group which struggles deeply with self-identification is individuals with invisible disabilities which were diagnosed later in life, as opposed to childhood diagnosis. Until the point of diagnosis, these individuals typically go about their lives feeling "different" than those around them, but not knowing or understanding the reason why. The point of diagnosis can be a complicated part in a person's development of self-image, which is a process that can be damaging to individuals who do not have the ability to understand themselves fully until early adulthood. On the other hand, the experiences of individuals who are diagnosed in the earlier stages of their lives are largely impacted by the people closest to them. For this group, the attitudes of their loved ones, in relation to the perception of individuals with disabilities, are deeply embedded in the willingness to disclose their disability in early adulthood (Davidson & Henderson, 2010).

Davidson and Henderson (2010) described the process of self-identifying disability as a parallel to the process individuals in the lesbian, gay, bisexual, transsexual, and queer (LGBTQ+) community go through when 'coming out' to those around them. In both situations, the

individuals are required to push against the stigma within their respective family dynamics and peer-groups to successfully accept their identity and self-advocate. However, if a person can easily “pass” as non-disabled and significant stigmas exist within their relationships, the more appealing option may be to withhold information about their disability. It is important to address that withholding of information in this type of way is not intended to be deceptive by those who make that choice. Instead, choosing the route of non-disclosure is often a defense of a person’s own self-image, reputation, and personal relationships (Davidson & Henderson, 2010).

Davidson and Henderson (2010) outlined repertoires in which individuals with non-disclosed disabilities use to self-identify. These repertoires are *keeping safe*, *qualified deception*, *like/as resistance*, and *education*. *Keeping safe* refers to a person protecting him/herself from discrimination by choosing non-disclosure of disability. *Qualified deception* focuses on the individual making intentional choices about who will or will not know about his/her disability and to what degree. *Like/as resistance* is the process of taking on a new identity by openly self-identifying with his/her disability. Lastly, *education* refers to participation in his/her community by building and advocating for others with disabilities (Davidson & Henderson, 2010).

### **Summary**

Post-secondary students with disabilities take on multiple identities, which are influenced by family, friend groups, and living conditions (Patton, Renn, Guido, & Quaye, 2016). Disability identity is described as “a matter of individuals, their environment, and the interactions between the two,” (Patton, 2016, p. 234). As Schlossberg’s theory (1984) explained, as new college students are adjusting to their new-found freedom and learning how to navigate a new environment, they may experience significant barriers personally, interpersonally, and within their community. For students who have not “come out” with having a disability, as

Davidson and Henderson (2010) discuss, they are likely experiencing significant barriers with their transition to college, their disability, and the intersection between the two.

## CHAPTER III

### Methodology

This study utilized Yin's (2010) five features of qualitative research as a framework for methodology. The first feature of qualitative research according to Yin (2010) is studying the meaning of people's lives under real-world conditions. This feature includes studying the participants' performance in their everyday lives. In a qualitative study, there are no pre-established answers to questions as there would be in a quantitative questionnaire, therefore, participants in this study had the opportunity to express themselves in whatever way they see fit. The next feature outlined by Yin (2010) is representing the views and perspectives of the people in the study. Specifically, the perspectives of participants in this study were not minimized by the research. Instead, individual perspectives were the major purpose of this qualitative research study.

Another major piece of performing qualitative research is covering the contextual conditions within which people live (Yin, 2010). These conditions include social, institutional, and environmental conditions which may serve as a strong influence in participant's lives. These conditions are difficult to study quantitatively, as significant conditions may be left out of the set of variables. Additionally, qualitative research is used to contribute insights into existing or emerging concepts that may help to explain human social behavior. Yin stated, "Qualitative research is driven by a desire to explain these events, through existing or emerging concepts," (2010, p. 8). Furthermore, Yin (2010) stated qualitative research should strive to use multiple sources of evidence rather than relying on a single source alone. These sources include the study of participants and the world they live in. The complexity of these sources can add to the credibility and trustworthiness of the research (Yin, 2010).

## **Design of Study**

This study utilized a qualitative approach to gain in-depth knowledge about the experiences of post-secondary students with non-disclosed disabilities. The researcher used a case-study method to achieve these results. According to Creswell and Poth (2018), case studies can be used for intensive data collection, which is warranted in this study. There were four participants included in this study and in order to collect data, the researcher conducted in-depth, one-on-one, private interviews with each participant (one interview for each). The researcher utilized a semi-structured interview format which consisted of a mix of open-ended and close-ended questions, as detailed in Appendix B.

## **Participants**

The researcher purposefully located four participants using the following criteria. All participants must (1) have a diagnosed disability which they have not disclosed to their institution, (2) be an undergraduate student. These criteria were used in order to obtain in-depth narratives about high-school to college transitional experiences of students with non-disclosed disabilities. The participants in this research are members of a vulnerable population. Therefore, there were additional steps taken to ensure the participants would not be physiologically unharmed before, during and after interviews were conducted.

To locate participants who met the outlined criteria, the researcher sent a request for participation email to undergraduate students at the research site (Appendix A). This email outlined the second criteria for participants and offered a \$25 Visa gift card incentive for students who met the outlined criteria and were chosen to participate in the research. All volunteers chosen for participation were asked to read, fill out, and sign a form stating they had an IEP in

high school, along with their informed consent to participate in research (Appendix C). The backgrounds and narratives of the four participants will be covered in detail in Chapter Four.

### **Research Site**

The research site for this study is a four-year mid-sized university located in the rural Midwest. The town in which the university is located within consists of approximately 22,000 residents. The researcher interviewed each participant in a private, secure, and confidential location based off the participant's locational preferences.

### **Instrumentation**

In development of instrumentation for this study, the researcher maintained a strong goal of obtaining all information through the perspective of the participants using non-leading, open-ended questions in a semi-structured interview setting. The researcher had a pre-determined set of questions for the interview but also asked follow-up questions throughout the process in order to gain a deeper understanding of the phenomenon being studied through the perspective of the participants. All participants were asked a semi-structured series of questions covering the following six topics: (1) demographic information, (2) high school experiences, (3) experiences transitioning to college, (4) utilization of support services, (5) disclosure of disability, and (6) student recommendations. Taking the vulnerability of the sample population into consideration, the researcher reminded all participants that they did not have to answer any question that they felt uncomfortable with and that they could opt out of the study at any time before, during, and after the interview. The researcher also debriefed each participant following their interview and offered a referral to a counselor if needed.

## **Data Collection**

The goal of this research was to study each case within real life settings and with multiple sources of information, as outlined by McMillan and Schumacher (2014). Data for this research was collected through semi-structured interviews in a private setting and data collection took place during the third week of the Spring 2020 semester. The first round of emails requesting participation were sent out during the first week of the semester. The first request for participation email received an appropriate amount of responses from the desired number of volunteers, so there was no need to send another round of emails in the next week, as the researcher had originally planned. Potential participants were asked to respond directly to the researcher, who then scheduled the interview. All of the interviews were scheduled for the following week. All interviews were conducted in a one-on-one and private setting to ensure confidentiality. Each interview was audio recorded, which was used by the researcher to transcribe and code each interview and analyze data.

## **Treatment of Data**

Data was collected through an audio recording, with the verbal and written permission of the participants. The researcher utilized the audio recordings to transcribe the interviews. The researcher used interview transcriptions to analyze the narratives of each participant. This data was analyzed using Yin's (2010) Five-Phased Cycle of Analyzing Qualitative Data which includes (1) Compiling, (2) Disassembling, (3) Reassembling, (4) Interpreting, and (5) Concluding (2011).

In the first phase, compiling, the researcher refined and organized all of the gathered data, which resulted in a working database for the researcher to use moving into the next four phases. In the second phase, disassembling, the researcher broke down the collected data into smaller

pieces and assigned each piece with a “code”. This phase was repeated several times until coding was deemed streamlined and effective by the researcher and her advisor. In the third phase, reassembling, the researcher worked on reorganizing the pieces of data from phase two by grouping and sequencing it into themed coding categories. This process was also be repeated several times until the desired outcome was reached. To follow the fourth phase, interpreting, the researcher used the rearranged data from the previous phases to “create a new narrative” (Yin, 2010, p. 179) for the data. Then, the rearranged and categorized data was used to provide analytic perspective of the key participant narratives. And lastly, in the fifth phase, concluding, the researcher drew conclusions based off the interpretation of the findings from the previous stages (Yin, 2010).

Additionally, there was a requirement to complete an informed consent form before participation in this study, which explained the study in relation to: purpose, procedures, potential risks and discomforts, potential benefits, confidentiality, participation and withdrawal, identification of investigators, and rights of research subjects. The informed consent documentation was stored separately from all other data obtained from interviews to ensure the privacy of all participants. All files were stored in a secure hard-drive to ensure confidentiality of the participants and will be disposed of within three years of collection, per Institutional Review Board (IRB) policy.

## CHAPTER IV

### Narrative

This chapter will examine the narratives of all four participants interviewed for this study while providing insight into their experiences. During their interviews, each participant was given the floor to describe their background, explain their experiences in high school, and speak about their transition into college. They also talk about what their support looked like in high school compared to what kind of supports they have currently. Through the use of participant dialogue and narrative, this chapter will provide a deeper understanding of the participants' experiences before the analysis of the interviews in reference to the research questions in the next chapter.

#### Becca

The first participant, Becca, is a 21-year-old white female. She is a senior Corporate Communication major with a 3.95 grade point average. Since Becca is currently in her last semester, she has been applying for marketing, public relations, communication positions in the area surrounding her hometown in Minnesota. Becca was diagnosed with multiple disabilities during her second year of high school and utilized an IEP until graduation.

**High school experiences.** When Becca was in her sophomore year of high school, she suffered from several sport-related spinal fractures. During her recovery, she was diagnosed with Attention Deficient Hyperactive Disorder (ADHD), depression, and anxiety. Until that point, Becca had been a competitive dancer since she was a small child. When describing her experience, Becca said,

It was honestly a huge identity crisis for me. Like, I've been a dancer since I was two years old and now I'm not a dancer anymore.

When reflecting on being diagnosed with depression, anxiety, and her learning disability, Becca describes,

I think there were a lot of things with my back problems and I think that aggravated everything. I think that made it really difficult for me to focus on anything. I used to be a really good student. I was, you know, the straight-A student, a really smart girl in the class, unknowingly smart sometimes. And then I couldn't be that person anymore. Then, that would cause me all sorts of anxiety and I would get depressed. And it would just all kind of spiral and everything would aggravate everything else. And I just wasn't the person that I wanted to be and that was really difficult.

When asked about where her support came from in high school, Becca mentioned that it was mostly her mother,

My mom worked for the school district where I was attending and she did a lot of advocating for me as far as getting my IEP in place and accommodating things with my teachers and stuff like that.

Becca also mentioned she received a lot of support from her teachers and her school counselor. Specifically, she stated,

I had some teachers who were really supportive, really helpful. They were very honest with me, very like, okay, well we don't need to work on this. Why don't you, you know, take all the time you need. And very always trying to kind of check in on me and make sure I was OK. I had a school counselor who was great and always knew what I needed. I was not the kind of person who wanted to say no and she would sometimes step in for me and say, okay, no, we're done now. Like she, she made the decision to pull me out of physics because I wouldn't do it myself. And she kind of placed herself in the position

where I could be mad at her, but I wasn't mad at myself anymore. I think I really needed that.

On the other hand, Becca expressed having teachers that were not accommodating with her disabilities and were hard to work with. When discussing this, Becca explained,

I had some teachers that were not very sympathetic or helpful. They were just very uncompromising with things. I had one teacher who really didn't like me because she didn't think that I advocated for myself enough. She thought that my mom stepped in a little bit too much to help me. It was really frustrating that she didn't want to make accommodations for me. So I had, you know, kind of a mixed experience. Some people were really great, some people were less helpful.

When asked about her grades in high school following her injury and diagnosis, Becca explained she fell behind. At one point, she missed over a month of school, resulting in one of her classmates starting a rumor she had died. When she returned to school, she had a hard time fitting in with her peers and catching up with her schoolwork. Specifically, when discussing this, Becca stated,

I had a lot of difficulty getting assignments done on time because I missed a lot of class. And then also I've really struggled with my ADHD, procrastination, and not being able to get things done. For those reasons, a lot of my participation and assignment grades went way down. There were classes that I failed and there were classes that, with accommodations and help from my teachers, I got A's, so it was really mixed.

Becca also explained she did not remain close with her friends from high school. She said her friendships began to fade away after her diagnosis, which she attributes to her self-isolation.

Although she is not close with her old friends at this point in her life, Becca said she still makes a

point to meet with them once or twice a year for coffee so they can catch up, so she has been able to maintain those friendships over the years.

**Transition to college.** Before attending her current institution, Becca attended a school in Florida for one semester. After that, she took a semester off school and then transferred her credits to her current institution, where she has been for the past two years. When discussing her experiences at her first college, Becca stated,

It was such a big thing for me to go to the fancy, private school. But I still wasn't doing well in school and I was still really struggling with my ADHD, my depression, and trying to get through all of that. I really struggled that semester. There were several classes that I did okay in but there were also a couple of classes that I failed. There was one that I just stopped going to because I just couldn't get the work done and I just didn't want to show up to class anymore.

After experiencing a hard first semester in a place very far from home, Becca decided to return home and take a semester off. She felt “burnt out” on school and knew she needed some time away. She spent her semester off relaxing, travelling, and doing volunteer work in her community. After her semester off school, she decided to transfer to her current university. When talking about her experiences at her current school, Becca stated,

I came here and I was really able to just focus on myself and get myself back together.

That was when I was able to start being successful and really managing in a healthy, positive way. I think I've gotten back to a place where I can actually perform well in the way that I know that I can. So, my experience here has been pretty good.

When asked about what her support looks like at her current institution, Becca explained she still struggles fitting in at times and keeps her friend circle small. Specifically, she said,

I still wouldn't say that I have a very large friend group. I always feel a little bit different than most of my peers. I've never been a real big party person. I always feel like I'm a little step away from everybody else. I have a lot of acquaintances; people I like to talk to. I have some coworkers that I really love. I also have my fiancé, he is originally from Minnesota and that's where I met him and then he ended up coming here for school, too. Now we're finally like in that place where we have, you know, friends that are married and who are in that same kind of mindset as we are. We're not concerned about where we're going to drink on Friday night. That's been really great for me as well, having people who have that same mindset.

Becca also stated the most rewarding thing for her about college has been knowing her past struggles and her ability to persevere through it all. She is very proud to say she is graduating from college at the conclusion of the current semester.

### **James**

The second participant, James, is a 22-year-old white male. He is a senior Political Science major with a 3.75 grade point average. James is graduating at the conclusion of the current semester and has been accepted into a graduate program to continue his studies of Political Science. Further, James is a soccer player and plans to continue playing through his two years of graduate school, as well. His main goal is to play soccer professionally once he is finished with his Masters degree. When James was in his first year of high school, he was diagnosed with Attention Deficit Disorder (ADD). He began taking medication for ADD immediately following his diagnosis and his school worked with him to create an individualized educational plan (IEP). He said through this, he was able to get extended time on tests and private learning space.

**High school experiences.** Unlike the other participants in this study, James attended a private college prep high school. When discussing this experience, James explained,

I asked my parents if I could go to a private school. They didn't make me do it. I just wanted to be challenged. I barely got into the school; I was on the waiting list because I didn't do well on the placement tests. I had to talk to the President of the prep school, do interviews, and I had, like, 10 recommendation letters I had to like give them. It was crazy but I finally got in. So, it was tough to get in and then once I was in the school, it was really hard, but I knew it would make me better and I wanted to be there.

James explained that although he was able to get into the school, he struggled to fit in with his peers. When explaining this experience, James said,

Basically all of the people that went to my school were rich, like, their families had a lot of money, and they had all gone to private school their entire lives. Then, there is me, this underachiever kid with ADD coming from a public school. Everyone was super smart and I was kind of at the bottom. And I hated having a learning disability because I got made fun of all the time. I always felt like everyone around me was geniuses and I was the one left out. Like, I'm not a genius. I'm a regular kid. I always felt like the weirdest one of the bunch when, in reality, I was probably the most normal.

In addition to struggling with fitting in and acclimating to his new school socially, James expressed having a hard time keeping up with his new workload at his high school and struggling to do well on his ACTs. James stated,

So I was in the bottom of my class, I'd say. My grades were bad; really bad. I didn't really under- okay. My freshman year, I didn't really understand what a grade point average was and why it mattered. So I was like, "Oh, I'll just get a D in every class and I'll pass." I

was doing whatever I could to get by. My freshman year GPA was probably a little bit above a 1.0 and then I barely got like a 3.0 my senior year. In my Junior year, I was trying to play soccer and my GPA was too low. To play at a high level school to play, you need to get the grades and I didn't have them. All my friends had so many options going to college. I didn't have many because of my grades. To boost my GPA, I had to take really hard classes when all my friends were taking home economic and gym classes for fun.

When asked about who helped support him through his struggles in high school, James said, It was mostly my parents that helped me through. They were always telling me what I should do to bring up my grades and helping me with my situation. They helped me ask for extended time with testing and they would talk to my teachers when I would forget an assignment or when I'd do bad on a test. So most of my parents were a big advocate for me during all of that. I was also super close with my religion teacher. He was definitely an advocate for me, too. He was close to my parents and was the closest thing I had to a counselor. I'd see him pretty often and he would just help me. Even when I didn't ask for help, he would vouch for me if I did bad on a test or needed help with something. He would always ask me things like, "Why aren't you going to see the teacher after school? You know you need to; you learn slower." It really helped me realize what I needed to be doing to help myself bring my grades up.

Ultimately, James found a silver lining to the difficulties he faced in high school. He stated, The challenge of going to a private school was good, though, because it helped push me through. I'm good with feeling challenged and I've known that from a young age. It kind of motivates me to do better. I feel like if I went to another school where the standards

were lower, I would have dropped down to those expectations. But when the expectations are higher, I always try to step up to those expectations.

**Transition to college.** James came into college with the expectation that it would be easier than his high school experience. However, he learned that he may have been mistaken in this assumption. Although the coursework was not hard, in his opinion, he was stretched thin with all of his commitments and started to fall behind. When discussing this experience, James said,

In my first couple years, I had a hard time with my gen. ed. (general education) classes. Those semesters were tough because I did 18 hours while we were in our soccer season, so I was always busy and I didn't have time for everything that I tried to do. I thought I could do it but I didn't get the best grades.

James also reflected on a low point for his academic involvement in his Junior year. He said that his grades were good, but that he did not feel engaged in the content of his classes and “let off” from trying to get involved. Specifically, when explaining this experience, James stated,

There's a lot of stress when you're always busy, you know, like a lot of anxiety. You're just going through the motions trying to get everything done that's on your plate. Like, you're in certain organizations on campus and doing so much stuff and it can be really overwhelming so you end up putting more effort in to some things and less effort into others. Like, for me, I kind of let off academically during my junior year when I started getting into classes for my major. I liked the classes I was in and I was really interested in the subject, but, I kind of let off by telling myself, "Oh, I'll be fine cause I like this stuff and know this subject well." I made good grades, but I kind of slipped off there a little bit and didn't put as much effort into my education as I would have liked.

James said that overall, he has had a good experience in college and has enjoyed it more than his time in high school. He explained that he always felt like he needed to use his accommodations through his IEP in high school but that he has not felt the need for it in college thus far. James explained,

I don't feel like I need extended time or like any of those like accommodations that I had in the past. I feel like I have kind of grown out of it, I guess. I feel like I'm more on top of my classes and less stressed than I was in high school. Plus, my time is more flexible because I make my own class schedule and I'm responsible for making sure it is balanced out. I've got a good routine now with soccer, so that's been nice to have that consistency.

Although James chose not to disclose his disability and use accommodations through his university, he stated that he feels supported by staff members at his institution. Specifically, James stated.

My old coach was a big advocate for me. He was not necessarily talking to teachers for me, but he always pushed me to do better in school. He knew I was a slower learner than some of the others, so he made me do more hours in the academic center for student athletes. Each team has their players do a certain amount of hours each week in the center and I was doing a little bit more because coach knew I needed it.

Beyond the social support he has received at his university, James has also made an effort to utilize the resources available to him on campus, such as the center for athletic advising and the library for studying and research.

### **Micah**

The third participant, Micah is a 19-year-old white transgender male. He is a sophomore Sociology major with a 2.8 grade point average. Micah is a member of the LGBTQ+ community

and hopes in the future, he will have an opportunity to learn more about the history of his community and stories of those who came before him. Specifically, Micah stated,

I would like to study about the experiences of people living in communities where it's not necessarily safe to be in as a queer person. I think it is kind of sad, but I am really interested in learning more about it. And I would like to be a part of fixing that.

When Micah was 6 years old, he was diagnosed with atypical autism. Immediately following this diagnosis, his school developed an IEP for him. However, when Micah was 17, he was re-evaluated and given a new diagnosis. He was told that he did not have autism, but instead, he had a communication disorder and ADHD. When speaking about his experiences with his IEP, Micah said,

I've had an IEP for as long as I can remember. By the time I was in high school, though, I was in all normal classes and was only using accommodations for extended time on testing and preferred seating. But, I hardly ever really used that by the end of high school.

**High school experiences.** By the time Micah was heading into high school, he was not taking any special education classes and was only using a few of his accommodations, as mentioned above. Micah said he was also able to take a few AP classes during high school as well. When speaking about his grades in high school, Micah stated,

My grades were like A's and B's and maybe one C every here-and-there, too. There were some classes that were really hard for me but I would say, overall, I had pretty average grades and didn't struggle too much.

Micah also expressed that near the beginning of his high school experience (specifically before he came out), he struggled socially and had difficulties making friends. When describing this experience, Micah said,

It was pretty hard for me to make friends actually and I didn't start making close friends until my senior year. That's because I became more comfortable with myself and my role in the LGBT community. So it's like, once I like figured that out, my life changed a lot. I just felt a lot more comfortable with myself after feeling really uncomfortable for so long. So in my senior year, I started making a lot of new friends and I was actually enjoying going out and hanging out with people instead of being a little hermit crab in my room. And I'm still super close with all of my friends from school. Two of my best friends I've known since like third grade and we still talk on a weekly basis.

Micah said that his biggest support came from his friends and teachers. Specifically, Micah said, I'd definitely say my friends were always there for me. And there was this one teacher that hosted Pride meetings every Tuesday. I was really close with her and she definitely helped me with a lot of stuff. So, my support was mainly from just teachers and my friends. They helped through a lot during high school, I would say.

Micah struggled with feeling unaccepted by his family, but he said he was lucky to be able to lean on the other people in his life for support during that time.

**Transition to college.** After graduation from high school, Micah started attending a community college near his home. During his first semester, Micah disclosed his disabilities in order to use accommodations for testing. He said he only used them for the first semester, however, stating,

I only used them for the first semester and then once I finished that semester, I just didn't think I needed them anymore. I just didn't really see the need to have it.

When Micah transferred to his current institution, he decided that he did not want to disclose his disabilities or request accommodations at all. When asked about what his reasoning was behind this decision, Micah answered,

When I transferred here, I just decided to not disclose any of that information here because I honestly just didn't really feel like I needed it anymore. I mean, it was nice to have but if I was never going to use it, I just didn't see the point in going through all of that to get it. At first, my thought was like, "Well like I much rather have it just in case," but like I said, it just wouldn't be worth it if I was never going to use the accommodations anyway.

The college experience has been "pretty normal" to Micah, although he admitted to struggling in some of his classes. When describing his overall experience in college so far, Micah said,

I mean, I'm taking all regular classes and stuff. I mean, honestly my experience just feels pretty normal, like every other student would feel like I do, probably. I do struggle in some classes, but I've been trying to study and have better study habits and stuff. That's something that I do have trouble with. But, I mean, I'm doing fine without accommodations. I think I'm doing pretty well without them. I just feel like people with an IEP... they're normal but I just feel like I'm too old or something like that, if that makes any sense.

When discussing grades, Micah expressed he has struggled to maintain good grades in college.

Specifically, he said,

I've had the lowest grades I ever have here. I got two C's last semester. And honestly, I worked my ass off in those classes. So, I mean, I did my best. In the end, I'm pretty happy with those grades because I worked hard for them. The rest of my grades here have been

A's and B's and I feel pretty proud of myself for that. My parents don't think the same, but I'm just like, "You know what? You try taking that class and you tell me how you feel."

Micah explained that his support system is a little different now than it was in high school even though he has been able to maintain his friendships from that point in his life. When discussing his support system, Micah stated,

My high school friends are definitely still there for me and I have a girlfriend so she's also definitely a major support for me. And I have like two or three friends here who are major support systems for me, too, now. They all really do want me to succeed and I want them to succeed. It sucks sometimes, though, because I really don't have time to hang out with a lot of my friends right now since I've been really busy with studying and stuff. But honestly, I mean I feel really comfortable around them. I met one of my friends here before school officially started; we actually met at the new student orientation. But, since school has started, I spend most of my time doing homework or studying. I've been trying to get that done and out of the way first before doing anything with friends or anything like that.

Micah expressed that he felt like he was able to acclimate to campus quickly. When explaining this, Micah said,

I definitely got settled in here pretty well. I was honestly just happy to leave my house, so I got settled in very easily, whereas a few other people that I know were really homesick and I'm just like, "This is the best thing ever." Being able to be myself has been so rewarding and this place is like home. Back home, I still have some family members that don't accept me for who I am. And I just feel kind of restrained by that. But living here, I just feel so much more open and happy about myself.

## Jasmine

The fourth and last participant, Jasmine is an 18-year-old black female. She is a freshman Public Relations major with a 1.8 grade point average. Jasmine is from Chicago, IL and hopes to return home after receiving her degree to give back to her community and work with the public at a Non-for-Profit organization. When Jasmine was in sixth grade, she was diagnosed with Dyslexia, a learning disability, and was put on an IEP in school to assist with her reading and writing skills.

**High school experiences.** Jasmine attended a charter school, which is a publicly funded school which operates outside of the state school system. Jasmine explained there are many charter schools in Chicago, and many of them are the best option for students like Jasmine living in substandard school districts. When explaining her experiences at this school, Jasmine stated,

I didn't really like high school. I felt like I had this perception of high school and how I wanted it to be. And then the high school that I went to was nothing like it... It was a very small charter school in the city and the population was more Hispanic than black. And I don't know, there's just very, I had a lot of challenges in high school. Like I said, I'm the kind of person that likes everybody to be treated the same. If I feel a certain type of way about something, I'm going to say something because a lot of people won't. In high school I tried to voice my opinion on a lot of things. But I couldn't do it by myself and I can only speak for myself and my experiences. I feel like that's one thing that, you know, was a big part of me in high school.

When discussing her grades in high school, Jasmine explained she struggled at first. Specifically, she said,

My grades in high school were okay. I feel like when I started high school, I wasn't doing well and I didn't feel smart. So at first I was getting bad grades but they got better by the end of my first year. I think using my IEP back then helped me. My grades after that... they weren't great, but I'd say they were average. I was involved in a lot, too. My high school was really big on extracurricular activities so I ran track, joined clubs, and did volunteer stuff with the school. I did a lot of that kind of stuff in high school and that is definitely one thing I'd like to do more of here.

Jasmine stated her biggest supporters in high school were her mother and her high school counselor. When speaking about her support system, Jasmine stated,

My support in high school was mostly my mom, but it's kind of complicated. Like, she is definitely not my emotional support. She's my physical, financial, everything else type of support, but not emotional. I had a counselor in high school. That's the one thing I can say about that school. They did support their students and I got a lot of support from them.

Jasmine continued to express appreciation for the support she was able to receive in school. She also explained that by the time she was in her last year of high school, she was no longer using her accommodations through her IEP, which ultimately led to her decision to not disclose her disability to her university.

**Transition to college.** At the time of her interview, Jasmine was in her second semester at her university and had been placed on academic warning for the semester prior. Specifically, she stated,

In my first semester, I can say I was kind of bullshitting and I wasn't being as serious as I should have. I remember it was because of a lot of things and I really had to get right with myself in so many ways. I ended that semester on academic warning. But, everything has

been going good this semester. I've been passing my tests and everything on the normal homework assignment. I feel like I work well under pressure, so I have six classes. I don't know why but I need that structure because if I have four classes, I drop the ball.

When discussing her friend group in college, Jasmine expressed she struggled to make friends in her first semester, too, stating,

I really don't know why, but I feel like I'm more so now getting into my college experience because first of semester I wasn't a very social person. I just usually don't like to socialize with people that often. So I kind of stayed to myself and didn't make friends last semester. So this semester is when I really tried to break out of that. Now I have some friends that are getting on my nerves and then I have some that are cool and laid back. I probably fall in between the two. So I feel like my group is growing but I definitely like to keep it small.

Although Jasmine has had some struggles during her time in college, she said that she feels like she has enjoyed it much more than high school. She feels more supported at her current institution than what she did in high school and has been able to develop better support systems.

When explaining her current support systems, Jasmine said,

I feel like I have more support now than I did in high school. I mean I don't go talk to counselors here; I just cry about it and figure it out, talk to my friends or cousins. But I feel like I have strong support because my friends are very supportive. And then with my mom, I don't know, she hasn't ever really been involved in my life. I mean she's been there but not really caring about anything other than my grades and stuff. But lately she's starting to come around more to ask questions and be more supportive. And my dad is very supportive, so that's good, too.

Jasmine said her favorite thing about her college experience is that anytime she needs help with something, there is always some kind of resource for her to use. She mentioned talking to her professors after class and utilizing the library often during her time at her current institution.

### **Summary**

This chapter explored the narratives all four participants while providing insight into their backgrounds and experiences in high school and college. Chapter Five will cover the analysis of all participant interviews and relate their personal narratives of their experiences to the research questions presented in this study.

## Chapter V

### Analysis

The purpose of this study was to examine the transitional experiences of undergraduate students with non-disclosed disabilities in a post-secondary educational setting at a mid-sized, four-year institution located in the rural Midwestern United States. The goal was to gain insight on the intentions of students choosing the route of non-disclosure in higher education. This chapter will explore the findings of the research through the participant interviews.

The following research questions were used to guide the study and analysis: (1) what is the high school to college transitional experience of students with non-disclosed disabilities, (2) what are the perceptions of students with non-disclosed disabilities on why they do not disclose, and (3) what insights do participants offer to future students who choose not to disclose their disability to their college or university. Additionally, Schlossberg's 1984 theory of transition and Erickson and Davidson's 2010 disability theory were used as guides for analysis.

#### **RQ1: What is the high school to college transitional experience of students with non-disclosed disabilities?**

To gain depth and understanding of the transitional experiences from high school to post-secondary education, the participants in this study were asked to reflect on their high school experiences and what their support system looked like during that time. They were also asked to provide insight and reflection on their transition into post-secondary education, how their experience in college has been, and what their support system in college has looked like compared to what it was in high school.

**Situation.** In the transition from high school to college, all four of the participants noted increase in workload and feeling overwhelmed with school work as the most challenging aspect of their transition to college. When discussing his overwhelming workload, James expressed,

There's a lot of stress when you're always busy, you know, like a lot of anxiety. You're just going through the motions trying to get everything done that's on your plate. Like, you're in certain organizations on campus and doing so much stuff and it can be really overwhelming so you end up putting more effort into some things and less effort into others. I liked the classes I was in and I was really interested in the subject, but, I kind of let off by telling myself, "Oh, I'll be fine cause I like this stuff and know this subject well." I made good grades, but I kind of slipped off there a little bit and didn't put as much effort into my education as I would have liked.

For Becca, in her first semester of college, before she took her semester off school, she stated that she was not managing well with her new workload and without her accommodations.

Specifically, she said,

I kept thinking to myself, "I'm going to be fine, I'm off college, you know, fresh start, I'm going to be able to manage this all by myself." Then, I got to the point when I started to realize I was not managing well; I was struggling and I knew I should've been getting help. But, by then, I felt like I was already too far in, you know what I mean? Like, it'd be weird to start saying things and asking for help now.

In Schlossberg's theory of transition, *situation* refers to the timing of the transition, the person's control over the situation, if the transition is going to cause a significant role change for the individual, duration of the transitional period, if the individual has previous experience with significant transitions, stress of the individual in transition, and reflection of transition

(Schlossberg, 1984). The change in workload from high school to college resulted in Micah, Jasmine, and James struggling with their grades. For Jasmine, she struggled during her first semester and was placed on academic warning. When explaining her struggles, Jasmine stated,

In my first semester, I can say I was kind of bullshitting and I wasn't being as serious as I should have. I remember it was because of a lot of things and I really had to get right with myself in so many ways. I ended that semester on academic warning.

**Support.** While reflecting on their high school experiences, three of the participants noted having a hard time maintaining friendships in high school and expressed that their support came, for the most part, from their parents. For Micah, he felt that his support system in high school was his friends and his teachers. He did not mention his parents or family when discussing his support system. However, for the three other participants, Becca, James, and Jasmine, all put their parents at the top of their list for who supported them during high school.

Becca mentioned her mother worked for the school district she went to school in, so she was aware of the requirements for putting an IEP in place and advocated for Becca while she was recovering from her injuries and dealing with her depression, anxiety, and ADHD. Becca mentioned that her mother's involvement in her academics seemed to bother some teachers, stating,

I had one teacher who really didn't like me because she didn't think that I advocated for myself enough. She thought that my mom stepped in a little bit too much to help me.

Similar to Becca, James named his parents as his biggest supporters during high school. James explained that his parents didn't stop at supporting him and giving him advice, they also directly advocated for him with the school and with his teachers. Specifically, he said,

It was mostly my parents that helped me through. They were always telling me what I should do to bring up my grades and helping me with my situation. They helped me ask for extended time with testing and they would talk to my teachers when I would forget an assignment or when I'd do bad on a test.

However, for Jasmine, she said she felt supported by her mother, but that it was a complicated situation. While reflecting on the ways in which her mother supported her during that time in her life, Jasmine said,

My support in high school was mostly my mom, but it's kind of complicated. Like, she is definitely not my emotional support. She's my physical, financial, everything else type of support, but not emotional.

In their interviews, each of the four participants mentioned receiving support from their high school teachers. Becca said that some of her teachers were very accommodating while others were not, Micah had a close relationship with a teacher who served as his school's Pride advisor, Jasmine said she felt overall supported by her teachers and her school system, and James was close with one teacher specifically. While explaining his relationship with his Religion teacher from high school, James said,

Even when I didn't ask for help, he would vouch me if I did bad on a test or needed help with something. He would always ask me things like, "Why aren't you going to see the teacher after school? You know you need to; you learn slower." It really helped me realize what I needed to be doing to help myself bring my grades up.

*Support* is a coping resource used by individuals experiencing life transitions utilized through intimate relationships, family units, networks of friends, institutions and communities (Schlossberg, 1984). In high school, many of the participants received support through their

parents and teachers. During their transition into college, support for all of the participants took a shift, which could have acted as a barrier if they were not able to facilitate new relationships with friends, faculty, or staff during their transitional period. However, all of the participants stated they were able to find new support systems in their new environment. For Jasmine, she expressed feeling more supported by friends and family in college than in high school.

Specifically, she stated,

I feel like I have strong support because my friends are very supportive. And then with my mom, I don't know, she hasn't ever really been involved in my life. I mean she's been there but not really caring about anything other than my grades and stuff. But lately she's starting to come around more to ask questions and be more supportive. And my dad is very supportive, so that's good, too.

Like Jasmine, Micah expressed feeling a high level of support in college. He attributed this to feeling accepted and welcomed at his university, which is not a feeling he had previously. When explaining his change in support, Micah said,

My high school friends are definitely still there for me and I have a girlfriend so she's also definitely a major support for me. And I have two or three friends here who are major support systems for me, too, now. Back home, I still have some family members that don't accept me for who I am. And I just feel kind of restrained by that. But living here, I just feel so much more open and happy about myself.

Becca also expressed feeling supported well in college and expressed that although she does not have a large friend group, she has received a lot of support from her fiancé and a few of her close friends. She said that as she has grown, she has been able to find supportive friends who are

interested in the same things as her, which has been rewarding. When discussing these friendships, Becca said,

Now we're finally in that place where we have, you know, friends that are married and who are in that same kind of mindset as we are. We're not concerned about where we're going to drink on Friday night. That's been really great for me as well, having people who have that same mindset.

While three of the participants reported feeling most supported in college by their friends, James stated his former coach was the biggest source of support for him during his time in college, specifically saying,

My old coach was a big advocate for me. He was not necessarily talking to teachers for me, but he always pushed me to do better in school. He knew I was a slower learner than some of the others, so he made me do more hours in the the academic center for student athletes. Each team has their players do a certain amount of hours each week in the center and I was doing a little bit more because coach knew I needed it.

In summary, the majority of the participants stated their parents advocated them in high school in regards to getting their IEPs put in place and suggesting use of accommodations. In the transition from high school to college, the participants were able to find new support systems through friendships and relationships with staff on campus, which likely served as a useful coping resource during their transition into their new environment. However, interestingly, none of the participants mentioned their parents as support during their post-secondary educational experience. Since the participant's parents were, for the most part, their advocates in regard to their facilitating their IEPs, disability diagnoses, and utilization of accommodations in high

school, the change in support by parents could be a significant factor in the participants' decision not to disclose their disabilities to their university.

**RQ2: What are the perceptions of students with non-disclosed disabilities on why they do not disclose?**

The participants in this study were asked various questions throughout their interviews which covered their definition of disability, how they viewed others with disabilities, how they think people talk about disability and how they've seen it portrayed in the media in an effort to gain perspective on why students with invisible disabilities may chose the route of non-disclosure in post-secondary education.

**Self.** During a significant life transition, once there is reasonable understanding of the situation one is in, there is a shift to one's *self*. This shift involves assessment of the way which the individual's personal and demographic characteristics are affecting how they view life (Schlossberg, 1984). Reflection on this aspect can help the individual in coping with their transition.

To gain better understanding of the participant's perspective on disability in conjunction with their own self-identity, each participant was asked how they define disability. This question came as a surprise for many of the participants, as many of them struggled to find the right words to describe what disability is in their perception and the majority made it a point to say they did not consider themselves as having disabilities or being disabled. When answering this question, Jasmine said,

I never really thought about what I think about disabilities. I guess I define it as someone who has something wrong with them. I think disability is like a certain type of disadvantage.

James explained that he believed disabilities could be a wide variety of things. Specifically, he stated,

I guess everyone has their own disability in some way or another, whether that's social, or physical, or whatever. I guess you always think that word is bad, though.

Becca said she considered disability as something that is limiting in different ways and can be somewhat of a subjective term, because having physical, mental, or social disabilities can limit people in many different ways depending on the person and the situation.

Although it was difficult for some participants to give their own definitions to disability, they were quick to describe how they identify others with disabilities. One of the major themes found through interviews for this study was that the participants were able to easily identify physical disabilities, which seemed to be on the forefront of their minds when describing what disabilities look like. It is significant for this study to note that even though every participant interviewed has a disability, none of them used themselves as an example or described a type of invisible disability in their initial response to being asked how they define disability. However, one participant, Jasmine, made a point that she did not consider her Dyslexia a disability, stating,

I don't feel like having an IEP means someone has a disability. Like, you can't tell me because I can't understand something the way that somebody else can, that I have a disability. I would disagree with that.

Like Jasmine, Becca and James also stated that although they had IEPs throughout their K-12 education, they did not like to call their struggles “disabilities.” A significant factor which presented itself in the participant interviews was that the majority of participants preferred to call their disabilities “struggles” or “issues,” instead of disabilities. When Becca was describing how she perceives people identifying disabilities, she said,

I think when people talk about disability, they generally mean the ones that you can... you can look at someone and physically see that they are not able bodied. You know, they can't run a marathon or they can't climb a tree or something like that. Things like cerebral palsy and tremors are very visible and easy to see disabilities but a lot of the time disabilities aren't. So, I think that's difficult for people sometimes to realize.

Similar to Becca's statement, James also mentioned he is quick to identify individuals with physical disabilities, specifically stating,

When you say disability, I'd say the first thing that pops in my head is, like, a person that has one leg.

As Becca mentioned, physical disabilities can be easy to see, but there are many people struggling with invisible disabilities. Jasmine mentioned this, as well, saying,

Disabilities don't even have to be physical because people can have disabilities that aren't physical, like down syndrome or something. Sometimes you can't tell if someone has a disability but sometimes you can tell.

Micah took a strong stance on identifying individuals with disabilities by quickly identifying individuals with cognitive disabilities. He explained,

I mean, to me, when I think of someone with a disability I think they're just, like, mentally held back or something. Like they have autism, or down syndrome, or something like that. I mean, I kind of see that as more of a disability than like being in a wheelchair almost.

***Keeping safe.*** Society typically paints an image of individuals with disabilities (intellectual disabilities, specifically) as socially incompetent and bizarre. In response to these negative social stigmas, many individuals with invisible impairments will make the choice to

disassociate themselves with that image by denying their disabilities (Bogart, Lund, & Rottenstein, 2018). While individuals with physical, visual, or hearing disabilities are less likely to 'pass' as a non-disabled, individuals with invisible disabilities can often times blend themselves in without their disability being noticed. This hiding of one's disabilities to avoid social stigma is referred to as *keeping safe* in Davidson & Henderson's (2010) disability theory.

The perceptions of disabilities among the participants may be a present factor in each of their decisions to not disclose their disabilities to their university. Social stigma and stereotypes of non-physical disabilities could have also played a part in this decision. All four participants mentioned experiencing negative social consequences of disclosing their disabilities in high school, such as being made fun of in school, social isolation, and being treated differently by their teachers. When reflecting on this, James said,

I hated having a learning disability because I got made fun of all the time. I always felt like everyone around me was geniuses and I was the one left out.

Jasmine also stated that individuals with invisible disabilities have difficulty being understood and identified, specifically stating,

When you can physically see that a person has something that's wrong with them, it helps you understand that they're just not able to do certain things. I feel like a lot of people try to downplay others that have disabilities, especially when it isn't physical. And it's crazy because a lot of people have family members that have disabilities but they still treat people differently if they feel like something is wrong with that person or because they're not regular.

Similar to Jasmine, Becca expressed frustrations with people not understanding what struggling with invisible disabilities looks like. When discussing this issue, she said,

I think there's some really obnoxious stereotypes like from, you know, movies and the news and stuff. I think honestly there's a lot of people who just don't know what struggling with mental health is like. And I think it's one of those things that it's difficult cause until you've experienced it, it's hard to know what that's like for other people and it's hard to know how to talk to them and help them.

During his interview, James admitted that he had once been on the other side of bullying and making fun of individuals with disabilities. When explaining his memories of this, James said,

When we were kids, we would make fun of people with disabilities all the time. It was always like, "I don't have that, so like I can make fun of you," kind of thing. I guess people always talk about disabilities in a negative way. But then on the other hand, if someone with a disability is successful, people always talk about the hardship they had with their disability and things like that. So, I guess it goes both ways.

Although Micah expressed feeling socially isolated during his childhood and teenage years due to his disabilities and social set-backs, he maintained a positive outlook on how others view individuals with disabilities and expressed a positive outlook on the issue, stating,

I definitely think, nowadays, people with disabilities are a lot more accepted and most people are comfortable talking about disabilities, whereas like, I mean even back like when I got diagnosed, it seemed like it was almost unheard of to have autism. Like, they didn't even know what it was back then. So I think that's part of the reason why I got misdiagnosed with it. I personally don't think that there's a stereotype or anything around it, especially since it's kind of becoming more normalized in today's society. I don't really see anyone talking negatively about it. And if someone does talk negatively about it, they're like shut down really easily by other people.

In addition to the social stigma perceived by the participants, another factor in their decision to not disclose their disability is the idea that the participants had “grown out” of their disabilities and no longer needed the label or the accommodations which come with it. For one participant, James, he stated that he felt better without having the label associated with having a disability or feeling like he needed to use accommodations because it made him feel bad about himself. Specifically, he stated,

My mom was on my ass about disclosing to disability services. I never did because I would have felt bad doing it because I feel fine now. I want to think, “I don't need that.” Because my grades are good and I feel better without it. I don't like feeling like I had a disability. I didn't like having that label. Yeah, I definitely didn't like that. So I decided, I just don't want to have that label; I just want to be a regular student.

Similar to James, Becca also did not want to disclose her disabilities to her university. For Becca, she felt very sensitive about sharing that information. When discussing her feelings about disclosing her disabilities, Becca said,

I didn't want people to know about my issues. It was very personal and private to me. I felt like there were a lot of expectations on me and I didn't want people to know about it and to know that I was struggling. And so, and I think that's a lot of people who kind of try and hide those things. I think if I had been a little bit more open and honest with people about what I was dealing with, then I could've gotten a lot more help. I think people would have understood a little bit more.

**Strategies.** When discussing being placed on academic warning after her first semester, Jasmine mentioned that she had been working on getting her grades up for her current semester and felt more confident in her work, stating,

Everything has been going good this semester. I've been passing my tests and all my normal homework assignments. I feel like I work well under pressure, so I have six classes. I don't know why but I need that structure because if I have four classes, I drop the ball.

In Schlossberg's 1984 theory of transition, one of the identified coping resources for individuals in transition is *strategies*. This coping resource is defined by modification of the situation, controlling or changing the meaning of the dilemma or issue, and managing stress (Schlossberg, 1984). All four participants expressed that although they struggled to maintain their workload at first, with time, they learned to cope with their stress levels and improve their grades.

Specifically, James shared,

My time is more flexible because I make my own class schedule and I'm responsible for making sure it is balanced out. I've got a good routine now with soccer, so that's been nice to have that consistency.

For Micah, he stated he is still working on improving his grades and study habits while maintaining his relationships, as well. He also explained that although he has struggled with his grades, he did not feel it was necessary to disclose his disabilities in order to utilize accommodations, stating,

I do struggle in some classes, but I've been trying to study and have better study habits and stuff. That's something that I do have trouble with. But, I mean, I'm doing fine without accommodations. I think I'm doing pretty well without them.

To gain better understanding about what resources are used by students with non-disclosed disabilities instead of Disability Services and accommodations, the participants in this study were asked what resources they have used during their time in post-secondary education.

Of the four participants included in this study, three stated they have often used the library as a resource. James said that the library is the resource he has used most frequently during his time. Additionally, two of the participants, Micah and Becca, reported they had used the Writing Center along with the library. For Becca, she mentioned that she has utilized Career Services, as well, but has not gone to the Counseling Center, which is a resource she mentioned throughout her interview. Specifically, she stated,

I go to the Writing Center every once in a while. And I've used the library and Career Services, but as far as the Counseling Center goes, I haven't gone there at all.

When asked about what resources she had used during her time in college, Jasmine stated she had not used any. However, she expressed that she would like to be more intentional about using resources available to her in the future, stating,

I haven't used any resources yet. I don't really know why I haven't. I know for certain that I want to join TRiO; I really need it for my English class. I want to start going to the Writing Center, I just haven't really talked myself into using any of the resources yet. I thought about going to counseling, too, but then I never did it. It's just things that I think about, I just haven't done them.

Although the participants in this study experienced significant struggles during their transition from high school to college, including troubles with managing their workload, stress levels, and grades, they did not reach out to Disability Services to disclose their disabilities and request accommodations as a strategy to cope with their situations of transition. The participants expressed they felt there was no need to disclose their disabilities to their university because they did not feel there was a necessity for accommodations anymore. Specifically, Micah stated,

I've had an IEP for as long as I can remember. By the time I was in high school, though, I was in all normal classes and was only using accommodations for extended time on testing and preferred seating. But, I hardly ever really used that by the end of high school. And then at my first college, I only used them for the first semester and then once I finished that semester, I just didn't think I needed them anymore. I just didn't really see the need to have it. Now, I think I'm doing pretty well without accommodations. I just feel like I'm too old to still use them or something like that, if that makes any sense.

Jasmine echoed Micah's perspective and said by the time she reached her last years of high school, she felt that it was no longer necessary to use her accommodations. In her explanation, Jasmine said,

I felt like by junior year in high school I was doing really well. When we took standardized tests or when I would take a test in class, I would get extra time even though I didn't need it. So now, in college, it's like there's no reason for me to use accommodations; I don't need them.

All four of the participants stated they feel they are doing fine without accommodations. Becca stated if she started to feel overwhelmed, she would reach out for help. Specifically, she said,

If things started to get bad in school, I think I would talk to my professors about my struggles because I think a lot of the professors I have right now would be a lot more open and accommodating about that than some of the teachers I've had in the past.

Despite the participants' views on self-disclosure of their disabilities, as the researcher moved into analysis of the final research question, it was found that all of the participants recommended future students to disclose their disabilities, if applicable, to disability services and obtain accommodations as a coping strategy for transition into college.

**RQ3: What insights do participants offer to future students who choose not to disclose their disability to their college or university?**

In addition to sharing the resources they have used during their time at their current institution, the participants in this study also offered their perspectives on what resources they think would be helpful for other students like them; students with non-disclosed disabilities.

**Utilizing accommodations.** When posed with the question of what suggestions they would give to other new students in their position, four of the participants recommended that other students should disclose their disabilities and utilize the accommodations available to them. One participant, Becca, specifically said,

I think I would recommend not being like me. I think I would tell other students that they should just pull that IEP information forward. Even if they just talk to Disability Services or the Student Success Center or anything like that. Even just talking to their professors about it with the intention that they don't need to use it or that they don't need to have that. It's like, if I had told someone when I first came here, even though I may not have needed any accommodations and I may not have needed any help, at least I would have had that safety net. And I think you don't have to use that support if you don't need it, but having that as an option would probably have been a much smarter plan for me.

Sharing this perspective, Micah also recommended that students with disabilities should disclose when entering college, stating,

I'd say like just transfer it over just in case. Because that's what I did with my community college. And if you don't need it, then you can always just have like the option of not using it. But, I would definitely bring it over just in case.

James also stated he felt that other students with disabilities should utilize accommodations if they are able to, stating,

I mean, if you can get resources and accommodations, you should definitely use them. If you need them, you need them. But like when you have the option to get them, you should, you should always get them just to help with everything. Like even if you don't use them, you know, just, you just don't use it. But like you have them there, like why not, you know.

The suggestions for future students with disabilities offered by the participants in this study are significant in analysis due to the strong disconnect between the participant, resources they were willing to utilize in college, and then resources they encourage others to use. They seem to understand that the best coping resource for new students with disabilities would be disclosing to Disability Services at their institution and requesting accommodations. However, despite this understanding and their struggles with their workload and grades, the majority of the participants believed they did not need accommodations and were unwilling to disclose their disability, likely due to the perceived social stigma previously mentioned. James acknowledged this by stating,

I'm sure a bunch of other people have the same thing, but just don't disclose it until they're actually struggling in school. So, I don't know, because there's such a stigma, but everyone has to realize they have a disability. They just have to go use the resources that they can. Like, Freshman year, you're still kind of vulnerable. You're still trying to make friends and trying to fit in. So, the last thing you think of is your IEP and telling people that you have a disability. You would just want to fit in.

**Suggestions for outreach.** In the wrap-up of the interviews with each participant, the researcher asked what suggestions the participants had for support services on campus to reach out to students with non-disclosed disabilities. The goal of this question was to gain insight to how this group of students may want to be marketed to. Each participant offered a unique perspective on how resources to support students in transition could be marketed to students with non-disclosed disabilities.

James focused on how his university could help eliminate stigma surrounding invisible disabilities and help students understand and develop their disability identity. Specifically, he stated,

I don't really know how you can advertise to get over the stigma. Maybe starting conversation online with a tweet hashtag? You could definitely use one of the mandatory entry classes to share information about resources. Maybe in those classes, they could teach a week about getting over like the stigma of disabilities. Because some people have undiagnosed issues, too, and they can be like, "Oh wait, maybe that's why I was struggling in high school. Should I look into this?"

Micah expressed that a useful strategy to reach students with non-disclosed disabilities would be to send campus-wide emails with information about resources and how to access them, stating,

Maybe if the Disability Services office just like sent out an email to everyone or something saying that like they were available, how to reach them, what services they can offer students who disclose, how people can disclose and that kind of stuff.

In comparison, Becca suggested most students would not check their email often enough to access information sent in that manner. Instead, she believed the best strategy for outreach is through faculty. Specifically, she said,

I might be the only college student who checks my email so wouldn't recommend that one. But even just having professors who are willing to tell their students about different services that are available, especially in the gen. ed. classes and stuff. And then, as you get into your higher level classes, when you get to know your professors a little bit better, it helps if they talk about it, too. Just having that mindset and making sure your students know that if there's something they need to talk about, they can talk to you or to counseling or whatever they need. Just trying to show it's not a big deal if you need help.

Jasmine expressed that based on her own experience, it would be hard to reach students with non-disclosed disabilities and beyond that, it would be even harder to convince them to disclose to Disability Services or use resources that they aren't interested in utilizing. Overall, the suggestions offered by participants on how colleges can market support services to students with non-disclosed disabilities would be fairly easy to implement amongst support services across any college campus.

## **Summary**

Chapter Five provided an analysis and reflection of the participants' discussions with the researcher from the interview process. The experiences shared by each participant can be reviewed through the lens of the research questions presented in this research. In Chapter Six, a discussion of the participants' narratives and the presented analysis will take place followed by the implications of this research and recommendations for further research.

## Chapter VI

### Discussion and Recommendations

This study was conducted to gain understanding of the transitional experiences of students with non-disclosed disabilities and insight into why they choose not to disclose. Previous research on this topic has found that individuals with invisible disabilities, such as learning disorders, are more likely to ‘pass’ themselves as non-disabled and do so in order to avoid social stigma (Davidson & Henderson, 2010). In this chapter, the results of the study will be presented and tied into previous research and theoretical frameworks. Additionally, implications of this research will be discussed, along with recommendations for future research on this topic.

#### Discussion

This discussion is guided by the findings from the three main research questions proposed in this study: (1) what are the perceptions of students with non-disclosed disabilities on why they do not disclose, (2) what is the high school to college transitional experience of students with non-disclosed disabilities, and (3) what insights do participants offer to future students who choose not to disclose their disability to their college or university. In addition to the research findings, implications and recommendations for student affairs professionals to use in practice and recommendations for future research will be covered in this chapter.

**Transitional experiences.** Due to the consistent increase in enrollment of students with disabilities, it is more important now than ever before for students, educators, support staff, and parents to understand the significant challenges students with invisible disabilities face in regards to their transitional experience (Eckes & Ochoa, 2005). The most significant challenges during transition found in this study were overwhelming workloads and stress. As James stated,

There's a lot of stress when you're always busy, you know, like a lot of anxiety. You're just going through the motions trying to get everything done that's on your plate. Like, you're in certain organizations on campus and doing so much stuff and it can be really overwhelming so you end up putting more effort in to some things and less effort into others.

For students with invisible disabilities, the transitional period between high school and college intensifies the significance of self-advocacy, as students no longer have a team of professionals advocating for them when they transition to college (Hadley, 2006). Instead, students are expected to self-identify their disabilities and request accommodations for themselves.

*Significant challenges.* Students with disabilities face significant barriers in comparison to their counterparts, especially when it comes to academic success and graduation rates (Abreu, Hillier, Frye, & Goldstein, 2016). Previous research has also found when students with learning disorders are faced with significant challenges in the classroom, they often do not feel comfortable discussing it with their professors, as they do not wish to disclose their disability (Hadley, 2006). Although one participant, James, mentioned he felt comfortable discussing his struggles with his professors when he needed to, the other three participants expressed hesitation in doing so. As Becca stated,

I didn't want people to know about my issues. It was very personal and private to me. I felt like there were a lot of expectations on me and I didn't want people to know about it and to know that I was struggling.

Self-disclosure has been found to be a significant challenge for students with disabilities (Hadley, 2006). The barriers and challenges in relation to self-disclosure can make the

adjustment period during transition into higher education feel overwhelming for students with disabilities. This challenge was found to be significant in this study, as all four participants expressed feeling overwhelmed by their transitional experiences and noted their workload and stress levels as the most challenging aspects of their transition to college. For example, when Becca was discussing her classes from her first semester of college, she stated,

There were several classes that I did okay in but there were also a couple of classes that I failed. There was one that I just stopped going to because I just couldn't get the work done and I just didn't want to show up to class anymore.

***Change in support.*** In their transition from high school to college, there was a significant shift in social support for all of the participants in this study. While some of the participants noted this as a positive change, there was an overall lack of advocacy for accommodations among all of the participant's college support systems in comparison to their high school supporters. In high school, many of the participants received support through their parents, with the majority of the participants stating their parents advocated them in high school in regards to getting their IEPs put in place and suggesting use of accommodations. However, in their transition into higher education, the participants listed their main supporters as their friends and no longer considered their parents to be in their main support system. For example, Micah stated,

My high school friends are definitely still there for me and I have a girlfriend so she's also definitely a major support for me. And I have two or three friends here who are major support systems for me, too, now.

Since the participants' parents were, for the most part, their advocates in regard to facilitating IEPs, disability diagnoses, and utilization of accommodations in high school, the

changes in support among the group's transition into college may be a present factor in the participants' decision not to disclose their disabilities to their institution.

**Barriers to disclosure.** In order to gain access to accommodations in institutions of higher education, individuals must self-disclose their disabilities to their institution. The participants in this study have disabilities that cannot be easily identified by others, which are often referred to as invisible disabilities. In order to avoid social stigma, many individuals with invisible disabilities choose not to disclose their disabilities (Davidson & Henderson, 2010), which is the path the participants in this study have chosen. As stated by James,

Freshman year, you're still kind of vulnerable. You're still trying to make friends and trying to fit in. So, the last thing you think of is your IEP and telling people that you have a disability. You would just want to fit in.

Unfortunately, research suggests it is more likely for students with hidden or invisible disabilities to fall behind educationally if they have not self-disclosed their disability to their institution (Leake & Stodden, 2014).

**Social Stigma.** Individuals with disabilities are a part of a minority group which has a recorded history of being stigmatized through labeling, stereotyping, separation, loss of status, and discrimination (Daley & Rappolt-Schlichtmann, 2018). The participants in this study expressed they were aware of the labels, stereotypes, and stigmas that exist for their population and one of the participants, James, reflected on being bullied in high school specifically due to his disability. Specifically, he said,

I hated having a learning disability because I got made fun of all the time. I always felt like everyone around me was geniuses and I was the one left out.

James also expressed that at the beginning of his transition into college, he was still very vulnerable and did not disclose his disability in order to avoid stigma and he suggested that there are likely many others like him who also make that same decision, stating,

I'm sure a bunch of other people have the same thing, but just don't disclose it until they're actually struggling in school. So, I don't know, because there's such a stigma, but everyone has to realize they have a disability.

Previous research has found that instead of gravitating towards other people with disabilities, individuals that are conscious of the stigma associated with their disability often feel pressure to assimilate and isolate themselves from other disabled individuals (Bogart, Lund, & Rottenstein, 2018), which seems to be a theme in this research.

***Disability identity.*** While individuals with physical, visual, or hearing disabilities are less likely to 'pass' as a non-disabled, individuals with invisible disabilities can often blend in without their disability being noticed. Disassociation is often an attractive option for these students due to the fear as being labeled and placed in a negative category by their peers, educators, and family (Davidson & Henderson, 2010).

Individuals with invisible disabilities can struggle deeply with self-identification, especially those who are diagnosed later in life, as opposed to childhood diagnosis. Until the point of diagnosis, these individuals typically go about their lives feeling "different" than those around them, but not knowing or understanding the reason why. The point of diagnosis can be a complicated part in a person's development of self-image, which is a process that can be damaging to individuals depending on the timing. As previously mentioned, both Becca and James were not diagnosed until they were in high school and they both expressed significant trouble with coming to terms with their disability identity in the past and present.

Micah was diagnosed with Autism Spectrum Disorder as a small child but it was not until he was 17-years-old when he found out he had been misdiagnosed. He expressed that he had embraced his previous diagnosis, but suggested that when he was diagnosed with ADHD and a communication disorder at 17, he no longer felt the need to reach out for help or request accommodations, stating he was too old for it,

I just didn't really see the need to have it. Now, I think I'm doing pretty well without accommodations. I just feel like I'm too old to still use them or something like that, if that makes any sense.

On the other hand, the experiences of individuals who are diagnosed in the earlier stages of their lives are largely impacted by the people closest to them. Jasmine suggested her relationship with her mother lacked emotional support, stating,

My support in high school was mostly my mom, but it's kind of complicated. Like, she is definitely not my emotional support. She's my physical, financial, everything else type of support, but not emotional.

This lack of emotional support could have had a large impact on Jasmine's disability identity, as research has found for individuals like Jasmine who are diagnosed in childhood, the attitudes of their loved ones are deeply embedded in the willingness to disclose their disability in early adulthood (Davidson & Henderson, 2010).

Despite the point of diagnosis for the participants, in order to successfully accept their identity and self-disclose, individuals with disabilities have pushed against the stigma within their respective family dynamics and peer-groups (Davidson & Henderson, 2010). Since all of the participants in this study could easily "pass" as non-disabled, and significant stigmas were identified by the majority of the participants, it seems that the more appealing option for this

group was to withhold information about their disability. The participant's withholding of information was not intended to be deceptive by any means. Instead, choosing the route of non-disclosure was used as a defense of each participant's self-image, reputation, and personal relationships (Davidson & Henderson, 2010).

### **Implications**

The participants in this study expressed their most significant challenges of their transition and offered suggestions for professionals working in higher education to better support students with invisible disabilities in the future.

**Encourage disclosure.** All of the participants in this study suggested the best way to support students with invisible disabilities is to encourage self-disclosure to Disability Services. Therefore, in order to properly accommodate for students with invisible disabilities, there needs to be a conscious effort to encourage disclosure early on in their education. However, an important part of this effort is to understand that these students will not be easily identifiable. Therefore, an important strategy to reach students with non-disclosed disabilities is to provide information about support services for disabilities early-on in their transition to college, through orientation, entry courses, and emails to all new students. Since this study found that students with non-disclosed disabilities do not like the label of being disabled, an important piece of encouraging disclosure for this student population may be using alternative terminology. For example, students with non-disclosed disabilities may feel more comfortable disclosing they had an IEP in high school and what struggles they have academically instead of reporting a *disability* to Disability Services. Ultimately, the word *disability* is in the title of the office they would need to disclose to, which indicates these types of offices may need to consider name changes that are more inviting to students with developing disability identity.

**Provide education about disabilities.** The participants noted that there would also need to be an effort to provide education and eliminate stigma about disabilities, especially invisible disabilities. Even if students with non-disclosed disabilities are made aware of the resources available to them, they may be hesitant to utilize those resources due to social stigma surrounding their self-identification. In order to assist in the development of disability identity, there should be an intentional focus on providing education to all students about disabilities to help eliminating stigma on campus. If students with invisible disabilities feel accepted and supported on their campus, they will feel more comfortable disclosing their disabilities and requesting accommodations, which will assist greatly in their success.

**Transitional plans.** In discussing their transition from high school to college, each participant was asked about what their transitional plan for their IEP looked like. As discussed in the review of literature, IEP transitional plans are focused around identifying obtainable and realistic goals for the future and creating a plan which will help the student successfully meet those goals (Eckes & Ochoa, 2005). When asked about their IEP transition plan, none of the participants could think of anything significant from their transitional plan that may have helped them during their transition to college. Further, the majority of the participants did not remember being involved in transitional planning before their graduation from high school. This information implies that IEP transitional plans may not be effective in supporting high school graduates through their transitional experiences and may need to be revised in order to provide better support to students with disabilities.

### **Recommendations for Further Research**

One of the most significant limitations proposed in this study was the assumption that the sample population at the research site would be too small to find enough participants. However,

when the request for participation email was sent out campus-wide, the researcher received 25 inquiries from potential participants. While a few of these potential participants did not fit the qualifications, many of them did. This suggests that future research at mid-sized and larger institutions could be conducted through quantitative methods. Conducting this type of research quantitatively may make the participants feel more comfortable in answering sensitive questions about their disability identity while also gaining perspective from a larger population, which could result in more significant findings from the research.

Further, it was evident that the participants in this study did not identify with their disability. For this reason, an interesting piece of the findings in this research is the recommendations in which the participants said they would give to other students with non-disclosed disabilities. With their main piece of advice being to disclose disabilities and request accommodations, the researcher in this study was left questioning, “why suggest others use resources that you don’t?” Unfortunately, this was not a question asked during the interviews with the participants, however, this question could be useful in future research on this topic.

Due to the findings of this research and the significant role parents played in facilitating accommodations for the participants in high school, further research may include parental perspective along with the student perspective. It may be significant to understand the experiences of the parents and how they view their support for their students during their transition. Additionally, parent perspectives on disabilities may be significant in their student’s development of disability identity.

## **Conclusion**

The purpose of this study was to examine the transitional experiences of undergraduate students with non-disclosed disabilities and gain insight on the intentions of students choosing

the route of non-disclosure in higher education. It was found that students with non-disclosed disabilities have significant challenges with managing their workloads and stress in their transition into college. This difficulty is noted at some point in each participant's narrative of their transitional experience and previous research suggests disclosure of disabilities and utilization of resources could significantly impact the academic challenges of students with invisible disabilities.

Additionally, changes in support from high school to college have a significant influence on self-disclosure of disabilities. As previously mentioned, the majority of participants reported they mainly received support through their parents prior to their transition into post-secondary education. It was reported that the participants' parents served a large role in facilitation of IEPs and utilization of accommodations in high school.

With parental guidance lacking from the participants' support systems in post-secondary education, it was found the changes in support among the group's transition into college may be a present factor in the participants' decision not to disclose their disabilities. It was also found that awareness of negative stigma towards disabilities can influence disclosure and disability identity in students with invisible disabilities. For these reasons, it is important for professionals in higher education to encourage positive conversations about disability and encourage students to disclose disabilities early in their transition.

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**Appendix A**  
**Candidate Email**

Hello,

My name is Sierra Headrick and I am a graduate student in the College Student Affairs program at EIU. You are invited to participate in a research study for my Masters Thesis, which will be conducted by myself under the advisement of Dr. Richard Roberts. You have been asked to participate because you are listed as an undergraduate student at Eastern Illinois University.

This study intends to explore the high school to college transitional experiences of students who had an IEP in high school, but did not to disclose that information to EIU's Disability Services. Therefore, I am looking for participants who: (1) had an Individualized Education Plan in high school and (2) did not disclose IEP information to Disability Services upon enrollment.

Participation in this study would include a private, confidential interview, which would take approximately one hour, and can be scheduled in a convenient location for you. Any information obtained for this study will be kept confidential, as all identifying information will be stored separately from interview data and the data will only be used for the purposes of my research.

All volunteers who are selected for participation in this research will be given a \$25 Visa gift card. This gift card will be given to each participant at the conclusion of the interview.

If you fit the criteria outlined above and would like to participate in this study, please contact me directly at [seheadrick@eiu.edu](mailto:seheadrick@eiu.edu). Rest assured that your participation in this study is entirely voluntary and confidential. If you choose to volunteer, you will have the ability to withdrawal at any time without penalty. I look forward to hearing from you! Thank you for your time.

Sincerely,

Sierra Headrick  
M.S. Candidate, College Student Affairs  
Department of Counseling and Higher Education

## Appendix B

### Interview Questions

Primary, secondary and tertiary questions.

- Tell me about yourself.
- What is your age?
- What is your major?
- When were you diagnosed with your disability or disabilities?
- How do *you* define disability?
- In your experience, how do you think people talk about disability?
  - a. Positive/negative? Stereotypes? Stigma?
- Tell me about your high school experiences.
  - a. Who was your support system in high school?
  - b. How were your grades in high school?
  - c. What year did you graduate from high school/high-school equivalent?
- Tell me about your support in high school.
  - a. Who were your main supporters/advocates?
- Tell me about your experiences so far in college.
  - a. How would you describe your friends in college?
  - b. Who is your support system now?
    - i. Does your support system from high school still help you?
  - c. How are your grades so far?
  - d. What has been the most challenging experience of college so far? Most rewarding?

- What campus resources have you utilized during your time here?
  - a. Tell me about your experiences using those resources.
    - i. Expectations vs. reality
- Have you disclosed your disability or IEP to any faculty/staff on campus? Have you disclosed to friends?
  - a. If there are any specific reasons for not disclosing / semi-disclosing, please explain.
- What advice or recommendations would you give to new college students who had IEPs in high school?
  - a. What support services would best benefit them?
    - i. How could these services reach students who choose not to disclose?  
Suggestions?

## Appendix C

### Consent Form

# CONSENT TO PARTICIPATE IN RESEARCH

## Experiences of Post-Secondary Students with Non-Disclosed Disabilities

You are invited to participate in a research study conducted by Sierra Headrick (supervised by Dr. Richard Roberts) from the Counseling and Higher Education Department at Eastern Illinois University. Your participation in this study is entirely voluntary. Please ask questions about anything you do not understand, before deciding whether or not to participate.

- **PURPOSE OF THE STUDY**

The purpose of this study is to examine the experiences of undergraduate students with non-disclosed disabilities at a mid-sized, four-year university.

- **PROCEDURES**

If you volunteer to participate in this study, you will be asked to:  
Participate in a semi-structured interview that will take between 40-60 minutes. The interview will be audio-recorded in order to obtain data by transcribing the discussion.

- **POTENTIAL RISKS AND DISCOMFORTS**

There are no foreseeable risks in this study.

- **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

You may not directly benefit from participating in this research. The results from this research could help the institutions of higher education to develop strategies to improve support services and outreach for students with non-disclosed disabilities.

- **CONFIDENTIALITY**

Any identifying information that is obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of using the password protected program store all

data. The primary investigator of this research, Sierra Headrick, and advisor, Dr. Richard Roberts, will be the only persons given access to your data. This data will be destroyed within three calendar years.

- **PARTICIPATION AND WITHDRAWAL**

Participation in this research study is voluntary and not a requirement or a condition for being the recipient of benefits or services from Eastern Illinois University or any other organization sponsoring the research project. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind or loss of benefits or services to which you are otherwise entitled. There is no penalty if you withdraw from the study and you will not lose any benefits to which you are otherwise entitled.

- **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about this research, please contact:

Sierra Headrick  
Department of Counseling & Higher Education  
600 Lincoln Ave  
Charleston, IL 61920  
Telephone: (217) 581-3827  
E-mail: seheadrick@eiu.edu

- **RIGHTS OF RESEARCH SUBJECTS**

If you have any questions or concerns about the treatment of human participants in this study, you may call or write:

Institutional Review Board  
Eastern Illinois University  
600 Lincoln Ave.  
Charleston, IL 61920  
Telephone: (217) 581-8576  
E-mail: eiuirb@www.eiu.edu

You will be given the opportunity to discuss any questions about your rights as a research subject with a member of the IRB. The IRB is an independent committee composed of members of the University community, as well as lay members of the community not connected with EIU. The IRB has reviewed and approved this study.