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College Students and Their Decisions to Disclose Disabilities

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This is to certify that the doctoral study by

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has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
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Walden University
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Abstract

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Dissertation Submitted in Partial Fulfillment

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Legislation in the United States mandates support services to assist students with disabilities in postsecondary settings, and research literature includes legislation and case law dealing with access rights to higher education and studies in areas of transitioning to postsecondary settings, including perceptions of support services and barriers to attainment. Yet, the processes that require students to divulge increasingly personal information related to their disabilities can discourage the students who need services. There is a gap in research and practice concerning the factors leading these students to decide to disclose; therefore, the purpose of this narrative inquiry was to explore the disclosure decision process. Self-determination theory informed this study. Research questions addressed how students describe their decision, experiences with disability services staff, and interactions with faculty that may influence the decision to disclose. The 4 interviewees attended different postsecondary institutions in the United States and had disclosed their disabilities to receive services or accommodations. Data analysis included emic and etic coding, and 4 themes emerged: the decision to disclose and the transition process, disclosure is not a singular event, importance of staff interactions, and inconsistent faculty interactions. Student services personnel were viewed positively, the participants shared an overall lack of support from most faculty. Academic leaders can use the findings of this study to improve policies and practices related to the disclosure process and bring about changes in personnel attitudes and perceptions regarding students with disabilities to enhance the experiences of these students while enrolled in postsecondary settings. These improvements could provide positive social change for students with disabilities and for all learners in postsecondary institutions.

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Dedication

I would first like to dedicate this doctoral study first to my Lord and Savior, Jesus Christ, “for everything comes from him and exists by his power and is intended for his glory” (Romans 11:36 NLT). To my wife, Andrea, thank you for taking this journey with me, for understanding how important the journey was to me, and for always believing I would see it through. To my boys, Ian and William, you are my inspiration and why I stayed up late and worked weekends on this study. I hope in some way this study opens doors for you and others who are as special as you. To my parents, thank you for your love, your prayers, and your unending support. To Aunt Lona, thank you for cheering me on through this experience. To anyone who works in disability services, you might not hear this enough, but you are heroes and you are doing God’s work helping students by showing them kindness and compassion.

Acknowledgments

First, I would like to thank Dr. Christina Dawson, my current Committee Chairperson, for guiding me through some really dark times trying to finish this study. Your guidance and support made all the difference in this study. Thank you, Dr. Laurel Walsh, Committee Member, for being my rock and my singular consistent member of my support team through the entire journey. Thank you, Dr. Nicolae Nistor, for your feedback and insights. Though not my choice, I had three different chairs through this process and would like to thank my previous chairs for their significant contributions to this study. Dr. Mark Earley helped me craft an approval-worthy proposal. Lastly, Dr. Annie Pezalla started with me on this journey and has been cheering me on from the sidelines. Thank you all for patience, your guidance, your mentorship, and your support.

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Chapter 1: Introduction to the Study

Students with disabilities must make the decision to disclose their disability upon applying to a college or university to attain eligibility for federally mandated support services designed to help them be successful college students. In this study, I sought to examine the disability disclosure process and the lived experiences of participants who disclosed their disability to receive access to support services in postsecondary settings. Studying the experiences of students with disabilities who rejected anonymity to receive services may provide higher education leaders with an opportunity to view service access policy and the impact nondisclosure has on student performance and institutional success measurements.

Chapter 1 consists of 10 sections, including the background, statement of the problem, and the purpose of the study. In this chapter, I also discuss the nature of the study, research questions, conceptual framework, and operational definitions. Finally, this chapter concludes with an examination of assumptions, limitations, and significance for social change.

Background

Students with disabilities require support to persist in postsecondary settings. This designation impacts 11% of undergraduate enrollments (Hinz, Arbeit, & Simone, 2017), so prioritizing appropriate accommodation strategies has created a challenge for higher education leaders. The disability disclosure decision process represents a privacy gateway for these individuals, creating scenarios where students who need support opt for anonymity and choose not to disclose their disability. The services needed to achieve success in higher education come at the cost of privacy and real or imagined stigma associated with being different from their classmates. Students with disabilities in a college or university represent an underserved and protected class of students with the most to gain from social change stemming from research examining inclusion in higher education (Artiles, Dorn, & Bal, 2016). A lack of social engagement and insufficient accommodations has left many students entering into postsecondary settings in a precarious academic situation, eventually pushing some of them out of school (Hall, 2016).

Problem Statement

The problem investigated in this study was why students choose to disclose their disability to access postsecondary support through registration with the office of disability services. Most schools have some foundational safeguards for support services through an office of disability services, yet more than 20% do not actively encourage students to disclose their disability to receive those services or engage faculty about student disability services (Raue & Lewis, 2011). Prior researchers have examined student levels of self-efficacy (Pearlman-Avnion & Aloni, 2016), approaches to developing services (Couzens et al., 2015), effectiveness of accommodations (Lindsey, 2016), and transitioning to college (Georgallis, 2015); however, few academic investigations have been undertaken to explore students’ disclosure process in postsecondary settings. To access appropriate support, each student must make the decision to disclose his or her disability. Based upon the numbers of students who receive academic accommodations in the form of an individualized education plan (IEP) at the high school level, an insufficient number of disclosures by students with disabilities are documented in the first or second year of college. In my home state of Kentucky alone, there were 3,132 special education students who graduated with a diploma in 2011 (“Special Education Students Who Graduated with a Diploma (State),” 2018), representing the potential for nearly 25% of admissions that year among Kentucky colleges and universities, almost double the national average of students with disabilities who disclose their disabilities (National Center for Education Statistics, 2018).

Overall academic success for students who have a documented disability stems from engagement and inclusion in campus life and utilization of support services (Knight, Wessel, & Markle, 2016). The marginalization of special needs students and the associated social stigma of being referred to as *disabled* leads many students to attempt to pass as nondisabled, a similarity observed in research focused on individuals who identify as gay, lesbian, bisexual, or transgender and remain closeted or individuals who are not distinctly a member of a racial identity (Cox et al., 2017). This *coming out* during the disclosure experience for students with disabilities presents a gap in the existing scholarly research because social stigma is a contributing factor in an individual closeting their disability (Leake & Stodden, 2014). Provided disclosure is not always a given, the reasons for nondisclosure vary and can include a lack of self-advocacy (Agobiani & Scott-Roberts, 2015) and intimidation by the range of services available (Hong, 2015).

The current research relies on colleges and universities to self-report their number of students with disabilities, but exact counts are unknown because the alternative methods of calculation, such as entrance exam notation of students with accommodations, infringes upon the 2008 amendment to the American Disability Act (Hees, Moyson, & Roeyers, 2015). Of the relatively unknown number of students with disabilities who enroll, students with less visible disabilities, such as autism spectrum disorder or attention-deficit hyperactivity disorder (ADHD) are even more unlikely to disclose their needs to the school, creating a misleading impression that the actual number of students who disclose is small (Leake & Stodden, 2014). Evidence suggests the disclosure decision is a complex one, centered on the services provided by the university, direct interactions with instructors, and each student's individual experiences prior to enrolling in a higher education institution. More insight into how a student makes the decision to self-disclose can be used to inform academic policy formation to potentially change how these at-risk students gain access to federally mandated support services.

Purpose of the Study

The purpose of this study was to explore the disclosure process used by students with disabilities as they transitioned from high school to higher education in postsecondary settings. The participants in the study included students who made the decision to disclose their disability so that they would be eligible to receive additional support and accommodations. Clear insight into the lived experience of the disclosure decision revealed hidden institutional supports and some impediments that impacted their decisions to disclose. Unlike the K-12 setting, where dedicated special education teachers identify and support a student's disability up to and including a separate but equal learning environment, all students with disabilities in college are mainstreamed, meaning there are no separate classes for them and accessing support services requires revealing their disability, even if it is nonapparent (Butler, Sheppard-Jones, Whaley, Harrison, & Osness, 2016).

Many factors lead students with disabilities away from attempting postsecondary educational pursuits, and those who persevere may benefit from an accurate assessment of their individual needs and potential accommodations. Gender, language fluency, and race can impact K-12 disability diagnosis and support, leading to situations where a disability creates exclusions from mainstream education and job attainment forcing individuals into isolation at medical facilities or to seek a remedy through the court system (Dorfman, 2017). Examination of current institutional policies, including the requirement to disclose a disability in order to receive services, yields support gaps in coverage for students with disabilities, creating social justice and accessibility issues evidenced by low graduation rates in populations of students with disabilities (Liasidou, 2014). In this study, I examined the experiences of students who decided to disclose a disability to the institution to gather their (a) perceptions of the role of the disability services office, (b) experiences working with faculty members upon initial disclosure to receive accommodations, and (c) perceptions of inclusionary policies and practices necessary to encourage students to disclose their disability and receive support.

Research Questions

Using the following research questions as guides, I explored the experiences of a select group of students and their decision to disclose a disability to receive support services in a postsecondary setting. The students’ perspectives of disability services and the faculty members who worked with them also received attention in this narrative inquiry. The findings of this study can be used to help educators understand the role of support services and faculty who work with students who disclose their special needs to the university (see McCall, 2015). Special education research has focused on the development of accommodations and services as well as the transition from high school to college but has not focused on the individual's decision to disclose their disability (Leake & Stodden, 2014).

The guiding research questions were as follows:

RQ1: How do students with disabilities attending a postsecondary institution describe their decision to disclose?

RQ2: How do experiences with the office of disability services inform the decision to disclose their disability?

RQ3: How do experiences with faculty members inform the decision to disclose their disability?

Conceptual Framework

The conceptual framework for a study of the disability disclosure decision must provide a lens through which to identify the reasons and motivations behind formally disclosing a disability. While federal law mandates protections for students with disabilities, these students must choose to disclose their disability to receive support (Smole, Naughton, Kuenzi, & Skinner, 2008). The norms in U.S. society related to intentional and unintentional ableistic behavior create environments detrimental for the self-esteem and motivations of these students, offering legitimate reasons to remain anonymous (Blockmans, 2015). Through narrative inquiry, I explored the motivation behind the student's voluntary disclosure process, not just the moment of signing the disclosure form but from determination of consent through life after surrendering anonymity.

The conceptual framework for this study was based on self-determination theory. Self-determination theory, developed by Ryan and Deci (2017), zeroes in on motivation and its role as an inhibitor, preventing personal growth and overall well-being. Self-determination theory is used to observe how an individual's quality of life and sense of self-worth respond to the factors stunting those areas of growth (Ryan & Deci, 2017). Other researchers have focused on students with disabilities from a services or transitional perspective but did not focus on the process an individual goes through to determine whether to relinquish their privacy. Self-determination and self-determination theory have been used in prior studies to relate student experiences in an online environment (Wolpinsky, 2014), explore the process of receiving services to assist in the transition from high school to college (Georgallis, 2015), and examine reasons students participate in support services at their school (O'Shea & Meyer, 2016). In this study, I used self-determination theory as a lens through which to view and analyze the data collected from participants about the motivations that influenced their disclosure and what worked against the affirmative disclosure event that provided access to support resources.

Nature of the Study

Federal mandates, which I will examine thoroughly in the review of the literature in Chapter 2 of this study, exist to require support for students with disabilities in an educational setting, but the nature of the support model pivots upon entry to college. Prior to exiting high school, students do not need to disclose their disability; however, institutions of higher education require a student to disclose and document their disability to receive services.

The phenomenon of the disability disclosure decision process, a gateway that presents itself as a voluntary decision that becomes mandatory to receive judicially protected support services, aligned with the qualitative approach utilizing narrative inquiry methods taken in this study. In this study, I gathered the stories of participants who experienced this personal and private disclosure decision and how it has impacted them and will impact them in the different states of past, present, and perceived future (see Clandinin & Connelly, 2000). Narrative research that places students as experts on the disclosure process and experience represents the potential to highlight the importance of inclusion and perceptions of institutional support services.

The boundaries for this study included students who completed high school, chose to further their education at a college or university, and elected to disclose their disability. Additional boundaries included the process of disclosure from the time the student learned of the need to disclose, who counseled them on making the disclosure decision, and real or perceived impacts from making the decision to disclose their disability. The participants in this study were not minors but consenting adults attending a postsecondary institution.

Definitions

Ableism: Discriminatory behavior or acts of prejudice toward an individual or group of individuals with real or perceived impairments or unique behavior (Blockmans, 2015).

Accommodations: A support service provided by a school to students with disabilities. Examples of accommodations include note-taking support, additional time or locations to take assessments, or a translator (O'Shea & Meyer, 2016). These support services require disclosure at the college level.

Disclosure: The definition of disclosure covers a broad area that usually describes containment of personal information (Lynch & Gussel, 1996). In the context of this study, disclosure is the deliberate act of a person sharing personal information about their disability with their college or university. Disclosure is a requirement to receive support services. While legislation supports the inclusion of students with disabilities in higher education, the framework required for compliance relies on a disclosure process that acts as a segregator (Liasidou, 2014). Most colleges and universities use online, secure access forms either as part of the admissions process or as a separate accommodation process. One example is the system the University of Kentucky (2016) uses to help students provide letters of accommodation through the use of an online portal that requires registration and access approval.

Individualized Education Plan (IEP): A guiding, and legally binding document used in K-12 for students identified with a disability. The IEP outlines and details the plan for progressing the student and addresses accommodations provided by the school. While in a K-12 environment, the IEP travels with the student but ends upon completion of high school. No equivalent exists in higher education, and the plan does not provide sufficient proof of disability, meaning these students must provide an updated medical evaluation at their own cost (Kelepouris, 2014).

Students with disabilities: A common label that defines a group of students with the identifier of having a disability. Using the National Center for Education Statistics as a reference for this study, the disability diagnosis necessary for inclusion in the students with disabilities category includes learning disability; developmental delay; and/or some form of autism, intellectual disability, attention deficit disorder or attention deficit hyperactivity disorder, hearing or vision problems, and/or bone, joint, or muscle problems (Hinz et al., 2017). Additionally, the National Center for Education Statistics (2018) suggested these students received some sort of accommodation or special education services while in school.

Assumptions

I made the following three assumptions in this study: (a) that participants were honest about their disability and their disclosure to their college or university; (b) that participants actively engaged with disability services to utilize their accommodations; and (c) that participants' accurately recalled their motivations to disclose their disability.

Scope and Delimitations

The scope of this study was students with disabilities attending a public college or university. The purpose of delimiting private colleges or universities was a result of the differences in legal requirements to support students with disabilities among private schools. The purpose of the study was to examine the disability disclosure experience among students with disabilities; therefore, another delimitation was study participants had to have participated in support services at their school, indicating a disability disclosure. Although the exclusion of private institutions of higher education limits transferability, the support requirement rules applied to private schools differ based on funding model for the school, potentially affecting the transferability regardless of inclusion in this study. Not limiting participants based on type of disability or mix of disabilities still offers the potential for transferability in other studies of students with disabilities in public higher education.

Limitations

I identified three potential limitations to consider for this narrative inquiry. First, I relied on social media and the Walden University participant pool to recruit participants for the study relinquishing medical documentation requirements of the participants’ claim to disability. Secondly, the participants possessed a variety of special needs; I was not focused on a single disability in this study. Lastly, because I did not focus on a single disability and participation in this study was voluntary, the results of the examination might not be generalizable to all postsecondary students with disabilities.

Significance

Students with disabilities served under the Individuals with Disabilities Education Act (IDEA) from kindergarten through high school graduation have IEPs that guide them through an assessment process to complete their studies (Hamblet, 2009). IEPs do not transfer to higher education in North America because the notion of a free appropriate public education only applies to IDEA, not Section 504 or the ADA (Kelepouris, 2014). Students who are of college age, have a disability, and desire accommodations must register with the school to receive services (Kutnak, 2014).

As of 2015, in the United States, there were 6,555,291 children served under IDEA (SAGE Stats, 2017a). In 2008, about 57% of those students spent more than 80% of their time in a traditional classroom (SAGE Stats, 2017b). As of 2012, just over 11% of college-eligible students have some disability (U.S. Department of Education, 2017). Although 11% is not a majority of students, an extrapolation to a large school of 30,000 full-time students could mean more than 3,000 students would require a spectrum of services or accommodations by staff and faculty members to ensure success in a postsecondary education setting.

Ultimately, the goal of the special needs movement is to achieve fair and equal treatment so students who have a disability can be socially accepted, respected, and supported (Liasidou, 2014). Higher education leadership plays a part in this effort by fostering communities of inclusiveness and empathy. This type of community sets an example for the world outside of campus. An inclusive campus is not a legal requirement, which makes it important for leaders in colleges and universities to lead by example in areas including examination of policies concerning support, admission, and interactions with students with disabilities.

Summary

The intention of this research study was to reveal stories of students who chose to give up their privacy to receive support services, helping them successfully navigate the college experience. Through the use of narrative inquiry, I sought to gain insight in self-determination at individual levels. The objective of using the qualitative method was to provide a voice to students who are experts on their disability and want to share their lived experiences related to their decision to disclose their disability.

In Chapter 2, I will provide the search strategies used to identify key areas in the literature and definitions of disabilities, including background on legislation, types of disabilities, and student perceptions of being a college student with a disability. Additionally, I will synthesize the research on the conceptual framework, revealing additional justification for this study.

Chapter 2: Literature Review

The problem I investigated in this study was the lived experience of students when disclosing their disabilities to receive support services in higher education. The purpose of this study was to research students with disabilities who transitioned from high school to higher education and their motivations behind disclosing. In this chapter, I explore the extant literature concerning five connected concepts that inform the current understanding of the self-disclosure experience by students in an educational setting: (a) legislation and the Disability Rights Movement, (b) identification and the types and characteristics of students with disabilities, (c) the transition from K-12 to postsecondary education, (d) experiences of students with disabilities in college settings and their attainment barriers, and (e) student perceptions of supports and accommodations.

Literature Search Strategy

My quest to find germane scholarly research about students with disabilities began with the search term *students with disabilities*. Using the ABI/INFORM, Academic Search Complete, EBSCO, SAGE, and ProQuest databases, this initial search led to a discovery of a set of disability classification labels, which included specific learning disabilities, intellectual disabilities, and emotional disturbances. The combination of these labels classified half of the total population of students with disabilities (Artiles et al., 2016). Researchers described or specified the types of disabilities in other ways, including the introduction of the term *non-obvious disabilities* as a way to distinguish between physical manifestation (i.e., blindness, paraplegia, and mobility limitations) from disabilities or impairments that do not (i.e., dyslexia, attention-deficit hyperactivity disorder, or autism spectrum disorder; O’Shea & Meyer, 2016). Focusing on a disability like autism spectrum disorder is not inclusive enough to cover the breadth of the challenges facing students with special needs in higher education. Additionally, the terms describing these students range from learning disorder to moderate to severely disabled. In the literature, students with disabilities differs from the term *learning disorder*, which tends to focus on disabilities like dyslexia. SWD, an acronym for students with disabilities, appears more frequently in articles referencing the nonobvious disabilities like autism, anxiety, or adult attention deficit disorder, which are groups shown in the literature that benefit from accommodations in a college setting (Knight, 2016).

Google Scholar aided my review by providing a genealogy of the literature, meaning each of the articles reviewed for this study has ancestors and descendants in a citation family tree, allowing researchers to view a variety of articles and dissertations written on the topic of differently abled students in higher education and the disclosure process. Use of the genealogy of the articles provided me with a tremendous amount of insights and opinions as well as differing perspectives on the topic.

A pivotal term defined in the literature is *disclosure* because it is the disclosure decision that prevents students from receiving accommodations. In the context of this study, disclosure is the act of an individual revealing their disability; an action that is not required, cannot be forced upon those with disabilities, and is protected under federal law (Hees et al., 2015). The disclosure decision is a personal and complicated process, not just for students entering postsecondary education, but extending into the workplace as well (von Schrader, Malzer, & Bruyère, 2014). In the context of the disability disclosure decision, the term disclosure consistently received mention alongside its predominant influencers to include the descriptors, *stigma* and *perception*, which are typical initial reactions when contemplating the disclosure decision (Lyons, Volpone, Wessel, & Alonso, 2017).

I started researching *self-determination theory* in the databases of ABI/INFORM, Academic Search Complete, EBSCO, SAGE, and ProQuest. That search yielded peer-reviewed articles on the impact of socialization of students with disabilities (Chen, Bundy, Cordier, Chien, & Einfeld, 2015), student success through appropriate services (Couzens et al., 2015), and services supporting students with a disability who transition from high school to college (McCall, 2015). In addition to providing the importance of internal and external motivation, each article on self-determination theory offered additional clues about legal obligations to provide appropriate accommodations for students with disabilities.

Legal protections provided in the Americans with Disabilities Act (ADA) served as the backdrop for this study in that the ADA is the precedent that requires colleges and universities to provide accommodations but does not mandate schools enforce disclosure (Kutnak, 2014). However, the ADA is only one aspect of legislation that impacts students with disabilities as I discovered by searching for case law and constitutional law in the databases of FindLaw and NexisUni. Before the ADA became a reality, the beginnings of significant rights movements stemmed from a central point in U.S. history: The ratification of the 14th Amendment. While the 14th Amendment typically aligns with discussions of *separate but equal* in relation to race, this constitutional amendment was found to be helpful in K-12 settings to gain similar accommodations that aided in the formation of the Disability Rights Movement (Martin, Martin, & Terman, 1996). I also used additional legislation to narrow my search results, the IDEA, *Title III of the ADA*, and *Title IV of Higher Education Act of 1965*.

Conceptual Framework

In this qualitative study, I used self-determination as the conceptual framework. Self-determination theory, developed by Ryan and Deci (2017), focuses on motivation in relation to personal growth, overall well-being, and factors that promote or inhibit those contexts. Self-determination theory is used to examine how those inhibiting factors can subvert and deteriorate an individual’s decision-making, sense of self-worth, or quality of life. An important social context for students with disabilities is the connection with the faculty member and the institution they attend (Brok & Tartwijk, 2015). The use of self-determination theory as the conceptual framework of this study was intended to illuminate gaps in understanding students’ motivation to disclose their disability and gain access to supportive accommodations.

Self-determination theory provides a lens through which to view the motivations at work in the personal disclosure decision process of college-eligible students with disabilities. Previous researchers have referenced self-determination and self-determination theory to study experiences of online students (Wolpinsky, 2014), transitioning from high school to college (Georgallis, 2015), and motivations to accept accommodations (O’Shea & Meyer, 2016); however, this study appears to be the first to incorporate self-determination theory and the degrees of self-determination to view the motivations in the disability disclosure decision process. The degrees of self-determination include intrinsic and extrinsic motivation (i.e., identified regulation, introjected regulation, and external regulation) as well as amotivation (Chen et al., 2015). To understand the impact of these degrees, it becomes necessary to comprehend the self-determination scale and its four characteristics of self-determined behavior: autonomy, self-regulation, psychological empowerment, and self-realization (Shogren, Kennedy, Dowsett, & Little, 2014).

Using the lens of self-determination theory, I examined the disclosure decision by students with disabilities to understand more about that unique experience and what motivations lead to their decision to disclose their disability to qualify for support services. I also examined the perspectives of students working with disability services leaders and the students' experiences working with faculty members on classroom accommodations. The results of this focusing on the triangulation of interactions between the student, his or her faculty, and the institution can be used to help higher education leaders understand the precipitating, counterbalanced factors that make the disclosure decision possible. In this study, I studied the role of cultural influence, fear, and/or a basic level of fit of services available to reveal a holistic view of this complex process with important implications for educators, higher education administration, and the individual students themselves.

Literature Review Related to Key Concepts and Variables

In this literature review, I highlight five connected concepts that, together, inform the current understanding of the self-disclosure experience by students in an educational setting: (a) legislation and the Disability Rights Movement, (b) identification and the types and characteristics of students with disabilities, (c) the transition from K-12 to postsecondary education, (d) experiences of students with disabilities in college settings and their attainment barriers, and (e) student perceptions on supports and accommodations. Reviewing current and historical disability legislation created the entry point to examine both the entitlement of accommodations available to students with disabilities and the barriers created through legal compliance on behalf of education institutions. While the role of identification of need requirements exists as a mandatory service in K-12, the service level and agreements change after release from high school, creating a potential gap in awareness of services available. This awareness gap could impact student motivation and their incorporation or consideration of transitory services. I incorporated these five common elements to illuminate students' motivations in the disclosure decision process. These motivations include the behavior of these differently abled students, comprehension of their legal protections, their attitude towards existing campus services, and the awareness of the school's requirement to disclose. This literature review also includes an appraisal of theoretical and empirical research relating to students with disabilities.

Legislation, Case Law, and the Disability Rights Movement

Open access to education, a core component of the Disabilities Rights Movement, requires necessary legislation to protect students with disabilities; yet, the laws depend on compliance and implementation. Critical landmarks in the Disability Rights Movement include IDEA, Section 504, and the ADA (Leake & Stodden, 2014). What started as oppressing and excluding treatment of individuals with disabilities now resembles protection and legislatively supported assistance (Artiles et al., 2016). Although Congress created a framework of support, the diversity of the spectrum of disabilities opens itself to differing interpretations of adequate remedies for appropriate supports, creating additional challenges for the individual (Artiles et al., 2016).

Although there are legislative protections against discrimination in place, students' precollege experience varies because the mandates do not always come with the requisite funds required for implementation. Most teachers and administrators do not receive professional development to create inclusive environments and students can leave their secondary education with an experience lacking inclusion even with mandated accommodations in place (LeMay, 2017). Each school has a gatekeeping system because there are no uniform access requirements. More information is needed from the higher education instructors' perspective on working with students with disabilities.

Disability Legislation

The 14th Amendment to the U.S. Constitution eliminated segregation in public schools, but the prominent racial divide comprises just one aspect of this critical amendment in the history of the Civil Rights Movement. Desegregation of U.S. schools began as a requirement in 1868, but the foundational amendment needed the intervention of the courts in 1896 with *Plessy v. Ferguson* and again in 1954 with *Brown v. Board of Education* to take root (Daniels & Pereira, 2017). The notion of separate but equal applies to more than race, and in the years since *Brown v. Board of Education,* this pivotal amendment became protection for an economic condition, gender, and level of ability.

The supporting language in the 14th Amendment, defining equal protection for all U.S. citizens, became the cornerstone of modern legislation defending all civil rights prior to 1964.

The Civil Rights Act of 1964 offered protection to the civil rights of people comprising diverse populations so they could go to school or get a job, and persons with disabilities had no voice in this act. Laws in the 1960s did not consider individuals with disabilities as stakeholders in the determination of law, but instead falling into one of two categories: requiring protection or best suited for living in an institution (Stephens, 2006). Only upon the passage of the Rehabilitation Act of 1973, and specifically its Section 504, were individuals with disabilities offered full legislative protections (Lynch & Gussel, 1996). The Civil Rights Act of 1964 fell short of protections for individuals with a disability, but the provisions of Section 504 guaranteed those students a place in higher education.

Section 504 of the Rehabilitation Act of 1973 forced change management upon the leaders of colleges and universities concerning their treatment of students with a disability. This legislative act required colleges and universities that receive local, state, or federal financial assistance to cease activities, policies, or procedures that discriminate against students with disabilities (Martin et al., 1996). Section 504 covers both mental and physical disabilities and points to protections for individuals who cannot gain employment because of a disability or whose employability depends upon adequate rehabilitation and support services (Jacobs & Jacobs, 1984). Section 504 filled a gap left in the Civil Rights Act of the previous decade by addressing the treatment of students with a disability and differently abled persons in general. Visible changes came to colleges, universities, and other government facilities through the mandates of Section 504, such as the retrofitting of ramps and elevators; however, supports for mental disabilities did not alter the campus' physical appearance.

Legislation designed to protect and extend opportunities to the children of the 1970s reached a cap at the end of high school. As the population aged, the law had to follow a maturation process as well. The IDEA began in Congress in 1975 under its original name, the Education for All Handicapped Children Act, and among its achievements includes free and appropriate public education (Currier, 1999). However, free and appropriate education extended to include the attainment of a general education equivalency or a high school diploma and did not reach into the space of higher education (Hamblet, 2009). Congress passed the ADA to modernize the legal protections of students with special needs by minimizing barriers to access (Currier, 1999), but the ADA unintentionally built new obstacles through the guidelines for qualifying for those accommodations (Shallish, 2015). IDEA and ADA brought a new level of access to students with disabilities, at least to those who could afford higher education. Prior to IDEA and ADA, the issue of higher education affordability for students with disabilities existed for decades and required modernization of legal codes.

An example of modern legislation that provides protections for students with disabilities is the Higher Education Opportunity Act of 2008. This act reauthorized the Higher Education Act of 1965 (Madaus, Kowitt, & Lalor, 2012) initially aimed to reduce hurdles to higher education faced by students of lower socioeconomic status (Capt, 2013). The protections included in the act assisted students with disabilities by providing access to federal funds, including grants and work-study funding for opportunities to work on campus while attending school (Smole, Naughton, Kuenzi, & Skinner, 2008). While acts of Congress provide the framework and definitions for these required protections, it is the interpretation of the laws through the district courts that define the levels of required advocacy for students with disabilities and the leeway in compliance for educational leaders so they understand the limitations of litigation (Stevens, Schneider, & Bederman-Miller, 2018).

Case law provides the context of the legal interpretations of the protections afforded students with disabilities and reveals the additional barriers placed in front of these students. Following the passing of the Rehabilitation Act of 1973, the district courts ruled that a community college was not in violation of Section 504 by denying a Nursing student with a hearing impairment access to the RN program ("Southeastern Community College v. Davis," 1979). The ruling in this case defined the descriptor of *otherwise qualified handicapped individual* to distinguish between a student who could successfully fulfill job responsibilities in their major with adequate supports from those whose disability hinders their ability to perform basic job tasks. This interpretation of Section 504 by the circuit court provided a precedent that placed a limitation on the legislative protections but provided important guidance to educational leaders on how to better write criteria so Students with disabilities can understand the barriers.

Circuit Court decisions provide guidance and interpret limitations, and they also affirm protections for accommodations for students who need them. In 1997, the district courts upheld accommodations support for students with learning disabilities at a time when their school began increasing requirements to receive appropriate supports (“Guckenberger v. Boston University,” 1997). The court’s interpretation of Section 504 upheld the rights of a student’s freedom from excessive and redundant documentation of disability in circumstances where shifting institutional policies impeded students’ rights to accommodations. In many instances, case law provides a balance between overburdening a school with unreasonable expectations for accommodations and creating unreasonable barriers to receive accommodations; however, the courts employ an ignorantia juris non excusat view on students’ responsibility to follow procedure and process to receive the accommodations (Brady, Russo, Dieterich, & Osborne Jr, 2019).

In civil action, the decision leans heavily on a student’s ability to provide a preponderance of evidence. To collect the appropriate documentation requires students to be fully aware of the available accommodations, understand the requirements to sustain them, and to recognize and collect evidence when there are distinct violations of their rights. Two cases that demonstrate student self-determination are *Shaikh v. Lincoln Memorial University* and *Buescher v. Baldwin Wallace University*. In the Shaikh case, the student failed to abide by the provided accommodations, leading to dismissal or other academic misfortunes (“Shaikh v. Lincoln Memorial University,” 2015), whereas in the Buescher case, the students could not provide enough evidence to indicate they understood the restrictions in place or the impact their disability had on meeting program criteria (“Buescher v. Baldwin Wallace University,” 2015). In both these examples, the onus is on the student to seek out, understand, document, and comply with any accommodations requested and granted by the institution. While legislation guards the rights of the disabled, the judicial branch provides the context and outlines clear expectations for students with special needs to self-advocate and take charge of their rights or lose the protective rights those laws afford.

Identification and the Types and Characteristics of a Student With a Disability

The term students with disabilities is broad and encompasses any disability and that diversity means that upon entering college, each student faces different considerations when making the disclosure decision. A student with a physically manifested disability cannot hide or mask their disability, whereas concealment and nondisclosure are alternatives for those with nonvisible disabilities (O’Shea & Meyer, 2016). Regardless of exhibition of the disability, focusing on one specific type of disability negatively impacts applicability because of the breadth in the spectrum of known disabilities. Regardless of the breadth of the disability spectrum, the center of the issue is the individual student’s experience in deciding to seek accommodations and selecting to disclose their disability to the institution.

One example of a varied disability is autism spectrum disorder, where diagnosis and behavioral markers are as diverse as the individuals with the prognosis. Essentially, many adults with autism spectrum want to interact socially, but only when the environment is conducive to their success, void of conflict or discomfort (Chen et al., 2015). Autism spectrum disorder generally does not have physical manifestations, and if the individual perceives social interactivity as an attainable goal and one that would help them succeed, there is an inclination to achieve success without disclosing their disability

(Couzens et al., 2015). While social engagement is only one attribute of a successful student, identification and disclosure of disability becomes important to ensure students receive the support needed to address all areas in the life of a new college student.

Legislation mandates support provisions for students with disabilities, but not all primary or secondary schools provide quality diagnostic assessments. National Assessment of Educational Progress data indicates higher levels of identification and, therefore, assistance, among White children and lower levels of identification and support for ethnic minority school-aged children (Morgan, Farkas, Hillemeier, & Maczuga, 2017). Under identification among ethnic minorities, females, or English language learners while in primary and secondary education means those students do not get the academic supports they need to be successful, creating a negative impact on their willingness to pursue accommodations in college (O'Shea & Meyer, 2016). Inadequate identification and accommodations early in life creates a knowledge gap regarding support services, and as the student continues on to college, it continues the cycle of poor academic performance that can be invisible to academic leaders.

Self-perception and the perception of others are relevant topics to understand when studying Students with disabilities. The literature varies in describing Students with disabilities in that the descriptors range from *lower social functioning* (Renty & Roeyers, 2016) to *low self-efficacy* (Pearlman-Avnion & Aloni, 2016) but also as *motivated for social engagement* (Chen et al., 2015). The experiences of students with disabilities tend to originate in their self-perception and how others perceive them (Zambrano, 2016). Peers, faculty members, and staff are important parts of the learning and social environment; yet, their relationships to students with disabilities receive minimal attention in the literature, which focuses more on academic performance stemming from self-perception and peer acceptance (Emmers, Jansen, Petry, van der Oord, & Baeyens, 2017). Many students have a desire to integrate socially, as is illustrated in this research on social challenges facing students with disabilities, including that they may be lacking self-efficacy and that they are strongly influenced by peer acceptance.

As a minority group, individuals with disabilities represent an intersection between race, class, and gender. Identification of disability sparks one of two events in the life of most students, protective supports or prejudiced, exclusionary behavior, because the majority is the group applying the disability label based on communication barriers, health disorders, or even racially profiled observations absent of known economic status or condition (Artiles et al., 2016). Identification of disability presents challenges to educators in that individuals who are differently abled have mandated protections; yet, the individual may possess indicators stemming from their ethnicity (language differences) or lack of opportunity (impoverished areas with minimal services options) and can be misdiagnosed or wrongfully diagnosed (Morgan et al., 2017). Identification of a disability in an educational setting remains an imperfect process that has far-reaching implications for student ranging from access to services to receiving the proper types of accommodations. The beginning of identification, evaluation, and servicing challenges to effective disability support begins in the primary and postsecondary school, but it is the transition to postsecondary education – and really, adulthood – that exacerbates a gap in the levels and types of support services.

Navigating the Transition From High School to College

The constructs of support found in a primary through secondary environment are substantially different than they are in postsecondary education. In a K-12 setting, an IEP reinforces a contractual agreement for the concepts of mainstreaming and least restrictive environment (Zirkel, 2011), as schools must adhere to adjudication stemming from parents following due process (Weber, 2009). In the United States, 57% of students have an IEP but spend 80% of their time outside a special education classroom. In a college or university, students who identify as disabled are adults taught by faculty members (most of whom are not trained to teach students with disabilities), requiring a higher level of self-advocacy if there is a need for accommodations.

All college students are mainstreamed, whereas in high school inclusion is not always guaranteed, creating a need for alternative diplomas, which some states provide students completing state requirements for high school while receiving accommodations (J. Rubin, 2016). The absence of a document that guarantees a custom and inclusive learning pathway, an increased requirement for self-advocacy, and no options for an alternative credential represent significant support changes for these students transitioning from high school to college.

Experiences of Students With Disabilities in College Settings and Attainment Barriers

Adequately supported students who have a disability can achieve academic standards on par with peers (Liasidou, 2014). Nevertheless, simply providing the services is not enough to guarantee success in students with disabilities. Because these services and accommodations require disclosure of need, education leaders must pay close attention to support service delivery and the reception those services receive (Shallish, 2015). Ultimately, the disclosure decision process can present a barrier between a struggling student and access to services that promote student success.

In examining the college experiences of students with disabilities, researchers have noted that these students are self-aware of the expectations and the obligations of college life, yet impediments separate them from ultimate success, not all of which stem from their disabilities. Students with disabilities can face challenges with finances, legal actions, academic preparedness for college, and the processes required by their school to gain access to accommodations (Beilke, Natalya, & Jayne, 2016). These college-aged adults spend a majority of their lives managing their situation, but these additional obstructions exist because of the pursuit of a college education. They do not exist when joining the workforce, buying a home, or planning a vacation. Students with disabilities spend their college years consumed with navigating pathways to access the legally-guaranteed assistance they need by balancing a myriad of factors including social perception, time to completion, and overall well-being (Emmers et al., 2017).

Student Perceptions of Supports and Accommodations

To students with disabilities, a successful journey to a college education is a cornerstone of overall well-being that represents more than academic achievement. Although the college experience comes with challenges, there is no aspiration gap even if there is an achievement gap. In a postsecondary setting, differently abled adults experience not only interpersonal gains of social activity, but also the opportunity to become a productive member of the community and being gainfully employed (Butler et al., 2016). Being a college student includes a balance of time spent as a learner, both in a classroom or focused on studies; time focused on social activities and involvement with the school; and daily living activities (Hees et al., 2015). The challenges of students with disabilities affect those areas and can create situations that negatively impact the other aspects of their lives. Students reach a balance in these areas by knowing which aspects of their disabilities create these negative impacts and self-advocate for the help they need to manage the college experience, but often their perceptions of the potential effects sway their decisions to get the help they need.

The emotional struggle stemming from meeting the needs of their inner and outward selves as college students with the effort required to balance their needs for daily life creates identity development problems for some students. Students with disabilities contemplate the notion of self-identity and weigh those opinions with external perceptions to often determine to keep their disabilities hidden to pass themselves off as “normal” (Cox et al., 2017). External perceptions and concern for the impact caused by a change in perceptions provide enough negative stimuli that convince students with disabilities not to “come out” and seek help or get the accommodations they need to be successful college students. The inner turmoil caused by significant overvaluing of the opinions and judgments of others creates situations which increase the struggles of students with disabilities in attaining a college degree (Hadley, 2017).

When a student with disabilities determines to pass as typical, that act of self-denial creates separation from receiving accommodations. Situations may develop where graduation pathways exceed typical expectations, or the risk of attrition increases (Knight et al., 2016). A student who identifies as disabled typically exceeds the recommended four years to earn a degree, but students who receive accommodations increase their likelihood of graduating (Knight et al., 2016). A school's legally mandated accommodations can aid in the creation of a positive support structure and contribute to greater academic success; however disclosure, and in some cases, medical evidence of disability, places a barrier to receiving these support offerings (Cox et al., 2017). Although the intent of medical documentation requirements and disclosure exist to protect the institution from fraudulence or deceptive practices, those conditions create barriers between support services and the students who need them most.

The Disclosure Decision

The current research relies on colleges and universities to self-report their number of students labeled with a disability, as such exact counts are unknown, as the alternative methods of calculation, such as entrance exam notation of students with accommodations, infringes upon the 2008 amendment to the ADA (Hees et al., 2015). Of the relatively unknown number of students with special needs who enroll, students with less visible disabilities—such as autism spectrum disorder or ADHD—are not likely to disclose their needs to the school, creating a misleading impression that the actual number of students with disabilities is minuscule (Leake & Stodden, 2014). Several articles support the notion that disclosing one's disability is not always a given, and the reasons for nondisclosure might vary.

Examination of studies on motivation in students with disabilities presents scenarios where a student’s decision to disclose their disability relies on their level of self-determination and perception of their quality of life. Students with disabilities who build an autonomous life for themselves tend to exhibit greater self-worth, but their self-determination and foundational pride of this accomplishment could also negatively impact a decision to pursue support services if they do not determine there is a need (O’Shea & Meyer, 2016). The literature does not provide examples of research of students with disabilities in college that studies the impact self-determination has on the motivations of the disclosure decision or the experience of those students who disclose their disability.

Research of students with disabilities does offer indications that autonomous decision making tends to influence other aspects of living with a disability positively compared to instances of coerced decisions towards desired behavior, such as the case of disclosing a disability to receive support services (Reeve, Nix, & Hamm, 2003). The literature proposes a connection between students’ decision making and the intrinsic determination of need but lacks examples of this connection in the disability disclosure process. One hint at the motivations behind disclosure is the motivation of behavior based on perceived improvements in quality of life (Renty & Roeyers, 2016). This emotional connection—either positive or negative—to gaining access to formal support services and ramifications of disclosure creates challenges in understanding the motivations and experiences of students with disabilities and acceptance of support services.

Hong's **(**2015**)** interviews with students who identify with a disability revealed a lack of self-advocacy and intimidation by the range of services available or even understanding their eligibility for those services. Self-advocacy is only one aspect, as Agobiani and Scott-Roberts (2015) noted the negative impact labeling of a disability has on self-esteem and self-image, especially in cases where more than one disability is present. Couzens et al. (2015) described situations where colleges and universities vary in their policies surrounding access to support services, with many schools requiring external verification. Prior research provided a simplistic view to enumerate the known universe of students with disabilities, and it is the nebulous aspect of the personal disclosure requirement that creates gaps in valid quantification.

Summary and Conclusions

The literature review revealed five major themes for students disclosing a disability that will be important in my study. First, accommodations are federally mandated, yet the circuit court interpretations can vary as much as the application of the services by the individual institutions. This wide berth of variation creates a need for a better understanding of the lived experiences of students who decide to disclose. Federally mandated accommodations require leaders in higher education to ensure adequate openness to support students with disabilities, and it is the circuit court system that administers the litmus test. The courts place significant emphasis on student self-accountability to pursue accommodations and document their self-advocacy efforts or suffer losses in court should their situation require litigation.

Secondly, there is an inherent double-blind risk of failure for students with disabilities entering college, and that risk makes the disclosure decision a crucial institutional benchmark. An unknown number of students do not receive an adequate assessment of disability in K-12, and those students matriculate through the system, eventually entering postsecondary education without fully understanding their disability. Those misdiagnosed students then choose to pass as typical college students, elevating their at-risk status. Nondisclosure prevents students from receiving adequate accommodations, but coming out does not guarantee appropriate services because, in their formative years, students craft their comprehension and perspective on their disability (O'Shea & Meyer, 2016) or could receive a faulty classification (Morgan et al., 2017).

Third, there is a well-documented complexity of the decision process for a student with a disability. Students with disabilities weigh personal experiences, external influencers, and benefits of coming out when entering college. However, the literature reveals reasons for students to remain closeted regardless of the benefits supporting disclosure. This theme in the literature could impact interpretation of available statistical data, which shows a disparity between the known numbers of college-aged adults moving on from K-12 with an IEP and the known quantities of students with disabilities by year in college, which is gained only through a voluntary disclosure process.

The insight gained from studying students who choose to disclose a disability could reveal a path for institutions to follow is the fourth theme. Students with disabilities aspire to be successful socially and academically and to do so they need support tailored to their individual needs to achieve these goals. A lack of understanding about the decision to disclosure and insufficient identification of the overall student body who attend the school with a disability can impede disability services leadership attempting to create a range of appropriate accommodations for students.

Finally, whether or not students select to disclose, or they select to pass as a mainstream learner, they display a desire to succeed, and to do so, they need accommodations appropriate for their disability. The existing literature reveals that the disclosure decision process is a personal and complex decision influenced by internal and external factors. This study attempted to reveal some of the complex interconnections that support or impede a student from disclosure during the first year of college.

When combined, these themes present a complex set of interconnected of challenges facing students with disabilities attempting to navigate their way to an increased social integration while pursuing a successful academic journey. In a time of rising budgetary constraints, providing educational leaders with accurate information about the disclosure experience of this growing population could assist in the prioritization of appropriate accommodation strategies and create positive social change for vulnerable learners in higher education settings.

Existing studies, legislation, and case law provides the requirement and enforcement of accommodations to support students with disabilities but does not reveal everything about the supporting processes. Chapter 2 revealed previous studies focused on transition from K-12 to postsecondary settings and examined the experience in school and barriers to attaining a degree as well as student opinion on the types of services, but the missing component in the literature is the decision process. Chapter 3 focuses on my research design and methodology to address my examination of this gap in the reviewed literature.

Chapter 3: Research Method

The purpose of this qualitative study was to examine the perceptions of students with disabilities attending a postsecondary institution to better understand what drives each individual's decision to disclose their special needs while attending college. Participants included adult students (i.e., those over the age of 18 years old) who disclosed their disability to the school. Conducting this study provided students with an opportunity to give voice to their motivations for disclosure. In Chapter 3, I discuss the research design and rationale, the role of the researcher, and the methodology used in this study.

Research Design and Rationale

The disability disclosure decision is more than a one-time experience or milestone in the life of a student with disabilities. The decision to forgo anonymity is something they must live with for the entirety of their college experience and perhaps after their graduation, including the factors leading up to disclosing to the school and their life from that point moving forward. The phenomenon of a voluntary decision, one that is mandatory to receive legally protected assistance, merited a qualitative investigation. Qualitative approaches are used to scientifically research, order, and analyze a central phenomenon within its environment (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). This approach provided an aligned way to study the disability disclosure decision-making process.

The qualitative method requires the observation of students' behavior in a way that places them in their own setting. A qualitative study to examine the disclosure decision required me to think differently about the disability disclosure in that while the focus can be solely the disclosure decision itself, deeper investigation can yield more interesting findings. The findings of this study were also derived from the events leading to the decision, the impact on the student’s life after the decision, and how the decision affected the student both internally and externally.

The different types and levels of severity of disabilities accounted for varying perspectives among study participants. Differing types and levels of disabilities add complexity to the potential reasons and motives that impact the disclosure process. This variation of disabilities and the opportunity to study the array of perspectives among the participants lent itself to narrative research as an appropriate research design for this study. Narrative inquiry allows for the examination of the participants in a manner that places both the subjects and the researcher in the middle of the subjects’ stories, providing the opportunity to study prior events, the current state, and future expectations while delving into the impact on the subject both internally and externally (Clandinin & Connelly, 2000).

Narrative inquiry captures the series of moments in the life of the study participants by depicting these events in a way that provides interpretation or meaning to the central phenomenon (Usher & Jackson, 2014). Using narrative inquiry allows the researcher to capture the participants’ reality in a way that uses the individual’s voice to convey their personal experience. Focus on the personal experience of students and their perceptions of the disclosure decision highlight the individuality of each participant’s experience with faculty, administrative staff, and how it defines their inner and outer selves.

Narrative research featuring students who disclose their special needs as the expert on their own disclosure experience can highlight the impact of inclusion through an introduction of different perspectives on the value of support services and the importance of faculty, staff, and administrators who work with students. Students who do not disclose attend school without the aid of available supports or have a negative predisposition towards support services (McCall, 2015). Special education researchers have focused on the development of accommodations and services as well as the transition from high school to college but have not focused on the individual’s decision to disclose their disability (Leake & Stodden, 2014).

The following research questions guided this study:

RQ1: How do students with disabilities attending college describe their decision to disclose?

RQ2: How do experiences with the office of disability services inform the decision to disclose their disability?

RQ3: How do experiences with faculty members inform the decision to disclose their disability?

Role of the Researcher

My position as a researcher shaped the relationship dynamics with the participants in the study. As a father of a child with autism, I am positioned in the narrative as an academic stakeholder seeking to better understand the marginalized students whose experiences require exploration, which helped add a level of intimacy required to perform narrative research (see Lewis, 2014). The topic of disability disclosure is familiar enough to me that it gives me the empathy to understand and effectively convey the experience of students with disabilities, a valuable asset for conducting research (seee Roni, 2013). My professional experience as a higher education administrator served as the counterbalance to help me maintain reflexivity. I used my combined personal and professional experience to help me as the instrument of field research to improve interactions with the participants in the study and support my responsibility to research this topic (see Kaderli, 2017).

Using an approach with a constructivist view of reflexivity, my experience as a parent, and my career experience allowed me to bring genuineness to this qualitative research project (see Probst, 2015). My work experience provides me with a dispassionate view of higher education business, leadership, and management. By balancing the practical elements of how higher education functions with the academic aspirations that all parents feel for their children, I hoped to provide insights that could create positive social change for students who have academic challenges to full participation in educational settings.

Even with a proper balance of specialized expertise in higher education leadership and personal experience as the parent of a special needs child, developing a close relationship with study participants to earn enough trust to capture their stories still presented the potential to introduce bias into my study. In order to contain the bias, I used bracketing methods that help qualitative researchers navigate the hidden or unknown preconceived ideas about their study (see Tufford & Newman, 2012). Journaling was the primary approach to bracketing my personal thoughts and feelings, but I also employed other methods. Through capturing my reflections in field texts, these journal entries become open for the audience to examine, providing additional layers of transparency to this research study (see Ortlipp, 2008).

Regular consultation with my dissertation committee provided opportunities to receive objective, third-party insight from experienced researchers as well as assisted with field text review, translation from field text to research text, and review of interview questions. As an additional measure of trustworthiness, I had multiple interactions with the study participants in an effort to develop a relationship, which provided opportunities for collaborative dialogue on the study and findings.

With students serving as the population for qualitative study—even though they are consenting adults—it is important to remember when conducting research that individuals with disabilities represent a group with the greatest need for protection. A dichotomy exists when researching a central phenomenon of intellectual disabilities: Those with the disability have the right to participate in studies that can impact their lives; yet, they represent a group frequently marginalized and are the most vulnerable (Carey & Griffiths, 2017). There is value gained by performing qualitative research in areas of special education, but existing research provides little to no discussion of the ethical challenges that field research represents (Brantlinger et al., 2005). As a protected class, the conduction of research focusing on students with disabilities elevates the attention required to assure the use of proper ethics, privacy, and confidentiality more than other participant pools, but they receive tremendous benefits from the results of studies, even if they present complications for researchers.

Methodology

I used narrative inquiry as the research methodology of this study. A narrative study design can be used to examine the disclosure decision among students in a way that tells a story of those students and their experiences that informed a disability disclosure decision. The primary reason I selected narrative research was to share the common experiences of students with disabilities at a postsecondary institution. Although other qualitative methods succeed at capturing the voice and experience of study participants, narrative inquiry goes beyond a place in time or a bounded case and presses into the past, contemplates the future, and considers how the central phenomenon impacts the inward and outward self of the participant, all while capturing the moment of the lived experience (Clandinin & Connelly, 2000). Disclosing a disability only requires the submission of a disclosure form, leaving a researcher ample approaches for two-dimensional research focused on the decision; however, to capture the personal experiences that create the determination to disclose and the impact of making the decision , the breadth and depth of a narrative study were required.

I considered two other research methods before selecting narrative research as the design for this study: phenomenology and case study. Phenomenological studies help qualitative researchers explore the point of view of the person experiencing the phenomenon by using the lived experience as a focal point (Usher & Jackson, 2014). However, a challenge with phenomenological research is how the construction of research questions seek to apply meaning and define that individual’s experience (Starks & Trinidad, 2007). Alignment of abstract concepts in phenomenology is different from the approach in narrative research, which is used to document and explore the experiences of those living the phenomenon to create a story that presents the participant’s reality in a way that the reader can make sense of the entire experience, not just definitions or a singular moment in time (Lewis, 2014).

As a practical example, an intent of using phenomenology would be to examine the experience of students submitting a disability disclosure form and use that moment of decision to define a more abstract concept corresponding to the disability disclosure decision. In this study, I documented the experiences of students with disabilities who are persevering through their college experience—as well as faculty and staff who work with them—and used their stories to examine the decision process to disclose their disability through investigation of both inward and outward benefits—or consequences—as well as capture their perspectives of their lives leading up to the moment of decision as they contemplate their future selves.

Phenomenological studies are used when seeking to provide common understanding across research participants with similar experiences (Creswell, 2007), but the desired participants for this study were not limited to a singular disability and had a broad array of physical, learning, and mental disabilities, each individual carrying perspectives as different as their disabilities. The spectrum of variability in the individual’s disability disclosure process could have created challenges in distilling the data to a single common theme.

The other method receiving consideration was the case study. A case study accomplishes similar research goals as phenomenological studies because case studies offer the opportunity to investigate a phenomenon within a real life context to provide deeper understanding that could lead to change in policy, approach to practice, or provide an impetus for social change (Simons, 2009). The case study is bound to a particular place and time with a particular population, whereas a narrative inquiry affords the opportunity to move through time with participants in a way that provides the additional benefit of understanding influences and internal or external motivations driving behavior (Clandinin & Connelly, 2000). Case studies possess the capability to create generalizations and universal application based on the environment studied (Simons, 2009).

For this particular population, all participants attended and disclosed their disability to a college or university, but their lives centered within diverse environments where some experienced more negative environmental factors than others, attended different postsecondary schools, and even possessed different types and combinations of disabilities. Each of the qualitative methods considered offer excellent ways to study students who disclose their disability; yet, narrative inquiry offered a different research experience, affording me the opportunity to learn more about the experience of an individual as a whole and collect unique perspectives of their motivations in the decision process—before, during, and after—and not apply blinders to study only the act of making the decision itself.

Participant Selection

The original, proposed location for this study was Kentucky, a southern state with several counties comprising Appalachia (Appalachian Region Commission, 2018), which I had compelling reasons for outside of proximity. In 2018, Kentucky ranked 17th in the nation in percentage of students served under IDEA (“Children Age 3 to 21 Served Under the Individuals with Disabilities Education Act (IDEA) (State),” 2018), posting a top percentile national average graduation rate among students with disabilities in K-12 (“Adjusted Cohort Graduation Rate for Public High School Students with Disabilities (State),” 2018) even though over a third of all students are victims of bullying because of their disability (“Percent of Students with Disabilities Who Have Been Harassed or Bullied on Basis of Disability (State),” 2018). Adding to the challenge of being a student with a disability attempting to persist to college, Kentucky places 20th nationally in total qualified special education teachers, the 4th lowest in Appalachia and among all Southern Region Education Board member states (“Highly Qualified Special Education Teachers (State)”, 2018). The data points hinting at the environment a student faces in school are only one aspect of the state’s demographics that present concerns.

The statistical data describing the employability and state of disabled individuals presents a bleak outlook as well. The population in Kentucky ranks higher than national average in categories including total blind and disabled Supplemental Security Income (SSI) recipients and unemployed disabled persons including a top 50 nationwide ranking for one of its largest counties (“Total Blind and Disabled Social Security Recipients (County)”, 2018). The environmental factors in the schools and in the state generates a complex framework of adversity that students with disabilities who choose to persist must face.

Finding students who reached a disclosure decision became a challenge as the disclosure decision process is one born of personal determination. The challenge in the participant selection process was many students ultimately weigh their decision to disclose with a desire to reinvent themselves (Moriña, 2017). Real or perceived pressure to prove themselves, combined with desires to retain aspects of privacy made my participant recruitment more difficult.

To assist in the recruitment process, I reached an agreement with the Kentucky Special Parents Involvement Network—KY-SPIN, Inc.—to be a research partner. KY-SPIN supports families of students with disabilities of all ages and serves as a conduit to resources and services for them and their families to help in transition, education support, and other services that support personal growth and development for individuals with disabilities ("KY-SPIN - Kentucky Special Parents Involvement Network," 2018). The director of outreach at KY-SPIN agreed to facilitate recruitment invitations to families and individuals they supported in the disclosure process. The KY-SPIN organization agreed to share my recruitment letters under the following conditions: (a) do not require confirmation of medical records or diagnosis; (b) document all measures taken to ensure privacy and anonymity; and (c) provide some incentivization for participation—a gift card equivalent to a sit-down dinner. In return, KY-SPIN agreed to share my recruitment invitation to Kentucky residents who worked with the agency, disclosed their disability to their college or university, and are no longer minors. However, after three months, KY-

SPIN’s assistance did not yield any responses or even accesses of my online recruitment form.

After the three-month delay, my chair helped me go back to the Walden Institutional Review Board (IRB) and pursue alternative methods for recruitment. Colleagues, social media contacts, and former coworkers already told me their institutions would not be willing to participate for reasons ranging from complications due to requiring their own IRB approval to being overwhelmed with student work. One contact at a local Kentucky university with 10,000 students admitted the office of disability services had a staff of one to support 200 students with special needs and would not be able to assist based on lack of available time. These factors led me away from using Kentucky as the recruiting territory and broaden to the use of social media and the Walden University participant pool to attempt recruitment of students.

With the help of my chair, Walden’s IRB team approved my change in recruitment methods. Over the next several months, my online form had a few views but still no commitments or responses from students willing to participate. Eventually, the use of the Walden participant pool yielded six participants, but only two ultimately agreed to be interviewed for my study. Through social media networks, an additional four people filled out the online consent form but only two agreed to be interviewed. From the day of my IRB application submission to the first interview was 364 days.

Instrumentation

Disclosure of a disability is a choice for students with disabilities. If the disclosure decision is truly a choice for them, then the application of self-determination theory to this choice means there must be the alternative for the student—a choice not to disclose (Reeve et al., 2003). To better understand the population in this research study, it was important to assess their level of self-determination. Application of the Perceived Choice and Awareness of Self Scale (PCASS) instrument during the research process accomplished this assessment and helped draw out an individual's awareness of themselves and their motivations of choice (selfdeterminationtheory.org, 2018). The PCASS is a 10-question instrument designed to provide indications of an individual's self-determination (See Appendix A for a sample PCASS instrument).

The PCASS scales responses on a five-point scale as participants express agreement with a choice of two statements. For example, one question asks the participant to gradate their choice between "I do what I do because it interests me," or "I do what I do because I have to." The PCASS scoring relies on reverse scores on an "Awareness of Self" scale. These 10 questions and the scoring mechanism informs the generation of additional interview questions in that the PCASS results provide insight into the participants' level of self-determination, which constructs an intrinsic motivation (Reeve et al., 2003).

The development of additional interview questions based on the scoring levels of self-determination are critical to getting the student to reflect on their decision to disclose their disability. For example, participants with a lower PCASS score might respond differently to questions about their decision to disclose. A lower PCASS score would indicate they are less inclined to be self-determined and follows decisions others make for them. A lower score in self-determination then warrants different questions including, “Was this disclosure your idea?” A higher PCASS score indicates the individual is more aware of themselves and more directly influential on personal decisions. A higher score requires different lines of questions including, “Did you speak with a peer or counselor before making this decision?” This insight can help guide the conversations with the students to uncover perspectives including inner-self versus outer-self or other reasons to give up their anonymity.

During the sessions with the participants, I utilized a five-phase approach for conducting a narrative interview. These phases were preparation, initialization, main narration, questioning, and small talk (Muylaert, Sarubbi Jr, Gallo, & Neto, 2014). A list of sample questions used in these phases is included in Appendix B.

Procedures for Recruitment, Participation, and Data Collection

The desired participants for this study needed to come from a group of adult students who disclosed their disabilities. KY-SPIN agreed to assist me with recruiting a population with that characteristic, with the hope of gathering a purposeful homogeneous group. However, the use of social media and the Walden participant pool yielded four students who disclosed their disabilities and received services from their school maintaining a homogeneous group, they just were not all from the same school or state as originally intended. I conducted individual interviews with these students, as interviews, historically, are most effective in eliciting detailed narratives (Ravitch, 2015); they are also more conductive to building rapport as opposed to a public, group-based forums such as focus groups (H. Rubin & Rubin, 2011). Additionally, the interviews probed the perspectives of students towards faculty-supported accommodations at their postsecondary schools and interactions with their respective offices of disability services complete the triangulation needed for this narrative inquiry.

The plan for data collection included multiple iterations of interviews and interactions with participants to capture the participants’ perspectives. The original plan was to conduct in-person interviews with the participants, but because of the wide geographic locations and the onset of the coronavirus pandemic, face-to-face interviews were not possible. I conducted the interview sessions using web conferencing but did not require video so as to accommodate the individuals’ preferences. Upon agreement to participate in the study, the interview sessions served as a way to ask questions about the past. The sessions asked participants to detail their memories of their decision to disclose their disability. Additionally, participants were asked to gather information about the present, including their current experience and interactions with campus faculty, staff, and administrators. Lastly, the sessions asked the participants to contemplate their future and how they see the disclosure supporting or negatively impacting their ability to continue in college socially and academically. Upon completion of the interview sessions, each participant received private, individual memos to aid in collaboration of the writing process, as discussed in the trustworthiness section of this chapter.

Because of challenges in the recruitment process, the generation of a substantial participant pool was not possible. In narrative research involving students with disabilities, the literature points to ranges from 10-150, but size was a secondary concern yielding to more important measures of sampling including saturation and quality of representative transferability (Schreier, 2018).Out of the four participants, one participant attracted the other through a snowball sampling method. Snowball sampling—or chain referral—is an effective method of recruiting additional participants to a research study (Tenzek, 2017). While snowball sampling has its challenges, including representativeness, ability to initiate the chain referral, and handling effects of research fatigue this method excels at gaining access to hidden population samples (Miller & Brewer, 2003). Students with disabilities in a postsecondary institution represents a population with that attribute, making snowball sampling a necessary part of getting enough participants to agree to participate in my study. Unfortunately for this study, that access to the hidden population only generated one additional participant.

Data Analysis Plan

The primary source of data collected in this study came from the transcripts of the interviews with the participants and that data required coding. Coding is one of many tools used to help researchers bring meaning to large volumes of data collected in the qualitative process. For this study, the coding process began with examining the flow of “code-categories-themes.” Codes are short phrases or words to sum up a piece of data (Saldaña, 2015). When applying synthesis to codes, categories form to create another view of the data (Saldaña, 2015). The end of the process chain is the theme, which reflects how the codes synthesized into categories (Saldaña, 2015). The application MaxQDA is the primary software package used in the data analysis of this project. While there is not a right or wrong way to code, the process of “code-categories-themes” within MaxQDA is essential to develop meaning of the qualitative data. The process of developing a framework for coding presents challenges for qualitative researchers.

Anthropology provides the terms “emic” (insider within a group) and “etic” (an outside of a group) and these terms help bring meaning to the coding framework for this study (Adair & Pastori, 2011). The approach of viewing coding through the lens of emic/etic helped view this qualitative data in a way that did not have to be singular or familiar during codification.

Trustworthiness

The establishment of trustworthiness in qualitative research requires rigor and fidelity. To reach high levels of legitimacy in research requires rigorous focus on trustworthiness through the lenses of credibility, dependability, and transferability (Nowell, Norris, White, & Moules, 2017). The preparation to achieve trustworthiness in this study comes from collaborative member checking, reflexive journaling, and crafting the narratives with fidelity and social change in mind.

Research using collaborative methods—either collaboration between researchers or the researcher and participants—aids in transparency and brings more meaning and greater credibility to the research study (Paulus, Woodside, & Ziegler, 2008). Member checking is useful to move the collected data from one interpretation of many possible interpretations to a place where there is consensus in the experience with the central phenomenon (Milsom & Sackett, 2018). The approach to member checking allows a desired level of collaboration, but the method used to perform member checking becomes as critical as the collaboration method itself.

A common method of performing member checking is to provide the participant a copy of the final study in or near a final draft stage. One prior example of a student-focused qualitative study used collaboration with significant others of participants to aid in triangulation by having them contribute to their perceptions of how participants cope with life in college (Ward & Webster, 2017). A challenge in using member checking with a research participant—including students with disabilities due to their unknown level of self-determination—is some participants cannot objectively read an interpretation of their life experience, creating an uncomfortable situation for the researcher and the participant (Josselson, 2007). Interjecting awkward exchanges into a research study in or near a final draft stage creates significant risk to the study itself. A better approach to member checking is to apply a Bakhtinian method and allow the research participants to coauthor their experience (Harvey, 2015). Rather than introduce the interpretation of their narrative at the conclusion of the study, this approach allowed the participant to refine and enhance the recounting of their experience during the writing process, funneling their dialogue from macro concepts to more detailed accounts.

Combining a collaborative approach to coauthoring the narrative with reflexive journaling helped limit the opportunities for the introduction of personal bias, yielding a more impartial view of the disability disclosure decision process. The process of reflexive journaling provides an avenue for the researcher to disclose and discuss their role and impact on the study (Ortlipp, 2008). The journaling process for this study included the constant review of the journals with my dissertation committee to ensure an adequate and proper level of transparency existed throughout the study.

Fidelity—or transferability—requires demonstrable integrity on behalf of the researcher. Research findings in narrative inquiry requires the researcher to communicate the stories of the participants within a context to assist the audience in the development of a vision for the social change that must follow the telling of the narratives in the study (Moss, 2004). Participants in this study were different from each other in terms of severity and types of disability and levels of self-determination but shared a singular decision to disclose their disability to their school and receive accommodations.

Ethical Procedures

Qualitative research centers on the individual and researchers cannot gain intimate access to the individual by disregarding ethical treatment of the individual directly involved in the central phenomenon. A qualitative researcher can distill the broad subject of research ethics down to a central notion: ethical vitality exists because qualitative research comes from the researcher's relationship with people (Ravitch, 2015). An important absolute in qualitative research is the researcher must behave ethically to ensure no harm comes to the participants of the study (H. Rubin & Rubin, 2011).

Fundamentally, if the researcher places priority focus on the relational ethics of the study its quality improves drastically over instances where ethics receive little or no focus. For my study, I worked alongside students with disabilities with the goal of capturing their lived experiences. Crafting a narrative of the disability disclosure decision placed me in a dual role—as a confidant to the participants and as a representative to the scholarship of education leadership—which created the potential for ethical challenges (Josselson, 2007). Close relationships are a necessity to gain enough trust that the participant feels compelled to reveal the reasons why they chose to disclose their disability as part of this study. The invasion of privacy represented by the need for revealing such intimate details elevates the need for substantial focus on ethics.

Paramount in ethical consideration is informed consent – verification from the participants in the study that they are volunteering to participate with an absence of coercion or implied additional supports based on the study (Carey & Griffiths, 2017). Participants needed to understand that their participation was anonymous, even though participation of recognizable faculty and staff was possible as part of the study. The recruitment plan included the use of an IRB-approved invitation to participate, shared with the students through social media or made available using the Walden participant pool. The recruitment materials consisted of an IRB-approved, accessible online form with additional goals and information about the study, including a checkbox for consent to receive a contact for scheduling an initial interview. During the initial interviews, participants answered a question vocally—no interpreters were necessary—on the recording with their agreement to participate in the study. This process captured three separate forms of consent agreement and details their privacy protections. The balance of anonymity and consent with multiple interviews and touch points advanced the opportunities to create relationships with the participants.

Data integrity and confidentiality was not a significant concern in this study. This study did not require access to protected health information including medical history, care providers, or other sensitive information. Eliminating personal health information as a concern left student privacy as the central ethical issue at stake in the study. Additionally, I was the only one accessing raw data used in data collection and the data storage features encryption and password protection for additional security. After the 5-year waiting period, the electronic data scrub through a Department of Defense-level data removal helps alleviate concerns of data exposure.

Walden University's IRB provided requirements for all steps of the research process to further ensure ethical procedures were followed. The IRB approval number for the study was #06-21-19-0661813. Using the Walden participant pool as a partner and gatekeeper to study participants provided a double layer of security and protection of privacy to help keep ethical issues from causing challenges with this study. There is no conflict of interest in this study. Participants received compensation for participation in this study by gift cards redeemable for a cash value of $35.

Summary

Disclosing a disability at the university level is a pivotal, challenging, and important decision in the lives of students with disabilities. These individuals can choose to cast off the ideas of their former selves along with the formal structures put in place as part of the secondary education experience and attempt to make their way through their college experience without help, or they can push aside anonymity and attain assistance provided through federally mandated issuance. This study uses narrative research methods to tell the story of individuals attending various postsecondary schools who choose to forgo anonymity to get access to services designed to help them succeed in higher education. By seeking to understand the participants level of self-determination and by triangulating the narrative through their conversations with faculty and staff who work with students with disabilities, the stories conveyed by the students give a voice to the experiences lived by these students who come forward to accept support services.

Chapter 3 addressed my research design and rationale and my roles as a researcher in this qualitative study. While my total number of participants was not what I hoped it would be, I followed the required ethics procedures and defined the levels of trustworthiness needed to gather and analyze the data. Chapter 4 provides the complete view of the results from my design and methods.

Chapter 4: Results

The purpose of this study was to investigate how students with disabilities determine to disclose their disabilities and receive accommodations while attending a college or university. The baseline eligibility for adult participants in the study included having made a disability disclosure for the purposes of receiving support services. During interviews with these adult students, I pursued more information about their lives prior to disclosing for college; their experiences with faculty and staff while in school; and their thoughts about deciding to disclose and to continue disclosing, allowing them to continue working with support services.

Chapter 4 includes six sections to discuss the results of my study. First, I examine the setting and provide details regarding my participant profiles. Next I discuss my data collection and discuss the emergent themes, organized by research question. Then, I provide a detailed list of results aligned by research question followed by providing evidence of trustworthiness. Chapter 4 concludes with a complete summary of the material covered in the chapter.

Setting and Participant Profiles

The setting for data collection consisted of separate, private interviews with four participants via web-conferencing. The initial data collection process spanned a 4-week period, but it was a year-long journey to begin the data collection process. More precisely, it was 364 days between IRB submission and the first interview with a participant. I dealt with issues getting approval of the method to collect consent data and contact information, a loss of proposed research partner after yielding no responses, and an additional round of changes to the IRB approval for inclusion and permission to utilize social media and the Walden University Participant Pool. The latter change widened the scope of recruitment but forced the study to move outside the state within the United States indicated in the proposal. The end result was a total of nine signups, netting only four participants who agreed to move forward, even after getting consent and PCASS scores for all nine inquiries. Of the four participants interviewed as part of data collection, two participants came from the Walden Participant Pool and two came from social media outreach campaigns on LinkedIn and Twitter. The pseudonyms for these participants are Elijah, Kylie, Noah, and Patricia.

Elijah was the first participant to come forward and agree to participate. He received his diagnosis of attention deficit disorder—ADD—in the third grade, but it was not until high school that doctors determined him to have Asperger’s, or high functioning autism. As an eighth-grader, Elijah scored highest in his school district on the SAT, enabling him to take classes at a local community college throughout his remaining years in high school. Even though he achieved high marks on the SAT, Elijah struggled with English. The accommodation that helped him most was the use of a computer in class and to complete his homework assignments.

Kylie is a doctoral student who slipped through the K-12 system without being diagnosed with dyslexia, although she did receive an anxiety and depression diagnosis earlier in life. Like Elijah, Kylie performed well academically, but struggled in English. Kylie transitioned from a small private school to one of the largest public schools in a metropolitan area to attend high school, providing an extra layer of transition issues for her. While Kylie does not always share her diagnosis with others, she does advocate for herself and encourages those who know her well to advocate for themselves.

Like Kylie, Noah is a doctoral student. In K-12, Noah was able to pass as a typical student even though he received a diagnosis of Asperger's. Like his fellow participants, Noah performed exceptionally in school, achieving status in the National Honor Society. It was this high level of academic achievement that allowed Noah to attend a local community college during his senior year. Noah, however, has struggled with underemployment, working in a bakery while holding a master's degree and working on his doctorate.

The final participant was Patricia. Patricia struggled in school, but her struggles were not significant enough for her teachers to realize she was dyslexic and suffered from ADD. She fell prey to misdiagnosis because her symptoms were less noticeable as a female compared to male peers in K-12. Patricia improved academically with the proper support, but it was her teachers and more typical peers who affected her psyche by telling her she did not look the part of someone who had a learning disability. Patricia discovered a passion for sign language and currently attends college studying to be a sign language interpreter.

Data Collection

The participants interviewed in this study are adult students who disclosed their disability to receive access to accommodations and services while attending a college or university. The aforementioned criteria remained intact from the proposal stage, but the recruitment strategy to identify participants for this study required drastic changes. After identifying KY-SPIN as a research partner, my expectation was to recruit from a population consisting of adult students with disabilities from any of Kentucky’s 120 counties. After 3 months of efforts and zero participant leads, KY-SPIN and I mutually agreed to cease further outreach attempts. Over the next several months, my chair helped guide me through the process of restructuring my recruitment strategy so I could approach the IRB with desired changes to recruitment processes to include the use of social media and the Walden University participant pool. The combined use of social media and the participant pool yielded four students who disclosed their disabilities, received services from their school, and were willing to commit to participation in my study.

After each interview session, the participants received a memo detailing my interpretation of their individual narratives. Performing this step earlier in the writing process is part of the Bakhtinian method of member checking. The purpose of this method was to gain access to participant feedback earlier in the draft stage and not at the end of the dissertation review process. Each participant had an opportunity to provide feedback on the three phases of the interview, which consisted of questions focused on the past, present, and future when considering their determination to disclose their disability. Two of the 4 participants voiced concerns with how the transcription affected the clarity in their narratives. Those two participants provided me with additional clarifications and modifications to their interviews. The collaborative member checking yielded the interpretation of the stories collected that is provided in this section.

Data Analysis

In addition to conducting interviews with the participants, I also collected PCASS scores from them, using the PCASS instrument found in Appendix A. Table 1 provides the PCASS scores and the recruitment method of these four participants. A higher PCASS score infers the individual has a higher level of self-determination, which is viewed as awareness of self and also as perceived choice (selfdeterminationtheory.org, 2018). The examination of the individual's PCASS score provides a different perspective on the answers each gave during the interview process.

Participants, PCASS Scores, and Recruitment Method

Table 1

Participants, PCASS Scores, and Recruitment Method

	Awareness of Self	Perceived Choice	Overall PCASS Score	Recruitment Method
Elijah	2	3	3.5	Social media
Kylie	4.6	2.2	1.8	Walden participant pool
Noah	3	3	3	Walden participant pool
Patricia	4.2	3.4	2.6	Social media

Elijah had the highest overall PCASS score, but his awareness of self was the lowest among the participants while scoring high on perceived choice. Elijah's responses to the interview questions indicated he knew he had a choice in his disclosure and was keenly aware of the accommodations that his school needed to provide him, but his low self-awareness presented itself in that he struggled emotionally with problems in housing arrangements. Conversely, Kylie had the lowest overall PCASS score but the highest in awareness of self. She shared how she knew she had a problem and wanted to use her struggles to enlighten others while indicating higher levels of self-awareness, but her challenges navigating accommodations and the overall support process indicated perhaps she was not aware of the choices she had in her power to make. The PCASS scores provided the story behind the story during the data collection process.

The transcription for each recorded Zoom web-conferencing session occurred through the use of a combination of Sonix.AI and Ravens-eye.net. Eventually, I ran all the sessions through Sonix.AI because of transcription quality issues with Ravens-eye. Once the recordings were transcribed, I performed contextual analysis with MaxQDA, specifically for coding and visualization of the data collected.

Coding Process and Subcodes

In the coding process, I utilized both emic and etic approaches to analyzing the interviews. The etic approach provides a view of the data from the outside looking in, while the emic approach is used to describe the lived experience of the participant from their perspective (Fielding & Fielding, 2008). The emic approach represents coding the data focusing on how the participant described their process and using their own words, and the etic approach focused on how their stories informed me as the researcher using terminology derived from the literature. I was able to use both approaches together to code as a way to see the same story from two different perspectives.

Appendix C provides a view of the codes I used during analysis. The etic codes represented broad descriptions of the participants’ stories and use words best described as cold and lacking emotion or absent of human feelings. Examples are the words: “documentation requirements,” “hiding,” “faculty interactions,” and “self-advocacy.”

The emic codes present themselves as the participants' own words and are warm in nature, reflecting raw emotion and personal feelings. Examples include "disappointed in myself," "fell apart," "knowing my rights," "normal," "struggle," and "treat me as a person." The distinction between cold and warm expressions is an important one because existing literature focuses on the obvious structural and transitional nature of students known to have a disability and their transition from high school to college (McCall, 2015). These participants shared their real experiences with me in their own words as they highlighted the impact the disclosure decision had on their lives.

Emergent Themes

The emergent themes came from examination of the emic and etic codes across the participants and through compiling the segments of their transcripts. Using this process, the following four themes emerged from the data: (a) making the decision to disclose disabilities and the transition process, (b) disclosure is not a singular event, (c) importance of staff interactions, and (d) inconsistent faculty interactions.

Discrepant Cases

The purpose of this study was not to focus on a single disability but to focus on how students describe the disclosure of that disability and to what extent their relationships with faculty and staff impact their disclosure process. The similarities in how they talked about that experience added more depth to my understanding of their personal experiences. The differences in their responses did not yield any discrepant cases in this study.

Results by Research Question

In this section, I discuss the themes that capture the overarching narrative derived from the four participant interviews. Each of these themes factor prominently in the stories relayed by each participant, and these elements represent the commonality of their experience dealing with the disclosure of their disability. The participants and I collaborated on editing the participant quotations provided in this section for clarity. The following research questions helped to frame the importance of the themes derived from my analysis of the data:

RQ1: How do students with disabilities attending a postsecondary institution describe their decision to disclose?

RQ2: How do experiences with the office of disability services inform the decision to disclose?

RQ3: How do experiences with faculty members inform the decision to disclose their disability?

RQ1

Theme 1: Making the decision to disclose disabilities and the transition process. None of the participants indicated hesitancy to disclose their disability upon entering college. Elijah and Noah both participated in dual credit programs while in high school, and their high school staff facilitated that disclosure process for them. Both of the male participants’ postsecondary experiences were at community colleges, and they were minors at the time of disclosure. After high school graduation, Elijah and Noah joined Patricia and Kylie at larger colleges and universities where they needed to make the decision on their own as adults. All four indicated college staff walked them through the process, but they all needed to initiate the process on their own. Each of the students interviewed relayed similar experiences where at least part of their overall diagnosis came at a young age, meaning these students dealt with their diagnosis and navigation for many years while navigating the K-12 support system.

Elijah received a diagnosis of ADD in the third grade. It was not until late in his high school career that Elijah received an additional diagnosis due in part to advocacy on the part of his mother. Elijah said, “I still had other issues, I still wasn't ‘normal’ and then got into high school, might have been a senior she (his mother) got me evaluated for Asperger’s or high functioning autism.”

Noah is a doctoral student in an online program. He received his diagnosis during the 1990s at age 9. His initial diagnosis was, in his words, “Asperger’s. A name that I frown upon. Now, I now consider myself to be autistic.” It is important to note for Elijah and Noah that Asperger’s no longer exists as a diagnosis. Practitioners today would diagnose these two participants as having autism spectrum disorder.

As a teenager in an urban, metropolitan area, Kylie did not have to study to perform well in school and described herself as “pretty smart.” Once she reached high school, that paradigm shifted as she began struggling. Part of the struggle stemmed from moving from a small, private school, to one of the largest public schools in the city, enrolling over 4,000 learners. Clarity on the balance of her struggles came in the form of a diagnosis of anxiety. Combined, Kylie believes these factors led to lower skills testing in English and reading comprehension.

For Patricia, her diagnosis also came after periods of academic struggles. She did not receive her diagnosis of ADD combined with dyslexia until middle school. It wasn't until a teacher discussed with Patricia's mother the things "she found consistent with the students who were in the special ed program." Kylie and Patricia's stories about their late diagnosis indicate evidence of challenges receiving adequate support in K-12 prior to attending college.

Elijah never received an IEP in high school. He shared with me, "My mom tried to get me accommodations at the high school, but it was a very underfunded high school." Elijah attributed a lack of IEP or additional supports to two determining factors. The first reason was his high academic standing in an upper percentile of students in his graduating class, placing in the 80th percentile of college-bound seniors while only in middle school. Secondly, Elijah performed well overall in school despite his dual diagnosis of ADD and autism spectrum disorder, but he struggled with English, a common theme amongst the participants. However, he had an English teacher who allowed him to use a laptop to do his classwork, even without an IEP. Elijah said, "I never got an official IEP or anything like that but…the main thing that really came of that was my English teacher let me use a laptop on tests to type out essays."

Socially, Kylie felt high school was an "okay experience, but not the greatest." She felt her English teacher was harder on her, which she initially attributed to shared gender and race with the teacher and the teacher's commitment and expectation for her to achieve in her classes. Later she began realizing it was sentence structuring at the center of her challenges. Once Kylie enrolled in a different English class focused on journaling, writing became easier. Kylie was a C student in English throughout high school except for her classes in poetry and informal writing where she fared better. There were no solutions for her in high school, leaving her with the thoughts of "I'm a smart kid, why is English so hard?" She shared that her struggles made her feel "dumb." Because Kylie was academically proficient, she did not receive an IEP or a 504 accommodation while in high school. She shared with me that she "was invisible to them."

Noah's high school social life included lots of extra-curricular activities like Yearbook, National Honors Society, and weight training with his peers. However, Noah was hiding his autism diagnosis. Noah admitted that during his high school years only a select group of people knew about his Autism. He found a way to "normalize" and not attend a separate school for children with autism. It was his academic performance granted him the opportunity to partake in college classes while in high school. Noah felt a strong aversion to vocational education, believing and advocating in himself to the point he wanted more academic challenges.

Patricia received testing based on one of her teacher's suggestions to her mother. Once tested, the results revealed additional problems hiding beneath the surface. She talked about how this late diagnosis completely detached her from her peers in a typical classroom and placed her in a special education classroom, indicating that her ADD went completely undiagnosed by her teachers as well as her dyslexia. At 14, the school removed her midyear from a typical classroom and placed her in the special education classroom. While the accommodations in the IEP helped Patricia, she began experiencing judgmental attitudes from her fellow classmates, saying the teachers in school presented unwelcome reactions to her requirement of having an IEP. Patricia’s teachers were not even aware of her IEP or that she needed one.

Patricia shared her frustrations with being in high school and the difficulties of transitioning from full-time traditional classroom to needing to be in special education. It was when she began fulfilling her foreign language requirement that she found a potential career goal that excited her about the future. She took a sign language class that completely changed her outlook on high school and moved her from hating school to being excited about searching for schools who offered majors in sign language after graduation.

All four participants interviewed found the timing and experience of college life created both some positives and negatives in their daily routines. The most significant area was time management. Patricia appreciated the differences in her schedule between high school and college. She commented on how the openness of the schedule allowed her to feel more in control of her anxiety.

Transitioning from high school to college presented vast differences in Kylie’s daily living routines. Her transition issues began in high school when she first changed school. Being an only child from a small school and having transferred from a small private school to a large urban school, she had few friends, citing it “was a culture shock for me with the amount of people.” She went from being in school from 8 a.m. to 4 p.m. every Monday through Friday during the school year to only having a few courses during the week, mostly from 10 a.m. to 7 p.m. However, the free time created challenges for

Kylie by opening her up to opportunities for anxiety to set in and build up, but overall, she made it work for her.

The schedule Noah maintained in college presented challenges to his overall well-being. He described periods of how feeling “low” created “chaos” for him. As a biology major, the schedule for labs created challenges for him, especially given the learning persists through the course, meaning mistakes or challenges understanding expectations or content built additional frustration the farther along he was in the course. He felt a lack of support trying to complete the lab assignments because of the large volume of content that required mastery to move forward. He admitted that the experience caused him to get “further documentation to define more services that were controversial at the time, like a word bank.”

Additionally, Noah found employment difficult while he continued his academic journey after his undergraduate degree. He talked about having to work in a grocery store, using the term “underemployed” because it was difficult to find work with his graduate degree. Noah went on to indicate it wasn’t until he began working on his doctorate degree, he achieved full-time employment with benefits.

For Elijah, his struggles with transitioning began during his dual credit program when he attended classes on a small college campus whose demographic skewed much older than him. He shared the social difficulties in that experience related to being the youngest person on a campus full of adult learners at a small community college. Additionally, it seems the local college missed a step when moving him into the program, forcing him to take an English class first, which he already shared was a problem area for him.

Theme 2: Disclosure is Not a Singular Event The literature discusses disclosure as a moment in time where a student makes the decision to forgo their privacy to access services that U.S. colleges or universities have a legal obligation to provide if they accept federal financial aid money. During the interviews with these four participants, it became clear that the disclosure is not a "one and done" experience, but a constant requirement. Disclosure requirements appear to exist not just to the academic staff who support students with disabilities, but extend to faculty, other staff, and sometimes their peers. Noah described the differences between disclosure today than in the 1990s saying it was "a bit more liberating then because it wasn't well known back then, and you can get by with not disclosing. It was only later in my life that I had to disclose to a few people."

Elijah went through two separate college disclosure experiences transitioning out of high school. First, he attended a small community college while in high school and for two years after. Secondly, he transferred his credits to attend a larger, public, 4-year institution where he needed to decide to disclose again. Getting admitted did not provide a hurdle as his selected institution was the only school to contact him back and offer help in applying and transferring. Elijah intimated, "I never felt like a number, even considering the size of the university."

However, in his courses, he had to come forward and approach the faculty member about his accommodations noting, "But I still had to approach them and discuss specifically what I expected and needed from them." While coming forward created a second act of disclosure, the faculty members he spoke with were helpful. One particular faculty experience led Elijah to pursue additional accommodations to get additional support in writing through the use of e-mail submission of assignments. Looking forward in time from his decision to disclose this disability, Elijah suggested that disclosure did not mean giving up private details about his challenges, that simply providing signed documentation that he needed certain accommodations was sufficient. He described this process of providing documentation and the level of details required as a deterrent.

> The fact that they're trying to put roadblocks in the way is distressing, even though I think it's to keep people from abusing it. To make sure people are not abusing the accommodations process they're going to force people to explain their disabilities, and to prove they need an accommodation when it technically shouldn't be doing that.

In addition to disclosing to the disability services office, Patricia's school requires her to disclose herself to the individual faculty members as well, to inform them of her accommodations. She described it as, "my responsibility then to go to the office hours of the professor, give them my disclosure form, introduce myself."

A disability services worker engaged with Noah at his local college he chose to attend and helped get him set up for accommodations while in school. Outside of the disability services staff, Noah admitted he was hiding while in college much like he did in high school and raised an important question, "So why disclose it if it isn't necessary?" Noah went on to indicate he is open about his disability with the right groups of people, including being a writer for a disability services publisher and being actively involved in local civic groups in the disability services community.

RQ2

The importance of staff interactions is the theme that aligns to the second research question. Across the four interviews, another emergent theme is the importance of the accommodations on their success, but the inconsistency in which processes occur to support students who disclose. These interviews contained positive stories, but the description of the whole process appeared varied, specifically accommodation determination and communication from the services office throughout the campus organization. Patricia offered a positive experience starting at the beginning, working with campus staff citing, “We went in to the school before the semester started and we gave them the information and then they sat down and we figured out what they can offer compared to what I was asking for or needed.”

Elijah’s greatest struggle with disclosure and acquiring accommodations came from an apparent lack of communication between the disability services office and the campus housing department. He shared that this disconnection in process or procedure significantly affected his mental well-being until resolution of the issue, saying “I would go in a tailspin for a week until I could finally get on the phone with someone and say, ‘this needs fixed.’” He went on to suggest he found a consistent disconnect between the accommodations department and the housing department on campus.

Kylie learned the hard way about how to handle difficulties navigating her college experience from the support staff. She shared that her dyslexia combined with a more diverse set of teachers with unfamiliar accents, led to Kylie failing a class for the first time. Kylie shared a story about the first class she failed in college because she could not understand her faculty member, who had “a very thick accent and I think he was from like Australia.” Working with support staff in the African American support office, she later found out she could withdraw from courses in favor of instructors who might be a better fit given her struggles with reading comprehension and writing. She declared that information on how to handle situations like this was not readily available to her. She went on to say, “not only was I dealing with my own issues, I was not knowledgeable about how to navigate through college either.”

Currently in school to pursue a career as a sign language interpreter, Patricia receives the following accommodations: note-taking during class, ability to record lectures, sitting in the front of the classroom, accommodative testing, extended time, separate location for exams, enlarged test, use of a calculator, and use of a word processor or other software. Looking ahead to her future as a college student, Patricia shared with me her plans to continue receiving services, saying, “I feel like they’ve helped me so far in my college career now, and it just provides me extra support if I need it and I don’t, I wouldn't want to give that up, especially since it’s helped so much.” Because of the negative interactions she had with her peers in high school and with the faculty member telling her she “did not need her accommodations,” Patricia did express some reluctance at the continued requirements of disclosure aspect of keeping her services.

Through the balance of his attending college, Elijah continued to utilize accommodations in housing, taking written assessments on a computer to type them, and for his emotional support animal. While he thought carefully about his decision to continue disclosure, he noted that the faculty member who encouraged him to pursue additional accommodations helped him more than just in the one class saying, “She helped me realize that getting an accommodation letter was better than not having it.”

Noah shared his current set of accommodations, which include extended time on a test, use of a laptop computer and software to assist in class, and he described these as minimal services. His comment on accommodations indicates that once the support staff determined he could succeed academically they “treated (him) as a normal person.” As he moves through his doctoral program, Noah indicated he continues to complete the paperwork for disclosure to get access to the accommodations he needs. He is on a path to continue work on his dissertation. At this point in his program, he indicated he is doing much better mentally and financially now with a full-time job with benefits.

Noah indicated that disability services for graduate students help course-based needs, but “those accommodations do not help when you have to work independently on the dissertation portion of your program.” Noah shared a desire that services provide additional structure for independent-facing work activities. He highlighted that many students he knew who received services dropped out at the dissertation phase for this reason.

RQ3

The final theme aligns to the final research question and it is the inconsistency of interactions with faculty. Across the participants, their narratives tied some of their struggles in college directly to faculty preparedness to work with students who require accommodations. They each had a wide scope of experiences engaging with faculty. While coming forward created a second act of disclosure for Elijah, the faculty members he spoke to were helpful. One particular faculty experience led him to pursue additional accommodations to get additional support in writing through the use of e-mail submission of assignments.

When asked about her experiences with faculty, Patricia recounted a story that left a great impression upon her but displays both a positive, memorable occurrence but also a negative interaction.

> One experience that I had was last year a professor was new and I went to introduce myself along with my accommodation form. I had her in class and. She sat me down, and usually the conversation between giving the disclosure form and introducing myself is quick. But she asked me, she’s like, oh, like, what do you feel like your strengths are? What do you feel like are things that you need to work on? She was kind of just trying to get to know me a little bit more and to try to understand my needs a little bit better. And I thought that was really quite powerful. That stuck with me.

The same faculty member who was open and inviting to Patricia, presented hurdles to actually receiving the support she needed to be successful in class.

> One of my accommodations is to have my classes recorded via audio. This class in particular was taken place on Zoom, this platform. And as you're doing, she recorded the class and she knew my accommodation forms. She knew that I said that I had to get my recordings of the class. I e-mailed her several times about it and she had yet to respond, to give me any indication that she'd gotten my e-mails and did not send any of the recordings. This was probably about halfway through the semester by the time that she finally started sending the materials, the recordings of the class. And that's only because of the intervention of the director of the accommodation services had to step in at that point. And she (the faculty member) made a comment to me saying, 'oh, you're doing just fine in the class. Like, it's not even like you need these.' And I was a little bit taken aback because she had said she was so open and receiving a few months earlier. And then when I needed her to, you know, go through with the accommodations, she kind of chalked it up to, 'oh, you're doing fine in the class. You don't need this.' And it's not a matter of if I need it or not. It's a service that's provided for me and it's part of my accommodations and whether I need it or not, I still need access to it. So that was a pretty unfortunate that it was the same professor that I had both a good experience and a not so great one.

Kylie would not commit to a full feeling of support from faculty. Her experiences with faculty indicate a more passive approach to supporting students with disabilities. She described the faculty attitudes as waiting on the student to ask for help and not being proactive enough to realize which students are struggling. However, her instructors never checked in with her to ensure she understood the content or if she required additional explanation. Kylie’s comments indicated the school performed well in helping her identify her struggles and defining accommodations to help her succeed, but the individual support from faculty left her facing challenges in her coursework.

Large amounts of content and assignments, his sense of underemployment affecting his mental and financial well-being, combined with the process of working in a doctoral program created significant challenges for Noah. He felt as though he was not getting enough support from faculty both in the classroom and as part of his dissertation committee. Lack of timely feedback on assignments and on his proposal led to the “valleys” as he described those emotional low points. Ultimately, he indicated these challenges led him to move to a different program and change his major. As Noah continues his pursuit of a doctoral degree in a new subject area, he implied the committee chair role is a revolving door, going through three different chairs, hoping to find a mentor who is willing to accommodate him and help him achieve success at the doctoral level.

Evidence of Trustworthiness

In Chapter 3 I discussed the need to establish trustworthiness in qualitative research through rigor and fidelity. The evidence of trustworthiness in this study comes from the use of collaborative member checking, reflexive journaling, and weaving together the narratives with fidelity and social change in mind (Kim, 2016). These strategies provide the substantiation required to show trustworthiness in the study.

Credibility is the operationalization of strategies used in the alignment of the stories told by participants with the interpretation by the researcher (Nowell et al., 2017). To qualify for this study, the requirements focused on students who disclosed their disability to receive accommodations while in college. However, participants were not asked to present hard evidence of their disability. Each participant did convey stories about their experiences in K-12, leading up their college experience, and what life has been like for them in college. Each participant had the opportunity to collaborate with me on the telling of their stories, aiding in the credibility of this study.

To achieve fidelity, or transferability, the findings in narrative inquiry require the researcher to render the participants' stories in such a way that the reader understands the required social change that must follow the end of the story (Moss, 2004). The fidelity challenge here is the group of students who disclose their disability is a difficult group to attract participants. As previously referenced, it took almost a year and required a change in course to attract nine people willing to sign up, yielding only four participant interviews. However, the four brave participants who came forward represent different college experiences ranging from large university to online university and graduate to undergraduate experiences. I made every effort to honestly reflect their experiences based on their disability and their particular college experience.

To aid in dependability researchers need to provide an intimate analysis of any details that impacted the collection and analysis and the emerging themes (Morrow, 2005). This paper presents detailed explanations of data collection, transcript, member checking, and data analysis used in the study. The completed study and dissertation received reviews from my faculty committee members and Walden University's IRB.

Confirmability requires the researcher to funnel thoughts on their role and impact on the study (Ortlipp, 2008). Given my experience as a parent and a previous college administrator, my committee helped me take every possible measure to handle and reduce the risk of any bias that might affect my study. Before each of the four interviews, I took the opportunity to review the interview questions, analyze the participant's PCASS score. During the interviews, it was important for me to listen carefully to the participant's story without doing any analysis on what they were saying during the interview to keep my biases from influencing an interpretation of what the students said to me. Giving the participants the opportunity to collaborate with me on the telling of their story also insured their voices came through and not my own. Through these processes to contain bias and reduce its influence on the study, I confidently affirm objectivity in the findings of my study.

Summary

I used interviews and analyses to gain insight into the disclosure process and the impacts of interactions with faculty and staff. The conceptual framework used is self-determination theory, which examines an individual's motivation and its role as an inhibitor, preventing personal growth and overall well-being (Ryan & Deci, 2017). Each of the participants revealed key motivations and details regarding their decision process used to determine the disclosure of their disability.

My interviews with these four participants were all online and each separate from one another. The design of the interview questions helped guide the participants into the areas of their experiences that impact their determination to disclose. After each of the interview sessions, my committee received the reflexive memos and provided the individual memos to the respective participants for their feedback and collaboration in telling their stories. The purposefulness of these steps impacted the overall general quality of the study.

The memos and my own researcher's journey log recorded any personal bias throughout the study. Although I have two sons with special needs, I do not have a complete understanding of postsecondary education because they are both currently in K-12 settings. My knowledge about the disclosure process came only from the literature itself. It was difficult to hear some of these stories and their struggles impacted me personally, and I noted those to my committee. These memos served as a method of preventing my personal emotions and bias from influencing the findings in my study.

As previously mentioned, the emic and etic approach of coding the data helped me triangulate the information found within the literature review with the stories from these students and hearing them in their own words. That approach helped me see things from their perspective while associating my understanding through what exists in the literature. Through each interview, the questions helped drive towards an understanding of their lived experiences. By capturing the stories of these students aided the discovery of the levels to which their interactions with faculty and staff influenced their desires to forgo anonymity and disclose their disability. Collaborating with the participants on the telling of their stories helped validate my understanding while ensuring their voices came through in this narrative study.

In Chapter 5, I discuss the findings organized through the tenants of the conceptual framework, self-determination theory, and provide interpretations of the findings. Additionally, Chapter 5 provides a discussion followed by recommendations based on further research on the disclosure process for students with disabilities. Lastly, the implications for positive social change receive attention.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this qualitative study was to explore the disability disclosure decision process used by students entering higher education. I used narrative inquiry to investigate the lived experiences of students who made the determination to disclose their disability to receive access to accommodations designed to help them succeed in their pursuit of postsecondary higher education. Self-determination theory (Ryan & Deci, 2017) was used to frame this study because I explored the impact of perceived choice and awareness of self in students with disabilities as they decided whether to disclose their disability. The four adult participants, who disclosed their disability and planned to continue the disclosure process, described their experience starting with childhood diagnosis; living with K-12 support services; and navigating the continual requirements to come out about their disability, including the impact of their interactions with faculty and academic staff on the decision process.

Disability disclosure is a voluntary process, but it is required to attain access to campus support services. Disclosure presents a problematic step in the transition from high school to higher education because the law stipulates admission counselors cannot ask students if they are disabled or can such a question appear on an admissions examination or questionnaire (Hees et al., 2015). However, according to case law precedents, the disclosure of a disability can lead to rejection from specific programs at the discretion of the admissions officers should they subjectively determine the student’s disabilities prevent them from being able to perform the academic or physical demands of the program (Kutnak & Janosik, 2014). At the intersection between a legally required obligation to provide accommodations and the support services designed to assist students, colleges and universities create a privacy gateway that requires students to forgo their anonymity or risk academic failure, increasing the risk of these students dropping out.

The findings of this study revealed students with disabilities described their initial decision to disclose to a school more as a required transaction to receive accommodations and that initial disclosure is only the first of many required to navigate college life. Researchers in the literature discussed that students with invisible disabilities (e.g., autism, ADHD, anxiety, or dyslexia) have different experiences from those who require wheelchair access or signs posted in braille to physically move throughout campus (O’Shea & Meyer, 2016). Participants in this study shared a variety of inconsistent experiences dealing with the follow-up disclosures required to receive accommodations, including challenges with campus housing and working with their instructors. Overall, the self-determination of the participants lead them to outweigh their acknowledgement of need over these amotivational inputs in their decision-making process to determine they will continue to disclose so they can achieve success in college.

In this chapter, I discuss the findings from this study and elaborate on recommendations based on data collected from the participants. The limitations of the study as well as the recommendations for additional research and implications for social change are also provided. Additionally, I direct portions of the chapter to the implications to practice facing faculty, administrators, and staff who support students with disabilities.

Interpretation of the Findings

The conceptual framework for studying the decision to disclose a disability required a lens through which to focus on the reasons and motivations surrounding the disclosure process. A student must disclose their disability even though federal law mandates colleges and universities provide accommodations to help them successfully navigate their college experience. In this study, I used narrative inquiry to examine the lived experience of students who disclose, starting from before they voluntarily check a box on an admission form through future, postanonymity decisions.

The literature revealed numerous legitimate reasons not to disclose, indicating adult students with disabilities require a sense of understanding how their decisions affect their academic progress (see Blockmans, 2015), so in this study, I leveraged self-determination theory as the conceptual framework. Self-determination theory, developed by Ryan and Deci (2017), is used to examine the role personal motivation plays as a detractor from personal growth and welfare. In this study, self-determination theory was used as the analytical lens to view the interview responses of participants who told stories about what influenced their disclosure and their experiences at work against persistent disclosure decisions required to continue to receive support resources.

RQ1

The participants described their decision to disclose as a required transaction more than a process requiring a decision, thereby demonstrating motivation to disclose their disability. The process of motivating a disclosure decision is what O’Shea and Meyer (2016) referred to as an *actualization of identity*, meaning the students saw these types of accommodations as part of who they are and used that understanding of self to accept the disclosure process upon entry to college. These students had integrated structures in place through their K-12 experience—even those who participated in dual credit programs in high school—and chose to accept that there was no other option but to disclose because the accommodations would help them achieve their academic goals. It was clear that all four participants possessed high levels of self-awareness.

The participants in this study each understood their diagnosis because they had lived with their disabilities for years before pursuing a college degree. These students were also keenly aware of the challenges they face. However, self-awareness did not eliminate feelings of amotivation from the process. Patricia spoke specifically about how the need for accommodations weighed against telling others about her disability, admitting that she thought about hiding based on peers and teacher exhibiting the discounting of her needs or not believing she needed help. Even with her prior bad experiences, Patricia still had an air of fearlessness about understanding herself and her needs, saying she was not afraid to advocate for what she needed.

Students described their decision to disclose as a continual process because disclosure is not a singular event. Each student described different ways in which they must continually disclose their disability. Each institution is different, so it was not surprising to hear the policies for classroom-based accommodations differed. While some communication or notification takes place between a disability services office and faculty, all four participants indicated there were formal and informal requirements to speak to the faculty about arranging the approved supports, constituting additional disclosures. In Elijah’s story, his efforts to get his housing accommodations corrected and reinstated annually constituted additional disclosure of his disabilities. These students must make conscious decisions each term, with each faculty member, and each academic year to forgo anonymity for the sake of surviving college because they understand they need the accommodations.

As he moves through his doctoral program, Noah indicated he continues to complete the paperwork for disclosure to get access to the accommodations he needs to help him continue work on his dissertation. At this point in his program, Noah indicated he is doing much better mentally and financially, now with a full-time job with benefits. Noah shared that he is open about his disability with groups of people with common interests, including being a writer for a disability services publisher and being actively involved in local civic groups in the disability services community. He commented that his concerns are also less about socialization and more directed toward completing his dissertation.

Kylie indicated in our conversation that she continues to receive support services from the office of disability services at her school throughout her undergraduate and graduate pursuits. She intimated that something she learned was to not be afraid to identify her needs. She indicated that asking for help and advocating for herself did not mean disclosing to other people that she is dyslexic or that she has periods of anxiety.

RQ2

Because each of the participants attended a different postsecondary setting, the preparedness of the disability services staff is unknown. The literature noted that few studies exist that research the impact and effect of disability services staff training related to effectiveness (Brock & Carter, 2017). All the participants in the current study found their interactions with the disability services office helpful. While they did find challenges navigating the process and the system, there were no negative comments about the supportiveness and attentiveness of the staff providing frontline assistance to them.

Interactions with services staff upon entry to the school come across as transactional. Three of the 4 participants had support from high school counselors to assist them, serving as a hand-off to the services staff at the college or university. In Patricia's story, her high school case manager provided a portfolio of documentation to help assist the transition to receiving accommodations in college. Patricia did note that she was prepared to expect that college supports would be different than what she experienced in high school, and she knew that she would need to discover the differences between what she needed and what the school would accommodate on her own.

Kylie had to discover additional services on her own through trial and error. Her disability services staff members helped get additional testing that uncovered her dyslexia, a service she did not know was available or even possible. The referral for testing came after struggling with some of her coursework. Reactive interventions on behalf of the institution could be used as case studies for academic staff and first year faculty professional development. Support staff cross training and professional development from members of the disability services team could potentially assist in earlier referrals for support for the students.

The beginning of the transition period into higher education appeared seamless to a majority of participants; however, it was postadmission challenges that highlighted Elijah's experience with his housing accommodations. After providing the necessary medical documentation, he still wound up not being placed appropriately, and these mistakes were not singular in occurrence but annual events. Elijah then wound up spending weeks mentally recovering from the effort and anxiety created over not having the proper housing accommodations the university agreed upon. In this case, the decision to disclose is followed by the need to consistently redisclose in order to advocate for appropriate accommodations.

RQ3

The student participants indicated the interactions they had with faculty were inconsistent. All four shared that an initial conversation, a disclosure to an individual instructor about their disabilities and notifying them of their accommodations, left them feeling encouraged. Each assumed that the faculty member understood their challenges, and all reported that there seemed to be a desire on the part of the faculty member to engage with them at any time with questions, problems, or concerns. In Elijah's story, he cited a specific faculty member who encouraged him to seek additional accommodations to allow him more time on tests and to electronically submit assignments, impressing Elijah with the care the faculty member displayed for his writing problems. It meant a great deal to him that the instructor took time to encourage him to seek additional help.

However, the initial meeting is where the student-first activity ceased, with each participant noting a lack of faculty engagement after the initial meeting, meaning no additional status checks to ensure the students were understanding the requirements, assignments, or suffering any maladjustment to the coursework itself. Kylie intimated she never felt fully supported in her courses because there was never any proactive involvement on behalf of the faculty; she had to do her best and hope it was satisfactory. Noah voiced his concerns on poor communication during the dissertation phase of his program, leading him to change chairs twice in the process.

Patricia was the only participant who noted that she had to escalate her requests to the director of disability services to receive her accommodations because the faculty member would not follow through on the approved accommodations. She noted this was the same faculty member who impressed her in the initial meeting with willingness to assist her but later questioned her as to why she needed the accommodation. Patricia did indicate this was a situation that made her pause to consider if she should continue to disclose but ultimately understood she needed these support services to be successful academically.

While it is the work of the disability services office staff to usher students into the school, it is faculty who have the most interaction with students with disabilities on campus, but perhaps know the least about legal requirements or fulfillment of accommodations. Becker and Palladino (2016) discussed faculty viewpoints in their assessment of instructor involvement in relation to students with disabilities and the overall impression is faculty perceptions and feelings towards student support are as varied as the needs of the individual student, indicating views ranged from supportive with limits to unwilling to make investments to learn or change teaching methods to improve a student’s chances for academic success . The stories conveyed by the students in my study echoed Becker and Palladino’s assertions. All four participants cited faculty interactions leading to feelings of amotivation to disclose—meaning these experiences pushed them to consider no longer disclosing—highlighting inconsistency in faculty relationships and exchanges.

Limitations of the Study

The three key factors impacting transferability of my study are limited size of participants, lack of a common demographic setting, and the higher degree of academic preparedness of the four participants. A key focal point for transferability is not to simplify the narratives and remove them from their context but rather to help readers understand if the narratives could apply to a different context (Schreier, 2018). Transferability is how convinced you are as a researcher that my study could be the start of additional research in your specific context. In the following paragraphs, I detail these concepts and discuss their impact on transferability.

An entire year of recruitment did not yield the large numbers I anticipated, leading to a smaller than desired number of participants. There were no open avenues to get onto a campus to get direct involvement with students. My research partner’s network of contacts—consisting of college-ready students with disabilities spread across all 120 counties in Kentucky—did not net a single person to come forward to participate in my study. My struggle to get four brave students to come forward aligns with the struggles O’Shea and Meyer (2016) discussed that students with disabilities are a difficult demographic to come forward, especially if they do not have an obvious disability. The disability disclosure decision is a personal decision and as the students in this study indicated, it is a constant series of disclosures.

Because of the struggles with recruitment, I did have to change tactics and spread the net beyond a single school or even a single state. My IRB-approved change in recruitment methodology lead me to attempt the use of social media and the Walden participant pool to find participants. Two of the 4 came from social media outreach and the other two came from the participant pool. Because of this change, not only do each of my participants have a different mix of disabilities, they do not share a common type of school, major, or geographic location.

The last factor impacting transferability is the level of academic preparedness of my participants. During the interviews with each of the students, the one consistent concept that did not align to my review of the literature is the level of academic preparedness. Previous studies similar to Beilke et al. (2016) addressed the transition from high school to college with indicators of preparedness on an emotional or self-sufficiency level, specifically noting challenges with academic preparedness. Two of the 4 participants informed me of their academic eligibility to take college classes while still in high school. The third, Patricia, completed advanced placement classes in high school once the school put her on an IEP after diagnosis in middle school. Kylie is currently working on her doctorate degree. The literature pertaining to transitioning and creating accommodations does not account for what these four students I interviewed displayed, which is high level of college preparedness in terms of higher test scores and successful participation in dual credit programs while in high school. My study of the literature discussed academic potential to achieve but generally referred to baseline satisfaction of high school requirements to graduate.

Recommendations for Further Research

The findings in this study generally add to the current understanding of students with disabilities transitioning from K-12 to higher education and the role disclosing their disabilities plays in overall academic performance. Additionally, my findings indicate there is more research required in three additional areas: (a) misdiagnosis in K-12, (b) the role of high school counselors, and (c) postgraduate completion rates among students with disabilities.

The first recommendation is additional research needed to understand misdiagnosis of disabilities in K-12 and the impact it has on performance in college attendance and completion rates. Three of the four students experienced either late or complete misdiagnosis while in K-12 settings. Elijah attended an underfunded school with limited funding for supporting students with special needs while Kylie came from a large, urban public school and her dyslexia went undiagnosed, even after struggles in English and writing. Patricia’s experience was similar to Kylie in that her support system failed to see her challenges earlier, citing the difference in manifestation between boys and girls. Misdiagnosis or late diagnosis leads to late intervention and it would be important to understand the role it plays on students with disabilities being able to overcome and persist to college readiness.

The second recommended area of study is the role of high school counselors and their impact on disclosure rates for students with invisible disabilities. Three of the 4 participants in my study indicated they had strong levels of support from their high school counselors or disability services staff to help them transition to college. Even though Elijah attended an underfunded, rural high school, he was able to participate in a dual credit program with the local community college. Additional research could help understand the effectiveness of high school counselor and staff support and the impact on dual credit programs of students with disabilities.

The last area of recommended research is the completion rates of students with disabilities seeking post-graduate degrees requiring thesis or dissertations. Two of the 4 participants are currently pursuing doctoral degrees. In my review of the literature for this study, I found no studies examining persistence of students with disabilities at the post-graduate level or what types of accommodations would be most impactful on student persistence, especially during the dissertation phase of doctoral study. Noah made specific mention that his accommodations helped him in the classroom experience but provided no value while working on his dissertation. Students with disabilities in graduate programs could be an emergent area for additional research.

Implications

As the participant Noah eloquently stated in his interview: “Why disclose if it wasn’t necessary?” Examination of the legislative history that is core to the disability rights movement shows progression in student rights. Evidence from prior studies indicate support services help students successfully complete a college degree. What remains is the outstanding issue regarding the relevance of disclosure when students with nonvisible disabilities could pass as a typical student.

My findings suggest the presence of a supportive K-12 environment—services like the existence of actionable IEPs and supportive counselors who actively help students transition to college—made the decision to disclose more of an acceptance that their disability is part of who they are as individuals and not a significant, life-changing decision point. The students in my study disclosed because they are aware of their limitations and know they need help to successfully complete college. However, simply checking a box on a disclosure form is only the first disclosure they needed to make as they continue to navigate higher education and a process they must make repeatedly as they continue pursuing a degree. The next section details the ways my study yielded social change implications and potential impact on the practice of faculty, staff and administrators working in support of students with disabilities.

Social Change

During a group therapy session where individuals exhibited less than supportive behaviors towards their group members when sharing private details, renowned psychotherapist Carl Ransom Rogers (1989) told the group about the risk involved in a situation when sharing personal details in that it gives that individual feelings of vulnerability as if they are exposed. Faculty, staff, and administrators working within institutions of higher education need to help students use disability disclosure—a sharing of information very personal and very private to the student—as a form of empowerment, not a reason to hide and risk failing them failing as college students. Noah shared that he actively shares his disability when there are common interests involved, specifically getting involved in local civic groups and authoring articles for a disability services publisher. Elijah’s experience of working with housing accommodations prepared him for his life after school by informing him of his rights. These are examples of where support through college are helping these two participants enact social change by helping and supporting others and themselves.

Opposite of those positive experiences, Patricia faced continual scrutiny of the need for accommodations because she did not look or act a particular, stereotypical way. She personally understood what her challenges were and how important overcoming the obstacles were to her academic success, even if the faculty members and peers did not share the same perception. Kylie came out and said that she never felt fully supported by her faculty as she progressed through her coursework. The stories shared by these students represent opportunities to academic leaders to bring about social change in attitudes and perceptions towards students with disabilities and help mold these students into citizens who embody the mission of higher education.

Recommendations for Practice

The recommendations for practice below are organized by the emergent themes: a) making the decision to disclose disabilities and the transition process, (b) disclosure is not a singular event, (d) importance of staff interactions, and (d) inconsistent faculty interactions.

Making the Decision to Disclose Disabilities and the Transition Process. Patricia provided interesting feedback about the degree of complexity she faced during the admissions process. Given the steady increase in the diagnosis of Americans with a disability and those applying for aid (Dorfman, 2017) there are already complex processes these students face at the beginning of their postsecondary experience. College entrance forms are the ultimate example of complexity, because entrance exams or admissions forms legally cannot outright ask the student if they have a disability (Hees et al., 2015). Because of this legal requirement, the process becomes less straightforward, especially if students are like Kylie, who had to learn all about admissions processes without any high school staff to support her in the transition process. The other three students followed more or less a streamlined process, either through dual credit or personal assistance to learn about getting access to accommodations. Admissions offices need to foster more personalized outreach to students with disabilities to help make the process easier while still abiding by federal regulations.

Disclosure is Not a Singular Event. Referring back to Hong's (2015) observation from interviews with students with a disability, complex layers of services presents challenges in understanding or even intimidation in accepting access to support services. Because access to additional support services requires additional disclosures, more anonymous assessments and recommended resource pairings could be accomplished without requiring disclosure. Technology affords many opportunities to help address academic need help in English or writing. As many classes require online submission of written assignments, an example of providing support without requiring disclosure would be to leverage technology that can analyze these artifacts and look for deficiencies and problem areas. Processes that align student academic needs with appropriate support services benefits all students, not just those disclosing a disability.

Importance of Staff Interactions. The second area of recommendations is institutional efforts towards improving faculty and staff professional development offerings including an improved communication process for campus employees. The Department of Education's (2017) Postsecondary Education Quick Information System survey showed less than half of all public and private colleges in the United States posted learning resources on their internal website, offered regularly scheduled meetings, or had other forms of formal communication with faculty and staff, or to foster professional development on the topic of interacting with students with disabilities (Hinz et al., 2017). Elijah's struggles with miscommunications between housing and the disability services team is an example of how inefficient communication processes or lack of training can negatively impact a student with disabilities ability to persist. In Elijah's case, these annual problems getting housing accommodations sorted resulted in significant challenges to his mental well-being and affecting his ability to perform academically.

Overall, all four participants focused time talking about the relationship they had with their respective disability services staff. The disability services support staff come across as unsung heroes in these students' narratives. Each participant cited instances where through initial consultation or a required escalation event, the support staff made a difference in the decision-making process to continue disclosing.

Inconsistent Faculty Interactions. The recommendation above for staff communication processes also applies to faculty professional development. For Noah, Kylie, and Patricia, the faculty interactions they described point directly to a required cultural shift. Until institutional leadership works to improve faculty execution when working alongside students with disabilities, students will continue to struggle. Noah experienced difficulties with his graduate committee and the delay of feedback, which triggered his anxiety. When asked if she felt supported while attending classes, Kylie highlighted she could not say she had because of the lack of faculty engagement during the term. Patricia’s experience requiring escalation to the disability services office highlighted yet another example of institutional changes required to improve engagement and support of students with disabilities.

Addressing these items of feedback requires an investment in professional development to help assist faculty and staff learn about appropriateness of interactions and how to display more empathy when working with students. Blockmans (2015) discussed how the wrong kinds of interactions can single students out from their peers and communicating in ways that does not assume level of disability. Fostering more empathetic interactions with students is another area that helps all students, not just those disclosing a disability.

The last recommendation comes from Noah’s story about his experience with support services while working with faculty members on his dissertation committee. Noah concluded an interview session with the declaration that disability services offered to help him with course-based needs, but those accommodations did not pertain to the work he had to do independently on the dissertation portion of his program. While it is possible that different programs could require additional work, he openly expressed discontent with the dissertation process and how there was room for change in support for students during independent scholarship. The common theme across the four participants was a universal struggle with formal writing. A recommendation would be to construct dissertation services accommodations that provide additional time with faculty members, library staff, methodologists, and other support staff where they help provide additional structure for independent-facing work activities.

Conclusion

The goal of this study was to understand how students with disabilities describe the disclosure process. I wanted to understand what impacted their interactions with faculty, administrators, and support staff, and see what impact these interactions have on their decision to disclose something as intimate as their personal disabilities. These students—specifically those with invisible disabilities—made a conscious decision to shed their anonymous life and ask for help because they understood and accepted who they are and each of them knew accommodations could help them achieve success in college. The decision to disclose was not a singular event, but one that happened repeatedly for these students with every teacher, in every course, with every term, every academic year.

If institutions work together to break the privacy gateway, academic leaders could enact positive social change. An evolution of the disclosure process could create a less invasive, less anxiety producing system that builds in motivating incentives that could cause students to connect more organically with the help they need to succeed. Making this change a reality requires additional investments in support and training to foster a positive culture of empathy and inclusion, which in turn would benefit all learners in the institution.

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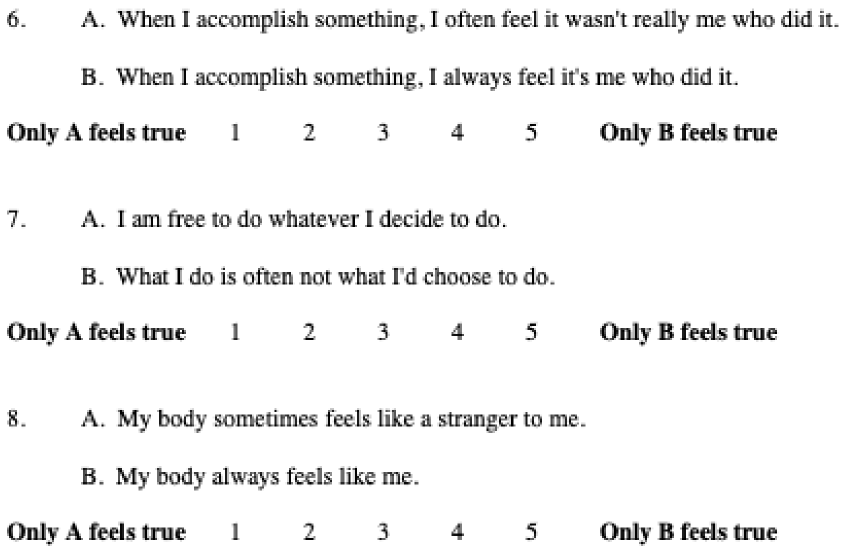
Appendix A: Perceived Choice and Awareness of Self Scale (PCASS) Instrument

The Perceived Choice and Awareness of Self Scale (PCASS) is a 10-question instrument designed to provide indications of an individual's self-determination (selfdeterminationtheory.org, 2018). Figure 1 below shows sample questions from the PCASS instrument.



6. A. When I accomplish something, I often feel it wasn't really me who did it.

B. When I accomplish something, I always feel it's me who did it.

Only A feels true 1 2 3 4 5 **Only B feels true**

7. A. I am free to do whatever I decide to do.

B. What I do is often not what I'd choose to do.

Only A feels true 1 2 3 4 5 **Only B feels true**

8. A. My body sometimes feels like a stranger to me.

B. My body always feels like me.

Only A feels true 1 2 3 4 5 **Only B feels true**

Figure 1. Sample Questions from the Perceived Choice and Awareness of Self Scale (PCASS) Instrument

Appendix B: Interview Questions

The three parts for these participant interviews focused on the past, present, and future in relation to describing their decision to go through the disability disclosure process. The past represented the time while in K-12 starting with when they received a diagnosis. The present represented their time while in college and receiving services. The future represented a look forward and if they intend to continue receiving accommodations. Below are the questions asked to each participant during the data collection process.

Part 1: Past

1. Talk to me about your diagnosis, specifically how long ago did doctors provide you with a diagnosis?
2. Tell me about a typical week when you were in high school, specifically, things like your schedule, your interactions with teachers, and your fellow classmates.
3. What was your process to determine you wanted to attend a college or a university?
    a. Did your high school provide you guidance on furthering your education?
4. When did someone tell you that you needed to disclose your disability to get access to services in college?
5. Tell me about that process of disclosing
    a. Did you have to provide supplemental insurance or documentation?

   b. What process did you go through to determine you would disclose your disability?
   c. Did you have anyone (friend, family, college representative, high school counselor) talk to you about the disclosure process?
   d. At any time, did you think about hiding your disability?
      i. If yes, why?
      ii. If no, why not?

Part 2: Present

1. Now that you disclosed your disability to your school, what services or accommodations do you receive?
2. Describe your schedule for a typical week in college.
   a. How different is this from your high school routine?
3. Describe your interactions with college staff, your faculty members, your fellow students.
   a. How do you approach faculty (or do you approach faculty) about your needs?
   b. Describe an experience with someone in college or receiving a service or accommodation where you feel supported, that you feel like the school cares about your success.
   c. Have there been experiences where you did not feel you receive appropriate support for helping you achieve success as a student in college?

Part 3: Future

1. As you continue in college, do you intend to continue receiving support from your Office of Disability services?
    a. If yes, why?
    b. If no, why not?
2. Thinking back to your positive experience with faculty, student, or staff, do you plan to be more or less outgoing about your disability?
    a. If more, why?
    b. If less, why?
3. What services do you think you will need as you proceed in school that you do not need or participate in today? (Things like certification exams for IT fields, nursing, teaching or assistance with an internship or other practical experience.)
4. What changes would you make about the disclosure process or the ways in which you receive support from your school?

Appendix C: Table of Codes

Table 2

Table of Codes

Emic Codes

- ADD
- anxiety
- Asperger's
- challenging
- college
- depression
- diagnosis
- disability
- disappointed in myself
- dissertation
- documentation
- dumb
- dyslexia
- Emotional Support Animal
- English
- feeling supported
- fell apart
- handwriting
- helpful
- Honor Roll
- housing
- IEP
- invisible
- knowing my rights
- learning disability
- math
- no help
- normal
- not ashamed
- not knowing
- probation
- smart
- social
- struggle
- stupid
- transition
- treat me differently
- treated as a person
- valleys

Etic Codes

- accommodations
- disclosure
- documentation requirements
- early age diagnosis
- employment
- faculty interactions
- hiding
- high performing in academics
- improvement from accommodations
- k-12 support failure
- Non-social
- ODS Support
- recommendation for improvement
- self-advocacy
- self-aware of problems
- staff interaction
- transition