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The Lived Experiences of Transition-Age Youth with Usher Syndrome Preparing for Postsecondary Education: A Retrospective Study

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UNIVERSITY OF NORTHERN COLORADO

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The Graduate School

THE LIVED EXPERIENCES OF TRANSITION-AGE YOUTH WITH USHER SYNDROME PREPARING FOR POSTSECONDARY EDUCATION: A RETROSPECTIVE STUDY

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

Tara Mae Brown-Ogilvie

College of Education and Behavioral Sciences
School of Special Education

August 2024

This Dissertation by: Tara Mae Brown-Ogilvie

Entitled: *The Lived Experiences of Transition-Age Youth with Usher Syndrome Preparing for Postsecondary Education: A Retrospective Study*

has been approved as meeting the requirements for the Degree of Doctor of Philosophy in the College of Education and Behavioral Sciences in School of Special Education.

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ABSTRACT

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Youth with Usher syndrome (USH) can experience unique challenges in postsecondary preparation. Currently, there is a paucity of research addressing the postsecondary preparation experiences of youth with USH. The purpose of this study was to learn from college students with USH about their lived experiences of preparing for postsecondary education; specifically, exploring K-12 educational supports, transition planning, and support systems that helped youth with USH prepare for postsecondary education. Due to the unique nature of this microcosm of deafblindness, qualitative and phenomenological methods were best suited for this study to garner first-hand accounts of those who have experienced this phenomenon themselves. A purposeful sample of 10 college students with USH engaged in individual interviews and focus groups guided by critical DeafBlind theory (CDBT) and Bronfenbrenner's ecological systems theory. A collective narrative was derived from these in-depth interviews, focus groups, and individualized reflective prompts. Additional data were collected through researcher notes to corroborate findings. Credibility and trustworthiness were addressed throughout the study through the qualitative means of triangulation, bridling, member checking, and peer review. Thematic analysis was completed using NVivo software and hand-coding to identify meaningful units, salient quotes, and emergent themes across participants. Three key themes related to the research questions emerged from the data: (1) limited K-12 educational supports for postsecondary preparation, (2) perceived lack of transition planning and postsecondary preparation, and (3) parents as the strongest support system. As many of the participants in the group recalled little to no transition planning or postsecondary preparation, this led to three additional themes: (4) discrepancy in Deaf/Hard of Hearing and vision services, (5) the multifaceted impact of USH, and (6) navigating the medical diagnosis. Sub-themes related to the anticipated and unanticipated themes will also be discussed.

Implications for practice for educators, professionals, and families include: (a) promoting earlier diagnosis by creating resources and better USH screening processes, (b) having a DeafBlind specialist on the educational team, (c) the importance of an individualized transition plan, and (d) recognizing that the USH population is evolving. Future research on peer mentorship, mental well-being, and working with diverse youth with USH is recommended. The shared narratives of these participants provide unique insights for parents, educators, professionals, youth with USH, and researchers. The results of this study can be used to inform future evidence-based research. Further, the findings of this study add to the limited body of research on the lived experiences of transition-age youth with USH preparing for postsecondary education.

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CHAPTER I

INTRODUCTION

During my interpreting training program or ITP, I went to a support service provider (SSP) workshop, where I first encountered someone with Usher syndrome (USH). I was paired with a young woman to practice being an SSP for a person who is Deafblind by providing human guide, interpreting short conversations in tactile ASL (TASL), and providing environmental information. As I bumbled through her holding my arm and guiding her across the room to a table full of lunch options, I asked her in TASL what she would like for her lunch. Instead of signing one of the options I gave her, she pointed to her choice on the table, to which I responded in surprise, “Oh?! You can see?!” I was embarrassed later, but this was normal for her. She smiled graciously and explained that she had USH, which meant that she had tunnel vision and could see some things while using TASL at the same time. With her being an experienced liaison with ITPs, she explained that this was a common misconception leading to persons with USH being labeled as “not really DeafBlind enough” and falling into their own sub-group of persons who are DeafBlind. After my initial experiences with the Deafblind community as an SSP, I went on to obtain a dual M.S.Ed. in Blind Rehabilitation and Orientation and Mobility, with a self-declared focus on deafblindness.

Since then, I have worked with young adults with USH in a multitude of roles, including SSP, vision rehabilitation therapist (VRT), TASL interpreter, certified orientation and mobility specialist (COMS) and Regional Coordinator for a national organization that serves youths and adults with deafblindness. During my 10 years working with this population, I have seen a notable trend of youth with USH coming into adult services lacking the skills necessary to transition successfully into postsecondary education. This can include areas such as academics, time management, self-advocacy, technology skills, daily activities of living, traveling independently, and communicating effectively with others. The students I have worked with are from all over the United States, and it seems that no matter the state or region, this issue was strangely consistent.

I remember my first student with USH; he was 27 years old and wanted support in going to college. He was motivated but required a lot of explicit training to make up for his lack of transition planning and postsecondary preparation. He would often tell me how he felt left behind when all his Deaf friends went to college, while he stayed home with his parents and was tired of feeling like a teenager, stuck in a time capsule at the age of 18 but ready to move on with his life. This made me ponder what experiences and transition planning supports he had in high school and even in middle school education that led him to feel that way. I then searched for resources and guidance to inform his postsecondary preparation as a person with USH but came up empty-handed. I found little to no research to inform transition planning and postsecondary preparation for students with USH. I stumbled through trial and error to support him and other students with USH in navigating university accommodations, assistive technology, communication access, and more. In time, he was able to take some community college courses with wrap-around services through support from his state vocational rehabilitation agency. I went with him to the college campus to practice his routes to classes, set up accommodations with the disability support office, and encouraged him to self-advocate for his accessibility needs in the classroom. After returning home from training, he enrolled in a local college and recently graduated. Today, I have seen about five of my former students with USH graduate from various colleges and universities in the United States. Yet, there is still little empirical evidence to support transition planning and postsecondary preparation for students with USH at a national level, along with a lack of mentors from the DeafBlind community to lead the way. These experiences inspired me to conduct this qualitative study to learn first-hand from college students with USH who have successfully navigated the transition planning and postsecondary preparation process to inform future research and practice.

Identity and Deafblindness

Throughout this study, I used various medical and identity-based terms for deafblindness, including dual sensory loss, combined hearing and vision loss, and Deafblind, among others. The term deafblind with a lowercase "d" and "b" with no hyphen demonstrates a unique disability greater than deafness plus blindness without assuming a cultural affiliation (Deeming et al., 2021; Lagati, 1995). If a hyphen is used in the term deaf-blindness, this generally refers to an educational or federal definition as appropriate. In contrast, capital "D" and capital "B" “DeafBlind” were used to indicate cultural and linguistic affiliation within the DeafBlind community (Edwards, 2014). Additionally, I am aware of the emerging use of identity-first language among members of the DeafBlind community (Conway, 2017). In this study, you will see both person-first and identity-first language to honor both preferences based on the context of the narrative.

Like many researchers, I am not a part of the population of which I am studying. In contrast, I am an abled White woman who is sighted and hearing without the lived experience as an individual with USH. I recognize that despite my fluency in visual and TASL, I will always be interpreting the participants' stories through my personal lens. I practiced reflexivity and other qualitative techniques to increase the trustworthiness of these findings such as by using member checking, peer reviewer, and triangulation (Creswell, 2013). In brief, I acknowledge that I am acting as a facilitator of information for participants with USH who wanted to share their lived experiences with the educational and research community at large.

Background of the Problem

Deafblindness is defined by the Individuals with Disabilities Education Act (IDEA, 2004) as "concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that cannot be accommodated in special education programs solely for children with deafness or children with blindness" (34 CFR 300.8(c)(2). Deafblindness, also known as dual sensory loss, is considered a low-incidence population as it includes less than 1% of children receiving special education services (Newman et al., 2011). Although deafblindness is one of the lowest incidence disability categories (Parker & Nelson, 2016), it is also one of the most diverse with over 70 known etiologies of deafblindness, including USH (National Center on Deaf-Blindness, 2023), all with variations in the age of onset, severity of sensory loss, progression or fluctuation, and presence of additional disabilities that necessitates individualized instruction (Dalby et al., 2009). As vision and hearing are considered distal senses, they can provide extensive environmental information, in contrast to near senses like touch, which are more restricted (Holte et al., 2006). Loss of one distance sense can generally be compensated for by the other core sense (Guerette, 2014; Guth et al., 2010), yet that is generally not the case with dual sensory loss (Dammeyer & Ask Larsen, 2016) due to both senses being impacted.

In their latest published Annual Child Count report, the National Center on DeafBlindness (NCDB) found that approximately 88% of children and youth with deafblindness had one or more additional disabilities, with over 52% identified with complex healthcare needs

(NCDB, 2023). Additionally, communication modalities can vary significantly, including speech, sign language (visual or tactile), gestures, behaviors, augmentative communication (i.e., communication board), lip reading and cued speech, and more (Cmar et al., 2018; Dalby et al., 2009). This population's low-incidence and heterogeneous nature can present challenges in conducting research and evidence-based educational programs specific to deafblindness (Ronnberg & Borg, 2001).

When compared to the fields of deafness and visual impairments, the field of deafblindness lacks the breadth and depth of understanding nuances of combined hearing and vision loss at different stages of life (Dammeyer, 2015; Parker & Nelson, 2016). Despite the additional barriers that students with deafblindness face when transitioning out of high school (Cmar et al., 2018; Newman et al., 2011; Petroff, 2010), there is limited research to guide educational programming for this at-risk population. According to Dammeyer (2015), there are several explanations for this phenomenon: (1) deafblindness is rare, (2) its heterogeneous nature makes it difficult to study one cohesive sample, (3) assessment tools are not designed/accessible for this population, and (4) communication with participants can be a barrier. Additionally, deafblind research often focuses on the medical aspects and etiology of deafblindness rather than the psychosocial or educational implications (Dammeyer, 2015; Warnicke et al., 2022). Research in deafblindness outside of the medical field tends to prioritize communication, specialized interventions, assistive technology, rehabilitative services, or age-related vision and hearing loss (Nelson & Bruce, 2016; Wittich et al., 2016). Commonly, this type of research is of qualitative design with small sample sizes such as with case studies (Nelson & Bruce, 2016; Dammeyer, 2015), which have limited general transferability to the DeafBlind population at large. In sum, research on deafblindness is scarce (Dammeyer, 2015; Nelson & Bruce, 2016; Ronnberg &

Borg, 2001; Vervloed et al., 2006), with even less being dedicated to USH and the specific discipline of transition planning and postsecondary preparation.

Even though students with deafblindness are reported as one of the highest at-risk disability groups for not transitioning successfully out of high school (Lipscomb et al., 2017), research in transition planning for this unique population has yet to be fully explored (Zatta & McGinnity, 2016). Even with guidance from the 2004 reauthorization of IDEA, only around half of the students who are deafblind graduated with a regular high school diploma (Peracchio & Stetler, 2009). Using American Community Survey (ACS) census data from 2019, Conway suggested that

> People with dual sensory loss aged 25 and older are half as likely to have a bachelor's degree (14.6% vs. 33.4%) and over twice as likely to have less than a high school diploma (27.2% vs. 11.2%) than are people without combined hearing and vision loss. (2021, p. 4)

Moreover, youth with deafblindness continue to enter adulthood at lower rates of postsecondary enrollment, employment, and residential independence (Haber et al., 2016; Newman et al., 2009) than their peers without disabilities. Without further research to inform specialized educational programming, students with deafblindness could be at risk of dropping out or graduating without a regular diploma, meaning, they would be less likely to be employed, engage in their community, and have a better quality of life as compared with their college graduate counterparts (Ma et al., 2019).

In the face of looming statistics, individuals who are deafblind continue to graduate and move towards competitive employment or higher education (NCDB, 2023). While there is no current record of how many students with dual sensory loss are enrolled in community colleges or universities in the United States, results of the National Longitudinal Transition Study-2 (NLTS-2) indicated that approximately 24% of graduates with combined vision and hearing loss were documented as enrolling in a 4-year college (Newman et al., 2009). The NLTS-2 was a large-scale study funded by the U.S. Department of Education to investigate the transition experiences of students with disabilities from 2001 to 2009, including students with deafness, blindness, and deafblindness per direct assessment and data reported by families and school districts (McDonnall & Cmar, 2018).

To date, there have been four prominent research studies on the experiences of college students who are deafblind in the U.S. The first was a case study of a college student who had acquired deafblindness due to illness (Bourquin, 1994). The second study by Arndt (2010) included in-depth interviews of 11 deafblind college students in ASL or TASL. The third was a study by Wolsey (2018) that examined the experiences of two deafblind college students through questionnaires, interviews in ASL, and observations. The fourth is a dissertation study by Graves (2022) that investigated the college preparation and transition experiences of congenitally DeafBlind college students using dyadic interviews with five students and their parents or family members.

The first three studies explored the experiences and perceived barriers of being a college student with deafblindness in the U.S., including some participants with USH, but with no mention of the transition process leading up to those college experiences (Arndt, 2010; Bourquin, 1994; Wolsey, 2018). Grave’s (2022) study included one student with USH and explored the retrospective benefits of K-12 educational supports for college preparation. In sum, there has yet to be a study that examines the transition and postsecondary preparation experiences of college students with USH.

Usher Syndrome

Usher syndrome is considered the leading cause of genetic deafblindness, as it accounts for nearly 50% of persons under the age of 65 who experience dual sensory loss (Castiglione & Möller, 2022). Usher syndrome is an inherited autosomal recessive disorder that can present as concomitant sensorineural hearing loss (SNHL), retinitis pigmentosa (RP), and, in some cases, vestibular dysfunction or balance issues (Pennings et al., 2003). Although USH is present at birth (congenital), USH is often cited as being an acquired form of deafblindness as the onset of sensory loss can occur after language acquisition (post-lingual) at varying levels of progression based on three clinical types (Dammeyer, 2012; Pennings et al., 2003; Zatta & McGinnity, 2016). Usher syndrome can be denoted as USH1, USH2, and USH3, with numerous subtypes (e.g., USH 1b) identified through genetic testing (Mathur & Yang, 2015). There are also claims of a fourth type of USH, referred to as atypical or ultra-rare USH, in which variant or mutated genes related to USH are present, but the collection of genes does not fit within the constructs of the three established USH types (Khateb et al., 2018). Atypical USH can be associated with a milder form of progressive SNHL and RP, presenting as varied forms of cone-rod dystrophy with hearing loss or non-syndromic RP with deafness (Rosalie et al., 2020).

Usher syndrome is also unique in that depending on the type and subtype (e.g., USH 1b), there can be a different progression of hearing and vision loss (Millán et al., 2011). This is possible because of the underlying eye condition RP can present as a slow decay of the retina, causing progressive tunnel vision and night blindness (Millán et al., 2011). It is often the case that central vision remains relatively unaffected, allowing for visual access to educational materials, incidental learning, and language development (Ingraham, 2007), which could make this subset of the Deafblind population more adept for transitioning into postsecondary education and the focus of this study. Currently, there is no cure for USH, although there are active medical trials (Ayton et al., 2023). Treatment can include a recommendation for hearing aids, cochlear implants, corrective lenses, physical therapy, and compensatory rehabilitative training (Castiglione & Möller, 2022; Ellis & Hodges, 2013).

Most of the research in the area of USH tends to be clinical, generally concerning medical trials, the discovery of new subtypes, and genetic testing with little focus on psychosocial considerations (Cohen et al., 2007; Möller et al., 2009; Sadeghi et al., 2004). According to Evans and Baillie (2021), there are five prominent studies specific to the lived experiences of adults with USH. Themes from these studies addressed everyday challenges with communication, mobility, identity, relationships, leisure activities, education, and employment (Côté et al., 2013; Damen et al., 2005; Ellis & Hodges, 2013; Högner, 2015; Wahlqvist et al., 2013). However, none of these explicitly examined transition experiences around college preparation. Further research is needed to better understand the needs of this unique population to support future students with USH in transition planning and postsecondary preparation.

Statement of the Problem

Youth with USH can experience unique challenges in transition planning and postsecondary preparation due to a lack of awareness and training of educators in USH (Arcous et al., 2020; Ellis & Hodges, 2013). Additionally, with the progressive nature and variance among the three USH types, early signs of dual sensory loss can go unnoticed, resulting in a singular diagnosis of deafness or blindness (Bruce & Borders, 2015). Once formally diagnosed with USH, youth are faced with losing another sense, such as vision, thusly needing to adjust their outlook on life and how they identify (e.g., Deafblind, USH, Deaf with Low Vision) moving forward (Miner, 1997). Additionally, USH can be considered a “hidden” disability as deafness can often be invisible on its own, and visual impairment can often be overlooked if there is no outward expression of visual impairment, such as the use of a white cane or guide dog (Ellis & Hodges, 2013, p. 177). This can lead to confusion and misunderstandings about what educational support services are needed, including transition planning and postsecondary preparation.

As previously stated, research in deafblindness is scarce (Nelson & Bruce, 2016; Ronnberg & Borg, 2001; Vervloed et al., 2006), with even fewer studies on transition planning and postsecondary preparation (Zatta & McGinnity, 2016). As deafblindness presents as a low-incidence disability within a heterogeneous population of countless etiologies (Correa-Torres et al., 2021; Parker & Nelson, 2016; Ronnberg & Borg, 2001), it can be difficult to produce high-quality, evidence-based research to inform individualized transition services (Bourquin, 1994; McDonnall & Cmar, 2018; Wolsey, 2017; Zatta & McGinnity, 2016). Practices can be adopted from sister fields of deafness or blindness (Parker et al., 2011), but ultimately customized instruction is needed to support students who are deafblind with their transition into post-school life (Luft, 2015; Zatta & McGinnity, 2016). Ferrell et al. (2014) explained that deafblindness is not additive but multiplicative. Simply combining curriculums for students with blindness and deafness may not meet the unique needs of students with deafblindness (Killoran, 2007; Luft, 2015) or USH, specifically. There are position papers, technical reports, and transition guides promoting postsecondary preparation for youth who are deafblind, but only with anecdotal narratives that do not equate to evidence-based research (Ingraham, 2007; NCDB, 2020; Zatta & McGinnity, 2016). Currently, no study has addressed the unique transition planning and postsecondary preparation experiences of college students with USH. As postsecondary education has been linked to overall quality of life (e.g., financial stability, self-worth, and social networking), it should be a supported path for students with USH (Ma et al., 2019).

Purpose of the Study

The purpose of this study was to learn from college students with USH about their lived experiences of preparing for postsecondary education, specifically exploring K-12 educational supports, transition services, and support systems in helping them prepare for college. This exploratory study intends to be the first of its kind to retroactively examine transition and postsecondary preparation supports of college students with USH. Due to the unique nature of this microcosm of deafblindness, qualitative and phenomenological methods were best suited for this study to garner first-hand accounts of those who have experienced this phenomenon themselves. A collective narrative was derived from in-depth interviews, focus groups, and individualized reflective prompts. All of these were conducted in the participant's preferred communication modality, whether that be spoken or written English, ASL, TASL, Pidgin Signed English (PSE), or another combination thereof. Additional data were collected through researcher notes to corroborate findings. Credibility and trustworthiness were addressed throughout the study through the qualitative means of triangulation, bridling, member checking, and peer review. In sum, the overarching goal of this study was to provide insights into the transition and postsecondary preparation experiences of college students with USH to inform future evidence-based research.

Research Questions

This study was guided by three research questions:

Q1 What K-12 educational supports did college students with USH perceive best prepared them for postsecondary education?

Q2 What K-12 transition services did college students with USH perceive best prepared them for postsecondary education?

Q3 What support systems were most influential for college students with USH in preparing for postsecondary education?

Definition of Terms

Combined Vision and Hearing Loss. Wittich et al. (2013) defined combined vision and hearing loss as a term that can be used to encompass a wide spectrum of vision and hearing loss.

Deaf-blind. Deaf-blind is a medical diagnosis of legal blindness and concomitant hearing loss per the Helen Keller Act. Specifically, a diagnosis of an individual

- (i) who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both these conditions;
- (ii) who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and
- (iii) for whom the combination of impairments described in clauses (i) and (ii) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation

(The Helen Keller Act, Sec. 1905).

Deaf-blindness. The IDEA (34 CFR 300.8(c)(2) defined deaf-blindness as

> Concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that cannot be accommodated in special education programs solely for children with deafness or children with blindness.

DeafBlind. Capital "D" and capital "B" are used to identify as a member of a cultural and linguistic community (Conway, 2017).

Dual Sensory Loss. Dual sensory loss can describe a person who experienced an initial loss of one sense for much of their life and later lost their other compensating sense (Wittich et al., 2013).

Support Service Provider (SSP). A support service provider (SSP) is someone who provides environmental information and human guide to a person with combined vision and hearing loss to support them in engaging with the community (Deeming et al., 2021).

Support Systems. Support systems is defined in this study as individuals or organizations that work together to provide support during the transition process for a person with USH such as family, friends, community members, local/state agencies, and resource centers.

Transition Planning. According to Mazzotti et al. (2013), transition planning is a collaborative approach to creating and implementing a person-centered plan to help prepare students with disabilities for transitioning from high school into adulthood.

Transition Services. The U.S. Department of Education defined transition services as

> a coordinated set of activities for a student with a disability designed within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.
> (Office of Special Education and Rehabilitative Services, 2020, p. 62)

Transition Specialist. Also known as a Transition Coordinator, this individual has training in transition and holds a specialized position to support transition planning and services under the IDEA. The transition coordinator’s role is to assist educators, parents, and related professionals by leading the coordination of transition services for students with disabilities (Morningstar & Clavenna-Deane, 2014, 2018). If a designated transition specialist is not available, this role can be filled by a special educator or, in the case of dual sensory loss, a specialized teacher, such as a teacher of the Deaf or a teacher of the visually impaired.

Usher Syndrome (USH). Usher syndrome is an autosomal recessive disease characterized by hearing loss, retinitis pigmentosa (RP), and, in some cases, vestibular dysfunction (Millán et al., 2011).

List of Acronyms

ASL: American Sign Language

DB: DeafBlind

CART: Communication Access Realtime Translation

CDBT: Critical DeafBlind Theory

IDEA: Individuals with Disabilities Education Act

NCDB: National Center on Deaf-Blindness

NLTS-2: National Longitudinal Transition Study

PSE: Pidgin Signed English

SSP: Support Service Provider

TASL: Tactile Sign Language

TOD: Teacher of the Deaf

TVI: Teacher of the Visually Impaired

USH: Usher syndrome

CHAPTER II

REVIEW OF LITERATURE

This chapter will describe the characteristics of deafblindness and USH in more depth, including the history of deafblind education. As USH is a relatively unexplored etiology, the educational portion will discuss instructional practices for students who are categorized under the umbrella of deafblindness. In a later portion of the review, I will expand on topics specific to students with USH and postsecondary preparation and then summarize studies involving college students who are deafblind, with select participants self-reporting as having USH. This literature review intends to provide a foundation of understanding for the need and purpose of this study: to learn from college students with USH about their lived experiences of preparing for postsecondary education.

Characteristics of Deafblindness

Deafblindness or dual sensory loss falls on a wide spectrum of vision impairment and hearing loss (Deasy & Lyddy, 2006). Despite popular belief, it is not common for students with dual sensory loss to experience complete deafness and blindness (Bruce et el., 2016). According to the 2022 NCDB annual child count of children and youth (birth to 21), only around 1% of students identify as having both profound hearing loss and total blindness (i.e., total deafblindness); the other 99% are documented as having some residual vision and hearing (NCDB, 2023). The IDEA definition of deafblindness includes youth who are deaf and have low vision, blind and hard of hearing, and low vision with mild hearing loss, as long as educational needs are affected. The IDEA (2004) definition of deafblindness also emphasizes that “educational needs cannot be accommodated in special education programs solely for children with deafness or children with blindness" (34 CFR 300.8(c)(2). Practices can be adopted from sister fields of deafness or blindness, but ultimately individualized supports are needed to provide robust transition services for students who are deafblind to aid them with their transition into post-school life (Luft, 2015; Zatta & McGinnity, 2016).

Ferrell et al. (2014) explained that deafblindness is not additive but multiplicative. Loss of one distance sense can generally be compensated for by the other core sense (Guerette, 2014; Guth et al., 2010). However, that is not always the case with dual sensory loss (Dammeyer & Ask Larsen, 2016). Instead, youth with deafblindness can struggle to understand the world around them (Lolli et al., 2010) and experience barriers to communication due to their combined vision and hearing loss (Emerson & Bishop, 2012).

There are over 70 known etiologies of deafblindness (NCDB, 2023), making this population even more complex. Additionally, deafblindness represents one of the most heterogeneous disability groups (Parker & Nelson, 2016) due to the age of onset, progression or stability of sensory loss, communication mode, and additional disabilities (Dalby et al., 2009). Within this diverse population, communication modalities can greatly vary, including speech, sign language (visual or tactile), gestures, behaviors, augmentative communication (i.e., communication board), lip reading and cued speech, and more (Cmar et al., 2018; Dalby et al., 2009). Supports that work for one student with deafblindness may not work for another (Nelson & Bruce, 2016).

There have been divergent efforts to create distinct categories of deafblindness based on the age of onset (Wittich et al., 2013). According to Ask Larsen and Damen (2014), terminology in the field of deafblindness is often littered with various terms and definitions being used without consistency. For the purposes of this study, the age of onset will be divided into two distinct groups: (1) pre-lingual congenital deafblindness, and (2) post-lingual acquired deafblindness (Dalby et al., 2009). Congenital or pre-lingual deafblindness will refer to those who experience a combination of vision and hearing loss at birth or prior to the age of 2 to the extent that it interferes with or delays their ability to acquire symbolic language (Munroe, 2001). Common causes of congenital deafblindness include prenatal complications, prematurity, CHARGE syndrome, and other hereditary conditions (NCDB, 2023). Children who develop dual sensory loss before language acquisition are likely to experience significant delays in communication, academic achievement, and activities of daily living (Dalby et al., 2009; Dammeyer, 2011). In contrast, acquired or post-lingual deafblindness occurs later in life, often due to genetic conditions, illness, or trauma that can present with simultaneous or sequential vision and hearing loss in progressive stages over time (Munroe, 2001). Usher syndrome can be considered both congenital and acquired, as it is a genetic condition present at birth, but the impact of dual sensory loss is often not evident until after language acquisition (Millán et al., 2011). For this study, USH will be considered post-lingual acquired deafblindness as the focus is on language acquisition prior to dual sensory loss.

While comparing the two groups, Dalby et al. (2009) found that individuals with congenital deafblindness "were more likely to have impairments in cognition, activities of daily living, and social interactions and were less likely to use speech for communication" than those with acquired deafblindness (p. 93). Those with post-lingual deafblindness are attributed to having ties to the Deaf community and high academic pursuits (Luft, 2015; Zatta & McGinnity, 2016). Youth with post-lingual acquired deafblindness are considered more likely to transition into postsecondary education, as they tend to have established language and concepts prior to experiencing a significant sensory loss (Zatta & McGinnity, 2016). With that being said, post-lingual acquired deafblindness will be the population of focus for this literature review.

History of Deafblind Education in the United States

Prior to the 19th century, educational services for students with deafblindness were virtually non-existent (Enerstvedt, 1996). During that time, students with dual sensory loss were generally devoid of educational opportunities and institutionalized (Freedman, 1978). The Hartford Asylum for the Deaf and Dumb (modernly known as the American School for the Deaf) claims that their pupil, Julia Brace, was the first student with deafblindness to receive an education in the United States in 1825 (Woodruff, 1849). Having lost her vision and hearing at the age of 5 from typhus fever, Julia learned some basic tactile sign language from her Deaf peers and found a way to live independently within the confines of the asylum (Woodruff, 1849). Baynton (2002) would argue that while Julia did learn some basic words in English using raised letters for the blind, Julia Brace was never fully educated to the extent that she could be successful outside of the Hartford Asylum for the Deaf and Dumb, where she spent much of her life cleaning, doing laundry, and other chores in exchange for room and board. Rather, Laura Bridgman, who received a more comprehensive education at the New England Institution for the Education of the Blind (now known as the Perkins School for the Blind), should hold the honor of the first student with deafblindness to be formally educated in the U.S. in 1850 (Gitter, 2002). Samuel Gridley Howe, who is well known for his efforts in blind education, took an interest in Laura Bridgman, as Baynton (2002) described, in the form of a "[quasi] experiment" to see if some who is deafblind could learn language.

> Howe hired a teacher, Lydia Drew, to devote her full attention to Bridgman, and they set about adapting methods of teaching blind students for someone also deaf. First, they

> placed embossed labels on the things in her room and taught her to associate them with their tactile names, later cutting the words into individual letters to teach her to spell. Bridgman quickly learned to read using this method (the Braille system was in its infancy and not yet widely known), write using a grooved board, and converse via tactile fingerspelling. Within a few years, Bridgman had sufficient command of English to communicate with others on everyday topics and to receive a general education. (p. 229)

As time passed, Laura Bridgman's education came to an end at age 20. She tried to return home to her family but felt isolated and depressed that she decided to stay on the Perkin's campus as a seamstress where she could communicate with others via tactile sign language and fingerspelling (Lane, 1984; McLetchie, 1995). At Perkins, Laura helped cultivate a young Anne Sullivan, a visually impaired student herself, as a tutor for Helen Keller (Robbins, 1983).

Said to be the antecedent to Helen Keller's success, teaching strategies such as introducing objects and fingerspelling simultaneously used for Laura Bridgman were later adapted for Helen Keller (Enerstvedt, 1996). Under Anne Sullivan's tutorage, Helen Keller also became fluent in tactile sign language and tadoma, an antiquated technique that involves "placing one's thumb on another person's larynx and other fingers close enough to the mouth so that the [vibration and] movement of the lips can be felt" (Nelson & Bruce, 2016, p. 3). Helen Keller became the first student with deafblindness to graduate from college in 1907, placing her in the public eye, where she eventually became a famous icon of deafblindness (Wagner, 2012).

However, the majority of students with deafblindness receiving formal education in the early 1930s were very different from Helen Keller. They did not have private tutors and were often sent away to specialized schools for the Deaf or blind. These specialized schools were often residential, with students who are deaf or blind living far away from their families in dorms on campuses generally unknown to peers without disabilities (Collins, 1995). It is interesting to note that the sign for "School for the Deaf" is often associated with the sign for "institute" to this day, as that was the foundation of these separate specialized schools formerly known as institutions (Kowalsky & Meier, 2013). Moreover, with the low incidence nature of deafblindness, this system seemed sufficient until the congenital rubella syndrome (CRS) epidemic generated an immense influx of children with deafblindness in the 1960s (Enerstvedt, 1996), growing from 150 students to over 5,000 over a 10 year period (Collins, 1995).

The drastic change in numbers mentioned above incited a great impetus for learning how to teach students with dual sensory loss on a greater scale. New deafblind educational programs were founded within general educational institutions, and educators came together to try and serve this new population of students with deafblindness, many with additional disabilities (Van Dijk & Nelson, 1997). This increased need for education strategies to support this population then led to technical assistance at the state level in the form of state Deaf-Blind projects (SDBPs) along with university training in deafblindness funded through the Office of Special Education Programs (OSEP) (Collins, 1995; Grisham-Brown et al., 2018; Parker & Nelson, 2016) to bring specialized education to local schools and home communities versus specialized schools. Nevertheless, most children with deafblindness were still being educated in separate classrooms rather than included with their typical peers receiving general education within the same school walls (Van Dijk & Nelson, 1997).

It was not until the enactment of the Education of All Handicapped Children's Act (Public Law 94-142) in 1975 that more inclusive practices began to emerge for students with deafblindness (Thompson & Freeman, 1995). Under this umbrella, all children with disabilities should have access to free and appropriate education (FAPE) in the least restrictive environment

(LRE) that is best suited to their educational needs (Hammer & Carlson, 1996). Within Public Law 94-142, children with a disability were defined as eligible under the following 13 conditions; (1) intellectual disabilities, (2) hearing impairment, (3) speech or language impairments, (4) visual impairments (including blindness), (5) serious emotional disturbance, (6) orthopedic impairments, (7) autism spectrum disorder, (8) traumatic brain injury, (9) other health impairments, (10) specific learning disability, (11) multiple disabilities, (12) deafness, and (13) deaf-blindness [20 USC § 1401(3)]

With the implementation of the Public Law 94-142, the individualized education plan (IEP) was first introduced to generate a legally binding plan between educators, related professionals, advocates, parents/caregivers, and the student to guide individualized delivery of special education services in the form of specialized instruction, accommodations, annual goals, transition services, and related services in regard to the designated disability category (Küpper, 2000). Related services provided for students with dual sensory loss can include but are not limited to audiological services, orientation and mobility, speech-language pathology, and more, dependent on the severity and progression of dual sensory loss (Küpper, 2000; Zatta & McGinnity, 2016). However, this can be a challenge, balancing additional services specific to deafblindness (e.g., braille instruction, assistive technology, orientation and mobility) while maintaining engagement in the general education curriculum (Sacks & Silberman, 1998). The result is often “pull out” services that involve taking a student out of the classroom for individualized instruction by specialists such as a teachers of the Deaf, speech pathologist, physical therapy, or other services related to sensory loss (Ferrell et al., 2014). Additionally, service provision can depend on how a student is identified on their IEP, which can lead to missteps if both vision and hearing loss are not equally denoted, as can happen with students who have USH (Bruce & Borders, 2015; Castiglione & Möller, 2022).

Understanding Usher Syndrome

Usher syndrome was discovered in 1858 by a German ophthalmologist, Albrecht von Grafe. The name Usher syndrome was officially given to the condition after being studied further in 1914 by Charles Usher, a Scottish ophthalmologist (Millán et al., 2011; Usher, 1935). Usher syndrome is an inherited autosomal recessive disorder that can present as concomitant sensorineural hearing loss, retinitis pigmentosa RP, and in some cases, vestibular dysfunction or issues with balance (Pennings et al., 2003). Retinitis pigmentosa refers to the deterioration of the retina, which can result in a loss of peripheral viewing, otherwise known as tunnel vision. Further, substantial field loss can cause varying levels of night blindness (Roborel de Climens et al., 2020). Additional physical or intellectual disabilities are generally not associated with a diagnosis of USH, yet mental health disorders such as depression and anxiety are commonly reported within this population (Dean et al., 2017; Mathur & Yang, 2015). Usher syndrome includes three clinical types with varying levels of onset and severity that can be denoted as USH1, USH2, and USH3, respectively (Pennings et al., 2003). There are also approximately 13 subtypes identified through DNA testing (Usher Syndrome Coalition, 2020). However, for the purposes of this study, this review of the literature focuses on USH1-3. The characteristics of USH type and prevalence levels can be found in Table 1.

Table 1

Characteristics of USH Types 1-3

Characteristic	USH1	USH2	USH3
Hearing loss	Severe to profound congenital hearing loss	Moderate to severe pre-lingual hearing loss	Moderate to severe post-lingual hearing loss
Progressive vision loss	Present in childhood or early adolescence	Present in adolescence to late adolescence	Present in adolescence to late adolescence
Vestibular dysfunction	Significant impact	Minimal to no impact	Variable
Prevalence	~ 40% of cases	~ 60% of cases	~ < 3% of cases

Note: Adapted from "An Update on the Genetics of Usher Syndrome" by J. Millán, E. Aller, T. Jaijo, F. Blanco-Kelly, A. Gimenez-Pardo, and C. Ayuso, 2011, *Journal of Ophthalmology, 2011* p. 3.

Usher syndrome is the most common cause of genetic deafblindness, occurring in approximately 50% of individuals under the age of 65 (Castiglione & Möller, 2022). The National Institute on Deafness and Other Communication Disorders (NIDCD) estimated that over 50,000 Americans and 400,000 people worldwide are affected by USH (2017). The prevalence rate of USH can vary, with the highest estimate being 16.7 for every 100,000 (Kimberling et al., 2010). Despite these seemingly large statistics, USH only represents half of the population of persons with the rare condition of deafblindness, making it extremely rare (Arcous et al., 2020; Evans & Baillie, 2021). This rarity can lead to unfamiliarity with how to support those with this relatively unknown genetic condition (Kamenopoulou, 2012).

Diagnosis of Usher Syndrome

Because USH is comprised of two separate diagnoses, retinitis pigmentosa and sensorineural hearing loss, it is not uncommon for misdiagnosis to occur (Castiglione & Möller, 2022). Due to the progressive nature and variance among the three types, early signs of dual sensory loss can go unnoticed, resulting in a singular diagnosis of deafness or blindness (Bruce & Borders, 2015). Children with USH1 have initially been diagnosed with non-syndromic profound deafness from their newborn hearing loss screening results and then only learn later in life about their dual diagnosis of RP once they start to encounter more difficulties with their vision, starting with night blindness and reduced peripheral vision (Castiglione & Möller, 2022; Evans & Baillie, 2021). Usher syndrome can manifest in incidents such as tripping over objects, bumping into other people, and having a hard time seeing at night, leading to an appointment with an ophthalmologist for further investigation (Roborel de Climens et al., 2020). With that, the age of diagnosis can vary from childhood to late adulthood, with individuals in their 30s learning about USH after experiencing the initial symptoms of night blindness (Evans & Baillie, 2021).

With advancements in genetic testing, an earlier diagnosis of USH could be given before dual sensory loss or vestibular issues became evident (Castiglione & Möller, 2022). However, it is also not unusual to hear of parents choosing not to share the diagnosis with their child in fear of their reaction to the possibility of “going blind.” For example, in the study by Ellis and Hodges (2013), one individual shared that her parents knew she had USH when she was 6 years old, yet they waited until she was 18 years old to tell her when they felt she could better manage the weight of the diagnosis. Unfortunately, her teachers and classmates were already starting to notice her having issues but were not in an informed place to best support her needs. As

Crawford noted, “An early diagnosis is important to ensure education, strategies, and coping mechanisms are used to enhance the individual's life chances and maximize their potential" (2018, p. 18). Without a proper diagnosis, it can be difficult to engage in disability-specific transition planning and postsecondary preparation (Bruce & Borders, 2015), in addition to physical therapy and mental health supports (Castiglione & Möller, 2022). For example, a student diagnosed with USH by age 10 could have appropriate support such as sign language interpreting, assistive listening devices, counseling, large print materials, and specialized instruction to aid them with transition planning and postsecondary education versus someone being diagnosed at age 22 when they are beginning to transition into college.

Impact of Usher Syndrome

The impact of USH can vary per person based on the age of onset, severity, communication mode, the influence of support systems, and more. Usher syndrome can be a “hidden” disability that can create frequent misunderstandings or prompt continuous disclosure with explanation to others who have no knowledge of this rare etiology (Evans & Baillie, 2021). Additionally, with the progressive nature of USH, residual vision and hearing can change over time or situations, which can create a sense of instability or uncertainty (Danermark & Möller, 2008). This ongoing cycle of acceptance and grief can be exhausting, with students trying to “pass” as someone who does not have USH (Ehn et al., 2016; Evans & Baille, 2021, Goffman, 1963). This continuous stress and fatigue can also cause headaches, make attending school tasks and socialization more difficult (Wahlqvist et al., 2016). A participant in Arndt’s study (2005) expressed that it took them more time and energy to complete their assignments, leaving them with little motivation to engage in extra-curriculars and social events. Over time, USH can become an identity, whereas for others, it is an unforgiving medical condition (Ellis & Hodges, 2013).

Identity

In the case of USH1, students can be profoundly deaf from birth, learn sign language as their main mode of communication, attend a residential school for the Deaf, and have an IEP that prioritizes "deafness" with little to no mention of vision loss (Miner, 1997; Roborel de Climens et al., 2020). This can elicit a sense of belonging to the Deaf community, being with others who use sign language and follow Deaf cultural norms (Holocomb, 2012), followed by confusion when they start to differ from the group with signs of visual impairment, limiting their interactions (Arndt, 2005). One participant from the Ellis and Hodges (2013) study described being bullied for being the only kid with USH at his residential school for the Deaf. Miner (1995) described how these interactions can lead to youth losing their sense of identity, leaving them to question and redefine themselves, which can be difficult when there is a lack of peers or mentors to relate to the same experiences and struggles with identity development (Ellis & Hodges, 2013).

Some youth with USH may find themselves among others with combined vision and hearing loss and identify as culturally DeafBlind, a sub-set of Deaf culture with its own rules, linguistics, and history (Edwards, 2014). Those with USH who do not use sign language can find it difficult to connect with this group, as identity can be closely linked to one’s communication mode (Ellis & Hodges, 2013). With such a diverse group, communication preferences can vary across youth with USH.

Communication

Even with the same diagnosis of USH, there is a great amount of variance in communication modes based on individualized levels of residual vision and hearing. Communication modalities for this subgroup of deafblindness can vary greatly, including: (a) speech; (b) sign language (visual, low-vision, or tactile); (c) gestures; (d) behaviors; (e) alternative augmentative communication; (f) writing or texting; (g) lip-reading; (h) cued speech; (i) pro-tactile or haptics, and (j); tactile cues; among many others (Cmar et al., 2018; Dalby et al., 2009; Edwards, 2014; Wolsey, 2018). Additionally, communication for this group can differ from how they receive and express information (Watters-Miles, 2014). For example, a young adult may use speech to express herself but requires tactile ASL because she cannot access information auditorily on a reliable basis. Speaking of reliability, one communication method may only work in certain conditions, such as whether a student's hearing aids are working properly or worn at all. One individual in the Ellis and Hodges (2013) study shared that he did not wear his hearing aids to school because he did not want to look different from the other hearing kids, but then the communication mode in his IEP was no longer successful. This can also be true for environmental and physical conditions that can impact the effectiveness of communication access for youth with USH on a day-to-day basis (Ehn et al., 2020), such as turning off the lights for a PowerPoint, turning on a noisy air conditioner, and more. Communication and access needs can change by the minute, making communication one of the most challenging areas for persons with USH (Côté et al., 2013; Damen et al., 2005; Ellis & Hodges, 2013; Högner, 2015; Wahlqvist et al., 2013) and limiting opportunities for social interaction (Ehn et al., 2018).

Social Interaction

Social interaction, or the ability to engage appropriately with others, is a critical skill that is considered a predictor of post-school outcomes for students with visual impairments (McDonnall, 2011; Wolffe & Kelly, 2011). Communication is key for social interaction, and like students with vision loss or blindness, youth with USH can struggle to learn social mannerisms through incidental observation and imitation (Zatta & McGinnity, 2016), including age-appropriate behaviors (Kamenopoulou, 2012). Moreover, peers in general education settings can be unsure of how to communicate or interact with students who are deafblind, possibly leading to peer rejection, so intentional supports should be considered for both sides of peer interaction (Hartshorne & Schmittel, 2016). Further, using adult supports or intervenors for students with USH to promote inclusion could also result in them spending more time one-on-one with adults than their peers (Correa-Torres, 2008), which could hinder their growth of social interaction skills. Generally, students with USH can feel socially isolated, which can lead to depression, behavioral issues, or other mental health conditions (Dammeyer, 2012; Hersh, 2013; Mathur & Yang, 2015).

Psychosocial Implications

Living with USH can evoke a range of emotions such as denial, grief, fear, frustration, and acceptance, among many others (Ellis & Hodges, 2013; Roborel de Climens et al., 2020). For some, a diagnosis of USH itself leads to depression and anxiety around having to give up the life they may have imagined before learning of their progressive vision and hearing loss (Ellis & Hodges, 2013). The loss of independence and feeling different by not having a driver's license like their peers can be very impactful (Gullacksen et al., 2012). However, for others, depression could result from isolation, feeling excluded, or other more personal factors (Dammeyer, 2012;

Hersh, 2013; Mathur & Yang, 2015). Moreover, the ongoing changes in vision and hearing loss can make it difficult to find a sense of stability. For example, there can be lots of change in that one can find a strategy that works well and then suddenly it is no longer efficient, such as having to transition from large print to braille or visual ASL to TASL (Ellis & Hodges, 2013). Additionally, some youth may rely more heavily on others for help, reducing their sense of autonomy and self-esteem needed to promote a high level of self-determination (Evans & Baillie, 2020; Miner, 1997, Wehmeyer, 2005).

Self-Determination

A strong research base suggests that direct instruction in self-determination can enhance community access and post-school outcomes for students with disabilities (Benitez et al., 2005; Shogren et al., 2015), including postsecondary education (Wehmeyer & Palmer, 2003). Self-determination was defined by Wehmeyer (2005) as including awareness of self and one’s ability to make autonomous decisions. Self-determination has been noted as a predictor of post-school success for students with visual impairment (McDonnall & Crudden, 2009; Monson, 2009). Self-determination can also include self-advocacy in the form of understanding disability law, requesting a sign language interpreter, and many others (Iowa Department of Education, 2013). While self-determination has yet to be fully understood in students who are deafblind, a study by Bruce et al. (2016) implied that structured social interactions with the support of adults can increase applications of self-determination in observed students with deafblindness. Ingraham (2007) further emphasized that the greater the exposure to self-determination skills in secondary school, the greater the ability of students with deafblindness to problem solve and make their own decisions as they transition into adulthood.

Orientation and Mobility

Another challenge for students with USH is mobility or the ability to travel independently (Jacobson, 2012). Independent travel is essential for students with disabilities to become active members of society (Buning et al., 2007; Cmar, 2015; Gallup et al., 2015). Youth with USH can benefit from formal O&M training to learn how to use a white cane or other mobility aid (Luft, 2015) but tend to decline or not fully participate until after graduation, when their vision loss becomes more severe (Ellis & Hodges, 2013). Denial is often evident in the refusal to use a cane or mobility device, which can be paralleled with accepting the label of blindness or deafblindness (Roy et al., 2021). According to a secondary analysis of NLTS-2 data, only 30% of students with deafblindness were reported as receiving O&M services between 2001-2009 (McDonnall & Cmar, 2018), with the number of students with USH likely less than 30%.

Further, orientation and mobility specialists (OMS) tend to have minimal training or experience adapting instruction for students with dual sensory loss in any form (Parker & Nelson, 2016). Huebner and Kirchner (1995) commented that there was a critical shortage of OMS with specialized training in deafblindness, and little to no progress has been made in the past 20 years (Parker & Nelson, 2016). Orientation and mobility instruction can also be difficult to access for students who struggle with speech discrimination, requiring a sign language interpreter or other modes of augmentative communication (Cmar et al., 2018). For example, the concept of alternative communication may need to be addressed to facilitate the O&M skills of soliciting assistance through the use of low-tech communication card or high-tech smartphone app to relay information using text-to-speech in order to interact with the public (Bourquin & Sauerburger, 2005; Hartmann & Weismer, 2016). In sum, a lack of independent travel skills can be a deterrent to a successful transition and postsecondary preparation for students with USH.

Educational Implications of Usher Syndrome

Students with USH can be found in various educational settings: mainstream, residential schools for the Deaf and Blind, home schools, and specialized or private schools. Ellis and Hodges (2013) cataloged various educational experiences among 44 participants with USH (ages 14-56) and found that none of the settings truly matched the needs of youth with both vision and hearing loss. Schools for the Deaf or Blind had staff skilled in one sensory loss but with little to no experience in the other. One participant kept switching school settings to find a good fit, while another moved from mainstream to a specialist school and said:

> I think the biggest challenge in [the] mainstream was "Oh, how do we deal with this child?" Then I went to a specialist school and found they dealt with one side of the disability, but then they weren't quite sure how to deal with the other. (Ellis & Hodges, 2013, p. 143).

In mainstream settings, Kamenopoulou (2012) found that the teachers she interviewed about working with students who are deafblind generally seemed unaware of ways to improve communication for students with dual sensory loss. Blaha et al. (2009) also noted that educators and specialists with general or special education backgrounds still seem to lack knowledge and experience in serving this unique student base. However, some educators may not have experience but are willing to try, which can be successful if specialists take the time to acquire additional resources and outside supports (Bourquin, 1994). In a study conducted by Correa-Torres and Bowen (2016), approximately 52% of educators who work with students who are deafblind reported that they would like more support in understanding the unique needs of students with deafblindness, while another 32.8% requested more information on effective teaching techniques, such as appropriate accommodations, for this population.

Accommodations

Providing appropriate accommodations for students with USH can be challenging as there is limited information available, needs can vary per student, some students may not disclose, and other students may not be aware of what might help them due to the rarity of their condition. Deaf/hard of hearing accommodations can consist of preferential seating, getting lecture materials ahead of time, use of an FM system, C-print or CART, note-taking services, and extended time for tests (Chanock et al., 2010; Ferrell et al., 2014; Ingraham, 2007; Skilton et al., 2018; Wolsey, 2018). Low vision accommodations can overlap with preferential seating, getting lecture materials ahead of time, note-taking services, and extended time for test taking with the addition of magnifiers, low vision devices, and large print or high contrast course materials (Chanock et al., 2010; Ferrell et al., 2014; Ingraham, 2007; Skilton et al., 2018; Wolsey, 2018). However, a common issue is that educators may be aware of or accommodating for one sensory loss, but not another, or not in combination due to the rarity of deafblindness and USH (Bruce & Borders, 2015; Ferrell et al., 2014; Parker & Nelson, 2016).

One participant in the Ellis and Hodges (2013) study expressed frustration in having fewer resources than a person who might have cancer or diabetes just because so little is known about USH. Ingraham (2007) recommended learning about a student’s residual vision and hearing to determine the best options for media access, such as braille, large print, audio, and other mediums. Skilton et al. (2018) suggested limiting visual and auditory distractions in the classroom. Table 2 provides a list of possible accommodations to meet the needs of students with USH (Ingraham, 2007; Skilton et al., 2018; Wahlqvist et al., 2016; Wolsey, 2018).

Table 2

List of Sample Accommodations for Youth with Usher Syndrome 1-3

Vision	Hearing	Combination
Increase font or use large print forms	Use of a sign language interpreter (visual, low-vision, tracking, or TASL)	Additional time to read materials, process questions, take exams, etc.
Use of high contrast (ex., colored paper or on iPad)	Closed captions on videos or video conference calls	Find resources and groups related to Usher syndrome
Optimal lighting (can vary)	Reducing background noise	Give opportunities to promote self-advocacy
Avoiding bright windows to reduce glare	Having a hearing aid check	Incorporating activities of daily living into school activities
Use of electronic magnifiers (stand-alone or built into a device) to increase size or contrast	Facing a student when speaking if they rely on lip reading	Interdisciplinary teamwork across specialists to reinforce skills across settings
Tactile models with hands-on demonstrations	Providing materials in multiple formats	Adapting P.E. and recreational activities
Specialized software such as a screen reader with audio or braille output	Giving presentation slides ahead of time	Having daily check-ins for level of vision and hearing "good or bad eye day."
Reduce visual clutter or distractions	Use CART* for real-time captions on a laptop	Encourage students to learn about USH and to teach others
Encourage the use of prescription filters for indoor/outdoor settings	Initiate turn-taking in the classroom with students giving their names before speaking "Sara speaking"	Offer school counseling and share resources related to Usher syndrome
Braille Materials	Assign a notetaker	Include comprehension checks

Note. CART stands for Communication Access Real-Time Translation.

Assistive Technology

In recent years, advances in technology have, in some ways, leveled the playing field for students with USH in the sense of providing a mainstream platform (smart phone or device) for communication, socialization, and access to information. Zhang (2000) noted that assistive technology can help students with disabilities enhance their interactions in the classroom and the community. Assistive technology (AT) is defined by IDEA as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a child with a disability” (IDEA, 34 CFR 300.5; 92 NAC 51- 003.04). Wolffe and Kelly (2011) noted that between 57%-70% of students with low vision or blindness in the NLTS2 sample reported having access to AT instruction. This included a variety of AT devices such as screen readers, braille displays, and specialized computer programs to increase the autonomy of students with visual impairments necessary for post-school success (Clark-Bischke & Crowley, 2010). Assistive technology can include assistive listening devices (ALDs) such as FM systems, hearing aid compatible smart phones, alerting devices, hearing loops, and more (Hartmann & Weismer, 2016). Shaver et al. (2014) found that nearly 84% of students who are deaf or hard of hearing made use of an ALD. However, within both sensory areas, the ability of students to learn how to use AT is dependent on the knowledge and experience of their instructor (Argyropoulos & Thymakis, 2014; Kelly & Smith, 2011). Students with USH require specialized instruction that considers their residual vision and hearing with room for hands-on demonstration using tactile methods (Ferrell et al., 2014; Hartmann & Weismer, 2016). Unfortunately, as stated earlier, educators with experience working with students who have combined vision and hearing loss, including USH specifically, are very rare (Blaha et al., 2009). Research in the area of teaching AT to youth who are deafblind is scarce, with only an emerging level of specific evidence-based practices (Ferrell et al., 2014). The manner in which children and young adults with deafblindness connect to AT may differ from their peers, but the benefits of information access and communication are just as essential to socialization and academic success (Hartmann & Weismer, 2016).

Transition Planning and Postsecondary Preparation for Students with Disabilities

The underlying goal of education is to prepare students for life after graduation. This fundamental passage from adolescence into adulthood is particularly crucial for students with disabilities, who struggle to successfully transition out of high school at the same rate as their peers without disabilities (Fabian et al., 2016; Lipscomb et al., 2017). Success in transition is characterized by measurable post-school outcomes in independent living, education/training, and employment. Even with the implementation of Public Law 94-142 and the introduction of IEPs, students with disabilities continued to struggle with transitioning out of school and into adulthood (Haring & Lovett, 1990; Hasazi et al., 1989). In 1990, the Public Law 94-142 was renamed the Individuals with Disabilities Education Act (IDEA). Within the reauthorization of IDEA (2004), there has become a greater emphasis on transition services to meet this need. Transition services are defined as,

> A coordinated set of activities for a student with a disability designed within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The coordinated set of activities is based on each student's needs, taking into account the student's strengths, preferences, and interests, and includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, the acquisition of daily living skills and provision of a functional vocational evaluation. [20 U.S.C. Sec. 1401(34); 34 C.F.R. § 361.5(c)(55)]

The transition plan was added to the IEP to help organize and document the progress of transition services (Küpper, 2000). All transition plans must be completed before an eligible student with a disability becomes 16 years old (Morningstar & Clavenna-Deane, 2018). Although, beginning the transition planning process at age 14 or sooner is encouraged (Kellems & Morningstar, 2010). The written transition plan typically includes an individualized course of action for supporting measurable post-school outcomes, including necessary school activities, community agency involvement, and educator responsibilities with student and family input (Office of Special Education and Rehabilitative Services [OSERS], 2020). This transition plan should evolve with the student as it will follow a student until they graduate or age out at the terminal age for graduation, varying from 21 to 24 in different states (OSERS, 2020).

Morningstar and Clavenna-Deane (2018) recommended that a trained transition coordinator or transition specialist should be assigned to a student to plan, coordinate, and evaluate transition services as their sole role (Morningstar & Clavenna-Deane, 2018). However, due to the lack of availability of designated transition coordinators, it is more common that a special educator, including teachers of the Deaf and teachers of the visually impaired, would take on a dual role to provide specialized transition support to students with dual sensory loss.

Additionally, representatives from adult vocational rehabilitation (VR) agencies can become involved in transition planning. Having a VR representative on an IEP team can provide consultation, early registration for adult services, and pre-employment transition services (Pre-ETS), as mandated by the Workforce Innovation and Opportunity Act (WIOA), established in 2014 (Castino, 2017). Pre-employment transition services can include training or counseling in employment or postsecondary preparation for eligible students ages 14-21 or who have not aged out or graduated at the time of service (OSERS, 2020). Pre-employment services can include: (1)

job exploration counseling, (2) work-based learning experiences, (3) counseling on postsecondary education, (4) workplace readiness, and (5) instruction in self-advocacy (OSERS, 2020). Postsecondary preparation will be the transition focus of this study.

Postsecondary preparation can include specialized instruction, supports, and services to prepare for attending college or other postsecondary institutions such as community colleges and trade schools. (OSERS, 2017). College enrollment for students with disabilities increased from 31% to 60% between 2004 and 2011 and is continuing to grow (Newman et al., 2011). Postsecondary preparation can include but is not limited to: (1) taking challenging courses to prepare for college; (2) being involved in school or community-based activities that involve work-based learning or internship opportunities; (3) having an active role in IEP meetings and transition planning; and (4) counseling around college readiness to review college requirements, programs of study, admissions process, and more (OSERS, 2020). Additionally, college preparation can include non-academic areas such as independent living skills, interpersonal relations, time management, and self-advocacy (OSERS, 2020; Mazzotti et al., 2009). Postsecondary education is considered a pathway to improved overall quality of life for all students (e.g., financial stability, self-worth, social networking) and will be the area of focus for this study (Ma et al., 2019).

Postsecondary Preparation for Students Who are DeafBlind

Despite efforts made in transition planning, students with disabilities tend to enter adulthood with lower employment rates, postsecondary enrollment, and residential independence (Haber et al., 2016; Newman et al., 2009). Youth who are deafblind are no exception. In fact, students with deafblindness are reported as one of the highest at-risk disability groups for not transitioning successfully out of high school (Lipscomb et al., 2017). Students who are deafblind are less likely to gain in-school employment and perform age-appropriate activities of daily living at the same level as their peers with Individualized Education Plans (IEPs) receiving special education services (Lipscomb et al., 2017). Additionally, students with deafblindness present their unique challenges to connecting with adult rehabilitative services, including referral to an agency specialized in one sensory loss area (blindness or deafness), communication access, and societal barriers (McDonnall & Cmar, 2018). Further, parental and teacher expectations can influence post-school outcomes for youth with deafblindness (Cmar at el., 2018; Haakma et al., 2016).

The National Post-School Outcomes Survey on Youth with Deaf-Blindness described low rates of graduates with deafblindness living independently (9%) and maintaining employment (23%) among 80 participants between the ages of 18-30 in the United States (Petroff et al., 2019). Further, Petroff (2010) and Petroff et al. (2019) findings showed an increase in the use of transition plans for youth with deafblindness from 55% in 2009 to 75% in 2019, yet no significant correlation between transition planning and post-school success was determined. To quote Petroff et al.,

> [This] may suggest that the planning for these youths was not robust enough to have an influence or that the factors related to inclusivity and general education may be more influential or both. These findings suggest that formal transition planning and a desire for post-school success may not be optimal for providing opportunities in post-school life for youths with deafblindness. Future research is needed to further investigate how transition planning may be enriched through inclusive practices in high school to improve post-school outcomes for youths with deafblindness. (2019, p. 280)

Historically, students with deafblindness struggle to successfully transition out of high school in comparison to their peers with disabilities, including those with vision or hearing loss (Barnhill, 2021; Cmar et al., 2018; Luft, 2015; Nelson & Bruce, 2016; Newman et al., 2011; Petroff, 1999; Petroff, 2010) despite having equitable levels of accommodation supports as their singular sensory disability peers (Newman et al., 2011). Due to scarce research in transition planning to support post-school outcomes for students with deafblindness (McDonnall & Cmar, 2018), practices from the sister fields of blindness and deafness are often adopted and utilized (Parker et al., 2011). However, these parallel practices alone may not be effective and generally require adaptation to meet the unique needs of students with deafblindness (Killoran, 2007; Luft, 2015) and, more specifically, those with USH.

Deafblindness, Usher Syndrome, and Postsecondary Education

Young adults with deafblindness can experience unique challenges in transitioning into postsecondary education. With research in the field of deafblindness being scarce, there are few studies in the areas of postsecondary education (Arndt, 2010; Chanock, 2010; Ronnberg & Borg, 2001; Vervloed et al., 2006; Wolsey, 2017; Zatta & McGinnity, 2016) with even fewer focusing specifically on USH. There is one case study conducted in the U.S. examining a college student who is deafblind (Bourquin, 1994). The person of focus was a 26-year-old international student from Japan with acquired deafblindness due to illness who utilized primarily tactile sign language and braille to access educational materials and lectures. The university staff had experience providing accommodations for students with deafness or blindness, but not deafblindness at that time. However, the Center for Students with Disabilities (CSD) was cited as being very proactive in supporting this student across university settings, including the classroom, library, dormitory, cafeteria, and extracurricular activities. Themes from this experience were a need for O&M training to navigate the campus, timely access to materials in braille, provision of experienced tactile sign language interpreters working in teams of two, and the inclusive attitude of the university staff and students. Bourquin shared, "To provide proper services in a mainstream college environment to deaf-blind students, institutions must be willing to bridge traditional roles, anticipate and prioritize needs, and be sustained by a student-centered philosophy of equal accessibility" (1994, p. 37).

Currently, there are three primary studies that encompass the lived experiences of college students with USH in the U.S. (Arndt, 2010; Graves, 2022; Wolsey, 2017). All three studies were qualitative studies with a purposeful sample of DeafBlind college students, including some with USH, attending universities in the U.S. (Arndt, 2010; Wolsey, 2017). Arndt's (2010) study focused on the area of academic supports, socialization, and adjusting to deafblindness in a college setting. Participants included 11 individuals with dual sensory loss between the ages of 18 to 23, with one outlier being 35. Within this sample, the vast majority self-reported a diagnosis of USH (~90%) at a university that catered to D/HH college students. Using grounded theory and a qualitative approach, Arndt (2010) found that the success of college students who are deafblind was often influenced by the support of college personnel, service providers, and family members. Recommendations for service providers from this study included: (a) providing assistance in accessing supports within the college and with agencies beyond the college; (b) being flexible in expectation of the time it takes to earn a degree; (c) being knowledgeable about deafblindness; and (d) fostering self-determination and advocacy skills (2010, p. 17). Arndt (2010) noted that future research should consider including the perspectives of family members, experiences of college students in mainstream universities (i.e., without faculty who use sign language or are aware of Deaf culture), and the transitionary preparation period leading up to higher education.

Wolsey's (2018) research examined two deafblind college students at a historically Deaf university with in-depth questionnaires, interviews in ASL, and observations. Also using grounded theory, Wolsey focused on communication, accommodations, and support services as both of her participants were fluent in low vision or TASL. Wolsey found that "access to information and communication" was one of the largest challenges for her participants in the sense of academic and social settings (p. 2,078). Wolsey also noted that college students who are DeafBlind could benefit from learning how to advocate for themselves in terms of accommodations and supports. This advocacy training can occur during transition planning with professionals, educators, and mentors (Wolsey, 2018). Both studies indicated a need for future research in transition planning and including college students with deafblindness who use language modalities other than ASL or TASL to better understand different experiences related to varying forms of dual sensory loss (Arndt, 2010; Wolsey, 2018).

Following the future research recommendations of Arndt (2010) and Wolsey (2018), Grave’s (2022) dissertation study included the viewpoint of parents or family members and participants who used speech instead of ASL or TASL and focused on transition planning and college students at mainstream universities. This qualitative dissertation investigated college preparation, transition planning, and the current college experiences of five congenitally DeafBlind college students. This study used dyadic interviews with students and their parent or family member (Graves, 2022). Only one of the five students was diagnosed with USH, and that individual’s communication preference was ASL. Some of Grave's resulting themes included experiences of being bullied, missing or inappropriate accommodations, low expectations from educators, parents as the strongest support system, and need to foster self-determination. Findings aligned with Wolsey’s (2018) suggestion of promoting self-advocacy during transition planning to help with requesting accommodations in college as well as supported Arndt’s (2010) statement that family members and invested educators can make a big difference in college preparation and success. In brief, these three studies created a starting point from which to better understand and support the transition of students who are DeafBlind. Still, more research is needed to better understand and support the college preparation and transition planning journey of students with USH.

Conclusion

Even with a shared diagnosis of USH, there is no definitive set of challenges for transitioning from high school into college. The lived experiences of transition planning and postsecondary preparation, as told by youth with USH, have yet to be explored. With three different types (e.g., USH1-3) and numerous subtypes, each student may experience varying levels of vision and hearing loss, which can translate into individualized challenges and successes. This exploratory study was intended to be the first of its kind to explore the transition planning and postsecondary preparation experiences of youth with USH. The findings of this study aim to inform future research and provide insights for parents, educators, and professionals.

CHAPTER III

RESEARCH METHODS

The purpose of this study was to learn from college students with USH about their lived experiences of preparing for postsecondary education. This study aimed to collect first-hand stories and narratives of their retrospective experiences. A qualitative design incorporating phenomenological methods was best suited for this study. A purposeful sample of 10 college students with USH engaged in interviews and focus groups guided by critical DeafBlind theory (CDBT) and Bronfenbrenner's ecological systems theory. Additional data were collected through participant reflections and researcher notes to corroborate findings. Credibility and trustworthiness were addressed through the qualitative means of triangulation, bridling, member checking, and peer review. Peer review occurred throughout the data analysis process by a researcher familiar with deafblindness, qualitative research, and USH. Data analysis was completed using NVivo software and hand-coding using thematic analysis to identify meaningful units, salient quotes, and emergent themes across participants. These findings aim to inform future research and provide insights for parents, educators, and professionals.

Theoretical Framework: Critical DeafBlind Theory and Ecological Systems Theory

Critical DeafBlind theory and ecological systems theory were used in tandem as the theoretical framework for this study. Critical DeafBlind theory was chosen for this study to acknowledge the unique experiences of persons who are deafblind (Hoffman, 2005; Young et al., 2008). Critical DeafBlind theory was developed by Shariff (2015) with roots in critical disability theory (CDT) or Dis-Crit embedded with inherent "values of the DeafBlind community" (p. 30).

Broadly speaking, CDT refers to the study of underrepresented groups in a mainstream culture, often pertaining to imbalances of power and privilege based on ability (Creswell, 2013; Ware, 2011), while CDBT goes one step further to depict systematic discrimination in the form of global inaccessibility for persons who are DeafBlind. Critical DeafBlind theory "challenges the hegemony of the visual and auditory" (Friedner & Helmreich, 2012, p. 81) mediums by moving towards tactile-based means for communication and access.

Critical DeafBlind theory differs from DeafCrit or CDT, which was developed by Gertz (2003), as DeafCrit does not encompass the experiences of someone with hearing and vision loss (Shariff, 2015). Particularly, with the Deaf community's visual centrism, such as the use of visual sign language (VASL), oppression of deafblind individuals can occur (Keating & Hadder, 2010; Wolsey, 2017). For example, ostracizing those who are deafblind from the Deaf community can occur by not accommodating their need for TASL, appropriate lighting, and more (Hoffman, 2005; Wolsey, 2017).

Critical DeafBlind theory speaks to the values and experience of persons with deafblindness within a predominantly hearing and sighted society (Shariff, 2015). Regarding young adults with USH, this can involve a lack of appropriate accommodations for transition planning (Llewellyn & Hogan, 2000), teachers or parents having low expectations (Cmar et al., 2018), along with environmental barriers (Hart, 2010). As a low-incidence population, students frequently experience deafblind-specific challenges to effective instruction (Bruce & Parker, 2012), with even less guidance on adaptations for students with USH. With that, CDBT was incorporated as the main theoretical framework to focus on the unique experiences of persons who are DeafBlind.

Ecological systems theory was also chosen as a secondary framework to aid in analyzing the unique experiences of college students with USH. Ecological systems theory was developed by Bronfenbrenner and has gone by several titles in its evolution over time, such as Bronfenbrenner's theory of human development, Ecology of the Child, as he made adaptations over six decades to enhance his bioecological theory (Rosa & Tudge, 2013). For the purposes of this study, the term "ecological systems theory" was used and defined as a social-learning theory that suggests social development is influenced by different social environments or ecological systems that can include bi-directional interactions and relationships with varying levels of impact over time. Bronfenbrenner's ecological systems theory consists of the child or young adult as the center nested within five ecological systems with varying levels of influence involving relationships, context, environment, and time frame (Bronfenbrenner, 1979, 1992, 2005). The five systems include:

1. The microsystem: relates to the first level, which is closest to day-to-day interactions in their home, school environment, etc.
2. The mesosystem: involves relationships across microsystems and can also include peer interactions within one's local community.
3. The exosystem: incorporates larger systems outside the student's day-to-day interactions, including social services, healthcare, and government agencies.
4. The macro system: approaches attitudes, values, and culture of an overarching society.
5. The chronosystem: refers to changes over time, including technology, laws, and access to information via technological advances.

In this study, ecological systems theory will focus more on the students' surrounding environment, support systems, and the time frame of their postsecondary preparation. This can include family involvement, geographic location, school culture, adult service agencies, peer mentorship, and more. Additionally, Bronfenbrenner's ecological systems theory takes into account living through a unique time period. The participants of this study were between the ages of 18-27, which could produce similar experiences to their transition time frame consistent with their age group in contrast to, for example, students with USH from the 1970s during the congenital rubella epidemic. In short, applying CDBT helps to find commonalities as an underrepresented group with dual sensory loss versus Bronfenbrenner's ecological systems theory viewing each student with USH as their own microcosms, to provide a holistic picture of transition planning and postsecondary preparation.

Research Design: Qualitative

Qualitative research, often used in the fields of education and social sciences (Merriam & Grenier, 2019), is well-known for generating a better understanding of lived experiences through descriptive narrative and visual data (Merriam & Tisdell, 2016). Qualitative design is also an appropriate methodology for investigating a purposeful sample from a highly heterogeneous population that would otherwise be difficult to study in randomized control trials (Creswell, 2014), such as with students with deafblindness. Hersh (2013) noted that surveys or other quantitative measures applied to the deafblind community can be inadequate, possibly due to inaccessible data collection methods not designed for this population; hence, the benefit of a more customized qualitative approach to provide a more complete understanding in the form of interviews, case studies, or focus groups (Arndt & Parker, 2016). Petroff et al. (2019) concurred with the need for qualitative research with this population. Petroff et al. (2019) stated,

> Future research is needed to further investigate how transition planning may be enriched through inclusive practices in high school to improve post-school outcomes for youths with deafblindness. A more detailed analysis may best be provided through qualitative research approaches that identify the specific nature and components of transition planning for youths who are deafblind. Such research should provide a more nuanced understanding of the transition planning process for youths with deafblindness and identify areas in which improved or new processes could be developed. (pp. 280-281)

Additionally, this study was exploratory as this research was the first of its kind to explore the phenomenon of transition planning and postsecondary preparation for youth with USH. Creswell (2014) stated, "One of the chief reasons for conducting a qualitative study is that the study is exploratory. This usually means that not much has been written about the topic or the population being studied" (p. 75). Lastly, in alignment with Meyers et al. (2014), qualitative methods can allow for the development of "a valid, in-depth understanding of a phenomenon under local conditions, rather than create broad generalized findings" (p. 114). The findings of this study were not intended to create transferability across college students with USH but rather to highlight individual experiences that could prove helpful to better understanding the phenomenon of transition planning and postsecondary preparation for youth with USH.

Research Genre: Phenomenology

Phenomenology is defined by Moustakas (1994) as a type of research genre that examines collective meaning or "essence" among individuals who have encountered the same phenomenon. A phenomenon can be a central concept shared among participants, such as psychosocial aspects (Creswell, 2013) of navigating a major life transition as a person with USH. Although elements of phenomenology are common across qualitative methods of studying the human experience (Merriam & Tisdell, 2016), phenomenology is a unique research design that focuses on the shared meaning of those who have encountered the same lived experience (Van Manen, 2014).

Hence, phenomenology was chosen for this study to investigate the phenomenon of transition planning and postsecondary preparation experiences of college students with USH. Following a phenomenological design, interviews were the primary method of data collection to derive meaning or essence from the overall experience (Patton, 2015). Focus groups were also used to enrich the qualitative data by allowing for authentic dialogue among participants to reflect and build on their experiences together (Creswell, 2013). To reduce research bias, I used phenomenological reduction or bridling by keeping a researcher journal and collecting participant reflections to differentiate between my pre-conceived concepts and those of the participants. This phenomenological study is intended to honor participants' stories and share their common experiences of transition planning and preparing for college as a person with USH to create a better foundation of understanding for parents, professionals, and researchers.

Research Questions

In the words of Moustakas, I want to understand "what" the participants have experienced and "how" they experienced it (1994). Therefore, the research questions for this study begin with "what" to reintroduce the focus on the participants' experiences rather than my assumptions and outsider perceptions. The following research questions aimed to examine the lived experiences of transition planning and postsecondary preparation from the perspective of college students with USH.

Q1 What K-12 educational supports did college students with USH perceive best prepared them for postsecondary education?

Q2 What K-12 transition services did college students with USH perceive best prepared them for postsecondary education?

Q3 What support systems were most influential for college students with USH in preparing for postsecondary education?

Methodology

Sampling and Recruitment

This study utilized purposeful and snowball sampling to gain access to participants who fit the inclusionary criteria (Creswell, 2013). Inclusionary criteria for this study included: (a) self-reported diagnosis of USH, (b) current enrollment in a postsecondary institution in the United States, and (c) being between the ages of 18 and 30. Postsecondary institutions are defined as two- and four-year colleges or universities. There was no restriction on student status (e.g., freshmen, senior, full-time, or part-time). Still, there was a preference for freshmen and sophomores and those under age 25 for recency effect. The presence of additional disabilities was documented but was not a criterion for this study. Participation was open to various communication modes (i.e., visual or tactile sign language, speech, or augmentative and alternative communication), and identifying as culturally DeafBlind was not required.

Purposeful sampling is often used in qualitative research as it allows the researcher to select individuals who can share a lived experience around a specific phenomenon (Creswell, 2013; Merriam & Tisdell, 2016). A small sample size is typical of qualitative research as it allows for a more in-depth understanding over a broad generalization (Meyers et al., 2014). In fact, Creswell (2013) suggested that 3 to 10 participants for obtaining saturation in a phenomenological study are appropriate. Hence, a sample size of 10 would fall within an acceptable range for this study, with consideration of potential attrition. Additionally, snowballing can boost recruitment by asking those who partake in the study to refer or share with others in their social circles who could also meet the inclusionary criteria of the study (Patton, 2015).

To solicit a national response, recruitment involved advertisement through social media groups related to deafblindness, including family organizations (National Family Association of Deafblind), professional agencies (National Center on Deafblindness), and consumer organizations (DeafBlind Citizens in Action), among others (Usher Syndrome Coalition). Permission was also requested to send recruitment materials to those registered with the Helen Keller National Center (HKNC) email distribution list, including those who are deafblind, their family members, and state agencies serving adults with dual sensory loss.

Recruitment materials were approved by the Institutional Review Board (IRB) of the University of Northern Colorado prior to dissemination (Appendix A). A Qualtrics survey was used to screen for inclusionary criteria (Appendix B) to ensure that the participants met the requirements for the study. My contact information was also provided over email and social media postings to contact me directly if the survey was not accessible. This aided in screening survey bots who attempted to enter the study without meeting the inclusion criteria, addressed in more depth in the limitations section.

Participants

The participants for this study were 10 college students with USH between the ages of 18-27 enrolled in a postsecondary institution in the U.S. This group represented six different types of USH (1B, 1F, 2, 2A, and atypical), with USH 2A being the most common among the group. This study was comprised of mainly White/Caucasian participants (80%) with 2 Hispanic participants (20%). This sample included 5 females and 5 males, making for equal gender representation. The primary mode of communication was speech (90%), with only one participant using VASL. a sign language visible at a distance without a restricted signing space or using tactile methods to relay information. Of the 10 participants, 4 reported having an additional disability, while the other 6 did not disclose having an additional disability. Additionally, these participants ranged in geographic location over eight different states, generally on the east coast of the U.S. (see Table 3).

Table 3

Participant Demographics

Participant	Gender Identity	Race or Ethnicity	Age	USH Type	Preferred Communication	Geographic Area
Dereck	Male	White	23	USH 2A	Speech	NY
Liz	Female	White	20	USH 1B	ASL	NY
Evan	Male	Hispanic	20	USH 1B	Speech	NJ
Zach	Male	Hispanic	18	USH 1B	Speech	NJ
Lily	Female	White	27	USH 1F	Speech	MA
Maxine	Female	White	24	Atypical	Speech	CT
Natalia	Female	White	21	USH 2A	Speech	MN
Adrian	Male	White	23	USH 2A	Speech	VA
Emmy	Female	White	19	USH 2	Speech	GA
Jeff	Male	White	27	USH 2A	Speech	KS

Note. Names presented are pseudonyms chosen by the participants.

Data Collection

Participants who matched the criterion for this study were then asked to complete a consent form (Appendix C) and a demographic survey (Appendix D). Demographic information was also requested using a Qualtrics survey that included personal characteristics such as gender, ethnicity, education level, and more to enrich qualitative findings. Once the consent form and demographic survey were completed, participants were contacted to set up an interview time and asked about their preferred time frames for focus groups. Two focus groups were conducted via Zoom, one with sign language interpretation and the other without. Both groups were provided with live auto captions via Zoom in a large font.

Following the interviews and focus groups, participants were asked to respond to reflective prompts through open-ended questions via email. Additional options for walking through the reflection together over the phone or via video were offered. Lastly, I maintained a researcher journal throughout the study to add notes about visual or unstated information from my interactions with participants (e.g., non-verbal communication, possible distractions, technical difficulties, etc.) and to reflect on my data collection and analysis process. The following sections will describe each form of data collection in more depth.

Interviews

Before conducting the interviews, an interview protocol with sample questions derived from the literature review was piloted with a peer reviewer and a college graduate with USH (Appendix E). The protocol for this study consisted of a semi-structured design with open-ended interview questions and follow-up probe questions to allow for flexibility while providing guidance as needed to relate back to the research questions (Creswell, 2013). The use of open-ended questions is also optimal for exploring a relatively new phenomenon as it allows for the empowerment of participants to add to the discussion when the questions are less structured (Merriam & Tisdell, 2016).

The primary data source for this study was one-on-one interviews with college students who have USH. Interviews were conducted using video conferencing software incorporating video, audio, synchronous text, and accessibility features such as live captioning. Individual interviews ranged from 45 to 60 minutes to allow time for accommodating communication access needs. All interviews were recorded, including visual and audio content, and saved to a password-protected UNC OneDrive account accessible only to the researcher, research advisor, and peer-reviewer. Participants could choose the setting in which they wished to be interviewed. A chosen setting could mean their home, school, or another place where they feel comfortable as opposed to a traditional in-person setting in a conference room, university lab, or other non-neutral location. Participants could also choose their preferred communication mode (e.g., spoken English, VASL, or TASL) and accommodations, whether that be closed captions, interpreting, or other by request. As I graduated from an ITP and experience communicating with persons who are deafblind over video phone and video conferencing software, I chose to communicate in ASL directly following the guidance of Arndt (2011), a researcher with a similar background who interviewed college students who are DeafBlind for her dissertation study. Arndt (2011) documented her experience and shared her recommendations for working with this unique group, such as having sufficient lighting, wearing contrasting colors to my skin tone, using a solid background to reduce visual clutter, and asking for clarification as needed. The recordings of the interviews, including videos of sign language dialogue, were transcribed for data analysis. The audio portions from the video recordings were sent to a transcription company to produce verbatim transcripts that the researcher reviewed and edited for additional accuracy.

The ASL portions were translated by the researcher, who has a bachelor's degree in ASL to English Interpreting, over 10 years of experience in the field of deafblindness, and fluency in both ASL and TASL. In addition to individual interviews, participants were asked to join a focus group to elaborate on their experiences with others who may have different backgrounds.

Focus Groups

Focus groups can enrich qualitative data by allowing for authentic dialogue among participants to reflect and build on their experiences together (Creswell, 2013). A focus group was defined by Hennink (2014) as an interactive discussion that the researcher moderates by posing interview-like questions to a group that shares the same knowledge or experience. Focus group questions were derived from a review of the literature along with initial findings from the individual interviews (Appendix F). Focus group participants should be purposely selected, preferably unknown to each other (Stewart & Shamdasani, 2015).

According to Krueger, (1994), a focus group can be between 3 to 12 participants. This study included two focus groups conducted via Zoom, with 3 participants in one group and 4 in another, for a total of 7 participants. In this study, the participants were purposely divided into two smaller focus groups. The reasoning behind this decision was that participants with dual sensory loss tend to need more time to share their experiences through various communication modalities (Skilton et al., 2018). Additionally, having fewer participants in a focus group allotted more time for sign language interpretation, processing the questions, and asking for clarification without feeling rushed.

Communication protocols were established at the beginning to enhance communication access for all participants. For example, participants were asked to raise their hand to be called upon and then said their name before speaking (e.g., Sara speaking) that helped to decrease talking over each other as well as provided a clear message to the sign language interpreters and those using assistive listening devices or captions. Starting the focus group with a communication protocol also sets the stage for a safe environment to stop the dialogue for clarification or requests, such as asking the facilitator to speak slower or repeat the question.

The online focus groups were recorded with the permission of all participants and stored on a password-protected UNC OneDrive account. Following the same process as the interviews, the audio portions from the video recordings were sent to a transcription company to produce verbatim transcripts, while the researcher translated the ASL dialogue. After the interviews and focus groups were completed, participants were asked to respond to reflective prompts.

Reflective Prompts

A reflective prompt protocol was developed based on the literature review (Appendix G). Within a week of their focus group participation, participants were given reflective prompts via email to share any additional thoughts, reflections, or feedback they felt could benefit the study. Patton (2015) suggested participants share their reflections within two days after an interview for recency, but as this study also incorporated scheduling focus groups along with the interview, participants were given one week to respond over email. One of the advantages of reflection is to allow participants time to process their initial responses and then further guide their own meaning from the shared experience (Patton, 2015). Particularly with a subject group with a documented history of communication challenges (Emerson & Bishop, 2012; Hersh, 2013; Nelson & Bruce, 2016), participant reflections allow each participant to further expand on the meaning of their interview answers. It is also possible that technical issues, miscommunication, nerves, or other factors could have influenced a recorded response. Participant reflections provide a second chance to answer the same type of questions asynchronously.

Regarding the implementation of the reflective prompts, there was a limited response. Many participants emailed back with "nothing else to add" or short responses. Follow-up emails offering an additional gift card were not effective. The collected reflective prompts were analyzed alongside the interview and focus group transcripts.

Researcher as an Instrument

Another characteristic of qualitative research is that the researcher serves as a tool for collecting and analyzing data (Creswell, 2013). As quantitative studies have measures to check instruments for reliability, qualitative methods include strategies for increasing the reliability of findings (Merriam & Tisdell, 2016). To reduce researcher bias, I employed phenomenological reduction or bridling (Dahlberg, 2006; Patton, 2015). Bridling can be described as actively reflecting on one's personal experiences, assumptions, and judgments throughout the research process (Dahlberg, 2006). Similar to bracketing, which encourages researchers to put aside or bracket their pre-conceived ideas of a phenomenon (Patton 2015), bridling acknowledges pre-understandings while also recognizing that it is not possible to fully bracket these notions, but better to observe them while interpreting participants "meanings [that] come to be" (Dahlberg, 2006, p. 16). Maxwell (2013) conferred that data analysis can never be entirely free of researcher bias. However, including a researcher's stance on prior beliefs and experiences around a phenomenon can increase transparency in the qualitative process to readers of the study (Creswell, 2013).

Researcher Stance

This dissertation was informed by my personal experiences and training in the field of deafblindness. I have taken on a variety of roles, including SSP, VRT, TASL interpreter, regional coordinator, and COMS. While I am active in DeafBlind communities across the

United States and have observed the phenomenon of transition for over a decade, I recognize that I have not personally lived this experience and must be mindful of my pre-conceptions as an outsider of this culturally and linguistically diverse (CALD) community. I intended to act as a conduit for describing shared transition experiences from college students with USH. To do this, I chose a peer reviewer who has experience with qualitative research and is a mother of a son who is a college graduate with USH. This helped with the qualitative analysis to confirm that the emergent themes were inductive and not solely a product of my inherent researcher bias. I also maintained an audit trail in the form of researcher's notes to document my processes throughout the study for others to investigate and verify as needed (Lincoln & Guba, 1985).

Researcher Journal

Maintaining a researcher journal aided me in understanding my processes as well as keeping track of salient information from interviews, focus groups, and participant reflections. A researcher journal can act as an audit trail by documenting how data were collected, interpreted into categories, and analyzed for qualitative themes (Creswell, 2013). Lincoln and Guba (1985) encouraged the use of an audit trail to increase the reliability of findings. Additionally, a research journal can allow for taking notes during interviews and focus groups denoting non-verbal communication such as signs of nervousness, talking or signing quickly, distractions, technical issues, and more that could be incorporated into the final analysis.

Data Analysis

Data analysis for this study was simultaneous with data collection. According to Bodgan and Biklen (2011), simultaneous data collection is a common practice that offers many advantages. For example, I could take notes while listening or reading interview transcripts to inform focus group questions. Emergent themes were identified through thematic analysis with a three-step process referred to as open, axial, and selective coding procedures until saturation was obtained (Corbin & Strauss, 2008). Thematic analysis was chosen as it was likely to reduce the use of pre-determined categories based on personal biases (Glaser & Stauss, 1967).

Beginning with the raw data from interviews, focus groups, and reflective prompts, I read through the verbatim transcripts and reflective prompts to become familiar with the data while searching for relevant statements, ideas, and quotes (Moustakas, 1994). I started with open coding to develop categories that appeared to be significant and made notes in my researcher journal (Creswell, 2013). Having experience with hand-coding and specialized qualitative analysis software (i.e., NVivo 12), I used a combination of both methods. I hand-coded two transcripts using the comment feature in Microsoft Word to easily share these with my peer reviewer for comparison. After the first few transcripts, I moved over to NVivo, recoding in some areas to better understand the overarching themes and how they fit together. Using NVivo made it easy to develop nodes (i.e., codes) and then pull up the highlighted text associated with that node or code across transcripts. This was especially helpful when needing to go back and reference quotes as well.

Next, I used axial coding to develop predominant categories further, keeping a running list in NVivo and my research journal (Creswell, 2013; Merriam & Tisdell, 2016). Further transcript analysis included selective coding, which narrowed the results. In this phase, I removed categories that did not apply to the majority of participants, combined similar groupings, and limited the number of emergent themes most applicable to the study's research questions (Creswell, 2014). Throughout all three phases of data analysis (open, axial, and selective), I saved and created different copies of the NVivo projects so that I could reference the initial open codes and preserve the stages of axial and selective coding.

Credibility and Trustworthiness

Multiple methods were incorporated throughout the research process to minimize threats to credibility and trustworthiness in order to ensure that this study produced accurate and intended results (Lincoln & Guba, 1985; Merriam, 2009). As the researcher acted as the tool for collecting and analyzing qualitative data (Creswell, 2013), there was a constant threat of internal bias that could influence findings. This study incorporated qualitative strategies of triangulation, peer reviewing, and member checking to increase credibility and trustworthiness.

Triangulation

One of the strategies for increasing credibility in qualitative research is triangulation or using multiple forms and data sources to corroborate findings (Lincoln & Guba, 1985; Merriam, 1988). Data were collected from interviews, focus groups, participant reflections, and a researcher journal to obtain triangulation in this study. Having a peer reviewer cross-analyze data can also be seen as a form of investigator triangulation by having another researcher provide their perspective (Merriam & Tisdell, 2016). Patton (2015) suggested that triangulation can increase the quality of findings while reducing researcher bias (Patton, 2015).

Member Checking

Member checking is another strategy in qualitative research used to increase the trustworthiness of findings by asking participants to review the results of their transcripts for accuracy (Miles & Huberman, 1994). Member checking can also enhance the credibility of findings by having some participants provide feedback on the initial themes or interpretations of the raw data by the researcher (Lincoln & Guba, 1985; Merriam & Grenier, 2019) to ensure that researcher bias or misunderstandings do not skew data analysis (Maxwell, 2013). All participants were given a week to review their interview and focus group transcript via email.

This technique also lends itself to a critical theoretical approach, as member checking can empower participants to guide the findings in a way that best represents their experiences and perspectives (Merriam & Tisdell, 2016). Additionally, member checking can help reduce issues with anonymity by allowing the participants to note specific information in the findings that could lead to identification.

Peer Review

Considering my researcher stance and background, appointing a peer reviewer to oversee certain aspects of my work was an appropriate use of qualitative methods to enhance the authenticity and rigor of my results. Peer review is commonly appointed in phenomenological research to provide an additional perspective to mitigate researcher bias and increase the trustworthiness of results (Moustakas, 1994). A peer reviewer should be someone familiar with the research methods and topic of the study who can provide insight into initial findings (Merriam & Grenier, 2019). My primary peer reviewer was a colleague with experience in qualitative research, the field of deafblindness, and a parent of a college graduate with USH.

During the initial data analysis process, my peer reviewer was given two transcripts to independently open code and then we met to compare our initial outcomes through discussion over Zoom. We found that our coding was very similar, and we agreed on the initial themes that appeared to be emerging. My peer reviewer also sat in on my first focus group and took notes. We later met after the first focus group and discussed further the emerging themes using the whiteboard feature of Zoom to group ideas together. This included discussing emerging categories. We also considered themes that were evident but perhaps not significant enough to report for this study. For example, there was a potential theme around the impact of covid on educational access, but then decided to remove that theme as it pertained to their current college experiences and not their retrospective transition experiences. The peer reviewer also used her professional and personal knowledge about students with USH preparing for college to verify that the initial findings were reasonable.

Additionally, my research advisor was given access to the interview transcripts, reflective prompts, demographic forms, NVivo code books, and other theme development researcher notes. My research advisor also coded three transcripts and met with me to compare our findings. We also found that our codes were similar. Lastly, this proposal was reviewed by a doctoral committee of subject experts in deafblindness, transition, and vocational rehabilitation to provide further insight and direction.

Ethical Considerations

This study was conducted within the ethical guidelines of the IRB protocol within the University of Northern Colorado (Appendix H). Participants had the option to withdraw at any time, as described in the consent form (Appendix C). The IRB status of this proposal was considered *exempt* as interviewing and conducting focus groups on transition planning experiences posed minimal to no risk for college students with USH. The peer reviewer was also added to the IRB application.

Upon entering this study, each participant chose or was given a pseudonym to be associated with their responses. Due to the low incidence nature of deafblindness and the even lower frequency of young adults who are deafblind attending college in the United States, participants might have been at risk of recognition (Arndt, 2005; Jones, 2001). To mitigate this concern, audio, visual, and demographic information data were de-identified and stored on a password-protected laptop with access limited to the researcher and research advisor through a

UNCO OneDrive account. Any personally identifiable information will be destroyed three years after the study is completed.

Interviews and focus groups recorded in VASL were translated into a narrative format. Discernible information such as the names of universities, high schools, geographical locations, teachers, VR counselors, and more were withheld from publication. I also refrained from using distinguishable personal traits in the results section to reduce the likelihood that professionals in the tight-knit field of deafblindness would be able to identify participants. Although a lack of anonymity could be considered a low risk for this study, participants had an opportunity to review pertinent data throughout the member-checking process and could request the removal of their information before publication.

Conclusion

The purpose of this study was to learn from college students with USH about their lived experiences of preparing for postsecondary education. Qualitative design incorporating phenomenological methods was found best suited for this study. A purposeful sample of college students with USH engaged in interviews and focus groups guided by a theoretical framework shaped by CDBT and Bronfenbrenner's ecological systems theory. Additional descriptive data were collected through participant reflections and researcher notes to corroborate findings. Credibility and trustworthiness were addressed through the qualitative means of triangulation, bridling, member checking, and peer review. Data analysis took the form of thematic analysis using hand-coding and specialized software (i.e., NVivo 12) to identify meaningful units, salient quotes, and emergent themes across participants. These exploratory findings aim to inform future evidence-based research and provide insights for parents, educators, youth with USH, and professionals.

CHAPTER IV

RESULTS

The purpose of this study was to learn from college students with USH about their lived experiences of preparing for postsecondary education; specifically, K-12 educational supports, transition services, and support systems that best prepared them for postsecondary education. Data were collected through individual interviews, focus groups, and reflective prompts. Thematic analysis (e.g., open, axial and selective coding) was used to address the following research questions.

Q1 What K-12 educational supports did college students with USH perceive best prepared them for postsecondary education?

Q2 What K-12 transition services did college students with USH perceive best prepared them for postsecondary education?

Q3 What support systems were most influential for college students with USH in preparing for postsecondary education?

In this chapter, the themes and subthemes that emerged will be presented. Three key themes related to the research questions emerged from the data: (1) limited K-12 educational supports for postsecondary preparation; (2) perceived lack of transition planning and postsecondary preparation; and (3) parents as the strongest support system. As many of the participants in the group reported receiving little to no transition planning or postsecondary preparation, this led to three additional themes: (4) discrepancy in Deaf/Hard of Hearing and vision services; (5) the multifaceted impact of USH; and (6) navigating the medical diagnosis. Additionally, sub-themes that emerged will also be discussed throughout the chapter.

Participant Demographics and Characteristics

The participants in this study were 10 college students with USH between the ages of 18-27 years old. Of the 10 participants, 7 had an IEP while 2 had no plan and 1 had a Section 504. There were 3 participants who reported using a white cane, although others had a white cane, but did not feel as if they used it enough to identify themselves as a white cane user. The majority of the group wore corrective lenses, 9 out of 10 (90%). Only 1 participant did not use hearing aids or cochlear implant, and she was also the only ASL user (10%). Additionally, 5 participants were not fully diagnosed with USH until the end of their high school career (ages 15 and 16) or after graduation (ages 21 and 23). Table 4 displays the participant's age of USH diagnosis and educational plan, along with the use of hearing aids or cochlear implants, FM system, white mobility cane, or corrective lens.

Table 4

Participant Questionnaire Responses

Participant	Age of Diagnosis	Use of Hearing Aids or Cochlear Implants	FM System	White Mobility Cane	Corrective Lens	Educational Plan
Dereck	16	Hearing Aids	No	No	Yes	IEP
Liz	11	None	No	No	No	IEP
Evan	7	Cochlear Implant	Yes	No	Yes	IEP
Zach	5	Cochlear Implant	Yes	No	Yes	IEP
Lily	11	Cochlear Implant	Yes	Yes	Yes	IEP
Maxine	23	Hearing Aids	Yes	Yes	Yes	IEP
Natalia	15	Hearing Aids	Yes	Yes	Yes	IEP
Adrian	21	Hearing Aids	No	No	Yes	None
Emmy	16	Hearing Aids	No	No	Yes	Section 504
Jeff	22	Hearing Aids	No	No	Yes	None

Note. Liz and Lily were in D/HH-specific programs but then transferred to general education. Jeff chose to close his IEP. Emmy transitioned from an IEP to a Section 504.

Limited K-12 Educational Supports for Postsecondary Preparation

There were limited participant responses to the first research question, “What K-12 educational supports did college students with USH perceive best prepared them for postsecondary education?” Many participants felt that they did not receive any specific K-12 educational supports that helped them to prepare for postsecondary education. Mostly, these students were mainstreamed and felt as if they were supported the same as their general education peers without transition specific supports. Additionally, a subtheme that emerged was participants bringing up a lack of awareness among educators and related professionals on USH-specific accommodations and resources.

While the majority of participants had nothing to report, a couple of participants agreed that the most beneficial K-12 supports were self-advocacy skills in requesting accommodations, knowledge of disability rights (e.g., ADA), and training in academic writing. Even those who did not receive training in these areas, mentioned that it would have been helpful in preparing them for college. Natalia shared:

> So, I think for me, the thing I felt most prepared for going into college was advocating for myself, because I felt like I'd had a lot of support on learning how to do that since I was literally in preschool and explained to people what my hearing loss is, what I need, why I need a microphone, etcetera. I wasn't as prepared on the vision side, but I think learning those skills was what prepared me, like, the thing I felt most prepared for going to college.

With Natalia, the self-advocacy skills required to explain her needs and request accommodations were seen as positive transferable skill for college. Zach had a similar sentiment when learning about the ADA with his teacher of the Deaf. Zach explained:

> Towards the middle and the end of my senior year, my teacher of the deaf, she started teaching me about ADA--Americans with Disabilities Act--and how I won't be covered under the IEP anymore, and how it transitions into that. She made me read a bunch of things on that and quiz me. I'll say quiz, but it was very casual, and just like quizzing. She ran me through everything and where the differences are, but where I can still get everything and where now, it relates to not just school but also the workforce. So, once again, I'm very thankful for my teacher of the deaf, who ran me through everything with that, as well as my writing.

Lastly, academic writing was an important topic, especially for these participants who experienced loss of hearing early in their lives and had mostly D/HH services. For them, written language was complicated, and academic writing was a challenge. Zach shared how his teacher of the Deaf (TOD) worked with him on his writing skills over the years and how much it helped him in college. Other participants explained that it was their greatest struggle in college and how they wished they had been given more support in that area. In essence, there was not a plethora of responses, but the common narratives suggested that the most beneficial K-12 educational supports for postsecondary education were self-advocacy skills in requesting accommodations, knowledge of disability rights (e.g., ADA), and training in academic writing.

Unawareness of Usher Syndrome Specific K-12 Educational Needs

A subtheme that emerged was participants corroborating a general lack of awareness among educators and related professionals on USH-specific accommodations and resources. Participants found educators and related professionals to be unaware of USH and its impact on tunnel vision, fatigue, and more; D/HH accommodations were often not the issue as those were generally well known. However, since these students were in a flux of combined vision and hearing loss, they often struggled to express their needs to educators. For some, their parents would step in to help with setting up accommodations and finding outside resources.

For example, Evan created a video with his mother about USH and would replay it when he had new teachers to save him the trouble of explaining himself all over again. A few participants did touch on having to constantly disclose and explain their needs, which was frustrating. Natalia shared that she wished that educators would take the time to do their own research and learn more about USH.

> Maybe this is unrealistic to expect, but I think it would have been really helpful if some of my support team kind of looked into Usher Syndrome a little bit on their own. I felt like I had to do all this explaining and educating when I didn't even know what Usher Syndrome really was. And, I was diagnosed at 16, so I was already an angsty teenager. And then, I was trying to explain to people I was going blind, which I didn't even want to think about the fact that I might be going blind. So, I think encouraging people to just, like, check out the USH Coalition's website.

Maxine commented that even if professionals or educators are not aware of USH, they can still sit down with students to try to better understand what they are going through and how they can support them, especially as needs and accommodations can vary per individual. She also suggested having members outside of the school, like an audiologist, join the meetings as well to help give the teachers a better idea about her level of hearing loss. Maxine shared,

> You can't know everything. Everything is evolving all the time. So, I think also just do your research, get to know the person, and really try to communicate, make a relationship with that person, and just try to connect, like . . . . I think the big thing is they really need to connect and get to know the student, get to know the student's family. What do they

> like? And just really try to connect and even if it means getting a team involved if that is beneficial, like an audiologist or whoever. But at the end of the day, you also need to value that student or that person that is getting taught.

Emmy agreed and felt like she could have benefited from someone sitting down with her to discuss the vision piece of USH, which was also new to her. She felt like she did not have the answers to give educators as she was still figuring it out herself. Emmy wished someone had taken the time to talk openly about the changes in her vision and USH-specific supports and resources that could have helped her at that time.

Perceived Lack of Transition Planning and Postsecondary Preparation

A common thread among these participants was a perceived lack of individualized transition planning and postsecondary preparation through their K-12 setting. Among all the participants, none of them reported having formal transition planning or postsecondary preparation experiences. For transparency purposes, it is important to note that these students may not have recalled their transition planning experiences due to a lack of awareness of what constitutes transition planning or postsecondary preparation. For instance, when asked about working with a designated transition specialist or coordinator, a few responded to the question by describing their meetings with general education guidance counselors.

Of those who stated that they met with general education guidance counselors, they all agreed that it was not very beneficial for their postsecondary preparation. The time spent with a guidance counselor was generally limited to scheduling classes and ensuring they had the correct credits to graduate, with no in-depth discussion about the college admission process. Natalia shared, "I went to a public high school, and each guidance counselor had 500 kids . . . guidance counselors were assigned by your last name. [Mine] seemed like checked out, like he looked high all the time." Emmy had a similar experience, explaining she only went to her counselor to get her class schedule, meeting once or twice a year. When asked how she would have benefited from a transition specialist, Maxine replied:

> I think it would have been a smoother transition. I think where that kind of fell off was because of my transition. I took a few gap years, whereas if I had transitioned directly from high school into college, I think I probably would have been better.

Another participant, Natalia, believes she was successfully accepted into college because of her parents hiring a private tutor to assist her with the college admissions, essays, and more. She expressed that she had a general guidance counselor at her school, but without this supplemental service, she would have been at a loss with her college preparation process. When asked the same question about the benefits of a transition specialist, Natalia's response was similar:

> I do think I probably would have benefited from a transition counselor just to kind of make things a bit smoother, but I didn't. So, it was mainly just my parents and I trying to kind of figure that out.

Additionally, none of the participants remembered being involved in formal transition planning, even though it is required for the seven participants with IEP plans. Adrian, a home school student, was unaware of formal transition planning altogether. Similarly, the other two participants who did not have an IEP shared that they did not recall having a transition plan either. Lastly, there was no evidence to suggest that a DeafBlind specialist was involved with the IEP team or transition plan.

Transition planning can also include independent living skills, if necessary for post-school goals (OSERS, 2020). When asked about learning independent living skills in college preparation, most students said they had no explicit training from their K-12 educators. Jeff said, "I prepared as any other 18-year-old would to go live on campus." Two participants were able to attend summer camps designed for blind and DeafBlind students through vocational rehabilitation funding that aided in their independent living training, whereas the rest were without any formal independent living training. A few participating students shared that they wished they had more support in time management, making their own medical appointments, budgeting, and writing academic papers. Otherwise, most of the participants felt there were still a lot of independent living skills that they had to learn by trial and error in college.

According to the OSERS *Transition Guide on Postsecondary Education and Employment for Youths with Disabilities*, the following are examples of post-secondary preparation: (a) being an active participant in IEP meetings; (b) learning about programs of study and the college admissions process; and (c) taking challenging academic courses to prepare for college (2020, p. 23).

While these guidelines are for students and not educators, there were reported challenges that interfered with these recommendations. For example, Jeff decided to "graduate off" his IEP, as he felt it was becoming a nuisance and not benefiting him in any way. Jeff shared his experience about educators being confused with him being on an IEP and taking honors courses at the same time:

> I took honors classes. And, my dad actually told the story of the IEP case manager. When I first got to high school, he hadn't met me. But I was enrolled in AP classes or honors classes, and then he called my dad up and said, "Sir, we think there's some mistake. Your student's enrolled in honor classes." He was like, "Were you trying to call my kid's stupid or whatever?" And, he's like, "No." But he hadn't taken the time to meet me. And, if you

> had met me, you would have known that I probably am capable of doing it. So, it was just kind of just some little weird things like that.

He did not like educators assuming his IEP status meant he was less capable and needed to take remedial classes. Unfortunately, he didn't feel that the support he was receiving was helpful and wished to stick with minimal accommodations only (e.g., preferential seating, getting lecture slides from teachers, etc.), which he could do on his own without an IEP. Consequently, Jeff was not able to be an active member of his IEP after he chose to “graduate off” his own IEP.

When it came to learning about the college admissions process, many of the students reported no involvement of educators. Instead, they worked with their parents or did research on their own. Emmy expressed that she had no help with learning about programs of study and the college admission process. She knew there were people she could hire to help, but that option was expensive, so she, instead, chose to try it on her own with the support of her parents. She described the process as overwhelming, trying to pick a good art school while navigating the impending effects of her vision loss on her career as an artist.

Lastly, in relation to taking challenging courses to prepare for college, there were a few participants that felt they were not properly supported. Instead, they were placed in remedial courses like Jeff and Dereck or in Lily’s case, into a self-contained program that would limit her ability to apply for college. Dereck had a similar story to Jeffs; he shared:

> In middle school, we had placement. It's like advanced placements and then remedial placements. And so, I was placed in advanced math and remedial math at the same time. I was placed in regular English and remedial English. So, we had those kinds of issues and kind of like, why? You're getting access to services, so we're going to place you here. It

> was based on the IEP as well. So, it was like that part was frustrating a little bit. I would say that was the first time. I saw, growing up, the assumptions and that kind of thing.

Additionally, Dereck was assigned an ASL interpreter in high school, even though he was not fluent in ASL. He chose not to say anything about the assumption that all D/HH students use ASL. Instead, the interpreter became like a paraprofessional for him. Dereck shared, "She was a great person. She supported me in different ways. Like she noticed when I'd missed something and would help me. But ASL wise, I got more out of hearing." In this case, the school was not providing him with his preferred accommodations.

Another participant, Lily, found herself in a D/HH resource room for 75% of her day through a district-wide D/HH collaborative. She had recently moved to the area and was placed in a specialized program for the Deaf because of the D/HH "label" in her paperwork. However, she quickly learned that enrollment in this program meant alternative achievement testing based on “Deaf norms,” as she called it, that would hinder her ability to graduate with a traditional diploma and later enroll in college. Once her parents learned the impact of her specialized educational placement, they immediately removed her from the D/HH placement. Lily shared:

> They had a deaf education program . . . and they said, why don't you get her services there? She can get her FM system. She can get a counselor just for her. And they didn't tell us what that really meant. And, my teacher, I should mention, brought in the director of that program to my IEP meeting . . . so they immediately start putting me with the deaf and signing students. Even for regular classes, I was clumped in there and they kind of put me in a label. But then to make matters worse, they were like, you need to look at the interpreter. I don't sign, I speak. Speak to me . . . it was really awful. My mom found off a

> full type of IEP in October where it says 75% special eds. . . . And my mom said it's going to harm her in college. Correct that immediately.

After leaving that program, Lily took the regular standardized achievement test and received above average scores, which further confirmed her inappropriate placement. Lily was then given an IEP with pull-out D/HH services and accommodations in a mainstream classroom that was a much better fit for her. However, Lily said that the effects of being in that Deaf program lingered as her former friends called her out for leaving the program, denying that she was truly Deaf. She found the overall experience traumatizing.

Even in a mainstream setting with pull-out D/HH services, Lily struggled with her TOD. Her teacher insisted she learn sign language, even though Lily had made it very clear that she preferred speech. Further, Lily told her story of how she missed out on adult services because of her TOD.

> So, I still to this day feel pretty angry at my teacher deaf for dropping the ball on the commission for the deaf, which would have helped me get an FM system, potentially CART, other services [such as financial aid] I wouldn't have had to go through for college. But because she dropped the ball, I had to pay for a lot of those consequences, which I still am paying for till this day.

Typically, a transition specialist or a related service provider such as a TOD or TVI would be knowledgeable of the benefits of adult service agencies, especially those specific to deafblindness such as the local commission of the Deaf, division for the blind, etc. The names of the organizations can vary per state, but OSERS does encourage involvement of vocational rehabilitative agencies, and it is considered best practice to include representatives of VR in transition planning discussions in order to help the student become registered in time to receive benefits to support them in college such as O&M training, financial aid, and more (2020). However, the reported vocational rehabilitation connections in this study were often made through family, friends, or other contacts outside the K-12 educational setting. Natalia shared,

> My parents assumed I wasn't blind enough to qualify [for VR] or whatever, right? I think I remember we met at a coffee shop with this woman who worked there wants to just kind of have a more informal chat, she was the friend of the friends or something.

In this example, the parents were not knowledgeable of VR eligibility, and Natalia could have potentially missed out on essential adult services to support her transition to college. Luckily, her parents were proactive and happened to have a family friend who was willing to meet with them outside of school hours. Unfortunately, in Lily's case, once you miss the transition window, it can be difficult to get VR services to help with college preparation.

Without these kinds of postsecondary preparation supports, two of the participants in this study were not initially successful in college, while others struggled with the preparation process. Dereck made his way through three different universities, dropping out twice and becoming homeless before he found the right fit at a culturally Deaf college. Maxine also did not feel ready for college right out of high school, so she tried to enter the workforce but then quickly realized her career of choice required a college degree. A few years after graduating, with the help of a national rehabilitation agency specializing in deafblindness, Maxine enrolled in a community college. She is now doing well with her studies and intends to graduate with a degree in disability studies.

Only one participant, Liz, the only ASL user in the group, had a dedicated TOD who helped with postsecondary preparation. She was the one stand-alone teacher who went above and beyond to help with college searches, preparation, and financial aid to set Liz on the right path to college success at a culturally Deaf university. Liz shared:

> Oh, she was with me every step of the way, for sure. She helped me fill out all the necessary paperwork to apply to schools. It was my first time, so I wasn't sure how to navigate it all. She also gave me feedback on my college admission essays. Really, she helped me so much.

Liz was the only Deaf child in the family, and her parents did not know ASL. In her senior year of high school, she was estranged from her parents to the point where she moved out of the house and had to file as an independent for financial aid services. With that, her TOD took on the role of a transition specialist to help her prepare for college. Her TOD taught her about the college admissions process, connected her to a vocational rehabilitation agency where she received VR training to learn IL skills, and did not hinder her ability to take challenging courses.

This TOD even went above and beyond the role of a transition specialist, almost acting as a parent, to help Liz move into her dorm and make sure she had support even after graduating from high school. Besides this outstanding example, most participants felt they were on their own while preparing for college. This led to parents being the strongest supporter of their postsecondary preparation.

Parents as the Strongest Support Systems

Except for Dereck and Liz, the other participants in this study reported parents as being their strongest supporters throughout their postsecondary preparation process. Parents were recognized for reviewing the college admission process, connecting with adult service agencies, and seeking out USH related resources. Parents were also supportive in learning about the USH, educating others about USH-specific accommodations, and more.

Adrian and his younger brother, who also has USH, were homeschooled with the support of a school district and had a TOD, speech therapist, and audiologist coordinated by his parents. Adrian's parents also opened their home to a Deaf friend to come to live with them for close to 5 years to increase their exposure to ASL. Other parents were there for every step of the USH journey, helping with the grieving process and looking for resources and support that could be beneficial. Maxine shared:

> And, I'm really grateful for my family as well. My parents have been really supportive about this, even though it's been a very difficult transition for all of us. It's new to everybody. Even though it's been between 6 and 9 years that this has been going on, it's still new. It's still hard. Everyone's still learning about these conditions and different things and just kind of adapting and learning what helps. But, yeah, I definitely think that that's been beneficial.

Another parent hired a college prep tutor, while others helped with the college search process. Evan, who found his mother to be the most supportive, said, "My Mom . . . she's literally involved with everything." His brother Zach, who also has USH, agreed that their family went above and beyond, not only supporting them but also being active in community organizations and large fundraisers for USH research. Evan also shared that his mom helped him come up with USH-specific accommodations:

> Basically, my mom came up with all the accommodations with, like, working with me. And then, I was always the one that explained Usher syndrome to my teachers and how to help. I was always the lead in the IEP meetings, explaining to everybody. When I was in Grade 4, there was a school speech contest, and I did it on Usher syndrome. We kind

> of use that speech pretty much everywhere we go to explain Usher syndrome to people. I don't have to do it anymore. I just play the video.

For Lily, her mom was the one who fought for her to be transferred out of the Deaf collaborative program as well as taught her how to be her own advocate when it came to getting accommodations in college. Lily's parents also set up a foundation to help find a cure for her rare type of USH and remained active in the field of research. Other parents also took an interest in research and became involved by joining the USH Coalition, which provides a network for people with USH to connect with each other and with researchers in the field. Parents often led the way in getting their children involved in vocational rehabilitation, consumer organizations, and social groups.

Discrepancy in Deaf/Hard of Hearing and Vision Services

The first unanticipated theme describes a perceived discrepancy between the D/HH and vision services. All the participants in this study were diagnosed with hearing loss at birth or shortly after. Many had a head start with assistive listening technology, speech therapy, and early intervention services. Only one of the participants was fluent in ASL and received ASL interpretation as one of her accommodations. Nine of the 10 participants in this study had hearing aids or a cochlear implant, attended a public school, were included in general education courses, preferred speech communication, and received mainly D/HH services and accommodations.

Half of the students received vision services (e.g., TVI or O&M) with less frequency than D/HH services. For those who did receive vision services, there were mixed feelings about whether they felt it was “too early” for them to be receiving these services when they still had plenty of residual vision, such as mobility and braille training. In contrast, many of these participants started early with D/HH-related services via early intervention and felt more comfortable advocating for their D/HH needs.

Deaf/Hard of Hearing Services

Deaf/hard of hearing accommodations consisted of preferential seating, getting lecture materials ahead of time, use of an FM system, C-print or CART, note-taking services, and extended time for tests. Students who were included in general education settings reported getting services from a teacher of the deaf, a speech therapist, and an audiologist for pull-out services. Many participants expressed positive experiences working with the TOD and the related service providers. The participants felt that the D/HH services they received helped them better understand their rights under the Americans with Disability Act (ADA) and how to request D/HH accommodations in college and explain their hearing loss and needs to others.

With the help of her TOD, Liz learned how to navigate the hiring, scheduling, and grievance process related to working with ASL interpreters. This happened because, although she was assigned an ASL interpreter as required per her IEP, she struggled to get a good-quality interpreter to meet her needs in high school. She shared her frustrations with her TOD of having unprofessional or unqualified interpreters. Her TOD helped with the screening process and finally found her a good match, but then that interpreter went on maternity leave followed by a slew of substitute interpreters who came and went. Finally, she found an interpreter that worked well for her, and she learned a lot along the way. Liz shared that interpreter issues are still a challenge in college, where she is responsible for setting up her interpreter schedule. Yet the experience of being able to communicate and work out these interpreting issues with the support of her TOD was very helpful in preparation for college. Liz wrote in a reflective prompt:

> Honestly, I would say that my experiences are different from other college students with Usher Syndrome because we have different experiences for support and others. My mother and teacher of the deaf (TOD) helped me through my journey of having Usher Syndrome. For example, I would share a story about a college student with Usher Syndrome that I recently learned about. I am a student representative of Deaf Blind Committee Support (DBSC). She was struggling with her journey to be a student here because she has a low vision so she needs to take care of her eyes. I understand that college is harder than high school, so you have to take classes. . . . It sounds like she is not prepared to be ready for college, like, how to set up for her accommodations and get interpreters for her classes, but now she did not do them because they never let her know how to do them. It is a part of the challenge for college. So yeah, my experience is different from hers because I know what to do. I was much prepared because my TOD taught me how to do adult things, so I knew how to contact them to get accommodations and interpreters and others. So yeah, now I am a second-year student and doing very well.

Adrian also had a very positive relationship with his TOD. Even though Adrian was homeschooled, he explained that his parents set up the TOD, and she would come to their home. It was not clear if the TOD was with the local school district or how that came to be without him having an IEP. Adrian was unsure of the details. Nevertheless, he shared that the TOD helped him learn about Deaf culture through field trips to a historically Deaf university near where he lived. Her focus was more on teaching him about the Deaf community than accommodations in his homeschool classroom environment, but this made Adrian interested in learning more about the Deaf community despite not knowing much ASL. Adrian also shared that he took some community college courses while in high school and felt comfortable asking for accommodations such as to get lecture slides ahead of time, ask the professor to repeat what they said, as well as sitting up front near the board in the classroom. Overall, the participants in this study felt that their TODs helped them with D/HH services, learning Deaf culture, and how to advocate for themselves in college when it came to D/HH accommodations.

Vision Services

As mentioned earlier, many of the participants in this study were not formally diagnosed with USH until their late teens or early 20s. Within this study, only 5 of the 10 participants received vision services through their K-12 education. This included working with an O&M specialist for mobility training and a TVI for low-vision accommodations, braille instruction, and requesting vision-specific supports. Participants' feelings were mixed about whether learning braille and O&M training helped them prepare for college when they still had a large amount of residual vision. Yet, almost all of them agreed that having a foundation of skills was helpful if they needed to relearn them in the future if or when they had more progressive vision loss. Additionally, these participants felt it was beneficial to learn about vision-specific accommodations in high school to request services and accommodations in college.

Liz was provided with both O&M and TVI services at the age of 10. Liz shared that she enjoyed her O&M class and thought it was quite fun to be blindfolded, but she was not sure of the reason behind the lessons at the time. It turned out that Liz was not aware of her USH diagnosis until age 16. Her mother had found out when Liz was 10 years old but decided not to tell her daughter nor allow others to tell her, yet she made sure Liz received all the training and vision services she needed. Later, Liz learned about USH from other peers at a Deafblind youth summer program after sharing her experiences with others who also had USH. Her TOD was the one to finally confirm her diagnosis when she returned from the camp, which put an odd slant on her perception of vision services. However, Liz said that she is happy that she had vision services as now she has a foundation to work with if she ever needs to learn it all again. Evan felt similar. He explained:

> I actually started mobility training well before I was legally blind, just getting familiar with a cane. Yeah, I've always been comfortable around a cane, more or less, so with actually using it. But the social circumstance, I'm still kind of a little bit . . . I feel capable enough to live without it, especially during the daytime.

In contrast, Dereck thought it was too soon for him to benefit from O&M lessons at his high school as he still had a lot of usable vision. As part of his training, the O&M specialists required him to be blindfolded. Dereck did not like being blindfolded in front of his peers on campus and ultimately resisted learning the skills. Dereck commented,

> They would put a blindfold on me, and we'd walk around school, and it just wasn't cool . . . they could have taken me off campus. I don’t know . . . I didn’t get much out of what we did.

Additionally, he said he would fall asleep in his braille classes because the TVI would dim the lights, and he would close his eyes to practice. Overall, Dereck was not motivated to learn these skills at the time and felt it was not a good match for him. However, when he dropped out of college the first time to find a job, he ended up with a position that involved services for the blind, so in the end, he felt it was helpful to have learned about braille and O&M regarding working with others who were blind.

Lily was also resistant to O&M training, more specifically, the use of a cane and what that symbolizes. She explains that at first, she hated her white cane and would hide it in her backpack to keep her peers or teachers from seeing it, but eventually, she grew to use her cane regularly. Lily shared:

> It was my senior year, and I did not like the idea of it. I still don't like using white cane because for me, I know there's always positive stuff in the Usher community, that white cane can be a good thing and that we need to take pride in it. For me, it felt like, in a way, saying, "I'm blind," when I still have a good chunk of my vision, but I needed to learn how to use it at night.

Lily said that she enjoyed working with her TVI who helped her learn how to use magnifiers, book lights, and a laptop to enlarge print. Her TVI taught her how to modify materials on her laptop instead of requesting print copies, which she found very helpful. Lily added:

> My vision teacher helped in that she also gave me some other great stuff, she gave me like good book lights, magnifier glasses, to really help me. My vision, she even helped me get access to get my books in large print physically, because I'm not a PDF person. My school had graphics department where they would take like an old trashy copy of the book. They would cut the spine and even enlarge with the scanner. Yeah, so, she was excellent. She was the best part.

There was also mention of being introduced to assistive technology for low-vision adaptations along with various requests for large print, as none of the participants in this study were fluent braille readers. Participants were in general agreement that the most beneficial part of the vision services was learning about vision-specific accommodations they could request in college, such as using a note-taker, extended time for testing, getting lectures ahead of time, preferential seating, and large print materials.

Participants appeared to be more receptive to D/HH services. Having grown up with hearing loss, they generally felt comfortable explaining their needs and requesting supports as needed. Relationships with TODs were generally positive. Regarding vision services, it was a bit more complicated. Relationships with vision specialists were not negative, but students had mixed feelings about receiving vision services. Some felt they did not need vision services yet, as they still had a lot of residual vision, while others were struggling emotionally with the idea of using a cane in public. Overall, there appeared to be a discrepancy between the D/HH and vision services that these participants received through their K-12 education.

The Multifaceted Impact of Usher Syndrome

The second unanticipated theme was the multifaceted impact of USH. Besides hearing and vision loss, participants described the social-emotional impact of USH, such as grieving, worrying about the future, and working toward self-acceptance in a world that does not understand USH. All of the participants shared their frustrations with common physical symptoms of USH but also commented on more overlooked aspects of this lifelong progressive condition. Additionally, there were themes of struggling with one's identity, being hopeful for a cure, and trying to find their place in the world as a person USH.

Physical Symptoms

While the participants in this study varied in their progressions of hearing and vision loss due to the type of USH, the majority commented on experiencing common physical symptoms of fatigue, tunnel vision, trouble hearing in loud environments, and night blindness, among others. Evan explained that it takes more effort in all aspects of life, such as school, work, and socializing, when you have USH. He shared, "We have to put in 200% energy just to keep up with everyone, but you know we keep going." The group was in consensus that USH comes with a lot of physical and mental fatigue, which most educators do not seem to realize is an aftereffect of variable dual sensory loss. Natalia shared an example of trying to find her way around a room when she is having a bad hearing and vision day.

> Sometimes it's frustrating because you're like, okay, I have the vision thing, but that's not working today. Then, the hearing thing is not working either. And so, it's just like, are you kidding me? But something that I do, and I use a cane or my guide dog now, but before I did that, I would kind of hug at the corner of a room and awkwardly stand there and try to let my eyes adjust, especially if I was going in . . . and then even if my eyes didn't adjust, do something like try to just look for a chair and just go sit down or something. But in general, I do, like, sort of think that going places with people is a little easier.

Even with residual vision in the daytime, tunnel vision can make it difficult to see those around you. Maxine described, "I remember sitting in the car and not being able to see my mom off to the side of me and not seeing things to the side." Maxine shared that her tunnel of vision has become smaller and blurrier to the point where she could no longer recognize faces or understand visual sign language. Maxine also has other medical conditions in addition to USH that impact the way she interacts with the world daily. She also described trying to hear in a loud restaurant:

> When I'm at restaurants, it's very hard to hold a conversation unless it's pretty quiet or I'm right in front of the person. So, a lot of times I've had with friends, we could either text back and forth. It streams to my hearing aids so that I can still kind of engage in communication where I feel comfortable and don't feel like I'm left out of the loop because there have been a lot of times where I'm just sitting there. I'm at dinner, but there

> are a lot of background noises, and I can't follow along with conversation at all. So, I'm just kind of like, "Okay, great." And that is literally what happened relatively recently, too.

Most of the participants discussed night blindness, where it becomes difficult to see in dimly lit areas such as in a movie theater, concert, or while outside at night. Those who can see enough to travel without assistance during the day suddenly have difficulty traveling at night. For example, Emmy was able to drive with a restricted license during the day but was not allowed to drive at night. She would have to rely on others for transportation to attend social events. Also, she felt that typical outings for someone her age such as going to a dark concert with friends could become nerve-wracking instead of enjoyable. Natalia explained:

> So, I think the main thing for me with concerts are, like, going with someone who I trust to guide me and not forget about me and leave me somewhere, which has happened more times than I'd like to admit. But, it's really hard being vulnerable and explaining to the person you're going with that you need them to stay with you.

For Natalia, night blindness meant a lack of independence and having to place her trust in others to get around. With Emmy, her progressive night blindness became problematic when she decided to pursue a film degree working in dark theaters. Emmy shared, "So, the night blindness is the worst part of the film stuff. I haven't been on set doing film stuff where I run into that problem. Now, I have run into the problem of the theater being too dark." Emmy explained that she was having difficulty seeing in the dark rooms for photography, backstage for theater, and in dimly lit film sets, but she also did not want her USH diagnosis to dictate her life.

Emotional Well-Being

Being diagnosed with a long-life progressive condition caused a wide range of emotions among the participants, such as grief, denial, acceptance, and fear of the future, among others, particularly with such a rare condition like USH, where it can be difficult to find peers and mentors to relate to with similar life experiences. The participants in this study were not prompted to delve into their emotional state while preparing for college. Yet, the topic of emotional state emerged throughout the interviews, focus groups, and reflective prompts.

Dereck explained how it was hard for him to focus on school with the knowledge that he might become completely Deaf and blind one day. He shared that he was in denial and became somewhat reckless in high school when he bought a sports car and drove it around carelessly, knowing the risk. He spent more time with his girlfriend and wanted to ditch his classes. He then became a young dad and looked into finding work before trying to go to college, living in the moment, and trying to not think about the future. Natalia, who felt she was in a better place with accepting USH, said:

> I'm at a very good place with it, so I'm religious, and I believe that I was created this way for a reason, and that helps me a lot and makes it a lot easier for me to accept it. So, in a weird way, it doesn't affect me all that much. It did, for a long time, for a long time . . . but I know I'm at a very good place where I want to work in the field of disability work. I feel, for the most part, that I will always be able to have opportunities because, you know, disability rights organizations are probably more likely to hire a disabled person, not always, but it'll be easier for me to be employed, I think.

Other participants, such as Emmy and Maxine, were looking to the future and what their lives would look like with the progression of their USH. Emmy worried that her choice of enrolling in an art school will make it difficult for her to be successful in the future; but for now, she is staying the course. Maxine initially wanted to become a para-legal but has now changed her major to disability studies with her progressive dual sensory loss in mind. Maxine shared:

> It's a tough transition period for anybody, given the school and the changes. Then you add on a dual sensory loss on top of that. Going through all those transitions together makes it much more difficult to try and figure out your place in the world. Like, "What do I do now? Can I still pursue a degree? Can I work? Can I do this?" And, yes, you can. It just takes more effort, and you need to find the right people to be in your corner. You find the right resources and get connected with them, and just kind of go from there.

Evan shared his story of being expelled from his high school baseball team because he only wanted to play certain positions that worked for his vision. He was frustrated and missed playing baseball, but he was determined to be a competitive athlete and got into swimming instead. There, he found a para-Olympian mentor who also has USH and is working towards his goal of being a para-Olympian one day. Evan and his family are highly involved in USH advocacy efforts. He embraces everything USH and meets many people with USH who struggle with acceptance. He said he wished he had more active partners in the USH community to keep the advocacy movement going forward to increase awareness of these shared experiences and issues.

Identity

In addition to the challenges of vision and hearing loss, participants shared that there is also a complicated case of identity when you live between the worlds of the hearing, the deaf, and the blind. Dereck shared that when he is in a group of mostly hearing people, he identifies as Deaf, but among Deaf students, he identifies as hard of hearing. Others explained that they had identified themselves as deafblind but did not feel "DeafBlind enough" to be worthy of that title as it seemed reserved only for those who use sign language visually or tactually. Dereck even experienced "DeafBlind guilt" when he won a scholarship essay about his experiences as a person who is DeafBlind, but then showed up to the award ceremony where most everyone there was fully blind. Dereck described the event:

> I felt kinda like a fraud. Um, but, uh, so I wrote an essay, and I ended up winning. And, I had to stand up in front and take pictures with the person handing me a check and everything. He was blind. And I, the first time I had met a blind person, I shook his hand, and it drew me into the world, and it kind of made me scared a little bit because, like, I didn't feel like I was supposed to be there.

Natalia also felt that because she did not use sign language, she was not "Capital D Deaf." She shared, "I wouldn't necessarily identify myself as Deaf, but I also know there are some people who probably have a similar amount of hearing loss to me who do identify that way." She also went on to say that it was interesting that she sometimes referred to her as deafblind and other times as hard of hearing/low vision, depending on the situation. When asked if she ever identifies to others as a person with USH, she commented that no one knows what USH is, so she will say "deaf-blind" instead. Natalia went into more depth explaining the progression of how she might identify herself with someone familiar with the disability world versus someone who is not:

> I'll just say it depends on the situation. If I'm talking to somebody who's more familiar with the disability world, I'll say deaf-blind. Somebody less familiar, if I said deaf-blind, they'd be confused because they're like, "Well, you can see me and you can hear me." They don't understand it's a spectrum.

Natalia also gave an example of students coming up to her when she was using a cane and asking her why she was pretending to be blind. They were confused as they had seen her navigate certain situations without a cane before. Maxine shared a similar sentiment of identity across different communities, moving between the blind, deaf, hearing, and deafblind worlds, especially when communication modes varied. Maxine stated:

> Because it's a little weird being in one community where everybody's visually impaired but hearing, or being in a deaf community and having some hearing but not a lot of vision. And then you have the community of both where it affects . . . I mean, it's a spectrum on all sides. But then you have a community of the deaf-blind community or the hard of hearing. Everyone kind of identifies differently. They use things differently, they communicate differently. . . . So just being able to fit into that where I'm not like in limbo, like, "Okay. It's not just one way or the other, it's both. But it varies for everybody." And, I think just trying to find that right community has been really helpful, especially mentally, just feeling like I couldn't identify somewhere and know where my place is in the world in a sense.

Other participants were not open to disclosing or identifying as someone who is deafblind. They tried to "pass" as sighted or hearing at times, getting themselves into sticky situations, adding further confusion to their variable and progressive hearing and vision loss. At this time, none of these participants were actively working with a specialist in Deafblindness or USH that could have potentially helped them to work through these feelings of uncertainty around identity.

Navigating the Medical Diagnosis

The third unanticipated theme was the impact of medical diagnosis on the transition experience for students with USH syndrome. Nearly all the participants were diagnosed with hearing loss at birth or shortly after, whereas their vision loss was not diagnosed until later in life, delaying their formal diagnosis of USH. Many of them also struggled with negative experiences with medical professionals while trying to figure out their diagnosis. This delayed diagnosis and acceptance of USH often lead to a lack of transition services and related educational supports to help these students prepare for college while navigating a prognosis of combined vision and hearing loss.

Newborn Hearing Screening and Deaf/Hard of Hearing Diagnosis

With the establishment of the universal newborn hearing screening around 1999-2000 in the U.S. (Joint Committee on Infant Hearing, 2000), all but one of the young adults in this study was diagnosed with hearing loss at birth. Nine of the 10 participants were fitted with hearing aids or cochlear implants and given speech therapy, provided with early intervention, and/or adequate educational services to address their hearing loss with an FM system, preferential seating, or sign language interpreting. Natalia expressed:

> I was super lucky because I was born literally right when Minnesota started requiring newborn hearing screens. And, it's really wild to think about because if it hadn't been discovered at birth, for me, things might have been really different. And, it's all about, like, early identification and stuff, so just to comment on that.

Some of these students only used basic ASL in certain situations to converse with other young adults who identified as having USH at a social event or if they were attending a culturally Deaf school with other Deaf students. Otherwise, all but one student had hearing aids or a cochlear implant and preferred to use speech as their primary mode of communication.

Vision Loss and Usher Syndrome Diagnosis

A few participants were suspected of having USH through a member of their support system rather than by a medical professional. Instead, a teacher, a parent, and a scout leader noticed things like an abnormal gait, missing visual information, and vertigo issues. For example, Dereck shared that he received glasses at age 13 but then started having some bad vertigo issues at age 16 when he noticed he was having difficulty seeing at night at the summer camp where he worked. He kept bumping into things and even busted his lip before meeting with his scout leader, who said, "It sounds like you have Usher. . . .You should get checked out." Sure enough, when he went to the eye doctor, Dereck had gone from 200 degrees of vision down to 13 degrees in less than a year. From there, he went through a chain of eye doctors before seeing a retinal specialist in New York who formally diagnosed him with USH. However, Dereck initially did not fully understand his prognosis and how it would affect him in the future. He also admitted to ignoring the diagnosis and not being receptive to vision services at the end of his high school career. He was one of the participants who dropped out of college twice before finding a good fit.

Adrian’s father suspected he had USH as he had noticed the signs and done some online research. His father said, "This is what you have," despite the audiologist telling him, "There's no way you have Usher syndrome." Adrian shared that this diagnostic process was very harmful as he was going back and forth on the prognosis. Finally, after more testing was done, and even though his audiologist told him, "Don't worry, this is just precautionary," he had a formal USH diagnosis.

This was not an uncommon theme amongst this group. Another participant, Emmy, had been referred for USH testing as a baby but then was told by doctors and nurses, "No, she just had fluid in her ear." In her junior year of high school, she was trying to prepare for college while also trying to find the right diagnosis, as she had many overlapping symptoms that correlated with different conditions. Emmy said, "We were in a constant limbo state." By the time she was diagnosed at age 16, she was already looking into art schools and planning her future as an artist. She did not take the diagnosis well and was not open to receiving vision services before college.

Misdiagnosis

In addition to these late diagnoses, one participant struggled with multiple misdiagnoses. Maxine had a rare form of "atypical" USH on top of many other medical conditions, such as Ehlers-Danlos syndrome and being born premature, that had an overlap of symptoms. The gene she had was deemed "a variant of unknown significance" as it was relatively new to the research world of USH. Therefore, it was difficult to diagnose since it did not fall into the typical USH categories of I, II, or III. In the meantime, she went through a slew of medical specialists and then three different high schools to find a good fit for services while still unsure of her diagnosis and what she needed. Emmy described it as,

> Very stressful at the time, especially just kind of going through that whole process and also trying to get diagnosed at the same time, so just trying to figure all of that out and get to the right spot. Well, I was in the process of trying to figure all of that out and having to explain that to professionals that don't understand or aren't familiar with it didn't really help. So, just trying to get your ducks in a row, so to speak, to know and have the knowledge and research, and be able to explain it more.

Like many other participants, she also had to travel far and wide to find a retinal specialist who specialized in USH syndrome. Finally, after seeing a slew of doctors, she was diagnosed with USH at age 23, post-graduation. Emmy said it was nice to finally have a name for her condition to learn more about it. Still, she wished that the medical professionals had made the process easier for her by having a better bedside manner.

Medical Professionals' Bedside Manner

After going through many different doctors and diagnoses, a few participants shared that they had very negative experiences with medical professionals’ "bedside manner." Experiences included being ignored by the doctor as a minor, mocked by the doctor for not realizing they had vision loss, or frightened by a blatant prognosis of total blindness. For example, Natalia, who was diagnosed at 16 years old, explained that she felt like the doctors ignored her, only speaking to her parents as if she was not in the room. Natalia pointed out,

> I had a lot of issues where the doctors basically ignored me, and they only talked to my parents, and would act like I wasn't even in the room, which was, (a) incredibly dehumanizing, (b) made me feel like I wasn't even involved in my own medical decisions or medical life. So, it made me try to separate myself from Usher even more.

Emmy expressed that she felt no empathy from her doctors while undergoing "horrible" tests that involved putting electrodes on her eyes. She wished doctors would have more empathy during the testing and diagnostic process instead of being "so cold and clinical." Instead, the general sense of prognosis was telling the parents that their child would become blind, so get them a white cane and some braille training without providing any specific information or resources, even when going to a specialist housed in a university. Natalia commented,

> I was diagnosed with Usher technically through a university. But the retinal specialist had never had somebody with Usher, so he was . . . well, he was utterly useless . . . he had nothing for me. Some of these people have never met a blind person before; they work with us every day, but they don't know anything. It's absolutely ridiculous. I just wish that both IEP teams and all that and doctors were better about having these resources and being able to give them to people and tell people about them.

In contrast to these negative encounters, some positive interactions were reported with audiologists, ophthalmologists, and USH researchers. Lily shared that she "had become very close friends with one of the researchers in the Usher syndrome community, so that helped a lot." The rarity of USH, combined with the two different specialty areas of vision and hearing loss, can make it difficult to diagnose and generate appropriate referrals for this group.

Conclusion

The purpose of this study was to learn from college students with USH about their lived experiences of preparing for postsecondary education, K-12 educational supports, and support systems. In the true nature of an exploratory study, themes emerged through participant-led discussions in relation to the primary research questions as well as additional themes related to the transition process. This resulted in a total of six major themes. Three key themes related to the research questions emerged from the data: (1) limited K-12 educational supports for postsecondary preparation; **(**2) perceived lack of transition planning and postsecondary preparation; and (3) parents as the strongest support system. As many of the participants in the group received little to no transition planning or postsecondary preparation, this led to three additional themes: (4) discrepancy in D/HH and vision services; (5) the multifaceted impact of USH; and (6) navigating the medical diagnosis. Although not included in the initial research questions, these additional themes provide a unique perspective on the experience of being diagnosed with a life-changing condition during such a pivotal time, such as while preparing to transition from high school into college. The results from this shared narrative can be used to inform future evidence-based research. Lastly, the findings of this study add to the limited body of research on the lived experiences of transition-age youth with USH preparing for postsecondary education.

CHAPTER V

DISCUSSION

The purpose of this study was to learn from college students with USH about their lived experiences of preparing for postsecondary education. This exploratory study collected firsthand stories and narratives on college students' transition planning and postsecondary preparation experiences with USH. A purposeful sample of 10 college students with USH engaged in interviews and focus groups guided by critical DeafBlind theory and Bronfenbrenner's ecological systems theory. Additional data were collected through participant reflections and researcher notes to corroborate findings. This chapter will discuss the significant outcomes of this study in relation to previous research. Implications for practice for educators, professionals, families, and youth with USH will be presented. Lastly, recommendations for future research and limitations of the study will also be addressed.

Revisiting the Research Questions

As evident in the literature review, there is limited research on the transition planning and postsecondary preparation experiences of youth who are DeafBlind (Zatta & McGinnity, 2016), with even less being known about students with USH specifically (Arcous et al. 2020). The research questions for this exploratory study were developed to delve into the transition planning and postsecondary experiences of college students with USH, only to find very limited transition planning experiences for them to report. This led to additional unanticipated themes relating to the multifaceted impact of USH and navigating the medical diagnosis. Despite diverting from the initial research questions, the results of this study add to the limited body of research on the lived experiences of transition-age youth with USH preparing for postsecondary education. Three research questions guided this study:

Q1 What K-12 educational supports did college students with USH perceive best prepared them for postsecondary education?

Q2 What K-12 transition services did college students with USH perceive best prepared them for postsecondary education? What K-12 educational supports did college students with USH perceive best prepared them for postsecondary education?

Q3 What support systems were most influential for college students with USH in preparing for postsecondary education?

Research Question 1

There were limited participant responses to the first research question as the participants did not feel they received many K-12 educational supports that helped them prepare for college. It is possible that K-12 transition supports were provided, but these participants were not aware of their impact on postsecondary preparation. For example, they could have received coursework assignments that involved time management but did not recognize that this activity was helping them to build their time management skills in preparation for college.

Another possible explanation could be related to the reported lack of awareness among educators and related professionals on USH-specific educational needs and resources. Previous research supports the idea of general and special educators being unaware of how to work with students with dual sensory loss (Blaha et al., 2009; Ellis & Hodges, 2013; Kamenopoulou, 2012). Further, Arcous et al (2020) also found that educators, especially those in mainstream settings, were vastly unaware of USH.

According to Nelson and Bruce (2016), a lack of knowledge and training in deafblindness among educators and professionals, has been an unchanged issue for quite some time. Blaha et al. (2009) suggested that students who are DeafBlind are likely served by educators or professionals who had never met a DeafBlind person before.

Another possible explanation is the siloed training of vision and hearing professionals who may be skilled in one sensory disability but not the combination of both (Ellis & Hodges, 2013). Correa-Torres et al. (2021) found that educators reported they needed training and support in "understanding the unique needs of students, teaching techniques effective with students who are deafblind, and accessibility to resources" (p. 1). These training areas of need expressed by educators reflect the sentiments of the student participants of this study.

Further, this lack of training in deafblindness is problematic as TVIs, TODs, and other sensory-related professionals such as speech-language pathologists are the ones who work with students with singular sensory loss and could recommend further assessment if they suspected dual sensory loss (Travers & Schles, 2023), that is, if they are knowledgeable and recognize signs of dual sensory loss or USH. This was the case with Liz, where the TOD noticed her atypical gait and issues with balance, which was later confirmed by her USH diagnosis. If educators who specialize in one area of sensory loss are not familiar with the signs of dual sensory loss, this can be yet another complication in identifying youth with USH (Okungu et al., 2020; Travers & Schles, 2023). Without a proper diagnosis, it can be difficult to provide the appropriate K-12 supports to youth with USH to help prepare them for postsecondary education (Arcous et al., 2020; Bruce & Borders, 2015).

Research Question 2

A common narrative among these participants was a perceived lack of transition planning provided through their K-12 education. None of the participants reported having a transition plan or assigned transition specialist to support them in navigating postsecondary preparation. Even though 7 of the 10 participants had IEPs, which are mandated by IDEA to have transition plans (OSERS, 2020), these participants had little to share in relation to this second research question.

A possible explanation for this perceived lack of transition planning and postsecondary preparation is that students may not have been aware of what constitutes transition planning or services unless it is explicitly stated. The term transition services can be nebulous. Without requesting the physical transition plans, it is inconclusive whether or not the transition plans were completed and to what extent they were individualized. Nonetheless, the participants' responses indicated that they were unaware of having a transition plan or having received transition specific services.

Another possible reason for this perceived lack of transition planning and postsecondary preparation could be delayed diagnosis. More than half of the participants were not properly diagnosed with USH until age 15, which could have limited their access or eligibility for specialized services, transition supports, outside referrals, and postsecondary preparation efforts. Jeff shared in his reflective prompt, “I was diagnosed later in life. It hasn't had as much of an impact on my ability to go places as it has for other people yet.”

This could also be due to their visual diagnosis being less than the threshold for being considered low vision (e.g., acuity of 20/70) at the time of transition, which might not have warranted vision services without request by the student, parent, or guardian. Previous research has documented that youth with USH can often go undiagnosed up until adolescence due to the heterogeneity and rarity of USH (Koenekoop et al, 1999; Miner, 1997). Because of the variance of the USH gene resulting in many different types with varying levels of progression, early signs can go unnoticed (Bruce & Borders, 2015). Additionally, with USH being two separate diagnoses (i.e., retinitis pigmentosa and sensorineural hearing loss) which can progress at different levels, misdiagnosis of only one form of sensory loss can occur. The delayed and varied onset of vision loss in USH can complicate early diagnosis (Blumsack, 2009). Without a formal diagnosis of dual sensory loss, the need for vision services can be overlooked (Bruce & Borders, 2015; Müller, 2006). As USH can be underdiagnosed and sometimes be an "invisible" disability (Ellis & Hodges 2013, p. 177), this can lead to misunderstandings about what educational support services are needed (Arcous et al., 2020).

Another possible reason could be denial or lack of acceptance of USH. Some of the participants in this study shared that they did not actively reach out for support. Similar to study results of Ellis and Hodges (2013), a few students tried to hide their deafness; they did so by covering their cochlear implants under their hair or wearing large headphones over their hearing aids. With mild hearing loss, they were generally “passable” and may have appeared as someone without hearing or vision loss, making it difficult for educators to recognize their needs without outward signs of dual sensory loss (Evans & Baillie, 2021). Arcous et al. (2020) also suggested that students with USH did not want to be different from their mainstream peers and would avoid acting in a way that would set them apart. This could include using a cane at school, being pulled out for O&M lessons, etc. Ellis and Hodges (2013) found that denial was a common reaction to a USH diagnosis, which could further interfere with getting the appropriate supports to help with postsecondary preparation.

Research Question 3

Responses to the third research question were more congruent, with participants reporting parents as their strongest supporters throughout college preparation. Parents were recognized for being actively involved with the school, providing college preparation support outside the classroom, and advocating for more USH research. These findings align with previous research suggesting that parents, guardians, and family members are the strongest support systems and advocates for students who are DeafBlind (Graves, 2022; Kyzar & Summers, 2014; Zatta & McGinnity, 2016). This also paralleled the findings of McKittrick (2019) that suggested parents are often the most informed members of the IEP team on deafblindness.

Murdoch (2004) recommended that educators and related professionals should work closely with parents, family members, and guardians of students who are DeafBlind. This bodes well with the ecological systems theory in that the microsystem, the system closest to the student, can be the most influential (Bronfenbrenner, 1979, 1992, 2005). Parents, family members, and educators can fall into the microsystem as they interact with the student daily or weekly, especially when educators or professionals work with a student for long periods, say a year or more, they may have more influence and can make a greater impact on the student, positively or negatively.

Hetherington et al. (2010) found that parents of students with disabilities were dissatisfied with educators around the transition planning process, particularly in the following areas: “(1) inadequate communication from school staff; (2) frustration with assumptions made about the student; (3) funneling of the student into traditional adult service programs; and (4) a lack of accountability from the schools” (p. 1). Similar to that study, parents, families, or guardians of participants in this study often supplemented transition services.

Parents in this study provided transition supports by making connections with adult service agencies, finding USH specific resources, and more. Barnhill (2021) found that out of 45 DeafBlind youth, only 20% were connected to adult service agencies through their school. This aligns with the participants’ reports that their parents were the ones to connect them to adult service agencies. Arndt (2010) also suggested that parents or family members often influenced college success.

Additional Themes Interpreted through Ecological Systems Theory

Aside from the research questions, additional themes emerged from the participant-led discussion. These additional themes include: (a) discrepancy in Deaf/Hard of Hearing and vision services; (b) the multifaceted impact of USH; and (c) navigating the medical diagnosis. Participants also provided insights into their individual life spaces or ecological systems as it related to postsecondary preparation. This section describes these results through the lens of Bronfenbrenner's ecological systems model to discuss relationships, environment, societal structures, culture, and time frame across the five ecological systems (Bronfenbrenner, 1979).

Microsystem

The microsystem refers to direct relationships with the people closest to you on a daily basis. These can include parents, siblings, and teachers. For the most part, participants found the greatest postsecondary preparation support to be from their parents. This reflects prior research that parents or guardians are often the biggest supporters of students who are DeafBlind (Kyzar & Summers, 2014; McKittrick, 2019; Murdoch, 2004).

However, for one participant, she did not share the same language as her parent. Liz shared in her reflective prompt that her relationship with her mom was difficult, but she did have support from her siblings. Her siblings did learn some sign language, while the mother did not. It is very common for hearing parents to not learn sign language (Dutra, 2020). Liz explained that her mother did not believe she could be successful with a degree from a Deaf college and, therefore, did not support her goal of attending a historically Deaf university. This disagreement led Liz to move out of her home, break ties with her mother, and file independently for financial aid. This is possibly why Liz’s teacher of the Deaf took on such a strong role in her life, helping her with the college application process and even helping her move into her dorm, which is above and beyond the role of a teacher of the Deaf or a transition specialist. While most participants had parents who supported their goal to attend postsecondary education, there was one outlier, which could have been the result of a language barrier and parental expectations.

Mesosystem

The mesosystem can be considered an extension of the microsystem involving teachers, peers, and family. This can also include peer relationships within a school or in a community. Within this participant group, there were sentiments of struggling to fit in with peers.

The majority of these participants attended mainstream schools and general extracurricular programs such as Boy Scouts or sports teams with able-bodied peers. There were themes of trying to fit in with these peers and avoiding anything that would make them seem different. Most of the participants in this study did not use a white cane during their K-12 education. A few participants added that the cane was a visual representation of blindness, which they were not ready to accept in front of their peers. Other participants chose to cover their hearing aids or cochlear implants with their hair or large headphones. Adrian shared, “It’s awkward . . . most people don't even know that I'm hard of hearing until I tell them,” which led to episodes of trying to “pass” as a person without dual sensory loss. Some participants said it was easier than having to constantly explain about USH. Evans and Baillie (2021) also found this to be true among USH participants--that it seemed easier to try to pass than disclose, especially since USH can be easily overlooked (Ellis & Hodges, 2013).

Additionally, a few of these participants experienced losing or never getting their driver's license, which made them feel left out but also dependent on their friends who were driving. One participant shared that she would do anything to have a car, not necessarily to be “normal” but to have the freedom to travel. These scenarios of feeling different from peers can also impact identity.

The group varied in how they identified when it came to deafblindness. Some chose to embrace it, while others preferred not to make USH a large part of their identity. Jeff commented, “Disability plays a part in it, but for some people, they may say it's a bigger part of their identity than it is for other people.” With that, some of the participants sought out others with similar life experiences, while a few chose not to have USH be a large part of their identity, leaning almost into denial and avoidance of USH for two participants. Those who sought out same-aged peers with USH found it difficult, likely due to the rarity of USH. The participants mentioned that they did not have mentors, which they felt could have been helpful. But, they were willing to be mentors for others.

Exosystem

The exosystem can include social structures such as government agencies, healthcare, and more. In this study, the exosystem focus appeared to be on healthcare systems, their lack of knowledge of USH, non-existent screening processes, and lack of resources. Without specific knowledge in USH, many of the participants were unaware of their full diagnosis until adolescence. As Jeff noted, he did not request or receive any vision-related services because he did not know he had USH until age 22. Then, trying to get vision services after graduating through a vocational rehabilitation agency proved difficult in that Jeff has no experience in this area.

Had better resources and screening processes been in place, some of these participants who went in for regular check-ups could have been diagnosed earlier with USH instead of learning about it in their 20s. For example, Maxine was misdiagnosed with different conditions until finally, at age 23, she learned she had atypical USH. Luckily, she was able to get accommodations for the symptoms she had, but she was not able to truly understand her diagnosis until she was already in college. Additionally, as many participants mentioned, there are limited resources when it comes to USH. This reflects findings in Ellis and Hodges interviews (2013) in which a participant commented that if she was diagnosed with something common like diabetes, then there would be resources, specialists, and systems in place to support her. With the rarity of USH, participants agreed that resources and supports were limited.

Macrosystem

The macrosystem refers to a society's overarching values, such as views on disability in the U.S. Many participants in the group had negative experiences of being treated differently because of their disability. For example, Zach shared that he never felt his swim coach treated him the same as his able-bodied peers, and this is after he quit baseball for lack of accommodations for his vision loss. Other participants shared similar stories of not being treated equally, along with becoming tired of having to constantly explain their diagnosis and needs to others who could not quite understand what it meant to be legally blind but have some vision. These sentiments align with the critical DeafBlind theory (Shariff, 2015) in that those with dual sensory loss can often encounter negative societal attitudes and misunderstandings.

Some participants added that views of disability or disability culture could also depend on the environment, such as being in a mainstream high school versus a historically Deaf college. Dereck found that instructors were much more understanding of his needs at a college that often worked with Deaf students. The requests were different, but the concept was the same. For a similar reason, Maxine was thinking about changing her major from paralegal to disability studies so that she could be in a more welcoming environment as well as potentially increase her odds of getting a job as a person with dual sensory loss and additional disabilities. Natalia also felt that it could be easier for her to get a job within an organization that serves people with disabilities and has a positive disability culture. These choices seem to be related to avoiding negative societal views on disability along with misunderstandings.

This seemed especially true when it comes to persons who are legally blind searching for employment opportunities with employers who may worry about their ability to commute to work, complete the necessary job tasks, and more (McDonnall & Antonelli, 2018). As Natalia commented, her job search was frustrating because many jobs required a driver's license, even when driving was not part of the job, meaning that she could not apply due to her vision loss which prevented her from getting a driver's license. Historically, persons with blindness or vision loss have been underemployed in the U.S. (Bell & Mino, 2013; McDonnall & McKnight, 2021). A few of the participants in this group did share their fear for the future if they were to lose more vision as they felt it could make it more difficult for them to work, travel, and live independently. Among these participants, it seemed that adapting to hearing loss was easier than vision loss. For hearing loss, they already created systems and knew how to get what they needed. But when it came to vision loss, there was far more trepidation. This theme coincides with those of the study by Andrade Figueiredo et al. (2013) that found over half of their 11 participants with USH were more worried about vision than hearing loss. This could be because of their own perceptions and experiences or societal views and barriers as a person with blindness or low vision in the U.S.

Chronosystem

The chronosystem refers to a time period or changes over time. In this study of college students aged 18-27, these participants were born at the cusp of the implementation of the universal newborn hearing screening in the U.S., meaning that all but one were diagnosed with hearing loss at or shortly after birth because of the required screening. This early identification of hearing loss allowed many of the participants to receive early intervention services such as speech therapy, learning how to use hearing aids, and more. As they were not yet diagnosed with vision difficulties due to the delayed progression and without a USH screening to provide a full diagnosis, this could possibly explain why most participants received more D/HH services in K-12 education.

Additionally, this group was raised at a time in which there was greater access to cochlear implant technology (Nelson & Bruce, 2019). While only 3 of the 10 participants had cochlear implants, the discussions about cochlear implants in this study aligned with the National Center on DeafBlindness (NCDB, 2013, 2023) child count data that the use of cochlear implants is quickly increasing. For example, the NCDB report found that the use of cochlear implants quadrupled from 2005 to 2012 and then increased from approximately 9% in 2012 to 13% in 2022 (NCDB, 2013, 2023). Having early intervention D/HH services and access to assistive listening technology at a young age could possibly explain why most of the participants in this study preferred speech (90%) over sign language (10%).

Further, researchers have noted that students with USH have moved away from specialized schools for the Deaf and have been attending more mainstream schools (Ellis & Hodges, 2013; Nelson & Bruce, 2016). This means that instead of Deaf peers who could be using sign language, these students are now more likely to spend time with hearing peers using speech. This could further encourage youth with USH to use speech over sign language.

Lastly, access to technology appeared to change how participants could be accommodated in this study. In the past, high contrast and large print materials would need to be printed on a large copier with colored paper per assignment (Ingraham, 2007). This could become burdensome and not always happen in time to meet the needs of the student. This group of participants attended K-12 education at the time when iPads were available and could be used to adapt electronic materials individually. Removing the need to rely on an educator or other person to enlarge the materials. The use of an iPad for these purposes does require training. Lily explained how her TVI showed her how to make these adaptations, and it made getting educational materials so much easier for her, a skill that she took with her into college. Overall, this change from low-tech to high-tech accommodations is interesting to note within the time period in which these participants prepared for postsecondary education.

Relation of Findings to Previous Research

As an exploratory study, there was limited research to compare findings on the transition and postsecondary preparation experiences of youth with USH. However, there have been four prominent research studies on the experiences of college students who are DeafBlind using qualitative design: (1) a case study of a college student who had acquired deafblindness due to illness (Bourquin, 1994); (2) a study that included in-depth interviews of 11 deafblind college students in ASL or TASL (Arndt, 2010); (3) a study that examined the experiences of two deafblind college students through questionnaires, interviews in ASL, and observations (Wolsey, 2018); and (4) a dissertation study which investigated the college preparation and transition experiences of congenitally DeafBlind college students using dyadic interviews with five students and their parent or family member (Graves, 2022). Among these four studies, there were some overlaps in findings.

With Bourquin's (1994) study, the common theme was the willingness of educators to "bridge traditional roles" and use individualized person-centered planning to best support students with deafblindness (p. 37). This was evident with the participant Liz who had a teacher of the Deaf take on additional roles to support her unique transition needs. Additionally, Arndt (2010) recognized the need for educators to become knowledgeable in deafblindness. Educators' lack of knowledge around deafblindness and USH was very apparent in these participant responses, suggesting a need for education and training. Results from this study also align with Wolsey's (2018) suggestion that students who are DeafBlind could benefit from learning how to advocate for themselves in terms of accommodations and supports. A couple of the participants shared about learning self-advocacy skills from the teacher of the Deaf and their parents.

However, the above studies focused on experiences of being a college student with deafblindness in the U.S., not specific to USH, with little to no mention of postsecondary preparation (Arndt, 2010; Bourquin, 1994; Wolsey, 2018). Additionally, the characteristics of this study differ from those of Arndt (2010) and Wolsey (2018) in that subjects in their studies primarily used ASL or TASL to communicate. In contrast, the majority (90%) of participants in this study used speech. Arndt (2010) and Wolsey (2018) acknowledged a need for future research in transition planning, including college students with deafblindness who use language modalities other than ASL or TASL to better understand different experiences related to varying forms of dual sensory loss.

With that, this study is more closely related to Graves' (2022) study which investigated retrospective college preparation and transition planning with a sample of congenitally

DeafBlind college students, who were mostly speech users (90%). There was also one participant who had USH. Graves (2022) used dyadic interviews with five students and their parents or family members to develop themes around educational and social experiences while in college and, retrospectively, when preparing for postsecondary education. Some of Graves' (2022) resulting themes described current college experiences, experiences of being bullied, and a strong connection to the DeafBlind or disability community which were not strong themes in this study. At the same time, there were many similar results, including several overlapping themes:

1. On-going support of a lone educator.
2. Missing or inappropriate accommodations.
3. Aspects of self-determination and self-advocacy.
4. Parents and family being a strong support system.
5. Lacking college skills such as time management, organization, and academic writing.
6. Need for more research into the effects of mentorship.

Although the ongoing support of a lone educator was only evident with one participant in this study, it was also present in Graves' (2022) study that a lone educator can grow with the student providing ongoing support even after they graduated from high school. With Liz, her TOD helped her to move into her dorm and stayed in touch with her while she was in college. An educator in Graves' (2022) study also contributed greatly to the transition process and "continued to provide guidance and assistance to her and her grandmother after she had left the educational system" (p. 121). In brief, these lone educators were an essential part of the support system that helped prepare them for college, especially when most educators lacked support and knowledge about deafblindness.

Many participants expressed frustrations about missing or inappropriate accommodations (Graves, 2022). In some cases, this led to increased self-determination and/or self-advocacy experiences for both sets of participants. Interestingly, in this study, Natalia stated that she was not taught how to advocate for her low vision accommodations. Still, the skills she learned from her TOD to ask for certain accommodations for her hearing loss were a good transferable skill for her to any area of advocacy. Lily also noted that her mother acted as a role model of advocacy. She eventually learned to make requests independently, such as setting up her own accommodations.

A strong sense of support from parents and family members regarding college preparation was evident, along with the holistic view of preparing for life after graduation (Graves, 2022). One parent in Graves' (2022) study developed a peer SSP program to help her son have more peer interaction during high school social activities. One of the parents in this study started a foundation for USH research for their daughter's specific gene. Overall, parents and family members were very involved in these participants' transition experiences and college preparation.

Both this study and Graves' (2022) examined the most beneficial K-12 educational supports that helped with college preparation, and interestingly, the answers were almost identical. Participants in both studies commented that learning time management, organization, and academic writing skills seemed to be the most beneficial K-12 supports for college preparation. This also included experiences with learning about disability rights and self-advocacy skills to independently request appropriate accommodations. Even if the participant in this study did not receive training in these areas, these topics were noted as beneficial from their current perspective of being a college student.

Additionally, this study and Graves' (2022) found that these college students lacked peer mentorship opportunities. Most of the participants in both studies expressed that they were in a position to become a mentor but did not have a mentor themselves. Still, they expressed the perceived benefits of having a mentor who is DeafBlind to help them navigate their transition from high school into college (Graves, 2022). Shariff (2015) also discussed the perceived benefits of DeafBlind mentors representing success, how to live independently, that it is okay to be DeafBlind, and that they are not alone. To quote one of Shariff's participants,

> Understanding that I have Usher syndrome made me think that I had no future. I didn't think I could get a job. I didn't think I would be able to have friends. I kept thinking of things that I thought would be impacted or that I would have lost by having Usher Syndrome. And then, I met my mentor. He had Usher Syndrome, also. He resided in the same state where I lived in Ohio, and he had earned a Ph.D. But he was a man who was completely Deaf and fully blind, and when I met him, he told me that I could be successful. He advised me to go to college and to learn to travel with a cane and to learn braille. . . . He mentored me by telling me how to prepare for my future. . . . Looking back at the situation, I now realize that he was right. Being DeafBlind does not mean the end of the world, NO! DeafBlind people can live independently. His impact upon me was so great because he was fully Deaf and fully blind, yet he lived completely independently. (Shariff, 2015, pp. 208-209)

In other disability areas, mentorship can be seen as a predictor for post-school success as it can enhance disability knowledge, self-confidence, and parent's perceptions of their child's abilities (Powers et al., 1995). In the field of deafblindness, there is limited research in this area. Pleet-Odle et al. (2016) suggested that introducing DeafBlind youth to DeafBlind mentors and role models who are successfully employed in different types of jobs can positively impact both youth and parents. Connecting with DeafBlind consumer groups and family organizations is one way youth can meet mentors (Bruce & Parker, 2012). However, Ellis and Hodges (2013) found that just having the same disability or etiology as another person did not make for an instant role model. Participants preferred to speak with people close to them in age with similar life experiences, preferably a peer mentor. Outcomes of peer mentorship on transition outcomes concerning college success in students with DeafBlindness have yet to be studied. Additional research is needed to better understand the benefits of peer mentorship on transition outcomes and postsecondary preparation for students who are DeafBlind, including those with USH.

Implications for Practice

Findings from this study provide implications for practice for educators, professionals, and families, including: (a) promoting earlier diagnosis through advanced USH screening processes; (b) creating resources for medical professionals; (c) the importance of individualized transition planning and postsecondary preparation; (d) having a DeafBlind specialist on the educational team; and (e) recognizing that the USH population is evolving. This section will describe each area in more detail.

Promoting Earlier Diagnosis Through Advanced Usher Syndrome Screening Processes

A unique aspect of this study was that it focused on one generation of youth with USH. Since this was a time-bound study, these participating college students (ages 18 to 27) experienced certain chronological phenomena that made them different from other individuals studied in the past. For example, the participants in this study were born around the same time that the universal newborn hearing screening was implemented in the U.S. Consequently, all but one of the participants was identified with hearing loss at or shortly after birth due to the newborn hearing screening.

Participants in this study who were diagnosed at an early age appeared to have more specialized educational programming, such as related services for hearing and vision loss, that could lend itself to individualized transition services. Yet, many participants also experienced a sense of denial, grief, and time needed to accept the ever-changing condition of USH. For those with a later diagnosis, it seemed harder for them to redefine who they were after years of living with the identity of a person with just minor hearing loss. For example, participants who had been diagnosed earlier appeared to have a better understanding and attitude towards USH as well as the ability to advocate for themselves as their needs changed with the progressive condition. These individuals and their parents were able to seek out resources and outside agencies to further validate and support their journey. As Crawford noted, “An early diagnosis is important to ensure education, strategies, and coping mechanisms are used to enhance the individual's life chances and maximize their potential" (2018, p. 18). Without a proper diagnosis, it can be difficult to engage in disability-specific transition planning and postsecondary preparation (Bruce & Borders, 2015) in addition to physical therapy, mental health, and other supports (Castiglione & Möller, 2022).

To promote earlier diagnosis, further measures could be taken to ensure that infants who fail the universal newborn hearing screening automatically undergo additional assessment or genetic testing for USH. The Joint Committee on Infant Hearing (2007) recommended that all infants with confirmed hearing loss receive an evaluation by an ophthalmologist, but it is not clear how often this is practiced. Blumsack (2009) commented that due to the rarity of deafblindness and lack of training, most primary care physicians may be knowledgeable about screening for one sensory loss, but not both vision and hearing. Also, it may be too early to screen for physical signs of visual impairment, hence the benefits of genetic testing for USH for early diagnosis in conjunction with detection through newborn hearing screening (Kimberling et al., 2010).

Further, schools for the Deaf or schools for the blind could also take it upon themselves to screen for USH, as these students might be more likely to have dual sensory loss. The Kansas State School for the Blind partnered with the Helen Keller National Center and other organizations to create a screening tool for USH (Houghton et al., 2016). Using or adapting such a tool at other state schools could have great potential for identifying students with USH at a younger age. The younger they are diagnosed, the more services they can receive to help them prepare for transition and college (Castiglione & Möller, 2022).

Creating Resources for Medical Professionals

One thing that all the participants had in common was receiving a USH diagnosis from a medical professional. In this sense, the medical professional was the "first point of contact." Medical professionals should be able to refer the student and their parents to appropriate resources, but that is not always the case. An implication of this study is to not only train educators and related service providers, but also to bring awareness to medical professionals. Blumsack (2009) suggested that primary care physicians are generally unaware of appropriate referrals and resources related to dual sensory loss.

Perhaps by way of the National Center on DeafBlindness, a federally funded organization that services children and youth who are DeafBlind (birth to 21), could create written materials such as brochures, fact sheets, resource lists, etc. For example, visiting a doctor's office and picking up a brochure on diabetes, this strategy could potentially aid medical professionals in referring newly diagnosed USH patients to organizations that could provide additional information on USH networks and make them aware of available services. Further, individual state DeafBlind projects that fall under the National Center on DeafBlindness could also reach out to major medical centers in their states. This could lead to another initiative to help with the early identification of children with USH so that they could receive services earlier in their lives.

Importance of Individualized Transition Planning for Postsecondary Preparation

Previous research on deafblindness suggests that the transition planning provided to DeafBlind youth may not be sufficient in supporting their unique needs (Petroff et al., 2019). The transition plan is mandated for eligible students with a disability before they become 16 years of age (Morningstar & Clavenna-Deane, 2018). Zatta and McGinnity (2016) emphasized the importance of an individualized transition plan for students with deafblindness to focus on their preferences, strengths, and abilities. Ferrell et al. (2014) recommended that the IEP transition planning be based on person-centered planning. Crudden (2012) also agreed that transition planning should be student focused. The OSERS also suggest individualizing transition plans while including measurable post-school outcomes, necessary school activities, community agency involvement, and educator responsibilities with student and family input (OSERS, 2020). The transition plan should also evolve with the student as it will follow a student until they graduate or age out at the terminal age for graduation, varying from 21 to 24 in different states (OSERS, 2020).

The transition plan is meant to be a guide in which students can plan their goals post-graduation. Without a robust transition plan, it could be difficult to ensure that the necessary steps are taken to set students up for post-graduation success (Zatta & McGinnity, 2016), not to mention the challenge of customizing the transition plan for students with dual sensory loss when educators are unaware of how to address the unique needs of this population (Correa-Torres et al., 2021). The reauthorization of IDEA (2004) mandated the transition plan to foster positive post-school outcomes for students with disabilities, including postsecondary preparation.

Historically, students with disabilities have struggled to transition from high school to adulthood (Poirier et al., 2022; Wehman, 2013). An emphasis on transition services was added to IDEA in 1990 to mitigate the issue of students with disabilities achieving fewer post-school outcomes than their peers without disabilities (Morningstar & Clavenna-Deane, 2018). Yet students who are DeafBlind were still reported as one of the highest at-risk disability groups for not transitioning successfully out of high school (Lipscomb et al., 2017). At the same time, the rate at which students with disabilities are applying to higher education is increasing (Dangoisse et al., 2020; Newman et al., 2011). Postsecondary education is considered a pathway to improved overall quality of life, including financial stability, self-worth, social networking, and more (Ma et al., 2019). Newman et al. (2011) found that students with vision or hearing loss were more likely to enroll in postsecondary education than other students with cognitive or multiple disabilities. However, as there was a limited representation of DeafBlind youth in the NLTS2 data, the postsecondary outcomes for those with both hearing and vision loss were inconclusive. (Newman et al., 2011). Furthermore, it is difficult to identify how many DeafBlind students are currently attending college (Graves, 2022) to better understand the rates at which DeafBlind students who wish to attend higher education are given the opportunity through proper transition supports.

Having an individualized transition plan should be the best practice, yet none of these participants recalled having or working with a transition plan. Perhaps utilizing a national organization such as the National Center on Deafblindness (NCDB) or the Helen Keller National

Center (HKNC) to centralize transition planning training and collaboration through the state, a DeafBlind specialist could further promote robust transition services for young adults with USH. Future research is needed to better understand the quality of transition plans written for students with USH. Further, research including transition plans and IEP documents would be beneficial.

Having a DeafBlind Specialist on the Educational Team

As mentioned above, it is well known that most educators are not adequately trained in working with students with deafblindness, let alone USH specifically (Blaha et al., 2009; Correa-Torres & Bowen, 2016; Nelson & Bruce, 2016). Being that deafblindness is a low-incidence disability (Newman et al., 2011), it would be unrealistic to train every general educator in the U.S. to work with this population. There are a few university-based programs that offer teaching endorsements, certificates, and coursework in deafblindness (Parker & Nelson, 2016), but most states do not recognize these endorsements, and there is a limited number of Teachers of the DeafBlind (TDB) or DeafBlind specialists (DBS) available (Bruce et al., 2018; Landa-Vialard et al., 2018; Parker & Nelson, 2016)

However, if early identification led to a referral to the student's state DeafBlind project, a DeafBlind specialist assigned to one state could follow the student throughout their educational career through elementary, middle, and high school. Although related to vocational services, McDonnall and Cmar (2019) supported having a designated state-wide DeafBlind coordinator if the DeafBlind population is too small to elicit multiple DeafBlind specialists. This way, an individual with specialized training in deafblindness could join the educational team as a consultant. This could aid in filling the gap of disability-specific knowledge that would help provide the appropriate accommodations, resources, and referrals to transition and postsecondary preparation services (Ferrell et al., 2016). In addition to the “hard skills,” such as recommending resources, DeafBlind specialists are familiar with the “soft skills” of working with students who are DeafBlind, including an understanding of the emotional impact of dual sensory loss. DeafBlind specialists who are connected to a network such as a state DB project can offer to introduce students to others with similar life experiences along with community organizations to promote mentorship opportunities. Additionally, DeafBlind specialists can bring in state vocational rehabilitation agencies that serve youth with sensory loss to ensure maximum services are offered to ensure post-graduation success, filling the gap between school and post-school supports.

Recognizing that the Usher Syndrome Population is Evolving

This sample of college students (ages 18 to 27) was born on the cusp of the implementation of the universal newborn hearing screening in the U.S. (JCIH, 2000). All but 1 of the young adults in this study were diagnosed with hearing loss at or shortly after birth. Nine out of 10 participants were fitted with hearing aids or cochlear implants and given speech therapy, provided with early intervention, and/or D/HH services to address their hearing loss using an F.M. system, preferential seating, or captions. Most of the participants in this study were speech users who used hearing aids or cochlear implants to access information in the classroom. Following generations will be born into a time where screening for hearing at birth is universal in the U.S.

With approximately 90% of Deaf children being born to hearing parents, who are likely to be unfamiliar with Deafness and ASL (Mapp, 2004), more students may go into the school system with cochlear implants or hearing aids. According to the National Center on DeafBlindness annual child count data, the use of cochlear implants quadrupled from 2005 to 2012 and then increased from approximately 9% in 2012 to 13% in 2022 (NCDB, 2013, 2023).

This upward trend could affect how instruction is best received through individualized accommodations. Many students in this study recalled being given an ASL interpreter as accommodation even though they were not fluent in ASL. This could also elicit a need to promote a bi-lingual/bi-cultural approach with parents to provide more choices for young students (Drasgow, 1993). For example, a few participants grew up in the hearing world using speech, then later found that as their hearing and vision loss progressed, they felt it was too late to learn ASL to attend social events and be part of the Deaf community. Nevertheless, the population of students with USH is changing, and educators and professionals should be prepared to address the unique needs of these future generations of youth with USH.

Limitations

While the findings of this study uncovered important insights related to the transition and postsecondary planning experiences of youth with USH, some limitations must be considered for future research. The first limitation was the study did not properly answer the research questions. As a researcher without the lived experience of someone with USH who transitioned from high school into college, I wrote research questions to examine the participant’s transition experiences from an educational and rehabilitative perspective. Having knowledge of IEPs and transition plans mandated by IDEA (2004), I assumed that the participants in this study would have transition planning and postsecondary preparation experiences to share. Surprisingly, the participants did not recall many K-12 transition supports or services for postsecondary preparation. Thus, the participant-led discussion moved toward other topics, such as interactions with medical professionals, navigating the diagnosis, and the multifaceted impacts of USH. In retrospect, having more open-ended research questions about transition and postsecondary preparation experiences may have been better suited for an exploratory design. Although some findings in this study were not directly related to the research questions, they still provide additional insights into the transition planning and postsecondary preparation experiences of youth with USH.

The second limitation was minimal responses to the reflective prompts. This may have been due to the construction of the reflective prompt questions. For example, one question asked, "What additional comments would you like to make after the interview/focus group?," and the common response was "none" or "no thanks." When provided with follow-up, the answer was the same, or no response was received. This provided insight into the process of creating and using more dynamic reflective prompts or setting up a follow-up time on Zoom to elicit a better response rate. In sum, it was easier to obtain reflections from the participants while connected via Zoom than it was to elicit a response via email with vague questions. In future studies, this reflection time could be built into the anticipated schedule so as not to appear to be an extra commitment to participants.

The third limitation was bots hacking the screening survey. Bots are automatic survey-takers that pose a risk to collecting data via online surveys as they auto-fill responses to receive survey incentives such as gift cards (Storozuk et al., 2020). While searching for a very specific sample of college students with USH between 18 and 30, the expected response rate was anticipated to be very low (> 30). Yet, the response rate was in the thousands. Fortunately, this was only the screening survey, so data were unaffected. Yet, it was very unfortunate for the recruitment process as some possible candidates could have been lost in the thousands of automated responses. At least from this experience, I built my surveys to be more resilient to bots. I used the built-in bot prevention features offered by Qualtrics that flag multiple submissions, duplicate IP addresses, and more (Qualtrics, 2024). For my second wave of recruitment, I learned not to advertise incentives, especially on social media platforms where bots can more easily discover them via search engines (Pozzar et al., 2020). Additionally, Chandler and Paolacci (2017) found that the higher the incentive, the higher the fraud. Once I identified participants, I set up a private survey link that only they could access via their email address. I also used custom passwords for survey links sent to certain organizations to avoid using CAPTCHAs, which can be problematic for screenreader users. Screen readers are assistive technology that can interpret visual elements on a computer screen and translate them into speech or refreshable braille, which can get stuck on CAPTHAs (Gauvreau, 2017). Principally, those that ask to identify something visual, such as traffic lights in an image, which may not be described to the screen reader can, therefore, limit access when the task to verify that you are a human cannot be completed. In sum, prevention measures seemed to be the key to detecting, blocking, or avoiding bot responses.

The fourth limitation was not including a question on socioeconomic status in the demographic form, as this would have provided more information about the participants' backgrounds. At the time, I was unsure about asking students about their parent's income, thinking perhaps they were unaware or would need to ask their parents and, possibly, creating a small hurdle in completing the demographic form. However, having access to the socioeconomic status of these students while living at home with their parents would have helped in understanding their access to services and supports outside of the K-12 educational setting that could have impacted their transition planning and postsecondary preparation experiences.

The fifth limitation is related to the homogeneity of the sample. While there was representation from eight different states across different universities, most of their educational institutions were considered mainstream, meaning that some of these findings may not apply to students preparing to attend a culturally Deaf university where faculty and other students use ASL as their primary mode of communication. The majority of the participants were recruited from the Usher Syndrome Coalition. The primary mode of communication was speech (90%), with only one participant using VASL. Most of the participants had a hearing aid or cochlear implant. Additionally, as 80% of the participants identified as White/Caucasian, these results may not generalize to students with USH from culturally and linguistically diverse backgrounds.

Recommendations for Future Research

Recommendations for future research include further investigating the transition planning experiences of youth with deafblindness from more culturally and linguistically diverse backgrounds to learn more about the intersectionality of USH and other factors that may affect college preparation. Culturally diverse backgrounds could include race/ethnicity, sexual orientation, socioeconomic status, parents' education level, communication mode, and more, preferably with a sample larger than 10 participants. Also, research into peer mentorship and mental well-being could benefit USH youth.

Another interesting area of study would be the effect of peer mentorship on post-school outcomes and college preparation. Participants expressed having no peer support and mentorship during college preparation. They may have been the only student in their school with USH, besides perhaps a sibling, and it was difficult to connect with other students at times, given all that was happening with their USH diagnosis. Many of the participants in this study had either younger or older siblings going through a similar experience that could have influenced their college trajectory but was not explored in this dissertation. Exploring the relationship of siblings with USH could also be a beneficial study.

In other disability areas, mentorship can be seen as a predictor for post-school success as it can enhance disability knowledge, self-confidence, and parents’ perceptions of their child's abilities (Powers et al., 1995). In the field of deafblindness, there is limited research in this area. In 2012, Bruce and Parker conducted a participatory action research study on civic engagement and advocacy, which was not focused on peer mentorship but had results that indicated that young adults who had DeafBlind mentors appreciated their role models, looking up to them as examples of what they could achieve in the future. As Graves (2022) mentioned, there is limited research on DeafBlind peer mentorship, and further research could lead to another possible support system that could help students navigate the transition from high school into college.

Lastly, research into the mental well-being of youth with USH could be beneficial to better support young adults with USH, especially in the early stages of their diagnosis. Previous research that focused on adults with USH has found associations with feelings of isolation, depression, anxiety, and low self-esteem (Dean et al., 2017; Hersh, 2013; Mathur & Yang, 2015; Wahlqvist et al., 2016). Further, the emotional state of navigating the life-changing diagnosis of USH can bring on feelings of shock, anger, and sadness (Evans & Baillie, 2021). Participants in this study also expressed feelings of denial and ignoring their diagnosis while trying to pass as "normal" amongst their peers and teachers. Many strong emotions can occur when young adults with USH are trying to figure out their identity and place in the world (Ellis & Hodges, 2013). Research into the mental well-being of youth with USH while in high school could be valuable and provide insight into how to best provide counseling and support for young adults with USH.

Conclusions

Youth with USH can experience unique challenges in transition planning and postsecondary preparation. The invisible characteristics of USH, such as staggered onset of sensory loss, retained central vision, and lack of outward expressions of visual impairment, can place young adults with USH in a precarious situation when it comes to seeking support from educators and professionals for preparing for college and life after high school (Ellis & Hodges, 2013; Evans & Baillie, 2021; Miner, 1997). Research in transition planning for DeafBlind youth is scarce (Zatta & McGinnity, 2016), and studies specific to college preparation for students with USH are practically non-existent. Hence, the impetus for this dissertation study.

Three key themes related to the research questions emerged from this study: (1) limited K-12 educational supports for postsecondary preparation; (2) perceived lack of transition planning and postsecondary preparation; and (3) parents as the strongest support system. As many of the participants in the group received little to no transition planning or postsecondary preparation, this led to the emergence of three additional themes: (4) discrepancy in Deaf/Hard of Hearing and vision services; (5) the multifaceted impact of USH; and (6) navigating the medical diagnosis.

Implications for practice for educators, professionals, youth with USH, and families include: (a) promoting earlier diagnosis through advanced USH screening processes; (b) creating resources for medical professionals; (c) the importance of individualized transition planning and postsecondary preparation; (d) having a DeafBlind specialist on the educational team; and (e) recognizing that the USH population is evolving. Future research is recommended in peer mentorship and mental well-being among USH youth, including more diverse populations of USH youth, along with parent insights to generate a greater understanding of their transition planning and postsecondary preparation experiences.

Through purposeful sampling, this distinct group of participants provided “rich thick descriptions” of shared experiences that can transfer across individuals with USH, such as the acceptance of dual sensory loss or navigating with the medical diagnosis (Palinkas et al., 2015, p. 10). In conclusion, the results of this study are beneficial as they can be transferable to similar populations. Further, the results of this study can also be used to inform future evidence-based research. In conclusion, the findings of this study can add to the limited body of research on the lived experiences of transition-age youth with USH preparing for postsecondary education.

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APPENDIX A

RECRUITMENT POST

UNIVERSITY OF
NORTHERN COLORADO

- ✓ Are you a college student with Usher Syndrome residing in the United States?
- ✓ Would you like to share your experiences of transition planning and preparing for college while earning a **$25 Amazon Gift card**?
- ✓ If you are interested, go to survey link ____________ to learn more about participating in this online study.
- ✓ This study will include an interview about your transition experiences from high school into college and a small focus group with other college students online.

Please reach out if you have any questions about being a part of this study. I would love to learn from you.

Tara Brown-Ogilvie
Doctoral Student
School of Special Education
University of Northern Colorado

APPENDIX B

INCLUSIONARY CRITERIA QUALTRICS SURVEY

Thank you for considering being a part of this study. Please answer the following questions to find out if you are eligible to participate and earn a $25 Amazon gift card!

1. Are you currently enrolled in a college or university in the United States?
2. Have you been diagnosed or self-report as having Usher syndrome?
3. Are you between the ages of 18 and 30?
4. Do you have around 3 to 4 hours to commit to this study?

(If answer NO to 1-4 will be given a message that they do not qualify)

(If answer YES to 1-4 will be redirected to the consent form with disclosures)

Congratulations! You qualify to be a part of this study, please answer a few more questions so we can reach out to you to get started.

5. What is your first and last name?
6. What is your email address?
7. What is your Phone/Video Phone number? (Option for text only)
8. What is your preferred communication mode? (Visual ASL, Tactile ASL, English, PSE, Other-Fill in)
9. Preferred form of contact? (Email, phone, text)
10. What days and times are best for you to participate in an initial interview? (Clickable options for Monday-Sunday and then a clickable option for Morning/Afternoon/Evening)
11. Any accommodations requests for the Zoom interview? (ASL interpreter, captions, other).

APPENDIX C

CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH

Project Title: Reflecting on the Transition Planning Experiences of College Students with Usher Syndrome

Researcher: Tara Brown-Ogilvie, Ph.D. Student, School of Special Education

Research Advisor: Dr. Silvia Correa-Torres

The purpose of this study is to learn from college students with Usher syndrome (USH) about their lived experiences of transitioning from high school into college and their postsecondary preparation in order to provide insights for future research and educational practices.

Procedures: Through participating in this online study, you will have a chance to share your experiences and perceptions on your transition experiences to guide future students with USH. Participation will include:

- Individual Interview (45-60 minutes)
- Focus Group (60-90 minutes)
- Responding to reflective prompts via email (30 min)
- Providing feedback on transcripts and the research process for improved accuracy (30 min)
- Completing a demographic questionnaire and related paperwork to consent to the study (15 min)

The one-on-one interview will take place online through video conferencing software for ease of communication in American Sign Language (ASL). The focus group will also be through video conference with other participants from across the United States. All interviews and focus groups will be recorded, including visual and audio content, and saved to a password protected OneDrive account that will only be accessible to the researcher and research advisor. Accessibility measures will be considered and implemented by request (ASL interpreting, captioning, etc.). Additionally, the reflective prompts will be open-ended questions sent via email for a written response. There will also be the option of meeting over the phone or online to discuss directly.

Demographic information will be requested and aggregated (i.e., ethnicity, age, etc.). Personal information will not be disclosed (e.g., name, contact information, university affiliation, etc.). All data collected from this study will be saved onto a password protected hard drive that will only be accessible to the researcher and research advisor for the purposes of this study. Additionally, pseudonyms will be given to provide confidentiality of participants' responses.

Risks to you are minimal. You may feel anxious about sharing your stories with others, but the names of schools, educators, and such will not be presented in the final results of the study. The goal is to gather similar experiences in order to make improvements in transition planning for students with USH. The benefits of participating in all aspects of this study include meeting others who have gone through similar life experiences and a $25 Amazon gift card, to be given at the end of the study via email.

Participation is voluntary. You may decide not to participate in this study and if you begin participation, you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Please take your time to read and thoroughly review this document and decide whether you would like to participate in this research study. If you decide to participate, your completion of the research procedures indicates your consent. Please keep or print this form for your records.

Questions: If you have any concerns about your selection or treatment as a research participant, please contact Nicole Morse, Office of Research & Sponsored Programs, University of Northern Colorado, Greeley, CO; 970-351-1910 or nicole.morse@unco.edu

APPENDIX D

DEMOGRAPHIC QUESTIONNAIRE

(Qualtrics Survey)

1. Demographic Information
    a. Gender/Identity
        i. Open Comment (ex: male, female, non-binary/third gender, transgender, prefer not to comment, etc.)
    b. Age
        i. Type in age (fill in)
    c. Ethnicity
        i. White (Non-Hispanic)
        ii. Hispanic American
        iii. Asian American
        iv. African American / Black American
        v. American Indian or Alaskan Native
        vi. Native Hawaiian or Pacific Islander
        vii. Other (fill in)
        viii. Prefer not to comment
    d. Etiology (ex: Usher Syndrome Type 1c, USHb, USH 3)
        i. Type of Usher Syndrome
            1. Type (short comment)
            2. Unknown
            3. Prefer not to comment
        ii. What age were you formally diagnosed with USH?
            1. Type in age
    e. Other Disabilities (ex. ADHD, Autism, Anxiety)
        i. Type in (short comment)
        ii. Prefer not to comment
    f. Do you use assistive listening devices or equipment, If yes, what kind? Select all that apply:
        i. Bilateral hearing aids
        ii. Hearing aid
        iii. Cochlear implant
        iv. FM system
        v. Bone conducting headphones
        vi. Other (fill in)

   g. Do you use a mobility device? Select all that apply:
      i. White cane
      ii. Dog guide
      iii. Identification cane
      iv. Other (fill in)
   h. Do you wear corrective lens?
      i. Yes/No
      ii. Other (fill in)
   i. How would you describe your vision and hearing? Such as visual acuity, decibel level, field loss, tunnel vision, night blindness, other?
      i. Large open comment (short essay answer)
2. Class year in college (drop down)
   a. Freshman
   b. Sophomore
   c. Junior
   d. Senior
   e. Other (type in)
3. Student Status
   a. Part-Time
   b. Full-Time
   c. Non-Traditional
   d. Other (type in)
4. What year did you graduate from high school?
   a. Type in answer
   b. Prefer not to comment
5. What year did you start college?
   a. Type in answer
   b. Prefer not to comment
6. What would you consider the culture of your university?
   a. Culturally Deaf as in the majority of students, faculty, and staff identity as D/HH and tend to use ASL.
   b. Mainstream/Hearing Culture
   c. Other (type in)
7. What adult service agencies did you connect with in high school? Select all that apply:
   a. Vocational rehabilitation
   b. Commission for the Blind
   c. Independent Living Center
   d. Community organizations
   e. Commission for the Deaf and Hard of Hearing
   f. Developmental Disability Services
   g. Other (type in)

APPENDIX E

INTERVIEW PROTOCOL FOR COLLEGE STUDENTS WITH USHER SYNDROME

1. What are you studying? (major/minor)

2. Where do you live while going to college? In the dorm, off campus, or with family/friends?

    a. How is living on your own while going to college? (Ex: making meals, cleaning, transportation, time management, etc.)
    OR
    b. How is it living with family/friends while going to college? (Ex: making meals, cleaning, transportation, time management, etc.).

3. If you worked with a specialist in high school? Please describe how their support helped you to prepare for college.
    a. Orientation & Mobility Specialist
    b. Teacher of the Visually Impaired
    c. Teacher of the Deaf
    d. Speech Language Pathologist
    e. Other

4. Please describe how your K-12 learning experiences in the following areas helped to prepare you for college.
    a. General Academics (reading, writing, math, science, history, etc.)
    b. Assistive Technology
    c. Communication Access (hearing aids, FM systems, captions, etc.)
    d. Self-Advocacy (Requesting accommodations)
    e. Extracurricular activities (social skills)
    f. Independent Living Skills (cooking, cleaning, budgeting, etc.)
    g. Other

5. If you worked with a transition specialist, guidance counselor, school social worker, VR case manager, or similar professional, how did they help or hinder your postsecondary preparation?

6. Please provide examples of how individuals in your support system seemed encouraging, discouraging, or neutral of your preparation for college?
    a. Parents
    b. Family Members
    c. Teachers or Specialists
    d. Counselors (VR or School)
    e. Peers
    f. Other

7. Please share your experiences related to <u>your personal involvement</u> in your transition planning and college preparation process.
    a. IEP / Transition Planning Meetings
    b. Applying for college

   c. Comparing colleges
   d. Campus visits
   e. Financial aid
   f. Other

8. Please describe <u>your parent, family, or guardian</u> involvement or role with your transition planning and college preparation process.
   a. IEP / Transition Planning Meetings
   b. Applying for college
   c. Comparing colleges
   d. Campus visits
   e. Financial aid
   f. Other

9. Please share <u>your educational team's</u> involvement in your transition planning and college preparation process.
   a. IEP / Transition Planning Meetings
   b. Applying for college
   c. Comparing colleges
   d. Campus visits
   e. Financial aid
   f. Other

10. If you connected with an adult service agency while still in high school, (such as Vocational Rehabilitation, Department for the Blind, Commission of the Deaf/Hard of Hearing, etc.)

    a. How did you learn about these adult service agencies?

    b. How did an adult agency support your transition from high school to college? Please provide examples.

11. How did you learn what accommodations worked best for you? (Ex. notetaker, extended time, braille/large print, etc.)
    Prompt: During high school or college?

12. What has your experience been in getting accommodations from a college disability center versus in high school?

13. Describe a positive experience around your transition planning and postsecondary preparation process.

14. Describe a negative experience around your transition planning and postsecondary preparation process.

15. What would have liked more training or support in while preparing for college?

16. What advice would you give to a student in high school with USH that would like to attend a college or university in the future?

17. Please share other experiences you would like to add about your transition planning and postsecondary preparation experiences.

APPENDIX F

FOCUS GROUP QUESTIONS FOR COLLEGE STUDENTS WITH USHER SYNDROME

Focus Group Questions for College Students with Usher Syndrome (USH)

1. Please introduce yourself briefly by stating your name, name sign (if applicable), and how do you identify in relation to DeafBlindness and USH and why? (ex. include culturally Deaf with Low Vision, DeafBlind, USH II, Blind/HH, etc.)
2. What recommendations do you have for other students with USH who are planning to attend college?
3. What recommendations do you have for professionals to support students with USH in transitioning into college?
4. Please share other comments or experiences you would like to add about your transition planning and postsecondary preparation experiences.

APPENDIX G

SAMPLE REFLECTIVE PROMPTS

Sample Reflective Prompts

(Prompts may change based on interview and focus group outcomes)

1. After completing the interview, what additional comments you would like to make? Or additional topics that come to mind that were not asked?

2. During the focus group, how were your experiences similar and/or different to other participants? Why do you think that is?

3. What else would you have wanted to mention or talk about during the focus group related to transition planning and postsecondary preparation experiences?

APPENDIX H

UNIVERSITY OF NORTHERN COLORADO INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

UNIVERSITY OF NORTHERN COLORADO

Institutional Review Board

Date:	05/24/2022
Principal Investigator:	Tara Brown-Ogilvie
Committee Action:	**IRB EXEMPT DETERMINATION – New Protocol**
Action Date:	05/24/2022
Protocol Number:	2205039020
Protocol Title:	TRANSITION PLANNING AND POST SECONDARY PREPARATION EXPERIENCES OF COLLEGE STUDENTS WITH USHER SYNDROME
Expiration Date:	

The University of Northern Colorado Institutional Review Board has reviewed your protocol and determined your project to be exempt under 45 CFR 46.104(d)(702) for research involving

Category 2 (2018): EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS OF PUBLIC BEHAVIOR. Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7).

You may begin conducting your research as outlined in your protocol. Your study does not require further review from the IRB, unless changes need to be made to your approved protocol.

As the Principal Investigator (PI), you are still responsible for contacting the UNC IRB office if and when:

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Institutional Review Board

- You wish to deviate from the described protocol and would like to formally submit a modification request. Prior IRB approval must be obtained before any changes can be implemented (except to eliminate an immediate hazard to research participants).

- You make changes to the research personnel working on this study (add or drop research staff on this protocol).

- At the end of the study or before you leave The University of Northern Colorado and are no longer a student or employee, to request your protocol be closed. *You cannot continue to reference UNC on any documents (including the informed consent form) or conduct the study under the auspices of UNC if you are no longer a student/employee of this university.

- You have received or have been made aware of any complaints, problems, or adverse events that are related or possibly related to participation in the research.

If you have any questions, please contact the Research Compliance Manager, Nicole Morse, at 970-351-1910 or via e-mail at nicole.morse@unco.edu. Additional information concerning the requirements for the protection of human subjects may be found at the Office of Human Research Protection website - http://hhs.gov/ohrp/ and https://www.unco.edu/research/research-integrity-andcompliance/
institutional-review-board/.

Sincerely,

Nicole Mor

Nicole Morse
Research Compliance Manager

University of Northern Colorado: FWA00000784