Assistive Technology Lifeworlds: Inclusive Qualitative Methodological Innovations for Diverse Bodyminds

by

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ABSTRACT

This multimodal study brought an open, constructively critical challenge to the standard means of process in, and knowledge production from, qualitative inquiry. Using as a context, dyslexia, and the assistive technology lifeworlds of postsecondary students, this study co-partnered with six college students with dyslexia. Co-partnership allowed for an emergence of new awareness that the experience of dyslexia and assistive technology is mediated through innumerable dynamics of interactions with and through the world. Methodologically, the study suggested that it is possible to: (a) situate, center, and validate disability throughout all phases of qualitative inquiry; (b) make the discrete parts of action research more inclusive of disability; (c) reduce physical and intellectual access barriers to qualitative inquiry; and (d) regard as reasonable and rigorous research that is produced by bodies and minds that may not process information in typical ways. Emancipatory action research was used to thread together an understanding of the complexities of self, being, and reality for a marginalized group and how systems, structures, interactions, spaces, and language are superimposed on experiences of disability. The emancipatory spirited study allowed space for co-constructed meaning making through dynamic multimodalities of method including audio-visual data co-constructed through narrative storytelling; an analysis through deep listening and video editing – illuminating 'bright spots' in the broader lifeworld perspective of dyslexia and assistive technology. The innovative co-constructed products of the dissertation were a 2-hour film, a researcher reflection video, professional development guides for assistive technology and qualitative inquiry, and a methods chapter as part of an edited book prospectus. By engaging with this study, the audience will experience consciousness raising with respect to disability experience and witness a reclaiming of the voice of that experience through inclusive research. This study offers a transformative perspective for future work by inviting critical consideration and co-construction of meaning of an expanded conceptualization of assistive technology as an embodied, negotiated experience; and increases awareness that diverse bodyminds offer powerful narratives of diversity in the human condition and why that matters.

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DEDICATION

This dissertation and the result of it is dedicated to innumerous individuals who were either directly or indirectly a part of my academic journey that culminated in me laboring from a position of ‘educational write off’ to a ‘doctor of education.’ There are those who were, without being consciously aware, the catalyst to my resolve to attain a doctoral degree. I am living proof of these words of Wade Boggs:

> Our lives are not determined by what happens to us, but by how we react to what happens; not by what life brings to us, but by the attitude we bring to life. A positive attitude causes a chain reaction of positive thoughts, events, and outcomes. It is a catalyst...a spark that creates extraordinary results.

The professional opinion was that due to standardized testing scores in combination with the way my cerebral palsy and learning disabilities impacted my educational progress and the type of accommodation that would be required to successfully navigate, contribute to and complete postsecondary education, my transition from high school would not amount to more than a vocational certificate of completion and attendance, and a type of sheltered work program. I do not harbor any ill feelings toward this shortsighted view of my potential. I appreciate it, in fact, in that it forged in me a God-given doggedness to not allow limited thinking, preconceived judgements and myopic takes on my abilities and capabilities to define my outcome; and use the product of my education for a purpose larger than myself, to ensure that no student is ever discounted because of disability and to advocate for equitable and accessible education. The remainder of this section is in Appendix E.

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Video Series Production Team – The multimodality of this dissertation would not have been possible without you. Thank you for embracing my concept --- using video as a means of centering, validating, and representing disability in research. Thank you for all the countless hours of pre-production, production, and post-production. Thank you for the professional treatment given to the final product. Together, I believe we created an impressively innovative modality for a dissertation.

Dr. Shemya Vaughn – I appreciate the investment of time made to edit the written products of this dissertation, ensuring not only that they conformed to ASU Graduate College Formatting Guidelines but also that the 'voice' of the dissertation was strengthened by the time and attention given to editing intricate details. The acknowledgements are continued in Appendix E.

TABLE OF CONTENTS

Page

CHAPTER Page

APPENDIX

PREFACE

A disability reclamation statement is advanced as an emancipatory exercise of this action research. This statement is written to confront the social and educational traumas and ableism I have encountered. This statement aims to positively reclaim those traumas and the ableism struggle contained in them as life events that have informed my motivations for engagement in scholarship focused on disability. Equally, this disability reclamation statement is an attempt to bring attention to the need to deconstruct ableist power structures inside and outside of academia. The emancipatory intent of this action research is increased accessibility and equitability in qualitative inquiry. I am reclaiming my disability experience as valid and my negotiation of impairment as an individual one. I acknowledge that the systematic continuance of restriction, exclusion, and the social rebuff of impairment is what allows for the creation, social legitimizing, and maintenance of disability.

I am not 'other'. I am not the burden. I am not the impediment to, nor the tragedy of the delimited space, access, and inclusion I am apportioned by society. Such curbing of space, access, and inclusion is the product of myopic views of human difference. Access and equitable inclusion are not endowments from society, they are my rights as a human being. I do not need 'qualifiers' to my competence based on my impairments. I choose to see my impairments and the disability within them as an asset. My impairments and the disability within them offer a unique perspective and displace the normative.

CHAPTER I

INTRODUCTION

Emancipatory action research is a type of critical inquiry that seeks to effectuate change through mobilizing empowering, person-centered, contextualized, and issue-salient research (Ledwith, 2017; Noel, 2016). Through emancipatory action research involving multimodality, the aim of this study is two-fold: (a) to more dynamically understand how postsecondary students with dyslexia describe and adapt to a negotiated existence with and through dyslexia and assistive technology from a lifeworld perspective – and how co-partnership can center and validate the disability experience; and (b) to provoke cognizance and purposive responsiveness with respect to physical or intellectual access barriers to engagement with traditional standards of qualitative inquiry and make the case that more diverse and inclusive methodological innovations are imperative to ensure more complete representations of dynamics of the disability experience in qualitative research. To accomplish these research aims, the dissertation is divided into four sections.

Section I addresses how the researcher's personal and professional background served as the impetus for engagement in disability-focused scholarship, as well as a brief explanation of how disability, both physical and learning, have impacted the researcher's experience and interactions with research methodology, allowing a unique perspective by which to advance an argument for more accessible and inclusive methodological innovations for the benefit of improved representations of dynamics of disability experience in qualitative research.

Section II details a two-part video series, exhibiting the use of video data as one component part of multimodality in qualitative based action research. The first video in the series encompasses participant narratives, with the video modality preserving the voice, authenticity, and the individual nature of how each study participant describes and adapts to a negotiated existence with and through dyslexia and assistive technology from a lifeworld perspective. The video is aligned with the fractions of lifeworld as advanced by Ashworth, including "selfhood, sociality, embodiment, temporality, spatiality, project, discourse, moodedness" (Ashworth, 2003; Ashworth 2016, as cited in Andrews, Hodge & Redmore, 2019, p. 6).

The second video in the series provides a reflective account of the methodological approach by which the action of the research was threefold: (a) demonstrating how the dynamics of disability can be situated in the qualitative research process so as to be centering and validating to individual experience and thereby, result in methodology that is more accessible and equitable; (b) exhibiting how the process of action research can be made more inclusive of disability; and (c) illuminating how research produced by someone of "diverse bodymind" using methods accessible to them intellectually and physically is both as valid and rigorous as traditional standards of qualitative research (Lester & Nusbaum, 2021, p. 19; Price, 2015).

Section III offers two discussion guides for targeted viewers. The first guide provides an opportunity for faculty and university staff to consider how postsecondary students with dyslexia describe and adapt to a negotiated existence with and through dyslexia and assistive technology. The second guide provides an opportunity for qualitative methodologists and education doctoral faculty to consider how to ensure more complete representations of the dynamics of the disability experience in qualitative research as well as means of accessible and equitable qualitative research.

Section IV provides a book proposal, with the intent of inviting qualitative methodologists and students to provide perspective on the following: (a) the centering and validation of individual disability experience in qualitative research; (b) practical means by which to make qualitative research more accessible and equitable; (c) physical and intellectual access barriers to traditional modes of qualitative research; and (d) how research produced by someone of diverse bodymind can and should be regarded as valid and rigorous (Lester & Nusbaum, 2021, p. 19; Price, 2015).

Personal and Professional Background

As a practitioner-researcher who studies and is part of the disability community, it is imperative that I begin by situating my first-hand positionality of disability and how I perceive the experience of disability. I assume a position of credibility from personal and professional experience with disability. Impairment is a natural part of the human experience, impacting all of us inevitably at some point in our life course, to varying degrees and manifestations. Considering that 15% (one billion) of the world's population is disabled, disability is among one of the most represented and least acknowledged minority groups (United Nations, n.d.).

In terms of aftereffects of impairment, the World Bank Group (2023) stated, "persons with disabilities are more likely to experience adverse socioeconomic outcomes such as less education, poorer health outcomes, lower levels of employment, and higher poverty rates" (para. 1). I view disability as a multifaceted, socially contrived consequence of impairment, constructed in part from the predominating attitudes and behaviors of society that typify idealized standards of perfected corporeal and intellectual functioning, produced, and reproduced in society through language, gestures, images, objects, and actions. Disability is an inherently fluid concept, instigated by a "disabling society" (Barnes & Mercer, 2003, p.19). The concept of disability is an amalgamation of social devaluations of impairment in conjunction with pervasively preclusive projections on to the lived experience of impairment. Adapting lifeworld fractions to disability experience, these projections ultimately impact the individual lifeworld through:

- attenuated selfhood (e.g., effects on agency, centred expression of experience, social valuations of impairment and acceptance or rejection of impairment)
- societal structure and power relation negotiations
- perceptible physical or emotional manifestations and negotiations
- 'biography', which is an enduring aspect of being disabled that informs 'punctuating events' of the experience and of the lifespan
- built or learning environment negotiation or purposive avoidances, which can include decision making about the places and spaces to include oneself, while simultaneously contending with patterns of control and consciously or unconsciously exercised and culturally accepted norms of inclusion and exclusion

- direct influence on assumed positionalities, interests, vocations, causes, devotions because of impairment and disability
- language and actions used to articulate the experience and presence of impairment
- implicitly or explicitly articulated mood or feeling regarding disability and impairment (Andrews, Hodge & Redmore, 2019)

The realities of impairment can have the power to preclude individuals from meaningful, thoroughgoing, efficacious interaction with, and participation in society on an equal and equitable basis with others (Kaplan, n.d.)

Disability stigma is often perpetuated in academia. Students with disabilities are, at times, myopically characterized as an impedance to the independent and decentralized nature of a scholarly community. There are times that disability in academia is viewed as a threat in that it is perceived as:

- redress-seeking to have reasonable accommodations legislatively afforded to students with disabilities to ensure an equitable and accessible educational opportunity
- upending conceptions of scholarly-appanage to exercise one's method and practice of teaching and intellectual-convictions
- exploiting the affordances of reasonable accommodation
- physically requiring modifications/retrofits to the built environment (Dolmage, 2017)

Dolmage maintained that the postsecondary environment perpetuates academic ableism under which, "academia powerfully mandates able-bodiedness and able-mindedness, as well as other forms of social and communicative hyperability" (p.70). From an educational perspective, Dolmage extended Campbell's (2001) articulation of ableism:

> A network of beliefs, processes, and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human. (p. 44)

It is important to understand that higher education, operating on a per-class basis to issues of accessibility, does not often afford the student with a disability full, meaningful inclusion in the learning environment and can stymie their academic value. How is such a reality possible? Course accessibility features are often retrofitted into courses rather than being considered at the outset of course design.

For example, Arizona State University's Student Accessibility and Inclusive Learning Services (SAILS) advocates for its university community to engage in universal design by stating that, "a culture of access and inclusion through collaboration with faculty, campus partners, and the use of universal design principles" help counter the adverse impacts that can result from course retrofit, and, instead, proposes universal access as a design aspiration (Educational Outreach and Student Services, n.d., para. 1).

It is suggested that the historical model of accommodation and the spirit of the legislation's standard of an otherwise qualified individual is suggestive of an institutionalized belief that the aim of students should be to, "achieve around disability or against it, or despite it. The disablism built into that overarching desire for able-bodiedness and able-mindedness comes from the belief that disability should not and cannot be something that is positively claimed and lived-within" (Dolmage, 2017, p.70).

Role of the Researcher

As a full-time staff member of Arizona State University where this action research study was undertaken, along with my oversight of the alternative format accommodation service area; and with my complementary personal background in disability, I assumed the role of insider researcher-practitioner. I served as both researcher and the primary innovation facilitator throughout all phases of the action research study including planning, acting, developing, and reflecting (Mertler, 2019). Brannick and Coghlan (2007) suggested that the perspective of an insider researcher is unique because such an approach uses equitable and forthright processes of internalized introspection. One can use self-analysis to elicit the details of the interworking of a system or community of practice and leverage their proximity to a given context as knowledge informing the study.

I worked directly with research participants using narrative interviewing / storytelling to center their experiences with assistive technologies and interconnections with lifeworld. It was imperative for this study to show sensitivity to marginalized voices. I had a responsibility as an insider researcher-practitioner to ensure that I allowed the authentic emergence of data from participant-voice and the dynamics of personal narratives. The imperative for such an approach is that "historically, disabled people have been the objects of study but not the purveyors of the knowledge base of disability" (Snyder & Mitchell, p. 198, as cited in Dolmage, 2017, p. 4).

Professional Background in Disability Services

I joined SAILS, formerly the Disability Resource Center, in June 2016, as a 20-year end user of assistive technology with eight years of professional and academic background in areas of assistive technology, disability studies and policy, alternative format production, and universal design for learning. Presently, I serve as the senior program coordinator for alternative format accommodation.

First, I am responsible for all accommodation management logistics and provisioning of accessible instructional materials (e.g., textbooks and course supplementals) for students impacted by print-related disability, blindness, visual impairment, physical disability, cognitive processing disorders, and/or learning disability. Second, I lead assistive technology and alternative format end-user training. Third, I actively advance university initiatives related to accessible instructional material and universal design for learning. Fourth, I modernize and streamline alternative format accommodation processes and policies, aligning them with departmental goals. Finally, I have requested to expand university influence in alternative format production to include either a regionally focused fee-for-service model, serving Arizonans with a print-related disability, or participating in federal grant competitions with a programmatic focus of leading accessible instructional material production and technical guidance, through the creation of an accessible instructional materials center.

Life Experience with Disability

I must now situate my own experience with impairment and disability. In February of 1985, at 11 months of age, I was formally diagnosed with cerebral palsy, after sustaining a dual-hemisphere cerebral hemorrhage, due to a prolonged lack of oxygen to the brain. At the time of my diagnosis, the medical opinion concluded that it was likely that cerebral palsy would pervasively affect every aspect of my development. It was assumed I would be unable to walk, engage independently in any activities of daily living, successfully navigate mainstream public education, and live independently.

In conjunction with cerebral palsy, it was anticipated that I would also develop various forms of learning disabilities and information-processing disorders. At one juncture, my family was warned as to how taxing caring for a child with cerebral palsy can be and that institutionalized care may be a necessity. My family ardently rejected this as a viable option and sought to help me navigate the world with my impairments, acknowledging them, but at the same time, not allowing them to wholly define my identity. We rejected any notion of limitation or myopic labeling of capacity or ability that the outside world may place on me in an unconscious ignorance of my impairments and “impairment effects” (Thomas, 2012, p. 211). I was conditioned with a formidable spirit toward my impairments, framing them as assets that accentuate the different perspectives and value-add my impairments can bring to the world.

Throughout my life with cerebral palsy and learning disabilities, I have endured educational, social, and vocational traumas. While there are innumerous examples of trauma that have informed my view of disability and impairment and my negotiation through the world as a result, I will provide a single punctuating example from my k-12 experience, which became the impetus for my pursuit of doctoral studies.

I was told, in a 10th grade Admission, Review, and Dismissal and Individualized Education Plan meeting that I would not be college material based on standardized testing scores in combination with the way my cerebral palsy and learning disabilities impacted my educational progress and the type of accommodations that would be required to successfully navigate, contribute to, and complete postsecondary education. The professional opinion suggested that I should resign to a vocational certificate of completion and attendance and enter a type of sheltered employment program, particularly hospitality management. I fervently rejected this as an option for my transition from high school and completed all requirements and exit exams (with minimal allowance for accommodations and assistive technologies).

I graduated high school with a diploma and began my postsecondary education in August of 2003, attending Blinn College, University of Texas – San Antonio, Arizona State University, Northern Arizona University, and Grand Canyon University. I have obtained a total of six degrees, including associate degrees, bachelor’s degrees, three master’s degrees, and a graduate certificate. I resolved that day in 10th grade when I was told that I was not college material, that I would take my education to the furthest extent that I could muster and use it to ensure that students with disabilities are empowered and afforded the educational access and equity that I assumed a defensive, counterattack to obtain.

Personal Experience with Methodology

Throughout my graduate training in research methodologies, I have struggled with analytical sense-making from the traditional and normatively focused means of research. This is not to suggest that I cannot perform the methodological tasks for which I was trained, but my struggle is situated in the normative means of processing through data and producing knowledge. As a researcher with cerebral palsy, learning disabilities, and information processing disorders, my engagement with qualitative research would stalemate at the juncture of analytic sense making to work through grounded theory. Grounded theory, as defined by Charmaz (2004), suggests that "these analyses provide focused, abstract, conceptual theories that explain the studied empirical phenomena" (p. 441). For me, the complication with this process would often begin at the stage of constant comparison – the process of continual examination and reexamination of data points against or in light of one another in effort to call out consistent happenings in the data, forming conceptual groupings and "develop a theory that emerges from and is therefore connected to the reality the theory is developed to explain" (Cohen & Crabtree, 2006, para. 1).

I have found it to be an arduous undertaking to intellectually access the abstracted, progressively connective properties of grounded theory because of the requisite nature of coding to the process. Strauss and Corbin (1990) described coding as a three-tiered process of graduated abstraction including open coding, axial coding, and selective coding. In the spirit of the emancipatory nature of this action research study – and its alignments with fractions of lifeworld, how do I describe my negotiated existence of disability and the access barriers I experience, from a lifeworld perspective with the process of research? This is an issue of space and place. Andrews, Hodge and Redmore (2019) described the fraction of spatiality as:

> How this event affects the places that we go and the spaces that we inhabit. The social and cultural norms that we encounter there and the meanings that we make of these. Who controls access to these spaces; where we are permitted to be and where we are excluded from. (p.6)

My experience with research, as someone with a diverse bodymind, is best pitted against the spatiality fraction of lifeworld because I have felt excluded from the research space. For example, the assumptions of grounded theory which presuppose that a researcher (and participants) can physically, intellectually, and normatively engage with cognitive connection with inductive reasoning styles – from the specific to the broad and be able to work through pattern and trend finding exercises. It presupposes that the researcher attends to repetitious, (back-and-forth) constant comparative methods that require cognitive agility to sense-make out of large data sets in a fluid, characteristically open-ended, indistinctive way, leading to increasing intricate, generalizations. This constant comparison phase:

> Incorporates the main processes of inductive analysis—namely, the reduction and organization of the volume of information that has been collected in order to construct a framework for presenting key findings—but at the same time it incorporates a complex, iterative process of data collection and coding. (Mertler, 2017, p. 177)

Another necessity of grounded theory is to work through the requirement to contend with abduction, meaning, and the ability to make a reasonably informed assumption based on incomplete data, “you may come up with some surprising findings and then have to think of all possible theoretical explanations for these findings that you subsequently go and check” (Charmaz, 2017, 3:30).

Finally, grounded theory presupposes a specific way of coding, which is repeatedly dealing with abstractions, nuances and patterns of emergence, convergence, and divergence in highly variable ways – and attempting to make analytically interesting connections from the data set. How might a researcher with multiple disabilities, one of which is information processing disorder feel excluded from or ‘othered’ by the processes outlined above?

First, when recounting this experience, and others like it that are naturally taxing on my physical and intellectual faculties, I can, in a hyper-conscious manner, sense the looming presence of my brain injury. I have a heightened awareness and sensitivity to the strenuous demands to receive, perceive, and interact with information whereby, I can feel the effects of efforts to process it – with deferred action on and expression of the information. Connection, graduated abstraction, and meaning making can and do occur, but feel arrested initially, requiring a hyper-deliberate, intensification of concentrated effort to make (and keep) those connections, abstractions, themes, and meanings. This process is continual and there is little naturally occurring automaticity in my ability to receive, perceive, and interact with information, which can make me feel out of place in certain spaces, particularly academia.

Secondly, there are privileged norms of knowledge production present in the critical activities of grounded theory, suggesting that one must be able to receive, perceive, and interact with information in a highly unpredictable and abstracted manner. The controllers of this type of research space privilege language production and processing in particular ways, which, even with all its command in "methodological self-consciousness," (Charmaz, 2017, p. 36) there remain obstacles to engagement with this process.

In my view, grounded theory comes up short in accounting for the dynamics of disability, how to situate it, and the extent of forethought given to physical and intellectual access needs of the researcher and participants. How might engaging in a method like grounded theory, which privileges intensive interviewing, for example, impact a participant with disabilities? Kerschbaum and Price (2017) provided a synthesis of privileged norms in qualitative interview settings. They suggested that physically produced speech is alleged to be the default and a traditional speaker-listener exchange is naturally occurring at a standard pace. They went on to state:

> [The] assumption is that interviewers are hyper-able research instruments capable of flexing and bending to any circumstance or situation they might encounter in their work. The importance of accommodating participants is often emphasized, without mentioning the fact that the interviewer might need to accommodate. (p.99)

They explained that standardizing suppositions about the conventions of qualitative research underscore that disability and the disabled bodymind are often not afforded constructive forethought in terms of how research design and methodological feature usage can uncouple or form physical and intellectual access barriers, removing ableistic prescriptions of what is right, wrong, valid, rigorous, and capable of being heard and seen. Instead, othering practices based on the privilege of a “normate” is allowed to persist (Garland-Thompson, 1997, as cited in Lester & Nusbaum, 2021, p. 13).

To address disability not being situated appropriately, there can be a conscious awareness of and purposive action by design that makes space for diversity in a more meaningful way. For example, a disabled bodymind may need a flexible, variability-tolerant space, and an environment to receive, perceive, and interact with information and other factors, like the qualitative interview, where there is constant emergence and nascent things happening.

Study Assumptions

What are the ontological, epistemological, axiological, and methodological assumptions of the study? What are some assumptions related to the field of assistive technology as well as disability and impairment? First, the ontological assumption of the study is that reality is not merely the constitution (or reconstitution) of observed facts situated in concrete physicality or the neutrality of measurement, it is instead mediated through individual perception. The ontological assumption of the study suggests that physical, mental, and emotional selectivity is invoked in meaning-making and that there is a spectrum of attentiveness given to detail and stimuli and the dispensation, systematizing, and rendering of that detail and stimuli. Second, the epistemological assumption of the study is what can be known through a centered representation of reality and experience or an “embodied, conscious relatedness to a world” (Ashworth, 2003, p. 15). With such centering, one can understand the tacit dynamics of experience and the systems, structures, interactions, spaces, language, tone, and life activities that inform it. Third, axiological assumptions about what is important in research, which includes disability, (situated with a social model interpretation) and assistive technology from a lifeworld perspective are discussed. Methodological assumptions related to the narrative inquiry are also addressed. Lastly, assumptions of the target population, students with disabilities in higher education are reviewed. Below, each of the assumptions has been placed in a subcategory.

Assumptions of Disability Research

- The engagement in research on salient topics of disability is the central feature. Research should invoke positive, enduring change in the experience of disability (Barnes, 2001).
- There is recognition that both tangible and intangible barriers create and reproduce disability in society (Oliver 1990; Oliver, 2013).
- The participant in disability-focused research should be involved as an equal, emancipatory partner (Barnes, 2003).
- Disability-focused research should not just be on or about the person with an impairment; it should center and validate the individual experience so it can be positively reclaimed (Barnes, 2007; Mertens, 2015).

Assumptions of Lifeworld Phenomenology

- Holistic validation of individual experience is paramount in lifeworld-focused research (Hodge, 2008).
- Arresting interpretive assumptions, ensuring not to superimpose, beliefs, values, and judgments onto individual experiences is an imperative (Schwandt, 2007).
- Lifeworld is concerned with a full accounting of "a person's subjective construction of reality" (Kraus 2015, p. 4).

Assumptions of Assistive Technology

- Assistive technology must be dynamically contextualized and responsive to the needs of the individual, environment of use, and task needs (Zabala, 2005).
- While assistive technology should be considered a functional increase, maintenance, or improvement; it is equally important to consider the tacit dynamics of assistive technology decision-making and experience along with the systems, structures, interactions, spaces, language, tone, and life activities that inform it.

Assumptions of Narrative in Research

- The narrative is intimately connected with being and negotiating life (Kartch, 2017).
- The narrative is predicated on social action (Atkinson & Delamont, 2006, as cited in Smith & Sparkes, 2008, p. 18).

- The narrative allows for an authentic exposition of experience and invites tacit understanding in the difficult-to-articulate the psychological, social, and cultural dynamics of experience (Kartch, 2017).
- "Telling stories is never an option or another obligation since to live is to enact a story about the kind of person we take ourselves to be" (Frank, 2004, as cited in Smith & Sparkes, 2007, p.17).

Assumptions of Students with Disabilities in Higher Education

- Students with disabilities in higher education are required to self-disclose because the university has no responsibility to identify a disability (Blinn College, 2023). It is assumed that self-disclosure alone does not account for all students impacted by disability in postsecondary settings (National Center for Education Statistics, 2022).
- Some students may have received accommodations, including assistive technology support, in k-12 that they opt not to utilize in postsecondary settings due to the requirement of self-disclosure.
- It is assumed that there is a subset of students with disabilities in postsecondary settings that have their educational experiences informed by educational traumas.
- It is assumed that students with disabilities in postsecondary settings are impacted by academic ableism in various ways.
- It is assumed that there exists, for some students with disabilities, a fear of assistive technology.

- It is assumed that some students have their decision to accept/abandon reasonable accommodations influenced by the extent to which assistive technology consideration, matching, implementation, and training quality were individualized and attentive to the student, environment, tasks, and tools (Zabala, 2005).
- It is assumed that experience with and through assistive technology is an embodied, negotiated one (Berndtsson, 2018).
- It is assumed that some students with disabilities will perceive assistive technology as a threat, while other students will adopt an orientation of asset.
- It is assumed that the experience of impairment, disability, and assistive technology are to varying degrees negotiated through social structures, social systems, social attitudes, and social interactions (Berndtsson, 2018).

Conceptualizations of Assistive Technology

Historically, assistive technology has been conceptualized, considered, and applied in situations of field practice within the confines of rehabilitative support, with a hyper-focalization on functional increase, maintenance, or improvement. Cook and Hussey (2002) suggested assistive technology is to be thought of as "a broad range of devices, services, strategies, and practices that are conceived and applied to ameliorate the problems faced by people with disabilities" (p. 5). Further, the federally endorsed definition in the Technology-Related Assistance to Individuals with Disabilities Act of 1988 (29 U.S.C 2202) states that assistive technology is "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (p.

3). The aim of assistive technology, from this perspective, is to integrate assistive technology into the life of an individual with disabilities to augment, bypass, or compensate for corporeal or intellectual capacity limitations.

The Assistive Technology Industry Association (2023) maintains that to be truly effectual, assistive technology interventions must account fully for the contexts of use. As Berndtsson (2018), Edyburn (2001), and Watts et al., (2003) have identified, there is a limitation in the scope of current conceptualizations of assistive technology as it relates to practical, real-world outcomes, research, and practice. Nalty and Kochany (1991) contended that the federally endorsed, functionally focused definition of assistive technology is “broad in scope and not very descriptive in the nature or category of tools that can be identified as assistive technology” (as cited in Watts et al., 2003, p. 2). In addition, Watts et al. (2003) pointed out that there have been previous attempts at expounding assistive technology and its scope, however, even these attempts remain functionally concentrated:

> [This was an attempt] (a) to augment an individual’s strengths so that his or her abilities counterbalance the effects of any disabilities, (b) to provide an alternate mode of performing a task so that any effects from an individual’s disabilities are compensated, or (c) to bypass entirely. (Lewis, 1993, as cited in Watts, et al., 2003, p.2)

Assistive Technology and Lifeworld

What is noticeably precluded from prevailing models of assistive technology is a recognition of the lifeworld that is superimposed on the successively layered, interconnected experience of assistive technology for individuals with disabilities. It will not be the aim of this action research to discount the critical significance of considering the functional and rehabilitative dimensions of assistive technology in practical, real-world outcomes, research, and practice. These functional and rehabilitative dimensions are crucial. This action research is intended to augment current conceptualizations of assistive technology with consideration of dimensions sparsely studied in the field, principally showing its interconnections with the lifeworld. Lifeworld phenomenology contends that there is not a wholly empirical form of reality, arguing that experiences are not mediated only by observed facts and that which is apperceived through the senses, but that “actuality is as perceived by the person” (Ashworth, 2003, p. 14).

Additionally, lifeworld phenomenology insists that reality becomes validated through “embodied, conscious relatedness to a world” (Ashworth, 2003, p. 15). With greater agency afforded to the individual and their frames of reference, the result is centered on the “individual meaning-construction of our situation” (p. 14). Lifeworld contains within it pervasively present, experience-ascribing fractions that aggregate into one’s complete perception of “empirical lifeworld” (p. 23), which include social identity/personal agency, relationship with others, physical and emotional perceptions, time-based perceptions, sense of place/space, dominating, critical or otherwise punctuating life activities, use of descriptive language, and situational tone (Ashworth, 2003; Hodge, 2008).

In her linkages of lifeworld to the experience of white cane acceptance, rejection, and use, the insights of Berndtsson (2018) can be broadly applied to other assistive technologies to assume an orientation that extends beyond the functional assistance it offers. She advocated to include an awareness that the world one negotiates with assistive technology in a manner that is not wholly objective nor subjective; and there is a negotiated existence with and through assistive technology that embodies a lived reality that disrupts, or is in contradiction to, the societally idealized corporeal standard of normal. This viewpoint is significant because an individual using assistive technology contends with a revised manner of being in the world due to their impairment, and their reliance on assistive technologies help them navigate life independently. As a result of impairment and reliance on assistive technologies, one's perceptions of the physical world, and the limits and opportunities it presents, differ markedly from individuals without disabilities.

Lifeworld Phenomenology and Fractions. Lifeworld phenomenology is "a description of 'things' (phenomena or the essential structures of consciousness) as one experiences them" (Schwandt, 2007, p. 225). Lifeworld was advanced by Husserl (1970), who argued that the methods of objectivity of the physical and life sciences that recognize reality as based on empirically based evidence are devoid of a capacity to critically explain dynamics of human experience. Lifeworld is an "inter-subjective world of human experience and social action; it is the world of commonsense knowledge of everyday life" (Schwandt, 2007, p. 179). In its original conceptualization, lifeworld suggested that there is no neutrality of reality. There is no impartiality to the truth.

Within lifeworld phenomenology, true knowledge is filtered through authentic perceptibility of an experience and meaning making through experiences that are produced through the personal processing of the cognitive and emotive aspects of experience. Schwandt (2007) clarified that Husserl offered two distinctive modes of being to explain the experience, which Husserl termed, "natural attitude", which is our mundane, "relatively unproblematic involvement with people, things, the world", and a “phenomenological attitude,” which is occupied with purposeful introspection of human experience, resulting from purposeful, internal suppression of judgement with regard to an experience in a state unfiltered by pre-given conclusions (p. 179).

What are fractions and how do they relate to lifeworld? Fractions were Ashworth’s (2003; 2016) effort to suggest that every experience in life has contained in it some inevitable, ineludible dynamics that constitute experience – and how we perceive it. Andrews, Hodge and Redmore (2019) suggested that Ashworth did not intend dichotomous treatments of life experiences by advancing the notion of fractions of experience. They argued that he felt very strongly that the fractions occurred with varying degrees of punctuating strength, depending on life incidences.

Bracketing is seen as an imperative with the intent of not compelling or inhibiting the narrative of experience. Bracketing appraises narratives against preconceived views, suppositions, or social and political postures that are held, or that which is contemporary to the field. From the act of bracketing, one can appreciate the strata of human experience (Schwandt, 2007). Related to the act of bracketing, Stewart and Mickunas (1990) explained that “phenomenological reduction” is that which is characterized as “a narrowing of attention to what is essential in the problem while disregarding or ignoring the superfluous or accidental” (p. 26). Second, “phenomenological epoche” is “a questioning of presumptions until they could be established on a further basis" (p. 26). Additionally, "experience is multimodal and embodied" (Sokoloki, 2000, as cited in Gorichanaz et al., 2018, p.882). Given that phenomenology is a study in subjective interpretations of events and the meaning one assigns to that event, Dahlberg et al. (2001) posited that "meaning is never finally complete but is always expandable, limited only by our readiness to enlarge our understanding" (p. 59).

Examples of Lifeworld and Interconnections with Disability Experience. The search for interconnections with disability experience brought forth some varying examples, such as, Wickenden's (2011) research study that used an ethnographic method to allow teenagers who are end-users of augmentative and alternative communication devices to have a space to express themselves, their perceptions, and experiences in a person-centered, authentically representative manner. The study involved fieldwork in natural environments of home, school, and extracurricular activities. The approach of the study was atypical, in the sense that it focused on individual experience, self-perception, and personhood, instead of privileged interpretations filtered by family, peers, professionals, and caregivers. Wickenden concluded that teenage users of augmentative and alternative communication devices were not hyper-occupied with their experience of disability but concerned with how their life experiences are complementary and parallel to others around them. "[Lifeworld] has increasingly been recognized as useful in disability research, where it allows that there is no one objective reality or fundamental truth to be discovered, but that the participants' understanding of the experience of their life is a valid and often overlooked one" (Hodge, 2008, as cited in Wickenden, 2011, p. 153).

Battalova et al. (2022) conducted a lifeworld phenomenological study, investigating the interconnections of the corporeal, relational, spatial, and material embodied negotiation with and through power scooter mobility aids. Battalova et al.'s study provided further confirmation of the dichotomy existent in assistive technology usage. Assistive technology has helpful, independence affording, rehabilitative, augmentative, compensatory properties, however, assistive technology also induces societal othering and avoidance. This paradox makes people with disabilities feel like their needs are neither recognized nor respected, and that their bodies are a spectacle, and objects of stare (Garland-Thomson, 2006, as cited in Battalova et al., 2022, p. 2).

Battalova et al. found four key themes to give better understanding to the embodied experience of power scooter mobility device usage:

- There was a reinforcement of stereotypical stare and gaze-avoidance, or hypervisibility and invisibility.
- Users contended with internal attitudes, beliefs, conceptions, and moods regarding reliance on the device – simultaneously contending with not wanting to be the focal point of unsolicited concern.
- Through the built environment and the persistent perpetuations of curbed or limited access provision, scenarios were created in which, "disability was accentuated and made more visible with a negative connotation" (p. 5).
- Users engaged in deliberate, conscious decision making about which mobility aids to use – and how to interchange them to lessen chances of social stigma and public focus on disability.

Matereke (2020) suggested giving practical redress to these absent, critical conversations to enhance empathic understanding of disabled lifeworld, and exercise the emancipatory muscle of disability studies. Matereke (2020) suggested that critical disability studies problematizes disability as an encounter with the culpability of society in allowing the production and reproduction of lived realities of disability in response to the presence of impairment and their entanglements with policies, systems and structures that permit its continuance. Matereke also suggested that with more intentionality to these discourses, a more complete representation of disability experience, access, and equity will emerge with contemporary perspective, and give space for critical introspection of a history that voiced, "nothing about us without us" (Charlton, 1998, p. 14) situating the disabled lifeworld more efficaciously.

Social Model of Disability

The social model of disability spawned out of the recognition that disability is socially constructed; and consciously and unconsciously imposed by tangible and intangible barriers. These barriers can take the form of architectural barriers, social barriers, physiological barriers, attitudinal barriers, and socioeconomic barriers. It is a prevailing assumption of the social model of disability that systematic barriers are what constitute a disability, not inherently the presence and manifestations of impairment. It is important to understand that there is a strict bifurcation of disability and impairment within the context of the social model and that the social model of disability is not intended to be a theoretical model in a strict sense. This model of disability is aimed toward the advancement of identifying barriers, problematizing barriers, and bringing corrective action to remove barriers that perpetuate the creation and reinforcement of disability (Oliver 1990; Oliver, 2013).

The locus of disability under the social model shifts from an individualized personal tragedy to an indictment of environments being liable for the denial of equitable inclusivity based on impairment. The social model contends with the culturally contrived dichotomy of normality and abnormality. What is abnormal, in the view of the social model, is the restriction, exclusion, and barriers because of impairment. Michalko (2002) articulated that "we do not suffer the condition of our impairments . . . we 'suffer' our society. We suffer what our society makes of our impairments" (p.54). The social model does not rebuff the problem of disability and holds society culpable for its causal factors (Oliver, 1990, p. 3). Essentially, the social model of disability contends that disability is the product of a disabling society, blameworthy of discounting the needs, contributive value, full citizenship, and social participation of individuals with impairments (Barnes & Mercer, 2004, p. 3).

Within the social paradigm of disability, Oliver (1990) contended that the devaluation and defamation of impairment are "institutionalised throughout society" (p.3). This devaluation and defamation can result in "a loss of 'full human status' and decline into second-class citizenship" (Siegler & Osmond, 1974, p. 116). Likewise, devaluation and defamation may leave the individual regarded as a "changeling . . . afflicted with a malady of the body that is translated into a cancer within the self and a disease of social relationships" (Murphy, 2001, p. 111).

Reconciling Lifeworld and Social Model of Disability

It is recognized that the social model of disability, with its political overtones and expectation of emancipatory outcomes, may appear to be in contradiction with guiding values, norms, and beliefs of lifeworld phenomenology. Upon a more critical, objective look at the pairing, one can see the contributive value in the centering of disability voice and experience. Some individuals who advocate a social model of disability, discount the value-add of the individual experience, suggesting that "by focusing on the experiences of disabled people we undermine or ignore the significance of the environment in which those experiences are shaped and, in so doing, simply re-emphasize, albeit possibly unintentionally, the personal tragedy theory of disability" (Barnes, 2001, p. 13). The discounting of the individual experience fails to center the experience of impairment and disability, perhaps unintentionally suppressing the voice it aims to emancipate. Barnes also clarified that that personal accounts hold merit but are only of consequence if that account elucidates systemic barriers that create disability. One must consider that lived experience contains a host of interconnected fractions and filters that coalesce around a holistic sense of self and being (Ashworth, 2003). An individual is more than the sum of the political dynamics they contend with while negotiating everyday life.

The social model, through its implicit suggestion that an individual's perception of lived, embodied experience and their meaning-making process, is somehow less material than the political perception is a narrow perspective. Some of the social model research is conceded when a stringently focused political overtone is used as an appraiser of the disability experience. This appraisal discounts the dynamics of experience and consequently, dilutes outcomes such as corrective action and affordance of a validated, centered voice in the spectrum that is disability experience. To reconcile the social model of disability and lifeworld phenomenology, it is imperative to situate such a reconciliatory uptake with an acute understanding of the foci of each and understand their complementary strength to one another. Below is Hodge's (2008) summary of the critical components of the social model of disability and lifeworld phenomenology which demonstrates where the tenets of the two models converge and diverge.

Tenets of the Social Model of Disability

- meaningful outcomes enable constructively progressive change in the experience of disability
- incitation of tangible and intangible barriers, which can take the form of architectural barriers, social barriers, physiological barriers, attitudinal barriers, and socioeconomic barriers allow for the creation, and societal and cultural maintenance and continuance of disability
- situate the disability community as equal, emancipatory partners in research
- ensure that research on topics of disability is not just on or about the person with the impairment, but that they have the right to their individual experience

Tenets of Lifeworld Phenomenology

- holistic validation of individual experience – acknowledging that the individual is intimately connected to their experiences and can articulate them in a manner that represents them authentically

- resist any impulse to project onto the research any speculative assumptions, personal appraisals, and interpretive filtering of the topic to give a centered voice to the participant
- the participant is the focal point; the centering of individual experience and voice is of critical primacy to the research
- the research product is focused on why phenomena occur in the manner they do; with a consciousness toward not bringing critical interrogations or contrastive questioning to individual interpretations
- lived experience contains a host of interconnected fractions and filters that coalesce around a sense of self and being, and should allow the research to elucidate how the experience impresses upon the lifeworld, rather than being subjected to compulsory boundings or forced interpretation

Williams (1996) reminded us that lifeworld "does not see the personal and the political as distinct; they are just parts of the lived experience. As all experiences are lived they are, therefore, embodied" (as cited in Hodge, 2008, p.30). Lived experiences should be attended to with judiciousness, openly acknowledging and muting assumptions that may misrepresent the voice of experience of the participant. In contrast, the social model of disability actualizes toward unconcealed political aims suggesting that scholars engaged in disability research should "either side with the oppressed or the oppressor" (Barnes, 1996, as cited in Hodge, 2008, p. 32). There is emancipatory value and connective methodological tissue to be found at the juncture at which lifeworld and the social model of disability critically examine and contextualize experience, systems, and structures; and acknowledge research as an emancipatory partnership.

Research Questions

a) Where do the dynamics of disability experience situate in qualitative research so that the individual experience is conveyed with completeness to be centering and validating to the individual, resulting in methodologies that are accessible and equitable?

b) How can the process of action research be made more inclusive of disability?

c) How can more accessible research methods be validated as rigorous and reasonable when a disabled bodymind presents with physical or intellectual access barriers to engagement with traditional standards of qualitative inquiry?

d) How do postsecondary students with dyslexia describe and adapt to a negotiated existence with and through dyslexia and assistive technology from a lifeworld perspective?

CHAPTER II

VIDEO SERIES

The produced video series consists of a participant-centered installment and a researcher-centered installment. ‘Centered’ is a term employed here with intentionality. To center is to act upon what Lester and Nusbaum (2021) advocated for, which is, a purposive disassociation from ableistic contentions that disability is to be passively studied on and about – but not actively, in partnership with. Lester and Nusbaum suggested that people with individual accounts of negotiated existence, with and through disability, are exactly who should be involved as sources of redress regarding incomplete and myopic understandings of disability.

The viewer is invited to critically view this video series, engaging with it purposefully to come to a personal sense making with respect to the dynamics of the issues raised in each installment of the series. By active engagement with this video series, the viewer is taking an emancipatory action. Ledwith’s (2017) suggestion surrounding meaning making is the act of translating punctuating experiences and individual or group-centered meaning makings into comprehensible, practicable, and actionable steps toward critical consciousness raising. The goal is to inspire an empathic understanding of systemic issues and a natural continuance of inquiry and meaningful progress. Artifacts from the analysis process can be found in Appendix A.

Preface to Participant-Centered Video

The first video in the series was produced between June 2023 and August 2023, consisting of six participants who met the participation criteria as outlined in the approved IRB protocol (see Appendix B). The edited participant-centered video consists of 17 questions that aligned with the eight fractions of lifeworld: selfhood, sociality, embodiment, temporality, spatiality, project, discourse, and moodedness (see Appendix C). Initially, the discussions were comprised of 18 questions and while this question was asked, it was ultimately omitted from analysis because all participants, to varying degrees, noticeably struggled with answering it. The question that was omitted was, *In your view, what is absent from assistive technology considerations to ensure that there is a more complete understanding of the individual and the context of use?* In the research interviews, each participant was asked all the questions in either an unstructured or semi-structured format, with five participants choosing unstructured interviews. The video series served as a proving ground for the following:

a. Dynamics of disability experience can be more appropriately situated in qualitative research through purposeful consideration of centering and validation in the research space, allowing open-share of individual experiences of negotiations with and through some phenomena, so that, the result is more complete representations of disability, with minimal filtering and editing – creating methodology that is physically and intellectually accessible as well as equitable.

b. Multimodality in research can remove physical and intellectual access barriers to qualitative inquiry for both participant and researcher.
c. Multimodality in qualitative research allows a natural space of flexibility to participants to describe and come to a more complete internal awareness of their negotiated existence with and through some phenomena.

The participant-centered video was aligned with Ashworth's eight fractions of lifeworld:

- selfhood
- sociality
- embodiment
- temporality
- spatiality
- project
- discourse
- moodedness

All eight fractions were adapted to the disability experience. Participants were given autonomy to choose the stylistic approach of the discussion, either unstructured or semi-structured questions. Participants were also provided a space to speak freely in relation to the guiding, lifeworld themed questions. The hyperlink for the participant-centered video is provided in Appendix D.

Preface to Researcher-Centered Reflection Video

The second video in the series, a researcher-centered video, was produced in October 2023. The overarching intent of this video installment was to engage purposefully with the requirement of action research to introspectively evaluate the impact and cogency of an action, and the methodological decisions made. Did the researcher achieve the stated aims? Recall the aims of the study:

- situate disability in qualitative research with more completeness so that individual experience is intact and results in centering and validation
- confront physical and intellectual access barriers in qualitative research
- increase inclusivity within action research
- demonstrate that research produced by a diverse bodymind is both reasonable and rigorous

The reader is invited to consider and co-construct meaning with this video installment. Does the researcher reflection make a diverse bodymind legible to a process of inquiry that historically has undercut the power of the variegated, non-dominant narrative of experience that is disability? The hyperlink for the researcher-centered video is provided in Appendix D.

CHAPTER III

DISCUSSION GUIDE

Part 1 - Assistive Technology and Lifeworld Discussion Guide

Companion to Participant-Centered Video

Target Audience

The target audience for this discussion guide includes disability service professionals and related support staff in postsecondary settings that work with students identified as having dyslexia and may either be directly or indirectly involved with assistive technology consideration, matching, implementation, and training for these students.

Scope of the Guide

To serve as a source of professional development for those who may benefit from a more judicious, person-centered, holistic approach to service and support to postsecondary students with dyslexia, to better understand their negotiated reality of dyslexia, which may be mediated through use of assistive technology. This guide contains two activities, a group discussion and Think-Pair-Share as an extended discussion exercise.

Context

This guide should be used synchronously, in person or online, in a small group setting following a full viewing of the *Assistive Technology Lifeworlds: Inclusive Qualitative Methodological Innovations for Diverse Bodyminds* video series.

Activity 1: Open Discussion Prompts

1. Did participant responses change or reinforce your conceptions about dyslexia? If so, how? If not, why not?
2. Why do you think that assistive technology (AT) is often not critically examined from a lifeworld perspective, even when evidence suggests that negotiated existence with and through the assistive technology embodies a very different lived reality for the individual?
3. From a lifeworld perspective, what does it mean for an AT user to contend with a revised manner of being in the world and why is this important?
4. How might consideration of AT from a lifeworld perspective strengthen a contextual, holistic, and individualized examination of AT from a Student, Environment, Tasks, Tools perspective? Refer to Zabala (2020) for more information about this perspective.
5. In your view, why is acceptance or abandonment of AT contextually dependent?
6. What are your thoughts on AT as a cognitive prostheses [1]versus a cognitive partner[2]? Why is this distinction important?

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[1] Cognitive Prothesis – refers to assistive technology being used for the purpose of augmenting, compensating or bypassing of some functional skill deficit in the process of learning (Cavalier et al., 1994 as cited in Holmes & Silvestri, 2012)

[2] Cognitive Partner – refers to assistive technology transitioning from a place of supplanting a skill deficit to supporting an active learning process for the end-user ((Cavalier et al., 1994 as cited in Holmes & Silvestri, 2012)

7. Participants voiced that dyslexia is an asset to them – and one of the assets mentioned was accentuated creativity and unconventional problem solving. How could these assets be used as a strategy to support students with dyslexia in actualizing toward academic and career goals?
8. When discussing power dynamics in society as it relates to adapting to a negotiated existence with and through dyslexia and as an AT user, participants mentioned four areas in which power dynamics impacted them: (a) teacher and curriculum biases; (b) incomplete educational equity; (c) sense of belonging; and (d) personal, academic and workplace productivity. Why do such societal reinforcements and discounting of dyslexia influence decisions to use AT and other reasonable accommodations?
9. Participants voiced that they had initially internalized feelings of ‘dumb’, ‘overwhelmed’, ‘frustrated’, ‘isolated’, ‘not enough’, ‘ashamed’, ‘a freak’, or ‘different’. In what ways could you validate and refocus these feelings for a struggling student?
10. Participants voiced having a hyper-awareness of needing to be more intentional in expressing themselves and learning. Knowing this, how could principles of universal design for learning be applied to support students who experience this sense of hyper-awareness?
11. Considering that participants voiced that the experience of dyslexia had a dramatic effect on their life, why might it be important to consider this fact when introducing tools, auxiliary supports, and reasonable accommodations to

students? What might their individual biography say about how they will accept or reject such supports?

12. Participants spoke about self-imposed space/place exclusions because they have dyslexia. Why would it be important to consider such self-imposed exclusions when considering tools, auxiliary supports, and reasonable accommodations?
13. Participants spoke about group exclusion being a part of their experience with dyslexia. Why would it be important to consider such group-imposed exclusions when considering tools, auxiliary supports, and reasonable accommodations?
14. Why is the language and mental attitude someone chooses toward an experience like dyslexia so important?

Activity 2: Think-Pair-Share

Directions

Using the Think-Pair-Share model of discussion, an identified facilitator for the group will have four responsibilities:

- Provide directions to participants.
- Deliver prompts for discussion.
- Manage time keeping for each step of the activity.
- Listen in on pair sharing.

Facilitator Script

Now that we have viewed the *Assistive Technology Lifeworlds: Inclusive Qualitative Methodological Innovations for Diverse Bodyminds* video as a group, we will engage in a discussion activity using the Think-Pair-Share model of discussion. Think-Pair-Share is divided into three steps:

Step 1 – Think – You will be given two minutes to think about and organize your thoughts on the topic. You may utilize a form of physical or electronic notetaking if you wish.

Step 2 – Pair – You will be given two minutes to pair with another student and discuss your thoughts on the topic, identifying areas of similarity and difference in response. During this step, the facilitator will listen in on pair sharing, identifying trends in discussions and any misconceptions that may be developing.

Step 3 – Share – Partner-pairs will share out their core ideas about the topic. During this step, the facilitator may need to actively correct any misconceptions.

To adapt Think-Pair-Share in a virtual learning environment, utilize the following online guides: *Using Breakout Rooms During a Meeting* (Zoom, 2023a) and *Virtual Think Pair Share* (Zoom, 2023b).

Part 2 - Inclusive Qualitative Research and the Diverse Bodymind

Companion to Researcher Video

Target Audience

The target audience for this discussion guide includes faculty of educational doctorate programs and qualitative methodologists with an interest in critically examining disability as an active part of qualitative inquiry and advancing discourse on accessible and equitable qualitative methodologies.

Scope of the Guide

To serve as a professional development guide offering critical reflection on the normate of inquiry and why this relegates disability to a position of being illegible in qualitative inquiry. Furthermore, this guide helps promote discourse regarding:

- centering and validating disability in qualitative research
- practical means to make the process of action research more inclusive of disability
- research produced by diverse bodyminds as valid and reasonable
- practical means of reducing physical and intellectual access barriers to qualitative research

Context

This guide should be used synchronously, in person or online, in a small group setting following a full viewing of the *Assistive Technology Lifeworlds: Inclusive Qualitative Methodological Innovations for Diverse Bodyminds* video series, including researcher reflection.

Activity 1: Open Discussion Prompts

1. In your view, why has a normate been privileged in qualitative inquiry and allowed to persist?
2. How do normative, accepted standards of qualitative inquiry serve to be exclusionary to diverse bodyminds? Why is this problematic?
3. How does co-partnership in research about disability allow for centering and validating of the experience?
4. How can flexibility in research approaches do more than just reasonably accommodate?
5. What are some examples of access barriers to qualitative research that render diverse bodyminds illegible and how could those barriers be ameliorated?
6. What are the strengths, limitations, and opportunities of multimodality research as a means of accomplishing Lester and Nusbaum's directive to, "invite participation, creation, and research designs from bodyminds previously unseen"?
7. What, if any, are the strengths, weaknesses, opportunities, and threats (positive or negative) of emancipatory action research, as characterized by Ledwith, through being, problematizing, conscientization, action, and making sense in making action research more inclusive of disability?
8. Does the current treatment of disability within qualitative inquiry reinforce institutionalized othering and academic ableism? If so, how? If not, why not?

9. How, if at all, does multimodality in qualitative inquiry address concerns of validity, reasonableness, and rigor?

Activity 2: Think-Pair-Share

Directions

Using the Think-Pair-Share model of discussion, an identified facilitator for the group will have four responsibilities:

- Provide directions to participants.
- Deliver prompts for discussion.
- Manage time keeping for each step of the activity.
- Listen in on pair sharing.

Facilitator Script

Now that we have viewed the *Assistive Technology Lifeworlds: Inclusive Qualitative Methodological Innovations for Diverse Bodyminds* video as a group, we will engage in a discussion activity, using the Think-Pair-Share model of discussion. Think-Pair-Share is divided into three steps:

Step 1 – Think – You will be given two minutes to think about and organize your thoughts on the topic. You may utilize a form of physical or electronic notetaking if you wish.

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Step 3 – Share – Partner-pairs will share out their core ideas about the topic. During this step, the facilitator may need to actively correct any misconceptions.

To adapt Think-Pair-Share in a virtual learning environment, utilize the following online guides: *Using Breakout Rooms During a Meeting* (Zoom, 2023a) and *Virtual Think Pair Share* (Zoom, 2023b).

CHAPTER IV

BOOK PROSPECTUS

It is my intent, post-dissertation, to engage in publishing an edited volume to continue discourse related to the critical cross-examination of the normate of qualitative research (Lester & Nusbaum, 2021, p. 13). The normate of qualitative research renders mute the disabled bodymind's voicing of experience and paralyzes movement through the process and production of knowledge through qualitative inquiry. In the emancipatory spirit of Charlton's (1998) "nothing about us without us" (p. 14), this edited volume will illustrate that disability has a space and a place to reclaim the sharing of individual experience. If this illustration is done in a way that is situating, accessible, and equitable –then centered and validated experience can have a fearsomely descriptive creditability to show the power of diversity.

Situating of disability can provide a more complete and empathic understanding of human difference so that we can better understand our negotiated realities, with and through the diversities that make us unique. Through a meaningful co-partnership in the process and production of qualitative research, the aftereffects would be positive, enduring change in the experience of disability, consciousness raising of barriers that create and reproduce disability in society; and research that allows for ownership of personal experience.

The edited volume will provide a space for the voices of diverse bodyminds. Regardless of the voice being from a qualitative methodologist or student of qualitative method perspective, both have value in the process providing a counter to a culture of exclusion in research. The style of this edited volume invites personal perspectives, using narrative vignettes. Topical coverage of this edited volume will be:

(a) centering and validation of individual disability experience in qualitative research;

(b) practical means by which to make qualitative research more accessible and equitable;

(c) physical and intellectual access barriers to traditional modes of qualitative research;

(d) how research produced by someone of diverse bodymind can and should be regarded as valid and rigorous; and

(e) investigations of multimodality in qualitative research as a means of producing knowledge.

This edited volume prospectus will be formally offered to Meyers Educational Press. As part of the prospectus, a sample chapter is included that details my perspective on action research and its subgenre, emancipatory action research. The chapter explains how this perspective supports the production of knowledge with the experience of disability appropriately situated, centered, and validated. In tandem, a sharing of my methodological process for my doctoral research study is offered, as an exemplar of how a diverse bodymind can be situated, centered, and validated throughout all phases of the process and production of knowledge through qualitative inquiry.

Sample Chapter

"Nothing about us without us" (Charlton, 1998, p. 14). This phrase is a compellingly, powerful personal, social, and political one, suggesting that no representation of people with disabilities through policy, system, or structure should be devoid of the voices of people with disabilities. Additionally, there should be no movement through said policy, system, or structure without those it claims to represent. This phrase historically has many iterations and applications, however, an application to disability rights was noted by James Charlton in his 1998 book, *Nothing About Us Without Us: Disability, Oppression and Empowerment* when he recounted that he had overheard the phrase used by two South African disability rights advocates at a disability rights conference five years earlier.

Like Charlton, I maintain that the empowerment factor to this statement is that it problematizes how exclusion and peripheral treatment can be overt or subtle – and can occur through an elevation of specific narratives and language that craft policy, system, or structure to suggest that only certain experiences should inform and have space and place in representation. Charlton also posited that "power derives from its location of the source of many types of (disability) oppression and its simultaneous opposition to such oppression in the context of control and voice" (p.3). In the case of disability, this power would be evident in a policy, system, or structure that others non-normative functions of the body and mind. This type of power creates the concept of disability through attitudinal, social, political, environmental, educational, and other barriers to suggest impairment and diversity of body and mind are insignificant and relegated to the sidelines of society. How can such a statement begin the conversation of the situated, centered, and validated diverse bodymind in qualitative research? Action research, particularly the purposively co-partnered use of emancipatory action research, can provide a staging for this critical conversation. In the next sections of this chapter, I will describe action research and emancipatory action research; how they interconnect with disability; how my doctoral research methodologies embodied a positive provoking of cognizance and purposive responsiveness with respect to physical or intellectual access barriers to engagement with traditional standards of qualitative inquiry; and made the case that more diverse and inclusive methodological innovations are imperative to ensure more complete representations of the dynamics of the disability experience in qualitative research.

Origins of Emancipatory Action Research and Disability

Emancipatory action research can claim an origin in the disability rights movement, which sought to hold accountable social, political, and economic structures and systems that were disabling, seeking equal rights and representation (Mertens, 2015). One aim of the movement was to have equal voice and representation in research. The disability rights movement advocated that research not be done on the disability community, but instead with the community, in a way that promotes tangible, positive, and enduring changes and accurately reflects the lived experience of disability.

What is the transformative benefit of emancipatory action research? Team TVS published a video, *Transformative Research*, where Mertens explained research is often thought of as demanding a stance of detachment from the systems and structural politics that undergird the experiences of populations of study and contentious or otherwise sensitive topical engagements (Team TVS, 2011). Mertens contended that such a view of research is impractical, in that experience is contextually informed by culture, politics, economics, and society and cannot be divorced from the individual or the system in which they function (Team TVS, 2011). Recognizing a disparity in traditional research paradigms as not being proportionally preceptive regarding the needs of marginalized and underserved populations, the transformative paradigm took shape. The transformative paradigm contends with the interplay of context and the privilege of dominant groups, Mertens formulated the transformative paradigm to research to articulate the presence of power dynamics and a means to subvert them (Team TVS, 2011). Mertens (2007) explained that, in transformative research:

> The role of the researcher in this context is reframed as one who recognizes inequalities and injustices in society and strives to challenge the status quo, who is a bit of a provocateur with overtones of humility, and who possesses a shared sense of responsibility. (p. 212)

Emancipatory Action Research

Emancipatory action research is a type of critical inquiry that seeks to influence and transmute actions through a person-centered, contextualized, and issue-salient investigative approach to research as a means of exposing and destabilizing systems; and structures that legitimize repressive inequities toward those on the societal periphery because they do not conform to a dominant group (Ledwith, 2017; Noel, 2016). In turn, the nondominant, underrepresented group(s) are relegated to delimited space, restrictive access, and exclusion. Emancipatory action research is aimed at offering transformative action against power disparities, as “a process of producing knowledge that can be of benefit to disadvantaged people and its key aim is to empower its research subjects” (Noel, 2016, p. 457).

Emancipatory action research was used in this study to align with the spirit of the social model of disability, which demands targeted problematization of the systems, structures, interactions, spaces, and language that create and reproduce disability in society; and expects the participant in disability-focused research to be involved as an equal, emancipatory partner. Equally, emancipatory action research was employed to respect the central tenet of lifeworld, which is a holistic validation of individual experience. Emancipatory action research also acknowledges that reality has a descriptive and interpretive quality which is informed by “the pregiven world, the existent world as we find ourselves in it” and the manner with which we negotiate the complex intersections of self and being (Adams & Van Manen, 2008, p. 617).

Ledwith (2017) suggested that emancipatory action research is a uniquely positioned iterative style of action research in that it aims to problematize and bring democratic corrections to distorted tellings of reality and experience, perpetuated through unquestionable acceptance of reality as produced and reproduced through the systems and structures of those predominantly represented in society. The current state of the marginalized individual and their experiences are either consciously or unconsciously trammeled between that which promotes dominant narratives and justifications as to why a societal practice, attitude, or belief is the way it is (p. 49). In turn, this socially rationalized state of the marginalized individual and their experiences shapes the collective contours of how history and politics are understood and perceived to be reality. Emancipatory action research aims to enable freedom from restraint and inequitable power relations through purposeful attempts to provide a representative, centered voice to marginalized groups, offering counter-hegemonic interpretations of reality through “participation: all people involved come together as co-participants in a process of education for critical consciousness that informs action for social change" (Ledwith, 2017, p. 56). There is transformative value in emancipatory action research because it brings forward honest introspections and contextualized understanding of privileges, interests, and prejudicial systems and structures and effectively merges theory and practice with the intent of dislocating the researcher and inviting co-participation.

Stages of Emancipatory Action Research. Ledwith (2017) suggested a multi-stage process of active engagement to actualize an emancipatory spirit of societal changemaking and a shifting of leading and preferred narratives in society. She suggested that power dynamics at play in society often go unquestioned and the story told is often well-ordered and given primacy as reality. However, only with a critical, introspective observation of the interests such favored narratives serve and why the narratives exist, can society begin to see “different possibilities for changing the story and therefore changing the world” (p. 49). Ledwith also advanced several practical means to shift narratives through a strategic use of emancipatory action research. First, the stage of being involves the contemplative awareness of a condition or happening that requires some critical attention. Second, the stage of problematizing involves using some medium (audio, visual, etc.) to raise issues with salience and social consciousness, depicting the issue in context and real-time to, "generate interest and evoke feelings, a generative theme" (Ledwith, 2017, p.58). Third, conscientization is a stage that involves the issue being contextualized against social and political systems; and structures to identify and meaningfully engage with actionable steps of correction to the problem. In this stage, the dominant narratives and their incongruencies with the reality of the marginalized individuals are placed into critical questioning.

Fourth, the stage of action invites co-engagement and participation with the community in the tangible production of change products and centers counternarratives of the issue (Ledwith, 2017, p. 51). Fifth, the stage of making sense involves translating punctuating experiences and individual or group-centered meaning-making into comprehensible, practicable, and actionable steps toward critical consciousness raising so that there is an empathic understanding of systemic issues and a natural continuance of inquiry and meaningful progress. As part of the emancipatory action research framework, Ledwith (2017) suggested that it is important to critically consider what she terms evidence questions, and quality and validity questions.

Below are examples of evidence questions:

1. Is there a necessary justice orientation to the change effort being advanced?
2. Does the change effort advance improvement to validation, centering and representation, or values of dignity, mutuality, and respect?
3. Is the change effort advancing a liberty of some sort?
4. Is the result of the emancipatory action making an enduringly noticeable change?

5. Does the emancipatory action positively influence structures in society to make collectively beneficial decisions related to action, resource, and systems?

Below are examples of quality and validity questions:

1. Is the method selected appropriate for emancipation-focused action?
2. What was the impetus for the research being focused on change efforts from an emancipation-focused lens?
3. Who framed the issue of concern and how?
4. Are power dynamics critically examined? Is there co-partnership involved?
5. Are the societal structures and systems that influence the issue of concern appropriately and critically contended with?
6. Does the research influence various intersections of experience (e.g., race, disability, age, gender, sexual orientation, faith)?
7. How does emancipatory action research and more mainstream versions of action research connect?

Action Research

Action research occurs in-context and is concerned with investigating problems of professional practice in real-time. It intends to arrive at solutions that are equal parts systematic, practicable, and scalable for complex problems. Action research also contains four stages, which do not necessarily occur in successive order, but retain a protean and responsive quality, including planning, acting, developing, and reflecting (Mertler, 2019). The stylistic emphasis of action research is on relational connectedness, purposive observance, empathic understanding, and trust. It can be regarded to make the solutions to the abstruse more tractable (Bradbury et al., 2019). Bradbury et al. maintained that action research is attentive to the boundaries of evidence-based inquiry of the social world, but it is also tempered by the inclusion of the empirical, which can offer balanced solutions of relevance to complex problems. Within action research, there is a pervasive sensitivity to problem solving. With the qualities of purposeful engagement and dynamic responsiveness to problems and meaningful action plans, action research can invite new learning and enduring change efforts.

Bradbury (2015) emphasized that, "action researchers are concerned with issues that require social or fundamental change among multiple stakeholders where systems are at work, and systems-thinking is prominent or required" (as cited in Bradbury et al., 2019, p. 12). Therefore, to be effective, action research must invoke a process of honest introspection of individual or systems practices that may require collaborative intervention supports to improve a problem area. Additionally, action research has an intersectional quality, in that it is aimed at dynamic responsiveness to change and understanding. It involves human dynamics (e.g., professional, personal) with the power dynamics of systems (e.g., social and political) exerting influence over practices in some areas and seems to invite correction to "wicked problems" at the local and systems levels, exacting its participant's collaboration, communication, and practical problem-solving (Rittel & Webber, 1973, p. 160). Finally, action research seeks to bring sustained, participant-informed correction to the status quo, "interdependence among norms, rules, skills, and values creates a pattern called the status quo that becomes so omnipresent as to be taken for granted and to go unchallenged" (Argryris et al., 1985, p. xi).

Inclusion of Disability in Research

What are some best practices for the inclusion of disability in research? What are some common misconceptualizations of disability in research and why does it matter to problematize those? This brief examination will consider these questions from a disability studies perspective, using critical qualitative research as a basis. In *Centering Diverse Bodyminds in Critical Qualitative Inquiry,* Lester and Nusbaum (2021) advanced a convincing argument that qualitative inquiry, as it is contemporarily conceptualized and practiced, legitimizes exclusionary, inaccessible, and inequitable methodologies that prejudice normative means of designing and implementing qualitative research. Qualitative research conducted in this manner is viewed as valid and rigorous, because it conforms to the typical physical and intellectual access of the standardizations and engagements with a qualitative inquiry. Any research methodology that deviates from this standard is relegated to a state of other, unrenderable, obscure, and threatening (Lester & Nusbaum, 2021).

Equally important is safeguarding the holistic and authentic quality of the disability biography, allowing it to be claimed by those who own its realities and any knowledge constructed from, and given perspective through, the lived experience of disability, should be appropriately centered. Lester and Nusbaum (2021) advocated being mindful to consider impairment and disability experience in all phases of research. The overarching question they asked was - is the design of your research and the way you are engaging with it equal parts representative, equitable, and accessible, considering the dynamics of impairment and disability experience superimposed on one's participation with and through the research process and products?

Two guiding principles of any inclusion of disability in research are the participant being involved as an equal, emancipatory partner (Barnes, 2003); and the research centering and validating the individual experience in a way that allows the individual to retain ownership of their experience.

Ferguson and Nusbaum (2012) characterized disability studies as "the interdisciplinary study and representation of the concepts, cultures, and personal experiences of disability in all its variations" (p. 70). They put forward five fundamental concepts of disability studies to include what scholarship including disability should consider and "put some flesh on to the bare bones of rhetoric about what is different and important about disability studies" (p. 72):

1. "The study of disability is social" (p. 72). Disability is understood from this perspective as a socially imposed consequence of impairment, with disability not originating from the pathological issue(s) one contends with in the negotiation of everyday life. Disability is a systems and social structure response to impairment, exacting barriers of access (e.g. physical, academic, attitudinal) and full participation on the basis of bodily or intellectual functioning differences. Best practices in scholarship states that such a conceptualization of disability provides a way of cognitively contending with understanding why disability is produced and reproduced in society the way it is. Equally important, the tragedy is not befallen on the presence of human

difference, but on the rebuff of that difference through systems and social structures that other it and allow impediments to inclusion and participation. By situating the experience of disability as social, disability research can more effectually problematize, critically question, and analyze the complexities of barriers that superimpose on human difference, and bring corrective action, "disability studies can contribute a social perspective from which to view and interpret scientific findings. Indeed, for most disability studies scholars, this is not really a choice. All research, all knowledge exists unavoidably in a cultural and historical context" (p. 73).

2. "The study of disability must be foundational" (p. 73). The purpose of disability studies could be not to understand disability as an experience in isolation from the rest of the human condition, but to better appreciate the human condition and how disability intersects with our understanding of ourselves, holistically. Disability is a part of identity, one that is intersectional with race, class, sexual orientation, and gender. "Disability studies is arguing that the issue is more than the distortion of science by social intrusions of systemic injustices such as racism, sexism, and poverty. Throughout history, the label of 'disability' has functioned as an accusation more often than an assessment" (p. 73).
3. "The study of disability must be participatory" (p. 74). This concept is imperative to have an authentic voice given to the experiences of impairment and disability by and through the individuals for whom it is a lived reality. In

other critical fields, scholarship is primarily led by those who represent a specific demographic. Disability research and practice should also be led from the vantage point of first-hand experience. Individuals with disabilities should be afforded a co-partnership in the types of research questions asked, who asks them, and how such questions are engaged with.

4. "The study of disability must be interdisciplinary" (p. 74). The study of disability deserves full expression and outlets to turn a critical light on the negotiated experience of impairment and the societally narrativized result that is disability. The intent of interdisciplinary study is integration – open, layered, and constructively critical dialogue about how something is produced and reproduced in society through history, the arts, and humanities, and how it's understood through the lens of legal, political, and applied fields. One nearsighted interpretation of the interdisciplinary approach in the past was that disability was the convergence among special education and rehabilitative interventions, with a fixation on "the main goal of learning how to teach and how to support individuals with disabilities" (p. 74). Interdisciplinary approaches to disability should extend beyond the business, medicalization, and special education of disability to truly accomplish the goal of integrated, critical thought about the experience of impairment and the production of disability. "Truly interdisciplinary (and not just multidisciplinary) disability studies can only flourish if the orientation and insights it makes possible are available to all parts of the academy" (p. 74).

5. “The study of disability must be values-based” (p. 74). The social model of disability advocates for disability research that focuses on issues of importance to the community, and positive change to lived experience. The lived experience must remain the focal point because disability is seen as produced by tangible and intangible societal barriers that create and reproduce disability in society. Therefore, to be effectual, emancipatory partnership with individuals who experience disability is paramount, with careful attention paid to the individual experience. Advocacy, empowering inclusion, and emancipatory-focused change is a common and customary thread in scholarship. However, values-based approaches are multifarious and compounding. Researchers focused on ideological purity maintain that the business, medicalization, and special education to support disability serve only to reinforce othering and overbearing treatment of disability (p. 75). This focus discounts researchers in the profession making good faith efforts for meaningful transformation of these negative tones in systems of support. Because society is content with an unhurried pace of change, change will unfortunately remain piecemeal and painfully gradual.

Because the current research study involved personal, narrative storytelling to provide a situated, centered, and validated representation of individual experience with disability, this section explains why narratives have power in conveying the individual experience of disability.

Narrative and Disability

Green and Loseke (2019) stated that, "narratives are omnipresent in all levels of social life…narrative is a meaning-producing communication form and relatively shared meaning is necessary for individual well-being and for social organization" (p.2). There is a dynamic interplay between the individual, the social, and the cultural when considering how narratives are constructed. First, how one relates to, consciously thinks about, reasons for, or recalls an event, is a narrative nucleus in which, "plots transform what otherwise might seem random events into patterns" (p. 2). Second, the way the narrative openly shares the mental perception and reaction to an event is a critical element. Third, narratives evoke introspection on the morality of given choices and behaviors and provide an outlet to express what one feels is acceptable or unacceptable.

The personal tragedy orientation of disability, normalized or otherwise fixed by some manner of intervention, is commonly rejected among disability scholars, and instead, there is a promoting of narrative constructions that problematize societally imposed restraints, overt or subtle controls, inequitable power relations, and dynamics that result from barriers that produce disability (Green & Loeseke, 2019; Oliver, 2013). There needs to be a critical reexamination of insistence upon narrative constructions of disability from an inflexibly stringent focus using the social model perspective. Some researchers caution that failure to do so, “may neglect, or even repress, the telling of disability stories that do not neatly conform to the primacy of social oppression central to the social narrative plot” (Darling, 2013, Shakespeare, 2014, Siebers, 2006, as cited in Green & Loseke, 2019, p. 3).

Smith and Sparkes (2008) proposed that the qualitative weight of the narrative is situated in its ability to allow stories to aid in the sense-making of live events, self, being, and identity. The narrative is a “storied effort” (Bruner, 2002, as cited in Smith & Sparkes, 2008, p. 18). It is suggested that the narrative is constituted from the struggle of making sense and giving structure to our understanding and knowledge about our lived experience that is given articulated voice through the narrative. “The stories people tell are useful as they ‘impart’ information about their or others’ ‘internalised’ world” (Smith & Sparkes, 2008, p. 18).

Additionally, the narrative is not inherently instinctive or organically occurring, but mediated through the interaction of society and culture that make up the narrative that is shared (Smith & Sparkes, 2008). The narrative invites an understanding of the interplay between time and space and how such negotiations of being in the world directly impact that which is expressed and personified in real life. An endowed power of narratives concerning disability and impairment is in its ability to help the storytellers reclaim self and identity from the imposing attitudes, beliefs, values, and structures that perpetuate disability. The emancipatory power of narratives of disability and disability studies is strengthened by the utility to “refuse and displace the tragedy story, that challenge and resist social oppression and that allow different body-self relationships to emerge” (Smith & Sparkes, 2008, p.19).

Multimodal Method Engagement

Utilizing narrative inquiry or storytelling, a total of six study participants engaged in multimedia discussions (Coghlan & Brydon-Miller, 2014; Kartch, 2017). Rapport building as part of the engagement method was critical. Initially, the researcher planned to engage in the pre-discussion activities listed below during production setup for the discussion. This plan was modified, following feedback from the first participant that while they were listening intently and attempting to engage, they were noticeably distracted by the behind-the-scenes pre-production setup (e.g., camera tests, sound level checks, set reconfigurations). As a result of this feedback, the pre-discussion activities were completed at least 24 hours in advance of the recorded discussion. All participants reported that this context was helpful to them because it expanded their understanding of disability and clarified research aims.

Pre-Discussion Activities

- Share with the participant the open, validating, centering intent of the discussion style
- Share with the participant my own experiences and background of disability and assistive technology
- Share disability reclamation statement
- Briefly share about the social model of disability

Active and deep listening in the discussion was a requisite to the discussion for purposes of participant centering and validation of individual experience which elicited more breadth and depth concerning phenomenological factors central to the study.

The inherent power of the multimedia narrative inquiry is that it offers a space for minimally filtered accounts of experience, that add an invaluable dynamic that “allows the researcher to hear and see the gestures, intonation, passion, pauses, and inflections throughout the analysis process” preserving participant's voice (Crichton & Childs, 2005, p. 42). During the deep listening phases of analysis, these dynamics were factored into selected clips, and they were edited to share the story. Crichton and Childs maintained that such a method deemphasizes the static written word of a transcript, favoring the full, nuanced context of audio and video and providing a dynamic preservation of the participant’s voice.

Informed by aspects of Coghlan and Brydon-Miller (2014), Crichton and Childs (2005), and Kartch (2017), the interview / discussion protocol followed a predominately unstructured questioning style. This questioning style aligns with Coghlan and Brydon-Miller (2014), Kartch (2017), and Walker and Boyer (2018), who all advocate for open, unstructured questioning that effectively invites the narrative rather than leading the interviewee. This approach allowed for the story to be told organically, capitalizing on how meaning is made from experience and how it informs one's sense of self and belonging. Such an approach simultaneously provides tempered direction to the telling of the story to effectively capture data that is meaningful to the scope of the research interest (Kartch, 2017). It should be noted that where appropriate, questions may have been asked, rephrased, or arranged in such a way to provide a sense of relationship to time to support the participants telling of their experience (Ayres, 2008). When needed, organizing questions in this way allowed participants the autonomy to underscore those events that are meaningful to them. Such prompts provided context to the primacy of that event in their life. Ayres explained, “the content and structure of the narrative contain implied meanings that are as important to understanding the narrative as the overt meanings—and perhaps more important” (p.1). Therefore, prompts were organized in a horometrical manner, when this was supportive for the participant, so as to mirror the flow of one’s lived experience.

In keeping with the spirit of the emancipatory, accessible research methods advocated by this action research, it planned for instances in which the nuanced nature of the open, indirect, unstructured discussion was not suitable. To ensure full, equitable, participatory accessibility, an alternative had to be devised. There was one such instance during the recorded discussions. For this participant, a more direct questioning style was employed to support the participant. The researcher supported participant needs and engagement preferences by merging discussion protocols when it was observed that the primary protocol was causing participant distress, and/or the participant presented with recall difficulties, which would be better supported by more direct questions.

Multimedia discussions (i.e., video and audio) were captured with technical assistance in three phases. The first phase was guided by open-ended or direct questions, as per participant preference, with the participant responding freely, with negligible levels of interruption. This phase of questioning aligned with lifeworld fractions and allowed participants the opportunity to share how they described and adapted to a negotiated existence with and through dyslexia and assistive technologies from a lifeworld perspective (Ashworth, 2003; Andrews, Hodge & Redmore, 2019). The second phase of questioning was reserved for gathering more information/clarifying details from participants about events and experiences. Typically, follow-up questions were asked immediately following the primary question(s). In the third phase of questioning, an optional multimedia discussion was reserved for the intent of addressing targeted questions to elucidate specific data/details on an as-needed basis. In acknowledgment of the nature of disability impacting not only myself, but the participants, one must consider any difficulty in immediate recall of intended follow-up questions. The researcher engaged with participants on an as-needed basis using asynchronous means of follow-up questions suitable for the participant to gather needed detail, which included emails, journaling, and recorded in-person or phone conversations, per participant preference. Of the participants that participated in follow-up questions, three participants preferences were for email to allow the participant time to process through their intended responses. One participant who opted to participate in follow-up questions felt more comfortable with an in-person, audio recorded discussion for the processing of intended responses. All participants who participated in the third phase of discussion, as part of this follow-up, were asked questions 19, 20 and 21 of the discussion/interview protocol (see Appendix B) to get their perceptions of the co-partnered research experience and whether they viewed it as; accessible, inclusive, equitable, centering, validating and representational. Immediately following the multimedia discussions, post discussion memos were drafted. The post memo is a technique encouraged by deep listening, where the researcher ruminated openly on the strength of rapport established with a participant. The post discussion memos are evidence of tangible and intangible situational factors and tone, in conjunction with the meaningfulness of the bond and mutuality of "an interaction between two embodied individuals" that affected the quality and outcome of the interview (Hart, 2021, p. 1). Hart also suggested that it is important to account for any actual or perceived impediments to the free-flow nature of the narrative.

Editing and analyses of the video data was completed with Transana, which offers flexibility in the preparation, treatment, and analysis of multimodal qualitative data – allowing the user a dynamic means to identify recurrency in relationships, patterns, and threads of meaning in multimedia datasets. As an analytic support tool, it allows individualized customizations to the process of analyzing an intermix of data including video, audio, textual, and photographic data into a cohesive single array (Mavrikis & Geraniou, 2011; Rush, 2014). Transana served as assistive technology during the analytical process for me, as a researcher with multiple disabilities. Assistive technology is recognized as, "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (Technology-Related Assistance to Individuals with Disabilities Act of 1988; 29 U.S.C 2202, p. 3).

Transana, by this definition, is a product system, acquired commercially that increased and improved my functional capabilities, allowing me to meaningfully engage with qualitative research and sense make in a manner that provided me equal physical and intellectual access to the research space. From an emancipatory perspective, Transana was selected because the traditional mode of coding presents physical and intellectual access barriers for me. The traditional mode of coding and analysis is incongruent with how I perceive, receive, and process information for analytic means. Transana also assisted in the analytic process, aiding in more efficient and precise identification of analytically appealing and thought-provoking connections between data. Additionally, Transana is dynamically responsive to the analytic needs of the researcher and the uniqueness of multimedia data. For example, data can be organized into collections and then categorized, rather than confining analysis to traditional methods of coding.

Editing of each installation of the participant-centered series was identified as "emergent storylines" in multimedia research (Knoblauch & Tuma, 2011, as cited in Walker & Boyer, 2018, p. 9). In this part of the process, data was meticulously scrutinized for "divergent statements . . . convergent statements . . . and unexpected statements" (p. 9). To access emergent storylines, participant narratives were strategically and cohesively intermingled in the editing process to illuminate naturally occurring points of divergent statements, convergent statements, and unexpected statements.

Along with deep listening, reflection and editing the participant voices and representations of disability were recorded. Additionally, a synthesis of individual experience was accentuated that such intentionality to the editing and analysis process allowed for organic development of divergent statements, convergent statements, and unexpected statements. It is in keeping with the emancipatory nature of the study and the invitation to the reader/viewer to co-construct meaning with the researcher. There was no engagement in, or an imposition upon the reader's/viewer's sense making. In response to the question, *how do postsecondary students with dyslexia describe and adapt to a* *negotiated existence with and through dyslexia and assistive technology from a lifeworld perspective,* there were standout observations from the discussions and video data that resulted in bright spots.

Bright Spot 1 - Dyslexia is an Asset

Participants shared that the diagnosis of dyslexia took an asset orientation for them in that, the experience helped them to see the world differently, and helped them solve practical problems in a non-standard, hyper creative way. Dyslexia was not a determinant of their ability, but an experience that accentuated other ways of doing things. In conversation with the participants, each person found value in their disability experience by accepting who they are, and how they learn and interact with the world.

Bright Spot 2 - Dyslexia Allows for Perceptive, Divergent, Lateral Problem Solving and Creativity

Participants mentioned being able to be more perceptive, and more divergent in their thinking and solutions. They saw themselves as non-linear in the way they receive, perceive, and interact with information, and are more intuitively creative in the way they negotiate the world. This was observed as a sort of empowerment in that they did not focus on the delay or deficit but owned the transformative power in accepting themselves and non-normative ways of being and doing in the world.

Bright Spot 3 - Dyslexia is a Pervasive Part of Experience and is an Accepted Part of One's Negotiated Reality

During discussion with the participants, the researcher asked, “Thinking about the disability reclamation statement I shared with you before our discussion began, can you tell me what a statement like that may say about you, your experience and perception of dyslexia?" Participants were observed centering responses that acknowledged dyslexia but did not allow it to define their realities. Throughout the conversation, they talked about difficulties with reading, writing, processing, and expressing that were inescapable. The participants chose to positively reclaim the experience and validate it as part of themselves and their being.

Bright Spot 4 - Assistive Technology Acceptance or Abandonment is Contextual

Another bright spot of the research was that AT acceptance and/or abandonment was contextual, meaning that there may be some flux in what someone uses, and how and if they use AT and when. Participants reported that acceptance of AT often occurred if they could see a practical application (and effectiveness) to it with respect to their dyslexia (reading, writing, expressing). However, AT was sometimes abandoned because of inconvenience, a lack of usability/overly complex instructions, personal preference for other strategies that they viewed as more engaging, and public stigma. Overall, AT was accepted in academic settings, but often abandoned in non-academic environments.

Bright Spot 5 - Assistive Technology can Transition from a Cognitive Prosthesis to a Cognitive Partner

AT could be looked at from the perspective of a cognitive prosthesis or an augmenting, rehabilitant, compensating or bypass of some functional skill deficit. At the same time, AT can also transition to a cognitive partner that supports the individual in the learning environment in a way that is actively supporting the process of learning (Cavalier et al., 1994, as cited in Holmes & Silvestri, 2012). This bright spot showed that, if appropriately matched to the student, environment, and tasks – AT will effectively and progressively promote empowerment and independence. As reported by participants, AT was a cognitive partner that allowed equity in spaces of expression, and one participant shared that AT also enabled independent learning and consuming of information.

Deep Listening

Lavee and Itzchakov (2021) defined effective, deep listening as listening beyond the superficial layers of what is being said and being perceptively present. Deep listening is done with impartiality and emotional investment to appreciate and understand diversity in meaning-making. Additionally, purposeful listening rests on "the researcher's ability to acknowledge the uncertainties and complexities in the participants' worlds in effort to disentangle their 'messes of reality'" (Law, 2004, as cited in Lavee & Itzchakov, 2021, p. 8). Deep listening is about relational connectedness through mutual vulnerability, and the researcher-participant relationship is one of genuine sensitivity in representation (Hart, 2021).

Deep listening is also listening to (and processing through) not only spoken words, but the emotive drivers of those words. In this way, deep listening is "more than hearing the words but includes a way of 'opening ourselves' to the other" (Hart, 2021, p. 2). The narrative in deep listening is attended to for subtle, tacit layers of meaning, meaning making, and context, "listening mixed with perception in which one can hear the emotions of the other" (p.2). Finally, deep listening was used in this research study to examine data for 'bright spots' related to lifeworld fractions, disability, and assistive technology.

The multimedia discussion was organized into a participant-centered video series, with the experience of postsecondary students with dyslexia and assistive technology situated against the eight fractions of the lifeworld to include selfhood, sociality, embodiment, temporality, project, discourse, and moodedness. There were four explicit steps used in this process:

1. There was a deep listen to each participant discussion and the start/stop time of each topic was noted. Key takeaways were noted by each topic, for each participant.
2. There was a deep re-listening by topic of each participant; using key takeaways from the previous time codes and were marked for the key takeaways in Transana. At this stage of the process, similarities and differences were noted, and takeaways were grouped together.
3. There was a compiling of topics with key takeaways from the video clips. Each topic was watched seven times. With each deep listen, patterns of convergence, divergence and emergence were noted, and a decision was made regarding which pattern most cohesively told the story. The specific time codes were marked where convergence, divergence, and emergence patterns were noted among narratives.
4. Using my notes and what I heard during the seven deep listening sessions to each topic, I wove the story of the topic by editing into video clips that cohesively told the story of the topic and the broader lifeworld perspective of

describing and adapting to a negotiated existence with and through dyslexia and as an AT user.

Through deep listening, I began to see how layers of experience made up how they described and adapted to a negotiated experience with and through dyslexia and as an AT user – and how the fractions of experience were evident in how they described it.

Innovation

The innovation brought an open challenge to the normate of qualitative methods for the researcher, as someone with a diverse bodymind, and for the research participants. For the participants, the design of the study allowed them space to consider their experience of dyslexia and as an AT user, from a perspective that they had not consciously considered before, aiding in emergence of awareness that the experience of dyslexia and that of an AT user, is one mediated by many dynamics and negotiations, both conscious and unconscious. The responses in the discussions have supported the idea that diverse bodyminds can be situated, centered, and validated throughout all phases of process and production of knowledge in qualitative inquiry.

With careful consideration, the call for “nothing about us without us”, can be realized in a vivid and compelling way that aligns with the expectations of disability in research. This request can be a positive change in the disability experience, increase cognizance toward barriers that produce and reproduce disability in society, encourage co-partnership in the process and production of knowledge with those who experience disability, build an awareness that disability should not be on or about a person with impairment, but fully represent that experience in a manner that allows empowered ownership of it.

Lastly, there is an invitation extended to the reader regarding the critical consideration of the issue of accessibility and equity in qualitative inquiry and the need to provide a space for co-constructed meaning through intentional use of multimodality of method. If truly situated, then diverse bodyminds can offer a more complete and empathic understanding of human difference and the value-add given to descriptions and adaptations made to collective negotiated realities, with and through diversities that make people unique. Disability does not need to be muted in the voicing of experience simply because the experience may run counter to the normate.

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APPENDIX A

METHODOLOGICAL TOOLS AND PROCESS EVIDENCE

Photo 1: Sticky note organization system. Question 2 about daily life and academics.

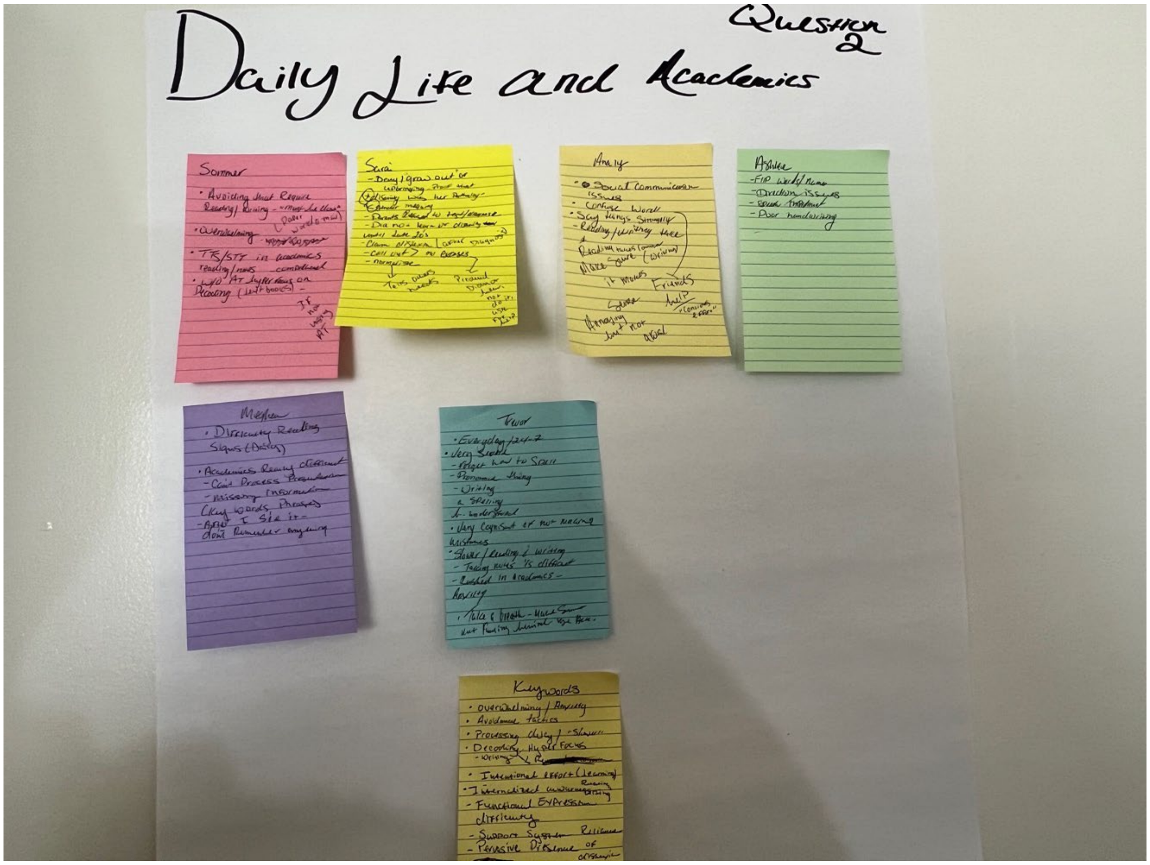
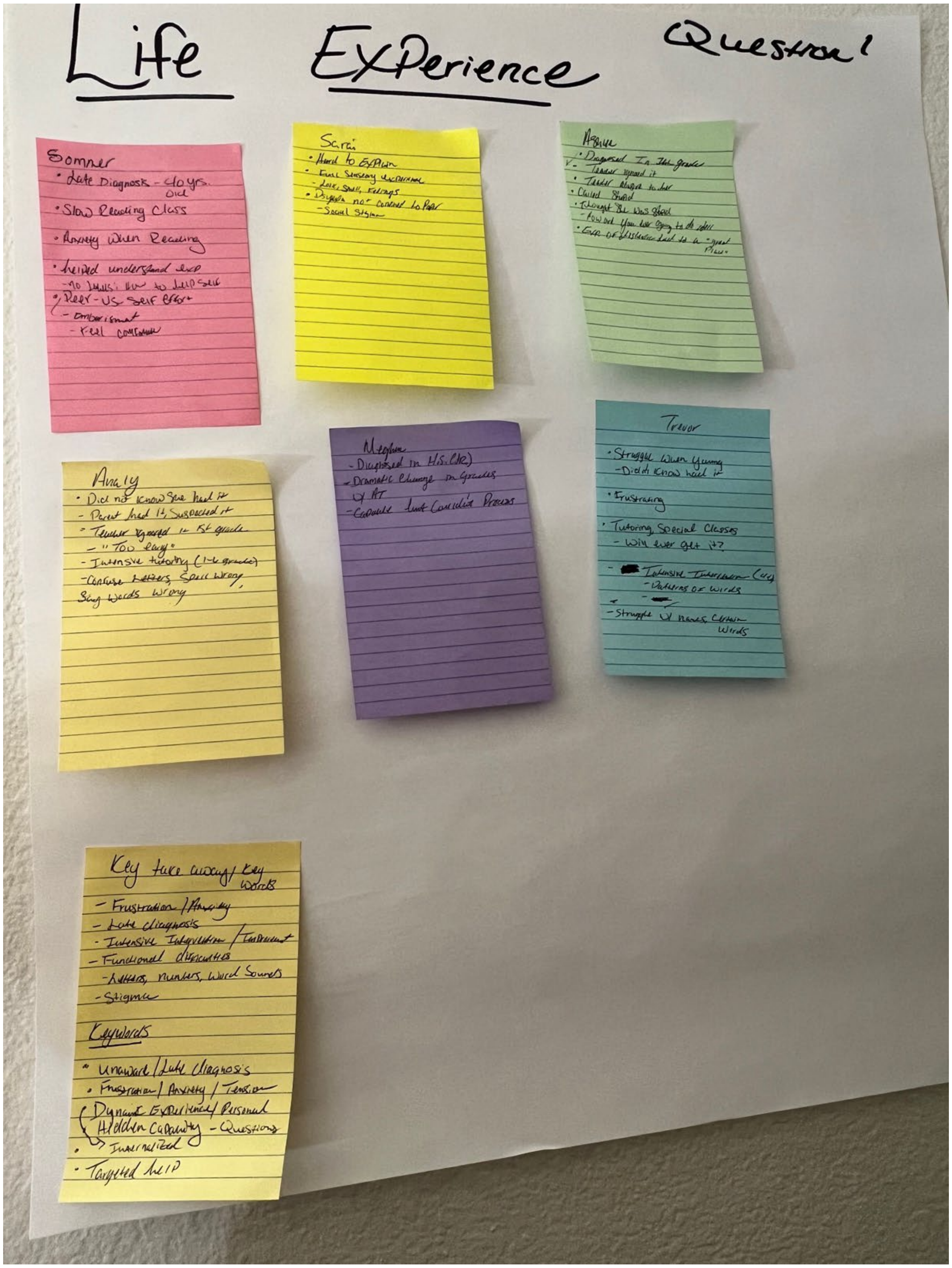


Image description: Seven colorful, long, lined sticky notes with handwriting under the main topic “Daily Life and Academics”

Photo 2: Question 1 about life experience



Life Experience

Question 1

Somner
- Late Diagnosis - 40 yrs. old
- Slow Reading Class
- Anxiety When Reading
- helped understand exp
  - no skills: how to help self
- Peer - vs self effort
  - embarrisment
  - feel comfortable

Sarai
- Hard to Explain
- Full Sensory experience
  - Look, Smell, Feelings
- Dyslexia not connected to Peer
  - Social Stigma

[illegible]
- Diagnosed In 3rd grade
  - Teacher ignored it
- Teacher [illegible] to her
- Called Stupid
- Thought She was stupid
  - How are you ever going to do this
- Ever of dyslexia lead to a "great place"

Analy
- Did not know she had it
- Parent had it, Suspected it
- Teacher ignored it 1st grade
  - "Too lazy"
- Intensive tutoring (1-6 grade)
- Confuse Letters, Spell wrong, Say words wrong

Meghan
- Diagnosed in H.S. (JR)
- Dramatic Change in Grades w/ AT
- Capable but Curriculum Process

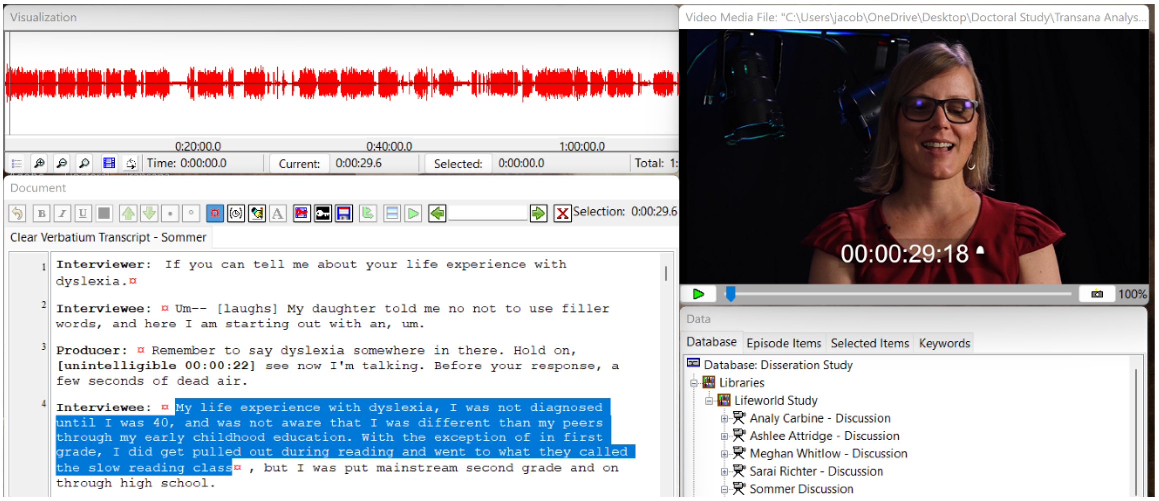
Trevor
- Struggle When Young
  - Didn't know had it
- Frustrating
- Tutoring, Special Classes
  - Will ever get it?
- [redacted] Intensive Intervention (4th)
  - Patterns of words
  - [redacted]
- Struggle w/ names, certain words

Key take away/key words
- Frustration / Anxiety
- Late diagnosis
- Intensive Intervention / Treatment
- Functional difficulties
  - letters, numbers, word sounds
- Stigma

Keywords
- Unaware / Late diagnosis
- Frustration / Anxiety / Tension
- Dynamic Experience / Personal Hidden capacity - Questions
- → Internalized
- Targeted help

Image description: Seven colorful, long, lined sticky notes with handwriting under the main topic "Life Experience"

Photos 3: Transana Screenshot



1 **Interviewer:** If you can tell me about your life experience with dyslexia.¤

2 **Interviewee:** ¤ Um-- [laughs] My daughter told me no not to use filler words, and here I am starting out with an, um.

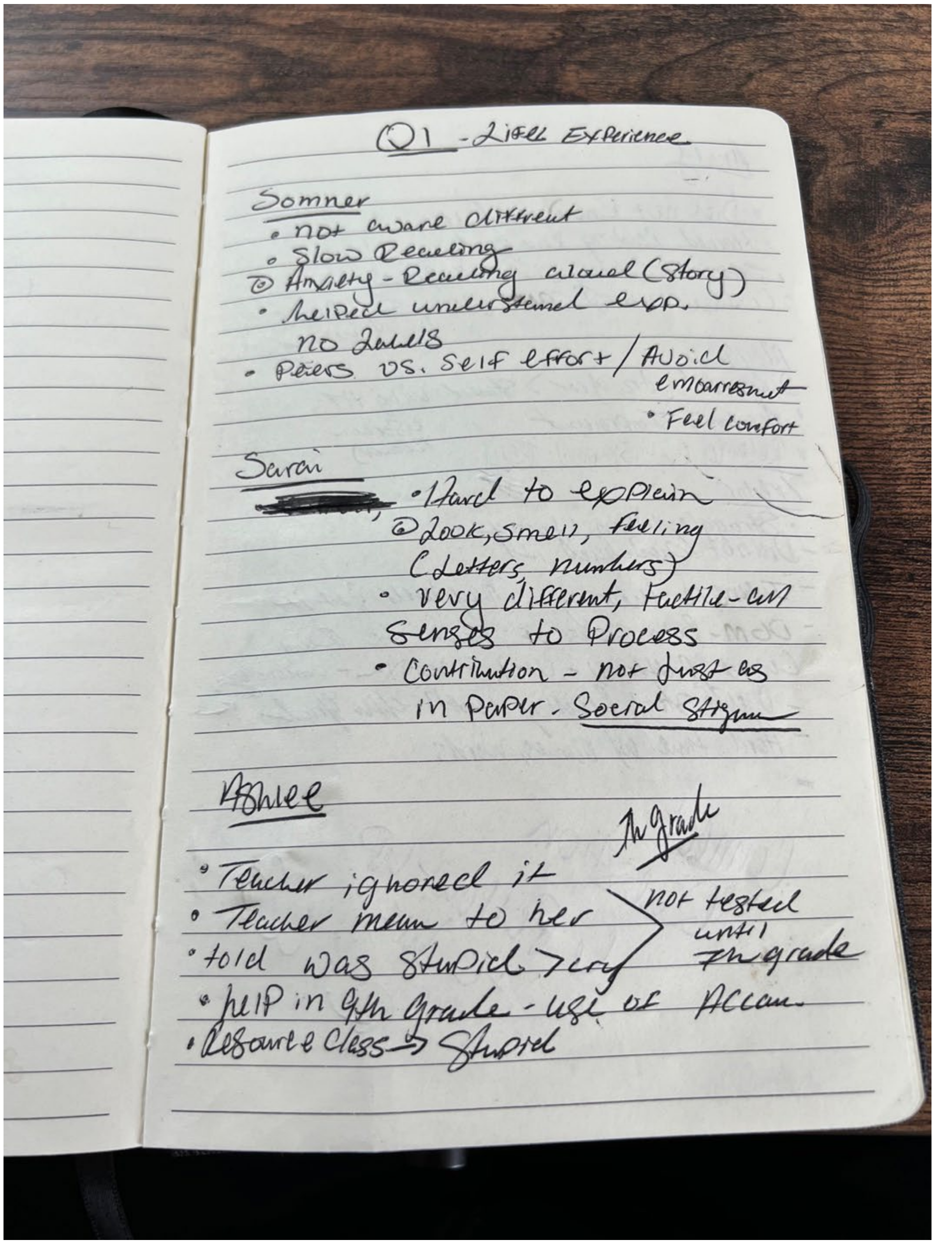
3 **Producer:** ¤ Remember to say dyslexia somewhere in there. Hold on, **[unintelligible 00:00:22]** see now I'm talking. Before your response, a few seconds of dead air.

4 **Interviewee:** ¤ My life experience with dyslexia, I was not diagnosed until I was 40, and was not aware that I was different than my peers through my early childhood education. With the exception of in first grade, I did get pulled out during reading and went to what they called the slow reading class¤ , but I was put mainstream second grade and on through high school.

Image description: Software screenshot with four quadrants. Upper left quadrant is a representation of the sound wave. Bottom left quadrant is the verbatim transcript. Upper right quadrant is the video image. Bottom right quadrant is an organizing screen with database, episode items, selected items, and keywords.

Transana Video Guides can be found by visiting: https://www.transana.com/tutorial/

Photo 4: Written memos – research notebook



Q1 - Lifel Experience

Somner
- not aware different
- Slow Reading
- ⊙ Anxiety - Reading aloud (Story)
- helped understand exp.
  no labels
- Peers vs. Self effort / Avoid embarresment
  - Feel comfort

Sarai

[redacted]

- Hard to explain
- ⊙ Look, smell, feeling (Letters, numbers)
- very different, tactile-all senses to Process
- Contribution - not just as in Paper. Social Stigma

Ashlee

~~7th grade~~

- Teacher ignored it
- Teacher mean to her
- told was stupid > cry

> not tested until 7th grade

- help in 9th grade - use of Accom.
- Resource Class → Stupid

Image description: A page of a notebook with notes from Question 1 "Life Experience"

Post Discussion Reflection Memo Example

Ashlee and I were able to build a strong rapport, beginning with the pre-discussion phase, in part due to similarities in our experience with, description of, and negotiation of dyslexia, including how that experience is mediated through assistive technology. Ashlee openly shared sentiments related to her experience that I could directly relate to. For example, she shared a Christian perspective which holds that all things are redeemed in Christ, including our outlook and attitude with respect to our struggles in life.

Some situational factors that impacted the outcome of the interview were that Ashlee was very engaged in the interview process, she exhibited a strong asset mindset with respect to her experience, and she was quick to respond to most questions, which was somewhat hard for me to process and keep up with. This interview did require more immediate follow up from me during the interview for clarification purposes, as some of the narrative shared was not clear in its relation to the question asked, and some responses lacked context. Irrespective of the fast pace of the interview, the occasional misreading of questions by Ashlee, and the sporadic lack of context, I did not entertain any assumptions, appraisals, and interpretive filtering, wanting to authentically give a centering, safe space for Ashlee to voice her experience.

Accounting for actual and perceived impediments to the free-flow nature of the narrative, some actual impediments were continually distracting, such as background noise, throughout the interview, which interfered with the recording process. Perceived impediments were (a) presence of off topic responses, (b) interview pacing, (c) occasional disjointed responses, making the follow up process necessary and complex to attend to, and (d) comment was made about if the question style selected, and the responses given, satisfied what the research was looking for.

APPENDIX B

IRB APPROVED PROTOCOL

	Page: 1 of 7
	PREPARED BY: IRB Staff APPROVED BY: Heather Clark

DOCUMENT TITLE: HRP 503 A Social Behavioral Protocol	DEPARTMENT: Office of Research Integrity and Assurance (ORIA)	EFFECTIVE DATE: 03.03.2023

ASU Knowledge Enterprise Development
ARIZONA STATE UNIVERSITY

INSTRUCTIONS

Complete each section of the application. Based on the nature of the research being proposed some sections may not apply. Those sections can be marked as N/A. Remember that the IRB is concerned with risks and benefits to the research participant and your responses should clearly reflect these issues. You (the PI) need to retain the most recent protocol document for future revisions. Questions can be addressed to research.integrity@asu.edu.

IRB: 1. Protocol Title:

Assistive Technology and the Lifeworld of Postsecondary Students with Dyslexia, Understanding 'Fractions' of Experience: Advancing Accessible and Inclusive Methodological Innovations for Improved Representations of the Dynamics of Disability Experience in Qualitative Research.

IRB: 2. Background and Objectives

2.1 List the specific aims or research questions in 300 words or less.
2.2 Refer to findings relevant to the risks and benefits to participants in the proposed research.
2.3 Identify any past studies by ID number that are related to this study. If the work was done elsewhere, indicate the location.

TIPS for streamlining the review time:

✓ Two paragraphs or less is recommended.
✓ Do not submit sections of funded grants or similar. The IRB will request additional information, if needed.

Response:

2.1 This study will be conducted to (1) more dynamically understand how postsecondary students with dyslexia describe and adapt to a negotiated existence with and through dyslexia and assistive technology from a lifeworld perspective – and how co-partnership can center and validate the disability experience, (2) to problematize limitations in qualitative research related to equitable representation of disability and barriers to engagement with traditional standards of qualitative inquiry, advancing accessibility and inclusive methodological innovations for more complete representations of the dynamics of the disability experience in qualitative research.

2.2 This study is low-risk, action research-based, and is intended to support the local context.

IRB: 3. Data Use - What are the intended uses of the data generated from this project? Examples include: Dissertation, thesis, undergraduate project, publication/journal article, conferences/presentations, results released to agency, organization, employer, or school. If other, then describe.

Response:

The data from the study will be used in; (1) dissertation, (2) book and related publications, (3) journal articles, (4) scholarly conferences (5) presentations. Results may be released to the institution and to participants.

IRB: 4. Inclusion and Exclusion Criteria

4.1 List criteria that define who will be included or excluded in your final sample. Indicate if each of the following special (vulnerable/protected) populations is included or excluded:

- Minors (under 18)
- Adults who are unable to consent (impaired decision-making capacity)
- Prisoners
- Economically or educationally disadvantaged individuals

4.2 If not obvious, what is the rationale for the exclusion of special populations?
4.3 What procedures will be used to determine inclusion/exclusion of special populations?

TIPS for streamlining the review time.

- ✓ ☐Research involving only data analyses should only describe variables included in the dataset that will be used.
- ✓ ☐Course evaluation data: if there is any intent to use the course evaluation data for research, submit to the IRB to get approval.
- ✓ ☐For any research which includes or may likely include children/minors or adults unable to consent, review content [here]
- ✓ ☐For research targeting Native Americans or populations with a high Native American demographic, or on or near tribal lands, review content [here]
  For research involving minors on campus, review content [here]
- ✓ ☐Research involving broader ASU student community where students are recruited outside IRB Principal Investigator's unit requires Provost Committee Approval. Please reach out to shelly.potts@asu.edu for questions regarding this process.

Response:

Minors, adults who cannot consent, and prisoners will be excluded from the study. Pregnant women, Native Americans, undocumented individuals, and economically or educationally disadvantaged individuals will not be excluded, but they are not being specifically recruited for the study.

IRB: 5. Number of Participants

Indicate the total number of individuals you expect to recruit and enroll. For secondary data analyses, the response should reflect the number of cases in the dataset.

Response:

In all, 6-10 participants with dyslexia as a documented diagnosis will be recruited and enrolled in the study. Participants may be (1) current, registered students within Student Accessibility and Inclusive Learning Services, or (2) recently 'archived', alumni within Student Accessibility and Inclusive Learning Services, (3) participants must have on campus designation or for recent alumni, must be in the local area.

IRB: 6. Recruitment Methods

6.1 Identify who will be doing the recruitment and consenting of participants.
6.2 Identify when, where, and how potential participants will be identified, recruited, and consented.
6.3 Name materials that will be used (e.g., recruitment materials such as emails, flyers, advertisements, etc.) Please upload each recruitment material as a separate document, Name the document: recruitment_methods_email/flyer/advertisement_dd-mm-yyyy
6.4 Describe the procedures relevant to using materials (e.g., consent form).

Response:

6.1 The Co-PI will be doing the recruiting and consenting. Student participants will be informed of the study and allowed to opt-in via communications sent on behalf of CO-PI from ASU Student Accessibility and Inclusive Learning Services. At the advisement of SAILS leadership, to protect student confidentiality, recruitment messaging will be sent on CO-PI behalf by Access

Consultants who have students that fit the criteria. CO-PI works for Student Accessibility and Inclusive Learning Services and will obtain permission for recruitment for SAILS leadership.

6.2. Co-PI will identify, recruit and consent qualified students from ASU through email. Recruitment will take place June-July 2023. Location: 1150 East University Drive, University Center, Building C – Suite 100L1, Tempe, AZ 85281

6.3 The Recruitment Consent Letter is attached.
6.4 Consent will be obtained by signed consent (physical signature) via email.

IRB: 7 Study Procedures

List research procedure step by step (e.g., interventions, surveys, focus groups, observations, lab procedures, secondary data collection, accessing student or other records for research purposes, and follow-ups). Upload one attachment, dated, with all the materials relevant to this section. Name the document: supporting documents dd-mm-yyyy
For each procedure listed, describe who will be conducting it, where it will be performed, how long is participation in each procedure, and how/what data will be collected in each procedure.

Report the total period and span of time for the procedures (if applicable the timeline for follow ups). For secondary data analyses, identify if it is a public dataset (please include a weblink where the data be accessed from, if applicable). If not, describe the contents of the dataset, how it will be accessed,

TIPS for streamlining the review time.

- ✓ ☐Ensure that research materials and procedures are explicitly connected to the articulated aims or research questions (from section 2 above).
- ✓ ☐In some cases, a table enumerating the name of the measures, corresponding citation (if any), number of items, sources of data, time/wave if a repeated measures design can help the IRB streamline the review time.

Response:

Participants will respond to questions in a semi-structured or unstructured questioning format, during a 3- phase multimedia (e.g. audio/video) discussion process. Participants will be given the opportunity to choose the style of the discussion process accessible to them. All participants will be provided their selected question formats in advance.

Phase 1, aligned with lifeworld fractions (Ashworth, 2003; Andrews et al., 2022) will allow the participant an opportunity to share; (a) how they characterize the experience of dyslexia and as a result, “embodied knowing” (Nagatomo, 1992) from the experience.

Phase 2, taking place in the context of the same discussion and will be reserved for gathering more information/clarifying details from participants on events and experiences described at the outset of the discussion and as needed.

Time commitment to Phases 1-2 is reasonably estimated to be 60-90 minutes.

Phase 3 is a as-needed discussion, conducted by telephone or online video conferencing technology using audio and video capabilities. The intent of discussion is to address targeted questions to elucidate specific data/detail on an as-needed basis. Time commitment to Phase 3 is reasonably estimated to be 20-30 minutes via the telephone or online video conferencing technology using audio and video capabilities.

This phase may also involve using asynchronous means of follow-up suitable for the participant to gather needed detail, which may include emails, journaling, or similar, per participant preference.

7.2. The Co-PI will conduct the discussions. The initial phases of the discussions will be long-form in nature, reasonably estimated to be 60-90 minutes in length. Discussions for phases 1 and 2, will be captured through video recording. The discussion of phase 3 will last about 20-30 minutes via the telephone or online video conferencing technology using audio and video capabilities. This phase may also involve using asynchronous means of follow-up suitable for the participant to gather needed detail, which may include emails, journaling, or similar, per participant preference.

7.3 The research will be conducted between June 2023 –August 2023.

IRB: 8. Compensation

8.1 Report the amount and timing of any compensation or credit to participants.
8.2 Identify the source of the funds to compensate participants.
8.3 Justify that the compensation to participants to indicate it is reasonable and/or how the compensation amount was determined.
8.4 Describe the procedures for distributing the compensation or assigning the credit to participants.

TIPS for streamlining the review time.

- ✓ ☐If partial compensation or credit will be given or if completion of all elements is required, explain the rationale or a plan to avoid coercion
- ✓ ☐For extra or course credit guidance, see “Research on educational programs or in classrooms” on the following page: https://researchintegrity.asu.edu/human-subjects/special-considerations.
- ✓ ☐For compensation over $100.00 and other institutional financial policies, review “Research Subject Compensation” at: https://researchintegrity.asu.edu/human-subjects/special-considerations for more information.

Response:

8.1 Participants will not receive any compensation or credit for their participation.

IRB: 9. Risk to Participants
List the reasonably foreseeable risks, discomforts, or inconveniences related to participation in the research.

TIPS for streamlining the review time.

- ✓ Consider the broad definition of “minimal risk” as the probability and magnitude of harm or discomfort anticipated in the research that are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.
- ✓ Consider physical, psychological, social, legal, and economic risks.
- ✓ If there are risks, clearly describe the plan for mitigating the identified risks.

Response:

There are no reasonably foreseeable risks, discomforts, or inconveniences related to participation in the research.

IRB: 10. Potential Direct Benefits to Participants

List the potential direct benefits to research participants. If there are risks noted in 9 (above), articulated benefits should outweigh such risks. These benefits are not to society or others not considered participants in the proposed research. Indicate if there is no direct benefit. A direct benefit comes as a direct result of the subject’s participation in the research. An indirect benefit may be incidental to the subject’s participation. Do not include compensation as a benefit.

Response:

Although there is no direct benefit to participants, they may benefit from participants being afforded a safe and centering space to allow them to reflect on their own experiences with dyslexia and assistive technology.

IRB: 11. Privacy and Confidentiality
Indicate the steps that will be taken to protect the participant’s privacy.

1. 11.1 Identify who will have access to the data.
2. 11.2 Identify where, how, and how long data will be stored (e.g. ASU secure server, ASU cloud storage, filing cabinets).
3. 11.3 Describe the procedures for sharing, managing and destroying data.
4. 11.4 Describe any special measures to protect any extremely sensitive data (e.g. password protection, encryption, certificates of confidentiality, separation of identifiers and data, secured storage, etc.).
5. 11.5 Describe how any audio or video recordings will be managed, secured, and/or de-identified.
6. 11.6 Describe how will any signed consent, assent, and/or parental permission forms be secured and how long they will be maintained. These forms should separate from the rest of the study data.

7. 11.7 Describe how any data will be de-identified, linked or tracked (e.g. master-list, contact list, reproducible participant ID, randomized ID, etc.). Outline the specific procedures and processes that will be followed.
8. 11.8 Describe any and all identifying or contact information that will be collected for any reason during the course of the study and how it will be secured or protected. This includes contact information collected for follow-up, compensation, linking data, or recruitment.
9. 11.9 For studies accessing existing data sets, clearly describe whether or not the data requires a Data Use Agreement or any other contracts/agreements to access it for research purposes.

11.10 For any data that may be covered under FERPA (student grades, etc.) additional information and requirements is available at https://researchintegrity.asu.edu/human-subjects/special-considerations.

11.11 If your study is sponsored by HHS: NIH, you will need to comply with the revised 2023 NIH Data Management and Sharing policy. Additional information and requirements are available at https://libguides.asu.edu/NIH-2023. Please be aware, per 2023 NIH DMS policy, DMS plan is required at the time of proposal submission

Response:

11.1 Only the PI and Co-PIs will have access to the data throughout all phases of the research process. Video data will be captured with the assistance of the Director of Student Creative Services at Arizona State University – functions including; recording assistance and post-production editing (with guidance from CO- PI). Co-PI will complete all aspects of pre-production.
11.2 Data will be stored on a password-protected computer for a period of four years.
11.3 Data will be deleted from the computer after four years.
11.4 All data will be password protected.
11.5 Video and audio recordings will be deleted from the original recording device upon transfer to the password-protected computer.
11.6 signed consent is used for this study.
11.7 n/a
11.8 Participant name, ASU email address, and phone number may be collected for purposes of recruitment and follow-up.
11.9 n/a
11.10 n/a

IRB: 12. Consent

Describe the procedures that will be used to obtain consent or assent (and/or parental permission).

1. 12.1 Who will be responsible for consenting participants?
2. 12.2 Where will the consent process take place?
3. 12.3 How will the consent be obtained (e.g., verbal, digital signature)?

4. 12.4 If your study is sponsored by HHS: NIH, you will need to comply with the revised 2023 NIH Data

   Management and Sharing policy. Additional information and requirements are available at https://libguides.asu.edu/NIH-2023. To comply with this policy, the informed consent should explain how data will be managed and shared. This sharing should be consistent with the DMS plan.

TIPS for streamlining the review time.

- ✓ ☐If participants who do not speak English will be enrolled, describe the process to ensure that the oral and/or written information provided to those participants will be in their preferred language. Indicate the language that will be used by those obtaining consent. For translation requirements, see Translating documents and materials under https://researchintegrity.asu.edu/human-subjects/protocol-submission
- ✓ ☐Translated consent forms should be submitted after the English is version of all relevant materials are approved. Alternatively, submit translation certification letter.
- ✓ ☐If a waiver for the informed consent process is requested, justify the waiver in terms of each of the following: (a) The research involves no more than minimal risk to the subjects; (b) The waiver or alteration will not adversely affect the rights and welfare of the subjects; (c) The research could not practicably be carried out without the waiver or alteration; and (d) Whenever appropriate, the subjects will be provided with additional pertinent information after participation. Studies involving confidential, one time, or anonymous data need not justify a waiver. A verbal consent or implied consent after reading a cover letter is sufficient.
- ✓ ☐ASU consent templates are [here].
- ✓ ☐Consents and related materials need to be congruent with the content of the application.

Response:

12.1 The Co-PI will be responsible for obtaining consent. Signed consent will be obtained from participants prior to involvement in the study.
12.2 via email.
12.3 Consent will be obtained by signed consent (physical signature) via email

IRB: 13. Site(s) or locations where research will be conducted.

List the sites or locations where interactions with participants will occur- Identify where research procedures will be performed. For research conducted outside of the ASU describe:

○ Site-specific regulations or customs affecting the research.

○ Local scientific and ethical review structures in place.
For research conducted outside of the United States/United States Territories describe:

- Safeguards to ensure participants are protected.

For information on international research, review the content [here].

For research conducted with secondary data (archived data):

- List what data will be collected and from where.
- Describe whether or not the data requires a Data Use Agreement or any other contracts/agreements to access it for research purposes.

- For any data that may be covered under FERPA (student grades, etc.) additional information and requirements is available [here].
- For any data that may be covered under FERPA (student grades, homework assignments, student ID numbers etc.), additional information and requirements is available [here].

Response: Site 1 – Student Creative Services – ASU - SCS Studio, Room 236; (Video/audio data capture) Site 2 – University Center – Building C – Suite 100L1, Office 104.

(Phone, video conferencing, using audio capabilities only, and/or asynchronous means of follow-up suitable for the participant to gather needed detail, which may include emails, journaling, or similar, per participant preference)

IRB: 14. Human Subjects Certification from Training. Provide the names of the members of the research team.

ASU affiliated individuals do not need attach Certificates. Non-ASU investigators and research team members anticipated to manage data and/or interact with participants, need to provide the most recent CITI training for human participants available at www.citiprogram.org. Certificates are valid for 4 years.

TIPS for streamlining the review time.

- ✓ If any of the study team members have not completed training through ASU's CITI training (i.e. they completed training at another university), copies of their completion reports will need to be uploaded when you submit.
- ✓ For any team members who are affiliated with another institution, please see "Collaborating with other institutions" [here]
- ✓ The IRB will verify that team members have completed IRB training. Details on how to complete IRB CITI training through ASU are [here]

Response:

14. Jacob Bunch, Co-PI, CITI Training - IRB – Social & Behavioral Research (Group 2) completed 06-Oct- 2019 and RCR – Social and Behavioral Responsible Conduct of

Research completed on 16-Apr-2020 Nicole Bowers – CITI Training completed Jun 18 2020

Consent for Doctoral Study Participation

I am a graduate student under the direction of Dissertation Chair, Nicole Bowers in the Mary Lou Fulton Teacher's College at Arizona State University.

I am conducting a research study to more dynamically understand how postsecondary students with dyslexia describe and adapt to a negotiated existence with and through dyslexia and assistive technology. Using this research context, the primary aim of this research is to advance accessibility and inclusive methodological innovations for more complete representations of the disability experience in qualitative research.

I am inviting you to participate, you must be 18 years of age or older to do so. Participation in the study will involve participation in a 60 to 90-minute video-recorded discussion. You will respond to questions in a semi-structured or unstructured format. Please clearly indicate your choice of format prior to the recorded discussion. To allow for pre-discussion preparation, each participant will be provided with their selected set of questions in advance.

You will engage in a multimedia discussion process of up to three sections. Phase 1 and 2 of the discussion will take place together, with phase 1 involving your chosen question set and phase 2 involving follow-up questions. Phase 3 is reserved for an as-needed basis, used to clarify details. The time commitment to phase 3 is reasonably estimated to be 20-30 minutes via telephone or online video conferencing technology.

As part of this research process, there may be a need for periodic follow-ups to address targeted questions and specific details. Follow-up may involve using asynchronous means of follow-up suitable for your access and participation, which may include emails, journaling, or similar, per your preferences.

You reserve the right not to answer any question, and to stop participation at any time. Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, there will be no penalty.

Although there is no direct benefit to participation, you may benefit from being afforded a safe and centering space to allow you to reflect on your personal experiences with and through dyslexia and assistive technology. There are no foreseeable risks or discomforts to your participation.

Only the principal investigator and Co-principal investigator will have access to the data throughout all phases of the research process. In addition, video data will be captured with the assistance of the Director of Student Creative Services at Arizona State

University. Data will be maintained in password-protected environments. Please be aware that due to the nature and mode of data collection, your responses will not be anonymous or confidential. De-identified data collected as a part of current study may be shared with others (e.g. investigators, industry partners) for future research purposes, publications or related media. Video data and other collected data from the study may be used in; (1) a multi-modal dissertation, (2) book and related publications, (3) journal articles, (4) scholarly conferences (5) presentations. Results may be released to the institution and to participants.

I would like to video-record this discussion. The discussion will not be recorded without your permission. You also can change your mind after the discussion starts, just let me know. When answering questions, as part of the discussion, please do not use the names of others when responding to the open-ended questions.

If you have any questions concerning the research study, please contact the research team at: (Nicole Bowers - nbowers1@asu.edu or Jacob Bunch – jcbunch@asu.edu). If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788. Please let me know if you wish to be part of the study.

By signing below, you are agreeing to be part of the study. Name:
Signature: Date:

Document Revision Date: May 30, 2023

Recruitment Letter

[INTRODUCTION SAILS ACCESS CONSULTANT OR LEADERSHIP]

This is being sent on behalf of Jacob Bunch, who is doing a research study as a part of his doctoral program. If you are interested in participating, please see the details below, which includes how to contact Jacob to participate in the study.

If you are interested in participating, please email or call, Jacob Bunch: Email - jcbunch@asu.edu
Phone - 480-965-3936

STUDY00018087: Assistive Technology and the Lifeworld of Postsecondary Students with Dyslexia

My name is Jacob Bunch, and I am a doctoral candidate in the Mary Lou Fulton Teachers College (MLFTC) at Arizona State University (ASU). I am working under the direction of Dr. Nicole Bowers, a faculty member in MLFTC. We are conducting a research study to more dynamically understand how postsecondary students with dyslexia describe and adapt to a negotiated existence with and through dyslexia and assistive technology. Using this research context, a primary aim of this research is to advance accessibility and inclusive methodological innovations for more complete representations of disability experience in qualitative research.

We are asking for your help, which will involve participation in a 60 to 90-minute video-recorded discussion. You will respond to questions in either an unstructured or semi-structured questioning format during a 3-phase multimedia discussion process. To allow for pre-discussion preparation, each participant will be provided with their selected set of questions in advance.

Phase 1 and 2 of the discussion will take place together, with phase 1 involving your chosen question set and phase 2 involving follow-up questions. Phase 3 is reserved for an as-needed basis, used to clarify details. The time commitment to phase 3 is reasonably estimated to be 20-30 minutes via telephone or online video conferencing technology. Video data collected for the study will be deleted from the original recording device upon transfer to a password protected computer, where it will be retained for a period of 4 years.

As part of this research process, there may be a need for periodic follow-ups to address targeted questions and specific details. This phase may involve using asynchronous means of follow-up suitable for your access and participation, which may include emails, journaling, or similar, per your preferences. The study is seeking 6-10 participants only.

In order to participate, you must:

(1) Be a student at ASU, actively registered with SAILS (or a recently ‘archived ‘alumni) (2) Have ‘on campus’ student status at ASU (or for alumni, be in the local area)
(3) Have dyslexia as a documented diagnosis
(4) Be 18 years of age or older

Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. Choosing not to participate in the study does not affect your standing at Arizona State University.

If you are interested in participating, please email or call, Jacob Bunch: Email - jcbunch@asu.edu
Phone - 480-965-3936

Thank You, Jacob Bunch

Knowledge Enterprise Development

Nicole Bowers

APPROVAL: EXPEDITED REVIEW

Division of Educational Leadership and Innovation - Tempe -
Nicole.Bowers@asu.edu

Dear Nicole Bowers:
On 6/4/2023 the ASU IRB reviewed the following protocol:

Type of Review: Initial Study	
Title:	Assistive Technology and the Lifeworld of Postsecondary Students with Dyslexia, Understanding 'Fractions' of Experience: Advancing Accessible and Inclusive Methodological Innovations for Improved Representations of the Dynamics of Disability Experience in Qualitative Research.
Investigator: Nicole Bowers	
IRB ID: STUDY00018087	
Category of review: 7	
Funding: None	
Grant Title: None	
Grant ID: None	
Documents Reviewed:	• ASU Student Recruitment - Data Collection Form , Category: Other; • ASU Student Recruitment - Data Collection Form- APPROVED , Category: Other; • IRB Social Behavioral Protocol_final 03.03.2023- lgw-with edits - jcb-5-30-23-IRB Resubmit 3.0.docx, Category: IRB Protocol; • JCB - Study Consent - with edits 5-30-2023-2.0.pdf, Category: Consent Form; • Recruitment Letter, Category: Recruitment Materials; • SAILS Leadership Recruitment Approval, Category: Other; • Semi Structured Discussion Questions - IRB - Dissertation Cycle - JCB-5-30-23-2.0.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);

• Un-Structured Discussion Questions - IRB - Dissertation Cycle - JCB-5-30-23-2.0.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);

The IRB approved the protocol effective 6/4/2023. Continuing Review is not required for this study.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc:
Nicole Bowers

Jacob Bunch

Pre-Discussion

Discussion Questions

Semi-Structured Questions

- Share with the participant the open, validating, ‘centering’ intent of the discussion style.

- Share with the participant my own experiences and background of disability and assistive technology

- Share disability reclamation statement

- Briefly share about the social model of disability

Style: Mix of semi-structured questions that include; introductory, probing and direct questions

Intended Use: During Phases 1-2 of the recorded discussion. Participant reserves ability to select preferred question set.

Briefing Statement

Thank you for agreeing to participate in this discussion. I am conducting a research study to more dynamically understand how postsecondary students with dyslexia describe and adapt to a negotiated existence with and through dyslexia and assistive technology. Please respond with your own thoughts about the questions. In your responses do not mention names of other individuals. May I record the discussion?

Questions

1. How would you describe the experience of dyslexia?
2. Describe how your lived reality of dyslexia is a part of your daily life and academics.
3. How do you process through or cope with the experience of dyslexia?
4. Describe how the experience of dyslexia makes you feel
5. Would you describe dyslexia as an ‘asset’ or a hindrance? (i.e. positive or negative) Why or why not?
6. If you were to construct a ‘disability reclamation’ statement like the one I shared, what would it say?

7. Do you feel that negotiating the world with dyslexia and through the use of assistive technology has an influence on your view of the world and how you interact with it? If so, how?
8. Do you feel that negotiating the world with dyslexia and through the use of assistive technology has influence on your independence? If so, how?
9. Has the experience of dyslexia and being associated with assistive technology had influence on your individuality and individual identity? If so, how?
10 .Has the experience of dyslexia and your associations with assistive technology had an impression on you physically, your psyche, will, and emotions. If so, how?
11 . Has the experience of dyslexia and associations with assistive technology had any impact on intersectional identities for you? If so, how?
12. Has society, social structures, social relationships, and power dynamics had an influence on your experience of negotiating the world with dyslexia and through the use of assistive technology? If so, how?
13. Would you describe the experience of dyslexia and the use of assistive technology as a significant life event for you? Why, why not?
14. Describe how the experience of dyslexia and your associations with assistive technology has had an impact on your 'biography'; past, present, and future?
15. Do you recall occasions when because of dyslexia and associations with assistive technology has influenced your decisions about spaces that you include or exclude yourself – or you are included or excluded by others?
16. How have your personal outlook, beliefs, attitudes, personal stances, and interests been influenced by the experience of dyslexia and your associations with assistive technology?
17. How would you describe your decision to accept or abandon assistive technology? Why was this your decision?
18. In your view, what is absent from assistive technology considerations to ensure that there is a more complete understanding of the individual and the context of use?
19. In your view, would you describe the mode of this research to be more accessible, inclusive, and equitable? Why, why not?
20. In your view, would you describe engagement with this research to be a validating and 'centering' experience? Why, why not?
21. In your view, will engagement with this research, will provide a more complete representation of the dynamics of the disability experience? Why? Why not?

Pre-Discussion

Discussion Question

Unstructured Questions

- Share with the participant the open, validating, ‘centering’ intent of the discussion style.
- Share with the participant my own experiences and background of disability and assistive technology
- Share disability reclamation statement
- Briefly share about the social model of disability

Style: Mix of unstructured questions that include follow up promptings for use as needed.

Intended Use: During Phases 1-2 of the recorded discussion. Participant reserves ability to select preferred question set.

Briefing Statement

Thank you for agreeing to participate in this discussion. I am conducting a research study to more dynamically understand how postsecondary students with dyslexia describe and adapt to a negotiated existence with and through dyslexia and assistive technology. Please respond with your own thoughts about the questions. In your responses do not mention names of other individuals. May I record the discussion?

Questions

1. Can you tell me about your life experience with dyslexia?
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
2. Can you tell me about how dyslexia is a part of your daily life and your academics?
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
3. Can you tell me about how you cope with dyslexia?
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
4. Can you tell me about how dyslexia makes you feel?
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?

5. Do you remember occasions when you considered dyslexia an ‘asset’ and other occasions when you considered it a hinderance? (i.e. positive or negative).
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
6. Thinking about the disability reclamation statement I shared with you before our discussion began, can you tell me what me what a statement like that may say about you, your experience and perception of dyslexia?
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
7. Do you remember an occasion when negotiating the world with dyslexia and through the use of assistive technology has had an influence on your view of the world and how you interact with it? If so, how?
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that? `
8. Do you remember an occasion when negotiating the world with dyslexia and through the use of assistive technology has had influence on your independence? If so, how?
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
9. Can you tell me about how the experience of dyslexia and association with assistive technology has influenced your individuality and individual identity.
   a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
10. Do you recall occasions when your experience of dyslexia and your associations with assistive technology has had an impression on you physically, your psyche, will, and emotions?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
11. Can you recall any occasions when your experience of dyslexia and associations with assistive technology had any influence on intersectional identities? If so, how?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
12. Can you tell me about how society, social structures, social relationships, and power dynamics have influenced your experience of negotiating the world with dyslexia and through the use of assistive technology?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
13. Is the experience of dyslexia and the use of assistive technology as a significant life event for you? Why, why not?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?

14. Can you tell me about how the experience of dyslexia and your associations with assistive technology has had influence on your ‘biography’; past, present, and future?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
15. Do you recall occasions when because of dyslexia and associations with assistive technology has influenced your decisions about spaces that you include or exclude yourself – or you are included or excluded by others?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
16. Can you tell me about how your personal outlook, beliefs, attitudes, personal stances, and interests been influenced by the experience of dyslexia and your associations with assistive technology?
    b. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
17. Can you tell me about your decision to accept or abandon assistive technology? Why was this your decision?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
18. In your view, what is absent from assistive technology considerations to ensure that there is a more complete understanding of the individual and the context of use?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
19. In your view, would you describe the mode of this research to be more accessible, inclusive, and equitable? Why, why not?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
20. In your view, would you describe engagement with this research to be a validating and ‘centering’ experience? Why, why not?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?
21. In your view, engagement with this research, will provide a more complete representation of the dynamics of the disability experience. Why? Why not?
    a. Follow Up – as needed based on response. Say something about? Further examples? Is it correct that?

APPENDIX C

QUESTIONS FOR THE PARTICIPANT-CENTERED VIDEO

Questions

1. How would you describe the experience of dyslexia?
2. Describe how your lived reality of dyslexia is a part of your daily life and academics.
3. How do you process through or cope with the experience of dyslexia?
4. Describe how the experience of dyslexia makes you feel.
5. Would you describe dyslexia as an asset or a hindrance (i.e., positive or negative)? Why or why not?
6. If you were to construct a disability reclamation statement like the one I shared, what would it say?
7. Do you feel that negotiating the world with dyslexia and through the use of assistive technology has an influence on your view of the world and how you interact with it? If so, how?
8. Do you feel that negotiating the world with dyslexia and through the use of assistive technology has influence on your independence? If so, how?
9. Has the experience of dyslexia and being associated with assistive technology had influence on your individuality and individual identity? If so, how?
10. Has the experience of dyslexia and your associations with assistive technology had an impression on you physically, your psyche, will, and emotions? If so, how?
11. Has the experience of dyslexia and associations with assistive technology had any impact on intersectional identities for you? If so, how?
12. Has society, social structures, social relationships, and power dynamics had an influence on your experience of negotiating the world with dyslexia and through the use of assistive technology? If so, how?
13. Would you describe the experience of dyslexia and the use of assistive technology as a significant life event for you? Why or why not?
14. Describe how the experience of dyslexia and your associations with assistive technology has had an impact on your ‘biography’; past, present, and future?
15. Do you recall occasions when because of dyslexia and associations with assistive technology has influenced your decisions about spaces that you include or exclude yourself – or you are included or excluded by others?
16. How have your personal outlook, beliefs, attitudes, personal stances, and interests been influenced by the experience of dyslexia and your associations with assistive technology?
17. How would you describe your decision to accept or abandon assistive technology? Why was this your decision?

APPENDIX D

PARTICIPANT AND RESEARCHER CENTERED VIDEO

Video Discussions

Below are the Vimeo hyperlinks for the Assistive Technology Lifeworlds: Inclusive Qualitative Methodological Innovations for Diverse Bodyminds video and the researcher reflection video.

Assistive Technology Lifeworlds: Inclusive Qualitative Methodological Innovations for Diverse Bodyminds – Runtime 2:06:58

https://vimeo.com/881874576?share=copy

Researcher reflection video – Runtime 28:10

https://vimeo.com/879840653?share=copy

This is a list of video segments organized by topic or question:

Life experience with dyslexia – Runtime 10:14

https://vimeo.com/879872605?share=copy

Dyslexia as a part of daily life and academics – Runtime 8:42

https://vimeo.com/879870107?share=copy

Coping with dyslexia – Runtime 5:04

https://vimeo.com/879868730?share=copy

Feelings towards the experience of dyslexia - Runtime 6:51

https://vimeo.com/879871044?share=copy

Dyslexia as an asset or hinderance - Runtime 11:09

https://vimeo.com/879870545?share=copy

Disability reclamation and dyslexia - Runtime 8:19

https://vimeo.com/879869387?share=copy

View of and interaction with the world - Runtime 4:31

https://vimeo.com/879874416?share=copy

Independence - Runtime 4:16

https://vimeo.com/879872204?share=copy

Individuality and individual identity - Runtime 9:02

https://vimeo.com/879871404?share=copy

Effects physically, on psyche, will or emotions - Runtime 5:21

https://vimeo.com/879873452?share=copy

Intersectional identities - Runtime 4:42

https://vimeo.com/879872398?share=copy

Society and power dynamics - Runtime 8:27

https://vimeo.com/879873692?share=copy

Dyslexia and assistive technology as a significant life event - Runtime 8:01

https://vimeo.com/879869738?share=copy

Impact on personal biography - Runtime 7:33

https://vimeo.com/879871845?share=copy

Space and place inclusion and exclusion - Runtime 7:02

https://vimeo.com/879874083?share=copy

Personal outlook, beliefs, and attitudes - Runtime 8:44

https://vimeo.com/879873102?share=copy

Impact on the decision to accept or abandon assistive technologies - Runtime 7:53

https://vimeo.com/879869031?share=copy

APPENDIX E

DEDICATION AND ACKNOWLEDGEMENTS CONTINUED

Dedication Continued

To Mom – You have been my fierce advocate, teaching me to navigate the world with my disability as a part of me, but not my sole identity. I recognize now that your tough love and the products of the many unpopular decisions you had to make in my interest are, in large part the reason I am where I am, who I am. While I am certain that the direction my life took was unexpected and was not 'Italy' as Emily Pearl Kingsley describes in her 1987 poem, you found, that 'Holland', her artful simile for disability is no less beautiful, awe-inspiring, or exceptional, just, as she says:

> A different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

I owe you more than a debt of gratitude for the unyielding way you raised me and the fruits of it. I can never repay that but, know that, to me, you are just as deserving of this degree as I am.

To Dad – As a father, I am sure you harbored daydreams when you learned I was coming into the world of what my life would be like and the man I would become, and I know, for you, just like mom, those daydreams turned into the raw, sometimes harsh and unforgiving realities of disability in February 1985, but instead of grieving conceptions of me and who I would become as a 'loss,' you, along with mom, chose to accept and love me for who I am – and have been a mainstay of support, encouragement, guidance and fatherly-love.

To Jennifer – To say that our lives together and individually are a mashup of collateral beauties is an understatement. Your life has taught me that unconditional love is a prerequisite to a rich and meaningful life – and that infectious positivity in the face of seemingly insurmountable obstacles, trials and tribulations is essential, so that, as our friend, Joni Erickson Tada reminds us, you are not paralyzed by your circumstances but can allow them to be used for good. I love you and recognize your sacrifice in this journey – knowing, as I do, that there is a purpose for it more expansive than self, accolade or position. Thank you for the space to complete this part of the journey – and for keeping me grounded in the 'why' of it.

To Jordan, Rusty, Jason – The three of you have all processed the realities of my disabilities differently and I acknowledge that it has affected the three of you in vastly different and individual ways, but what the three of you have in common is not seeing me as different, limited or incapable, and always pushing me outside of the realm of what I see as possible. The three of you are ready and willing to support, love, encourage and lovingly lighten the mood of some often, hard-hitting realities. I hope that my life has taught you all that different is not bad, limitations are opportunities, and that challenges, while they are packaged differently for all of us, if we allow them to, they can open doors of witness in character-building strength and unyielding resolve.

To Keith – You are the epitome of best friend and what God intended when he allowed the word to take definition. You are more than my best friend; you are my brother. You are, without a doubt, part of the reason I find comfort in boundary-pushing. You are part of the reason I found my voice – and became secure in myself and the realities of my life, while, at the same time, not allowing them to define who I am or what I would become. You are with me in everything I do. As I navigate this world from a different vantage point, you have helped me to see that this vantage point is an asset and not a hinderance – proof that disability does not have to be a 'handicapping' experience.

To Tony – I thank you for your willingness to love, support and guide me as one of your own. You have selflessly given to ensure that I have what I need to be successful and independent.

To Donna – I remember, during the Admission, Review, and Dismissal/Individualized Education Program meeting to determine my reasonable accommodations for my entry into high school that you advocated for me against professional opinion that suggested accommodations were left only to the selective choice and untended discretion of a classroom teacher, almost as if reasonable accommodations were a 'suggestion' and not a legal obligation. I began to feel in that meeting that I did not matter and that the way I learned was disregarded. I remember the way you explained my learning process to the teacher – and how having no accommodation would impact me. You said, "Not allowing for accommodation in your class is like requiring Jacob to jog backwards on a running track while reading Shakespeare." The analogy you used that day stuck with me and gave me a clear outlet to explain my experience in 'teachable moments.' In many ways, my entire educational journey has been akin to that but, irrespective of the unceasing struggle, I have endured to 'finish the race' so to speak, to prove that no one should ever be counted an 'educational write off'. I thank you for your love, support, and that pivotal moment of advocacy.

To Dr. Joy Zabala – Thank you for your mentorship and encouragement. You were one of the first to hear of my study and how I was going to be looking at assistive technology from a lifeworld perspective, which you saw as something critical and missing. I appreciate all that you contributed to the field of assistive technology and universal design for learning during your time on earth. Most of all though, I am honored to have known you as a mentor. Your spirit lives on in this dissertation.

To Joni Erickson Tada – I could not have imagined how our lives have intertwined because of the dive you took into the Chesapeake Bay on July 30, 1967, rendering you quadriplegic. To think, an event that happened 17 years before I was born would be divinely repurposed for good. As a result of that accident, your life has been used as a powerful platform of ministry. To have the honor of calling you friend and more so, to be mentored by you in a very personal way, both as a friend and as an intern of Joni & Friends have changed my life, my attitude, and my outlook on disability in dramatic fashion. I know that you do not recall this exchange, but I remember years ago, in one of our conversations, you said, “you can choose to be paralyzed by your circumstances or choose to utilize them – but the choice is yours.” Your ever-present words of encouragement, whether through your writing, music or art have helped me to repurpose my disabilities for good.

To my ASU Family – I cannot begin to explain in words the affinity I have for Arizona State University and the honor it is to be an alumnus and to have the opportunity each day to serve fellow Sun Devils. We share, as a community, core values of educational access and equity for all. To Lance – you were at the start of my ASU journey and to have you as a part of my doctoral journey brings it full circle. Your impression on my life is enduring and something I am indebted to you for. I pray that I make you proud as I strive to serve fellow Sun Devils in the spirit of the way you have served me – as a student and a colleague. To Renae – it is because of you that I was able to realize a dream that I once thought was out of reach – working at ASU. Not only did you help me to find purpose and an assurance of my calling, but because of the door you opened for me, I have been given a pathway to reach this pinnacle of my educational journey. One of the most impactful things you said to me was, “give yourself grace and space” – it is this advice that has kept me grounded and centered in living out my gift of serving students with disabilities. You mean more to me than I can ever express. I am honored to call you friend and mentor. Dr. Allison – thank you for your reassurance that I have every capacity to learn and lead. I thank you for the friendship, leadership, gentle development and coaching. To Chad – thank you for giving me the opportunity to be a part of advocating for educational access and equity. You see my disabilities as an asset to the service of others and that means more than I can say. I thank you for leading the way you do. I have learned so much from your example. To Cedric – thank you for your continued friendship, honesty and ‘realness’ with me. You ‘get me’ in ways that few co-workers do. You accept me for who I am, and I am honored to call you friend. To Christine – thank you for your years of friendship and your tough-love approach that helped me to realize my professional potential and aided me in honing my Sun Devil Service skills with each day I serve the ASU Community. To those of my ASU family not mentioned here, due to limited space, know that you are equally a part of this journey and in innumerable, positive ways, you all have impacted the trajectory of my professional life. To those of you not explicitly mentioned here, your prayers and support throughout this journey are not to be diminished. Each of you have, in some way, made an investment in me that was no less a part of helping me to realize this aspiration – more than an educational goal, more than the rights and responsibilities that come with a conferred degree, but a statement that, I am not ‘other’ and that my voice has place and value.

Acknowledgements Continued

Study Participants - I thank you for your investment of time and willingness to share, vulnerably with me as a co-partner in this research process. My hope is that from this experience, you were able to benefit from being afforded a safe and centering space to reflect on your personal experiences with and through dyslexia and assistive technology. Moreover, it is my hope that you found this research to be a genuine attempt to be more accessible, inclusive, and equitable and ensuring that your voice was represented, validated, and centered.

Dr. David K. Woods – Thank you for your development of the software, Transana, which is the multimedia data analysis software used for the analytic process in this dissertation. Transana is, for me, as a researcher with multiple disabilities, a positive example of assistive technology. Transana was an integral part of my ability to meaningfully engage with qualitative research and to ‘sense make’ in a manner that provides me equal and equitable physical and intellectual access to the research space. Thank you for the space that Transana has afforded me to have an active voice in research.