The Lived Experiences of Adults who Acquired Motor, Mobility, and/or Communication Disabilities: Identity Changes and Creative Pursuits

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Abstract

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Adults who acquire complex motor, mobility, and/or communication disabilities (MMCD), such as spinal injuries or amyotrophic lateral sclerosis (ALS), often rely on assistive technologies (AT) for daily living. Many of these individuals experience profound changes in their lives as a result of acquiring their disability. Adults with complex MMCD who use AT often experience a decrease in opportunities for active engagement and participation, which can ultimately result in poor mental and physical health. As a result, overall quality of life can be perceived to be diminished. While research has shown that access to creative pursuits has positive impacts on typically aging older adults and adults with chronic health conditions, little is known about how active engagement in creative pursuits impacts adults with acquired MMCD who use AT outside of directed therapeutic programs. Creativity is a fundamental human need, however, accessing creative pursuits can be challenging for adults who acquire MMCD and use AT.

In this dissertation, I explore how access to creativity impacts the perceived quality of life of adults who acquire MMCD and use AT. First, I examine the experiences of adults who acquire MMCD mid-career, and demonstrate that adults who acquire MMCD and use AT want to continue to be mentally engaged even after leaving their careers. However, adults who acquire MMCD and use AT, particularly those with progressive health conditions, require activities that are flexible without set time pressures. I also show that options for alternatives to work that are accessible to adults with MMCD who use AT are not well-known. I then explore the experiences of seven adults who acquired MMCD and use AT who have engaged in accessible creative pursuits outside of directed therapeutic programs. I demonstrate that engaging in creativity can lead to the formation of a positive creative identity which has a positive impact on perceptions of quality of life. I also show that the discoverability of accessible creative pursuits is challenging, and the lack of discoverability and access to creative pursuits can negatively impact the reclamation of a positive creative identity.

In this dissertation, I provide two methodological contributions. First, I synthesize literature and my own experiences to establish a framework of qualitative research best practices when working with participants who use AAC. Second, I create the Aligned Co-Design method, an accessible co-design method in which adults with MMCD who use AT can engage in co-design research equitably.

The dissertation concludes with a discussion of the role accessibility has in quality of life. I propose that accessibility should be explicitly recognized as a fundamental human need. Access to creative pursuits can have profound positive impacts on an individual’s perceptions of identity, health, social connections, and overall quality of life.

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Chapter 1. Introduction

The ability to walk, use your hands, and speak with your voice is so natural that many of us take these abilities for granted. Yet, over one million people worldwide are estimated to have complex mobility disabilities combined with communication disabilities [26]. These individuals comprise a diverse group of ages and diagnoses. For example, someone with an acquired condition such as Amyotrophic Lateral Sclerosis (ALS) might have lost their ability to move their arms and legs as well as their ability to speak and swallow, whereas someone with a spinal cord injury might have limited arm and leg movement, but retain their ability to speak. Regardless of the cause of the disability, many adults who develop complex mobility, motor and/or communication disabilities (MMCD)[1] rely on accessibility features and assistive technologies (AT) for communication and computer access [11,26,212]. My own professional experience as a speech-language pathologist (SLP) and Augmentative-Alternative Communication (AAC) specialist has shown just how important the role of technology is to people with disabilities that involve MMCD.

1.1 Motivation

The motivation for this dissertation stems from my clinical work as an AAC and AT specialist who worked with people with MMCD. There is a lack of research on how the quality of life of individuals with MMCD is impacted by technology access. Quality of life involves social, emotional and physical well-being [90,362]. Quality of life can also be thought in terms of "being, becoming and belonging" [252]. For my dissertation, my research questions address quality of life through an emic approach, in which I address factors related to quality of life based on the perspectives of the participants themselves [239]. In this dissertation, I explore quality of life for a specific population: adults with acquired mobility, motor, and/or communication disabilities (MMCD) who use Assistive Technologies (AT) for daily living.

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[1] While MMCD is not a standard abbreviation in the literature, I use the abbreviation in this dissertation as a way to capture the specificity of the abilities of a population without writing out the full term, "motor, mobility, and/or communication disabilities," throughout the dissertation. The and/or term is deliberately used to be precise. Participants in this dissertation could have any combination of motor, mobility, and/or communication impairments as part of their disability.

Quality of life is affected by an individual’s perception of their position, or identity, within a culture [362]. For many adults, their career can shape their identity and position within a socio-cultural context [213]. In this dissertation, I begin with a practical look at how acquiring a disability as an adult can impact employment, and in turn, identity. Prior work has shown that people with a variety of disabilities found it difficult to find or maintain employment, and people with disabilities have a higher rate of unemployment than people without disabilities [112,156,210,211,219]. However, we do not yet fully understand the impact acquired disability has on the identity of adults who acquire MMCD and who need AT quality of life.

Quality of life is influenced by the ability to engage in creativity [86,204]. The basic definition of creativity is to act on original ideas [361,363]. The ability to produce, engage with, and act is a central concept to the definition of creativity and to be creative [361,363,364]. Prior work with adults who do not require AT for daily living have experienced positive changes to their identities when engaged with creative pursuits [257,258]. However, as yet, there is limited understanding of how adults who have MMCD and use AT engage in creativity and what impact creativity has on their quality of life.

In this dissertation, I investigate how acquiring a disability as an adult impacts a person’s quality of life. I frame my investigation through two different aspects of life: (1) identity and employment, and (2) identity and creativity. I then dive deeply into how the intersection of technology design, creativity, and identity intersect. Findings from this research illuminate how technology design and creativity influence quality of life.

1.2 Reflexivity on My Motivation

How do you respond when someone begs you for something . . . anything . . . to keep their mind occupied while their body fails? I have experienced this more than once in my professional career as a speech-language pathologist specializing in assistive technology and it is heart wrenching. While the people I worked with had varied circumstances, the core problem was always the same: how do you help people when they are no longer able to use their hands, arms, or legs and are no longer able to speak, but want to remain mentally engaged? Is it possible?

I am a speech-language pathologist (SLP) in an Information Science doctoral program with a focus on Human-Computer Interaction (HCI). I have worked in multiple countries, in public schools, at non-profits, and in technology companies. My diverse background has significantly shaped my approach to research. In this dissertation, I aim to bridge the different disciplines from my background to holistically address my research questions. As a constructivist, in which I believe that I cannot fully separate my experiences from my research practices, it is important to explicitly reflect on how my background has shaped my dissertation [52,253].

I begin my thesis with an exercise in reflexivity: the practice of reflecting on how my experiences impact my research while being mindful of how my perspective influences my dissertation [65,239]. In this process, I recognize that experiences in my clinical work influenced my motivation, preconceptions, and approach to my research studies. While I acknowledge how my research might be influenced by my experiences, I use this knowledge to inform my research approach…sometimes taking a step back to adjust my expectations and sometimes using my background to guide me to areas of research which have not yet been explored heavily by the research community but have been identified as areas of need by the clinical community.

1.2.1 Three families I carry with me in my dissertation

I share three stories that I carry with me as my motivation for this dissertation. None of these experiences or people are part of my research. Instead, the experiences are formative, in which they shaped my perspective in approaching this dissertation.

I carry the memory of a family. They had two very young children and the parents were highly engaged and loved discussing world events. One of the parents had Motor Neuron Disease (MND) and was losing their ability to use their hands, arms, and legs in addition to losing their ability to speak and to swallow. The parent died within months of me prescribing their AAC device. I often wonder if there was anything else I could have offered to enrich their last days together as a family. Could there be technology that would have let the family continue to engage together in fun ways, despite the parent’s limited physical abilities? How can technology facilitate positive family experiences that are meaningful when someone has a progressive disease?

Another experience that I carry is also of a family in which one parent was diagnosed with MND. The parent implored me to provide some form of technology which would keep their mind challenged while their body deteriorated. This parent specifically told me that they did not want to end their days laying in bed, watching television. I provided the only technology that I could think of that was readily available, challenging, and accessible. Later, I visited the parent again to pick up the device and found them laying in bed, watching TV. They did not make eye contact with me when I spoke with them. How can we design accessible technology that is challenging and engaging? How do we facilitate someone's desire to remain actively engaged rather than a passive spectator?

My third story is of a man diagnosed with Amyotrophic Lateral Sclerosis (ALS). He was an amateur musician. As he lost his abilities to walk, speak, breathe, and move his arms, he was finishing a musical piece that he was composing for his family. I was asked to determine if the music software he was using to compose his final, farewell piece to his family could be accessed with AT, since he was quickly losing the remaining motor control he had in his hand. During my visit, the man's family came into his room and he played his composition for us all, starting with an excruciatingly slow, deliberate click of the mouse. As I talked with this man and his family, I realized that the conversation and focus of attention of everyone in the room was about the music he created, not on the details of his health or his physical deterioration, but on the meaning of his music and how important music was to him and his family. This was the first time I experienced a situation where I had been brought into a family home and the topic of conversation had shifted so dramatically from a technological and clinical focus to something more positive, creative, and enduring. Was the shift in focus triggered by the creative act of composing music? Is there something about the act of creativity that changes how we interact with the world, perceive our situation in life, and ultimately, changes how we interact with others?

What do you do with your time when you lose your ability to communicate independently and move independently? What is your purpose? What is your identity? What do you need to be able to do to have a good quality of life? Those questions have motivated my thesis work, and I begin to address these questions with this dissertation.

1.3 Research Questions and Thesis Statement

Over the course of this dissertation, I address the following research questions:

RQ1: How does acquiring a disability as an adult, which includes a motor, mobility, and/or communication impairment, impact a person's identity and employment when the person needs to use AT for daily living?

I start my research with a focus on understanding how adults, who are mid-career, experience identity change after acquiring their disability. Through semi-structured interviews, I show how acquiring complex disabilities impacts identity. Based on these interviews, I also discover that there is a need for discoverable alternatives to traditional full-time employment that are accessible and meaningful. I then conduct a survey exploring the attitudes of adults who use AT for MMCD towards alternative options to traditional work. While answering this research question, I surface a gap in knowledge on best practices for conducting interviews with adults who have complex conditions and who use AAC, which leads to RQ2.

RQ2: What are the best practices for qualitative research with adults who use AAC?

I provide a methodological contribution in answering RQ2. To answer this question, I draw on qualitative research from the Rehabilitation Science, AAC, and HCI communities. I also reflect on my own experiences during the process of answering RQ1 and RQ3. As a result, I develop a methodological framework for researchers who engage in qualitative research with adults who use AAC. I also suggest best practices and discuss opportunities for future work to improve research engagement with adults who use AAC.

RQ3: How does engaging in creative pursuits impact the quality of life of adults who acquired motor, mobility and/or communication disabilities and use AT for daily living?

I build on findings from RQ1 and use best practices described in RQ2 to conduct semi-structured interviews with adults who use AT. I recruited seven individuals who engaged in creative pursuits, for one year or longer, outside of a directed, therapeutic program. I explore aspects of quality of life related to creative engagement and identity. Analysis shows how information discovery is a key predecessor to identity change. The data from RQ3 leads to an expansion of existing identity frameworks. Findings demonstrate how accessible technology and creativity are catalysts for identity change, which in turn, impacts an individual’s perceived quality of life.

RQ4: How can co-design methods better accommodate the needs of adults with motor, mobility, and/or communication disabilities who use AT for daily living?

I provide a second methodological contribution, motivated by the desire to include adults who use AT in co-design. Drawing on core co-design principles, I develop the aligned co-design method (ACD). I use ACD with six participants to explore key design aspects of accessible creative pursuits. I then analyzed participants’ feedback and refined the method, resulting in a method to include diverse participants in co-design and thus providing adults with MMCD who use AT a viable means to participate in technology design research.

1.3.1 Thesis statement

In the process of answering these research questions, I demonstrate the following thesis:

Adults who acquire motor, mobility, and/or communication disabilities that require the use of assistive technology experience feelings of loss and identity change. Access to creative pursuits can result in a positive impact on quality of life and identity formation. Limited accessible creative technologies and a lack of discoverability of those technologies are gating factors that impact people's ability to engage in creative pursuits. To further explore the topic of accessible creativity, it is paramount for researchers to use accessible research methods which include participants who use AAC and AT as partners in research.

1.4 Dissertation Setting

To answer the research questions described above, I conducted three studies: (1) interviews and a survey about employment and identity, (2) interviews about creativity and identity, and (3) a co-design methodological study. I present the studies in-depth in subsequent chapters of this dissertation, along with related work specific to each study. The studies took place in different locations and in different socio-cultural contexts. The employment study (Chapter 4) was conducted both online and in participants' residences, before the COVID-19 pandemic. The creative models study (Chapter 6) was conducted over the span of three years. Therefore, the first interview for the creative models study was conducted in a participant's residence before the onset of the pandemic, while the remaining interviews were conducted online, during the pandemic. The co-design methodological study (Chapter 7) was borne out of the pandemic, in which I sought to find a safe and accessible method to engage participants in co-design. All co-design sessions were conducted online.

For each study, participants provided consent. All study procedures were reviewed and approved by the University of Washington's Institutional Review Board.

1.5 Dissertation Overview

The research in this dissertation spans multiple disciplines, including: Information Sciences, Human Computer Interaction (HCI), Augmentative and Alternative Communication (AAC), Assistive Technologies, Disability Studies, and Rehabilitation Sciences. However, I position my research outside of the disciplines of directed, therapeutic creative arts interventions, such as music therapy or art therapy. Whereas topics such as art therapy and music therapy have existing bodies of research to support those therapeutic disciplines, e.g. [7,120,130], this dissertation addresses an under-explored research area: the impacts of creative engagement outside of directed therapeutic programs on adults with MMCD who use AT.

I focus my analysis in the areas represented by the departments of my thesis committee members: Information Science/HCI, and Rehabilitation Science. Therefore, my thesis is written for two disciplines: HCI and Rehabilitation Science. I conducted three distinct research studies for my thesis and provide two methodological contributions. Each study in this dissertation is written with an introduction, methods, findings, and discussion.

My thesis research builds on my findings, chapter by chapter (Table 1). The chapters present a story, beginning by establishing a need to explore accessible forms of active engagement. Then, I deeply explore the effects of accessible creativity on quality of life. I summarize my chapters below in Table 1, with notations regarding the disciplinary orientation.

Table 1. Summary of Chapters Related to Research Questions which Build Off of Each Other

Chapter Number and Title	Research Questions	Purpose	Chapter Field of Orientation
4. Employment Experiences and Identity Changes of Adults with Acquired Disabilities who use AT	RQ1	Establishes need for exploratory research on alternatives to work for adults who acquired disabilities and who use AT for mobility, motor, and/or communication.	Rehabilitation Science
5. Qualitative Research Methods for Involving AAC Users as Primary Research Participants	RQ2	Methodological contribution. Presents a framework for best practice in conducting qualitative research with adults who use AAC based on systematic literature review.	HCI
6. Creative Models: Creative Experiences of Adults with Acquired Disabilities who use AT	RQ3	Analyzes the impact engaging in creative pursuits has on aspects of perceived quality of life. Provides new framing of creative identity in the context of acquired disability. Shows that a lack of information sharing is a barrier to creativity.	HCI and Rehabilitation Science
7. Aligned Co-Design: A Method for People with Diverse Abilities in Diverse Locations	RQ4	Methodological contribution. Pilots a method to co-design with participants who use AT for MMCD. Presents Aligned Co-Design (ACD) method.	HCI

This dissertation is divided into a total of 8 chapters. I abbreviate chapter titles below for brevity.

In Chapter 2, Background and Related Work, I summarize the main related works on which my thesis is grounded: (1) Acquired Disabilities and Assistive Technology, (2) Quality of Life, (3) Creativity. In this chapter, I discuss how identity intersects with creativity and disability. More specific related work to each study is described in subsequent chapters.

In Chapter 3, Methods, I discuss the methodological foundation of my thesis work. I describe Grounded Theory Methods (GTM) and how I position myself in the Constructivist GTM approach. Specific methods for each study are described in subsequent chapters.

In Chapter 4, Employment Experiences, I describe the first study in this dissertation, which addresses RQ1. In this chapter, I summarize related research specific to employment and disability. I then describe the study, which is divided into two parts. First, I conducted semi-structured interviews with seven adults who acquired MMCD and use AT. Based on the analysis from those interviews, I then surveyed six participants about their attitudes towards crowdsourcing and remote work. This chapter contains a manuscript published by Taylor & Francis in Disability and Rehabilitation: Assistive Technology in 2023, https://doi.org/10.1080/17483107.2023.2221312 [19].

In Chapter 5, Qualitative Methods for AAC Participants, I present the first methodological contribution, addressing RQ2. I conducted a literature review of research methods used with people who use AAC. I analyze the literature and reflect on my own interview experiences with adults who use AAC. I present a framework of qualitative methods and discuss best practices for qualitative research with participants who use AAC. I conclude with a discussion of future opportunities to improve tools for engaging in qualitative research with AAC participants. This chapter contains a manuscript published at the ACM CHI Conference on Humans Factors in Computing Systems in 2020 https://doi.org/10.1145/3313831.33768 [17].

In Chapter 6, Creative Models, I summarize related research to creativity, identity, and disability. I then describe the second study of this dissertation, in which I interviewed seven adults with MMCD and use AT, who engaged in creativity after acquiring their disability. Based on findings, I present a model of an identity change cycle, in which discovering accessible creativity is a catalyst for identity change. I discuss how expert knowledge of AT and creativity are critical gatekeepers to discoverability of accessible creative pursuits.

In Chapter 7, Aligned Co-Design (ACD), I present a second methodological contribution, the result of the third and final study of this dissertation. I describe the ACD method, with examples from the co-design study I conducted using ACD. I then describe participants' reflections on the method, the subsequent refinement of the method, and how the HCI community can be more inclusive in design and co-design. This chapter contains original materials not published in addition to an original manuscript that is accepted for publication and in-press at the time of this dissertation by Taylor & Francis in the International Journal of Human Computer Interaction in 2024, https://doi.org/10.1080/10447318.2024.2436038 [20].

In Chapter 8, Discussion and Conclusion, I provide a high-level overview of the findings from this dissertation. I then discuss how the findings from the studies, taken as a whole, contribute to an emerging theory of identity, creativity, accessibility, and quality of life. I also acknowledge limitations of this thesis, discuss areas for future research, and provide a summary of key findings and contributions.

Chapter 2. Background and Related Work

2.1 Acquired Disabilities and Assistive Technologies

Adults who have developed or acquired complex mobility and communication disabilities mid-life must contend with a significant change in their lifestyle—— from that of an active, and often employed, adult to a passive participant, dependent on others. People with complex mobility and communication disabilities spend a great deal of their time at home, and a lot of their time engaged in passive leisure activities, such as watching TV or listening to audio books [9,172]. Our perception of quality of life is heavily influenced by social ties and active engagement [201,217] therefore a lack of active engagement can result in depression, anxiety, and poor health [60,250]. Most adults who have developed complex mobility and communication disabilities do not want to be relegated to passive leisure activities [9,210,211,303]. However, many adults with complex mobility and communication disabilities have limited opportunities to actively engage in work, volunteering, or other social activities [156,210,344]. Technology that is accessible through assistive technologies (such as through eye control or other alternative computer access methods) can provide critical assistance for preserving social networks, augmenting communication, and combating isolation.

The need for accessibility for a variety of disabilities is well documented in the human computer interaction (HCI) literature. There are a variety of constructs regarding accessible design available, such as inclusive design [124,237], universal design [181], and ability-based design [336]. While much of the accessibility research in HCI has focused on people with visual [28,181,237], hearing [203], mental health [234], or physical disabilities [221,335], research with adults who acquire both mobility and communication disabilities is more limited [194]. It is also important to recognize that accessibility is just one component in a complex technological system used by people with mobility and communication disabilities. While accessibility often has the goal of providing the user with complete independence, complete independence is not always a realistic goal for people with complex disabilities. Instead, the concept of interdependence, in which collaborative accessibility and design is emphasized, might be a more affirming perspective [24]. HCI technology research also has recognized that designing for social factors is important, and that the use of dedicated assistive technologies may influence social interactions and identity [282,284].

2.2 Quality of Life: Creativity, Identity and Health

Quality of life incorporates a variety of factors which contribute to a person's well-being [333]. The way a person feels as well as the way a person is able to function can contribute to well-being and perceived quality of life [142,266]. The World Health Organization (WHO) defines quality of life as *"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"* [362]. A person's position in life ties into how they identify themselves. Quality of life is heavily influenced by social ties and active engagement [201,217], and a lack of active engagement and social ties can contribute to poor quality of life.

Quality of life involves perception, and can be perceived differently for different populations. There are a number of quality of life (QOL) measurement instruments available, including instruments for specific populations such as people who have ALS [35]. These instruments are often presented as surveys or questionnaires, such as the Neuro-QOL measures [49,106]. However, accurately capturing quality of life can be challenging because quality of life is contextual and related to perception. A literature review of the term *"quality of life*" used in spinal cord injury research highlights how the phrase *"quality of life"* is used with different metrics and as a result, refers to different outcomes even within one specific population (in this case, people with spinal cord injuries) [246]. Therefore, for the purposes of this dissertation, I do not use one specific assessment tool to address or measure quality of life. Instead, I focus on a set of constructs which relate to and can influence quality of life.

The constructs I focus on related to quality of life for my dissertation research include creativity, identity, and health. The concept of creativity impacting various aspects of quality of life through therapeutic interventions has been heavily explored as part of therapeutic disciplines such as art and music therapies, e.g. [7,78,130,199,206,247,349]. In 2008, Creek reviewed literature on creativity and people with a variety of illnesses and disabilities, including rheumatoid arthritis, multiple sclerosis, and spinal cord injuries [62]. Despite the limited research available on the topic, Creek found evidence that creativity can promote health and well-being. Creek also found that when impairment restricts independent access to activities, it is necessary to facilitate access to creative activities, which can include facilitation through human interaction or through technology. While Creek's limited literature review shows a promising positive interaction between creative engagement and quality of life for some populations, it does not deeply address my research questions nor the population of my dissertation work.

The impact of creativity on quality of life outside of the therapeutic context is currently under-explored, particularly for adults with acquired disabilities who use assistive technologies. In the following sections, I describe the three concepts I choose to explore in my dissertation research related to quality of life: creativity, identity, and health.

2.3 Creativity

Creativity involves bringing something new into existence [364]. Creativity can take many forms and be considered a basic human need. Creativity is represented both in Maslow's hierarchy of needs [202] and in Max-Neef's matrix of fundamental human needs [86,205,359]. In contrast to Maslow's hierarchy, Max-Neef's matrix is flexible and non-hierarchical (Table 2). The matrix cross-references fundamental human needs with satisfiers which meet those needs, in the forms of being, having, doing, and interacting. Max-Neef's fundamental needs include the needs of creation and identity. Max-Neef's broad concept of creation, coupled with the dictionary definition of creativity [361], means that creation can include traditional creative pursuits such as art or music, as well as more recent forms of creative engagements such as gaming in virtual worlds.

In his book on creativity, Csikszentmihalyi states that *"when we are involved in it [creativity], we feel that we are living more fully than during the rest of life"* [66:2]. Csikszentmihalyi describes that many creative pursuits are *"autotelic"* in which the primary reason for engaging in the pursuit is to feel the experience. However, Csikszentmihalyi also explains that *"no matter how gifted a person is, he or she has no chance to achieve anything creative unless the right conditions are provided by the field"* (p. 330). In this case, Csikszentmihalyi is referring to a socio-cultural context, but it could be argued that the *"right conditions"* also need to exist for physical access to tools to express creativity.

Table 2. Max-Neef's Matrix of Fundamental Human Needs (Abridged) [204]. Complete Matrix Listed in Appendix A.

Needs	**Satisfiers**			
	Being (qualities)	**Having (things)**	**Doing (actions)**	**Interacting (settings)**
Creation	Imagination, boldness, curiosity, inventiveness, autonomy, determination	Skills, work, abilities, method, techniques	Invent, build, design, work, compose, interpret	Spaces for expression, workshops, audiences, cultural group, temporal freedom
Identity	Sense of belonging, self-esteem, consistency, differentiation, assertiveness	Symbols, language, religion, values, work, customs, norms, habits, historical memory, sexuality, reference groups, work	Get to know oneself, grow, commit oneself, recognize oneself	Places one belongs to, everyday settings, maturation stages, social rhythms

The National Endowment for the Arts (NEA) has explored ways in which people with disabilities can be better included in employment in the arts [354]. Multiple reports from the NEA reveal consistent barriers to artistic employment for people with disabilities, including lack of training, funding, and accessibility [355–357]. While the NEA reports are helpful in shedding light onto the generalized problems which people with disabilities face in attempting to engage in employment in the creative arts, and provides suggestions for policy and systems changes, the reports do not provide deep insights into the benefits that creative engagement can provide. Moreover, the NEA's work has not been specific to individuals who use assistive technologies, but includes the full range of people with disabilities.

Max-Neef included creativity as a fundamental human need. Creative pursuits, in the form of employment, is a documented barrier based on the NEA reports. The socio-cultural context which Csikszentmihalyi describes as necessary for creativity may simply not exist for many people with disabilities.

2.4 Identity and Intersectionality

In the context of my thesis, it is impossible to discuss identity without discussing intersectionality. Crenshaw described the critical importance of intersectionality with black women and feminist theory, explaining that the intersection of racism and sexism must be explored and analyzed [64]. Crenshaw describes how black women, because of the intersection of race and sex in their identities, can experience and challenge multiple forms of discrimination within their identities. Recognizing the intersection of social, political, and contextual factors on identity increases a researcher's sensitivity during analysis [8]. In the context of my thesis, intersectionality refers to overlapping identities which are influenced by social and contextual categories. I examine two intersections of identity: identity and creativity and identity and disability.

2.4.1 Identity and Creativity

Max-Neef's matrix provides flexibility when considering the interaction between creativity and identity. The matrix is not hierarchical or linear, and it allows for changes in identity, such as individuals who develop chronic illnesses. For example, in her research with 10 women with chronic illnesses, Reynolds' describes the tie between identity and creativity as *"identity reconfiguration through artistic expression"* [258]. Reynolds' found that both the onset of illness as well as the loss of identity based on prior occupation created a crisis for all 10 participants. Three of the 10 participants had engaged in artistic textile work prior to the onset of their illness, six participants engaged in textile artwork post-onset through serendipitous events, and one participant was encouraged to engage in textile arts through therapeutic intervention services. Through artistic engagement, the women were able to reconnect with their pre-illness self, resulting in positive identity growth, increased self-esteem, and a socially validated identity (Table 3). Reynolds' study, while focused on people with chronic health conditions only, directly ties together the concepts of identity formation through creative engagement, and is one of the only published studies to do so. Even though Reynolds' does not cite Max-Neef's matrix of fundamental human needs, Reynolds' work nicely complements Max-Neef's theoretical framework to provide an understanding of the flexibility and influences of identity and creativity on each other.

Table 3. Reynolds' Processes of Identity Reconfiguration through Artistic Occupation [258].

Main Processes of Identity Reconfiguration through Artistic Occupation	Processes Enabled by Artistic Occupation
A Reconnection with the Previous, Pre-Illness Self	Allowing expression of interests and skills developed during previous careers. Reviving interests that have been dormant since school or adolescence.

Main Processes of Identity Reconfiguration through Artistic Occupation	Processes Enabled by Artistic Occupation
	Connecting self with the interests and occupations of parents or grandparents. Enabling enactment of long-standing personal and family values.
Positive Personal Identity Growth and Development	Symbolic reintegration and griefwork. Expressing personal “voice.” Finding a positive way forward and fulfilling long-term aspirations.
Restores a Sense of One’s Own Expertise, Status, and Self-Esteem	Visible products. Gaining skills and knowledge through courses and classes. Initiating new artistic designs and craft techniques. Interacting with professional artists.
A Socially Validated Identity	New roles and membership of groups of textile artists. Receiving the praise and feedback of others. Sharing knowledge with others. Gaining status and sometimes fame.

2.4.2 Identity and Disability

In her autoethnographic paper, *“From the Streets to the Stage: Disability and the Performing Arts”,* Carrie Sandahl describes the effects of the socio-political nature of theater-arts regarding disability on her identity [270]. Sandahl describes the experience of having a disability to that of always being in a performance, in essence, performing the experience of disability on a continuous basis, for all the world to see. In this way, a person’s identity is very much tied to the appearance and manifestation of their disability. Sandahl describes a postpositivist realist view of how identity is both real and constructed, while at the same time identity is both variable and historical [269]. Essentially, Sandahl describes the critical intersectionality related to identity and disability. For example, Sandahl describes a performance piece by Lynn Manning, in which two identities are explored and ultimately intermingled: that of a black man, and that of a blind man. Manning’s identity of a blind man is acquired, and overlays and blends with his identity as a black man. Based on Manning’s work and Sandahl’s description of his work, acquiring a disability significantly impacts an individual’s previous identity and leads to the construction of a new multi-faceted identity.

A 2017 survey of research related to disability identity indicates that identity formation is heavily influenced by social connections [96]. Forber-Pratt’s framework of disability identity demonstrates the significance of social and societal influences on identity formation (Table 4) [98].

Table 4. Forber-Pratt Disability Identity Conceptual Framework

Status	Description
Acceptance	Become disabled and/or born with disability Person accepts own disability Close friends and family are accepting of the disability
Relationship	Person meets others like herself/himself Engages in conversation with these individuals Learns about the ways of the group
Adoption	Adopts the shared values of the group
Engagement	Become a role model for others Help those who may be in other statuses Give back to the disability community

In Forber-Pratt's framework, the identity stage of *"engagement"* involves an identity of someone who gives back to others, which is similar to Reynolds' identity stage of *"a socially validated identity"* in her identity reclamation through artistic occupation framework (Table 3).

In a study of 30 participants learning to use wheelchairs in a rehabilitation facility, Papadimitriou found that a re-embodiment of identity occurred as participants' abilities and use of assistive technology changed (in this case, wheelchairs) [238]. Papadimitriou found that identity change with disability became an embodied process that takes time, particularly as individuals who acquired their disability learn the parameters of their new abilities. In one case, a participant reported that the discovery that rock climbing was still a possible activity for her, despite now being in a wheelchair, made her realize that *"I can still DO a lot of stuff"* [238:698].

The intersectionality between societal norms, social connections, physical abilities, and assistive technologies may be critical factors in identity formation for adults who acquire disabilities and rely on assistive technologies [284]. Using assistive technologies for verbal communication is perhaps one of the more obvious forms of AT which can impact social identity. Wofford et al. highlight the importance of Augmentative and Alternative Communication (AAC) devices in the intersectionality of identity formation [339]. Wofford et al. state that the intersectionality between technology and identity, in this case, the use of AAC to communicate and express identity, is critically tied to quality of life parameters [339]. For people with communication disabilities, the access to communicate in a way which reflects an individual's identity is an essential factor in emotional health, social connections, and personal rights.

Communicating one's identity ties back to Max-Neef's matrix of fundamental human needs (Table 2). We see that the column of *"Having"* cross references with *"Identity"* in the form of having the ability to communicate identity through language and symbols. *"Having"* also maps with *"Creativity*" in the form of abilities. The intersection of identity and creativity relate to abilities and communication, and in the case of adults with acquired disabilities who use assistive technologies, identity and creativity may be accessed through assistive technologies. However, as yet, Max-Neef's fundamental human needs have not been applied to adults with acquired MMCD who use AT.

2.5 Health

Engaging in creative pursuits positively impacts mental and physical health of typically aging adults [95]. Access to creative pursuits, such as art creation, music creation, or interactive gaming (such as in virtual worlds) can increase intellectual stimulation, active engagement, and help reduce depression [9,62,171,188,206,293]. Specific, targeted therapies (such as music or art therapy) have shown benefits for adults who have mental illness, aphasia, cognitive disabilities and typically aging adults [9,57,62,91,95,201,206,254,267,329]. Similarly, children who have cancer [168] and young adults who have physical and intellectual disabilities, experience benefits from engaging in leisure activities and interactive gaming [255,303].

A case study of three pre-teen and teenage oncology patients revealed that playing video games during chemotherapy reduced anxiety and distress compared with baseline symptoms [168]. Creative participation benefits the mental health of individuals with chronic illnesses [201] and people with diagnosed mental health conditions [329]. Creative engagement can provide distraction from pain and anxiety, decrease apathy, and assist with coping through the process of long-term illness [62,172].

Perhaps the most notable and prolific fields of research in the exploration of creativity and health is research involving older adults [55,57,95,353]. Cohen et al. followed 300 typically aging adults (ages 65+) divided into control and intervention (creative pursuits) groups over the course of two years [57]. Intervention groups attended weekly art classes, which naturally combined creative engagement with social participation. Results indicated that intervention groups experienced benefits to morale, decreased incidence of depression, had fewer overall doctor visits, less medication usage, and fewer falls than control groups.

The growing interest in the effects of creative engagement on health can be seen through investments from federal health agencies collaborating with arts councils and community art organizations, both in the US as well as in the UK e.g. [15,358,365–367]. However, specific research and discussion on the impacts of creative engagement for people with disabilities is less prominent, particularly for individuals who rely on assistive technologies for daily living.

2.6 Summary

Adults who experience a dramatic change in their physical abilities might be at great risk for depression, particularly with a prevalence of accessible passive leisure activities rather than accessible active leisure activities. Access to technology can be especially critical as adults who acquire disabilities shift their identity from who they had been, to who they are now, given their new circumstances and abilities. Prior research has indicated that creative engagement can positively impact the mental and physical health of aging adults and people with complex health needs. However, little research has explored the impact creative engagement has on adults with MMCD who use AT.

Currently, there is a gap in the literature specific to the population that is the focus of this dissertation: adults with acquired MMCD who use AT. Little empirical work has explored the identity changes which occur with this population. At this time, there is limited understanding of how creativity may impact this population’s quality of life and identity.

In this dissertation I blend the research disciplines of Rehabilitation Science, Human-Computer Interaction, and Information Science. I do this through the lens of exploring the intersection of identity, acquired disability, assistive technology, and creativity.

Chapter 3. Method

My research questions are firmly grounded in my professional experiences from the last 20 years. The people that I have worked with and the experiences I have had in my professional practice directly inform my research and view of the world. Therefore, my research methodology is influenced heavily by the constructs developed during my professional practice regarding assistive technology and disability, and I position my discussion of research methods within a constructivist framework [253].

The specific methods I use are discussed in more detail within each subsequent chapter of my dissertation. Therefore, in this methods chapter, I address my overall methodological stance as a constructivist, drawing heavily on Grounded Theory Method (GTM). I begin with a brief overview of GTM. Because my dissertation research spans multiple fields and is motivated by own clinical background, I then provide a discussion of the use of GTM used in two fields: speech-language pathology (my clinical background) and Human-Computer Interaction (my current field of study). I focus on the applications of GTM most closely related to my dissertation topic.

3.1 Grounded Theory Method

Grounded theory, initially developed and proposed by Glaser and Strauss in 1967, is built on the principle of using data gained from the field to develop a theoretical construct to increase understanding [109]. Initially conceived as a qualitative methodology to be used in the social sciences, grounded theory method has evolved and splintered into different forms, and now can be thought of as a family of *"Grounded Theory Methods"* (GTM) [42,235]. The family of GTM holds three principals at their core: (1) analysis is grounded in the data, accompanied by memo writing as a part of the analytic process, (2) targeted, ongoing data sampling occurs simultaneously as the data is analyzed, to better inform theory development, (3) data is constantly compared within itself, even as new data is gathered, in order to reframe developing constructs and concepts that will form the basis of the theory [42,109,164,239,312].

Glaser and Strauss used GTM in their research on the experiences of terminally ill patients in *"Awareness of Dying"* [108] and *"Time for Dying"* [110]. Since then, GTM has been used in a variety of social sciences, including nursing and education fields [42]. However, due to the wide variety of interpretations of GTM, and the continuing evolution of GTM (such as combining GTM with Action Research), one “true” GTM research approach is debatable [42]. There are primarily three widely cited variants of GTM: (1) *“classic”* or *“Gaussian,”* (2) *“Straussian”* or the *“Strauss Corbin”* approach, and (3) *“Constructivist”* [42,123,164,305].

3.1.1 Constructivist GTM

Constructivist GTM draws from the belief that a researcher’s experiences influence their interpretation of the data [42,52]. Charmaz states that *“viewing the research as constructed rather than discovered fosters researchers’ reflexivity about their actions and decisions”* [52:13]. In this way, the researcher can consider their own position and societal influences during their analysis.

Kenny and Fourie describe constructivist GTM as relatively open-ended, with the intention that the researcher will gather and analyze data (while comparing and contrasting with existing data and literature) with an ultimate aim of developing a theory [164]. After a period of initial open coding, the researcher begins the process of refocused coding which uses constant comparison to refine and broaden codes [42,52]. As part of this process, the researcher engages in memoing [52]. Charmaz describes the importance of memo writing as a way to construct analytic notes and begin the refocused coding process, in which the researcher thinks about the data [52]. Memoing may also be thought of as a form of reflexivity. During writing, researchers take a stance which inherently reflects their perspectives [65]. During this time, researchers may find surprising findings, which forces them to engage in abductive reasoning- a search for theoretical reasonings behind the data while maintaining a critical perspective [52].

As with other versions of GTM, the ultimate aim of constructivist GTM is to develop theory, which requires detailed, rich data [52]. However, in reality, many researchers use GTM more generally as a method for analysis, rather than a method to generate theory [52,312].

3.1.2 GTM and Speech-Language Pathology

The field of speech-language pathology is traditionally based on the medical model of research. When I was in graduate school, our primary textbook on research methods was heavily steeped in a positivist, experimental research approach [275]. In fact, my Master's thesis was commended by my committee as being innovative in using a mixed-methods approach, in which I included both qualitative with quantitative research methods [21]. Therefore, it should not be a surprise to find that GTM has not yet permeated the field of speech-language pathology research. A literature review in 2007 of five research publication databases (CINAHL, MEDLINE, EMBASE, ERIC, PUBMED) found eight speech-language pathology-based research publications which used GTM to varying degrees [288]. While all eight papers were in the field of communication disorders, five of the papers focused on professional issues related to being a speech-language therapist. None of the eight publications had a focus on assistive technology, however, one paper's research focus is related to my interest area: quality of life. Markham and Dean investigated the quality of life of children with speech and language disorders using a method *"with characteristics most closely associated with the grounded theory of Strauss and Corbin (1990)"* to analyze recorded discussions from focus groups [200].

While it is likely that the use of GTM research in speech-language pathology has grown since the literature review conducted in 2007, as evidenced by two papers published in 2009 and 2010 which cite GTM, the incidence of GTM used in speech-language pathology research remains relatively small [60,311]. Compared to the limited appearance of GTM in speech-language pathology research, the field of human-computer interaction (HCI) has a much more prolific use of GTM in general throughout the discipline.

3.1.3 GTM and Human-Computer Interaction

Since 1992, research papers in the field of human-computer interaction (HCI) have increasingly used GTM, with over 300 published papers in the ACM Digital Library mentioning *"grounded theory"* since 2008 [235]. Studies within HCI have covered a wide range of populations, resulting in some excellent examples of how GTM can be put into practice and reported, such as Wyche and Grinter's detailed description of their use and application of GTM [342]. However, there is very little research on the topics of creativity, disability, and identity within the HCI literature and of those, even fewer that explicitly state they use a GTM approach. Bennett, et al.'s research on identity and prostheses is one of the few studies that combines the use of grounded theory methods with studying identity and assistive technology [25].

Bennett, et al. interviewed 14 individuals with upper-limb loss about their identity related to prostheses. Methodologically, the researchers describe generating “stories” based on multiple rounds of open and thematic coding, while simultaneously generating analytical memos and discussing theme generation within the research team. The research team’s paper reports the findings in the form of vignettes, but do not propose a formal or substantive theory as a result of their research. While the ultimate goal of GTM is to generate theory, Bennett, et al.’s paper is typical in the field of HCI (and, indeed, in other disciplines using GTM) in which analysis does not ultimately lead to theory development. Lack of theory development is a common criticism within the GTM literature about researchers who use GTM [42,312]. However, Bennett et al.’s study highlights how GTM can be successfully and appropriately applied to the concepts I explore in my dissertation: identity, disability, and assistive technology.

3.2 Methods Summary

Grounded theory methods (GTM) have the core principles of constant comparison, ongoing analysis using memoing, and selective/theoretical sampling in order to ultimately generate theory [42,164,312]. My background as a speech-language pathologist significantly influenced the formation of my dissertation research. Therefore I draw on a constructivist approach, in which I recognize that my background influences my research, my research design, and my methodology and I reject a positivist, objective stance to my dissertation research analysis [52,65]. My thesis research is person-centered and draws heavily on participants to provide their perspectives and insights into the data collected [239]. Consequently, I approach my analysis from an *“emic”* perspective, in which I attempt to position myself from the perspective of the participant [239].

Throughout this dissertation, I use a constructivist GTM approach. Each chapter builds upon the findings and methods of previous chapters. First, in Chapter 4, I explore the employment experiences of adults with acquired disabilities. Based on initial interviews, I discover an unexpected finding: a lack of information on accessible alternatives to employment. In keeping with GTM philosophy, I dive deeper into that unexpected finding by conducting a second study: a survey on possible accessible alternatives to traditional employment. I then engage in purposeful sampling to understand one accessible alternative to traditional employment: creative pursuits. The resulting chapter, Chapter 6 *“Creative Models,”* explores how access to creativity influences identity and quality of life through the perspectives of participants. Finally, I use a GTM approach to analyze and synthesize all of the findings across my thesis work to develop an emerging theory. I address this in my final discussion chapter, Chapter 8.

The many forms and interpretations of Grounded Theory can result in a variety of views as to whether research is conducted *"appropriately"* using GTM. By positioning myself within the Constructivist GTM approach, I narrow the parameters of how my research is evaluated. I also acknowledge that my dissertation work does not develop into a robust theory which has been applied to a variety of populations and circumstances. Glaser and Strauss might refer to the emerging theory I propose as a substantive theory, where the theory is applied to one specific population [109]. However, since I am not following a classic GTM approach, I do not label the type of theory generated from my thesis work as substantive. Instead, I generate an emerging theoretical concept of how creativity can impact quality of life and further— how accessible technology can foster a positive quality of life through accessible creativity.

Chapter 4. Employment Experiences and Identity Changes of Adults with Acquired Disabilities who Use Assistive Technologies

In this chapter, I explore the experiences of adults who acquire disabilities which results in the need of assistive technologies (AT) for daily living. I address my first research question (RQ1): **How does acquiring a disability as an adult, which includes a motor, mobility, and/or communication impairment, impact a person's identity and employment when the person needs to use AT for daily living?** The answer to this research question sets the stage for upcoming chapters of my thesis.

4.1 Introduction and Background

Adults who are working at the time that they acquire a disability, such as through progressive Motor Neuron Diseases, often find it challenging to balance the demands of their current work with their healthcare needs and changing physical abilities. Many adults express a desire to continue working, but, over time, may find that they are no longer able to continue the same job they had prior to onset of their illness [211].

Engaging in work or volunteering is beneficial for the mental health and quality of life of people who have complex physical and communication disabilities [156,208,211]. People who use assistive technologies (AT) want to work, and report that being employed, or even volunteering, can have positive impacts on their mental health and quality of life [156,311]. However, many barriers prevent people who use AT from paid employment. Common barriers to employment for these individuals include a lack of transportation or physical accommodations, as well as discrimination and attitudinal barriers from potential employers [156,210]. Secondary barriers include both government policies regarding disability benefits, and employer policies regarding purchasing additional technologies/equipment for workplace accommodation [210,226,344]. People who use AT can also experience anxiety related to difficulties securing paid employment [156]. Further, concern over losing government funded benefits amidst pressure to find paid employment can cause additional anxiety in a population that is already dealing with significant and stressful health concerns.

Maintaining social ties through employment is important for adults who have developed or acquired severe physical and/or communication disabilities mid-career. For example, adults who developed ALS and require augmentative-alternative communication systems (AAC) found that social and intellectual stimulation were important benefits of continuing employment during the progression of their disability [211].

The option to work from home has been increasing over the years and has risen dramatically with recent events related to the COVID-19 pandemic [80,309,360]. Telework—remote work from home rather than from an office—is one option that has been increasingly accepted and explored as an accommodation or as a standard option for employment, particularly since the advent of the COVID-19 pandemic [187,212,309]. Occasional, part-time work options, such as crowdsourcing [36,137,166] might be another possible telework opportunity, which can meet both the accessibility needs as well as health-related needs of people with progressive conditions. Crowdsourcing work is typically computer-based, requires an internet connection, and can be done from home, generally at times that are convenient for the worker.

Crowdsourcing can include micro-tasks that can be completed in minutes, or online freelancing services, which typically involve professional skills for a designated project [169]. Crowdsource workers' pay varies widely, depending on the type of work performed. In 2016, approximately half of workers on the crowdsourcing platform Mechanical Turk, earned less than USD $5.00/hour [243]. While not a traditional form of employment, crowdsourcing might be an option to balance an individual's need for intellectual stimulation with the need for a variety of physical accommodations, which can be made in the home work environment.

The majority of current research in the field of employment, accommodation, and AT includes a wide variety of disability populations, such as people who have congenital conditions, cognitive, vision, and hearing disabilities, e.g. [156,344]. The challenge with this heterogeneity is that workplace accommodations are not necessarily the same between disability populations, or even within individuals in the same disability population. Therefore, a gap exists in the literature that is specific to work experiences in certain populations, such as adults with acquired disabilities who use assistive technologies for motor and/or communication. To address this gap, I seek to understand the employment experiences of adults who acquire motor, mobility and/or communication disabilities and use AT for daily living and their interest in existing online work options, such as crowdsourcing work.

4.2 Materials and Methods

I used an inductive, qualitative approach to investigate the employment experiences of adults who acquired disabilities mid-career and who use AT for daily living, with a focus on people who use AT for mobility and/or communication. Two components were included in the study. First, I conducted in-depth, semi-structured interviews with seven participants. An eighth participant, located in a geographically different region, completed an online questionnaire regarding their workplace experiences as an alternative format for the interview. Second, I conducted a survey about crowdsourcing work opportunities with six participants

4.2.1 Research Participants

Due to differing participants in each study, I describe participants under each study of this research project: Study 1 and Study 2. I provide generalized, descriptive information on participant age ranges, ethnicity, and geographical information to protect participant privacy. I include specific information regarding participant reported disability areas and AT used in Table 5. All participants provided informed consent to participate in the research study. All research activities were reviewed and approved by the University of Washington's Institutional Review Board (IRB).

4.3 Procedures

4.3.1 Study 1: Employment Experiences

Participants included in the semi-structured interviews consisted of adults: (1) who worked prior to acquiring a disability, (2) had a communication, motor, and/or mobility disability, and (3) used AT for daily living. Participants were excluded if they had a diagnosed cognitive disability. All participants owned some form of assistive technology for daily living, including apps on tablets and smartphones, as well as dedicated forms of assistive technology for mobility, computer access, and/or communication (Table 5).

Table 5. Participant demographics as reported by participants in Study 1.

Study 1- Employment Experiences		
Participant ID	**Impairment(s)**	**Assistive Technologies Used**
P1-1	Speech, Upper and Lower Limb	Alterative computer access; wheelchair
P2-1	Speech	Alternative communication technologies; Walker; Scooter
P3-1	Upper and Lower Limb	Alternative Computer Access; Wheelchair
P4-1	Fully body, Speech	Alternative Computer Access; Alternative Communication Technologies; Mechanical Ventilation
P5-1	Lower Limb, Speech	Wheelchair; Scooter; Alternative Communication Technology, Ventilation
P6-1	Lower Limb, Speech	Walker; Alternative Communication Technology
P7-1	Ful body, Speech	Alternative Computer Access; Alternative Communication Technologies; Wheelchair
P8-1* (Data Saturation Participant)	Speech	Alternative Communication Technology
Aggregate Race and Ethnicity	**N (%)**	
Caucasian/White	8 (100%)	
Hispanic	1 (12.5%)	
Non- Hispanic	7 (87.5%)	
Aggregate Gender	**N (%)**	
Male	2 (25%)	
Female	6 (75%)	
Other	0 (0%)	
Aggregate Age	**N (%)**	
40-50 yrs	3 (38%)	
51-60 yrs	1 (12%)	
61+ yrs	4 (50%)	

In total, I recruited seven participants in semi-structured interviews (protocol in Appendix B). Two participants identified as men and five as women. Participant ages ranged from their 40's to 60's. Diagnoses ranged from disabilities resulting from Motor Neurone Diseases to injuries resulting from a car accident. Six interview participants were located in the Western United States, one participant was located in the United Kingdom.

All interviews took place at a time and place of the participants' choosing. Four interviews were held over Skype, in which one of those interviews was conducted primarily with the participant responding via writing in the chat window due to speech impairment. Two interviews were conducted with caregivers present in the room for a portion of the interview.

One additional participant (P8), located in the Eastern United States, completed a questionnaire (Appendix C) that was created based on the interview data obtained from the first seven participants. The purpose of the questionnaire was to determine if data saturation was reached. This participant identified as a woman, and her age fell into the same age range of the interview participants. This participant also used a similar form of assistive technology and had similar disabilities as the interview participants. In total, seven participants identified as white and one as Hispanic.

4.3.2 Study 2: Interest in Existing Online Work Opportunities

Based on the initial findings from semi-structured interviews, I conducted an internet search on alternative employment options for people who use assistive technologies. I used key words, such as *"employment," "jobs," "accessible work," "accessibility," "assistive technologies,"* and *"disabilities."* in various combinations. I then reviewed search results, specifically looking for paid employment options in which the employee could work from home, at their own pace, and in which the work was likely accessible via assistive technologies. A list of resources from this search are in Appendix D. All judgements about the accessibility and flexibility of work options were based solely on the public-facing materials provided by the online employers.

From a list of 13 work options identified in the internet search, I chose four options of crowdsourcing work because they offered a wide range of employment options which appeared to be accessible and flexible. The four types of online work opportunities included a selection of crowdsourcing platforms: UpWork[2], TranscribeMe![3], Appen[4], and Mechanical Turk[5,6]. I then created a survey to better understand how people with degenerative conditions might feel about engaging in crowdsource work as a form of

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[2] https://www.upwork.com/i/how-it-works/freelancer/

[3] https://www.transcribeme.com/transcription-jobs#monetize-downtime

[4] https://connect.appen.com/qrp/public/faq;jsessionid=37CF286663444D3DF408976DD0A47AD4

[5] https://www.mturk.com/worker/help

[6] Disclaimer: I am not affiliated with or have any interest in these crowdsourcing platforms.

alternative, occasional paid employment (Appendix E). I deployed the survey using Qualtrics, an online survey platform, and I used a format that was accessible via alternative computer access.

Participants were recruited through known networks. Inclusion criteria for participants in the survey included adults who: (1) had a progressive disability impacting motor, mobility, and/or communication, (2) used AT for daily living. Participants were excluded if they did not have access to a computer or if they had a diagnosed cognitive disability. A total of six adults participated in the survey. Participants included people diagnosed with Multiple Sclerosis, Primary Lateral Sclerosis, and Friedrich's Ataxia. Three participants reported they were currently engaged in part-time or occasional work, and three participants reported that they were currently not working. Survey participants used a variety of assistive technologies, including text to voice output apps on phones or tablets, walkers, wheelchairs, voice dictation software, alternative mice, and voice amplification (Table 6). All participants were located in the Western United States.

Table 6. Participant demographics regarding AT reported by participants in Study 2.

Study 2- Interest in Existing Online Work Opportunities		
Participant ID	**Impairment Type**	**Assistive Technologies Used**
P1-2	N/A	Alternative Communication Technology
P2-2	N/A	Alternative Computer Access
P3-2	N/A	Assistive Communication Technology; Wheelchair
P4-2	N/A	Wheelchair
P5-2	N/A	Walker; Assistive Communication Technology
P6-2	N/A	Alternative Computer Access, Assistive Communication Technology
Aggregate Gender	**N (%)**	
Male Female Other	2 (25%) 6 (75%) 0 (0%)	

In the survey, participants were shown the four examples of different online-based work opportunities. Participants were asked if they had heard of the work opportunity before participating in the survey. Participants were then asked to rate their interest in further exploring those work opportunities on a 5-point Likert scale (Appendix E). The survey incorporated a screenshot from each platform, with basic information regarding the types of employment available for each platform (and the reimbursement rates, when available).

4.4 Analysis

I used an inductive analysis approach for both studies, in which I iteratively developed a series of codes: open codes which lead to axial codes, which broadened to themes derived from the data analysis [42,65,123,164,235,239,305]. The iterative coding approach allowed me to refine emerging codes and categories by using a method of constant comparison of data as it was generated, incorporating a process of reflection, refinement, and action during analysis and data generation [109,200]. I collaborated with three additional researchers as I refined the emerging themes. An independent researcher reviewed a random sample of the interview data set (Study 1) against open codes and axial codes to provide an additional perspective on the wording of the codes and the development of themes. The researchers discussed any disagreements in codes and themes until consensus was achieved.

To ensure that I accurately captured data from interview participants, I conducted member-checking with interview participants (Study 1) [29,60,65]. I sent emails directly to the two participants who had caregivers present during the interview, to confirm my interpretation of their answers to specific questions. In both cases, the participants confirmed or added to the data collected during the interviews. As I further refined axial codes, I wrote emerging themes in the form of statements in a member-checking questionnaire, which could be easily accessible to participants, and all interview participants were asked to rate their level of agreement with the statements. Three interview participants completed the member-checking questionnaire. I then sent a final questionnaire with the themes generated from the analysis to an eighth participant who was not involved in the original interviews. This eighth participant was asked about their experiences related to the emerging themes which helped determine if data saturation was reached. Final analysis revealed two themes, discussed in the findings, and a third theme emerged which led to the development of the survey (Study 2).

After analysis of Study 1 (the interviews) was complete, I developed, deployed, and analyzed the survey data about online work options (Study 2). I used open coding to analyze quotes from open text fields in the survey. I then analyzed data across both studies (interviews and survey) to develop the third and final theme, discussed below.

4.5 Findings

Findings revealed three themes: (1) changing physical abilities impact both employer and employee attitudes and expectations regarding acceptable work productivity, (2) adults who acquired disabilities experience feelings of loss, regret and identity change related to their careers and (3) options for accessible, alternative, and occasional work opportunities are not well-known, but wanted.

The first two themes are derived entirely from the interview data (Study 1) and the third theme is a result of the interview and survey data analyzed together (Study 1 and Study 2).

4.5.1 Theme 1: Changing Physical Abilities Impact Both Employer and Employee Attitudes and Expectations Regarding Acceptable Work Productivity

Participants identified that self-perceptions of productivity and performance as an employee was as significant to maintaining employment as the employer's attitudes. In fact, some participants judged their work productivity as harshly or more harshly than their employers.

4.5.1.1 Employee Attitudes: Self-comparison and critique

Participants compared and judged themselves based on their abilities pre- and post- acquiring their disability. For example, one participant discussed how their own expectations of themselves significantly impacted their feelings of obligation to their employer. As the participant's physical abilities changed, they found that they progressively lost efficiency and productivity in doing their work tasks. Eventually, even AT fell short in providing reliable assistance that met self-perceived expectations of work productivity. The participant explained, *"It was becoming harder. My hands don't work well anymore. I had Dragon [for alternative computer access] but Dragon doesn't work very well with spreadsheets, which was a huge* *part of my job."* Despite support from the employer in providing accommodations, the participant felt dissatisfied when comparing their current productivity to their performance prior to developing their disability. Ultimately, the participant left employment because of their own expectations. The participant stated:

> *"I feel like the only limitations and expectations were self-imposed, absolutely. They [employer] were happy to keep me in a limited capacity. It was my own work ethic that made me feel like it was time to leave. I wasn't as productive. They weren't getting their money's worth, as it were. It was never really any pressure I felt from them [employer]."*

Participants often felt that they could no longer meet the work expectations of themselves, their employers, or their coworkers. For example, another participant also chose to leave work based on their expectations of what their abilities should be, stating *"I gave up work because of safety concerns for myself and others I work with."* In this case, the participant's job duties required physical demands that the participant felt they were no longer able to execute safely. Therefore, the participant discontinued their current job because of concerns not only for themselves but for the impact they might have on others' safety.

A different participant's acquired physical disability led to the participant judging themselves harshly in the workplace, stating *"my skills weren't what they used to be. I didn't feel as competent… I guess I was kind of ashamed, and… embarrassed."*

Yet another participant felt that they had no choice but to leave work, due to the nature of their job duties and their changed abilities. This participant stated:

> *"I was forced to leave this very lucrative and intellectually challenging career because my speech was deteriorating…without an intelligible voice, I could not do my job. The frustration with not being able to talk is indescribable!"*

All participants had some form of AT to facilitate participation in employment, however, these findings indicate that despite having AT, many participants thought that assistive technologies did not bridge the gap between their job performance pre-onset vs post-onset of their disability. As a result, AT helped to get by with daily living and basic job duties, but the perceived deterioration in job performance negatively impacted participants' willingness to stay in the same career. In these cases, the employer's willingness to provide accommodations helped participants continue working only up to a point.

In this study, most participants were as critical of their work abilities after onset of their impairment as their employers, and perhaps even more so. Participants put pressure on themselves by comparing their performance as an employee post-disability with their performance prior-disability. Even participants who were provided with work accommodations continued to feel dissatisfied with their work performance, particularly for those participants with degenerative conditions or disabilities which impacted speech production. Ultimately, for most participants, their change in physical abilities became the major reason they discontinued with the employment they had prior to acquiring their disability.

4.5.1.2 Employer Attitudes: Impact employees' attitudes about their value as a worker

Participants reported a variety of employer attitudes toward their disability and need for accommodation. While most of the employers were supportive, this did not occur instantaneously, and in some cases, employers remained unsupportive as their employee's disability progressed.

Employer attitudes generally manifested through their engagement in providing accommodations to their employee. For example, one participant explained that initially, their direct manager did not approve an accommodation request when the participant was no longer able to easily walk up and down stairs. When discussing their request for work accommodations, the participant said:

> *"That was kind of a rigmarole actually. My manager…became a real stickler about what technically my job entailed, which of course, there's that tricky catch-all 'other duties as assigned'… so that's when I had to officially get HR involved and start documenting my conditions with them."*

In this participant's case, the Human Resources team assigned an internal case worker to the participant, and the case worker worked with the participant and manager to clarify why accommodations were needed. Over the years, the participant needed additional accommodations, including changes to the physical accessibility of their workspace as well as AT for computer access. Although there was initial resistance to these accommodations, additional accommodations and support for the employee's contributions was more readily achieved as time went on and their manager had a greater understanding of their employee's disability. The participant stated:

> *"That is absolutely the number one reason that I could work as long as I did… [to]conserve energy. Getting dressed is a whole thing, and then getting in a chair, and then getting to work…if they hadn't done that [allowed work from home] I wouldn't have been able to work as long as I did."*

By providing ongoing accommodations, the participant's employer reinforced the value that the participant had as an employee. The participant felt supported and valued, because their employer made accommodations and *"made sure I knew I had a job until I wanted to leave."*

Other participants experienced supportive attitudes and accommodations from their employers from the beginning. One participant described how their employer provided continued accommodations as the participant's physical abilities changed, including an internal job transfer to a less stressful position, in a more accessible location which reduced physical demands. The employer was in consistent communication about special projects that capitalized on the employee's talent, in addition to offering flexible work hours to help manage fatigue and allow extra time to prepare for work. As a result, the employee held their employer in high regard and also felt valued, stating *"My company was great about it. They were so awesome… anything I wanted, they were behind me 100%!".*

In contrast, another participant experienced unsupportive attitudes and a lack of accommodation from their employer, following a return to work after an extended medical leave. This participant noted:

> *"My employer was not very encouraging to me. I guess they wanted to get rid of me. I was getting episodes of illness….and they just got tired of people having to substitute my position…I wasn't secure. They weren't warm and sympathetic…They weren't encouraging and I needed a lot of encouragement to stay in my same field, just a lot of encouragement. It was too daunting to pretend like I could do everything like before."*

In this instance, the participant felt that their employer's attitude was a barrier to continuing work, attributing a lack of experience in working with people with disabilities or significant illnesses as one root cause, stating *"no one had ever known anyone with a disability- they were all young and healthy."* The result was an uncomfortable workplace environment for the participant which impacted the participant's feelings of value and worth to their employer. The participant stated *"If your office didn't want to hire you or you were a pain in the butt, it's not very pleasant."* As a result of this dynamic, the participant ended up leaving their employment. A second participant had a similar experience regarding employer expectations and lack of accommodations, saying, *"they didn't offer anything and I didn't have the resources [knowledge of AT and community supports] yet…I was specialized [in career choice] and realized that I couldn't continue, so I left with grace."* While both participants explained that their job duties were specialized, and were heavily dependent on specific communication skills that had been affected by their disabilities, neither reported that they were offered alternative career options or work duties.

Findings from interviews with participants reveal that employer and employee attitudes regarding disability and employment are interconnected. Participants found that their employer's attitude and willingness to provide accommodations impacted their ability to work. Employee's attitudes of their own value and worth were also influenced by employer attitudes. However, findings show that participants' own attitudes regarding their work performance (often measured against their pre-disability work performance) played a significant role in employment discontinuation.

4.5.2 Theme 2: Adults Who Acquired Disabilities Experience Feelings of Loss, Regret, and Identity Change Related to Their Careers

Most interview participants attempted to maintain their original employment after initially acquiring their disability. Two participants had transitioned to part-time work, primarily unpaid, (and continued to be engaged in those careers at the time of the interview), one interview participant continued to work, full-time, at the time of the interview.

Participants spoke of leaving their employment with a sense of significant loss, and struggled with their decision to do so. One participant explained:

> *"I really didn't want to [leave work] because in society, so much of your identity is tied to what you do. How you justify your existence is with a paycheck…part of me still wants to have an answer to 'what do you do?'"*

After exhausting a variety of work accommodations, including an internal job transfer, another participant finally ended work due to the significant health impacts, saying *"It was bittersweet. I knew that it would be better for me to quit [because of health]. But it was so hard to give up my career. But I knew that I could never continue."*

Despite choosing to leave work, participants expressed a desire to continue work and contribute to society in some way. Many participants similarly noted that they *"loved work"* and *"missed working."* Participants expressed a feeling of loss at having to end their careers earlier than intended. One participant explained, *"it's not really regret, but I miss work. And I wish I was still there. I love what I did."* Another participant explained that they were depressed after having to resign from work, particularly because they felt *"it wasn't my choice [to acquire their disability]."* In many instances, participants expressed regret at the decisions they had to make because of their health needs or their disability.

Participants described how they shifted from identifying themselves as a productive member of society, as an employed person, to being unemployed. For example, one participant explained they did not want to be a *"burden"* on society by relying on publicly funded benefit programs, but that they needed those programs for the consistent health insurance.

4.5.3 Theme 3: Options for Accessible, Alternative and Occasional Work Opportunities are Not Well-Known, but Wanted

Analysis of both interview and survey data indicated that participants would like something to do that filled the void they felt in leaving their careers. Analysis of each data source is discussed below.

4.5.3.1 Study 1 Interviews: Need for engagement through work

Interview participants spoke of the social and intellectual engagement that future work opportunities could provide. One participant explained *"I want something to do. There's nothing wrong with my faculties."* Another participant stated, *"Being of some intelligence, you get bored quickly. There's only so much TV you can watch really."* However, participants had little knowledge of specific options available to them.

Participants voiced a desire to work or volunteer to remain socially engaged in society, but simultaneously voiced concerns about their physical abilities to do so. One participant explained, *"I want to be helpful to someone for a little while…I'm just worried about what I can commit to."* Participants, particularly those with progressive health conditions, spoke of the challenges in balancing their own health needs with a desire to engage in meaningful work. Participants indicated that future work would need to be flexible, without hard deadlines or specific time dependencies to accommodate their health needs and fatigue.

Two interview participants were able to find part-time, primarily unpaid, work as an alternative to their previous careers. In both cases, the part-time work was occasional and involved known social networks, such as family members and/or friends. Many other participants expressed interest in volunteering as an alternative to continuing with paid work. When asked why volunteering was more appealing than seeking out paid work, participants indicated that volunteering seemed more flexible and less stressful than paid work, thus they would feel more capable, and their health was less likely to be impacted.

Overall, interview participants indicated a desire to continue engagement with society through some form of work, however, most participants did not have a specific work or volunteer opportunity in mind. When asked about online work opportunities, only one participant had engaged in taking surveys through a research service, in which they were paid very small amounts of money (less than $1.00). However, that participant discontinued the survey work quickly due to a mismatch of their abilities and the able-bodied assumptions within the questionnaire. Other participants spoke of potential volunteering within their community or with organizations they had previously volunteered with, however, few participants had actively explored these opportunities after leaving their careers. Findings indicated that few participants had specific ideas of where to begin looking for flexible and accessible alternative employment or volunteering opportunities.

Data from participant interviews as well as survey participants clearly indicate the need for computer-based work. One participant stated, *"paraplegics who want to be employed use the computer."*

4.5.3.2 Study 2 Survey: Crowdsourcing and alternative work options

Survey data confirmed the findings from the interviews that alternative options to “traditional” work are not well known. Of the four crowdsourcing platforms included in the survey, one participant reported having known about online transcription work (such as TranscribeMe!) as a work option prior to participating in the survey, however, none of the participants had heard of Upwork, Appen, or Mechanical Turk. Participants responded somewhat favorably to the Upwork platform, with four participants indicating that they would “probably” search the website for more information, and two participants indicating that they “might or might not”. None of the survey participants indicated that they would definitely look further at any of the four crowdsourcing platforms.

Survey participants indicated that their current abilities made computer-based work *“most realistic,”* because *“physical disability makes going out into the world an ordeal.”* However, two survey participants indicated that they would like to learn of other employment options that included the potential for being around people.

When asked about preferences for volunteering vs paid work, one participant indicated that they preferred volunteering, two participants indicated they preferred paid work, and three indicated no preference. Reasons for preferring paid work included: *“I need an income,” “the amount of energy needed would require paid work.”* Responses also indicated that the purpose of the work was important. One participant stated: *“If the cause is legit, I’m happy to help. If it’s just making money for someone else, no thank you,”* and another participant explained *“[volunteering] is more in line with my personal philosophies.”*

At the conclusion of the survey, participants were asked if their feelings about alternative work had changed, based on the information they learned through the survey. Four respondents indicated that their feelings had changed, one indicated that their feelings had not changed, and one indicated that their feeling might have changed. Participants who indicated that their feelings had changed stated that there were more opportunities than they had been aware of: *“I didn’t realize that there are so many opportunities to work from home,”* and *“There are more opportunities than I realized, and more variety.”* Findings show that just sharing information about alternative work options resulted in most survey participants changing their attitudes regarding alternative work.

4.6 Discussion

The results from this study show that the attitudes of employers and employees significantly impact employee feelings of worth and value as a contributor to society. The results of these studies highlight a need for additional research on flexible, meaningful engagement opportunities for adults who acquired disabilities mid-career and who use AT for daily living.

4.6.1 Identity Changes and Purpose is Lost: Acquiring a Disability Changes Pre-Conceived Notions of Self

People who use AT, including people who use AAC, can associate maintaining employment with societal success [210]. Our findings show that interview participants lost their identities as workers and as contributors to society when they were no longer able to continue their work. Not only did participants feel societal pressures regarding their identity as someone disabled and unemployed, but participants also felt personal pressures to remain engaged with society and to have purpose. Prior work has found that adults with acquired physical disabilities go through a process of identity change in which participants initially focus on comparing what they could do prior to their disability, not realizing the potential of what they can do with their changed abilities [238]. Disability identity is heavily influenced by social connection [98]. My findings show that social connections, through the work environment, can influence a person's identity and attitude about themselves. Participants who had supportive employers continued to work with accommodations as long as they could whereas participants without supportive employers felt discouraged to try to continue to work.

These findings illuminate a practical application of Max-Neef's Matrix of Human Needs in the stories shared by interview participants. In Max-Neef's model, identity involves a sense of belonging [86]. As interview participants' abilities changed, their sense of belonging changed as they believed they could no longer maintain their employment. This lack of belonging occurred even when employers were supportive in providing accommodations to participants, if the participant felt that they were not performing to their personal standards.

Identity reclamation after a significant change in health or physical abilities can occur outside of seeking traditional employment [51,258,260]. Prior work with individuals with health conditions, such as multiple sclerosis or cancer, has shown that individuals can use a variety of ways to reclaim their changed identity, including engaging in different forms of creative expression, ranging from tattoo design to art-making [87,141,258]. The findings from this study indicate that additional research on how adults who acquire disabilities mid-career can reclaim their identities should be explored.

4.6.2 Accommodations are Not Enough: People Want Something to Do

Findings indicate that even when accommodations are made based on an employee's physical abilities, traditional work is simply not flexible enough to meet the needs of individuals with complex needs. Interview participants spoke of needing work that did not have time pressures and allowed them to work flexibly, based on when they had the energy and ability to work, rather than working based on external deadlines. Participants spoke of volunteering as a possible alternative, because volunteering was perceived as having more flexibility and less pressure than paid employment. Prior work with people who use AT and AAC similarly speak to the need for flexibility, in particular, the ability to work from home [212]. Survey respondents from my research indicated that they had an interest in crowdsourcing opportunities after learning about them, but none stated that they would definitely look at the platforms' websites, indicating participants had some interest, but not a strong interest, in investigating crowdsourcing work further.

Although working from home is becoming increasingly common, particularly with the advent of the COVID-19 pandemic, working from home is not enough of an accommodation for some people [360]. Interview participants who were able to work from home and who had technological accommodations still struggled with their expectations of their productivity as their health conditions progressed. As a result, paid work simply is not a viable option for them.

Yet, interview participants indicated a strong desire to contribute to society somehow, to do something meaningful. As one participant noted, *"there's only so much TV you can watch."* Prior work also has indicated that passive leisure activities are often a main activity for people with significant disabilities who use AT for daily living, even though engagement in active leisure opportunities (not passive) can enhance social participation and perceptions of quality of life. [62,72,197,303]. Unfortunately, finding accessible active leisure activities can also be difficult for people with complex needs [9]. Thus, in addition to examining work-related engagement, more research is needed to explore different ways in which adults with disabilities, who use AT, can find meaningful engagement as an alternative to work.

4.6.3 Limitations of the study and future directions

This study was conducted prior to the onset of the COVID-19 pandemic. Since the pandemic, awareness of telework and flexible work may have changed [360]. Additionally, this study has a small participant pool which draws largely from the Western United States and future work might address a larger geographical distribution. Based on the results of this study, I believe that research exploring ways in which adults with acquired disabilities can more easily discover alternative, accessible work options would be beneficial.

4.8 Contribution

In this chapter, I presented the findings of two studies which explored the experiences of adults who acquired disabilities mid-career, and their interest in alternative work options. Based on analysis, I demonstrated that adults experience identity change after leaving their career and that they wish to continue contributing to society in some way, but accessible options are not known. I contribute to the fields of Rehabilitation Science and Information Science by demonstrating that participants are unaware of the range of accessible alternative work opportunities available and that there is a need for further research in the area of flexible, accessible forms of active engagement for adults with acquired disabilities who use AT. In the next chapter, I draw on the methods used in this chapter to develop a framework of qualitative research best practices with participants who use AAC.

4.9 Declaration of Funding

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opinions or policy of Policy Research, Inc., SSA or any other agency of the Federal Government.

Chapter 5. Qualitative Research Methods for Involving AAC Users as Primary Research Participants

In Chapter 4 I heavily relied on semi-structured interviewing, using a pre-written interview protocol primarily consisting of open-ended questions. However, the reality of interviewing adults who use Augmentative and Alternative Communication (AAC) devices is that, at times, high-tech AAC systems do not work. In those instances, participants are not able to respond to open-ended interview questions and instead, must use no-tech AAC such as eye blinks in response to yes/no questions. As a result of the research in Chapter 4, I sought to better understand best practices of interviewing people who use AAC from the existing literature. I did not find any such guidance. Therefore, I posit the second research question of this dissertation (RQ2): **What are the best practices for qualitative research with adults who use AAC?**

5.1 Introduction

In a position paper outlining high-level principles towards AAC research in practice, Blackstone et al. [32] state that people who rely on AAC should be actively participating in AAC research. The authors recognize that *"the most important voices are often the hardest to hear,"* acknowledging that there are challenges to including AAC users in research. The authors also recognize that including AAC users in research as primary contributors often requires various levels and types of support.

Unfortunately, HCI literature has limited resources dedicated to the discussion of appropriate qualitative methods and levels of support to include AAC users as primary research participants. As a result, researchers with little exposure to working with disabled participants, and in particular, with people who use AAC, may feel unsure of the best practices for including AAC users in their research, even when AAC users fit the researcher's inclusion criteria. Therefore, researchers may not include AAC users as research participants as frequently as participants who are able to communicate verbally. Even researchers who have experience working with participants who use AAC might be *"feeling their way"* with the research methods they use.

In this methods chapter, I provide an overview of a range of methods used for conducting qualitative research with participants who use AAC. First, I examine currently published qualitative research in the fields of HCI and AAC that focus on AAC users as the primary research participants and I provide a meta-review of methods that have been used in research with AAC users, synthesizing studies from a variety of research disciplines. Second, I draw on my own experiences of conducting qualitative research with people who use a variety of AAC systems. I provide four case examples of adults using different forms of AAC while participating in qualitative research interviews. I describe the tactical methods used in conducting those interviews and how I modified my methods when interviews with AAC users did not go as planned. Through comparing and contrasting the literature review and case examples, I propose a framework of qualitative research methods best practices to involve AAC users as research participants.

5.2 Literature Review

A number of excellent research studies on the topic of AAC use methods such as observational data, empirical assessment measures, and/or interviews from communication partners, sometimes in combination with feedback from AAC users themselves e.g. [4,30,81,93,102,125,145,231,290,351]. However, the purpose of this chapter is to provide guidance to HCI researchers who want to use qualitative methods, such as interviews or focus groups, with AAC users themselves as the central (and sometimes only) research participants. Qualitative HCI researchers will be familiar with a variety of methods that can be used with participants who communicate verbally, but the application of these methods to AAC users is less straightforward.

In the literature review, I explore qualitative research studies that specifically target the perspectives of the AAC user as central to the research methods used. I focus on papers that describe their research methods in great detail. I begin with a description of my procedures for conducting the literature review.

5.2.1 Procedures

This literature review primarily draws on related work from two disciplines: HCI and AAC. A search of the ACM Digital Libraries with the keywords *“augmentative and alternative communication”* and *“AAC,”* resulted in a total of 108 papers as of September 1, 2019. I reviewed the abstracts of all 108 papers, and if the title and abstract implied AAC users participated in a qualitative study, I then reviewed the methods section of the paper. If the methods indicated that AAC users were the primary participants in the qualitative research, I included the paper for additional review. I defined AAC users as individuals who required some alternative form of communication for unfamiliar listeners. Next, I systematically reviewed a total of 216 published titles from 2011 up until July 2019 in the journal *"Augmentative and Alternative Communication."* If the title implied that qualitative methods were used in the paper, I reviewed the abstract. I then selected qualitative research papers in which the primary research participants were AAC users for inclusion in the final review.

I further refined the literature review to include research in which the opinions, experiences, and perceptions of AAC users were actively solicited as the primary data collection method, rather than participants who were observed or who were evaluated based on quantitative measures, such as in the use of typing tasks, standardized assessments, or observed and recorded interactions between communication partners and AAC users. In addition, I included relevant research found from citations listed by the papers reviewed in the searches described above. I sought out research from secondary sources which used research methods that I did not readily find in the systematic HCI and AAC literature reviews. I also drew on related work to the case studies described in this paper. As a result, some papers prior to 2011 from the AAC journal are included, as well as papers from qualitative methods journals and other related disability and rehabilitation publications. Ultimately, papers which provide rich details of the methods used were included in the final, in-depth literature review. Details of the most relevant papers on qualitative research methods are described below.

5.2.2 Participation Rates and Common Methods Used

When examining qualitative methods in which AAC users are the primary participants, three common methods are used: surveys/questionnaires [94,121,289], focus groups [48,72,207,210,211], and interviews [60,76,161,311]. At times, studies incorporate two or more of these methods [59,160,310]. Participant numbers for studies utilizing focus groups and interviews range from 5 participants [211] to 23 participants [54]. One multi-year survey study included 26 participants [59]. In-depth, single case studies of AAC users is a method used more frequently in therapeutic and rehabilitation disciplines [9,185,233] than in HCI [343]. We also find member checking used with AAC participants, in which researchers provided participants with an opportunity to review and amend their responses [60,76,220,310,311]. I address the specific tactics of the methods used below, highlighting published research studies in which the authors deeply describe their methods.

5.2.2.1 In-Person Research Methods

A number of research studies note that fatigue can be an issue when conducting in-person interviews with people who use AAC [60,94,161,307]. As a result, some researchers break up the in-person interviews into multiple segments [60,307,311]. Another method to help with fatigue is to email interview questions to the AAC users prior to the in-person interview, so they may begin composing their initial responses in advance [161,220]. Also, researchers can anticipate that interview responses from AAC users may be shorter than when interviewing people providing verbal responses [76,307] and that responses to questions might take longer to produce [161].

In addition, other people aside from the AAC user may attend the in-person interview and these people may or may not be intended to be additional participants [60,161]. For example, Cooper et al. [60] describe how one participant's mother attended a portion of an in-person interview, during which the AAC user ended up relying on his mother to reply to questions instead of answering for himself. The authors also describe how another AAC user's attendant was present during her interview, but did not engage with the researchers. As a way to ensure the interview data truly reflected the AAC users' perspectives, the researchers utilized member checking with each participant over the course of two interviews, providing transcripts of the interviews to the AAC user participants and inviting the participants to confirm, clarify, or add information.

Conversely, researchers might choose to purposefully encourage AAC users to invite an additional companion to attend the in-person interview, as Kane et al. did in their study [161]. Six of the seven AAC users chose to bring a companion with them to their interview. While the researchers acknowledge that including a companion during the in-person interview creates a risk that the AAC user might not be as actively engaged, the researchers took precautions against this by setting parameters for the companions' involvement. The researchers asked AAC users to choose a companion who they communicated with often, and who knew them well. The researchers explained the focus of the study before and throughout the interview, as a reminder that the companion's role was that of a support to the primary research participant. As an additional check, the researchers ensured that the interview topic was focused entirely on the AAC user. Finally, the researchers encouraged the AAC users to email any follow up comments they might have after the interview was completed.

5.2.2.2 Asynchronous Research Methods

Asynchronous qualitative research methods, in the forms of online focus groups and interviews, can be advantageous for a variety of reasons. Asynchronous communication methods can be used to ensure that AAC users are able to use their own preferred access methods to engage in communication without becoming overly fatigued. In general, asynchronous communication provides more flexibility and greater opportunities for AAC users to compose their responses at their own pace [310]. In keeping with the affordance of responding at their own pace, online focus groups can span anywhere between 3-9 weeks in duration, with the researcher introducing one question at a time, at set intervals throughout the research period [48,72,210,220,310]. For example, Therrien's [310] study with eight adult AAC users, which examined the topic of making friends, included both an online interview as well as an online focus group. Drawing on prior work which used a password protected Wikispace [48], Therrien conducted individual interviews using a private inbox on the Wikispace for each participant, while the focus group used a threaded discussion board. The focus group was structured by themes for each of the four weeks of the study. Participants were first instructed to introduce themselves in the discussion thread, and then asked to share their personal experiences for each theme. The discussion thread remained open for a fifth week, to provide participants with the opportunity to add any final comments to any of the discussion topics. At the conclusion of the study, the researcher conducted member checking by sending individual emails to each participant's inbox with a summary of the data, and participants were asked to contribute additional information, if appropriate.

Morris et al. [220] also engaged in asynchronous member checking by using an online discussion board (GoPost) for a focus group. After conducting in-person interviews with 12 AAC users, all 12 participants were invited to participate in an online focus group to review the themes generated from the interviews as a form of member checking. Four of the original 12 participants engaged in the online focus group. The online focus group was asked to discuss topics which were introduced every three to five days over the course of three weeks.

Ison's study [149], which explored the experiences of 18 young people with Cerebral Palsy, is an example of providing the option of asynchronous interviews for all interview participants, both participants who use AAC and participants who do not use AAC. In the study, four of 18 participants opted to engage in the research via email interviews (three in combination with in-person interviews). With the option for email interviews, individuals are able to participate in research studies when they may otherwise have been excluded, due to factors such as fatigue, distance, or scheduling. Email also provides a forum for participants to provide richer and more in-depth responses than they might be able to express during an in-person interview. Ison also notes that email interviews are beneficial for the researcher as well as the participant. The researcher is able to save travel time and email interviews allow for participants located in a variety of time zones to be involved in the research study. Ison also notes limitations of email interviews, including the inherent socio-economic pre-requisites for access to email, as well as literacy and language skills.

5.2.2.3 Surveys and Questionnaires

Surveys and questionnaires targeting AAC users are less frequently found in the literature, however, there are some examples. Hamm and Miranda [121] utilized surveys to investigate post-school quality of life for AAC users. After mailing 30 surveys to potential participants, eight AAC users' surveys met the completion criteria. Here we see that surveys, particularly in the form of mailed surveys, have relatively low participation rates.

Fiannaca et al. [94] used an online questionnaire method to inform the design of a mobile AAC application, and used separate questionnaires for both AAC users and their communication partners. The researchers note that using an online questionnaire format provides AAC users with the ability to complete the questions at their own pace, and limits the strains of travel. Eight AAC users completed the questionnaire. AAC users averaged 27 minutes to complete their questionnaire (of 33 questions) whereas their nine communication partners averaged 13 minutes to complete their questionnaire (of 29 questions), reinforcing the concept that fatigue and speed of communication are significant factors for AAC users when participating in qualitative research.

When exploring the topic of sexual abuse with adults who use AAC, Collier et al. [59] used questionnaires as their initial method for data collection. The researchers sent 147 questionnaires to local AAC clinics and disability groups, resulting in 26 participants for the study. The questionnaires surveyed participants' comfort with their current knowledge and resources available on a range of topics related to sexuality. This study is notable not only for the topic of research and the length of the study (3 years), but also for combining secondary forms of data collection in addition to providing a service to participants and their community as part of the research design. The researchers conducted facilitated group discussions with optional one-on-one consultations with participants. The group discussions and consultations were designed to promote discussion of sexual topics and provide education, counseling, and legal advice as needed. Focus groups comprised of relevant family and community members were also held to share back the results of the research.

5.2.2.4 Including AAC Users with Diverse Abilities- Visual Communication Methods

People who use AAC have diverse abilities. Each person's motor abilities can vary significantly from individual to individual. In addition, some people who use AAC may have cognitive impairments and/or limited literacy skills. I focus the literature review in this section on alternative communication modalities used by the researchers to better meet the needs of the participants. Specifically, I review research methods which incorporate visual forms of communication used by the researcher and the participant.

When exploring the loneliness experiences of six young adults with Cerebral Palsy, Cooper, et al. [60] describe their methods in great detail, beginning with their information sheet about the research study. Recognizing that their participants had diverse literacy skills, the researchers created information sheets about the research study that were both in text and picture-symbol formats. At the initial interview, the researchers read the consent forms aloud and asked the participants four questions about the study to ensure their understanding of the consent. Six participants were interviewed for the study, all using semi-structured one-on-one interviews which were between one and one and a half hours in duration. In their reporting, Cooper et al. describe in their methods section that two participants had family members or care-providers present during their interviews, and the authors also describe the roles and level of activity these additional individuals engaged in during the interview.

In addition to the detailed description of the methods used prior and during the interviews, Cooper et al.'s research is also notable for the detailed description of member checking the researchers used in their study. All six participants were interviewed in-person a second time, during which time the participants were given a verbal summary of the interview transcript from their first interview. Participants were also provided with a copy of the full transcript from the first interview, and were asked to correct or clarify any information presented. After the second interview, participants were sent a copy of the second interview's transcript and asked again to correct or revise any information listed.

In Teachman and Gibson's [307] exploration of social inclusion and exclusion, 13 AAC users participated in interviews which incorporated both photo-elicitation and graphical elicitation methods. During the photo-elicitation, the participants were loaned a switch-adapted camera for two weeks, after which they selected and discussed photographs with the researchers. In addition, the researchers used a graphic elicitation method that included a Belonging Circles diagram. Participants were encouraged to reference photographs within the diagram to represent degrees of belonging and inclusion. In addition to using these novel methods with participants who use AAC, the researchers explicitly describe their choices to conduct interviews in the participants' homes and to allow participants to communicate in any way they preferred, including using a family member or caregiver to mediate the conversation. The researchers observed that participants who chose to have a familiar communication partner present during the interviews provided a greater amount of rich data than found in previous studies in which the researchers did not include additional communication partners at the interviews

Teachman and Gibson also describe their use of a visual consent framework to obtain informed consent from all participants. In addition, the authors detail their use of an ethics approach in which the researchers elicited ongoing consent throughout the research process, by reminding the participants that they could discontinue the interview or withdraw from the study at any time.

5.2.2.5 Including Children who Use AAC as Primary Participants

Much of the research involving children who use AAC draws heavily on data from therapists, peers, family members, teachers, observational data from the children themselves, and/or formal assessments e.g. [30,31,53,89,104,145,152,186]. However, there are some studies in which researchers use interviews and focus groups with young adults and children. Clarke et al. [54] conducted focus groups and one-on-one interviews with young adults and children who used AAC. Recognizing that their participants' literacy skills were varied, the researchers used symbol systems for the participants to provide feedback on a variety of topics. Participants placed symbols visually within set boundaries, to indicate the strength of their opinions (e.g., feel strongly or feel less strongly) as well as the content of their opinion (e.g, cool/uncool, useful/useless). In this way, participants were able to visually represent their opinions during the in-person research sessions.

Other researchers have used Talking Mats, a symbol-based approach, for their interviews with children who use AAC [40,216,223,323]. When interviewing eight children who use AAC, Midtlin et al. [216] used the Talking Mats visual symbolic tool in conjunction with each child's individualized AAC system. The researchers asked children open ended questions, using corresponding visual symbols to represent the topic of the question. Children had the option to respond to questions using visual representations of the concepts: *"like," "do not like,"* or *"unsure."* The researchers conducted pre-interviews in which they discussed the interview procedure with the children while in the setting that the interviews would take place (the children's school). The actual interview was conducted in the same location as the pre-interview in order for the children to feel comfortable in a familiar setting. The researchers noted that a risk in interviewing children who use AAC is the temptation to *"put words in their mouths."* They note several precautions they took to guard against overinterpreting children's responses, including: creating questions that were easy for children to understand, ensuring that researchers had training in AAC, and checking the children's responses with the children's teacher after the interviews were completed.

5.3 Case Examples

In this section, I provide four case examples of qualitative research conducted with participants who use a variety of AAC systems. The purpose of the case examples is to supplement the literature review by providing detailed descriptions of the research tactics and methods used during in-person interviews. The case examples are from participants of two separate interview-based research studies (described in Chapters 4 and 6). Participants described in these case examples provided consent both to the original research study they participated in and also provided additional consent to describe the research methods used for the purposes of this paper. The Institutional Review Board reviewed and approved both the original research studies as well as the research describing the methods of the studies.

All of the participants were asked to participate in semi-structured, one-on-one interviews. All participants were adults, but to protect participants' privacy, specific details regarding participants' ages, locations, and genders are omitted. Each participant example was chosen to highlight a different AAC modality used by participants.

The following case examples are not intended to describe ideal case scenarios for interviewing AAC users, rather, they describe actual events of what happened when interviewing people who use AAC, including unexpected situations that can sometimes happen during any field work. These examples show different ways in which researchers can adapt to participants' needs while conducting qualitative research.

5.3.1 Interviewing Using Conferencing Tools

Our first case example is with a participant who was not able to communicate verbally, but who was able to use a mainstream mouse and keyboard. The participant used an app to produce voice output and was independently mobile. Prior to the interview, the researcher sent the participant an initial set of interview questions, with the explanation that due to the semi-structured nature of the interview, additional questions were likely to arise based on the participant's responses. The participant was told that they did not need to look at the interview questions in advance if they did not wish to. The participant responded via email, stating that they had begun to type out some of their responses in advance in preparation for the interview.

After rescheduling the interview to accommodate the participant's fatigue due to an unexpectedly busy schedule, the interview was held via Skype, utilizing the chat window at the participant's request. The participant copied and pasted their pre-written responses into the chat window. The researcher responded to the participant's chat messages verbally, and asked follow up questions verbally.

Even though the participant used the chat window for responses to the interview questions, both the researcher and participant utilized video during the entire course of the interview. In this way, the participant was able to supplement their typed responses through non-verbal behaviors, such as facial expressions, head shakes or nods, and gestures. As a result, the researcher was able to make notes regarding the participant's answers which captured the participant's non-verbal communication in addition to the typed responses. The participant was also able to quickly reply to yes/no questions without needing to type by using a head shake or nod.

Member checking took place at a later date, in the form of an online survey in which the participant was asked to rate their level of agreement with preliminary themes and sub-themes which emerged from the data. The participant completed the survey and also provided the researcher with additional confirmation regarding the themes via email.

5.3.2 Interviewing a Participant who Uses High-Tech AAC

In this case example, the participant was an expert user of their high-tech AAC system, utilizing eye control as their access method. They were also able to access and respond to emails independently and relatively easily. When asked their preference for interview format, the participant indicated that email interviews or in-person interviews were best. In addition, the participant indicated a need to schedule the interview after a rest period after other commitments and the participant also indicated the best time of day for in-person interviews based on their fatigue and daily schedule.

The participant indicated that they would like interview questions sent in advance explaining that it will *"save time on the day"* of the interview. Unfortunately, the participant was injured prior to the scheduled interview and was only able to compose a response to one of the interview questions in advance. Despite their injury, the participant agreed to continue with the interview in their home as planned, but as a result, the researcher limited their questions and the participant and researcher took multiple breaks during the course of the interview. The researcher followed the participant's lead based on their non-verbal communication, such as asking the participant if they wanted to take a break if the participant appeared to be in discomfort. At times, the participant verbally expressed the need to take a break via their AAC system. In addition, the researcher checked with the participant multiple times throughout the interview to see if they felt that they would like to end the interview or wanted to continue. The interview concluded when the participant indicated they were ready to discontinue the interview.

Overall, the participant's responses via their high-tech AAC device took some time to write out and the content was generally short and to the point. The researcher checked with the participant to see if they would like to provide additional details to their responses via email, at their own pace. The participant explained that they were responding with their AAC system as they normally would respond verbally. In this way, the participant indicated that despite being injured, and despite using an AAC system, they were responding as they typically would respond to the interviewer's questions.

Because of the participant's condition at the time of the interview, the researcher engaged in member-checking via additional email follow ups with the participant some months after the interview, when the participant had fully recovered from their injury.

5.3.3 Interviewing with a Participant-Chosen Mediator

Our third case example is also a participant who used a high-tech system which they accessed via eye control. In this case, the participant was interviewed via Skype, with the video feature enabled. Unlike the previous two case examples, scheduling the interview for this participant was largely conducted through a third party, based on the participant's request. In this case example, two other people were present with the participant during the entire interview. At the beginning of the interview, the participant began by responding to the researcher's questions with their voice-output AAC system, but quickly abandoned that method of communication in favor of communicating to one of the care providers in the room, who then interpreted the participant's communication for the researcher. As a form of checking, the researcher noted the participant's non-verbal communication in response to the researcher's questions. The researcher also asked for confirmation from the participant regarding some responses provided through the interpreter, by asking yes/no questions.

At the conclusion of the interview, the researcher made notes of any responses which may have been influenced by other people in the room, and emailed the participant directly to clarify their responses. The participant was able to independently access email, but the process was challenging, so the researcher kept their requests for the participant's responses limited. The researcher also invited the participant to clarify and add to any other information shared during the interview. The participant replied to confirm the information that had been shared during the interview was accurate. At a later date, the participant was offered a second form of member checking, in which preliminary themes and subthemes were shared via an online, accessible survey.

5.3.4 Interviewing a Participant Using No-Tech AAC

Our final case example involves a participant who used a high-tech AAC system and had two different methods of alternative access to the system. The participant was able to independently access email but not attachments, therefore the researcher included the research questions within the body of the email when the questions were sent to the participant in advance of the interview. The participant replied to the interview questions sent in advance via email, thanking the researcher for the opportunity to read and reply to the questions in advance.

On the day the researcher arrived to conduct the in-person interview with the participant in their home, they learned that the participant was having trouble using one of the access methods to their high-tech AAC system and that their secondary access method was having technical issues. As a result, one of the participant’s care providers explained the no-tech system the participant used for responding to yes/no questions. To accommodate the participant’s communication needs, the researcher quickly modified the semi-structured interview questions to take the form of yes/no questions instead of the open-ended questions originally created. The care provider stayed with the participant for the initial portion of the interview, interpreting the participant’s yes/no responses to the researcher’s questions. After the researcher felt comfortable recognizing the participant’s yes/no communication, the care provider asked the participant if they felt comfortable with the researcher’s understanding of their yes/no communication. The participant indicated that they were comfortable with the researcher’s interpretation of their yes/no and the care provider left the room so the participant could complete the rest of the interview privately.

Periodically, during the remainder of the in-person interview, the researcher asked the participant if they were continuing to correctly understand their yes/no signals. This was intended as a check on the part of the researcher, and to prevent any frustration on the part of the participant if the researcher was misunderstanding them. After the completion of the interview, the researcher emailed the participant directly to follow up on responses in which the researcher felt clarification was needed. The participant replied via email with the requested clarification.

5.4 Discussion

I use a combination of literature review and case examples to understand the methods available to HCI researchers when conducting qualitative research with AAC users as key research participants. The case examples demonstrate how interviewing people using AAC does not always go according to plan, just the same as interviewing any other participants or conducting any other field-work. Based on the case examples and literature review, I provide a framework to guide HCI researchers when they include AAC users as primary research participants, with a focus on considerations for interviews.

Each individual researcher's epistemological stance will ultimately guide their research design and their methodology. In the discussion section, I discuss specific, tactical methods in a way that can be applied to a variety of qualitative methodologies.

In addition, researchers will need to ensure that they carefully consider their study's overall inclusion and exclusion criteria as part of their decision- making process. Just as with any potential research population, AAC users vary in their abilities and characteristics and researchers will need to consider an AAC user in relation to their inclusion and exclusion criteria, just as they would do with any other participant.

I end the discussion with an exploration of opportunities for HCI researchers to innovate on research methods used with AAC users. These opportunities are uniquely suited to HCI designers, researchers, and practitioners, and can benefit researchers in all disciplines who work with AAC users.

5.4.1 Flexible Research Design is Better for Participants and Results in Better Data

Upon reviewing the related research and case examples, we see how diverse AAC users' needs are, and how a variety of methods increase participants' abilities to engage in the research. The fact that research participants are using alternative forms of communication should inherently imply that alternative methods for their participation in the research study are appropriate, as long as those methods are well-documented and have supporting rationale. To further transparency, researchers should acknowledge diverse methods when used, and document the benefits of the methods to the participant and to the research study.

5.4.1.1 Accommodate Participants' Preferred Communication Methods

Upon reviewing the literature, and reflecting on the case examples, I suggest that researchers should expect AAC user research participants to use a variety of communication methods during qualitative research studies. Teachman and Gibson [307] suggest that AAC users' communication, when mediated by a familiar communicator, provides richer data with more content than when relying on the AAC system alone. We also see that when Kane et al. [161] suggested that AAC user participants have the option of bringing a familiar communication partner to their interview, the majority of participants chose to do so. In the case examples, we also see how one participant quickly abandoned their high-tech AAC system in favor of communicating with a care provider who interpreted for the researcher. Allowing participants to guide the researcher with their preferred communication methods, including having communication mediated by a familiar communication partner, respects the participant's preferences and needs for engaging as a research participant. It is possible that restricting participants' communication modality to that of an isolated, one-on-one setting, may result in truncated and sparse data collection [307]. Therefore, I suggest that researchers using in-person methods include the option of having a familiar communication partner available during the interview or focus group. Researchers can put checks in place to ensure that the AAC users' perspectives are accurately shared, such as those described by Kane et al. [161], and through the various approaches to member checking [60,220,310] described in the related literature and case examples.

5.4.1.2 Document Non-Verbal Communication and the Environment

As demonstrated in the case studies, non-verbal communication signals, such as head nods, eye blinks, body language, and gestures provide details to AAC users' responses by adding emphasis as well as content. Non-verbal communication can also be a faster and less fatiguing method of response for some AAC users than having to use a high-tech AAC system. Other studies also recognize the importance of including non-verbal communication in analyzing qualitative interview data, such as through analyzing videos of interviews [139]. While the observation of non-verbal communication is primarily applicable to in-person interviews and focus groups, there may be opportunities for HCI designers and researchers to create novel tools to capture similar communication sentiments asynchronously, which I discuss in more detail in a later section.

5.4.2 A Framework to Guide Qualitative Research with AAC Users as Primary Participants

There are common qualitative research methods used within the greater research community for including AAC participants' perspectives as the primary sources of data. We can be guided by the literature to inform which methods are best suited to meet the needs of the participants as well as the researcher.

First and foremost, the researcher needs to determine what parameters are most appropriate for their research study, such as: Do all participants need to participate in the same way?, Do participants need to be available at a specific time or within a specific timeframe?, Can elements of the research process be done asynchronously?, Do participants need to interact with each other? Do participants need to have reliable access to technology? Do participants need to be able to communicate through writing? After determining the parameters of the research study, the researcher can determine the degree of flexibility available for the study. When reflecting on their inclusion and exclusion criteria (which include the questions listed above) the researcher can determine how inclusive their study will be for participants who use a variety of AAC methods. For example, if a researcher's inclusion criteria is geared towards children, they need to consider the most appropriate communication method for each child as they develop their research study procedures [54,216]. If literacy abilities of participants vary, alternative forms of consent and interactions may be needed [60,307]. When appropriate, the researcher should also ask participants themselves for their preferred method(s) of communication. It may also be appropriate to include a care provider to discuss the logistics of the research study. Some AAC users find communication regarding logistics easier if taken care of by a care provider or third party (as evidenced in the case examples). Ultimately, the researcher is directed by the AAC user's preferences, and when those preferences are combined with the researcher's study parameters, they lead to the methods used in the research study.

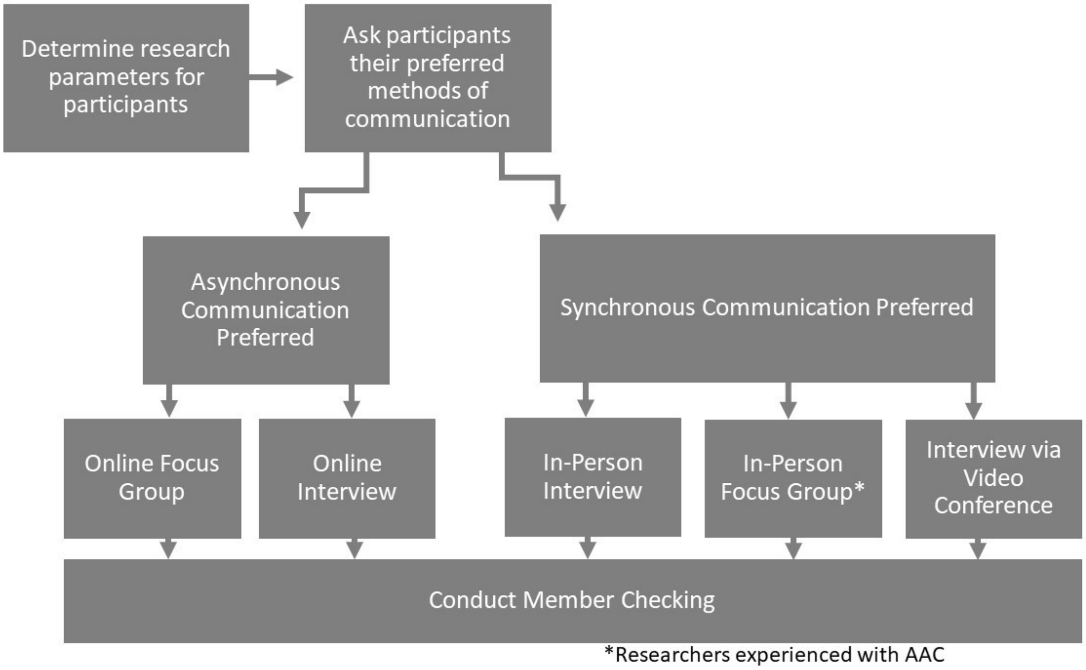

Figure 1. Framework of Potential Qualitative Research Methods Used with AAC Users as Primary Participants

The methods outlined in this framework represent the most common methods used with AAC users, based on a literature review of HCI and AAC qualitative research. I categorize the methods broadly into *“Asynchronous Communication”* and *“Synchronous Communication”* (Figure 1). While I describe asynchronous and synchronous methods separately in the framework, one research study could certainly use both types of methods, or at least make both methods available to participants, e.g. [149].

Asynchronous communication methods can be used for surveys/questionnaires [59], focus groups [48,72,210], and interviews [310]. When conducting research utilizing asynchronous communication, the researcher will need to use accessible communication tools which AAC users are able to easily engage with. Tools described in the current literature and based on our case examples include email, and password protected Wikispace [48,149,310]. A major challenge in using asynchronous communication is the challenge of ensuring participants are able to access the technology platform chosen, and researchers might need to consider multiple forms of technology for the same study in order for all included participants to participate. Socio-economic and literacy dependencies will also need to be considered, as described by Ison [149]. Benefits of using asynchronous communication include the ability for participants to respond at their own pace, potentially providing more thorough and detailed responses.

Synchronous communication with AAC research participants lends itself towards in-person interviews, typically in one-on-one settings [60,161,311]. Synchronous communication could also take the form of interviews conducted via conferencing or distance communication tools which include video presence, in the way Skype was used in the case examples. In the same way researchers need to ensure that asynchronous tools are accessible to participants, conferencing and distance communication tools for synchronous interviews also need to be accessible to participants. In addition, researchers should consider the potential need of extra time for participant responses, as well as possible needs for breaks due to fatigue [60,94,161,307].

While synchronous, in-person communication can be used for focus groups as well as interviews, the logistics of attending focus groups might be challenging for AAC users. There are only a few examples of in-person focus groups used with AAC users at this time [54,59,207]. Specific, tactical details on how to conduct an in-person focus group with AAC users are sparse. Managing in-person group conversation with individuals using AAC can require a different level of experience than when conducting one-on-one, in-person interviews. The timing of communicating using AAC systems can vary from individual to individual and can be a barrier to engaging in conversations [161,209,220,289] which can be challenging to manage in a group conversational setting. The researcher managing an in-person focus group would need to ensure that everyone has had a chance to compose their messages and relay them to the group. While I embrace the concept of in-person focus groups for AAC users, particularly when considering the positive social networking benefits for the participants themselves, I include in-person focus groups with an asterisk in the framework. The asterisk for in-person focus groups indicates that this method should be used by researchers who have AAC experience. The framework is intended to be a reference built on well-documented methods, enabling a researcher with little experience in AAC to understand the methods available for their study. Hopefully researchers experienced with AAC will provide more details on conducting in-person focus groups in the future.

The framework includes member checking as a final step, no matter which methods are used. The rationale for always engaging in member checking with AAC users is based on both the literature review and case examples. Not all AAC users will choose to participate in member checking, however, this is an essential step which provides the AAC users an additional opportunity to ensure that their perspectives are being accurately represented. Member checking is especially important for AAC users, because member checking provides time for the AAC user to reflect and provide additional information they might not have been able to provide during the time of their interview or focus group. Member checking also provides an accommodation for those instances when the data collection procedure did not go as planned, as I describe in the case examples. Without engaging in member checking, the researcher might have nagging doubts about how they interpreted certain responses from their participants. Member checking helps to alleviate those concerns. In the case example where the researcher had to modify their questions to yes/no format, member checking provided a way for the researcher to return to the open-ended structure of the interview questions originally planned.

Member checking can have challenges. The most easily accommodated challenge is for researchers to conduct the member checks early enough in the research so that any substantive clarifications or changes made by a participant can easily be incorporated during the data analysis phase. As prior work has discussed [29], a harder challenge is when participants have serious health conditions, and the researcher is unsure of the participant's condition at the time that member checking is ready to be deployed. For example, in Morris et al.'s study [220], one participant had died and one participant was too ill to participate at the time of the member checking phase. One strategy to ensure that member checking is not a burden on participants or their families is to send an email to the participant that is brief, and makes it clear that member checking is optional. By ensuring that it is clear that member checking is optional, participants who are ill, or unable, or uninterested in participating do not feel overburdened by the researcher. In the case of a participant who has died, the family members or care providers who might encounter the email will also understand that the request is purely optional.

5.4.3 Opportunities for HCI Researchers to Innovate on Research Practices and Tools Used with AAC Users

There are exciting opportunities for HCI designers and researchers to improve the tools used for conducting research with AAC users as primary participants. I discuss two distinct opportunities here.

5.4.3.1 Create Innovative and Accessible Elicitation Tools

Aside from Teachman and Gibson's use of photo elicitation [307], I did not find any examples of using elicitation tools to prompt participants for richer, more detailed interview data. This creates an interesting opportunity for HCI researchers to build on methods, such as stakeholder tokens [347] and sensual evaluation instruments [147,148] and to adapt them for use with AAC users in qualitative research. Isbister et al.'s [147] sensual evaluation instruments are abstract shapes, which can be physically held by participants, and are designed to foster emotional feedback during the design process. The adaptation of these tangible abstract shapes to a digital form would increase the accessibility of these tools, and could be used with both the synchronous and asynchronous qualitative methods described in this paper.

In a similar manner, researchers could build on Sobel et al.'s [290] work on awareness displays, which uses abstract imagery as a method for expressing complex concepts and emotions. Sobel et al.'s work explored the possibility of AAC users incorporating awareness displays as part of the AAC system itself. However, it might be interesting to use the concept of awareness displays in a similar manner to sensual evaluation instruments, in which the awareness display is a tool to elicit descriptions of emotions and abstract concepts. Combining elicitation concepts and techniques into a digital-based system where participants are able to select abstract images, which they relate to and can discuss could be a powerful research tool. Many AAC users rely on alternative access methods to engage with technology, and there is an exciting opportunity to create digital versions of visual elicitation methods to increase their accessibility. Digital forms of elicitation tools can be used not only for AAC users, but also for other participants who are unable to physically engage with these tools, such as participants in remote locations.

5.4.3.2 Improve Asynchronous Research Tools

There are many advantages to using asynchronous research tools with AAC users in qualitative research; however, these tools could be adapted and improved upon. HCI designers and researchers have opportunities to explore how these tools can be improved, both from the researcher and the AAC users' perspectives. One opportunity is to create an easily accessible tool that provides both one-on-one and group messaging, and that also allows for video clips to be shared to capture non-verbal communication.

This tool could also utilize symbolic forms of communication as well as text. In addition, this tool could allow users to share photos or participate in graphical representations to visualize their experiences and input as used by Clarke et al. [54] and Teachman and Gibson [307]. Finally, the tool would be accessible via a range of alternative access methods, be secure, and be able to allow a participant to take many breaks during the composing of a message, picking up wherever they left off. A research tool with these characteristics could be beneficial to many diverse participants in HCI qualitative research studies, in addition to participants who use AAC.

5.4.4 Limitations and Future Work

While this methods chapter does not contain an exhaustive list of research methods used with AAC participants, it does provide insights into a range of qualitative methods used by researchers from a variety of fields, with a focus on papers that describe their methods in detail. This paper does not discuss research methods which involve evaluation, testing, or other objective measures to describe usability, nor observational methods used with AAC users. As a result, many excellent research papers involving evaluations of systems, or exploring AAC with children using observational techniques, are not described here. Instead, the focus of this paper is on methods that historically rely on verbal communication from participants.

This chapter also does not focus on co-design with AAC users. While I found a few papers which mentioned co-design with AAC users, or users with limited verbal skills (such as some children with limited expressive language or adults with expressive aphasia), I did not include co-design in this chapter. Co-design with participants who use AAC is an exciting area for further investigation and warrants an extensive exploration and discussion as a stand-alone topic and is therefore the subject of Chapter 7 of this dissertation.

5.5 Contribution

In this chapter, I presented an analysis of literature from two fields: HCI and AAC (a subfield of Rehabilitation Sciences and Speech-Language Pathology). The contribution of this chapter is methods-focused, with (1) a synthesis of existing qualitative methods used with AAC users across disciplines, (2) an easily accessible framework for including AAC users in qualitative research, (3) guidance that all qualitative research with AAC users should include member checking, (4) suggested areas for advancement in qualitative research methods that include AAC users (and could potentially benefit many other research participants). The primary contribution of this chapter is to provide a reference for HCI researchers who want to involve AAC users in qualitative research. An additional contribution is that I bridge the divide between the HCI and the therapeutic research communities on the topic of AAC research methods. Research conducted in both the fields of HCI and therapeutic AAC are often published in different venues, and this chapter is intended to increase awareness of the different methods and topics covered between the two disciplines. I also provide a contribution by highlighting the lack of information on accessible co-design methods for adults who use AAC. A final contribution takes the form of design suggestions, in which HCI designers can innovate on qualitative research tools, that can be used with AAC users and other research participants.

Chapter 6: Creative Models: Creative Experiences of Adults with Acquired Disabilities who Use AT

In Chapter 4 I studied the employment experiences of adults who acquired MMCD and who use AT for daily living. While employer support and accommodations can positively affect an employee’s ability to continue working, findings demonstrated that the employee often judges their own abilities and compares them with their pre-disability self. Participants who left work due to their health and ability changes experienced feelings of loss, regret, and identity change. When participants left work, they wanted to continue engaging in something meaningful, but that something was often elusive. Participants’ knowledge of alternative work options was limited. The act of being exposed to information of accessible work options increased participants’ receptivity to investigating them further. Therefore, it is likely that learning about accessible alternatives to traditional work might be beneficial to adults who acquire MMCD. But what options are available? And what types of activities could have a real impact on quality of life?

In this chapter, I build on concepts introduced in Chapter 4, specifically two areas: (1) identity changes and (2) a desire for accessible, flexible, and meaningful activities. In doing so, I address the following research question (RQ3)**: How does engaging in creative pursuits impact the quality of life of adults who acquired motor, mobility and/or communication and use AT for daily living?**

6.1 Introduction

Having the opportunity to engage in creative pursuits has tremendous benefits for mental and physical wellbeing [295,300]. Broadly defined, creativity is to bring something into existence [364] and to produce and use original ideas [361]. Creativity can take many forms, often including elements of novelty and problem solving [5,66,138]. Engagement in creative interventions such as art therapy e.g. [141,153,177,247], music therapy e.g. [114,126,242,349], and recreational therapies e.g. [13,119,254] have both mental and physical health benefits. However, many people with complex disabilities have limited opportunities to actively engage in daily creative pursuits, and instead, are often confined to passive consumption of creative outputs, such as listening to music or audio books [9,172]. People who lack active engagement and are confined to passive activities can experience depression, anxiety, and poor health [61,250,294]. In contrast, active engagement in creative pursuits can decrease anxiety and depression and increase perceptions of health and well-being [83,116,117,300]. Moreover, engagement in creativity can foster positive views of identity and self-worth [37,141,258].

A number of accessible creative tools have been explored and prototyped, such as art tools for individuals with acquired communication disabilities e.g. [227] and motor disabilities e.g. [134]; and music tools for individuals with complex disabilities e.g. [33], and acquired motor and communication disabilities e.g. [150,241,315,319]. While many of these tools have shown promise, few are available outside of the research context. Therefore, I seek to understand how adults with disabilities engage in everyday accessible creativity and what the impact of creative engagement has on individuals over time.

Prior work has shown that adults experience a sense of loss after acquiring motor and mobility disabilities [19,238]. However, research has not yet explored the impact of long-term creative engagement outside of directed therapies on the quality of life of adults with acquired MMCD. Therefore, I interviewed seven adults, across three countries, with acquired MMCD who use assistive technologies and who engaged in a variety of creative pursuits for one year or more. Drawing from a constructivist framing, I holistically explore how creativity, technology, accessibility, and disability intersect and affect quality of life.

6.2 Background

Creativity is a broad construct which can be applied to a number of domains [5,328]. Creativity can be considered within the framing of problem-solving, a cognitive activity, embodied action, or tool-mediated expert activities [138]. In this thesis, I define creativity through the use of tools and embodiment as well as through the individual's cognitive processes. Creativity is a process in which an individual engages in cognitive acts that brings about something novel. Creative pursuits can take a variety of forms, including art, music, poetry, theater, and interactive gaming. While prior work has discussed that gaming can be perceived as an enabling form of creative expression for people with disabilities [16,45], there has not yet been empirical research which has explicitly explored the intersection of quality of life within the context of disability, creativity, and technology across a wide range of creative pursuits. To be creative is when an individual actively builds, composes, designs or invents— bringing about something by a course of action or behavior [86,364]. Using this definition, creativity can take many forms and be considered a basic human need, as represented both in Maslow's hierarchy of needs [202] and in Max-Neef's theoretical matrix of human needs [86,204,205].

In contrast to Maslow's hierarchy, Max-Neef's matrix is flexible and non-hierarchical (Table 7). Max-Neef's matrix of human needs illustrates how both creativity and identity can be conceptualized through creative *"doing"* by inventing, building, and composing and by defining their identity through *"interacting"* in everyday settings. Using this framework, individuals who design their upper limb prostheses and breast cancer survivors who use tattooing are representing their *"being"* through the satisfiers of *"doing"* and *"interacting,"* all within the framing of creativity and identity.

Table 7. Max-Neef's Matrix of Fundamental Human Needs (Abridged)

Need	Satisfiers			
	Being	**Having**	**Doing**	**Interacting**
Creation	Imagination, boldness, curiosity, inventiveness, autonomy, determination	Skills, work, abilities, method, techniques	Invent, build, design, work, compose, interpret	Spaces for expression, workshops, audiences, cultural group, temporal freedom
Identity	Sense of belonging, self-esteem, consistency, differentiation, assertiveness	Symbols, language, religion, values, work, customs, norms, habits, historical memory, sexuality, reference groups, work	Get to know oneself, grow, commit oneself, recognize oneself	Places one belongs to, everyday settings, maturation stages, social rhythms

6.2.1 Creativity and Identity

Engaging in creative pursuits can have a profound effect on identity. A creative identity occurs within a sociocultural context and can be reflected through creative actions [66,257]. For example, Bennett et al.'s work on selfhood and upper-limb loss shows how creativity intersects with disability and identity through different forms of creativity: embodied creative design and problem solving [25]. One participant identified herself as "the girl with the hook," and customized her prosthesis with rhinestones to better represent her personality. Another participant explicitly viewed their identity as a person who did not need to use a prosthesis but as someone who could creatively problem solve motoric barriers with everyday tools. In these examples, individuals took ownership of their physical bodies as a means to display their identity, similar to how cancer survivors have used tattooing to represent their identity [87].

In a study which specifically explored the reconfiguration of identity, Reynolds' studied 10 women with chronic illnesses who engage in textile arts [258]. Reynolds' found that both the onset of illness as well as the loss of identity based on prior occupation created a crisis for all 10 participants. Through artistic engagement, the women were able to reconnect with their pre-illness self, resulting in positive identity growth, increased self-esteem, and a socially validated identity (Table 8). Reynolds' study, while focused on people with chronic health conditions rather than disability and AT, directly ties together the concepts of identity formation through creative engagement, and is one of the only published studies to do so. Without citing Max-Neef's matrix of human needs, Reynolds' work nicely complements Max-Neef's theoretical framework to provide an understanding of the flexibility and influences of identity and creativity on each other. Reynolds' describes the process as *"identity reconfiguration through artistic expression"* [258].

Table 8. Reynolds Framework of Identity Reconfiguration Through Artistic Occupation.

Main Processes of Identity Reconfiguration through Artistic Occupation	**Processes Enabled by Artistic Occupation**
A Reconnection with the Previous, Pre-Illness Self	Allowing expression of interests and skills developed during previous careers Reviving interests that have been dormant since school or adolescence Connecting self with the interests and occupations of parents or grandparents Enabling enactment of long-standing personal and family values.
Positive Personal Identity Growth and Development	Symbolic reintegration and griefwork Expressing personal "voice" Finding a positive way forward and fulfilling long-term aspirations
Restores a Sense of One's Own Expertise, Status, and Self-Esteem	Visible products Gaining skills and knowledge through courses and classes Initiating new artistic designs and craft techniques Interacting with professional artists
A Socially Validated Identity	New roles and membership of groups of textile artists Receiving the praise and feedback of others Sharing knowledge with others Gaining status and sometimes fame

Reynolds' work shows that creative engagement, through the medium of textile arts, can result in a positive identity formation for people with chronic health conditions [257–259]. People with disabilities have also found textile arts to be a form of positive expression of identity and social collaboration [70]. Outside of disability and chronic illness populations, explorations on creativity and identity have shown that engagement in a variety of creative pursuits, such as the open-ended exploration of worlds within gaming, provide creative platforms for self-expression [224]. Identity formation within creative pursuits are complex, and the intersection of a variety of socio-contextual factors contribute to the formation of identity [281].

6.2.2 Disability and Identity

While Reynolds' et al. have demonstrated a connection between identity, creativity, and complex health conditions, less research has explicitly investigated the relationships between identity, creativity, and disability. More work has explored the relationship between disability and identity. Disability identity, like a creative identity, exists within a socio-cultural context [69,73,179,327]. A 2017 survey of research related to disability identity indicates that identity formation is heavily influenced by social connections [96]. Sandahl describes the experience of having a disability to that of always being in a performance, in essence, performing the experience of disability on a continuous basis, for all the world to see [270]. In this way, a person's identity is very much tied to the appearance and manifestation of their disability. In his performance piece, Lynn Manning showed how acquiring a disability significantly impacts an individual's previous identity and leads to the construction of a new identity, or in his case, a dual identity, that of a black man and a blind man [269,270]. A key concept in identity formation is that of intersectionality, in which multiple factors intersect to form identity, such as race and disability [64,339].

Based on in-depth interviews with 17 adults who identified as having a variety of disabilities, Forber-Pratt developed a conceptual framework to describe identity formation within the context of disability [98]. This framework highlights the importance of social relationships on identity formation (Table 9). However, Forber-Pratt's framework is generalized to people with a broad range of disabilities and does not specifically address identity formation for the population addressed in my thesis: adults who acquired disabilities and use assistive technologies.

Table 9. Forber-Pratt Model of Social and Psychological Disability Identity Development.

Status	Description
Acceptance	Become disabled and/or born with disability Person accepts own disability Close friends and family are accepting of the disability
Relationship	Person meets others like herself/himself Engages in conversation with these individuals Learns about the ways of the group
Adoption	Adopts the shared values of the group
Engagement	Become a role model for others Help those who may be in other statuses Give back to the disability community

For individuals with acquired disabilities, identity formation is often shaped by changed physical abilities, their perceived limitations, and comparisons with pre-disability identity [18,46,238]. Wofford et al. found that assistive technology learning and use intersects with social relationships and culture, which in turn can influence identity [339]. In a study of 30 participants learning to use wheelchairs in a rehabilitation facility, Papadimitriou found that a re-embodiment of identity occurred as participants' abilities and use of assistive technology (wheelchairs) changed [238].

6.2.3 Creativity and Health

Not only does creativity impact identity, but creative engagement can impact health. A literature review of research on health and creativity found that engagement in a variety of creative pursuits, such as music, art, dance, and creative writing, all had positive health impacts, although the authors note that the majority of the research was conducted in hospital, rather than community settings [295]. Creative participation can provide mental health benefits [83,151,174,300] as well as physical health benefits [117,271,295]. For example, arts and music activities have been shown to positively influence both the physical and mental health of kidney dialysis patients [265]. Emerging evidence shows that active engagement in gaming can produce similar neurological effects as other forms of creative pursuits, including the potential for experiencing a state of flow and increase in neuroplasticity [103,251]. Creativity through gaming can increase a sense of well-being [157], fosters social connections [58], and optimism [214]. Video games can reduce anticipatory symptoms related to chemotherapy [168]. Virtual reality can decrease pain levels in people with burn injuries [128,191]. In general, active creative engagement can provide distraction from pain and anxiety, decrease apathy, and also assist with coping with long-term illness [62,74,172,256].

One of the more prolific areas in the exploration of creativity and health involves older adults, e.g. [37,55,57,95,192]. One two-year study followed 300 typically aging adults (ages 65+), divided into control groups and intervention groups across three U.S. cities [55,56]. Intervention groups attended weekly art classes, which combined creative engagement with social participation. Results indicated that intervention groups experienced benefits to morale, decreased incidence of depression, had fewer overall doctor visits, less medication usage, and fewer falls than control groups. Another longitudinal study of 7,301 older adults demonstrated that participants who did not engage in active creative pursuits, such as playing music or designing arts and crafts, had a higher overall mortality rate than participants who did engage in creative pursuits [294].

The growing interest in the effects of creative engagement on health can be seen through investments and research into “arts on prescription” programs and collaborations between healthcare agencies and arts organizations e.g.[15,43,83,167,300,365]. Yet, the field of health and creative engagement is still relatively new and researchers continue to call for further research in this domain [116,151,294]. Currently, research on the long-term effects of creative engagement on the health of people with acquired disabilities has been less prominent in the field, particularly for individuals who rely on assistive technologies for motor and mobility disabilities.

6.1.4 Technology, Disability and Creativity

Design approaches, such as inclusive design [63,162,173,229], universal design [124], and ability-based design [336,338] view accessibility as a first-class design principle, and can be applied to a variety of technology applications, including applications for creative expression. A robust body of research exists in the area of creating accessible forms of music. Music technology innovations have been developed for individuals who are deaf, blind, have dementia, or who have multiple disabilities and health conditions [33,150,225,240,241,292,316,319]. Other HCI explorations in the areas of creativity and disability have revealed opportunities for accessible applications in textile arts, such as weaving [34,70,107] and knitting [117]. Researchers also have explored accessible art creation tools, such as Inker [227], CreaTable [228], and ComicSpin, [304], art creation tools for individuals with aphasia, and EyeDraw, a tool for eye-controlled art creation [133,135]. Research innovations have also addressed the accessibility of gaming [113,165,183], including the design of games and tools for individuals with motor disabilities [1,2,144,278]. There are also commercially available forms of assistive technologies and tools to increase the accessibility of creative pursuits, most notably in the area of gaming, such as the adapted Xbox controller [368] and the quadstick [369].

While a great deal of work has explored the design and development of tools to access creativity, there is a lack of research on the role technology plays in the formation of a creative identity. Using an interdependent design lens, in which access is viewed within a relational framing [24], I seek to understand what happens after an individual engages in accessible creativity. I address this gap in knowledge by seeking to understand the experiences of adults with acquired MMCD who engage in creative pursuits outside of directed therapeutic programs.

6.3 Creative Models Methods

My research questions are firmly grounded in my professional experiences from the last 20 years. I have worked with a variety of people, both children and adults, who required assistive technologies to interact and communicate with others. The people that I have worked with and the experiences I have had in my professional practice directly inform my research and view of the world. Therefore, my research methodology is influenced heavily by the constructs developed during my professional practice regarding assistive technology and disability and I position my methods within a constructivist framework [52,253].

Due to the limited research on the topic of creativity, identity, and acquired disabilities I use an exploratory methodological approach for my research question: How does engaging in creative pursuits impact the quality of life of adults who acquired motor, mobility, and/or communication and use AT for daily living? Grounded theory methods (GTM) are designed to be grounded in data for exploratory research questions. GTM have the core principles of constant comparison, ongoing analysis, and selective/theoretical sampling in order to ultimately generate theory [42,164,312].

To answer my research question, I conducted semi-structured interviews with participants. I explored their experiences regarding the onset of their disability, their discovery of accessible creativity, and their creative process. My methodological approach is similar to related studies which explored the experiences of individuals who had complex chronic illnesses [51,258,260]. A significant difference in methodology is that the participants in my study used AT, including participants who used AAC to communicate. I therefore adapted my interviewing approach as needed for each participant's unique communication needs, drawing on the methods and best practices described in the previous chapter (Chapter 5).

6.3.1 Participants

This study is focused on a specific and under-explored population: adults with acquired disabilities who engage in creativity outside of a dedicated, therapeutic program. Inclusion criteria for participants included: (1) adults who acquired a motor, mobility, and/or communication disability, (2) participants who are literate and speak English, (3) participants who use some form of assistive technology for daily living, and (4) participants who engage in a creative pursuit that is in some way different from the creative engagements they engaged in prior to the onset of their disability. For example, individuals who had been professional artists prior to acquiring their disability and were continuing to engage in the same type of professional artwork after their disability were excluded. However, an individual who engaged in casual, occasional artwork prior to their disability and then began engaging in a different form of artwork as a dedicated creative pursuit would be included in this study.

All participants included in the study changed the nature of their relationship with creative pursuits after acquiring their disability. The change could be in the **type** of creative pursuit itself (such as an entirely new creative pursuit), the **form** of the creative pursuit (such as using a different medium), or the **extent** of engagement with creative pursuits (such as engaging professionally or seriously instead of occasionally or casually). The nature of the creative pursuits were open to anything that met the definition of creativity: in which the participant actively builds, composes, designs or invents [86,204] and brings about something by a course of action or behavior [364]. As a result, participants' creative pursuits span a wide range of activities, from art creation to gaming in a virtual environment.

Due to the narrow inclusion criteria, finding participants was challenging. Recruitment and interviews spanned the course of three years. Recruitment activities included outreach to assistive technology specialists around the world. Participants were also identified through popular press articles about their stories and creative works. The first participant was interviewed in 2018 and the last participant was interviewed in 2020. In total, I was able to recruit seven participants from three countries who met the inclusion criteria (Table 10).

Table 10. Participant Information Including Participant Chosen Pseudonyms

Participant ID	AT Used	Began current creative pursuits using AT	Age at time of interview	Creative Pursuit(s) Engaged with After Developing Disability
Ava	Wheelchair, Speech generating device, eye control for AAC and Computer Access	6 years before interview date	53	Art- painting using two applications on Windows AAC system
Robin	Wheelchair, Mouse emulation software and Dictation software for computer access	Engaged in preferred creative pursuit for approximately 12 years after diagnosis, not engaged in preferred creative pursuit at time of interview	67	Art- painting and mixed media (not using AT)
Lucy A.[7]	Dictation Software, Wheelchair, Accessibility Features in Software and on Phone, Adapted Gaming Controller	Pottery, approximately 1 year before interview date, gaming 6 months before interview date	32	Pottery -adapted pottery wheel, gardening, gaming- adapted controller, printing
Tim	Rollerball mouse, Eye Control, Speech generating software	Approximately 10 years before interview date	50	Design- uses Splash
Reuben	Head mouse, switches, sip and puff, quadstick	Began web design and video editing approximately 1 1/2 years before interview date, gaming approximately 1 year before interview date	38	Gaming, web design, video and photo editing
Lucy B.[8]	Eye control for AAC and computer access, wheelchair	Approximately 1 year before interview date	27	Gaming
Alex	Wheelchair, switches, quadstick	Approximately 1 year before interview date	39	Gaming

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[7] Participants who chose the same pseudonym are given the additional designations of A. and B. after their chosen first name.

[8] Participants who chose the same pseudonym are given the additional designations of A. and B. after their chosen first name.

Participants were not asked for their specific diagnosis per IRB agreement to protect their health information; however, most participants proactively offered information regarding their diagnosis, which included motor neuron diseases, multiple sclerosis and spinal cord injuries.

Six of the seven participants reported that they engaged in creative pursuits—such as music, gaming, or painting— at some point in their lives prior to acquiring their disability. All participants were engaged in new **forms, types,** or **extents** of creative pursuits after acquiring their disability. New forms of creative pursuits included using a new medium of creative expression, such as computer-based graphics software instead of physical drawing/painting. Some new forms of creative pursuits were entirely different genres of creative engagement which participants had not engaged with prior to their disability, such as gaming, pottery, or video editing.

6.3.2 Procedures

I conducted semi-structured interviews (Appendix F) that were held either in-person or online. All interviews were completed in one session. Interviews ranged in time from one hour to two and a half hours. Participants were offered opportunities for breaks during interviews and were also offered the option to complete the interview across multiple time periods. Interviews were conducted between 2018 and 2020. All participants were native English speakers and lived in the United States or in countries within the greater United Kingdom. Two participants had caregivers present during portions of their interviews; of those, one participant's caregivers provided information during the interview with the participant's permission [17]. Interviews were recorded and, when possible, I recorded video of the participant engaging in their creative process.

After interview data had been captured, I reviewed and analyzed any publicly available creative works published and/or shared by the participants, as well as any blogs, websites, or popular press articles about the participants as additional artifacts demonstrating their creative pursuits and community engagement. Participants were also invited to share images of their creative works with me as additional artifacts (Appendix G).

I analyzed data using open coding and memoing to identify surprising or related concepts across interview transcripts. Open codes were refined after multiple passes of reading and re-reading the transcripts, during which open codes were grouped together to form categories, which eventually developed into even broader themes [42,52].

Upon conclusion of data analysis, participants were sent a general summary of the emerging themes from the data analysis and were asked to provide comments if they felt that any of the themes did not resonate with their experience. Only one participant responded with additional comments regarding the findings, which reinforced the accuracy of the emerging themes. Participants were also asked if they wanted to choose their pseudonym. When participants chose the same pseudonym, the pseudonyms are differentiated by an initial after the pseudonym (e.g.- A, B).

6.4 Findings

Analysis of interview data, blog posts, popular press articles, and images of participants' creative works revealed two over-arching themes. The first theme, *"Accessible Creativity Shapes Identity and Quality of Life,"* reveals how participants' identities change over the course of three phases, which can repeat as a participant's disability progresses. The second theme, *"Information is Critical to Access Creativity,"* shows how information sharing plays a key role in participants' discovering and accessing creative pursuits.

6.4.1 Accessible Creativity Shapes Identity and Quality of Life

Findings show how access to creativity impacts participants' identities and perceptions of their quality of life. The findings reveal three sub-themes, which represent the three phases of an identity change cycle. The components of the identity cycle are: (1) loss of identity and purpose, (2) exploration and discovery, (3) reclaiming a creative identity. I discuss these three themes in depth, using illustrative quotes from participants within each theme.

It is important to note that identity change can be cyclical as an individual's abilities continue to change, particularly for individuals with progressive health conditions. At the core of the identity change cycle was a sense of loss of identity and purpose. This sense of less was followed by a stage of creative exploration and discovery, which is then followed by a stage of reclaiming identity and purpose. Participants can be at any stage of the cycle at any given time, depending on their changed abilities and access to technology and creative pursuits.

6.4.1.1 Loss of Identity and Purpose

Participants spoke of different aspects of their identity being taken away as a result of acquiring their disability. In this analysis, I focus on two aspects of loss: creative identity and social identity.

Participants spoke of their creative identity being lost in terms of their physical abilities and the creative pursuits they engaged with pre-disability. Reuben described the loss of their creative identity as: *“[playing guitar] that was the hardest thing. It was one of the hardest things that got taken away….I tried music creation software and it just wasn't the same for me. It wasn't that feel that you get of the instrument in your hands.”*

For Reuben, the loss of the ability to physically hold and play an instrument was directly tied to their identity as someone who played guitar. Not being able to have the same feel of the guitar that they had pre-disability meant that their identity as a guitar player was lost forever. The creative outlet of music was gone.

For participants with progressive conditions, the sense of loss of their creative identity can re-occur as their abilities change. Robin went through grief and loss at no longer being able to engage in the creative pursuit they had first discovered after acquiring their disability: painting. Like Reuben, the tactile aspect of creativity was the aspect that was lost with Robin’s changing abilities. Robin described their love of painting: *“the smell of paint, the getting dirty, the use of the paintbrush, it just opens my soul up to this creativity.”* Now, because Robin is no longer able to paint, they engage a paid assistant to write as their creative outlet. Robin explained, *“I really want to create art and trying to do that is really hard. [so] I’m doing more writing…but I don’t like writing because I can’t do drafts.” Robin explained that “If I had the ability to use my hands, I would not do it.”*

The loss of physical abilities directly impacts the creative identity of participants. The loss of physical abilities also impacts participants’ social identities.

Acquiring a disability can result in the loss of social connections, which can lead to the loss of the identity as a valued friend. Reuben explained: *“After the accident, it was such a huge thing to happen. Everything’s like, everything’s taken away from me…my social network was really cut down, like I had friends who I spent every day with…and then all of a sudden they just don’t want to know you.”*

Ruben talked about how the social identity of being a valued friend is directly tied to acquiring a disability. The identity of being a valued friend is lost when friends no longer prioritize staying socially connected. The physical constraints due to acquiring a mobility disability directly impacted participants' social identities. For example, Alex explained: *"Not a lot of people have accessible houses, so I don't get to see my friends as much and so yeah, it definitely shrinks your social circle."*

With the sense of loss of identity came a loss of purpose. Participants described uncertainty about what to do next, particularly after first acquiring their disability. Robin explained: *"I resigned [from work due to acquired disability] and I thought, 'what am I going to do with my life?'… I was really soul-searching."* Participants discussed how, in this phase of loss, they had low expectations of what they would be able to do, particularly related to their creative identities. Alex stated, *"I thought I was done playing video games forever. I never even thought that was an option."*

Participants describe their sense of loss of identity and purpose as profound events which affected them deeply. Participants lost not only their physical abilities but their abilities to do the things which contributed to their core identity as a person. Ava stated: *"I lost myself totally after diagnosis. I was just the illness."*

Lucy A. summarized this phase of identity loss as a transition phase and as a call to action:

> *"I was really struggling, not necessarily physically but just mentally with the change to my, well, what I could physically make, what I could make and draw. It was different to what I could do before [acquiring disability] and no one else could see that necessarily apart from me, but I knew it was different than what I could do before and I was really struggling with that…Now, having a disability I'm not expected to do anything and everybody is just glad that I'm alive…that's ok for a year or two because you've still got a lot of processing to do…but then after the transition, you've got to find things to do, otherwise you're just going to vegetate."*

6.4.1.2 Exploration and Discovery

In the exploration and discovery phase, participants began to imagine the possibilities of reshaping their creative identity. A key component in the phase of exploration and discovery is the acquisition of personalized technologies which meet each individual's specific needs to engage in creative pursuits.

Accessible technology was especially critical for participants who had both communication and motor disabilities. Discovering accessible technology led to identity change, in which technology became an integral component of an individual's identity. All participants spoke of the importance of technology related to their identity and self-expression. Tim stated: "*Before M.N.D [I] never used a computer…now the computer is my way to talk to the outside world. I would be LOST without my COMPUTER."* Ava stated: *"When I got my first computer, I came back. Now I don't think of myself as the illness, just me."*

Accessible technology facilitated participants' searches for accessible creative pursuits. The ability to access a computer provided participants with agency over exploring accessible creative pursuits, thereby facilitating the possibility of reshaping their creative identities.

As participants discovered the possibilities of accessible creative pursuits, they engaged in creative problem solving to improve their access to creativity. Lucy B. described how the initial experience of loss and grief changed after seeing a specialist in assistive technology and creative pursuits. Lucy B. said *"It [disability] mad me sad initially, but then I searched online and found [specialist]. That made me excited."* Tim stated that the assistive technology and the accessible design software they received from their specialist providers *"does make a difference in my life."*

The identity phase of exploration and discovery is characterized with the identity formation of being a problem solver, one who is exploring and discovering their own abilities and capabilities within the context of accessible creative pursuits. Alex stated, *"I have to figure out ways to be creative, to go against other people [while playing games online] because there are so many different things that other people can do that I'm not able to."* Lucy A. explained that learning how to engage with creative pursuits in a new way is:

> *"A bit like learning to walk…so when I had my accident first I remember trying to eat a biscuit and I put it in my eye because I'd lost connection between…what my hand was doing and what my brain was doing…so doing pottery or gaming to start, you're using*

> *that brain physical connection again which is actually…quite complicated for your brain…it's because they're new skills, so rather than doing it, I'm learning it…it's a challenge…I think to be a successful person with a disability in a world that's inaccessible, you have to problem solve constantly."*

In exploration and discovery, participants identify themselves as problem solvers, letting go of their preconceptions of how to do something the way they did things before acquiring their disability. Alex said that it is important to *"know that you can pivot to different things. You don't have to do it the same way that you did it before [acquiring disability] and you can always learn new ways of doing things."*

Participants first had to explore and discover accessible creative pursuits based on their individualized abilities. They became problem solvers who learned the capabilities of their bodies, AT, and accessible creative pursuits. Their identities shifted from a person who has lost abilities to one who is learning new abilities. After the problem of accessing creative pursuits is removed and participants have mastered their access methods, participants began to focus on honing the creative pursuits themselves, leading to the next identity phase: reclaiming a creative identity.

6.4.1.3 Reclaiming a Creative Identity

Participants reclaimed a positive creative identity when they continued to push themselves in their newly chosen, preferred creative pursuits. In this phase, participants spoke of pride in their abilities, of being able to compete with people who do not have disabilities, and of giving back to others by sharing their creative works. In contrast to the exploration and discovery phase, in which participants problem solved their newly discovered abilities in relation to creative pursuits, the reclaiming a creative identity phase is focused on the pursuit of excellence in one or more chosen creative pursuits. As part of this process, participants spoke of finding purpose and of increasing their social connections, which formed a positive self-identity.

Alex described their experience in reclaiming their creative identity:

> *"With gaming it was just, it well, just opened up something. You know when you get everything stripped away and you're like bare and…I'll never get to do this and like all the things that I never get to do, all the fun things, and then all of a sudden you're able*

> *to do this. And it's like wow, I can do something else again and then now, I'm better at this than other people. You know, it really makes me feel better about myself, you know, gives me more self-esteem, makes me happier."*

Within the context of their preferred creative pursuit, gaming, Alex spoke of pride and a pursuit of excellence. Alex goes on to explain how their creative accomplishments reinforce a positive identity change from earlier identity phases. When reclaiming a creative identity, participants spoke of their creative works as integral to their identity and achievements. Achievements include achievements in their creative pursuits as well as achievements in strengthening and expanding social networks. In this phase, participants reclaim their identities as valued social connections.

Engagement in creative pursuits opened pathways to connecting with others. Participants used creative pursuits to reconnect with existing friends and family, reshaping their identity within that established context. Lucy A. described how gaming with their partner increased their connection: *"we're sharing something and doing something together" and went on to say that "when [partner's] not here … and I'm on the Xbox and I just killed some great monster I'll go 'Tell [partner] I killed the great monster Alexa.'"*

By engaging in creative pursuits, participants had something to talk about and share with others, which established common ground as equals within the creative pursuit. Reuben provided dramatic examples of how accessing creative pursuits influenced their social connections. After starting web design and photo/video editing, Reuben re-established connections with friends, saying, *"now I speak to [one friend] every single day whereas before [creative pursuits] we may connect once every month."* By deeply pursuing a variety of creative pursuits, Reuben re-established even more connections with friends. After Reuben began playing games with one friend, he described how his social connections increased: *"so then another friend from my university days started playing with us, and now with those two, every night we're playing games."* Engagement in creative pursuits has also established new connections with family members, in which Reuben's use of assistive technologies are seen as special and desirable. Reuben explains that prior to engaging in creative pursuits, younger relatives *"just sat in the lounge playing on* *their iPads…but now though, they want to come play games with me because I've got a TV and a computer and they've just got iPads and they want to play what I'm playing."*

In this phase of reclaiming a creative identity, participants not only describe strengthening existing social connections and reshaping their identity within those social connections, but also of expanding social connections.

Participants report that access to creative pursuits have fostered new social connections in a variety of ways. Lucy B. stated *"definitely I am having more fun than I would have [without gaming using AT] but also gaming has introduced me to people I probably wouldn't have known before."* Robin and Lucy A. took classes to learn various creative pursuits and made social connections through those classes. Lucy A. explains the importance of making new social connections*, "I love pottery because part of it is leaving the house, going to the pottery studio, doing it with other people, making new friends."*

With increased social connections, participants reclaimed their creative identities as a person who creates and gives to others. Ava, Robin, and Tim have shared their creative works publicly and have given interviews about their work. Tim donates their creative works: *"With me making [horse] show jumps, [the jumps] help raise money for my few charities close to my heart."* Ava and Robin have also been featured in mainstream media and have exhibited their creative works. Participants in the reclaiming a creative identity phase are proud of their creative works and want to share them, resulting in the establishment of a positive creative identity.

While not all participants in this phase publicly shared their creative works in an identifiable manner, participants all share the same characteristic of pride in their creative achievements. A part of that pride is the ability to do something for others. Lucy B. stated: *"Originally, I identified myself as [someone] who loves playing new games but now I identify myself as someone who still loves to play games but also as someone that helps other people with [assistive technologies and gaming] too."* Reuben said, *"With the video editing, I just enjoy working with my friend doing something together. I just like helping my friends."* Lucy A. described how creativity impacts identity because creativity gives an individual *"something to strive for, something to work towards, and something to be social about."*

The sense of pride and achievement with reclaiming a creative identity also impacts perceptions of quality of life. Reuben explains that the acquisition of assistive technologies and accessible creative pursuits impacts quality of life *"greatly, immensely, [it's] just really powerful. You know, just having friends again, to have people to talk to you…just having friends again in the world…it was before [creative pursuits] well not lost [friends] before but…now I just feel included and not missing out…yeah, it's really powerful."*

When reclaiming a creative identity, participants not only strengthened and expanded their social connections but also reported that creativity positively impacted their health. Alex explained that *"there's the mental health aspect of [creativity]. It's really big. Because you're just thinking about it, just like…a switch that'd been turned off that you never thought would get turned on again, and then like, you turn the light on and you're like, whoa! There's so much I can do."*

Participants also described how engagement in creative pursuits required significant attention and focus, which helped with both mental and physical health. Reuben explained how creative pursuits differ from engagement in passive activities: *"When you're just watching something passive, you're more present in your head, whereas like playing games…your head is more involved."* Lucy A. compared the effects of active versus passive engagement on pain management. Lucy A. explained that when they engage in creative pursuits while in pain, then *"I'm concentrating on working and doing [creative] things whereas if I'm in pain and I decided to sit on the sofa and do nothing, I'm still in pain doing nothing." Reuben explained that when gaming "you don't think about [pain]…[gaming] is way more powerful than any drug or painkiller."*

Participants described the effects of creative engagement in terms of positive mental health and well-being. Ava explained the effects of creativity as *"I feel more relaxed"* and Lucy B. said that *"[gaming] definitely reduces stress."* Lucy A. stated that *"it takes such a lot of brain power and connection with what you're physically doing that you cannot think about anything else…so it's really therapeutic at the time."*

Findings indicate that engagement in creative pursuits has the potential to impact physical health as well as mental health. Participants spoke of how engagement in creativity through their assistive technologies have improved their physical abilities to use the assistive technologies themselves. Lucy B. stated that *"[gaming] also encourages you to maintain focus and using the physical control you have, in my case, eye gaze, so physically you build up stamina."* Alex also stated that their physical health improved as a result of their creative pursuits: *"It hit me one day where I'm like, this is a lot easier than it* *used to be. And like I noticed my lung function, my breathing was actually improving and I was able to do things faster…hold buttons longer without taking a breath and just little things where I'm like, this wasn't like this when I started."*

Participants describe how their engagement in creative pursuits fosters a positive reclaimed creative identity through their perceptions of improved health, social connections, and quality of life. In the reclaiming a creative identity phase, participants focus on developing their creative skills which, in turn, positively impact other areas of their lives.

6.4.2 Information is Critical to Access Creativity

Analysis of interview data shows that information was critical to facilitating participants' discovery of their creative abilities and creative engagement opportunities. Participants spoke of searching for and discovering information on accessible creativity with the help of AT specialists, a key factor in discovering accessible creativity for individualized needs. Whether through their own deliberate searching or through accidental discoveries, learning about the tools involved in accessible creativity was a necessary precursor for all participants before they engaged in creativity. I discuss three sub-themes which fall under the over-arching theme of information is critical to access creativity: (1) lack of discoverability, (2) energy cost of searching for individualized solutions, and (3) need for sharing of expertise.

6.4.2.1 Lack of Discoverability

Learning about accessible creativity to meet individual needs was not easy for some participants. The lack of awareness of accessible options for people who use AT delayed some participants' engagement in creative pursuits by years. Alex described that while volunteering at their rehabilitation clinic, they met a specialist in adapted gaming who was giving a demonstration of an accessible game controller. Alex said *"So he's the one that brought me and showed me how to use it…I was instantly hooked. I was super excited about it…I'm like, why didn't I know about this three years ago? Why am I this far behind on it? Why does nobody know?...It's not common knowledge."* After discovering and trying the adapted gaming device, Alex subsequently found a documentary about a gamer with disabilities. Alex said*, "At the very end of the documentary he said he was the best.. [and that he] would challenge anybody. And I heard that and I'm like, whoa, we'll see, give me a little time."*

Alex’s story highlights the lack of easily discoverable knowledge about accessible creative pursuits for people who use AT. Alex expressed frustration at not being told about accessible gaming for three years by asking: *“why does nobody know?”* Not knowing that accessible creative pursuits are available inherently limits any search activities for accessible creative pursuits.

Reuben talked about the lack of discoverability of accessible creative pursuits in terms of active and passive leisure activities. Reuben said: *“The 10 years prior to [gaming] I was just watching TV…and now we say, ‘why the hell haven’t we been doing this [gaming] for the last 10 years.”*

Even knowing that an accessible creative pursuit is available did not ensure success in discovering information about that creative pursuit. Tim and his caregiver tried to find information on the accessible creative software that a specialist had previously installed on Tim’s computer. The software was accessible for Tim’s needs, but discovering how to find the software without the specialist’s help proved impossible. Tim’s caregiver said *“I tried to find it to download it but I cannot find it again.”*

The lack of discoverability of accessible creative pursuits can result in years of lost social connections and missed opportunities, as highlighted by Reuben and Alex’s stories. Lack of discoverability can be intensified by the time and energy needed for people who use AT to access the computer and perform searches, which leads to the next sub-theme.

6.4.2.2 Energy Cost of Searching for Individualized Solutions

Using AT for computer access itself can cause fatigue, particularly when first learning to use AT. Lucy B. describes *“The first time I used eye gaze I got tired quite quickly but now [years later] I can use eye gaze all day fairly easily.”* The energy cost of using AT can compound the energy cost in conducting searches for information about accessible creative pursuits. Participants used different forms of AT and different configurations of AT to meet their individualized needs which made searching for specific solutions even more challenging. For example, Reuben described his unique requirements for using a head mouse, *“I've tried a few of them [head mice] and they don't have light filtering. I wear glasses….so [with his current head mouse] you just turn [on] the light filtering…it keeps the mouse on the proper spot where its supposed to be.”* However, Reuben stated that his current solution, which he discovered 12 years ago, is not easily discoverable any longer. *"It's great, it works really well for me. The problem being its discontinued….I'm sure you can still buy them from some places."*

Discontinued accessible products further exacerbates the challenges when searching for individualized solutions that meet individualized needs. Each participant had unique needs and requirements for AT use. Even when participants used the same form of AT, such as eye control, the way in which they used the AT system varied, with different eye control interfaces and different types of communication software. The cost of searching for individualized accessible creative pursuits was, at times, too much for participants.

A case example is Robin, who, after acquiring their disability, discovered art through an existing social connection. Robin explained: *"my neighbor dragged me by the hair saying 'come to my art class.' And it was a neighborhood art class, not fancy, but I absolutely fell in love. I instantly knew that's what I wanted to do. It totally changed my life."* However, as Robin's abilities continued to change over the years due to their health condition, Robin was no longer able to engage in art in the same way, saying *"I struggle with that every day because I really want to create art and trying to do that is really hard."* Robin actively searched for accessible solutions to their changing abilities in a variety of ways. Robin contacted AT practitioners, technology developers, attended seminars, and learned about support groups, but Robin was unable to find the right AT solution to meet their needs. Robin explained the trade-off between searching for and trying new solutions and their energy reserves: *"you can do it [learn new ATs] but it was really hard, it was like you had to say 'nothing else in my life exists'… I don't want to give up my life."*

The energy needed to first, search for information, and then, to try out different solutions, took away from other aspects of Robin's life. The lack of easily discoverable information on individualized solutions used too much energy that Robin wanted to dedicate to other aspects of their life. In one of their creative works, Robin showed the power balance between having a life with changing abilities and relying on others to share their knowledge, and described the artwork as: *" [it] really describes a narrative: one, a narrative of disease, the journey of trying to eek out some power in being a patient, power of being, and also recognizing the importance of clinicians and other helping professions."*

The importance of clinicians and helping professionals who are knowledgeable about accessible creative pursuits and technologies is emphasized with Robin's story. As Robin's abilities became more restricted, Robin was no longer able to engage in art creation in the same way they could after first acquiring their disability. Robin is missing a resource with information about individualized solutions tailored for their unique needs. During the interview, Robin asked about other participants in this research study and their accessible creative pursuits, expressing a desire to meet other creative people who used AT and to learn about the tools they use. Robin still desired a solution, but the energy it took to try to find an individualized solution to meet their needs was too great a cost. Robin also was unsure if the solutions available would be appealing, saying: *"there's lots of areas of technology out there but you need hands, and I think…as far as I know, there's nothing that lets you do things without hands. And even if I could use it I'm not sure that it would be attractive to me that much….it depends on what your options are. If there's no other options, I'll love it. I'll get into it. I'll make it work."*

The lack of information about the types of individualized accessible creative tools leads to speculation and uncertainty. Robin indicates that if all of the options are known, then if there are no other choices, then Robin will *"make it work,"* but without knowing the options, Robin is not able to make an informed choice about whether or not they can engage in various creative pursuits. Whereas other participants spoke of discovering individualized solutions through searches and AT specialists, Robin's case demonstrates the ongoing challenges when a solution or specialist with expertise are not easily discoverable. In particular, the cases of Robin, Alex, and Reuben highlight that the lack of discoverable information on accessible creative pursuits can result in years of delay in creative engagement.

6.4.2.3 Need for Sharing of Expertise

While interviews highlighted the challenges of finding information on accessible creative pursuits to fit individualized needs, interviews also showed that gaining information on accessible creative pursuits can be life-changing. A key factor to gaining information is locating expert information sources.

Ava had a similar creative trajectory as Robin. While progressively losing their abilities, Ava shifted from their preferred forms of creative expression (art creation) to writing, which was the only accessible form of creativity available to them at the time. Ava stated: *"It [disability] did stop my creativity but I had to express myself so I had to start writing."* After Ava connected with an AT specialist who was knowledgeable about accessible creative pursuits and individualized AT systems, Ava was able to engage in their preferred form of creativity, art creation. Because their abilities had changed, Ava's art creation was through a new modality: digital art. Technology-based art creation is now Ava's focus in creative pursuits. Ava said that now, *"I haven't written for years. [I] prefer painting. [I stopped writing] because I got the technology [providing access to accessible painting]."*

Ava's story demonstrates how sharing knowledge and successes are important, and can by cyclical. Ava discovered AT options and the possibility of accessible creative pursuits through shared information: *"on social media, on Twitter, and [from AT specialist]."* Ava was able to engage in digital art creation because they found a specialist who shared their knowledge of accessible creative pursuits and who could also address Ava's individualized needs. Moreover, Ava has subsequently shared their knowledge of accessible creative pursuits based on their experience. Ava has given interviews and presented at exhibitions, demonstrating the tools they use to create art and has engaged in a performance art piece to raise awareness about their disease.

Three participants described how they actively searched for accessible gaming options. Lucy B., Reuben, and Lucy A. engaged in online searching, where they found AT specialists who worked with accessible gaming and could see examples of accessible gaming. By watching videos of people playing accessible games online, participants gained knowledge of what was possible and the tools that were available. Reuben described their process:

> *"I got the same software [as seen online] and started trying to use it myself with the two [AT] buttons…and slowly I got used to moving around and being able to do certain things [in the game]. Then I managed to get a visit from [specialist] and they were amazing…they gave me a [AT] straw...so then that gave me five other things I could do [in the game]. And a week or so later I thought, hang on a second, I can use two straws, so I got two straws in front of me and I had like 12 things I could do."*

Reuben describes how the act of learning about accessible gaming tools directly influenced his behavior and abilities. The act of having discoverable, shared knowledge available online allowed Reuben to begin his journey in accessible gaming.

Six of the seven participants had contact with an AT specialist who directly helped them with their AT systems and discovery of accessible creative pursuits. The knowledge sharing from AT specialists then translated into knowledge sharing by the participants to others. Three participants have actively engaged with mainstream press to share their stories of how they are able to engage in creative pursuits. Other participants have not publicly shared their stories through mainstream media but have shared their stories at the individual level.

The importance of sharing knowledge and success is viewed by participants as a way to help others. For example, Lucy B. explained how having AT and being able to successfully use AT allows them to share information with others: *“The eye gaze games creates a medium for me to be able to help out and to show people [eye gaze technology].”* However, Lucy B. does not yet engage in widespread, public knowledge sharing, saying: *“I watch Twitch but don’t stream…[I might stream] in the future.”* Alex, like Lucy B., had not yet started to publicly share their story through a mainstream public platform like Twitch. However, at the time of the interview, Alex revealed that they had purchased equipment to begin streaming their gaming. Alex had been inspired by watching a documentary: *“What really drove me is I watched a documentary, you know, Rocky No Hands. He’s got one out there that’s like 40 minutes long.”*

During interviews, Robin and Alex expressly indicated a desire to learn from others, and to talk with others with similar accessibility needs and similar creative interests so that they could learn new skills and techniques to increase their own creative engagement. Alex stated: *“I need to figure out a way to get in contact with [Rocky No Hands]. It would be so cool. I’d love to pick his brain on what he knows and his little tricks, you know anything that helps…[and to tell him that he] totally inspired me to play.”*

6.5 Discussion

This study explored the experiences of adults who acquired disabilities who use AT for daily living and engage in creative pursuits. Findings reveal that accessible creativity fosters a positive identity reconfiguration, positively impacts mental health, and increases social connections. Based on these findings, I focus on two areas for discussion: (1) the critical aspect of exploration and discovery as part of identity reconfiguration and (2) that expert knowledge sharing of AT and creative pursuits is needed.

6.5.1 Exploration and Discovery of Accessible Creative Pursuits are an Important Precursor to Positive Identity Reconfiguration

Whereas prior models illustrate a linear identity change path, e.g. [97,258], the identity change process is cyclical for adults with acquired MMCD who use AT and engage in creative pursuits. Similar to identity change experienced by adults with chronic illnesses [51], the cyclical nature of identity change for adults with acquired disabilities who use AT involves a sense of loss. Adults with acquired chronic health conditions and disabilities experience a loss of purpose and a loss of their pre-disability identity [19,50,51,238]. Prior work has shown that active engagement in leisure activities can provide a positive sense of identity of people with chronic health conditions [141,258,260]. A contribution of my research is that it expands the field by demonstrating that individuals who use assistive technologies for daily living benefit from engaging in a range of creative pursuits, and that the process of discovering accessible creative pursuits is critical.

Engaging in creative pursuits, such as gaming, can be transformative [313]. However, unlike previous models of identity change, I present a contribution to the field by highlighting how technology impacts identity. Adults repeat the identity change cycle as technologies change or as their abilities change. For example, when Robin's abilities changed, they began to repeat the identity change cycle, returning to exploration and discovery, searching for technology that meets their needs and provides access to their preferred creative pursuits. Similarly, when existing, specialized technologies are discontinued, such as Reuben's 12-year-old head mouse, the identity change cycle will restart when a replacement technology is needed, sought for, and discovered.

The identity change cycle is broadly comprised of three phases (Figure 2), in which the discrete components of the phase *"reclaiming identity, purpose and meaning"* are reflected in an expanded version of Reynolds' framework. While Reynolds' original framework was based on participants who were able to use their hands and communicate verbally [258], my findings show that individuals who use AT also experience identity reconfiguration through artistic occupation. My findings expand Reynolds' framework to include individuals who cannot use their hands or communicate verbally. Thus, a version of Reynolds' framework lies within the *"reclaiming identity, purpose and meaning"* phase of the overall identity cycle.

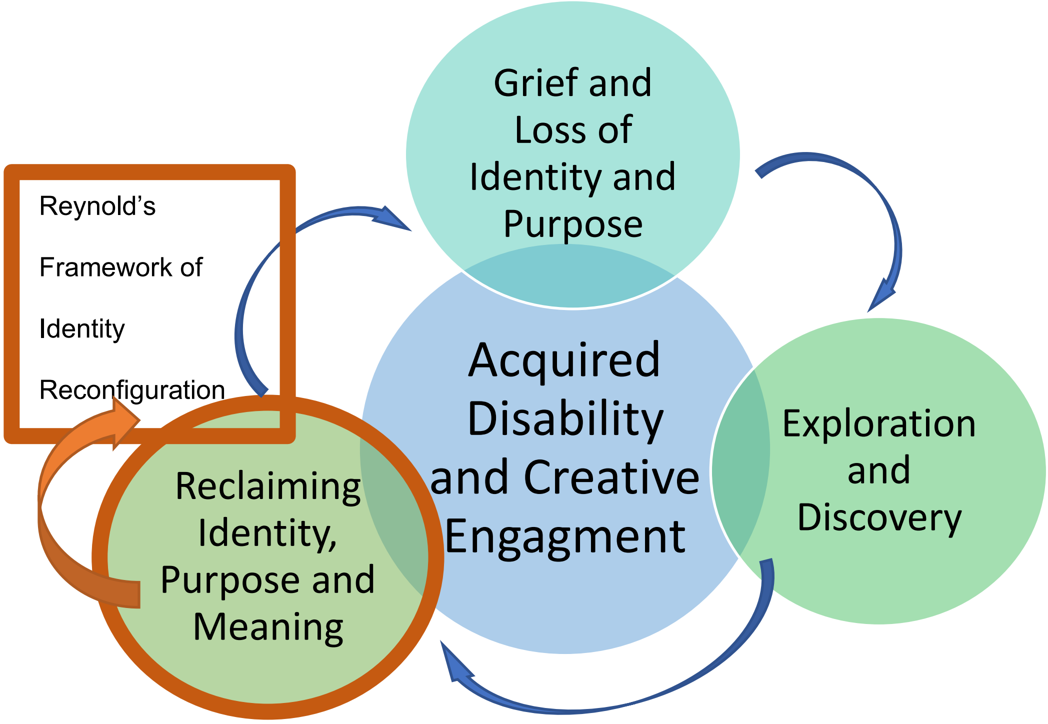


Figure 2. Identity Change Cycle Including Reynolds' Framework of Identity Reconfiguration

In expanding Reynolds’ framework to include individuals who use AT, I add the concept of “acquisition of accessible creative pursuits” as a necessary precursor to Reynolds’ framework (Table 11). For example, Ava’s disability progression highlights the critical importance of acquiring accessible creative pursuits. As described earlier in the findings, Ava was no longer able to engage in their preferred creative pursuit as their disability progressed. Ava stated: *“It [disability] did stop my creativity but I had to express myself so I had to start writing.”* Individuals who use AT must first acquire accessible creative pursuits before Reynolds’ process of identity reconfiguration can occur. Ava’s story provides an example of how, once they found accessible creative pursuits, they stopped the less preferred creative format of writing, and reconfigured their identity to that of an artist. In Table 11, I use quotes from participants to demonstrate how Reynolds’ framework can be applied to adults who use AT. I also highlight the precursor to Reynolds’ framework with a quote from Ava.

Table 11. Reynolds' four process of identity reconfiguration through artistic occupation with the inclusion of exploration and discovery of accessibility as a precursor to identity reconfiguration

Reynolds' Identity Reconfiguration as a Result of Artistic Occupation	Quote examples from thesis participants
Essential precursor: Acquisition of Accessible Creative Pursuits	Ava: *"When I got my first computer, I came back. Now I don't think of myself as the illness, just me."*
A Reconnection with the Previous, Pre-Illness Self	Lucy B.: *"Originally, I identified myself as [someone] who loves playing new games but now I identify myself as someone who still loves to play games but also as someone that helps other people with [assistive technologies and gaming] too."*
Positive Personal Identity Growth and Development	Reuben: *"just having friends again in the world…it was before [creative pursuits] well not lost [friends] before but…now I just feel included and not missing out…yeah, it's really powerful."*
Restores a Sense of One's Own Expertise, Status, and Self-Esteem	Alex: *"It's the fact that I am able to beat other people that have a ginormous advantage over me. I'm able to go against people that are using their hand on controllers or on a computer…and I'm able to beat them using [AT]."*
A Socially Validated Identity	Tim: *"With me making show jumps, [the jumps] help raise money for my few charities close to my heart."*

The identity change cycle represents the major identity change phases based on the findings of this study. When we combine the concept of identity reconfiguration with the potential physical and mental health benefits of engaging in creativity [17,19,26,46], we have empirical evidence to support Max-Neef's premise that creativity is a fundamental human need [24], expanding the concept to a novel population: adults with acquired MMCD who use AT. We also see how a reclaimed positive identity is tied with increased social connections, improving participants' perceptions of their quality of life.

Quality of life is *"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"* [362]. By reclaiming a positive identity, participants set goals and expectations for themselves within the context of their creative pursuits and their social connections, such as Alex's goal to improve in gaming and Reuben's goal to help their friends. Through access to creativity, participants' perceptions of their position in life changed as their identity changed, leading to improved perceptions of quality of life.

In his book, *“Creativity,”* Csikszentmihalyi describes that living a creative personal life can provide the ultimate fulfillment in life [66]. The author states that engaging in creativity *provides “the possibilities for uniqueness and growth inherent in the human condition”* [66:21]. The findings from my work show that, for the seven participants I interviewed, identity reconfiguration through access to creative pursuits did indeed provide positive growth and change. Ultimately, access to creativity directly impacted participants’ identities, which in-turn, affected their perceptions of their quality of life.

6.5.2 Sharing Expertise and Knowledge about AT, Accessibility and Creativity is Critical

Knowledge of what was possible, and conversely, the lack of knowledge of what was possible, influenced participants’ actions and identities. My findings show that a creative identity is predicated on the discovery of accessible creative pursuits. Winograd and Flores state: *“our understanding of being is closely linked to our understanding of knowledge”* [331:81]. After acquiring their disability, Lucy A. described how they were not expected to *“do”* anything. Without knowledge of the possibility of accessible creative pursuits, participants lived with the knowledge of passive activities, rather than knowledge of accessible creative pursuits, which negatively impacted their perceived quality of life. For example, Reuben described how he had been watching TV for 10 years instead of playing games with friends, because of a lack of knowledge about accessible gaming options.

My findings highlight the importance of sharing knowledge and expertise of accessible creative pursuits and AT solutions. Ultimately, six of the seven participants met with AT experts who shared their knowledge and facilitated the participants’ access to creative pursuits. However, the lack of discoverability and the effort required to search for expert knowledge about accessible creative pursuits hindered participants’ abilities to search for and engage in creative pursuits.

Although Shannon’s theory of communication is a mathematical model describing the technical means of sharing information, it provides a useful analogy for breaking down the problem of information sharing into discrete parts [280]. We can consider AT experts with knowledge of accessible creative pursuits as one **information source**. Using Shannon’s model, we need to consider how the information source can be transmitted via a channel and receiver to the **destination**, in this case the destination is adults with MMCD who use AT and want to engage in creative pursuits. By using Shannon’s model, we see that the destination has unique requirements. One key requirement is the physical accessibility of receiving the information source. Another requirement is to limit the energy and time required for discovering the information source.

Adults with degenerative conditions or concurrent health conditions have limited reserves of energy to spend on searching for information. Findings from my study and prior research have discussed how using AT for computer access requires more time and energy than using a traditional keyboard and mouse [29,34,56]. Adults who acquire disabilities spend their energy on learning their AT system when it is first introduced, as Lucy B. described earlier in the findings. Depending on how long it takes to learn their AT system, adults may not have the energy to search for accessible creative pursuits for some time. Even after learning their AT system, using energy to search for accessible creative pursuits may be too costly a trade-off, as described by Robin in the findings.

One solution to alleviate both the physical accessibility requirement and the energy cost of accessing web search tools is designing with Web Content Accessibility Guidelines (WCAG). Using Shannon's model, WCAG may be thought of a way the **receiver** reconstructs the message so it is accessible to the **destination**. While WCAG standards are widely known, and have been around since 1999, studies continue to show that design implementation of WCAG standards vary widely across websites [47,163,244]. Therefore, in practical terms, relying solely on modifying the receiver to improve information transmission, while helpful, is not enough to reach all destinations.

By analyzing the problem of information sharing using Shannon's model we see that in addition to physical barriers to information sharing, there are additional barriers beyond physical access of an information sharing system. These barriers relate to awareness and identity as demonstrated by Alex and Reuben describing how years went by before they became aware of the possibility of accessible creative pursuits. Building on Winograd and Flores' statement that a person's concept of being influences their concept of knowledge [331], we must address concepts of being and identity as well as physical access to promote information sharing of accessible creative pursuits for individuals using AT.

6.5.2.1 Creative Models: Increasing Awareness of People who use AT and Engage in Creative Pursuits

While prior research has explored the design and development of new and emerging creative technologies for specific populations, such as textile arts for the blind and vision impaired (e.g. [34,70,71,107,117]), there is a paucity of research on how accessible creative technologies are discovered and can be made more discoverable.

Developers who create technologies for people with disabilities should consider how they will share out information about those technologies to make them easily discoverable. Prior work has called for designers of new technologies to use their technologies as catalysts for social change [35]. By considering who might benefit from learning about accessible creative technologies, outside of the HCI and research communities, developers and researchers can promote awareness of the possibilities that technology can offer. By broadly disseminating findings and technologies to organizations involved with people who use AT, developers can increase end-users' awareness of the possibility of accessible creative pursuits.

In addition, sharing information about individuals who use AT and who are engaged in accessible creative pursuits can also increase discoverability and provide a model of a positive, creative concept of being. Earlier, Alex described the motivation they found after watching a video of a gamer with similar disabilities. Increasing the visibility of people with acquired disabilities who use AT and their accessible creative pursuits can provide *"creative models"* which can inspire others to explore their own creative potential. Prior work has called for researchers to recognize that individuals with chronic health conditions have unique accessibility needs and can provide valuable expertise [193]. My findings show that adults with MMCD who use AT also have unique accessibility needs and can provide valuable expertise regarding accessible creativity. I use the term *"creative models"* to describe individuals who can provide expertise, or model, accessible forms of creativity and the impacts of engaging in creativity.

The idea of *"creative models,"* the title of this chapter, is inspired by Roger's concept of early adopters in the context of the diffusion of innovations [261]. Early adopters of innovations share their use of innovations through communication channels. In the case of adults who engage in creative pursuits using AT, sharing their stories and how they engage in creative pursuits is a way to diffusely distribute information about accessible creativity. By encouraging these *“creative models”* to share their stories publicly, we increase the chances of people discovering accessible creative pursuits sooner. As Reuben and Alex both shared, not-knowing about the possibility of creative pursuits can result in years of a diminished quality of life.

The HCI community has an opportunity to design information sharing platforms and tools which are easily accessible to AT users. Currently, barriers to entry maybe too high for some creative models to share their stories widely. As Alex described, extra equipment and support is currently required to share their creative accomplishments. Purchasing equipment and coordinating personnel support can be costly. The HCI community could help design cost-effective and accessible tools for individuals to share and celebrate their creative accomplishments with a wider audience, thereby increasing information sharing and discoverability of accessible creative solutions.

6.5.2.2 Creative Technology Expertise: Sharing Knowledge from AT Experts

A key problem identified in my findings is the lack of easily discoverable specialist expertise which can be applied to specific, individualized AT situations. None of the seven participants interviewed in my study used the exact same technologies or configurations for their AT needs. While increasing awareness of accessible creative pursuits can instigate the start of further exploration and perhaps even the acquisition of technologies, expert assistance is likely needed to help with accommodating individual needs. For example, six of the seven participants in my study met with AT experts who had specialist knowledge of both AT and accessible creative pursuits. However, as Robin’s story points out, it can be a challenge to find specialists with expertise in both AT and accessible creative pursuits.

Prior work has recognized the importance of AT specialist knowledge in the design and implementation of AT [129,230]. AT specialist knowledge could be used to create a repository of AT information [129]. I suggest that AT specialist knowledge not only be captured about AT systems, but that knowledge of accessible creative pursuits combined with AT system information be captured and shared. A repository of accessible creative pursuits, combined with information on different types of AT systems would provide necessary information on how specific access methods integrate with creative pursuits. For example, in the findings, both Lucy A. and Lucy B. engaged in gaming, as did Reuben and Alex. Lucy A. used an adapted game controller, Alex used a different adapted game controller than Lucy A. used, Lucy B. used eye control, and Reuben used a head mouse. Knowing that a game is accessible is not enough information to understand how a specific individual who uses AT could access the game. An information sharing system needs to be in place to capture access methods, AT technologies, and creative pursuits.

Research on global AAC and AT services indicates that most professionals provide generalized services to broad populations, rather than exclusive specialization in AT and AAC, and that professionals feel they need more training on AAC and AT [158,287,301]. The lack of knowledge in AT and AAC within the generalized professional population answers the question raised by Alex of *"why does nobody know?"* Therefore, locating professionals with expert knowledge in both AT and accessible creative pursuits is needed to share information more widely with the general population of professionals who provide AT services. The very specialized knowledge of accessible creative pursuits, and how they can be incorporated with AT systems likely is held by a very small percentage of AT experts throughout the world.

HCI researchers, information scientists and designers have an opportunity to locate individuals with expertise knowledge and create a repository of information which can be shared broadly. Increasing access to specialist knowledge could help generalized professionals who provide AT services to a small percentage of their overall client population. In addition, the repository could be designed to be accessible not only by professionals but also by individuals who use AT and their families. The repository could include vignettes from *"creative models,"* such as the individuals interviewed for this study. A combination of information on AT systems, accessible creative pursuits, and stories from creative models could prove to be an inspirational and life-changing resource. Information sharing could also take the form of creative outputs, as with the HIVE project, in which healthcare providers, researchers, artists, and healthcare consumers collaborated to create an informational art installation [326]. One can envision a situation in which creative models, AT experts, family members, and people with MMCD who use AT all collaborate to design and develop creative works which inform and educate about accessible creative pursuits, resulting in a creative installation and repository which may also increase the discoverability of information.

6.5.3 Limitations and Future Work

Because this study focuses on a very specific population, has a narrow inclusion criterion, and a small participant size, caution should be used when generalizing to other populations. Findings reported on health impacts of creative pursuits are based on participants' reports and future work should more deeply explore both mental and physical health impacts from engaging in creative pursuits. Additionally, the findings from this study indicate that access to specialist AT experts is a key gating factor to accessing preferred creative pursuits with individualized AT systems, however, this is based on a small sample size. Future work should further explore locating AT specialists with knowledge of accessible creative pursuits and the design of an information repository to share specialist knowledge. Future work should also continue to explore and locate creative models, and explore accessible ways for creative models to share their stories. Finally, this study indicates that the problem solving involved in overcoming barriers facilitates the formation of a positive creative identity. Future work should explore the role of AI in the creative process, and how AI can be developed so that individuals can continue to form a positive creative identity, which may include the need to problem solve and overcome barriers.

6.6 Contribution

In this chapter, I presented a qualitative analysis of interviews and related artifacts to understand how creativity impacts adults with acquired motor, mobility and/or communication disabilities who use AT. Based on this analysis, I developed a framework of an identity change cycle, which incorporates a modified version of Reynolds' framework as one component of the cycle. I broaden existing work in the field of Rehabilitation Sciences to demonstrate that adults with disabilities who use AT for daily living can benefit from access to creative pursuits outside of a directed therapeutic context. I demonstrate how engagement in creative pursuits positively impacts quality of life, tying together Max-Neef's concept of creation as a fundamental human need with the World Health Organization's definition of quality of life.

I contribute to the fields of Information Science and HCI by demonstrating how a lack of discoverability of information negatively impacts quality of life. I suggest the design of an information repository to increase the discoverability of accessible creative pursuits with specific design considerations to make the repository useful to professionals and people who use AT.

In the next chapter, I continue my contribution to the fields of HCI and Rehabilitation Science with my second methodological contribution: co-design with adults who use AT for MMCD.

Chapter 7. Aligned Co-Design: An Interdependent, Adaptive Method for People with Diverse Abilities, in Diverse Locations

In Chapter 6, I demonstrated how accessible creativity positively impacts quality of life. However, accessible creative applications are not well known or easily discoverable for individuals who have customized AT. Following these findings, I sought to conduct co-design studies with potential users to better understand the design parameters for accessible creativity. Yet, most co-design methods present barriers for individuals who have motor and/or communication disabilities that can consequently limit their opportunities for engaging in meaningful dialogue and collaboration with designers. Therefore, I first had to develop a co-design method that could engage adults with MMCD who use AT as true co-design partners.

In this chapter, I present my second methodological contribution. In doing so, I address the following research question (RQ4): **How can co-design methods better accommodate the needs of adults with motor, mobility, and/or communication disabilities who use AT for daily living?**

7.1 Introduction

The ideals of participatory design and co-design are grounded in democratizing the design process through a partnership with potential users. While work has addressed how co-design may be used with a variety of underserved populations, co-design and participatory design approaches may cause unintentional harm to participants [122]. For instance, researchers may not have the background knowledge needed to address the power dynamics involved when partnering with marginalized populations. Researchers may also lack the knowledge required to craft equitable inclusion of participants who cannot engage in traditional co-design sessions, such as participants who are not able to use their hands during co-design sessions. Subsequently, design outcomes may reflect the researcher's agenda with limited population representation, rather than reflecting an interdependent and co-constructed design agenda with diverse end-users.

While a body of work has advocated for inclusion of people with disabilities in design e.g. [24,229,248,249,283,285,337], researchers have also documented the challenges of engaging in formative research and design with adults who have communication and motor disabilities and use AT [160,297]. Many traditional co-design activities, such as manipulating objects to express design ideas, require participants to use their hands. This pre-requisite ability in co-design can exclude individuals with motor disabilities, such as individuals with spinal cord injuries or Multiple Sclerosis (MS). Moreover, individuals with communication disabilities can have difficulty fully expressing their ideas with the competing voices of others in group settings [322]. Individuals who use assistive technologies (AT), such as wheelchairs, alternative computer access devices (like eye control), or Augmentative and Alternative Communication devices (AAC), are likely to have difficulty in sharing or representing their ideas fully within time constraints, particularly within group settings [161,317]. In addition, individuals with progressive conditions impacting both motor and communication abilities, such as Amyotrophic Lateral Sclerosis (ALS) or MS, experience fatigue and other social barriers to active participation in public settings [14].

As a result, the design and development of technologies for people with MMCD who use AT frequently involve end users as expert consultants who inform design through interviews or evaluate prototypes, rather than as co-designers e.g. [93,150,160,290]. Given the particular challenges within formative research and design to engage individuals who use AT for MMCD, I apply an interdependence perspective in developing an accessible co-design method, which establishes aligned, mutual understanding.

In this chapter, I discuss the development of the Aligned Co-Design (ACD) method to address the challenges in co-design faced by designers and individuals with MMCD who use AT. Within this context, I address the power dynamics of co-design including accessibility, the pacing and timing of the co-design process, and researcher/designer assumptions. I present the components of ACD with example interactions and artifacts from a pilot ACD study. I also describe reflections from participants, which were used to help refine the method. The reflections from participants highlight the need for HCI researchers to be transparent about the co-design research process itself, including the potential impact of their research on the wider community.

7.2 Background

A number of frameworks have advocated for the inclusion of people with disabilities in the design process, such as User Sensitive Inclusive Design [229], Tenets for Social Accessibility [282], and Ability-Based Design [337]. The development of ACD is inspired by these frameworks, and I sought to create a framework for accessible, inclusive co-design. HCI researchers who work with participants with diverse abilities often have to modify or adapt existing research methods, and, at times, create new methods [195]. The ACD method was designed for a specific population, adults with MMCD who use AT, at a specific time, during the COVID-19 pandemic. The ACD method was designed using my professional knowledge from working as a speech-language therapist while simultaneously drawing on prior work in design and co-design.

7.2.1 Applications of Language and Communication Theory in HCI

Understanding peoples desires and needs for future technology is deeply rooted in the ability to engage in productive dialogue. Work in the fields of applied linguistics and multimodal communication have treated interpersonal communication as a collaborative, dynamic, and multimodal process [115,154,189], where different parties gradually take turns to create shared meaning, noticing and building on each other’s contributions [182,268,274]. This social constructivist, dialogic conceptual grounding is reflected in a number of prominent HCI traditions, such as participatory design [286], experience-centered design [341], and other ecological-grounded approaches [262,298].

In the context of designing alongside end users who have motor and speech disabilities, this collaborative, dynamic, and multi-modal view of communication becomes highly relevant, particularly when working to achieve mutual understanding and alignment of ideas in co-design. Constructing and aligning shared meaning requires a flexible, multimodal approach which is contextually accessible to all communication partners. It is widely understood that language is a code in which we express our ideas through an accepted system of signals to communicate [170]. However, language and meaning making also requires access to multimodal vocabularies, which are socially constructed and can change across contexts [170,302]. Words can carry different meanings and connotations for each person based on their own experiences, culture, and belief systems [132,170]. Recent HCI studies with people who use

Augmentative and Alternative Communication (AAC) have highlighted the importance of attending to multiple modes of communication [17,145] as well as strategies which enable AAC users to contribute to conversations in a timely manner [161,279,314].

Scandinavian co-design and participatory design research methods have also highlighted the importance of carefully considering language use [84,85]. In their discussion of design research, Ehn [277:64] builds on the philosophical approach of Wittgenstein [334]:

> *To label our experiences is to act deliberately. To label deliberately, we have to be trained to do so. Hence, the activity of labeling has to be learned. Language is not private but social. The labels we create are part of a practice that constitutes social meaning.*

Ehn builds on the concept of social language labels and discusses the role of *"language games"* in co-design, in which participants reconcile their different backgrounds and find a common language to collaborate and design together [84,85,277]. Similarly, Schön describes conversation between people as a *"collective verbal improvisation,"* in which participants are making something through the use of language [276:30]. As such, we must carefully consider how our use of language may be interpreted by others and how we interpret participants' language.

Prior work has highlighted that researchers' questions in co-design sessions with developmentally diverse children may be misaligned with participants' expectations, highlighting the importance of addressing researcher assumptions at the beginning of co-design sessions [320]. A misunderstanding of language can be the cause of misinterpretations of data in research. Misunderstandings and mistaken assumptions can be easily made when communicating with people who use AAC [220]. When working with individuals who have communication disabilities, researchers need to think deliberately about how to design interactions to accommodate communication abilities so that participants can fully express their ideas and to ensure that the research team does not misinterpret participants' communication. Therefore, when approaching the design of ACD, we explicitly consider the ways in which participants can easily and comfortably correct any misinterpretations of the data made by the researcher.

Design is a form of knowledge making [236]. Participatory design methods with children have highlighted the ways in which identity shapes knowledge, influencing co-design and participatory design sessions [41]. Based in the constructivist view that *"words of language do not carry meanings that remain stable"* [302], ACD incorporates the concept of member-checking, in which participants are encouraged to review their research data and to amend that data as appropriate [17,149].

In the development of the ACD method, I acknowledge that establishing shared meaning through language is emergent and collaborative. Therefore, I designed ACD to build shared understandings of language and we include member-checking in real time to force both the researcher and participant to confront their assumptions and correct researcher misinterpretations.

7.2.2 Utilizing Visuals to Enhance Understanding

The field of AAC utilizes a variety of visual representations of language, including physical objects, drawings, icons, and photographs for individuals who are unable to use their voice to communicate [26,27,155]. Visual renderings of concepts can also enrich spoken communication. For example, the use of drawings and icons can support shared understanding for people with aphasia [218,267], dementia [176,177], or other cognitive disabilities [175]. Lazar and colleagues discuss how art therapists use a *"third hand"* to assist and empower older adults to express themselves [175]. Piper and Lazar encourage researchers to use empathy, contextualize information, and empower individuals during art creation in co-design research, particularly with participants who have complex health needs [245].

Sketching and drawing in co-design is a common technique for capturing initial design ideas. Outside of co-design, Suchman and Trigg [299] have studied the role of whiteboards in facilitating work collaboration, and Rooksby and Ikeya have identified ways co-workers use visual representation of their work to share focus, mutually orient, agree and disagree [264]. More universally, the use of drawing to capture information has been formalized through the use of *"sketchnotes"* [44,92,263,352]. Like whiteboarding, sketchnotes are drawings of presented information, frequently created in real-time. Sketchnotes often include a mix of text and imagery. Proponents of sketchnoting indicate that the process of drawing helps with the acquisition and retention of knowledge [79,92,296]. Visual sketching in the context of participatory design can facilitate slowing down, becoming more self-aware, and foster interpersonal connections [308]. The use of sketching to process and synthesize information can not only benefit the person capturing the information, but also allows the synthesized information to be shared with others [296].

The use of sketchnotes is typically employed as a method for capturing information that is being taught or conveyed in a one-way information transfer process. However, in the ACD method we employ the concepts of sketchnotes, not in a one-way transfer process but rather, in a dynamic, interactive approach of drawing as a form of active graphical listening— in which we communicate our understanding and assumptions through language and visual mediums. Through using this multi-modal communication approach, we produce shared meaning and understanding together as interdependent co-designers.

7.2.3 Co-Design Methods

In addition to the concept of language games, Ehn describes the importance of including nonlinguistic artifacts as part of the co-design process. These non-linguistic artifacts supplement and complement the language games that occur during the design process. Ehn describes how "design by doing," in the form of creating mockups and prototypes, provides deeper understanding and sharing during the design process [85]. Methods might include: prototypes [346], layers of artifacts produced by other participants [325], design "non-proposals" (i.e. lightweight concepts that reflect important values, politics, and ideas without prescribing a specific course of action) [306], and the functional but incomplete designs of technology probes [143]. Within co-design methods, physical tools are prominent, including: crafts and household materials [6,22], photographs [321], tokens [348], drawing materials [127], and robots [140].

The majority of these methods were designed with the expectations that co-designers use their voice to communicate and their hands to draw or physically manipulate objects to create low-fidelity prototypes. With the onset of the COVID-19 pandemic, researchers have adapted co-design methods for remote settings, e.g. [88,180,340]. However, the majority of these remote methods continue to depend on co-designers' use of their hands and voice to participate. While drawing on the core concepts of co-design, I seek to push the boundaries of current methods by creating a method that does not require co-designer participants to use their hands. I also seek to create a co-design context in which individuals who use AT for communication or motor access are able to participate fully within their own timeframe, rather than the researcher's time constraints.

7.2.3.1 Adapting Co-Design for Diverse Abilities

Researchers have increasingly addressed the need to include participants with diverse abilities in co-design methods, e.g. [100,146,178,198,215]. However, adaptations to include one population do not necessitate that the method is then accessible to all populations. For example, developing co-design methods to include participants who are blind or have vision disabilities has been an area of continuing work in the HCI community, e.g. [12,39,332]. These adapted co-design methods often utilize spoken language, sounds, and tactile interactions as primary modalities for the co-design process. While the use of spoken language and sounds can also facilitate inclusion of individuals with motor disabilities, the use of tactile interactions with physical objects are barriers to inclusion. Similarly, co-design activities that rely on rapid verbal interactions within small groups might inadvertently exclude the opinions of participants with communication disabilities [161]. Individuals who have communication disabilities might benefit from the use of visual representations whereas individuals who are blind or have visual disabilities may not.

While there are some examples of techniques to adapt activities for individuals with communication disabilities, these adaptations typically involve including co-participants who do not have communication disabilities to assist with informing the design process e.g. [68,318,330]. Other common adaptations are to limit participant sizes, conduct the study over a period of time, and use a variety of methods of data collection in co-design studies. In an example of using all of these adaptations, Valencia et al. engaged in a 12-month case study co-design process which incorporated diary studies, interviews, prototyping sessions, and surveys with an AAC user and their family members [318]. In their multi-phased, co-design approach with primary school age autistic children, Wilson et al. [330] observed interactions with the children's physical objects to convey meaning and interviewed the children's teachers and therapists. Other examples include the use of technology probes and prototypes to inform iterations of those prototypes. For example, Curtis et al. first engaged with speech-language therapists and specialists in the user-design process, eliciting feedback and iterating on prototypes, and later conducted co-design focus groups with adults with aphasia with the high-fidelity prototypes [67,68]. O'Connor and colleagues also created exploratory prototypes as technology probes for an adult with complex physical and communication disabilities in a single case study [232]. These studies show how co-design adaptations have typically included co-participants without disabilities and pre-made technology probes and prototypes.

While the inclusion of non-disabled co-participants with knowledge related to the end-user group is helpful, we seek to understand how we can include the end-user as the primary co-design partner in the formative stages of co-design, rather than using ready-made probes and additional participants outside of the targeted end-user group. An example of the complexity of engaging in co-design with the end-user as primary co-design partners is from Kane et al. [159]. Kane et al. conducted a co-design study with five adults with aphasia, utilizing interviews, observations, focus groups, in addition to both low and high-fidelity prototypes over a period of six weeks. The sessions were conducted at an aphasia center, in which the research team initially presented a series of scenarios to the end-users, refining their prototype based on participants' reactions to the scenarios. When working with adults with aphasia, language, communication, and cognition may be impacted [190], which can limit the ability of participants to generate design ideas in the earliest, formative stages. Therefore, Kane et al. [159] used ready-made scenarios and technology probes as tools to engage participants. In contrast to prior co-design work with people who have aphasia, our focus is on co-design with adults who have communication disabilities or motor disabilities, and who do not have diagnosed conditions which can impact cognition or understanding of language. Rather, we seek to develop a method in which we must understand how to engage participants who use AT both for computer access and for communication, in the earliest stages of formative co-design.

In an example of early stage formative co-design activities that were adapted for people with motor and mobility disabilities, Gerling and colleagues [105] used a multi-stage co-design process with nine early teens and young adults. The multi-stage process limited the potential for participant fatigue. The researchers used "guiding questions" to encourage participants to share their interests regarding the research topic (gaming) and to ensure that the next iterations of the co-design sessions were tailored towards the participants' interests. As a result, the co-design sessions became increasingly more relevant and meaningful to participants throughout the co-design process. As part of the co-design process, participants were asked to dictate drawings to the researchers. The researchers drew sketches based on the participants' descriptions and directions. In this way, the researchers gave power and control to the participants over the drawings, while the research team merely executed the physical drawing task itself.

In designing ACD, I build upon Gerling et al.'s work, in which I expand upon the concepts of guiding questions and dictated drawings and broaden the user population to include participants with communication disabilities in addition to participants with motor and mobility disabilities. I also further expand to include participations with MMCD who use AT.

7.2.4 Addressing Relationships in Co-Design

In co-design, researchers must not only focus on adapting activities for accessibility, but also address how the design and implementation of our research impacts the relationship we build with participants. Bennett et al. emphasize the importance of considering the relationships within the contexts discussed in Ability-Based Design when designing for people who use AT [24]. Using an interdependent framing, Bennett et al. advocate that designers should consider relationships and interactions to be mutually reliant. Thus, using the framing of interdependence in design, the hierarchical nature of designer and user is rejected. The designer and the user are equally dependent on each other. Accessibility is not strictly about obtaining a linear goal but about creating a context in which everyone and everything contributes to create access.

Prior work has highlighted unintentional hierarchical practices within participatory design research, in which the researcher's agenda can dominate over participants' needs and expectations [122]. A hierarchical agenda can be communicated in a variety of ways, including through the timing and modality of the co-design sessions in which the researcher's schedule can dictate participation. Prior work has shown that flexible research approaches, such as those which include asynchronous components, can provide participants with greater agency to participate and communicate [48,196]. In fact, asynchronous research participation can outperform synchronous participation in research [3]. An example of a language-based, remote, co-design study with people with physical disabilities is from Fortune et al. [99], who used a design thinking approach with four young people with cerebral palsy and four parents. In contrast to the population we address in ACD, Fortune et al. [99] did not explicitly work with participants who required AT for computer or communication access which enabled participants to convey design ideas and feedback through both verbal and written communication methods using online post-it notes on a Miro Board.

Approaches which address psychosocial factors and context when working with AAC users are critical [184]. Consideration of all contexts throughout the end-to-end research process can foster equitable inclusion for people with a variety of disabilities and health conditions, as shown with Dewing's work with participants with dementia [77], in which multiple, deliberate, approaches were used for participant-driven informed consent.

ACD builds on the concepts of interdependence and contextual accessibility while deeply exploring how communication informs relationships and design. In the development of ACD, I created a method that is flexible for a number of different research and design agendas, and is accessible to a specific population: adults with MMCD who use AT. The population of focus also may have concomitant health conditions, such as ALS, which requires a co-design method that is not only accessible but accommodates health needs, including fatigue.

7.3 Method

The initial impetus for creating a new co-design method was based on two factors: (1) participant demographics and (2) environment. I initially planned to adapt existing co-design methods to be conducted in the homes of participants, so that they would not need to travel, incorporating some of the methods that Gerling et al. [105] and Wilson et al. [330] used in their studies. However, with the onset of the COVID-19 pandemic, the co-design sessions had to be held remotely, adding an additional constraint. Therefore, the co-design method for the study had to be flexible, adaptable, and accessible to individuals who used AT for computer and communication access. Since much of the richness of co-design sessions involve co-designers working together in real-time, I sought to find a solution that could involve real-time design, using video conferencing software.

In this section (7.3), I discuss the ACD method itself, including key constructs which guided the development and implementation of ACD. In Section 7.4, I describe ACD in-practice and the participants who piloted ACD. In Section 7.5, I provide concrete examples from the pilot study.

7.3.1 Aligned Co-Design Method Summary

ACD encompasses three separate, iterative, co-design sessions. The processes used in those three sessions consist of: (1) creating shared understanding, (2) visual summarizing, (3) asynchronous reflection, and (4) reconciliation and revision (Figure 3). In ACD, the researcher is learning and re-learning the rationale for discrete design elements in addition to the purpose of the overall design. The processes of ACD occur with an initial, synchronous session in which the participant and researcher engage in creating shared understanding and the researcher uses visual summarizing. At the conclusion of the first session, the researcher and participant engage in asynchronous reflection, and have the option to continue visual summarizing to perpetuate shared understanding. The second and final synchronous co-design session is when both co-designers reconcile any misinterpretations, amend the design based on additional reflection, and revise the design collaboratively. The final synchronous session concludes with an agreed upon final design, with the rationale of the design developed and expressed throughout the ACD process.

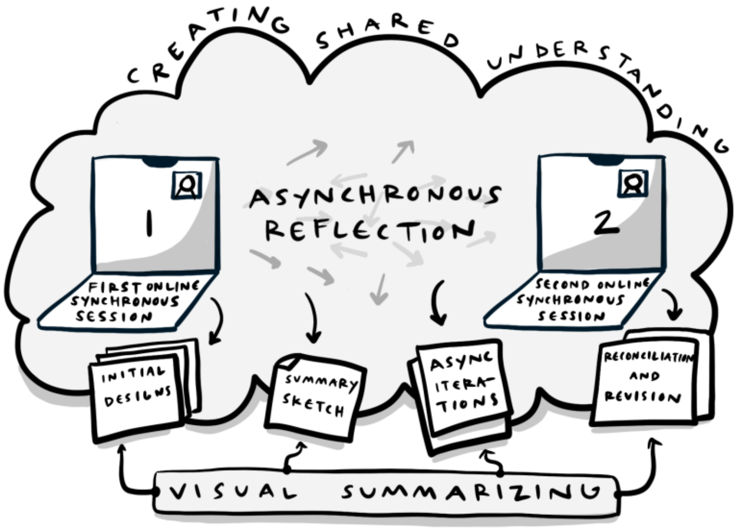


Figure 3. Sketchnote of ACD method, including the four processes held across two synchronous, remote sessions. This sketchnote was created by Beck Tench and is re-produced with their permission.

7.3.2 Key constructs in the Development of ACD

ACD was designed for the inclusion of participants with MMCD and who use assistive technologies (AT) in co-design. ACD was also designed to address the health needs of participants who have concomitant health conditions, such as Amyotrophic Lateral Sclerosis (ALS). I build on theoretical constructs and practical applications from speech-language therapy, neuroscience, communication theory, co-design, and visual thinking to inform the key constructs of ACD. These constructs should always be in the mind of the researcher during the ACD process, and by keeping these constructs in mind, the researcher and participant form an interdependent partnership in co-design that is mutually beneficial.

7.3.2.1 Power Dynamics

As discussed in the background, participatory research can be unintentionally hierarchical and have the potential to cause harm [122]. When designing with individuals who have communication disabilities, power dynamics can manifest in the speed and nature of communication interactions, inhibiting participant's abilities to fully express their ideas [161,314,317,320]. Therefore, ACD was designed to intentionally follow the participant's communication pacing. By designing for individuals with communication disabilities, ACD also accommodates the needs of individuals who may need extra time due to health needs.

I address power dynamics in ACD through the underlying structure of the method. First, ACD is held in one-to-one co-design sessions with the researcher and participant as co-designers. Using a dyadic format gives the researcher the ability to follow the participant's lead in the pacing of the co-design session. Second, ACD uses both synchronous and asynchronous sessions, which also creates an opportunity for the researcher to follow the participant's lead with the timing and pacing of the co-design process.

Finally, ACD was developed so that participants could leave the co-design research study at any time throughout the process, while still providing the researcher with useable data. Theoretically, all research studies should provide opportunities for participants to discontinue the research process at any time. ACD embeds that theoretical principle into the formation of the method, in which the researcher and participant both engage in the process as they are able. Because data collection is taken during each step of the

ACD process, and participants are given explicit opportunities throughout the process to continue to engage or disengage from the co-design research, participants have less pressure to keep up their participation if the research process is not benefitting them or causing unintentional harm. The extended asynchronous time between the two synchronous sessions, determined by the participant, not the researcher, not only provides an accessible time for the participant to engage in co-design but also provides the participant with an opportunity to take ownership of their involvement in the research study with low-cost barriers to discontinuation.

7.3.2.2 Accessibility

ACD was designed to be accessible for a specific participant population: adults with MMCD who use AT. Accessibility in this context includes a variety of factors which could impede participants' abilities to fully engage in co-design. First, ACD is designed to be physically accessible. Sessions are held remotely so participants do not need to spend time, money, or physical effort to transport themselves to a physical location, which can inhibit participation [23]. Due to the variability of AT systems which potential participants might use; it was critical for the method to rely on existing software solutions that could be compatible with various AT systems. Participants who use AT for computer access may be limited to one particular video conferencing software platform that is compatible with their technology, so it was important to ensure that the technical aspects of ACD could be used across various platforms. Therefore, the tools of ACD are unremarkable, everyday tools used for remote communication. The researcher uses video conferencing, screensharing, a slide deck, and sketching tools. The participant uses whatever forms of computer access that they typically use.

A second form of accessibility is timing. As described earlier, the pacing of the synchronous sessions are designed to follow the participant's lead. The dyadic format of ACD aids in cooperative communication turn-taking between participants with communication disabilities, particularly those who use AAC, and the researcher without extraneous time pressure [273]. The asynchronous timeframe is dictated by the participant, who chooses when they want to schedule the second synchronous session, based on their needs and priorities.

ACD uses spoken language, visual communication, and written communication forms in deliberate ways throughout the co-design process to stimulate different regions of the brain and to foster shared understanding between co-designers. This form of accessibility benefits both researcher and participant to increase their collaboration and understanding as they co-design.

7.3.2.3 Multi-Modal Communication

ACD is based on the concept that language is a socially constructed system to create shared understanding [170,302,334]. Thus, the focus of ACD is an iterative, recurring process of generating a shared understanding between co-designers which are enabled through spoken language, non-verbal communication, visual representations of concepts, and textual communication. Non-verbal forms of communication are often essential for individuals with communication disabilities who experience fatigue or who use AAC systems [17,27]. Therefore, the use of synchronous online sessions provides opportunities critical opportunities for observing non-verbal forms of communication. Synchronous sessions also provide the researcher with the ability to notice any signs of participant fatigue or hesitation during the co-design process which may not be expressed verbally.

During ACD, the use of iterative sketches reflects the collaborative idea generation between co-designers, facilitating easy and accessible ideation. ACD blends the use of drawing with a focused effort on developing a shared understanding of language, resulting in a form of visual summarizing, in which the researcher sketches in real-time during design ideation. By employing the use of drawing as a form of participatory, collaborative information transfer and co-creation ACD uses methods that are accessible to participants with motor and communication disabilities who use AT, establishing an interdependent partnership in design. In addition, the researcher collects a variety of artifacts during the co-design process, spoken, written, and visual, which provide a data trial of the rationale and iterations of the design.

7.4 ACD Method In-Practice

I present an example of ACD in practice, with descriptions of the four processes involved in ACD and examples of each process. ACD consists of three sessions: (1) synchronous, online session, (2) asynchronous reflection, and (3) synchronous, online session. During these sessions, the researcher and participant engage in four processes which build on the key constructs described earlier. These four processes are: (1) creating shared understanding, (2) visual summarizing, (3) asynchronous reflection, and (4) reflection and revision.

The examples used in this chapter are from a pilot study of the ACD method, in which the co-design topic follows with the theme of my dissertation: creativity. The pilot participants were asked to design tools to increase access to their preferred creative pursuits. In this dissertation chapter, I describe and discuss the method of ACD, rather than the results of the co-design sessions.

7.4.1 Participants

I recruited six participants to pilot the ACD method. Participants were recruited through my existing professional and research networks. Recruitment and participation in the study occurred from July 2020 through November 2020, with participation timelines directed by the participants. All participants were adults with MMCD who used assistive technologies, which included: wheelchairs, voice recognition software, eye control, adapted mice, head mouse, and speech-generating devices. One participant used AAC, AT for computer access, and AT for mobility. The other five participants used AT for mobility and computer access.

One participant identified as Asian, one as Asian/white, and four as white. Three identified as women and three as men. Participant ages ranged from 32-79. Participants were located across the United States and the United Kingdom. All participants were literate, spoke English, and did not report any diagnosed cognitive disabilities. Three of the six participants engaged in a meta-reflection of the ACD method after the co-design process concluded. The three participants who engaged in the meta-reflection of the ACD method ranged in age from 32-63, two women and one man. This study was reviewed and approved by the University of Washington IRB and all participants consented to be part of the study.

7.4.2 Method and Tools

The development of the ACD method was tested with two individuals who did not have communication or motor disabilities. The primary purpose of testing was to ensure that real-time drawing could be used with a variety of video conferencing software platforms, ensuring that I could still view the participants on-screen while drawing. Participants who use AT for computer access may be limited to one particular video conferencing software platform that is compatible with their technology, so it was important to ensure that the technical aspects of ACD could be used across various platforms. Being able to see participants on-screen while sharing screens, in particular, when drawing, was essential for observing non-verbal forms of communication. Non-verbal forms of communication are often essential for individuals with communication disabilities who experience fatigue or who use AAC systems [17,27]. Additionally, the ability to observe participants is important for noticing any signs of fatigue or hesitation during the co-design process.

Testers were asked to provide feedback on the technical aspects of the method. Minor adjustments were made to the method based on testing, including technical adjustments to the tools used for real-time drawing so that the drawings were easily visible to participants during the synchronous online sessions. I chose to use an iPad tablet and pencil, with Notability software [370] for drawing. At the time of the study, 2020, this configuration was compatible with various video conferencing software solutions, allowing me to share real-time sketching easily while simultaneously seeing the participant on-screen. The two video conferencing software options that were used with best result were Zoom and Skype.

Once the ACD study was deployed, five of the six participants completed all three sessions of the ACD method. The ACD method itself was reviewed by three of the six participants at the conclusion of the ACD sessions, responding to open-ended questions about what they thought of the method and what suggestions they had for improvement. The responses to these questions were brief, but informative. I then used thematic analysis to inform the final iterations of the ACD method [38].

7.5 Implementation of the ACD Method

The following sections describe each of the four processes used in ACD, used across three sessions (two synchronous and one asynchronous). In the examples provided, ACD was implemented in a dyadic format, with the researcher and the participant as the co-design partners. By using a dyadic format, participants are able to communicate at their own pace, without pressure to communicate quickly or in a specific manner. ACD is comprised of three separate co-design sessions. The processes used in those three sessions consist of: (1) creating shared understanding, (2) visual summarizing, (3) asynchronous reflection, and (4) reconciliation and revision. During the processes of ACD, the researcher is learning and re-learning the rationale for discrete design elements in addition to the purpose of the overall design. The processes of ACD occur with an initial, synchronous session in which the participant and researcher engage in creating shared understanding and the researcher uses visual summarizing. At the conclusion of the first session, the researcher and participant engage in asynchronous reflection, and have the option to continue visual summarizing to perpetuate shared understanding. The second and final synchronous co-design session is when both co-designers reconcile any misinterpretations, amend the design based on additional reflection, and revise the design collaboratively. The final synchronous session concludes with an agreed upon final design, with the rationale of the design developed and expressed throughout the ACD process.

7.5.1 Creating Shared Understanding

Based on the concept that language is a socially constructed system to create shared understanding [170,302,334], we begin the process of creating shared understanding during recruitment. Potential participants are directed to a webpage that provides information about the scope of the co-design study and the elements involved in participation, including the time involved in active participation in the study. The use of a webpage allows participants to take as much time as they need to access and absorb information about the study at their own pace. The inclusion of time estimates for participation is used to foster mutual understanding of the research process and dissemination process of results, which may take more time than participants might expect. It also provides an opportunity for participants to ask questions about the dissemination process of the research. In addition, email communication between potential participants and the researcher establishes shared understanding of the logistics involved with the study, such as the different choices of video conferencing software that could be used for the synchronous sessions. The time and date of the session are discussed individually with each participant through the participant’s preferred communication method (often email). The researcher accommodates the participants’ time preferences as much as possible, asking the participant what date and time of day they feel would be best for them. In this way, the researcher acknowledges that participants are experts on their energy and fatigue levels, and when they can best collaborate as co-designers. This early discussion about time creates a shared understanding between researcher and participant of both the researcher's and participant's constraints, and establishes a precedent of following the participant's lead for pacing.

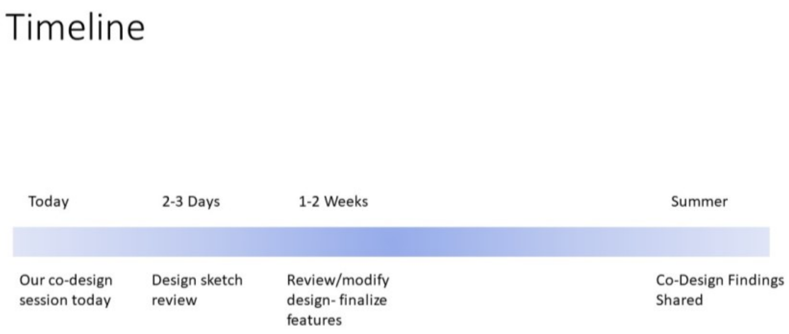
The initial synchronous session between the participant and researcher begins with explicitly checking on the communication tools and methods used for the session. The researcher closely observes and actively listens to the participant throughout these initial activities to learn the participant's communication style, language use and to begin creating a shared understanding.

Excerpt from start of Process 1 of ACD:

> Researcher: *So now I'm sharing [screen], has that messed up [AT software]?*
>
> P2: *[indicates 'no' non-verbally]*
>
> Researcher: *I'm so glad. Good. Alright, so I'm going to move forward then….[pause and observes P2 on screen]. Unfortunately, it made your video a bit smaller. But I'm assuming you're typing or resizing the screen. [long pause].*
>
> P2: *It took some adjusting but I am good now.*

In this excerpt the researcher is beginning the creating shared understanding process in the first ACD synchronous session, which involves sharing the researcher's screen. First, the researcher checks to ensure that screen sharing has not interfered with the on-screen AT software the participant uses, a common problem for individuals using AT for communication and screen sharing. Through this questioning, the researcher also reinforces their understanding of the participant's communication use: using non-verbal signals to indicate yes and no. The researcher continues to stay actively engaged in attending to the participant's non-verbal communication by observing the participant's actions. In this case, the participant appeared to be focused on an aspect of their screen rather than the screen sharing window or the researcher's speech, so the researcher paused and checked in with the participant as means of explicitly checking their assumptions that the participant was occupied with a task. The participant verifies that they were engaged in figuring out how to use their AT software with screen sharing. This interaction, though short, is critical to establishing a shared understanding of both non-verbal and verbal communication. Establishing a shared understanding of communication is essential for any collaboration but particularly essential for collaborating with individuals who use AT for communication and computer access. Because of the limited view the researcher has of the participant during the online session, participants are encouraged to express their needs throughout the entire synchronous session, such as needing to take a break.

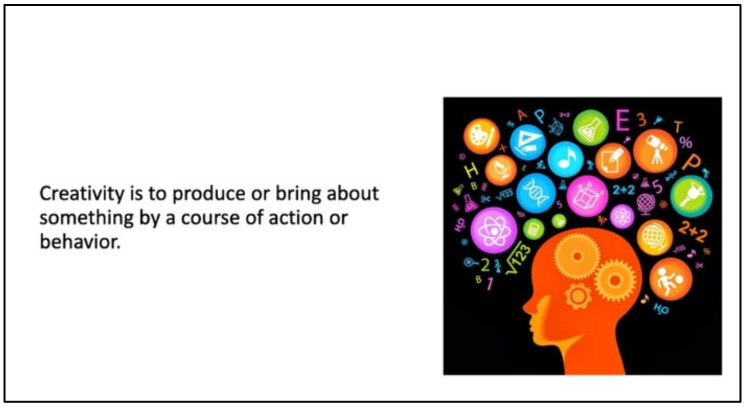
Next, the researcher shares a slide with a visual timeline of the research process. This timeline has the same information as the recruitment website, and provides an opportunity for dialog about the research process and expectations (Figure 4). Throughout the session, the researcher uses slides with visual text as well as spoken language to ensure that the participant had opportunities to engage in the manner most suited to their communication style. Each slide was limited to one question or concept, to assist with processing time and to provide focus to each concept. After the timeline slide, the researcher shares slides defining key concepts/jargon used in the research study (Figure 5). These slides assist in creating shared understanding, in which the researcher and participant are able to align their vocabulary for the co-design session. In the example study, the first author presented a slide that asked the participant/co-designer to share a creative activity they would like to engage in.



Timeline

Today	2-3 Days	1-2 Weeks	Summer
Our co-design session today	Design sketch review	Review/modify design- finalize features	Co-Design Findings Shared

Figure 4. Timeline slide of ACD process shared with participants/co-designers.



Creativity is to produce or bring about something by a course of action or behavior.

Figure 5. Example of slide defining a core concept for co-design session about accessible creative tools as part of the creating shared understanding process.

Excerpt from ACD Process 1 Transcript with P4:

> Researcher*: That's good. So as far as gardening goes, that's an interesting one to me. Because it's a different form of creativity than most people think about. But you and I had talked about it a lot [during a previous study]. How is it inaccessible to you right now? What are the barriers with gardening?*
>
> P4*: Well, you extend what you want. I would like to deadhead more easily.*

Creating shared understanding continues throughout the synchronous session in a deliberate manner, in which the researcher intentionally prompts the participant with questions designed to inform the researcher of the participant’s interests and the participant’s use of language to describe those interests. In this excerpt, the researcher and participant had previously discussed gardening, which provided the researcher with context. When the participant uses the phrase *“extend what you want”* and *“deadhead more easily,”* the researcher infers that the participant is referring to a tool used to cut off wilted flowers. The researcher will be able to confirm or amend this assumption as they enter the next process: visual summarizing.

7.5.2 Visual Summarizing

The visual summarizing process evolves naturally as a byproduct of creating shared understanding, in which the researcher begins to visualize design ideas as the participant expresses them through real-time sketching. In the previous process of creating shared understanding, participants are asked broad questions about their own interests related to the design problem. In the visual summarizing process, the guided questions are more specific about how the participant might design something to meet those interests. During the process, the researcher actively listens to participants and begins prompting participants for details through drawings that the researcher creates and shares in real-time as the participant is speaking. Because each participant's physical abilities can vary significantly, the researcher takes the lead on initial sketching based on the participant's discourse. Participants who are physically able to draw in real-time are encouraged to draw their own sketches during the ideation process as a companion to the researcher's drawings.

During the initial process of visual summarizing, the first sketches are based on the participant's answers to guided questions. Then, as the focus shifts from spoken language to a combination of spoken language and visual representations, the participant and researcher discuss and refine the concepts further. During the process of refinement, the researcher creates new sketches based on the discussion. The participant may agree or disagree with elements represented in the sketches or they might make additional suggestions. This time of co-creation and ideation is when the researcher and participant use their shared language to build on each other's ideas.

The co-creation and ideation may involve tensions between design ideas based on the co-designers' different experiences and backgrounds, but those tensions are reconciled through ongoing dialog and visual iterations of the design concept. At this time, a deep conversation regarding the rationale of design elements occurs, providing rich data for the researcher to analyze at a later time.

I continue sharing the example of P4, who earlier provided context for their design by stating that they would like to *"deadhead more easily".* After the initial response from the participant, the researcher changed screen sharing to share the image of a blank Notability canvas [370], and the researcher began to sketch based on the participant's response using an iPad and Apple Pencil. During the sketching process, the researcher and participant focused their communication to refine the initial sketch drawn by the researcher. Through this technique, the researcher and participant use the shared language established during the shared understanding process to discuss the nuances of the design concept more easily.

Excerpt from ACD Process 2:

> Researcher: *Ok, so here are the scissors and I assume you need a handle, do you want fingerholes?*
>
> P4*: yeah, I don't even think you need that because they would do it themselves.*
>
> Researcher*: Oh! Ok, so maybe you would just have one handle. [starts new drawing of blades of scissors only]*
>
> Researcher: *Ok, they open and shut themselves so these are the scissors, but they need a handle, do you have a straight handle?*
>
> P4*: Yeah, a straight handle.*
>
> Researcher: *Ok. Awesome. So then you just have a handle here. Does it matter to you, like the grip, if it's thicker or… [draws straight line out from blades]*
>
> P4*: Yeah, something quite large and with maybe a silicon handle that is grip-able. I mean, you don't want to accidentally drop this on your toes.*
>
> Researcher: *Does it matter or does it help you to have some sort of texture?*
>
> P4: *I think for knives and things I just use a silicon handle…*
>
> Researcher: *Nice. Nice. Ok, so ….. [draws larger handle and writes notes by design]*
>
> P4: *The other thing that is an important aspect of any design is that you want it to look nice.*

The researcher used a combination of written words and visual sketches to capture the ideas shared by the participant/co-designer. Together, the words and visuals helped the researcher and participant see any discrepancies between their understanding in real-time and could use language to refine ideas and come to a common understanding. In this excerpt, we see that the word *"scissors"* created different images for both the researcher and participant. This discrepancy was visualized in the real-time drawing created by the researcher (Figure 6). For the researcher, the term scissors referenced hand-held instruments used in cutting paper or fabric, whereas for the participant, scissors denoted garden shears. In this example, we see how the word scissors holds different conceptual meanings for both co-designers, highlighting how active visual summarizing enhanced shared understanding of the vocabulary being used.

Through ongoing questioning regarding the design's elements, the participant corrected the researcher's misinterpretation (Figure 7). With visual summarizing as well as written text and drawings, participant and researcher form a shared understanding of the design.

Figure 6. Initial sketch of scissors based on researcher's interpretation of the word "scissors."

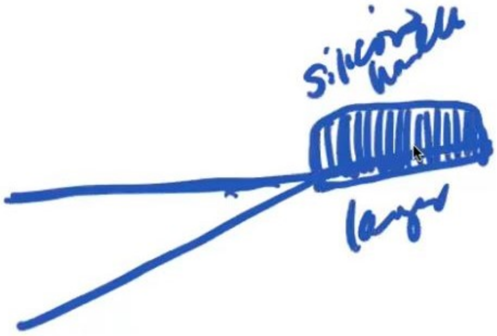


Figure 7. Revised sketch of scissors after re-establishing shared understanding.

As the ideation process continues, the researcher and participant come to a mutual understanding of the design concept. At the conclusion of the first synchronous session, the researcher returns to the timeline slide to summarize what they had accomplished and what the next steps are for the co-design process. The researcher asks the participant for their preferences regarding logistics and timing for the upcoming processes of the co-design study, including what file types are most accessible for the participant for a final visual summary. The session concludes with an agreement for the next steps based on the participant's preferences, and with the researcher committing to sharing the final visual summary from their synchronous design session with the participant in the asynchronous manner of the participant's choice (via email or a shared folder/drive).

After the conclusion of the synchronous ACD session, the researcher reviews the iterative drawings and creates a visual summary of the final design concept. The researcher includes written text to support the sketches, highlighting key concepts generated in the synchronous session (Figure 8). By taking time after the synchronous portion of ACD to reflect on the design, the researcher can deliberately highlight the concepts they interpreted as important, using colors, visuals, and text. The exercise of creating the summary is a means for the researcher to synthesize the information and engage in reflexivity. The summary also documents the research data and provides a form of member-checking with the participant for the next process of ACD.

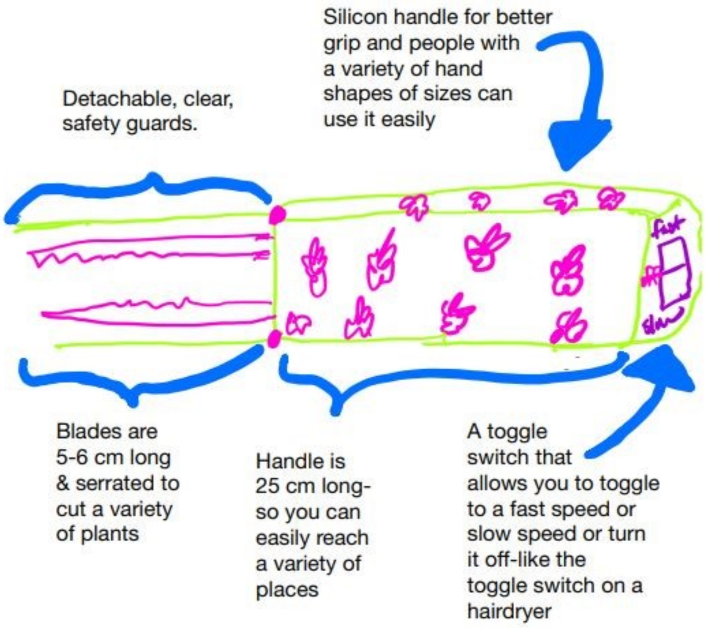


Figure 8. Summary sketch after first synchronous co-design session with P4 after multiple iterations.

7.5.3 Asynchronous Reflection

The focus of the asynchronous reflection is to allow participants to reflect and iterate on the design process in the way that is most accessible and easiest for them. The researcher shares concept sketches and brief, written summaries of the designs created with the participant within three days of the synchronous session, while the session is fresh in the co-designers' minds. Participants are asked to reflect on the sketches and to send the researcher any further ideas they have on the design concept. Participants are encouraged to use a variety of digital formats to provide feedback: their own sketches, images, videos, and/or written text. This reflection process incorporates member-checking [17,149] midway through the co-design process in a way that allows both the participant and researcher to take time to reflect on the design.

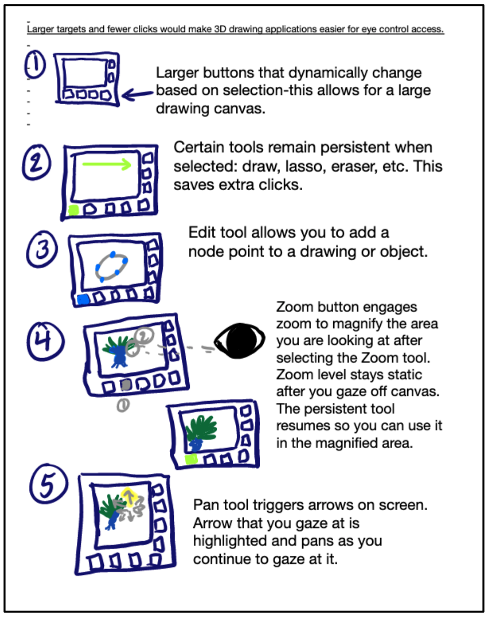
During asynchronous reflection, participants are also able to reflect on their participation in the research process itself. Providing this time for reflection can serve as an additional check for participants who might have extenuating circumstances that make ongoing participation a challenge. Near the conclusion of the asynchronous reflection process, the researcher contacts the participant to confirm that the participant would like to meet again for the second and final synchronous session. At this time, the researcher intentionally provides an opportunity for the participant to opt-out of continuing in the study, without any penalty to the participant. By providing this time for reflection, participants have the option to discontinue the study without feeling pressure from the research team.

In one example, P2 opted not to continue with the study during the asynchronous reflection process based on their health. The energy required for the participant to continue with the ACD study was energy that the participant wanted to put towards engaging with their family instead. By having the asynchronous reflection time built into the co-design process, the participant was able to reflect and make their choice to discontinue their participation in the study without the pressure of being online, or in-person, with the power dynamics of a researcher present.

Even with P2 discontinuing the co-design process, the participant's contribution to the research in the first synchronous session was acknowledged and utilized by the researcher. The participant was able to discontinue the study based on their needs, while still having made a notable contribution to the data set for the study.

In another example of the asynchronous reflection process, which highlights the importance of checking with participants on file types that are accessible with their AT, P3 had the ability to directly open and edit a PDF. The researcher sent the co-design summary from the first synchronous session in PDF format. The participant edited the PDF and emailed it back to the researcher, adding both written comments and copied/pasted images. In this way, the participant was able to build on the initial co-design work and clarify concepts that they felt were important directly in a shared document. Importantly, the participant did not have a tight time constraint in which they needed to share their ideas. The flexible asynchronous reflection process provided enough time for the participant to use their AT system to access the PDF and make the changes they wanted.

The summary visualization and asynchronous reflection process served both as a form of member-checking as well as a platform for further design development. Figure 9 shows the original summary generated by the researcher after the synchronous co-design session, which was shared at the beginning of the asynchronous reflection process. Figures 10 shows a page of the edited summary generated by the participant during the asynchronous reflection process that was shared back to the researcher before the start of the final synchronous session.


Larger targets and fewer clicks would make 3D drawing applications easier for eye control access.

① Larger buttons that dynamically change based on selection-this allows for a large drawing canvas.

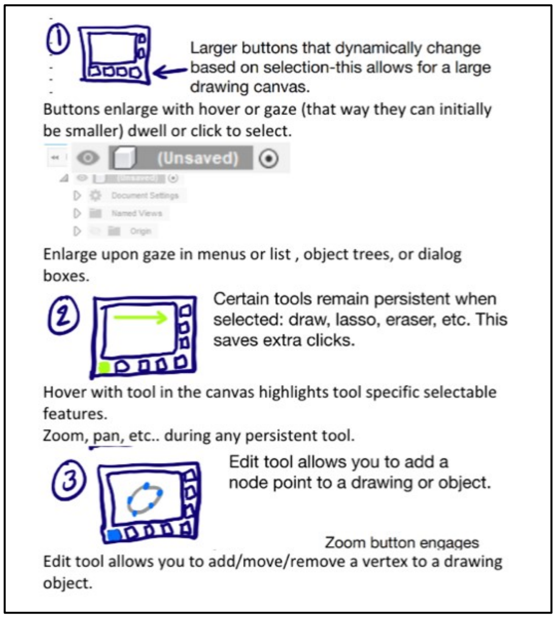
② Certain tools remain persistent when selected: draw, lasso, eraser, etc. This saves extra clicks.

③ Edit tool allows you to add a node point to a drawing or object.

④ Zoom button engages zoom to magnify the area you are looking at after selecting the Zoom tool. Zoom level stays static after you gaze off canvas. The persistent tool resumes so you can use it in the magnified area.

⑤ Pan tool triggers arrows on screen. Arrow that you gaze at is highlighted and pans as you continue to gaze at it.

Figure 9. Visualization summary sent to P3 at start of asynchronous process.


① Larger buttons that dynamically change based on selection-this allows for a large drawing canvas.

Buttons enlarge with hover or gaze (that way they can initially be smaller) dwell or click to select.

Enlarge upon gaze in menus or list , object trees, or dialog boxes.

② Certain tools remain persistent when selected: draw, lasso, eraser, etc. This saves extra clicks.

Hover with tool in the canvas highlights tool specific selectable features.

Zoom, pan, etc.. during any persistent tool.

③ Edit tool allows you to add a node point to a drawing or object.

Zoom button engages

Edit tool allows you to add/move/remove a vertex to a drawing object.

Figure 10. First page of summary edited by P3 during asynchronous phase with pasted image.

7.5.4 Reconciliation and Revision

The final process of ACD revises and reconciles the asynchronous reflection with the initial visual summaries. A second online, synchronous session is held with participants in which the researcher and participant review the initial design concept, the problem it was trying to solve, and the asynchronous reflections. This final process incorporates principles of positive design in which we address the subjective well-being of people who might use the design [75]. The focus of the session is for the researcher to understand the participant's perspective on how the design might impact them, and others, and how this impact is reflected in specific elements of the design concept.

Just as with the first synchronous session, both visual, textual, and verbal information is conveyed to accommodate a variety of abilities. At the beginning of the session, the researcher shares an outline of what to expect during the session, using visuals and text, following the principles of creating shared understanding. During this second synchronous session, participants who reviewed the design summary but who were unable to submit any feedback during the asynchronous reflection process (either due to accessibility issues, time constraints, or other barriers) are able to continue iterating on the design, with the researcher responding to the participant's feedback in real-time through screensharing and sketching.

During reconciliation and revision, the researcher uses the following guiding questions to understand the participant's perspective on the design: (1) what benefits will this design provide, (2) what are the essential features of the design, and (3) who might use this? The final output from ACD reflects the answers to these questions. The researcher and participant continue to iterate on the design, as appropriate, based on the responses to the questions. The design iterations conclude when the participant feels satisfied with the final concept sketch after responding to the guided questions.

Five of the six participants engaged in the reconciliation and revision process. In one example, P6 had emailed the researcher with edits to the initial visual summary PDF during the asynchronous reflection stage. The edits involved re-organizing visual and textual elements from the researcher's visual summary from the first synchronous session with additional textual information regarding access methods. After receiving the edited PDF summary during the asynchronous reflection process, the researcher was unsure if they were interpreting the edited text correctly. Therefore, during the final synchronous session, the researcher and participant collaborated to create shared understanding regarding the design features. The researcher used visual summarizing on the collaborative PDF document in real time to ensure that the participant and researcher were aligned in their interpretation of the design elements (Figure 11).

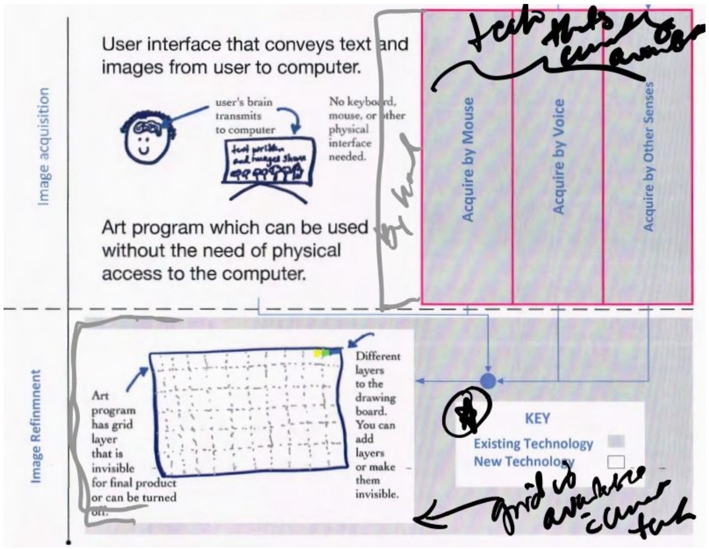


Figure 11. Reconciled design with P6 during final synchronous session.

In another example, in preparation for the final synchronous session, the researcher took P5's textual feedback from the asynchronous process, and used a screenshot of an existing desk to visualize P5's text-based reflections on the design. This provided both co-designers with a visual medium to reconcile any misinterpretations the researcher might have and to revise the final design features (Figure 12). In this way, the reconciliation and revision process incorporate earlier processes: creating shared understanding, visual summarizing, and asynchronous reflection.

The reconciliation and revision process concludes by revisiting the timeline that was shared in the first synchronous session. The researcher discusses the anticipated timeline for sharing the results of the co-design research and provides any updates to the timeline that may have occurred since the first session with the participant. In this way, the researcher is transparent with participants about their contribution to the research study and aligns expectations for when the results of their co-design work might be shared. The timeline provides another opportunity for the participant to ask about the research and also provides the researcher with an opportunity to explicitly recognize and celebrate the participant's contribution to the research process.

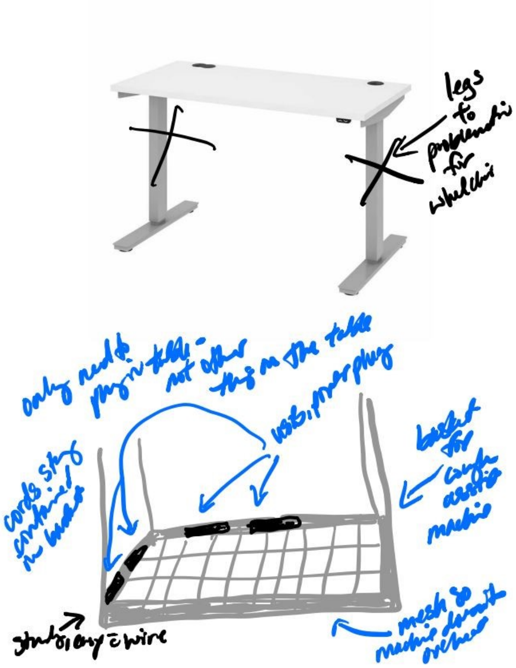


Figure 12. Reconciled design features with P5 incorporating screenshot and visual summary.

7.6 Participants' Meta-Reflections on the Method

As part of the process of trialing a new co-design method, participants were asked to share their feedback on the ACD processes, and provide suggestions for improvement. These reflections occurred at the conclusion of the final synchronous session and were brief conversations between the researcher and participant in which the researcher asked the participant to provide feedback regarding the process. Three participants (P1, P3, and P4) engaged in this reflexive process with the researcher on the ACD method.

All three participants indicated that they found ACD to be a positive experience, emphasizing the benefits of having co-designers with different backgrounds partner together. P1 stated: *"Creativity can't exist in a sterile environment. You need somebody else to bounce the ideas off of and look at things from a different light. You and I are going to have different perspectives on everything just because of who we are. So, for us to bring all of our different experiences to this idea and see it in different lights, it's been a blast."*

Participants reflected on how the initial processes in the first synchronous session (creating shared understanding and visual summarizing) impacted the types of designs they generated. The openness of these processes enabled the researcher to intentionally follow each participant's specific interests and ideas. However, P1 explained: *"It took me a while during our first session to get it through my head that literally anything goes. Because I was trying to think within the limits of existing technology, but that's not what this project is about. So it took me a little while to get past that and once I did, I think we created something amazing."*

P3 reflected on the merits of the co-design process itself within the bounds of technology development, stating: *"The type of collaboration between the researcher, between the developer, and the users…is really the only way to really, really [sic] fine tune usability."* P3's reflection on participating in ACD focused on the outcomes of the co-design process and the role of users in technology development. P3 explained: *"If the ideas were picked up by a developer and they wanted to develop [the idea], I think the ideal would be to go back to the co-designer and say, 'Hey, we like your ideas, would you like to expand on those ideas [and] work with our developer?' Then we get that sense of purpose and satisfaction [to] accomplish something."*

While the original intention of including the meta-reflection process was to learn about participants' reactions to the ACD method, the resulting discussions provided an opportunity for frank discussion about HCI research, participation, and dissemination, which I expand upon in the discussion section below. The meta-reflection also provided an opportunity for closure and celebration of the ACD process. Based on the participants' reflections, the final synchronous session now includes an opportunity for reflexivity and open discussion of the research process, analysis, and dissemination.

7.7 Discussion

The development of the ACD method was borne out of necessity, due to the COVID-19 pandemic. In-person co-design sessions were impossible, particularly when working with people who had significant health concerns. ACD provides an opportunity for participants with diverse abilities to engage in co-design. ACD is a temporally flexible method, expanding on Friedman and Yoo's concept of *"pause"* [101] by introducing explicit participant-led pausing. The incorporation of the timeline, the explicit invitations to take breaks as needed during the synchronous session, the asynchronous reflection, and the participant-led timing of the second synchronous session are designed to equalize the power-balance between researcher and participant. Ensuring that participants feel comfortable in continuing with their participation is particularly important for marginalized populations so that they do not feel they are being used to promote the researcher's agenda [10,122].

The resulting ACD method is not only accessible to the target population, but as a method, it provides extremely rich data. Through ACD, the rationale for each element of a design is discussed at length throughout the process of co-design, leaving a trail of design rationale as the co-design process evolves. Through the interdependent partnership and the four processes of ACD, the researcher has intimate knowledge of the motivations behind each element of the design.

7.7.1 Discussing next steps and anticipated outcomes of research as interdependent co-designers

Prior work has highlighted the potential for a mismatch between researcher expectations and participant expectations for the outcomes of the research process [10,122,229]. As P1 pointed out, participants' understanding of the co-design process is influenced at the start of the co-design session. Based on participant feedback, researchers employing the ACD method should explicitly address the expectations and constraints (or lack of constraints) in the co-design process.

As a result, ACD was modified to include an explicit explanation of the co-design process and where the researcher positions their study within that process. Drawing on Sanders and Stappers' concept of the co-design process, the researcher includes a visual of the process at the start of the first synchronous session and positions the study within that process [272]. In the case of the pilot study described in this chapter, I positioned the study entirely within the *"fuzzy front end,"* as an exploratory study [272].

The graphic from Sanders and Stappers' [272:6] provides dedicated time to discuss the research study, thereby incorporating visuals, text, and words to enhance shared understanding of expectations. The ACD method now incorporates the timeline slide after introducing the co-design process graphic and at the end of the co-design sessions. These slides provide a platform for the researcher and participant to have a frank conversation about anticipated outcomes and the time and processes involved in dissemination of research, increasing transparency of the larger research design process.

7.7.2 Towards Expanding the Use of Aligned Co-Design

In the meta-reflection, P1 described how creativity inherently needed to be collaborative, stating that creativity *“can’t exist in a sterile environment.”* P1’s comments mirror Sanders and Stappers’ description of co-design as *“creating new domains of collective creativity”* [272]. With the development of ACD, we build on creating new domains of collective creativity by expanding the diversity of participants who *can* participate in co-design. The participant population who took part in the study were comprised of people who had diverse motor, speech, and accessibility profiles, all of whom used AT. I propose that ACD could be extended further to be used with an even broader participant population. The design of ACD, with the use of visual summarizing and emphasis on creating a shared understanding, as well as the flexibility of participant-controlled scheduling of sessions, lends itself towards other populations who may not otherwise be able to attend in-person or group co-design sessions. ACD is conducted in a 1:1 setting, which may open co-design up to populations who have difficulty in group settings either because of abilities, logistical feasibility, or health concerns.

The development of ACD connects to a broader, ongoing discussion across HCI that is considering how to develop and sustain longer term relationships for co-designing which mutually benefit both researchers and participants, as in the case of designing with children [82,136,345] and people who have disabilities [100,131,324]. With the ACD method, I offer a first step towards finding workable ways for negotiating time commitments that are flexible and participant-led to ensure that technologies can be respectfully designed with diverse populations.

7.7.3 Challenges in HCI participant involvement: what happens after co-design?

With the development of ACD, I challenge technology designers and developers to think about how individuals are included in the research and development process. Drawing on P3’s comments about the need for engagement with end-users when a design idea is expanded upon for development, I suggest two challenges for the HCI community to discuss and debate. These challenges complement the findings from Chapters 4 and 6, in which I demonstrate the lack of discoverability of information to be a key problem for adults with MMCD who use AT. Based on P3’s comments in this chapter, we see how, once again, discoverability of information is an unmet need for individuals with MMCD who use AT.

Challenge 1: “If the ideas were picked up by a developer and they wanted to develop [the idea], I think the ideal would be to go back to the co-designer and say, ‘Hey, we like your ideas, would you like to expand on those ideas [and] work with our developer?’ (P3). P3’s comments pushes the discussion on equitable participatory design [122] towards considering how participants are involved in development after design. The HCI community has an opportunity to expand approaches such as Ability-Based Design [337] and interdependence [24] from the act of design to the act of development and testing. HCI has excellent examples of individuals with motor and communication disabilities providing feedback in the prototyping phase of the design process, e.g. [160,222]. However, P3 challenges us to think about how we can create systems in which participants learn about the outcomes of the research designs, particularly when designs are iterated on in further research and development. A challenge to the HCI community is: how can we create a system for participants to learn about the end-results of their participation? Or, conversely, how might we help developers engage end-users with disabilities in testing and providing feedback during development?

Challenge 2: While the discussion around the first challenge will likely require time to resolve, I address a short-term challenge for the HCI research community. P3’s comments highlight the desire research participants have: to know what will happen with the research. I challenge the research community to explicitly tell participants what the anticipated outcomes are of the research process. I do not suggest that researchers state the anticipated findings, but what possible outcomes may result. A publication?, a prototype?, a class presentation?, informing policymakers?, or something else? As researchers, let us be clear about our intentions with the research study we are conducting and talk about it more than once with participants. Assuming it does not harm the study procedures, I challenge HCI researchers to reveal their research intentions up front and to include these protentional types of research outputs in the procedures described in their study. I challenge researchers to discuss projected output both at the beginning and at the end of their studies, and to invite discussion. Participants may have ideas of impactful forms of sharing research that the researcher has not considered. It could be argued that this challenge is best practice, but it could also be argued that this does not happen regularly in the HCI community. I challenge the HCI community to discuss what we actually do in reality compared with what we should do to increase transparency.

The challenges I pose build on previous chapters from this dissertation, using P3's comments as a prism to focus challenges specific to research and design in HCI. In Chapter 4, I demonstrated how adults who acquire disabilities mid-career continue to seek for something to stay actively engaged and to contribute to society. Challenge 1 provides one solution to this unmet need: recruiting individuals with disabilities as co-designers and testers. Challenge 2 builds on the findings from Chapter 6, in which I show that a lack of discoverable information ultimately impacts quality of life. Challenge 2 expands the need for discoverable and accessible information to making HCI research, in general, more accessible and discoverable to participants.

7.7.4 Limitations and Future Work

There are a number of limitations to the ACD method. ACD was designed for a specific participant population: adults with motor and communication disabilities. ACD, as currently designed, might not be appropriate for some participants. One limitation is that the ACD process requires that co-designers are able to read and are sighted. Alternatives need to be explored to include participants who are blind or have low-vision. Further iterations of the ACD method could be designed to include participants who are not able to easily read by increasing the use of drawing and visual representations of concepts during the ACD process, which might also be a viable option for including young children as participants. Another limitation of ACD is that participants must have access to technology (computer and internet access). Potential accommodations for outreach to populations who might not typically have access to reliable internet could include partnerships with public libraries to reserve computer stations for ACD sessions, but this needs to be investigated further.

7.8 Contribution

In this chapter, I presented the Aligned Co-Design Method (ACD). I described the development of the method, provide examples of the method in practice, and discuss refinements to the method based on analysis of participant feedback. I also build on concepts presented in Chapters 4 and 6, and discuss challenges to the HCI community to improve discoverability of information and increase involvement of participants with MMCD who use AT.

I contribute to the fields of HCI and Rehabilitation Science by providing evidence of an accessible co-design method. I also contribute to the field of HCI by presenting challenges to researchers, to increase discoverability of information and inclusion of adults with MMCD who use AT.

In the next chapter, I conclude this dissertation with a discussion of the collective findings from my thesis. I broaden the discussions from previous chapters and build a theoretical framing of creativity, accessibility, and quality of life.

Chapter 8. Discussion and Conclusion

In this final chapter, I briefly summarize prior chapters and my findings. I then demonstrate how those findings build toward the development of a theory of creativity, accessibility, and quality of life. I then describe how I answered each of the research questions that were introduced in Chapter 1. I conclude with a summary of my contributions, discussion of limitations of this work, and suggestions for future research.

The aim of this dissertation was to address an under-explored topic within a specific population: creativity, identity, and quality of life of adults who acquired mobility, motor, and/or communication disabilities (MMCD) and who use assistive technologies (AT). Using a constructivist grounded theory method as a foundation, I conducted qualitative studies in which I explored different perspectives of quality of life. I also engaged in methodological queries to best engage with adults with MMCD who use AT.

8.1 Summary of Prior Chapters

Creativity is a Fundamental Human Need. In Chapter 2, I summarized background and related work. I discussed how Max-Neef includes both *"creation"* and *"identity"* as fundamental human needs **[86,204]** and how creative engagement has positively influenced identity in adults with chronic health conditions **[258]** and the health of older adults **[57]**. In Chapter 3, I describe my methodological positionality within a Constructivist Grounded Theory Method **[52]**.

Adults Experience Loss and Identity Change After Acquiring a Disability Mid-Career. In Chapter 4, I discuss the employment experiences of adults who acquired disabilities with MMCD and use AT. I conducted seven semi-structured interviews, and based on the analysis of interview data, I then deployed a survey to six participants. Findings showed that participants felt loss, regret, and an identity change after acquiring their disability. Participants wanted to do something after leaving work, but were unsure of the options available. Findings also showed that the act of presenting information about accessible work alternatives can change a participant's attitude regarding accessible work alternatives: learning about accessible work alternatives can increase receptivity to exploring accessible work alternatives.

Qualitative Research with AAC Participants Must Be Flexible. After completing the interview study in Chapter 4, I sought to better understand best practices for qualitative research with people who use AAC and discovered a lack of peer reviewed methodological best practices. Building on the methods used in Chapter 4, I conducted an extensive literature review to discover best practices of qualitative research with adults who use AAC. I developed a framework of qualitative research methods for participants who use AAC. I highlight the importance of using flexible, adaptive research methods with AAC participants. Member-checking with AAC users is critical to provide participants with the time needed to fully express themselves in their own time. I also call for further exploration on accessible asynchronous research methods which can adapt to participants' needs and abilities.

Identity Reconfiguration Through Accessible Creativity Can Positively Impact Quality of Life. Building on the identified need established in Chapter 4, and using methods from Chapter 5, I sought to find "Creative Models": adults who engaged in creative pursuits after acquiring MMCD. In Chapter 6, Creative Models, I explored the experiences of seven adults with MMCD who used AT and who engaged in creative pursuits after acquiring their disabilities. Findings revealed that the discovery of accessible creative pursuits is a gating factor to creative engagement which, in-turn, is a catalyst for identity change. I expand on prior work **[258]** and describe a cyclical identity change model which demonstrates the interdependence between discoverability, technology, creativity, and identity. I discuss how sharing expertise in accessible creativity and sharing the stories of creative models are critical to increasing discoverability of accessible creative pursuits.

Making Co-Design More Accessible. Chapter 7 consists of my second methodological contribution. In Chapter 7, I conducted a study on designing accessible creative tools using a new co-design method: Aligned Co-Design (ACD). I discuss the novel method in-depth, using examples to describe each of the four processes of ACD. The examples include co-designs related to the topic of this thesis: designing accessible tools for creative pursuits. Building on concepts from Chapters 4, 6, and 7, I challenge researchers to consider ways to involve participants further in the design and development of technologies and to make research findings more discoverable.

8.2 Discussion

This dissertation lays the foundation to develop a theory of acquired disability, creativity, identity, and quality of life. Building on the studies discussed in previous chapters and on Max-Neef's matrix of fundamental human needs, I propose a conceptual model of creativity, identity, accessibility, and quality of life.

8.2.1 Access to Creative Technologies is a Fundamental Need for Adults who Use AT

Max-Neef's matrix describes fundamental needs in terms of needs and satisfiers (Table 12) [205]. The needs are described as *"invariant"* while the satisfiers are listed under conceptual principles: being (qualities), having (things), doing (actions), and interacting (settings) [118,205,291]. Concepts that are listed as potential satisfiers can change based on an individual's traditions and norms [86,205]. For example, *"identity"* is a fundamental need. The satisfier of *"Having (things)"* for the need of *"identity"* includes the concepts: *"Symbols, language, religion, values, work, customs, norms, habits, historical memory."* The specific items within that satisfier, such as symbols and language, can change based an individual's traditions and norms. However, **the findings described earlier in this dissertation demonstrate that participants were unable to *"have"* those *"things"* until the things became accessible to their unique abilities.**

Table 12. Max-Neef's Matrix of Fundamental Human Needs (abridged).

Needs	**Satisfiers**			
	Being (qualities)	**Having (things)**	**Doing (actions)**	**Interacting (settings)**
Creation	Imagination, boldness, curiosity, inventiveness, autonomy, determination	Skills, work, abilities, method, techniques	Invent, build, design, work, compose, interpret	Spaces for expression, workshops, audiences, cultural group, temporal freedom
Identity	Sense of belonging, self-esteem, consistency, differentiation, assertiveness	Symbols, language, religion, values, work, customs, norms, habits, historical memory, sexuality, reference groups, work	Get to know oneself, grow, commit oneself, recognize oneself	Places one belongs to, everyday settings, maturation stages, social rhythms

The studies described in this dissertation discussed, in-depth, two fundamental needs within Max-Neef's matrix: identity and creation. As discussed in Chapters 3 and 4, limited knowledge of accessible options available inherently suppresses access to creative pursuits, perhaps as much as any physical limitations. Therefore, a **theory that describes creativity, identity, and acquired disability MUST also address the accessibility of information as well as accessibility to the tools involved in creation.**

Based on the findings described in this dissertation, **accessibility is an overarching gatekeeper to the fundamental needs of identity and creation for adults with MMCD who use AT.** In keeping with the terminology style Max-Neef used to describe satisfiers, in which satisfiers are described as conceptual concepts with a parenthetical, **I propose an additional satisfier in Max-Neef's matrix of fundamental human needs: accessing (tools).**

While it might be argued that accessibility (accessing) is implied in Max-Neef's matrix of fundamental human needs, the counter-argument is that accessibility is, in fact, merely implied, rather than stated outright. As described in Chapter 4, participants may have some of the necessary satisfiers for creation (being, having, doing, and interacting) but they lacked the ability to truly access the *"things"* needed to engage in creativity.

For example, within the need of *"creation"* (Table 12) a person may hold the satisfiers and goods of *"being"* (e.g. imagination), and *"having"* (e.g. skills). However, the satisfiers of *"doing"* (e.g. design) and *"interacting"* (e.g. spaces for expression) can be blocked if those satisfiers are inaccessible. Moreover, accessibility could also impact aspects of *"having"* (e.g. techniques). The work in this dissertation shows that without the ability to access, satisfiers and needs are unmet. Therefore, access must be an additional satisfier in order to meet the fundamental needs described in Max-Neef's matrix.

Within the context of the population described in this dissertation, I add *"accessing"* as a satisfier to fundamental human needs (Table 13). Accessing as a satisfier can change based on an individual's traditions, norms, and abilities in a similar way to Max-Neef's existing satisfiers (being, having, doing, and interacting). To describe the satisfier of accessing, I use the word *"tools,"* drawing from Zabala's AAC assessment framework [350]. Zabala's framework for AAC assessment uses the concepts of Setting, Environment, Technology and Tools (SETT) as fundamental influencers on AAC use [350]. Tools for AT can include a wide-range of technologies, both high-tech and low-tech. In the context of Max-Neef's matrix, I use the phrase *"tools"* in a broader sense than Zabala, in which I follow Max-Neef's precedent of using satisfiers as a means to describe principles, rather than material elements [86,205,291]. The inclusion of *"accessing (tools)"* as an independent satisfier explicitly shows that fundamental needs cannot be met without individualized access to those needs.

Table 13. Matrix of accessible fundamental human needs.[9]

Needs	**Satisfiers**				
	Being (qualities)	**Having (things)**	**Doing (actions)**	**Interacting (settings)**	**Accessing (tools)**
Creation	Imagination, boldness, curiosity, inventiveness, autonomy, determination	Skills, work, abilities, method, techniques	Invent, build, design, work, compose, interpret	Spaces for expression, workshops, audiences, cultural groups	Knowledge and choice of forms of communication and expression, creative pursuits, technologies, tools
Identity	Sense of belonging, self-esteem, consistency	Symbols, language, religion, values, work, customs, norms, habits, historical memory	Get to know oneself, grow, commit oneself, recognize oneself	Places one belongs to, everyday settings, maturation stages	Independent access to tools for expressing oneself as desired

8.2.2 Accessibility to Creative Pursuits Is Necessary for Quality of Life

Based on the findings described in earlier chapters of this dissertation, I argue that **creative pursuits are a viable alternative to work when re-forming a positive identity** for adults with acquired disabilities who use AT after the loss of their career-identity. The range of creative pursuits are vast and varied. In Chapter 4, I described how individuals who engaged in a variety of creative pursuits follow a similar identity change cycle after discovering accessible creative pursuits. This **change cycle is not dependent on the type of creative pursuit**; however, the change cycle **is dependent on the accessibility** of an individual's chosen creative pursuit. For individuals with progressive conditions, their identity change will

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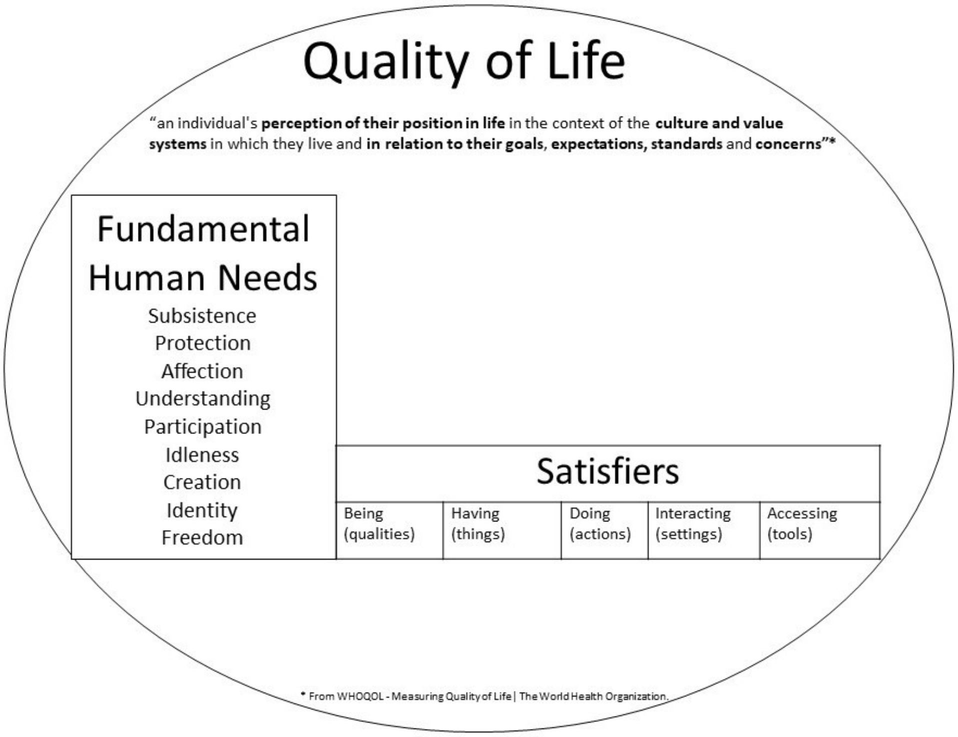
[9] The accessible matrix of fundamental human needs is derived from the findings of this dissertation. While the tools described with the needs of *"creation"* and *"identity"* are the only concepts based on the findings in this dissertation, other accessible tools described in this matrix would need to be explored more fully in future research and are listed only as possible tools for fundamental needs.

continue to cycle as their abilities change and accessibility to creative pursuits change. Therefore, **accessibility to creative pursuits is critical in forming a positive identity.**

A positive identity can be connected to quality of life. The World Health Organization defines quality of life as *“an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”* [362]. In this dissertation, I used an emic perspective to understand individual’s perceptions of their positions in life, their values, and how creativity influenced their goals, expectations, and standards of living. In Chapters 4 and 6, I demonstrate how participants felt a loss regarding their perception of their position in life in relation to their goals and expectations, after acquiring their disabilities. Moreover, in Chapter 6 I demonstrated that the ability to engage in creative pursuits positively influenced participants’ perceptions of their positions in life by improving their perceived relationships with others, physical and mental health, and identities. Accessibility to creative pursuits can improve perceived quality of life. Max-Neef’s fundamental human needs and satisfiers have been described in terms of what is needed for a good life [291], which can be framed within the WHO’s definition of quality of life. Figure 13 shows how fundamental human needs and their satisfiers lie within the definition of quality of life and thereby contribute to an individual’s perceived quality of life.



* From WHOQOL - Measuring Quality of Life | The World Health Organization.

Figure 13. Quality of Life Comprises Fundamental Human Needs and Satisfiers.

As a result of the work in this dissertation, I submit that access to creative pursuits is a fundamental human need which, in turn, directly impacts quality of life. As discussed in Chapter 6, active creative engagement positively impacts social connections, health, and identity. Based on the findings from Chapter 6, the benefits of engaging in accessible creative pursuits is, in part, related to the work involved in perfecting creative skills which involve problem solving and active mental engagement.

8.2.3 The Future of Accessible Creative Pursuits with the Advent of Generative AI

While the research conducted for this dissertation largely took place prior to generative AI becoming ubiquitous, it is worth briefly discussing the findings of this dissertation within the context of AI. The results of this dissertation highlight the importance engagement in creative pursuits has on perceptions of quality of life. While one might think that generative AI can help facilitate increased creative engagement, it is worth noting that the findings in this dissertation indicate that engaging in the creative process itself promotes positive identity changes. The findings in Chapter 6 indicate that benefits of engaging in creativity are related to the effort involved in honing creative skills. For example, Alex indicated that learning to improve his gameplay improved his physical and mental health because of the time put into practice. Alex's motivation was to become good enough to beat other players. Time, effort, and flow are inherent aspects to engaging in creativity [66]. In Chapter 6, Lucy A. and Reuben discussed how the time spent in the flow of creative pursuits helped with pain management precisely because of the time and effort involved in creative pursuits. We may assume that the participants interviewed in Chapter 6 may have had different experiences and perceptions of self if they did not have to engage in problem solving and practice to overcome barriers. I suggest that developers of AI systems for creative applications consider if AI is enhancing the creative experience or if AI is replacing the creative experience.

Using AI to generate a creative visual product can be beneficial in certain use cases, but is unlikely to provide the same depth of changes to quality of life that were found in Chapter 6. Similarly, the proliferation of AI to perform creative tasks has the potential to stymie social connections, which in turn, impacts quality of life. In Chapter 6, Reuben's positive identity as someone who can help their friends with video editing fosters their social connections and perceived quality of life. In the near future, one can imagine that Reuben's friends might be able to use an AI video editor to perform the same function, perhaps more quickly, which would negate the need for a friend to help out. At the same time, one could imagine that Reuben could use AI tools to perform video editing more quickly themselves, if the AI tools are accessible, while still preserving the human element of knowing what their friends may/may not like.

In Chapter 6, findings revealed that the effort put into discovering accessible creative pursuits, in particular, discovering accessible creative pursuits that work with an individual's specific AT system, is a barrier, along with access to expertise knowledge of AT and creative pursuits. This discoverability barrier presents an opportunity for AI researchers. Large language models that are trained on identifying key accessibility concepts across a variety of creative applications, tools, disability needs, and assistive technologies could become a valuable resource to adults with MMCD who use AT and are seeking accessible creative pursuits. While current AI systems provide mixed results when used by people with disabilities [111], AI training could be focused with additional input from individuals with expertise in the domain. Building off of Chapter 7's discussion, engaging adults with MMCD who use AT as testers to inform AI training could benefit not only the AI but also individuals who use AT and are looking to engage more deeply with research and development. As found in Chapter 4, many adults with acquired MMCD who are no longer able to engage in traditional work are still looking for something to do that can accommodate their health needs, and providing an opportunity to test AI might be a reciprocally beneficial opportunity.

At the time of writing this dissertation, the future of AI in creative pursuits is in its infancy, but is developing quickly. Designers of creative AI tools need to design AI to facilitate accessible creativity without diminishing the benefits of time, practice, and learning creative pursuits. AI should not replace the challenges which foster the development of a positive creative identity. AI should enhance discoverability of accessible creative pursuits.

8.3 Limitations and Future Work

The work of this dissertation lays the foundation for an under-explored topic: the impacts of creativity on adults who acquired MMCD and use AT. I describe the limitations of each study in detail within the previous chapters. In this summary of limitations, I acknowledge that as a whole, this dissertation has limitations. The participants included in the studies were all English-speaking. It is likely that adults with acquired MMCD, who use AT and engage in creativity, and who do not speak English would contribute additional insights into the topic of creativity and identity. Future research should include participants from a wider variety of countries, cultural backgrounds, and languages.

An additional limitation to this dissertation is the proposal of amending Max-Neef's matrix of fundamental human needs to include accessing (tools). The purpose of this dissertation was to explore the impacts of creativity on adults with MMCD who use AT. The proposed modification to Max-Neef's matrix is a result of the findings of this dissertation, which focused on the fundamental human needs of creation and identity. Therefore, future work should explore if the addition of *"accessing"* is appropriate for all needs within the matrix, and if the satisfier of accessing could be broadened to populations outside of the narrow population that is the focus of this dissertation.

Future work should also explore a recurrent finding across the studies described in this dissertation: discoverability of information. The research of this dissertation was largely limited to the United States and the United Kingdom. A global study on the awareness of accessible creative opportunities should be conducted, with an exploration on how participants discover information about those opportunities. Such a study would be an important precursor to designing an information sharing system on accessible creative pursuits.

Finally, there are a number of opportunities to explore the role of AI in accessible creativity. As the development of AI tools continues to proliferate, I believe that this area of research is extremely pressing.

8.4 Summary of Contributions

I provide a summary of contributions within the context of my research questions.

RQ1: How does acquiring a disability as an adult, which includes a motor, mobility, and/or communication impairment, impact a person's identity and employment when the person needs to use AT for daily living?

Contribution: I demonstrate that acquiring an MMCD mid-career can impact an individual's identity, which in turn, leads to a sense of loss and uncertainty. I demonstrate that participants have a desire to continue to contribute to society in some way, but are unsure of how they contribute in a meaningful way, which accommodates their disability and health needs. I provide a further contribution by showing that participants' attitudes can change when presented with information regarding work alternatives.

RQ2: What are the best practices for qualitative research with adults who use AAC?

Contribution: I provide a methodological contribution by developing a framework for researchers who engage in qualitative research with adults who use AAC. I provide a further contribution by highlighting qualitative research best practices as a result of an extensive literature review. Key components to best practices involve flexibility on the part of the researcher and engaging in member checking.

RQ3: How does engaging in creative pursuits impact the quality of life of adults who acquired MMCD and use AT for daily living?

Contribution: I contribute to an as-yet unexplored population and topic in the empirical literature outside of directed, therapeutic creative interventions. I demonstrate how access to creativity can positively impact components to quality of life: social connections, perceptions of health, and identity. I expand upon existing identity frameworks and develop an identity change cycle framework, in which accessible technology and creativity are catalysts for identity change.

RQ4: How can co-design methods better accommodate the needs of adults with MMCD who use AT for daily living?

Contribution: I provide a methodological contribution motivated by the desire to include adults with MMCD and who use AT in co-design. Drawing on core co-design principles, Sketchnote practices, and adding flexibility for participants, I developed the aligned co-design method (ACD), a method which can be used with adults who have MMCD and use AT.

8.4.1 Thesis statement

In the process of answering these research questions, I demonstrate the following thesis:

Adults who acquire motor, mobility, and/or communication disabilities that require the use of assistive technology experience feelings of loss and identity change. Access to creative pursuits can result in a positive impact on quality of life and identity formation. Limited accessible creative technologies and a lack of discoverability of those technologies are gating factors that impact people's ability to engage in creative pursuits. To further explore the topic of accessible creativity, it is paramount for researchers to use accessible research methods which include participants who use AAC and AT as partners in research.

8.4 Concluding Remarks

Over the course of this dissertation, I have shown that adults with acquired MMCD who use AT want to participate, contribute, and engage in meaningful activities. Creative pursuits provide a variety of opportunities based on an individual’s interests and talents. The primary barriers to engaging in creative pursuits are lack of discoverable information, changing abilities, and lack of accessible technology. The HCI and Rehabilitation Science fields can collaborate together to improve access to creative pursuits. The methodological contributions from this dissertation can support informed, participant-driven innovations to overcome the barriers identified in this dissertation. The participants from Chapter 6, the *“Creative Models,”* show how impactful access to creative pursuits can be on quality of life. I hope that this dissertation is the first step in a long-line of research and innovation in which creativity is accessible to everyone.

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Appendices

Appendix A

Complete Matrix of Fundamental Human Needs

Table 14. Max-Neef's Matrix of Fundamental Human Needs. Based upon table described in [205].

Needs	Being (qualities)	Having (things)	Doing (actions)	Interacting (settings)
Subsistence	Physical, emotional, and mental health	Food, shelter, work	Work, feed, procreate, clothe, rest, sleep	Living environment, social setting
Protection	Care, adaptability, autonomy	Social security, health systems, rights, family, work	Cooperate, plan, prevent, help, cure, take care of	Living space, social environment, dwelling
Affection	Respect, tolerance, sense of humor, generosity, sensuality	Friendships, family, relationships with nature	Share, take care of, make love, express emotions	Privacy, intimate spaces of togetherness
Understanding	Critical capacity, receptivity, curiosity, intuition	Literature, teachers, educational and communication policies	Analyze, study, mediate, investigate	Schools, families, universities, communities
Participation	Adaptability, receptivity, dedication, sense of humor	Responsibilities, duties, work, rights, privileges	Cooperate, propose, dissent, express opinions	Associations, parties, churches, neighborhoods
Idleness	Imagination, curiosity, tranquility, spontaneity	Games, parties, spectacles, clubs, peace of mind	Day-dream, play, remember, relax, have fun	Landscapes, intimate spaces, places to be alone, free time
Creation	Imagination, boldness, curiosity, inventiveness, autonomy, determination	Skills, work, abilities, method, techniques	Invent, build, design, work, compose, interpret	Spaces for expression, workshops, audiences, cultural groups
Identity	Sense of belonging, self-esteem, consistency	Symbols, language, religion, values, work, customs, norms, habits, historical memory	Get to know oneself, grow, commit oneself, recognize oneself	Places one belongs to, everyday settings, maturation stages
Freedom	Autonomy, passion, self-esteem, open-mindedness, tolerance	Equal rights	Dissent, choose, run risks, develop awareness, be different from, disobey	Temporal and spatial plasticity (anywhere)

Appendix B

Interview Protocol for Employment Experiences Study

1-4 sent out in advance
1) What kinds of work have you done?
2) What specific tasks/responsibilities did you have most recently at work?
3) Can you tell me a bit about your work experience around the time you started needing assistive technologies or other accommodations? (if applicable)
4) What types of assistive technologies or accommodations do you currently have and how do you use them?

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5) What would make it easier to work given your current situation?
*Prompt: What barriers prevent you from working in a way that you'd like? (deep-dive into barriers cited by participant)
6) What alternative kinds of work would you like to do that you think you could do?
7) What would help you be able to do work online?
8) What do you think of crowdsourcing work opportunities, such as Mechanical Turk?
*Prompt: Have you looked for alternative, part-time work, such as through Facebook, Craigslist, or Mechanical Turk? (provide demo if needed)
*Prompt: Are there any policies that prevent you from looking for alternative work opportunities?
9) On a scale of 1-10, how important do you think computer access is to you? How important is computer access to be able to work?

Appendix C

Questionnaire For Member Checking Work Experiences Interview Data

Employment, Mobility and Communication Impairments (Synthesized from Interviews)

About This Survey

This survey is based on the information from the interview phase of this study. Your interview information was synthesized with other participant's interview data to form the basis for this survey.
I'm sharing out this survey to you as a way to check that the synthesized information from the interviews reflects your experiences.
The survey will take anywhere between 20-40 minutes.
If you have any questions about the survey, please contact Erin Beneteau at [email].
You are not under any obligation to complete the survey, you can discontinue at any time.

Employer Attitudes
Please review the statements below and rate how these statements relate to your feelings based on your experience. Choose "N/A" if a statement is not relevant to you.
2. My employer's attitude significantly influenced my decisions about continuing work.
Disagree, Neutral, Agree, N/A
3. I feel more secure about continuing work and am more willing to continue work if my employer is clear about the types of accommodations they are willing to provide me.
Disagree, Neutral, Agree, N/A
4. When an employer does not offer any accommodations to help me, I do not feel comfortable continuing to work in that environment.
Disagree, Neutral, Agree, N/A
Leaving Work
Please review the statements below and rate how these statements relate to your feelings based on your experience. Choose "N/A" if a statement is not relevant to you.
5. Giving up work was a difficult choice.
Disagree, Neutral, Agree, N/A
6. I stopped work because I could no longer meet the physical demands of work and/or the stress of work negatively affected my health.
Disagree, Neutral, Agree, N/A
Barriers to Work
Please review the statements below and rate how these statements relate to your feelings based on your experience. Choose "N/A" if a statement is not relevant to you.
7. The change in my physical abilities were the primary reason I felt I could no longer work at the job I had when I acquired my impairment/disability.
Disagree, Neutral, Agree, N/A
8. The pressure that I put on myself to be as productive and competent as I was before my impairment contributed to feeling like I could no longer stay in the same job.
Disagree, Neutral, Agree, N/A
9. Needing to take time off for medical appointments was a barrier to being as productive as I wanted to be at work.
Disagree, Neutral, Agree, N/A
10. Fatigue is an ongoing barrier to work.
Disagree, Neutral, Agree, N/A
11. Lack of technology to accommodate my needs is a barrier to work.
Disagree, Neutral, Agree, N/A
Transition from Work
Please review the statements below and rate how these statements relate to your feelings based on your experience. Choose "N/A" if a statement is not relevant to you.

12. Employers can positively help people like me by providing information about disability insurance, health insurance, and disability benefits.
Disagree, Neutral, Agree, N/A
13. Information about disability benefits is not easy to find.
Disagree, Neutral, Agree, N/A
14. I had help from an organization, friend, or professional to learn about and sign up for disability benefits.
Disagree, Neutral, Agree, N/A

Work Accommodations

Please review the statements below and rate how these statements relate to your feelings based on your experience. Choose "N/A" if a statement is not relevant to you.

15. I want to work.
Disagree, Neutral, Agree, N/A
16. I want to do work that is meaningful, helpful, and intellectually stimulating.
Disagree, Neutral, Agree, N/A
17. I need work to be flexible: I need to be able to work from home when I need to, and I need to have flexible work hours.
Disagree, Neutral, Agree, N/A
18. I need work that doesn't require specific physical or verbal communication skills.
Disagree, Neutral, Agree, N/A
19. I need work that doesn't have any strict time dependencies or deadlines.
Disagree, Neutral, Agree, N/A
20. I don't know how to find out about work opportunities that meet my needs.
Disagree, Neutral, Agree, N/A
21. Volunteering seems less stressful and more flexible than paid work.
Disagree, Neutral, Agree, N/A
22. I must have computer access for any type of employment.
Disagree, Neutral, Agree, N/A

Survey completed!

Thank you for your time in completing this survey and helping me to ensure that I reflect your interview information accurately.

If you have any questions, please email me: XXXX

Appendix D

Lists of Alternative, Occasional Employment Options

State Vocational Rehabilitation Agencies: https://askjan.org/concerns/State-Vocational-Rehabilitation-Agencies.cfm
Volunteer Match: https://www.volunteermatch.org/
United Way: https://www.unitedway.org/get-involved/volunteer
501 Commons (professional volunteering opportunities): https://www.501commons.org/
Social Security Redbook: https://www.ssa.gov/redbook/

Table 15. Possible Alternative Paid Work Opportunities Based on Internet Search

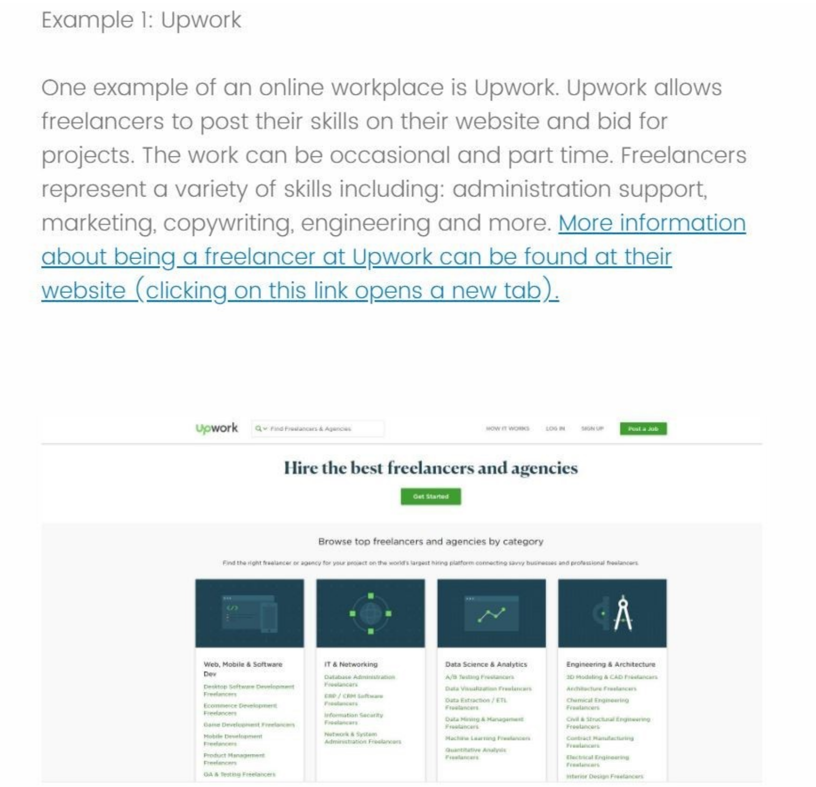
Opportunity	Resource
Mechanical Turk	https://www.mturk.com/worker
Zooniverse	https://www.zooniverse.org/
Flexjobs	https://www.flexjobs.com/jobs/writing-editing-journalism
ProBlogger Jobs	https://problogger.com/jobs/
Website evaluation jobs	https://connect.appen.com/qrp/public/jobs/list
Website evaluation jobs	https://www.dreamhomebasedwork.com/lionbridge-work-from-home/
Work from home w/disability options	https://www.disabled-world.com/disability/employment/home/
Tutoring	https://www.thepennyhoarder.com/make-money/side-gigs/online-tutoring-jobs/
Transcription- Transcribe Me!	https://workhub.transcribeme.com/Account/Register
Transcription- Rev	https://www.rev.com/freelancers/transcription
Transcription- CrowdSurf	http://crowdsurfwork.com/get-started-on-work-market/
UpWork	https://www.upwork.com/i/how-it-works/freelancer/

Appendix E

Alternative Work Options Survey Example

This survey is designed to get your perspective on alternative work opportunities after acquiring a mobility and/or communication disability.

This survey will take approximately 15-30 minutes to complete. Please take your time. If you have any problems completing the survey, please contact Erin, who can arrange a time to go over the survey with you by phone or via online conferencing.



Example 1: Upwork

One example of an online workplace is Upwork. Upwork allows freelancers to post their skills on their website and bid for projects. The work can be occasional and part time. Freelancers represent a variety of skills including: administration support, marketing, copywriting, engineering and more. More information about being a freelancer at Upwork can be found at their website (clicking on this link opens a new tab).

Hire the best freelancers and agencies

Browse top freelancers and agencies by category

Find the right freelancer or agency for your project on the world's largest hiring platform connecting savvy businesses and professional freelancers.

Figure 14. Screenshot Example from Alternative Work Survey.

Have you heard of Upwork before this survey?
    Yes, No, Maybe
Do you think you might check out Upwork's website?
    Definitely yes, probably yes, might or might not, probably not, definitely not
Why or why not?
    [open text box]
What concerns do you have about considering a service like Upwork?
    [open text box]
[Survey goes through 4 examples of work options]
Concluding questions:
Would you be more interested in part-time, alternative paid work that is NOT computer based?
    Yes, No, Maybe- I'm not sure

Why? [open text box]

Do you have a preference between seeking volunteering opportunities versus occasional, part-time paid work opportunities?

I prefer volunteering, I prefer paid work, No- I don’t have any preference between paid work and volunteering

Why? [open text box]

Has your feeling about looking into occasional, part-time work changed at all after having taken this survey from when you first started the survey?

Yes, No, Maybe

How has it changed?

[open text box]

Optional: Feel free to write any additional comment you have regarding alternative, occasional part-time work here: [open text box]

Appendix F

Creative Models Semi-Structured Interview Protocol

1) How did you become interested in engaging in creative pursuits?
2) Which creative pursuits do you currently engage in? Are there other forms of creativity that you'd be interested in exploring? If so, are there any physical or technological barriers to doing so?
3) What types of tools do you use to access your creative pursuits?
4) Did the onset of your impairment impact your pursuit of creativity? If so, how did the development of your impairment facilitate or hinder the development of your creativity?
5) There are many ways people identify themselves. I'm interested in how your identity has evolved as an adult. How do you identify yourself now? How is it different from before the onset of your impairment? Do you identify yourself differently since you engaged in creative pursuits? How do you think others identify you?
6) How do you communicate with others about your creative work?
7) Do your creative pursuits impact how others communicate with you? Is this a change from how people communicated with you prior to engaging in creative pursuits?
8) Why do you continue to engage in creative work?
9) How has your engagement with creativity impacted your quality of life?
10) Do you believe that your engagement with creativity has impacted your health? If so, how?
11) Have you met other people who have had similar experiences regarding impairments and creativity? If so, how are their experiences similar or different to yours?
12) For the second part of my thesis work, I'm hoping to work with adults who are not currently engaged in creative pursuits. Do you have any advice to give someone who has developed or acquired a severe impairment as an adult about exploring creative pursuits?

Finally, if you have any pieces that you created that you believe are representative of changes in your health, identity, or quality of life and you are comfortable sharing them with me, I welcome an opportunity to learn more about your journey through your creative pursuits. If you are comfortable with me taking photos of these creative pursuits, I embrace the opportunity to do so, but if you only want to share them and discuss them, but not have any photographs taken of them, I am equally happy to honor your wishes.

Appendix G

Creative Models Optional Sharing of Artifacts

Optional- Share More of Your Creative Process through Photos
As a supplement to our interview, I'd like to invite you to share 5 photos of your choosing that illustrate how your creative engagement has impacted you. This is purely optional, but it would provide me with some additional insights into what is meaningful to you about your creative work and creative process.
Guidelines:

1) **Please choose 5 photos (or feel free to take 5 new photos) that illustrate your creativity and how creative engagement has impacted you.**
2) **Please write some accompanying text with each photo that describes why you chose it.**
3) **Let me know if you'd like to have another interview scheduled, so you can talk through the photos, or if you're happy to just email them to me.**

*Please note, that I might reproduce these photos as part of my thesis research. The idea of this research technique is that using visuals, such as photos, can convey additional meanings that words might not capture.
If you want me to "erase" elements of the photos (such as someone's face so they can stay anonymous), please let me know and I can do that for you. I would show you the edited photo to get your approval before including it in the research.
This is purely an optional follow up to our interview. Please don't feel obligated to do this activity. However, if you are interested, please let me know and I'll be excited to see the photos that you select.