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UNIVERSITY OF CALIFORNIA,  
IRVINE

Advancing Critical and Socially-Oriented Approaches to Domestic Accessible Computing  
Research

DISSERTATION

submitted in partial satisfaction of the requirements  
for the degree of

DOCTOR OF PHILOSOPHY

in Informatics

by

Kevin M. Storer

Dissertation Committee:  
Assistant Professor Stacy M. Branham, Chair  
Professor Gillian R. Hayes  
Associate Professor Anne Marie Piper

2022



# DEDICATION

To Kenneth, who worked as hard for this as I did.

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Ali Abdolrahmani, Kevin M. Storer, Antony Rishin Mukkath Roy, Ravi Kuber, Stacy M. Branham. ACM Transactions on Accessible Computing (TACCESS), Volume 12, Issue 4, January 2020, Article 18, 35 pages.

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**Apr 2016**

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# ABSTRACT OF THE DISSERTATION

Advancing Critical and Socially-Oriented Approaches to Domestic Accessible Computing  
Research

By

Kevin M. Storer

Doctor of Philosophy in Informatics

University of California, Irvine, 2022

Assistant Professor Stacy M. Branham, Chair

A growing body of Accessible Computing (AC) research addressing the design of computing systems for disabled users suggests that social factors, like stigma and the presence of nondisabled others, impact the success of AC systems. To date, the vast majority of research aimed at understanding how social factors influence AC system design and use has focused on public and work-oriented contexts—neglecting, in particular, domestic spaces. But, examining the ways social factors impact the design and use of AC systems for domestic contexts may be particularly prescient; Human-Computer Interaction (HCI) research which does not examine disability consistently demonstrates that social aspects of domesticity impact the design and successful adoption of digital technologies in home environments. But, it remains unclear whether the social factors impacting the design of domestic AC systems are similar to, differ from, or extend beyond those identified in HCI studies of nondisabled people. Additionally, it remains unclear why this gap in knowledge exists, given the increasing acceptance of social approaches to AC and consistent demonstration of the need to understand social factors in domestic HCI.

Toward advancing social approaches to domestic AC research, this dissertation makes three contributions, through three studies. Firstly, I empirically examine blind adults' perspectives

on social considerations of domesticity relevant to AC design research, in their roles as parents, through a content analysis of a social media group for blind parents and, in their roles as partners, through a paired-interview study of blind and sighted intimate partners. Secondly, I investigate AC design researchers' perspectives on social considerations of domesticity relevant to AC design research, to explore whether patterns of research praxis contribute to a lack of scholarly attention in this domain, through a critical discourse analysis of recent domestic AC literature. Thirdly, and finally, through synthesizing these studies, I compare blind adults' perspectives and AC design researchers' perspectives on social considerations of domesticity relevant to AC design research, to understand whether and how AC design researchers may need to adjust their approaches to better attend to the lived experiences and perspectives of disabled users, like blind adults.

I found that blind adults' perspectives and AC design researchers' perspectives on social considerations of domesticity relevant to AC design research differ in three primary areas: 1) Conceptions of disabled people's resource contributions to the household, 2) directionality and reciprocity of care in familial relationships between disabled and nondisabled people, and 3) desirability of disabled people's individual agency and autonomy in domestic spaces. In response to these tensions, I outline a framework of AC design research principles based on Disability Rights advocacy intended to align the perspectives of AC researchers and those of the anticipated disabled users of their domestic technologies.



# Chapter 1

## Introduction

The ache for home lives in all of us.

The safe place where we can go as we are and not be questioned.

-Maya Angelou, *All God's Children Need Traveling Shoes*

Despite computing's workplace-oriented origins, many technologies are designed to be deployed in homes. While this shift in context, from professional to private environments, has enabled opportunities for computing to enhance domestic life, it has also necessitated changes to research approaches employed to examine technology use. Introducing digital technologies in domestic settings can have unintended consequences for significant aspects of domestic life, like intimate relationships (Thayer et al., 2012), domestic labor (Ames et al., 2010; Rode, 2010), and familial roles (Mazmanian and Lanette, 2017). But, because homes are familiar to most people, these social factors may seem unremarkable—and remain unexamined—if researchers are not reflective and critical in their analyses (Bell et al., 2005). Though well-established in computing research concerning people-not-specified-as-disabled, few studies in Accessible Computing (AC) examine domestic technologies for disabled people through social lenses (Branham and Kane, 2015a; Dawe, 2006). However, orienting toward social aspects and employing critical approaches may be especially important for domestic

AC researchers because of historical connections between disability and housing, which add nuance to researching domestic AC.

Homes are one of the most significant places in the lives of many; in ideal situations, one of refuge, safety, acceptance, self-actualization, relaxation, connection, and joy. Yet, the sanctity of home has too often been denied to many people, in particular, to disabled people. Homes and housing have been a central component of disability rights advocacy—and also of ableist discrimination. Carceral institutions, sometimes euphemistically referred to as “homes,” have been a primary residence for disabled people in Western societies throughout much of modern history. Adopted in the United States of America (USA) during the 1850s, institutionalization was the default “method of handling” disabled people, labelled “deviant, defective, or delinquent,” for over a century (Noll, 2018). There are numerous accounts of unspeakable abuses in institutional settings (Deutsch, 1948; Johnson, 2003). But, the institutional system remained largely unchallenged until the 1950s, when growing awareness of abuses and medical advances prompted calls for deinstitutionalization, or the transition of disabled people to community-based settings (Davis et al., 2012). In the wake of this transition, disabled activists and their allies continued to push for further deinstitutionalization and full civil rights under the banner of the Independent Living (IL) Movement (Dejong, 1979). The IL Movement’s goals were, and are, broader than deinstitutionalization. But, its namesake evidences the pivotal role of (de)institutionalization and housing in disabled people’s fight for justice.

Because social factors impact technology design in domestic spaces, and housing is linked to disability rights, the successful design of domestic AC systems likely requires critically understanding the social significance of housing for disabled people as contextualized by (de)institutionalization. But, critical and social approaches to AC research are still an emerging area of scholarly interest (as described further in Section 2.2), which have not yet been applied broadly in domestic settings. The complex and problematic historical

connection between disability, domesticity, and housing and the importance of social and cultural considerations of domesticity to technology design prompted the research executed and described in this dissertation, directed at understanding the social considerations of domesticity relevant to disabled people, here blind adults specifically, and the ways in which the historical context of (de)institutionalization shapes those social considerations and the way we, as AC researchers, approach conducting research in, and writing about, domesticity.

This dissertation describes the findings of three studies directed at understanding the social considerations of domesticity relevant to blind adults and as described in AC research publications. It is organized as follows. In the remainder of this section, I provide clarification of terms, historical context, research positionality, and disability language, before outlining the thesis statement of this work, research questions addressed, and contributions. In Chapter 2, I provide an overview of existing bodies of literature to which this dissertation contributes. In Chapter 3, I describe the execution and findings of two empirical studies of blind adults' domestic technology use and reflect upon the social considerations of domesticity relevant to AC design research that are highlighted in these studies, separately and together. In Chapter 4, I describe the execution and findings of a Critical Discourse Analysis conducted on a body of AC research articles, to uncover AC researchers' perspectives on social considerations of domesticity relevant to AC design research. In Chapter 5 of this study, I synthesize the findings of these three studies and critically analyze points of alignment and tension in blind adults' and AC researchers' perspectives on social considerations of domesticity relevant to AC design research. In Chapter 6, I propose a Deinstitutional framework for aligning points of tension between blind adults' and AC researchers' perspectives on social considerations of domesticity relevant to AC design research and reflect upon the implications of the principles outlined in this framework for each of the three studies described in this dissertation. Finally, in Chapter 7, I summarize my works' findings and contributions and invite further engagement in this space.

## 1.1 Accessible Computing and Human-Computer Interaction

Broadly, this dissertation contributes to two fields of computing research: Accessible Computing (AC) and Human-Computer Interaction (HCI). AC is the computing discipline which addresses the design and research of computing systems created for disabled users. AC shares many cores domains of interest with HCI, both encompassing the wide intersection of human activity and digital technology. In fact, AC may rightly be regarded as a subdiscipline of HCI, even occupying its own subcommittee at the ACM CHI Conference on Human Factors in Computing Systems, the premier conference for HCI research (ACM SIGCHI, 2021).

In this respect, the key differentiating factor between AC research and HCI research that is not considered AC research is often whether disability and ability are addressed in analysis. At the same time, because HCI research that is not considered AC research does not typically address disability and ability in analysis, it cannot be said that populations of interest in such are uniformly nondisabled—only that disability is not examined. For this reason, it cannot be said that AC research and HCI research that is not considered AC research necessarily have different populations of interest.

Still, for clarity, throughout the remainder of this dissertation I use a distinction between HCI research, to refer to research in which the population of interest is not defined as being disabled, and AC research, to refer to research in which the population of interest is explicitly defined as being disabled. But, given the above considerations, this distinction is admittedly simplistic, and it should not be interpreted that AC research is a niche within the wider discipline of HCI, that AC research does not have implications for HCI research that does not consider disability and ability, nor that the implications of HCI research are necessarily derived from a nondisabled population and, as such, are irrelevant to disabled populations. Accordingly, while the contributions of this work are most squarely in the

domain of AC research, my work also contributes to the wider body of HCI research, both because AC can be categorized as a domain of HCI and because the distinction between AC and non-AC HCI is largely arbitrary and dependent upon whether non-AC HCI researchers choose to examine disability and ability in their analyses. It is my hope that, by articulating ways in which disability intersects with social considerations in the design of domestic digital technologies, this work encourages more non-AC HCI researchers to challenge this distinction by considering disability and ability.

## 1.2 Design, Research, and Design Research

In the field of HCI, describing designed artifacts is a well-established form of academic contribution (Wobbrock and Kientz, 2016). Yet, design and its relationships to, and within, academic scholarship is a debated topic in the HCI literature. Of particular interest to debates in this domain are the rigor and validity of the contributions to knowledge and scholarship made through design—especially as contrasted against the contributions of scientific research. For instance, Nelson and Stolterman argue design is an act of engaging with the “ultimate particular,” a phrase describing the set of complex factors impacting a specific artifact, in a specific context, for a specific purpose, in order to transform a specific aspect of the world into some desirable state (Nelson and Stolterman, 2014). Here, design differs from science in that the insights it offers are highly local and holistic, rather than universal and tightly scoped. Zimmerman et al. distinguish between design and science, suggesting science contributes “true” knowledge, engineers contribute “how” knowledge, and anthropologists contribute “real” knowledge, all of which is synthesized by designers, whose role is simply to apply these knowledges (Zimmerman et al., 2007). Fallman argues comparably that HCI ought to distinguish between “research-oriented design” and “design-oriented research,” in which the former describes an act of design which might generate “real” knowledge, like ap-

plied experience and personal competence, and the latter describes an act of research aimed at supporting design by generating “true” knowledge which may inform designers’ efforts (Fallman, 2007).

This dissertation does not seek to address epistemologies of design and scientific research, nor to necessarily distinguish between the two. At the same time, because these debates are relatively common within the HCI literature, it is prudent to note that my own discussion of design, research, and scholarship, is not intended to support or reject any of these views. Given this context, in the remainder of this work, I use the phrase “design research” to refer to any scholarship that is directed at understanding designed technologies, whether through design, empirical, or critical methods, regardless of the epistemological commitments or assertions of its authors.

### **1.3 Housing and Disability**

The historical social and cultural connections between housing and disability form a key analytical framework for Chapter 4 of this dissertation. But, at the same time, the historical connections between housing and disability contextualize the motivations of this dissertation and its focus on social approaches to domestic AC design research. So, here, I share a necessarily brief recounting of this history for background, but note that a more complete history is also available in Section 4.1.1.

Within the context of disability, “homes” has a dual meaning. On the one hand, “homes” may refer to any type of dwelling or permanent residence. On the other, “homes” is frequently used as a euphemism to refer to carceral, quasi-clinical institutional settings, like asylums and skilled nursing facilities, which have served as a primary residence for disabled people throughout much of modern history. Adopted in North America in the 1850s, institutions

served as the default “method of handling” disabled people, who were labelled “deviant, defective, or delinquent,” for over a century (Noll, 2018). Though built under the guise of benevolence and care, numerous accounts of unspeakable abuses occurring in institutional settings challenge these narratives (Deutsch, 1948; Johnson, 2003). These inhumane living situations remained largely unchallenged until the 1950s, when growing awareness of their abuses and medical advances prompted calls for deinstitutionalization, or the transition of disabled people from institutions to community-based domestic settings (Davis et al., 2012). In the wake of this transition, disabled activists and their allies continued to push for further deinstitutionalization and civil rights under the banner of the Independent Living (IL) Movement (Dejong, 1979), whose very namesake is evidence of the centrality of homes to disability rights. This history likely creates an additional layer of nuance in understanding the sociocultural significance of homes in AC, beyond those that have been shown to impact digital technology design in HCI.

This history, and the centrality of homes and housing to disability rights and activism, suggest that social approaches to domestic AC design research may be both beneficial and fruitful. Yet, as described in Section 2.3., this domain has been underexplored in the academic literature. It is this history and the corresponding gap in research which motivate this dissertation’s focus on social approaches to domestic AC design research.

## 1.4 Positionality

The work described in this dissertation began with an empirical exploration of blind parents’ strategies and motivations for co-reading with their children. In its early phases, it was clear to me that this domain necessitated research, because of the immediate perceptibility of the access barriers that would be experienced by blind parents in co-reading—printed text is inherently visual. While the insights gained through this work about accessibility in

co-reading were fruitful, the process of conducting this research led me to larger questions beyond the domain of co-reading. The article describing this research was awarded an Honorable Mention for Best Paper for being the first empirical study of the ways in which blind parents read with their children in either Human-Computer Interaction (HCI) or Education research. Although I was honored by this recognition, I was also deeply troubled by the lack of research in this space. I wondered what other work needed to be completed to advance scientific understanding of this space and, more importantly, why this gap existed, at all.

I have spent the subsequent three years exploring these questions, filling gaps that I identified with empirical work, while searching for underlying explanations for this gap as I continued. The research I have conducted in that time is detailed in the remainder of this dissertation. But, I remain deeply troubled as I was when I first began this work; I have found that research into the social considerations relevant to domestic Accessible Computing (AC) research is more important than I initially believed, and the gap in research I identified is simply too large for any one person to fill.

It is for these reasons that I have chosen to contribute, in this dissertation, both empirical findings and a framework for domestic AC design research, which may inform future research in this space. It is my desire that, by providing principles to fill this existing gap in research, this dissertation will form the foundations for constructing a body of research in this space of a magnitude beyond what I could achieve alone in a lifetime. I remain skeptical that research in this space will ever approach the scale that would be necessary to adequately bridge the gaps in current scientific understanding of this domain, even with significant uptake of the ideas advanced here. At the same time, as a researcher, this may also be a source of optimism—exploring the social considerations relevant to domestic AC research will likely be fruitful and enlightening for researchers who choose to work in this space, because of the sheer number of problems which are not yet examined. I hope that my candor, here, in describing my own journey, struggles, desires, and disappointments when engaging in this



research will be of comfort to readers of this dissertation who will accept its call to action.

In the remainder of this chapter, I begin by providing an overview of domains and concepts necessary for contextualizing and understanding the work described in this dissertation, before outlining the thesis statement, research questions, and contributions of this work, and summarizing its remaining chapters.

## 1.5 Models of Disability, Disability Language, and Philosophical Stance

Disabled people are widely regarded as the world's largest marginalized community, representing an estimated one billion people globally (World Health Organization, 2011). Accordingly, many—if not most—people have some conception of what “disability” *means*. Yet, what “disability” *is* remains an open, philosophical, political, and, often, contentious question.

Debates about the nature of disability, as a descriptor or characteristic of people, often concern the modeling of disability and the assertions those models make about where disability exists or is produced. While many models of disability exist, two models of disability dominate such debates: 1) the Medical Model of Disability, and 2) the Social Model of Disability. The Medical Model of Disability posits that disability is the result of some physical condition of an individual's body which causes that individual's physical or cognitive abilities to deviate from those of a normative or standard body (Brisenden, 1986). Within the Medical Model, disability is asserted to be intrinsic to the individual and belonging to their body. Conversely, the Social Model of Disability posits that disability is primarily a form of marginalization that is produced by social and physical infrastructures and attitudes which demand a specific set of abilities from individual bodies in order to avoid discrimination

(Oliver, 2013). Within the Social Model, disability is not considered to be intrinsic to the individual, but rather denotes exclusion from a dominant group that is characterized by their having an arbitrary and socially-constructed set of abilities that confer social privilege. Consider, for instance, that individuals may have different running speeds, but being a slow or fast runner does not determine whether one is oppressed, and, as such, running speed does not determine whether one is considered disabled.

Because the Medical Model and Social Model each carry unique philosophical assumptions about the nature of disability, the language that adherents to these models use to describe disability and disabled people differs. Equally and accordingly, the language used to describe disability and disabled people often represents adherence of the language user to a particular model of disability. Person-First Language (Ferrigon and Tucker, 2019), exemplified by the phrase “people with disabilities,” is often associated with the Medical Model of Disability, because “with disabilities” implies that disabilities are a physical thing an individual may “have” or “be with.” Since it positions “people” at the beginning of the phrase, Person-First Language is often promoted for its identification of disabled people firstly as people and secondarily as disabled. Conversely, Identity-First Language (Ferrigon and Tucker, 2019), exemplified by the phrase “disabled people,” is often associated with the Social Model of Disability. By placing “disabled” syntactically first, Identity-First Language emphasizes the claim that disability is not a physical thing, but an identity which is socially-constructed and used primarily for discriminatory purposes.

Here, I have used, and will use in the remainder of this dissertation, Identity-First Language to reflect my personal philosophical commitment to the Social Model of Disability. However, my language use in this dissertation is not intended to contribute to, or weigh in on, current debates surrounding disability politics through language. There are valid reasons for research to adhere to the Medical Model of Disability, particularly medically-oriented research in which individual diagnosis and treatment are primary goals. Here, adhering

to the Social Model of Disability is reflective of the fact that understanding disability as socially-constructed is congruent with the socially-oriented lens through which my dissertation research is analyzed and approached.

## 1.6 Thesis Statement

Blind adults' and AC design literature's perspectives on social considerations of domesticity relevant to AC design research differ in ways that may impact the success of domestic AC systems, and should be aligned through the adoption of housing-based Disability Rights principles outlined in the Deinstitutional design research framework I propose here.

## 1.7 Research Questions

**RQ1:** What social considerations of domesticity are relevant to AC design research from blind adults' perspectives?

**Approach:** To answer this question, I conducted two empirical qualitative studies of blind adults in their roles as parents and intimate partners, concerning the use and potential for digital technology to overcome inaccessibility in domestic activities and the social considerations of domesticity shaping perceptions of technology's appropriateness for this purpose.

**RQ2:** What social considerations of domesticity are relevant to AC design research from AC researchers' perspectives?

**Approach:** To answer this question, I conducted a discourse analysis of 101 scientific AC research articles describing disabled people's domestic spaces, focusing on the ways in which the social considerations relevant to domestic AC design research are characterized and understood.

**RQ3:** Do the perspectives of blind adults and AC researchers on the social considerations of domesticity relevant to AC design research differ and, if so, how?

**Approach:** To answer this question, I compared the findings of the studies addressing RQ1 and RQ2 above, to identify whether, and what, tensions exist between blind adults' and AC researchers' perspectives on social considerations of domesticity relevant to AC design research.

**RQ4:** Do the perspectives of blind adults and AC researchers on the social considerations of domesticity relevant to AC design research need to be better aligned and, if so, how?

**Approach:** To answer this question, I examined the consequences of the tensions identified in answering RQ3, and searched for opportunities to align points of tension in historical Disability Rights advocacy.

## 1.8 Contributions of Dissertation

The body of work described here makes four primary contributions to AC research: 1) an empirical account of the social considerations of domesticity relevant to AC design research from the perspective of blind adults in two distinct social roles, as parents and as intimate partners, 2) a critical analysis of the social considerations of domesticity relevant to AC design research from the perspective of AC researchers, 3) a critical analysis of points of alignment and tension between these two perspectives, and 4) a Deinstitutional framework for design research, based upon housing-oriented principles of Disability Rights advocacy, which provides a basis for reducing tensions identified.

# Chapter 2

## Related Work

Broadly speaking, this dissertation contributes knowledge to fill gaps in existing bodies of literature which concern social and critical approaches to understanding AC design research, primarily outside of domestic spaces, and social and critical approaches to understanding HCI design research in homes, where disability and ability are not examined or analyzed. At the same time, because social and critical approaches to design research in AC and HCI are contextualized by, and in many ways responses to, traditional approaches in AC and HCI which prioritize individual technology users and concerns for labor and efficiency, my work also contributes to these larger bodies of literature in AC and HCI, by serving as a mechanism for critiquing and expanding upon such traditional modes of thinking. Accordingly, in the remainder of this chapter, I outline three domains of literature to which my dissertation contributes: 1) Traditional approaches to AC design research, 2) Social and critical approaches to AC design research, and 3) social approaches to domestic digital technology design for nondisabled people.

## 2.1 Traditional Approaches to Accessible Computing Design Research

Traditional approaches to AC design research differ from the social and critical approaches outlined below in Section 2.2. in two main ways. Firstly, they focus primarily on the ways in which technology might increase accessibility for efficiency in labor- and productivity-oriented activities of public and professional life. Secondly, they focus primarily on individual users acting with technology, alone. Because this manifests differently in academic research depending upon the nature of the disabled population of interest, here, I illustrate these qualities of traditional approaches to AC design research in works addressing blind and low-vision users, who are also the population of interest in my empirical studies described in Chapter 3.

Wayfinding and navigation tools for blind and low-vision pedestrians are the subject of a large body of research in AC. Many of these applications aim to assist blind and low-vision pedestrians through the vocalization of visual information collected from a mobile phone's GPS or predefined in a database. For instance, Guy and Truong developed *CrossingGuard*, a mobile system which provides auditory, sidewalk-to-sidewalk directions for pedestrians with visual impairments at traffic intersections, based on information in a crowd-compiled database (Guy and Truong, 2012). Likewise, Ross and Blasch used a “sonic carrot” to play a bell tone in stereo earbuds, marking the approximate direction of the intended destination as determined by a phone's GPS (Ross and Blasch, 2000). Other tools have attempted to capitalize on advances in computer vision to support blind and low-vision navigators. For example, Brock and Kristensson attempted to provide information about the layouts of indoor environments, by “sonifying” indoor environments using the cameras of a Microsoft Kinect harnessed to a user's stomach, and translating the details of a room through variations in an auditory output's pitch, pan, and volume (Brock and Kristensson, 2013). But, while

the technical approaches of these tools differ, goals of research aimed at supporting blind and low-vision users in wayfinding overwhelmingly focus on the logistics of traveling to a specified destination, rather than on the enjoyment of the journey. For instance, Ross and Blasch evaluated the effectiveness of their device by measuring the *time taken to cross an intersection* (Ross and Blasch, 2000). Similarly, Brock and Kristensson evaluated their application by measuring the time taken to complete a contrived obstacle course (Brock and Kristensson, 2013). Noticing this trend, Yang et al. extended these approaches by including audio cues to indicate predefined “points-of-interest” in a user’s area, or along their route, to support more serendipitous explorations (Yang et al., 2011). But, even so, such points-of-interest are predefined by the research team, rather than spontaneously identified by blind and low-vision pedestrians, themselves.

Similar focus on the utilitarian values of efficiency over enjoyment can be seen in other domains of AC research for blind and low-vision technology users. For example, because of the rising prevalence of touchscreen devices—which are inaccessible to blind and low-vision users because their interfaces are not static or tactile—alternative input methods for touchscreens are another common domain of inquiry for AC research. For instance, Kane et al. designed *Slide Rule*, a set of multi-touch interaction techniques that allowed users to scan lists, select items, and browse hierarchical information non-visually, through spatially-independent gestures and tap patterns (Kane et al., 2008). Azenkot et al. leveraged these multitap interactions to develop *PassChords*, a mobile phone security passcode which allowed users to verify their identity by tapping a specific sequence (Azenkot et al., 2012). Southern et al. even applied these multi-touch, tapping interactions to typing Braille through mobile phones—which are markedly less expensive than traditional Braille typing tools—in the design of *BrailleTouch* (Southern et al., 2012). Outside of exploring multitap inputs, Azenkot and Lee studied blind users’ mobile text-entry patterns when using talk-to-text as compared to a touch keyboard and screen-reader, finding speech to be much faster Azenkot and Lee (2013). But, although these approaches differed technologically, these works still

share a focus on efficiency, rather than enjoyment. Most commonly, such applications are evaluated in terms of *time to complete a specific task* (Azenkot et al., 2012; Kane et al., 2008) and the *speed of users' input* as compared to an inaccessible method (Azenkot and Lee, 2013; Southern et al., 2012).

Importantly, the works outlined above also share a focus on individual users acting with technology. In fact, supporting “independence” has long been the defining goal of wayfinding systems for blind and low-vision users (Campbell et al., 2014; Hub et al., 2004; Loomis et al., 1994). This strong focus on individual disabled users acting outside the presence of others is prevalent enough in the AC literature to have been the subject of its own critique (Bennett et al., 2018).

## 2.2 Social and Critical Approaches to Accessible Computing Design Research

More frequently than many communities, AC scholars propose research agendas, design principles, and analytic lenses for guiding efforts within the community. Written primarily by AC design researchers, for an intended audience of AC design researchers, the goals of these pieces have shifted significantly during the last two decades as accessibility has become increasingly central to technology design. Early works in this space were primarily rhetorical, emphasizing the need to consider accessibility in design as a moral imperative or sound economic decision (Stephanidis and Salvendy, 1998; Shneiderman, 2000). However, more recent works grapple with the complexities of designing for and with disabled people, often by revisiting previous results through nuanced lenses of disability.

A particularly influential agenda-setting work in AC is Mankoff et al.'s (Mankoff et al., 2010) introduction of Disability Studies (DS) to AC in 2010. A key contribution of this work was



challenging AC’s use of the Medical Model of disability, which posits disability is caused by an individual’s bodily impairments and can be “fixed,” in this case, by AC systems. In its place, the Social Model of disability, which posits disability is caused by external structural factors and larger systems of oppression, has become a popular perspective. Accordingly, a growing body of work addresses social factors impacting AC design, like how access is constructed through social interactions (Branham and Kane, 2015a; Storer and Branham, 2019; Thieme et al., 2018; Wang and Piper, 2018), the social acceptability of AC systems (Profita et al., 2016, 2018; Shinohara and Wobbrock, 2011, 2016), and how digital technologies mediate social interactions between disabled and nondisabled people (Branham and Kane, 2015b; Brewer and Piper, 2016; Gugenheimer et al., 2017; Storer et al., 2020). But, the success of adopting the Social Model in AC has also inspired explorations into other models of disability in AC, like Critical Realist (Frauenberger, 2015) and Political/Relational (Bennett et al., 2018) models, each with their own strengths. More broadly, the success of employing the critical approaches of DS in AC has inspired works adopting critical perspectives on topics like dementia (Lazar et al., 2017), aging (Vines et al., 2015), mental health (Ringland et al., 2019), independence (Bennett et al., 2018), and empathy (Bennett and Rosner, 2019). These recent works stand in sharp contrast to the traditional approaches to AC design research outline above in Section 2.1., which focus primarily on efficiency and individual users.

Despite the growing popularity of social and critical approaches to AC research, few works have examined domestic AC design research through these lenses technology design. But, those which have suggest social considerations of domesticity are relevant to AC design research. Dawe found nondisabled family members of cognitively disabled people should be understood as stakeholders in AC system design, because they may be responsible for device maintenance (Dawe, 2006). Branham and Kane found accessibility of domestic spaces for blind inhabitants depends upon the skills and empathy of sighted housemates, who, for instance, prepare spaces to be accessible for blind housemates by consistently orienting objects in agreed upon ways (Branham and Kane, 2015a). Although these works demonstrate

a need to further examine domestic AC design research from social and critical perspectives, there has not yet been in-depth exploration in this space.

## **2.3 Social and Critical Approaches to Domestic Digital Technology Design Research for Nondisabled People**

Today, the proliferation of a wide variety of digital technologies throughout our home environments is a largely mundane phenomenon. Yet, relatively recently, the intersection of homes and technology was a niche topic in HCI literature, filled with speculation about what particular considerations might be involved in realizing the vision of the “smart home.” Just over two decades ago, Debby Hindus issued a community-wide call for HCI and CSCW scholars to more fully explore domestic digital technologies, which, in 1999, had “received little attention within the research community” Hindus (1999). Hindus argued that the study of domestic technologies differed from the study of technology in corporate settings in three primary ways. Firstly, because homes are not workplaces, their physical infrastructures may not be designed with digital technologies in mind. As early as building construction, many workplaces benefit from the professional expertise of technologists in planning, installing, and maintaining digital technologies and their supporting infrastructure. But these tasks may be expensive, time-consuming, and altogether infeasible for home consumers. Secondly, and similarly, because consumers are not knowledge workers or technologists, their motivations for purchasing technologies likely differ. In professional settings, purchases are primarily driven by productivity concerns. Home consumers are more likely to consider aesthetics, fashion, and self-image, in addition to a technology’s functional aspects. Lastly, families are not organizations with rigid policies and strict hierarchies. The decision-making processes

involved in deciding which technologies to purchase and how to use them happen quite differently in families than in workplaces, even varying across individual families.

Because of these particularities of domestic environments, the methods and approaches employed in understanding domestic technology adoption and use must be fundamentally different from those which are commonly used to understand public and professional technologies. In particular, domestic design research methods often place primary importance upon identifying individual and collective experiences of an environment through rich and open-ended elicitation techniques, and upon designers adopting an interpretive and deeply reflective stance. For instance, Gaver, Dunne, and Pacenti developed Cultural Probes as a method for designers to gain insights into the environments in which their users reside Gaver et al. (1999). Cultural Probes are packages of materials designed to provoke inspirational responses from participants. Building upon Gaver et al.'s Cultural Probes, Blythe et al. developed the Technology Biography, a field study technique for inquiring into technologies' roles in the home Blythe et al. (2002). Technology Biographies adopt a past/present/future orientation towards requirements elicitation of products developed for home use, in which participants are asked to identify past developments and historical trends of importance, their current uses of domestic technology, and concerns, problems, and by implication, desirable future developments. More traditional research methods, like ethnography, are also employed in studies of domestic technologies (for example, (Crabtree et al., 2012; Irani et al., 2010; Strengers et al., 2019)). Though such ethnographic studies often contribute descriptive behavioral insights, rather than prescriptive design recommendations, they share a similar recognition of the situatedness of domestic environments.

For these reasons, in HCI research addressing nondisabled people, domestic spaces are understood as a particularly nuanced context for technology design, which can be explored from a multiplicity of perspectives. A recent review by Desjardins et al. found HCI has as many as seven different genres of research on domestic technologies, each with unique goals and

metrics of success (Desjardins et al., 2015). Some approach domestic spaces primarily as a testing site for novel smart-home technologies (Brush et al., 2011; Kidd et al., 1999). Others examine them as a site of interpersonal connection and intimacy (Branham and Harrison, 2013; Judge et al., 2010, 2011). Still others approach domestic spaces as a context with embedded sociocultural values, impacting technology design and use (Bell et al., 2005; Bell and Dourish, 2007).

Although these perspectives of domestic spaces in HCI are diverse, they are not necessarily discretely bounded. Many empirical works indicate connections between disparate social considerations of domestic spaces. For instance, technologies which negatively impact commonly held values, like privacy, can be tolerated if they increase familial connection (Judge et al., 2010). Technologies for managing domestic labor, like shared calendars, can impact interpersonal relationships by prompting negotiations about sharing content (Thayer et al., 2012). Technologies designed to increase interpersonal connection, like teleconferencing, can introduce domestic labor, like tidying the space in a webcam’s view (Ames et al., 2010). Divisions of labor involved in maintaining digital technologies are affected by larger societal values, like gender norms (Rode, 2010). Domestic technologies can even affect perceptions of social roles within a family, for example, by altering conceptions of how to be a “good parent” (Mazmanian and Lanette, 2017). Because of these complex social factors impacting domestic technology design, Bell et al. (Bell et al., 2005) recommend adopting a deeply reflective and critical stance when working in domestic spaces, to develop holistic understandings domestic technology design.

The finesse required in domestic technology design research is well established in HCI literature addressing nondisabled people. But, social and critical approaches to domestic AC research remain rare. So, it is unclear how social considerations of disability in domestic spaces exist alongside, intersect with, or extend beyond those identified in prior studies of nondisabled people. This dissertation probes this domain.

## Chapter 3

# Blind Adults' Perspectives on Social Considerations of Domesticity Relevant to Accessible Computing Design Research

The first contribution of this dissertation is an examination of blind adults' perspectives on social considerations of domesticity relevant to AC design research. To understand these perspectives, I conducted two separate studies of domestic technology use with blind adults.

In the first study, I explored the experiences of blind parents facing inaccessibility when reading books with children, a routine parenting activity for many sighted parents. To understand these experiences, I conducted a qualitative content analysis on set of social media posts, discussing shared reading between blind parents and their children, posted to a blind parenting support group. Within this data set, I probed specifically for ways in which both social and material factors shaped the reading techniques that were desirable

and suitable for making shared reading accessible.

In the second study, I explored the experiences of blind intimate partners with sighted partners in choosing whether to adopt voice assistants (VAs), which are accessible to both blind and sighted people, in their homes. To understand these experiences, I conducted paired-interviews with cohabiting intimate partner pairs, in which one partner was blind and one was sighted. I asked each pair, broadly, about how they used VAs in their daily domestic lives, how the accessibility of shared VAs impacted domestic routines, and the way that pairs arrived at the decision to purchase and adopt VAs in their homes.

Across both studies, I examined commonalities in the types of social factors that blind adults identified as relevant to domestic AC system design research. I found that both blind parents and blind partners indicated ways that their choices about, and requirements for, domestic digital technologies were shaped by 1) a desire to contribute to the household, 2) responsibilities of caring for other disabled and nondisabled family members, and 3) a fundamental need to exercise autonomy and agency in domestic activities.

The remainder of this chapter is structured as follows: I begin by providing relevant background for understanding my decision to examine blind adults' roles as parents and intimate partners. I then describe each study separately, providing background motivation for executing each study, research methods used, findings, discussion of how those findings inform the domain each addresses, and a critical analysis of the social considerations relevant to domestic AC design research that each study highlights. After detailing each study separately, I conclude the chapter by synthesizing the studies, to examine higher-level commonalities in the social considerations relevant to domestic AC design research which are present in both studies.

## **3.1 Parent and Partner as Social Roles**

Social roles within families, like “parent” (Mazmanian and Lanette, 2017) and “partner” (Rode, 2010), are known to impact and intersect with digital technology use within homes. It is for this reason that, in this dissertation, I examine blind adults’ perspectives on social considerations relevant to domestic AC design research across two studies, each of which examines a unique social role that blind adults may occupy within a family, specifically, as parents and as partners. But, the social roles of parents and partners also have unique sociocultural and individual meaning, because of their centrality to defining family structures and influencing individual well-being and self-efficacy.

### **3.1.1 Parent and Partner Relationships and Family Structure**

The social roles of parent and partner form the basis for analyzing family structures in many traditional Sociological approaches to understanding families. For instance, a common feature of Sociological studies of families is a distinction between “family of orientation” and “family of procreation” ((Adamek and Koller, 1984; Bhandari, 2018; Quinn and Keller, 1981), for example). A family of orientation refers to the family into which an individual is born, and is therefore defined primarily by the relationship to one’s parents. A family of procreation refers to the family that a person forms with a partner, traditionally through marriage, for the purpose of childbearing, and is therefore defined by both partner and parental relationships.

In contemporary Sociology, however, the changing nature of families over time—for example, through the increasing prevalence of same-sex couples, single-parent families, adoption, blended and step-families, polyamory, and voluntary childlessness—has prompted questions about whether classifications of family structure have utility for Sociological studies of fami-

lies, and whether “families” are an appropriate unit of analysis for Sociological inquiry, at all (Turner, 2005). Still, because parent and partner relationships form the basis of many common understandings of what social roles and relations define a family unit, my dissertation focuses on blind adults who occupy these roles of parent and of partner.

### **3.1.2 Well-Being and Self-Efficacy in Social Roles as Parents and Partners**

In addition to forming a defining feature of family units, parent/child and intimate partner relationships and the successful occupation of parent and partner social roles are known to impact individuals’ self-image. Perhaps the best known articulation of the relationship between individual self-image and the successful occupation of social roles is Albert Bandura’s theory of self-efficacy (Bandura, 2010). Self-efficacy refers to the degree to which one believes that one is capable of operating effectively within a given context.

Self-efficacy is an important component of individual well-being. Outside of specific contexts, general feelings of self-efficacy are associated with increased abilities to cope in stressful situations and positive psychological health (Bandura, 2010). Similarly, parenting self-efficacy, or the belief that one is an effective parent, has been associated with reduced levels of stress in daily parenting activities, even if children’s problematic behaviors are not resolved (Bloomfield and Kendall, 2012). Likewise, feelings of self-efficacy in romantic relationships, or the self-perception that one has the capability to meet the demands of romantic relationships, predict long-term relationship success and satisfaction (Riggio et al., 2013).

Self-efficacy, in either parenting or romantic relationships, is not analyzed further in this dissertation and examining feelings of self-efficacy is not a core goal of my analysis. Instead, this discussion of self-efficacy is intended to demonstrate how the occupation of social roles in families, specifically as parents and as partners, is not simply a matter of defining often-



arbitrary classifications of family units (as in Section 3.1.1.), but also of personal, individual well-being.

## 3.2 Blind Parents’ Perspectives on Social Considerations of Domesticity Relevant to Accessible Computing Design Research

My exploration of blind parents’ perspectives on social considerations of domesticity relevant to AC design research arises from a study of blind parents’ experiences of facing, and techniques for overcoming, inaccessibility when reading books to and with their young children. This study was originally published with the title *“That’s the Way Sighted People Do It”: What Blind Parents Can Teach Technology Designers About Co-Reading with Children*, at the 2019 ACM SIGCHI Conference on Designing Interactive Systems, where it was awarded an Honorable Mention for Best Paper (Storer and Branham, 2019).

Here, I share background, methods, and findings of this work in relation to blind parents’ experiences of inaccessibility in shared parent/child book reading, often called “co-reading,” in Sections 3.2.1.–3.2.3. Then, in Section 3.2.4., I describe how approaching the findings of this study through a socially-oriented analytical lens surfaces and highlights broader social considerations relevant to domestic AC design research, exemplified in the case of inaccessibility for blind parents when co-reading with their children.

### 3.2.1 Study Background

#### Parent/Child Co-reading

Co-reading—when parents read aloud with their children—has been shown to be an effective activity for developing literacy skills and interests in young children (Mason, 1990). A 2011 meta-analysis of 99 studies on children’s leisure time reading associated early print exposure with improved reading comprehension, technical reading and spelling skills, oral language skills, and lifelong academic achievement (Mol and Bus, 2011). Reading together offers unique opportunities for parents to model reading behaviors, and for dialogic engagement (when parents ask additional questions, and prompt discussions about a story external to its content) (Whitehurst et al., 1988), which helps children to connect with, and make sense of, texts (Doyle and Bramwell, 2006).

For many parents, co-reading with their young children is a simple and routine aspect of daily parenting activities. More than half of children under eight years of age read, or are read to, for 30 minutes or more per day (Common Sense Media Research, 2013). Co-reading is widely identified as a fun bonding activity by both parents and children (Scholastic, 2015). However, for blind parents, co-reading may pose particular accessibility barriers, because most printed text requires vision to read.

Digital technologies could help make co-reading more accessible to blind parents. But, recent shifts in the types of available reading materials, specifically from paper to digital media, have raised concerns about young children’s literacy development amongst literacy scholars. Today, children’s in-home literacy development involves engagement with a wide variety of interactive technologies (Marsh, 2004). While many scholars hail the opportunities afforded by emerging technologies like the iPad (Flewitt et al., 2015), others argue that interactive technologies remove children from the benefits of traditional methods of teaching literacy

(House, 2012). How digital technologies may affect co-reading has also been a point of debate. Several studies have examined how the literacy development benefits of co-reading may be impacted by introducing digital media (Chiong et al., 2012; Fisch et al., 2002; Kim and Anderson, 2008; Krcmar and Cingel, 2014), with mixed results.

The use of digital reading technologies for educational purposes has been discussed extensively by literacy scholars (see (Miller and Warschauer, 2014) for a recent review). The use of digital technologies in co-reading has been the subject of a smaller, but still substantial, body of work in the domain of education. Often, such studies of digital technologies and co-reading, like those of Fisch et al. (Fisch et al., 2002) and Kim and Anderson (Kim and Anderson, 2008), examine parent-child interactions, across digital and print formats, where disability is not examined. Several literacy scholars, like McClanahan et al. (McClanahan et al., 2012), and Peppler and Warschauer (Peppler and Warschauer, 2011), have rightly identified the potential for digital reading technologies to support the educational needs of disabled people. But they focus primarily on disabled children, rather than disabled parents. More broadly, and in contrast to this study, studies of digital technologies in education-oriented disciplines concern evaluating the educational efficacy of reading technologies as they are presently designed. I focus instead on examining current co-reading practices, to consider how digital technologies might support these activities.

In HCI and Interaction Design, supporting co-reading has been the subject of a small, but growing, body of literature. Cingel and Piper (Cingel and Piper, 2017) investigated the use of haptic feedback in parent/child co-reading practices. They found integrating haptic feedback into e-reading technologies increased dialogic engagement, but may reduce parents' narrative expressivity. Similarly, Raffle and colleagues (Raffle et al., 2010, 2011) have explored familial co-reading at a distance, by designing augmented teleconferencing systems like StoryVisit. They describe design implications for shared family activities, like creating a playful UI, allowing single users to take ownership over other family members' accounts, and using

a story's content to structure co-reading activities. But, outside of the study described here, researchers have not yet examined how parent/child co-reading practices may differ for disabled parents or, more specifically, blind parents.

## **Reading, Print, Braille, and Blindness**

Reading printed text presents inherent accessibility barriers for blind people, because print relies strictly upon visual sensory channels to relay information to readers. Perhaps the best known alternative to printed text is Braille, a form of writing in which characters are presented as a unique combination of raised dots that made be read through touch. Unfortunately, Braille is far from a universal or perfect solution to the inaccessibility of printed text for blind adults; gaining access to Brailled reading materials can be challenging, and even then, fewer than 10% of blind adults read Braille (National Federation of the Blind, 2015). At the same time, Braille is not only a tool for providing nonvisual access to written text, but carries specific cultural meaning and significance for many blind people. More specifically, Braille literacy is associated with higher socioeconomic status amongst blind adults. Only 32% of blind adults in the United States are employed, and 93% of those blind adults who are employed read and write Braille (Faherty, 2006). Likewise, a 2015 survey of more than 1,000 legally blind adults found that those who read Braille on a weekly basis had an increased likelihood of both being employed and receiving a higher salary than those who do not read Braille (Bell and Mino, 2015). Similarly, a survey of 443 legally blind adults found that Braille readers had higher self-esteem and life satisfaction than those who had never learned Braille (Silverman and Bell, 2018).

Yet, despite the known benefits of Braille literacy for blind adults, there is reason to believe that Braille literacy rates may not increase in the near future. In fact, many of the same aspects of digital reading materials which prompt concerns about impacts on print literacy for children also prompt concerns about impacts on Braille literacy for blind people of all



Figure 3.1: Examples of how PWVI might read a book. From left to right: (a) Traditional Braille books are written as raised characters on high-quality paper, (b) Twin-vision books are written in both print and Braille, which, here, appears beneath the printed text, (c) Refreshable Braille displays dynamically raise Braille characters to display digital text, and (d) Text-to-audio technologies, like audiobooks, or e-books read by the iOS native screen-reader VoiceOver, can be used to vocalize digital texts.<sup>1</sup>

ages. Though Braille has been a principle reading format for blind people for over 200 years (National Federation of the Blind, 2009), the availability of consumer-grade text-to-audio technologies for blind people have created new opportunities for making printed information more accessible. Figure 3.1 shows only a few examples of the variety of tools available to blind people, for reading in the digital age. Screen-readers, which read aloud textual content of personal computer windows are becoming increasingly common. For instance, Apple’s screen-reader VoiceOver comes standard on their devices. Advances in automated character recognition even allow mobile applications, like SeeingAI, to interpret and translate real-world text to synthesized speech. Some digital reading technologies for making text accessible incorporate Braille in their outputs, like refreshable Braille displays which can convert digital text to Braille on a flexible membrane display. But, the increasing availability of text-to-audio technologies has contributed to views that Braille is obsolete (Johnson, 1996) and have been used to justify a decline in Braille education (Faherty, 2006) and Braille literacy rates (Rex, 1989).

However, the notion that blind people should rely primarily on auditory channels to obtain

<sup>1</sup>Image Attributions: (a) “A person reading a braille book with two fingers” by antonioaxalonso is licensed under CC BY 2.0, (b) “Braille” by Roland DG Mid Europe Italia is licensed under CC BY 2.0, (c) “Une page braille utilisée avec un netbook” by Sebastien.delorme is licensed under CC BY-SA 3.0, (d) “1st generation Apple iPad showing iBooks, with the book Alice’s Adventures in Wonderland” by Evan-Amos and “Alice’s Adventures in Wonderland” by Lewis Carroll are of the public domain.

information has led prominent advocacy groups, like the National Federation of the Blind (NFB), to sound the alarm on the “Braille Literacy Crisis in America” (National Federation of the Blind, 2009) and call for specific action to increase Braille education for blind children and adults. Of course, text-to-audio technologies are not solely responsible for declining Braille literacy rates. But, the Braille Literacy Crisis speaks to extant concerns that text-to-audio technologies may affect the nature of literacy and emphasizes the particular significance of such debates for blind adults (Alper, 2000). The importance of literacy for sighted people has long been recognized—and should be for blind people, too. Put succinctly:

If we were to propose that sighted children no longer needed to learn to read and write, that they could get all their information from radio, television, or tapes, the idea would be rejected immediately. (Johnson, 1996)

Given this context, it is clear the stakes of designing reading technologies are disproportionately high for blind people. Yet, disabled people, like blind adults, are often not included in the beginning stages of design (Churchill, 2018; Shinohara et al., 2018).

In this study, I examined the co-reading experiences of blind adults, not only to forefront accessibility in the design of future technologies—but because the creative workarounds used by blind adults, and their perspectives on literacy development in a time of declining Braille education, offer unique insights into the diversity of co-reading practices, and the cultural significance of literacy and parent/child co-reading. While this work does not directly address Braille literacy, the perspectives on literacy development through co-reading shared by blind parents in my sample are shared against the social and cultural backdrop of the present Braille Literacy Crisis, and the social and economic importance of literacy for blind people.

## **Disability and Parenting**

In addition to the importance of being a parent and parenting, in terms of understanding societal family structures and individual well-being, it is imperative to acknowledge that parenting carries additional significance in the context of disability. Specifically, disability is often used as a justification for discriminatorily revoking fundamental parenting rights from disabled parents. Disabled parents are more likely than nondisabled parents to have their children removed from their home by Child Protective Services, and are less likely to gain custody and visitation of their children in legal disputes (National Research Center for Parents with Disabilities, 2017). Additionally, 35 of 50 American states have enacted laws which permit the denial of parent rights to disabled people, strictly on the basis of their being disabled (parentalrights.org, 2018). So, disabled parents facing the removal of their children from their home and custody have very little, if any, recourse for challenging discriminatory patterns in the United States' family law system.

### **3.2.2 Study Methods**

#### **Content Analysis of Extant Data**

To examine blind adults' experiences of facing, and techniques for overcoming, inaccessibility when co-reading with their children, I conducted a content analysis of extant data posted on social media. Content analysis refers to the study of documents, often of textual artifacts (Krippendorff, 2018). Extant data refers to data which exist prior to research being conducted, that have been created for purposes other than research (Charmaz, 2006). Extant data stand in contrast to elicited data, which are created through the process of conducting research, in service of that research. Content analysis of extant data has been proposed as a particularly valuable method of inquiry for research concerning disabled people (Abdol-

rahmani et al., 2020), because disabled populations are difficult to recruit and, as such, are often oversampled and overtaxed by participation in elicitation studies with questions that could be answered through alternative means, which are less burdensome to participants. Here, content analysis was performed on a set of extant data collected from a Facebook group dedicated to discussions of blind parenting.

## **Participant Demographics**

One limitation of conducting content analysis on extant data is that it is difficult to determine participant demographics, because demographic information cannot be elicited from the individuals who are observed. In this case, the Facebook group that was observed is described as serving “blind parents,” and as such, I refer to this group as BPF (Blind Parenting Forum) for anonymity, and refer to its members as “blind,” as it is aligned with the way that this group identifies itself. However, this should not be interpreted as indicating any one member’s specific identities or abilities, as the visual acuity of the parents described was observed to be highly diverse, and the insights shared speak to a wide range of visual abilities.

At the time of this study, BPF had more than 1,500 members and was a very active community, with new posts daily. Because BPF is a closed Facebook group, two members of the research team requested access to the group and were admitted. The second author of the original publication messaged the moderators to describe the study and request permission to observe the discussions occurring on this page. Two admins responded granting permission, and BPF members were informed of the presence of our research team in multiple public posts to the group. I note that it is not typical for this particular group to admit sighted members. So, the posts I observed were written primarily *by* blind parents, *for* a blind parenting audience. This allowed me to identify aspects and difficulties of co-reading which are particularly salient, from the perspective of the blind parenting community.



## **Data Collection Procedure**

To collect a corpus of extant data relevant to inaccessibility in co-reading, a research assistant used Facebook’s integrated search feature to query all posts containing the keyword “read”. I then reviewed each of these posts and all comments posted in reply to them. Posts returned by this search that were not related to co-reading with children were removed from further analysis (e.g. Adults reading Braille alone, children playing with sticker books). Data were gathered and analyzed in one-month intervals, moving backward through time until the point of data saturation, in which no new insights are gained from additional collection (Fusch and Ness, 2015), was reached. In total, the analyzed corpus was comprised of 497 unique posts and comments, from 229 unique users, during the 16 months from June 2017 to September 2018. For anonymity, I refer to these BPF users here as BPs (blind parents) 1–39, and use singular they/them pronouns to refer to both parents and their children.

## **Analysis Procedure**

To identify salient themes within the corpus of collected extant data, I conducted a thematic analysis of these BPF posts (Braun et al., 2014), following an inductive approach, using iterative comparisons of the themes and codes (sub-themes) applied. I refined my themes and codes until they accurately encompassed the structure and details of all data in the corpus. Themes and codes were refined and discussed with other research team members. My analysis was guided by three primary research questions: 1) Which practices, strategies, and methods do blind parents use to co-read with their children? 2) How do blind parents determine which specific co-reading methods to use? 3) How does blind-parent/child co-reading, as an activity, inform the design of AC systems, more broadly?

### 3.2.3 Strategies for Co-reading Accessibility

In the corpus of collected extant data, I identified 312 references to specific co-reading practices. These include seeking advice, providing tips, sharing personal methods, and debating the merits of a particular co-reading strategy.

Here, I use this analysis only to identify the range of practices discussed by blind parents, rather than to indicate preferences for any specific method. That some practices appeared in the data more frequently than others shows that those practices are more widely *discussed* by blind parents, but not necessarily more widely *used*. I note that the practices identified are not discrete, nor are they exclusive of each other. Often, a combination of these methods was used to co-read. I provide an overview, here, of the diverse methods identified.

#### Braille

Braille was by far the most referenced method for co-reading in our data. In total 137 comments discussed using Braille for co-reading, comprising nearly half of all references to specific practices identified. Strategies for co-reading using Braille included: using two copies of the same book in Braille and in print, using twin-vision books in which Braille is written alongside print, reading digital materials with an external Braille display, and applying Braille overlays to print books. Despite the low and declining number of people who read Braille (discussed above in Section 3.2.1.2.), Braille is often the default recommendation for blind parents seeking advice for co-reading. A large portion of advice-givers first inquired “Are you a Braille reader?” before offering other options to advice-seekers.

## Text-to-Audio Technologies

Text-to-audio technologies were a frequently identified strategy for co-reading (99 comments), but the individual technologies used varied. Audiobooks were most commonly discussed, likely because of the mixed opinions on these technologies. Audiobooks are frequently recommended because they are particularly accessible. But many BPF members feel they are “just not the same” as paperback books. Similarly, borrowing books-on-tape or CD-ROM from the local library, or using interactive e-books, were often viewed as subpar options. Text-to-Audio technologies were perceived negatively for a variety of reasons—many parents found the presence of a narrator is obtrusive to parent-child bonding, others felt being able to read to one’s own child is an important part of their self-efficacy, and some simply found certain narrators’ voices irritating. Some clever parents, like BP1, augmented these technologies by listening to audiobooks through a headphone, and repeating the words they heard to their child, noting the importance of allowing “*your* [children to] hear *your* voice and *your* interpretation” (emphasis added).

Other text-to-audio technologies have significant technological barriers, in addition to being “just not the same.” For instance, Voiceover (Apple’s integrated screen reader) and SeeingAI (a 3rd party mobile application, which vocalizes text in an image) are only able to determine the semantic content of texts written in certain fonts. Children’s books, in particular, use a wide variety of unusual fonts to engage children’s attention. BP2, a veteran user of SeeingAI, expressed disappointment that the app cannot read many books’ contents, though it can “at least read the cover of the book.”

## Alternative Methods

Though Braille and text-to-audio comprised the vast majority of comments concerning specific co-reading methods, several other strategies were shared and regularly portrayed more

positively in discussions.

Often, expectant and new parents perceived the impetus of co-reading to be solely upon themselves—but more experienced parents suggested *having the sighted child read*, instead (17 comments). BP3, replying to a parent concerned about their ability to co-read with their first, newly literate child, soothed their fears suggesting, “I think your [child] will be more helpful than you realize. Once [they] learn the letters, [they] will be able to read them back to you, so that you know what the word is... This works well for my [child].”

While blind people are often perceived as a homogenous group, defined by their visual impairments, many BPF members (16 comments) identified using *eyesight* as a technique for co-reading, or for scaffolding other co-reading methods. For instance, BP4 listens to audiobooks on headphones, repeating the story back to their child, using their partial vision to support this practice. They state, “I can see pictures fairly well, so... I can stay on the right page!”

Frequently, parents indicated the benefits of *telling imagined stories* (14 comments). This practice, too, was often scaffolded by blind parents’ partial vision. For instance, BP5 suggests “if you can see the pictures... just make up a story corresponding to [them].” Though it could be debated whether fabricating a story can be considered co-reading, this practice was identified as central to many parents’ co-reading methods. Some parents even flipped the pages of a book while telling oral stories, to mimic reading the words printed on the page.

Because children’s stories are relatively brief, many parents found it easiest to *memorize* the story, and repeat it verbatim to their child (12 comments). These parents may listen to an audiobook version of their child’s printed book, or have a sighted companion recite the book to them, until they have memorized its contents. BP6 jokingly noted, “My eldest is twenty-three [years old] and I could still recite some of [their] board books!”

Several parents suggested finding *read-aloud videos on YouTube* (12 comments). This strat-

egy is particularly advantageous for engaging young children because “[the reader] will show you the pictures [in] the book while they read it” (BP6). Still, some parents were skeptical of YouTube read-alouds, including BP7, who stated “it’s just not the same as sitting down on the side of [my child’s] bed, tucking [them] in, and reading a good old hardcopy book.”

Lastly, the least common method identified in our data, was *deferring co-reading responsibilities to a sighted companion* (5 comments). It is not insignificant that this method was the least frequently discussed. Co-reading with one’s own child holds a particular significance for many parents, and likely for those in our group—evidenced by BP1’s (and others’) insistence on having their child hear their own voice and interpretation, as described above.

### **3.2.4 Factors Impacting Strategy Selection**

I found that a wide variety of factors affect which techniques are desirable, accessible, and eventually incorporated into parent-child co-reading practices. For many blind parents, I found that parents’ motivation to co-read determined which methods were perceived as desirable and effective. Which methods were feasible depended on both the parents’ abilities, and socially-supportive others’ abilities to scaffold parent/child co-reading practices. However, which methods were ultimately implemented was primarily determined by the availability of reading materials from commercial publishers—and the choice of a publisher was itself influenced by a variety of consumer concerns.

#### **Motivation to Co-read**

The motivation for engaging in co-reading determined which co-reading practices were seen as desirable, and how the effectiveness of these practices was evaluated. Sometimes the motivations of parent and child conflict. The parents in my sample were most often driven

to co-read to 1) contribute to their child's pre-literacy skill development, or 2) partake in an intimate, bonding activity with their child. Their children, unsurprisingly, often just wanted to have fun.

Parents primarily motivated by developing their child's pre-literacy skills often used methods which prioritize the accurate coupling of the book's written content, and the words spoken by the reader. For instance, read-aloud videos posted on YouTube were a common suggestion for parents concerned about their child's ability to read. BP8, giving advice to another parent, suggested to "search for 'read aloud' or 'story time' on YouTube and [you'll find] videos of people reading kids' books aloud, and they show the [book]... Tons of parents of print learners do this and they learn to read just fine." BP9, too, noted that "videos on YouTube of other parents reading picture books to kids... got me through the phase where they needed to see the book as we read." Similarly, these parents were more likely to defer their child's co-reading activities to someone else, like BP8, who suggested parents "have sighted friends or family read books to [their child] over Facetime."

But, many of these methods proposed by parents motivated by pre-literacy development were viewed unfavorably by parents seeking bonding time with their child. BP10 voiced reluctance, stating "I've been having to resort to those read aloud books on YouTube, which is just not the same." Even parents who deferred the bulk of their child's co-reading time to a sighted other often wanted to personally co-read with their child. BP11 shared, "[my spouse] is sighted and usually will read the books, but it is something that I would like to do, also."

While audiobooks were a frequently suggested method for co-reading, they were perceived negatively by both parents aiming to develop their child's literacy skills, as well as parents seeking bonding time with their child. BP12, an expectant parent, stated, "I would absolutely love to read to my child when they get here, but I don't feel like putting in an audiobook is appropriate at all. It doesn't give *that intimate vibe* to me" (emphasis added).

Conversely, BP13 expressed skepticism of the educational merits of audiobooks, saying, “I don’t know about using too much that is only audio in the early years. They could miss out on a lot of fundamental visual learning that way.”

In contrast, the advantages of simply making up a story were advocated by both types of parents. BP1 suggested parents make up a story, while performing reading behaviors, like flipping pages. While they note “this really only works with really small children who don’t yet understand that the words on the page meant anything... it does allow you to teach your child some valuable pre-literacy skills, like learning what books are, how to turn pages, how to read from left to right in a sequence... etc.” Similarly, BP14 notes the advantages of oral stories for bonding, suggesting that it is “the communication between parent and child that matters most. So, go ahead and make up your own words to the book. Your baby will love it!”

Braille was also perceived as meeting both parents’ pre-literacy and bonding goals, especially using twin-vision books, which closely resembles the co-reading practices of sighted parents with sighted children. Some parents, especially expectant parents, like BP15 expressed concern about “being able to point at the words” while reading twin-vision books, where Braille and print are spatially separated. But more experienced parents, like BP16 reminded them that simply because “that’s the way *sighted people* do it, that doesn’t mean it’s the *only way* to do it, by any means” (emphasis added). Additionally, children’s desire to be entertained often complicated reading Braille in twin-vision books. BP17 shared, “[my child] was always pushing my hands out of the way to see the pictures, so I gave up.” Likewise, BP18, a professional Braille teacher, notes “I’ve been able to read one-handed and upside-down for some time... but I’ve never had a little reader steal pages from me!”

Parents often make the final determination of which co-reading practices to use. But, in this way, children’s motivation to be entertained by a book may prevent parents from choosing strategies which meet only their own goals. The effectiveness of a particular co-reading tech-

nique, then, depends on how well it meets both parents' and children's individual motivations for co-reading.

## **Parents' Abilities**

Perhaps surprisingly, I found eyesight was a frequently identified component of co-reading—emphasizing that blind people do not have uniform (dis)abilities, or necessarily total visual impairments. For example, some parents who can see book illustrations used pictures as reminders of a story's content, while they recited a book from memory.

In the context of co-reading, ability to read Braille was far more significant than parents' vision impairments in determining which co-reading techniques were feasible. Several parents noted the importance of reading Braille for gaining access to the sizable selection of Brailled children's books. Providing advice to a parent concerned about the limited selection of accessible books that do not require Braille skills, BP19 stated, "These [other methods] are all very good suggestions, but this is a very good reason to learn Braille... Ultimately, I think Braille is the best solution for this dilemma [of finding accessible reading materials]."

However, reading Braille is far from a universal skill amongst people with visual impairments. In particular, for people whose visual impairments were not present at birth, Braille reading may be a relatively new skill. The present importance of Braille for finding accessible co-reading materials inspired some parents to learn Braille. BP20 shared, "I've had to learn [Braille] as an adult and it's never been that easy. Each month, when [my child and I] get a new book, I see it as a chance for me to practice... it's been beautiful how both of us have the chance to learn to read together." For other parents, reading Braille is unfeasible for other reasons, like BP21 who indicated, "even though I learned Braille, due to a nerve condition, it is very tedious for me to read, even preschool books." Despite the many reasons a parent with visual impairments may not be able to read Braille, much of the currently available



“accessible” reading material privileges this skill.

### **Others’ Abilities**

Which co-reading methods were available was not determined solely by the abilities of the blind parent, but also by the abilities of others who might participate in, and support, accessible co-reading practices.

Most directly, as children’s literacy skills developed, they were able to either scaffold their parent’s reading by spelling the first words on a new page, or children may take the primary role in performing most of the reading themselves. BP22 suggested, “when they know how to read a little bit, have them read it with you and make it a game,” to continue advancing children’s literacy. As children’s literacy developed further, some parents facilitated their child’s education by performing co-reading tasks in everyday settings. BP23, for instance, attributed their child’s advanced literacy to their visual impairments, saying, “I was always getting [my child] to spell things to me so that I could know what it said and then eventually [they could] read to me short, little things, like in the grocery store.” Similarly, BP24 shared, “[my child] reads the numbers on the doors to find [their] doctor’s office. [They] also spell out signs to us when we are in a car,” adding jokingly, “[they’re] really good at reading the Toys‘R‘Us sign!” While co-reading, here, has a different connotation than co-reading a book, it shares many of the same practices. Parents facilitate their child’s learning by encouraging them to read real-world materials, and can correct their child’s reading, when they feel a misidentified food item, or hear a well-known retail chain’s name mispronounced.

However, children’s developed literacy did not always increase the number of methods available to the parent-child team. Sometimes, it obsolesced previously used methods. For instance, BP25 indicated, “when my [child] was younger I [could] read Braille to [them], but now, since I’ve learned Braille as an adult and I’m not very proficient, [they are] much more

fluent in print than I am in Braille and [they tire] of my slow reading rate.”

External to the parent-child team, other socially supportive adults may also contribute to making co-reading accessible. Sometimes, social supports contribute directly, by reading to the child books which are otherwise inaccessible to the blind parent. For instance, BP26 shared, “I can’t read the books [my child] brings home from the library, but we have family and friends who come over and read those books for [them, so they’re] still getting exposed to literature and reading.”

External social supports may additionally perform preparatory tasks to make co-reading accessible for the parent-child team. Applying custom Braille to children’s books ensures any book children may want to read is accessible to their parent. But this process is time consuming, and often requires a sighted companion to read and label the book. So, parents who used this method, like BP27, often suggested it is best saved for “when maybe you and your [spouse] have some time.”

In these ways, the co-reading methods available to the parent-child team, partly depended upon the abilities of the child and supportive others.

### **Availability of Reading Materials**

Motivation for co-reading and the presence of social supports determined which co-reading techniques were desirable and feasible. But which techniques were ultimately implemented depended primarily upon the reading materials available from commercial publishers. Each of the strategies identified (with the exception of making up stories), in some way, relied on the features of the printed or electronic materials used. Seeking a specific book or reading material format often led parents to initially consider certain publishers. However, selecting a source for purchasing reading materials was shown to be a complex decision affected by a number of common consumer concerns, and considerations specific to blind parents.

Some common consumer concerns, like quality and cost of the materials offered, affected parents' decision to purchase books from a publisher. Quality of the book's material was of particular concern for parents with young children. BP28 noted that they were looking specifically for "board books, because [my child] is only 15 months [old], and any paper [becomes] crumpled or torn."

Cost, too, is a concern for most consumers, but especially for blind parents of young children. Often, accessible formats, like twin-vision books, are more expensive than children's books written only in print. The cost of accessible books is prohibitive for many parents, like BP29 who expressed, "I glanced through [a well-known, twin-vision book publisher's] selection a while ago, but gave up pretty quickly based on the prices I saw." Also, as young children age and their literacy skills develop, their interests and reading levels change rapidly—meaning parents with young children buy new books frequently. BP30 noted, "even [for] those of us who [already] have a handful of books, kids get bored after a while."

The cost of acquiring materials was unreasonable for many parents, even leading some parents in this group to propose taking collective actions. Some shared their contact information, to form a book exchange club. One of these parents, BP31, noted, "we do probably have a lot of the same [books, but] even so, being able to borrow back and forth prevents each parent from having to actually buy each book new themselves." Others suggested submitting collective requests to publishers for specific accessible books. BP32 indicated, "I am thinking, maybe if we all requested some certain books, it would be more likely to be Brailled, [which might be cheaper than] how much more it costs to request a special Braille."

In addition to concerns about the quality and cost of book materials, many parents expressed concerns with the accessibility of acquiring books from certain sources. For instance, local libraries were frequently suggested as sources for free books. But, as BP33 noted, "it's not like sighted parents who can go to the library and refresh their supply easily." For many blind parents, especially in areas with limited public transportation, traveling to the library

is difficult, and may involve the support of a sighted companion.

Recognizing this issue, several non-profit organizations offer programs which deliver twin-vision children’s books to the homes of registered members. However, these programs typically have strict qualifications for who may register. Most often, these qualifications limit this service to blind children, rather than blind parents. Despite this, some parents worked around these qualification requirements to register. For example, BP34 stated, “I [registered] through a phone call, explained my situation, [and] they signed us right up!” But other parents felt a responsibility to the wider blind community, in observing these qualification requirements, like BP35 who indicated, “I just don’t want to take [resources] from blind *children*, as a blind *parent*, if you know what I mean” (emphasis added).

Many parents indicated a similar allegiance and responsibility to the blind community when considering the rapport of a specific source. In particular, parents specifically sought accessible book publishers who have rapport with the blind community—operated by blind people or owned by known friends and allies. For example, one publisher was recommended by BP36, because “it was set up by a dad who is blind [who] wanted to read stories independently with his children.” Similarly, another publisher who was a member of the BPF at the time of our observation, was frequently recommended because they are identified as a friend to the blind community and a personal friend of many BPF members. This publisher was recommended in 26 separate posts, by 17 unique BPF members, during our observational period.

While many of the considerations addressed above were identified in relation to acquiring printed books, purchasing electronic books involved many of the same considerations. In fact, purchasing electronic books presented unique considerations, in addition to those of acquiring printed books. For instance, some parents were irritated by the style of some e-book narrators. BP37 shared, “audio books are great, but I hate some voices and I hate paying for books, [when] I can’t listen to the narrator’s voice.” Consequently, many parents

preferred to use the familiar narration of Apple’s integrated screen reader, VoiceOver. But VoiceOver is not a perfect solution—“not all books are compatible with VoiceOver” (BP38), often due to unrecognized fonts, and some parents simply “have trouble with understanding VoiceOver” (BP39).

Parents must consider each of these factors when seeking a source from which to purchase accessible reading materials. The availability of materials which are 1) of good quality, 2) affordably priced, 3) accessible to acquire, 4) produced by reputable publishers and, often, 5) compatible other AC systems, affects which co-reading techniques can be used. While motivations for co-reading influence which techniques parents *prefer* to use, and the abilities of the parent and other social connections affect which techniques are *feasible*, I found the format and features of available materials most directly determined which techniques were *implemented*.

### **3.2.5 Social Considerations of Experiencing and Overcoming Inaccessibility in Co-reading for Blind Parents**

While the findings shared above have direct implications for designing AC systems for supporting accessibility in parent/child reading for blind parents, approaching these findings through a critical and socially-oriented lens also highlights ways in which social considerations and wider cultural factors impact and contextualize the perspectives that blind parents shared in BPF. Below, I discuss three ways in which my findings regarding the inaccessibility blind parents face in co-reading with their children surface larger social considerations in the design of technologies that are currently used, or may be designed in the future, to increase accessibility in this domain.

## Cultures of Reading and Blindness

Braille was, by far, the most discussed technique for co-reading with children in my corpus of BPF posts. On the surface, this is not surprising, as Braille is a very well-known method of rendering printed text accessible to blind readers. But, within the context of the ongoing Braille Literacy Crisis and the cultural importance of Braille for blind people, as described in Section 3.2.1., the frequent discussion of Braille in BPF is not insignificant.

Consider, for instance, BPF members prefacing their suggestions for co-reading techniques by first asking “Are you a Braille reader?”. On one hand, the answer to this question has direct implications for the types of techniques that might be feasibly suggested, particularly, whether Braille or twin-vision books are viable tools for parent/child reading. To ask about Braille, before even suggesting other methods, speaks to the continued importance of Braille and its particular appropriateness for accessible parent/child co-reading. On the other hand, the answer to this question provides insights into much deeper, and potentially stigmatizing, aspects of the advice-seeker’s lived reality. That is, for many blind people to be a Braille reader is to be *literate*, and an indicator of having had the privilege necessary to access Braille education and of having the privilege that being literate bestows. Asking whether an advice-seeker can read Braille is not simply a question about an individual’s ability to use Braille as a tool, akin to asking whether an individual can use Microsoft Excel; it is a question about the advice-seeker’s very literacy and a request for potential disclosure of socioeconomic status.

An additional indicator of the complex social and cultural context surrounding Braille in these data is the understanding amongst many blind parents in BPF that Braille education and Brailled media are scarce resources. Consider BP35, who indicated, “I just don’t want to take [resources] from blind *children*, as a blind *parent*, if you know what I mean” (emphasis added). Here, the statement that applying for a Braille book subscription (for which BP35

qualifies) is *taking from* a blind child speaks to the notion that Braille education and Brailled media are limited, and if one person receives them, someone else will not. In this case, it is interesting that BP35 chooses not to apply for these services, given their access to this subscription service would reduce barriers to their own child's literacy development. In this sense, this scenario represents one parent weighing the literacy development of an imagined blind child against that of their own child or, at least, against BP35's ease of participation in their own child's literacy development. In this scenario, BP35's obligations and responsibilities of belonging to the wider blind community are weighed against the obligations and responsibilities of being a parent which motivate BP35's desire to read with their child.

Perhaps most importantly for this discussion, these nuanced understandings of data concerning Braille, which are gained by adopting a critical and socially-oriented lens in analysis, have implications for AC system design. From a strictly technological perspective, the frequent discussion of Braille in BPF might suggest that creating a system which displays children's books as Braille is an appropriate approach for increasing accessibility in co-reading. However, given that Braille is accessible to very few blind adults—and typically those with the most status and privilege—it is not clear Braille-oriented solutions are appropriate. At the same time, given the understanding amongst blind parents in this sample that Braille literacy is important—and the knowledge that text-to-audio technologies contribute to the Braille Literacy Crisis—it is also not clear that technologies which serve as workarounds for Braille illiteracy are appropriate, either. Rather, in the context of co-reading, AC system designers may need to consider the potential social impacts and tradeoffs between systems which are accessible to only a small and privileged group of Braille readers and those which are accessible to wider audiences of blind adults, that may inadvertently make Braille education even more scarce.

## Sighted Norms of Parenting

A recurring theme across BPF posts created by parents seeking advice about co-reading techniques for blind parents was feelings of anxiety arising from a perception that blind parents are, in some way, unable to adequately read with their children. Interestingly, when expressing feelings of falling short, many parents alluded to an idealized form of parent/child co-reading in their assessments of the merits of accessible co-reading techniques suggested. For instance, BP12, an expectant parent, stated, “I would absolutely love to read to my child when they get here, but I don’t feel like putting in an audiobook is appropriate at all. It doesn’t give *that intimate vibe* to me” (emphasis added). Similarly, BP10 shared, “I’ve been having to resort to those read aloud books on YouTube, which is *just not the same.*” (emphasis added). In each case, BPF members expressing skepticism about the merits of a given co-reading technique indicate that the accessible technique suggested, in some way, does not compare favorably to some other implicitly referenced method for co-reading.

However, other parents who expressed similar anxieties about the inadequacies of suggested co-reading techniques were more explicit in their comparisons; the co-reading techniques suggested compare unfavorably to the techniques that BPF members imagine sighted parents use. Consider the exchange between BP15, an expectant parent, who sought advice about co-reading on BPF because of a concern about “being able to point at the words,” in twin-vision books where Braille and print are physically separated, and BP16 who replied, “that’s the way *sighted people* do it, that doesn’t mean it’s *the only way* to do it, by any means” (emphasis added). Here, BP15’s anxieties are rooted in both material concerns about the way that twin-vision books are printed with geographically distant Braille and print and the belief that their own co-reading practices should resemble those of sighted parents. In this way, even within a social media forum specifically designed for blind parents, sighted norms of parenting pervaded discussions about the appropriateness of co-reading techniques, often more subtly. For instance, BP11 shared, “[my spouse] is sighted and usually will read the



books, but it is something that I would like to do, also,” suggesting that because their spouse is sighted they will naturally be the primary co-reading partner for their child. Similarly, BP8 suggested other parents should “search for ‘read aloud’ or ‘story time’ on YouTube and [you’ll find] videos of people reading kids’ books aloud, and they show the [book]... Tons of parents of print learners do this and they learn to read just fine.” Here, BP8 implies that this method of co-reading is appropriate, adequate, and justified because “Tons of parents of print learners do this.” In another example, BP13 expressed skepticism of the educational merits of audiobooks, saying, “I don’t know about using too much that is only audio in the early years. They could miss out on a lot of fundamental visual learning that way.” Here, although BP13 is blind, they indicate that visual channels are “fundamental” to their child’s learning. While visual channels have been shown to be important to children’s development, this quote from BP13 exemplifies the vision-first worldview that is held by the dominant, ableist society, which contextualized many BPF members assessments that the accessible co-reading techniques suggested were, somehow, lacking.

Importantly, the nuanced ways in which adherence to sighted norms of parenting pervaded BPF members’ assessments of co-reading techniques, both explicitly and implicitly, offers important implications for the design of AC systems. Here, whether a specific technique or tool was deemed appropriate by BPF members was not simply a matter of whether that tool was accessible to them, individually. Instead, BPF members’ assessments of techniques were based upon both the accessibility of the technique for them personally and whether that technique was perceived as providing an analogous co-reading experience as the techniques BPF members believed sighted parents use. So, an AC system designed to support co-reading between blind parents and their children should not only aim to make co-reading easy for blind parents, but also to create co-reading experiences of equal caliber to those that blind parents believe are available to sighted parents.

## Social Supports for Accessible Reading

The social supports provided to BPF members by other people in service of making parent/child co-reading accessible were perhaps the most visible way that social considerations relevant to domestic AC system design research manifested within these data. Most directly, the social support of others was the primary factor in determining whether the co-reading responsibilities of the blind parent were ultimately deferred to a sighted other, for example, in the case of BP11 above, or BP8 who suggested parents “have sighted friends or family read books to [their child] over Facetime.” While deferring co-reading responsibilities to a sighted other was not ideal for many parents, who desire to participate directly, it is important to acknowledge that the simple presence of supportive connections with sighted people expanded the number of available options for co-reading.

Interestingly, other people were also found to play a role in co-reading strategies which placed the primary responsibilities for co-reading upon blind parents, themselves. For example, because of the lack of available Brailled reading materials, many BPF members suggested the advice-seekers who are Braille readers apply custom Braille overlays to their children’s books. However, the application of these overlays requires the use of vision, to read the print in the books and replicate it in Braille. So, some parents who used this method, like BP27, suggested that applying Braille overlays is best saved for “when maybe you and your [spouse] have some time.”

Importantly, social supports of sighted others in co-reading did not always come from adults, but also from the children of blind parents who are directly involved in the process of co-reading. That is, many BPF members described the ways that, as children’s literacy developed, they could scaffold the co-reading process for their blind parents, without the need for third party support. For example, BP22 suggested having child “read it with you and make it a game.” BP23 explained they were “always getting [the child] to spell thing to me

so that I could know what it said.” Similarly, BP24 described having their child read “the numbers on the doors to find [their] doctor’s office.” BP23 even argued that asking their child to spell printed text for them increased their literacy abilities.

Understanding these ways that the social supports of others were a determining factor in the methods for accessible co-reading that were ultimately available to blind parents in BPF has important implications for the design of domestic AC systems. Particularly, these scenarios highlight the fact that within the intimate bonds of a family, there may be multiple points of intervention for increasing accessibility for disabled people individually. That is, in the case of designing to support accessibility in co-reading for blind parents, it may be equally appropriate to design a system for a sighted adult partner or friend to make applying Braille overlays more efficient, or a system for a sighted child to help them identify letters and spell words on printed text, as it is to design a system in which the blind parent is the intended user.

### **3.3 Blind Intimate Partners’ Perspectives on Social Considerations of Domesticity Relevant to Accessible Computing Design Research**

My exploration of blind intimate partners’ perspectives on social considerations of domesticity relevant to AC design research arises from a paired-interview study of blind and sighted intimate partners’ experiences of adopting smart speaker voice assistants (VAs) in their homes. This study was originally published with the title “*All in the Same Boat*”: *Tradeoffs of Voice Assistant Ownership for Mixed-Visual-Ability Families*, at the 2020 ACM SIGCHI Conference on Human Factors in Computing Systems (Storer et al., 2020).

Here, I share background, methods, and findings of this work in relation to blind and sighted partners' experiences of adopting and integrating VAs into their homes, in Sections 3.3.1.–3.3.3. Then, in Section 3.3.4., I describe how approaching the findings of this study through a critical and socially-oriented analytical lens surfaces and highlights broader social considerations relevant to domestic AC design research, exemplified in the case of adoption and use of VAs in homes where some occupants are blind and some are sighted.

### **3.3.1 Study Background**

#### **Digital Technology and Intimate Familial Relationships**

Studying technology in domestic contexts often requires a deeply reflective research stance (Bell et al., 2005), in order to surface the ways technology use and adoption are affected by the complex connections between interpersonal dynamics, social roles, and domestic labor in families. Familial considerations can complicate the decision to integrate and use technologies in homes, because adoption may require agreement between multiple parties with different priorities (Hindus, 1999). Alternatively, familial considerations can be a catalyst for adopting technologies. For example, Judge et al. found that the importance of maintaining familial relationships can prompt users to deprioritize concerns about using a technology, like loss of privacy, which are significant barriers to use in other contexts (Judge et al., 2010).

After technologies are adopted into the home, they can have nuanced and unanticipated impacts on family life. For example, Mazmanian and Lanette found integrating new technologies in homes can create new responsibilities for occupying social roles within a family (Mazmanian and Lanette, 2017). Additionally, Rode found that the “digital housekeeping” involved in administering shared devices often disproportionately complicates social roles for women, where demonstrating technical self-efficacy may increase gender equity in their families' interpersonal dynamics, but also add to their domestic labor (Rode, 2010). Ames et al.

found that digital tools intended to maintain familial relationships, like video-conferencing systems, may also require substantial domestic labor to use (Ames et al., 2010). Conversely, Thayer et al. found that digital tools intended to decrease domestic labor, like shared calendars, may also require family members to renegotiate their interpersonal dynamics (Thayer et al., 2012).

Though less is known about the role of AC systems within domestic contexts, Dawe found that the decision to adopt AC systems involves agreement between multiple family members with different priorities (Dawe, 2006), and Branham and Kane found inaccessibility affects interpersonal dynamics, social roles, and domestic labor in homes shared by blind and sighted people (Branham and Kane, 2015a), similarly to the above works examining families who are not specified as disabled. So, it is likely that family dynamics intersect with AC system adoption and use in homes, although this area remains underexplored.

## **Disability and Intimate Partner Relationships**

In addition to the significance of intimate partner relationships, in terms of understanding societal family structures and individual well-being, it is important to recognize that intimate partner relationships carry additional significance in the context of disability. Disability and being disabled are known to carry social stigma (Susman, 1994), which can have negative social and personal consequence for both disabled people and their families (Green et al., 2005). In fact, it is through the example of close associations between nondisabled and disabled people that famed sociologist Erving Goffman first articulated his theory of “courtesy stigma,” or stigma that is attached to a person by way of associating with someone considered deviant (Goffman, 2009). Disabled people are roughly half as likely to be married as their nondisabled peers (Cohen, 2014), and the courtesy stigma that may be applied to nondisabled partners of disabled people has been explored as one explanation for this disparity (Goldstein and Johnson, 1997).

But, the potentially negative impacts of nondisabled/disabled romantic relationships are not solely for nondisabled people. Disabled people who are eligible for, and receiving, Disability Insurance in the United States may have their financial benefits and healthcare coverage severely reduced, or even revoked entirely, upon marriage (Pulrang, 2020). That is, it may not be advantageous for either disabled or nondisabled partners in romantic relationships to legally enter a union. This reality has even prompted some advocacy groups to challenge the notion that marriage “equality” has ultimately been achieved in the United States (Star, 2019). Though these issues are not unpacked further in the remainder of this dissertation, they form an important backdrop for the following discussion of blind/sighted intimate partnerships.

### **Voice Assistants for Blind Users**

While conversational interaction is unique to VAs, audio-out and voice-in modalities have long been used to provide access to blind users in a variety of other digital tools. For example, auditory outputs are leveraged in screen readers, like JAWS (noa, b) and NVDA (noa, c), as well as “talking” technologies, like clocks and calculators (noa, e). In HCI and AC research, audio outputs for blind users have been used in a variety of domains, like accessible web traversal (Bigham et al., 2006, 2008), graph translation (Alty and Rigas, 1998), and wayfinding (Guy and Truong, 2012; Ross and Blasch, 2000; Yang et al., 2011). More recently, the turn to inaccessible or unusable touchscreens (Kane et al., 2008) and the increased fidelity of speech recognition technologies have prompted explorations into the use of voice inputs by blind users. For example, Azenkot and Lee found that blind and low-vision users employ voice inputs on mobile phones more frequently than sighted users, primarily because it is more efficient than keyboard text entry (Azenkot and Lee, 2013). Ye et al. also found blind and low-vision people are more likely to use voice inputs on their phones to enter text because of their efficiency, despite raising concerns in public and work settings

(Ye et al., 2014).

The widespread availability of VAs like Google Assistant, Cortana, Siri, and Alexa, has been a topic of recent interest in HCI (Ammari et al., 2019; Beneteau et al., 2019; Bentley et al., 2018; Fitton et al., 2018; Lovato and Piper, 2015; Lovato et al., 2019; Myers et al., 2018; Pantoja et al., 2019; Porcheron et al., 2018; Purington et al., 2017; Yarosh et al., 2018), several studies report on the limitations of VAs for people who are sighted (Cho et al., 2019; Cowan et al., 2017; Luger and Sellen, 2016). Cowan et al. document a range of frustrations of “infrequent users” of VAs (Cowan et al., 2017). Luger and Sellen found that users expect VAs to be more useful or intelligent than they are in practice, and ultimately express disappointment with their VA experience (Luger and Sellen, 2016). Similarly, in a longitudinal deployment, Cho et al. found that use stagnates and declines over time as users come to accept the limitations of their device (Cho et al., 2019). By contrast, many studies of VA use by disabled people, for example people with motor (Corbett and Weber, 2016), cognitive (Balasuriya et al., 2018), and age-related (Portet et al., 2013; Schlögl et al., 2013) impairments, report generally positive experiences, suggesting VAs are a universally usable technology (Shneiderman, 2000). Likewise, when examining a range of disabilities, Pradhan et al. found that some 85% of Amazon Alexa reviews related to disability were positive (Pradhan et al., 2018).

Because their core interaction mechanisms are non-visual, a growing body of work has explored VA use specifically by blind people; findings suggest that blind users also generally perceive VAs positively. For example, following a content analysis of product reviews, Pradhan et al. interviewed blind participants and found that many perceived VAs as “an integral part of their lives” (Pradhan et al., 2018). Similarly, Abdolrahmani et al. found that VAs contributed to feelings of “empowerment” among blind and low-vision users (Abdolrahmani et al., 2018). Vtyurina et al. even found that blind VA users identified some advantages of VAs over traditional AT like screen readers, particularly that they are easier to learn

(Vtyurina et al., 2019).

This divergence in experiences between blind and sighted users has prompted some of these scholars to suggest there may be fundamental differences in the patterns of use of VAs across visual abilities. For instance, Pradhan et al. (Pradhan et al., 2018) state that their finding regarding blind users contrasts the conclusion drawn by Luger and Sellen (Luger and Sellen, 2016) that sighted users perceive VAs to be “gimmicky”—a difference that may be attributable to either differences in devices or abilities. Similarly, Abdolrahmani et al. (Abdolrahmani et al., 2018) suggest that blind users may use VAs for fundamentally different types of tasks than sighted users, like work-related tasks. Further, blind users may be more willing to use imperfect VAs because they have no other alternative to access certain third-party apps (Abdolrahmani et al., 2018). Perhaps this lack of alternatives allows blind people to remain optimistic about the current capabilities and future potential of VAs, despite a lack of customizability in the interface (like variability of the voice speed) which would allow for even more efficient interactions (Branham and Mukkath Roy, 2019).

### **3.3.2 Study Methods**

#### **Paired-Interviews**

Paired-interviews are a method of collecting qualitative data in which two people are interviewed together, simultaneously (Wilson et al., 2016). Importantly, paired-interviews are distinguished from the conducting of two individual interviews in that they are designed to collect data from the pair as a unit, by facilitating interaction between the individuals being interviewed, rather than attempting to collect data from one participant at a time. In examining the adoption and use of VAs in homes where one partner is blind and one is sighted, paired-interviews are appropriate for examining whether conflicts exist in perspectives of each partner and to surface interpersonal dynamics in partnerships which may impact the



choices made, by the pair, about VA adoption and use.

## **Participant Demographics**

For these paired-interviews, I recruited six pairs of blind/sighted intimate partners through an existing list of interested participants and with the participation of national blind advocacy groups, over a period of eight weeks. To be included in this study, participant pairs 1) self-identified as cohabiting intimate partners, where 2) only one used a screen reader as their primary mode of accessing digital technologies, who 3) had at least one child 5-13 years old, and 4) owned a smart-speaker VA. There were no other inclusion criteria. Each partner received \$100 for their time, for a total of \$200 for each pair.

Interviewees ranged in reported age from 30-50+. Four pairs had more than one child. Children living in the household ranged in age from 2-16, with one family declining to report their children's exact ages. Children were not interviewed, however parents often discussed VA interactions that included them. In three pairs, a family member other than the identified screen reader user (Partner 1 in Table 1), also identified as being disabled. In one interviewed pair, Partner 2 identified as being legally blind, but accessed digital technologies using vision and screen magnification. In another, Partner 2 identified as hard of hearing, and used hearing aids, closed captioning, live transcription, and sound amplifying headphones. Finally, in a third family, the only child had a vision impairment (reported visual acuity of 20/150), and used a screen reader situationally. The interviewed screen reader users used a variety of other assistive devices, including white canes, braille terminals, and alternative input devices. A full list of reported visual abilities and assistive device use of the interviewees and their families can be found in Table 3.1.

| P1     | P2     | P1 Vision        | P1 AT  | Kids                     | VAs Owned <sup>2</sup> | Other Disabilities   |
|--------|--------|------------------|--|--------------------------|------------------------|--|
| Vince  | Paula  | Light Perception | Screen Magnification, High-Contrast Displays, Keyboard-Only Navigation, White Cane | 2, ages 8 & 16           | GA, AS                 | Paula is legally blind with acuity of 20/200, uses vision for many tasks, and screen magnification tools |
| Ben    | Carrie | Completely Blind | Braille Terminal, Keyboard-Only Navigation, White Cane                             | 2, ages 2 & 9            | GA, AA                 | Carrie is hard of hearing with 50% acuity, uses hearing aids, captions, and amplifying headphones        |
| Fatima | Ahmed  | Light Perception | Braille Terminal, White Cane   | 1, age 7                 | GA, AS, AA             | None   |
| Jen    | Daniel | Acuity 20/500    | Screen Magnification, Bioptics (high-magnification eyeglasses), Guide Dog          | 1, age 12                | GA, AS                 | Daughter has visual acuity of 20/150, uses screen reader situationally                                   |
| Ryan   | Cooper | Acuity 20/200    | Screen Magnification, High-Contrast Displays, Alternative Input Devices            | 5, ages N/A <sup>1</sup> | GA, AS, AA             | None   |
| Hung   | Yvette | Completely Blind | Braille Terminal, Keyboard-Only Navigation, White Cane                             | 2, ages 6 & 8            | GA, AS                 | None   |

Table 3.1: Summary of participant demographics. All participants pseudonymized. Each pair owned a smart speaker for over two years and used VAs multiple times per day. <sup>1</sup>Ryan and Cooper declined to report the ages of their children. <sup>2</sup>VAs Owned abbreviated as Google Assistant (GA), Apple Siri (AS), and Amazon Alexa (AA)

## **Data Collection Procedure**

I conducted interviews remotely using Google Meet. This allowed me to maximize the reach of this study, and increase the geographic diversity of the sample. Each remote meeting lasted approximately 90 minutes and included an introduction to the study, the interview session, and a debriefing period. The content of each interview session was video- and audio-recorded. Interviews lasted between 50 and 94 minutes, averaging 80 minutes per pair. In total, I collected 8 hours of data from six pairs.

Broadly, I asked participants 1) how they use VAs individually, 2) how they use VAs with other family members, 3) whether and how they performed the identified tasks prior to owning a VA, 4) what performing the identified tasks with a VA has changed for them, 5) what they would like to be able to do with VAs that they cannot currently, and 6) why a VA would be better than their current strategy. Participants' answers and follow-up questions often explored tradeoffs involved in owning VAs.

The interview script was structured using the example of Google Assistant as the VA in question. However, each pair owned at least one other VA, including Apple's Siri and/or Amazon's Alexa. Participants often did not distinguish between VAs, and frequently employed comparisons between VAs or stories about using a variety of VAs in their responses. As such, I note that the insights of the participants are not particular to Google Assistant, nor are these findings specific to Google Assistant.

## **Analysis Procedure**

I conducted all of the interviews and took detailed notes during each session. All audio and video recordings were transcribed in full, using automated software. From these transcriptions and typed notes, I developed open codes to capture commonalities between participants'

responses. I grouped open codes which were common to multiple participant pairs into wider axial codes. Each axial code reported in this analysis was common to at least four of six participant pairs. After all authors of the original work agreed to the validity of the axial codes identified, I returned to the raw video recordings and transcribed quoted passages manually. In reporting these findings, I denote participants *who are not screen reader users* with (V), to mean that they use vision to navigate digital devices, including Paula, who is legally blind.

### **3.3.3 Voice Assistant Use by Blind Adults and their Intimate Partners**

At a high level, I observed differences in domestic VA use between blind adults and their partners. I found that blind partners were more often the first person interested in acquiring a VA, used VAs more frequently, and were more proactive in learning about VAs' functions than their partners. Interestingly, the types of tasks which were performed were more similar between partners in the same home, than they were between partners with the same visual abilities.

In five pairs blind partners were the household member who was first interested in acquiring an in-home VA, and in the sixth pair, both partners were interested. Jen and Daniel's (V) daughter, who has a vision impairment, first brought VAs into their home when she asked for a smart-speaker as a Christmas gift. Carrie (V) shared that she did not know that Ben had even ordered a smart-speaker VA, until the shipping box had arrived. Even for Vince and Paula (V), who both have vision impairments, Paula was not as excited about acquiring a VA as Vince, and thought it would be "basically for Googling things with your voice."

Likewise, blind partners used VAs in the home more frequently than their partners. In each of the interviewed pairs, the participant who was a screen reader user reported using VAs

more often than, or equally as much as, their partner. In Jen and Daniel's (V) home, VA use corresponded directly to visual acuity: Jen was the most frequent user, followed by their daughter who has more vision than Jen, while Daniel (V) used VAs least often. In some cases, like Hung and Yvette's (V), sighted partners expressed using VAs little, or not at all. Yvette (V) shared:

**Y(V):** I still don't [use the VA]. You know, I see it as something that Hung and the kids do —and I think it's fun that they do, and I'm glad they do, and it's useful. But, I don't do... (interrupts herself to ask Hung) What do I use it for?

**H:** ...I encourage her to use it for timers, that sort of thing. But, it's still, it's still unnatural, I guess, for her.

Additionally, blind partners learned about the features of their VAs more proactively than their sighted partners. Blind partners frequently sought information about VAs online, on technology review sites, or in technology-affinity groups. By contrast, their sighted partners primarily learned to use VAs from the more-knowledgeable blind partner. For example, Paula (V) often learned about features of their VAs from Vince who searched for this information online. Similarly, Yvette (V) learned how to use their VA by “trying to copy” Hung, who learned about their features through his social media connections. Ben, similarly, learned about the features of VAs from social media, while Carrie (V) learned through brute-force-trial-and-error or from Ben. They shared:

**B:** The ‘Eyes-Free List’ is a Google Group... I get it in ‘digest mode’ in my email... [They share things] like, for example the Assistant can now turn on and off TalkBack, just like Siri can turn on and off VoiceOver. That's very recent...

**C(V):** If I'm thinking about something, I'll just ask and ‘you know who’ [the VA wakeword] pops up. And it's like ‘Oh, hey! It can do this!’ But, usually, I find

out more stuff from Ben... He'll be like, 'Hey, babe! You got to check this out!' [or] 'have you tried this feature out?' And I'm like, 'No. I didn't know it could do that!'

Although I observed differences in the motivation to acquire, use, and learn about VAs across visual abilities, partners mutually identified eyes-free, hands-free accessibility as the primary purpose of using VAs instead of other methods. But, the way they expressed this value was different, where blind partners recognized the role of vision and sighted participants did not. That is, sighted participants primarily described scenarios where VAs were appropriate—those where they had situational visual impairments (e.g., while cooking, or to multitask while looking at another screened device). By contrast, I found that blind participants often described the value of VAs in relation to an inaccessible method for completing the same task, in particular, setting timers, controlling home environments, and shopping. For example, when asked about the value of VAs timers, Hung concisely stated he does not use the stove's timers, because "that's not accessible." Though Paula (V) could set timers on the microwave, when asked why the family now used VAs' timers, Vince interjected:

**V:** Because vision! Because of vision, it just takes so much more effort... when you could just bark orders at our robot friend, over here.

Similarly, blind partners often compared using VAs to control home environments against the inaccessibility of traditional home infrastructure, especially thermostats. Though her family did not own a VA-connected thermostat, Fatima was interested in purchasing one, and explained:

**F:** I do want to get the thermostat, definitely, because it will give me [an alternative to] figuring out, 'Okay, what's the temperature?' ... [Now,] I just randomly press buttons, and I don't know what I'm doing.

Blind partners also often indicated the value of VAs in contrast to accessibility barriers in routine household shopping. For example, even though Ryan and Cooper (V), both frequently ordered household items through their VA, visual abilities affected when they placed orders, because they considered the cost of accessible methods for getting to the store. While they agreed that they preferred not to ship orders of single items, Ryan was willing to purchase a single item “if [they] really need something,” because the cost of shipping that item may be less than the cost of the rideshare he would take to make the purchase in person.

Despite differences in frequency of VA use, and vision playing a primary role in VA use for both partners, I found virtually no difference in the types of tasks performed by blind partners and their sighted partners. Many tasks, like timers and information retrieval, were commonly performed by all participants. Less common tasks, however, were primarily performed by both or neither partner in a household. For example, in five of six pairs, neither partner made purchases on their VAs, because partners often had agreements about whether to trust VAs with shared credit card information. Ryan and Cooper (V) were the only pair who agreed to trust VAs—and only certain VAs—to place orders, because of the accessibility benefits for Ryan. But, both indicated making purchases often and independently added needed items to a list stored in a shared virtual shopping-cart. So, while some tasks were prompted by accessibility, they often became common to both partners.

### **3.3.4 Tradeoffs of Adopting Voice Assistants for Blind Adults and their Intimate Partners**

Although partners across visual abilities identified eyes-free, hands-free accessibility as the primary value of VAs, they described a wide variety of social considerations outside of accessibility in their assessments of VAs. Participants routinely identified VAs’ potential impacts

on 1) interpersonal relationships, 2) domestic labor, and 3) physical safety as major considerations of owning and using VAs. In each domain, VAs presented tradeoffs that were weighed against each other, and against accessibility.

## **Interpersonal Relationships**

In assessing their overall VA experiences, partners described numerous positive impacts of owning VAs on the interpersonal relationships in their homes. Many families used VAs to play games together, because traditional board and card games are inaccessible to blind partners. Ben and Carrie (V) particularly enjoyed playing audio adventure games with their children, because “that [VA] girl, is gutsy, man! She’s not afraid of anything [in the fictional dungeon].” While the voice-only medium of a VA might seem restrictive, providing a limited or subpar gaming experience, we saw similar enthusiasm across all families. VAs games were as fun as, if not more fun than, games in other formats, in part because voice allowed all family members to more frequently play together. Jen found VAs made it easier for her to be included in family games:

**J:** It’s hard for me to see the board game, or read the cards... So, I find myself saying, like, ‘No, fine. You guys go play a board game [without me]’... I can play the games more now, because you don’t need any cards.

Yvette (V) even suggested VAs created a more equal play experience for her, Hung, and their children. She shared:

**Y(V):** Print does get in the way of our games, sometimes... [and VA trivia] kind of equalizes our experience, because we’re all in the same boat, hearing the question together.



Daniel (V) and his daughter, who has a vision impairment, played games together nightly, to pass the time while Daniel administered her prescription eyedrops:

**D(V):** At night, I have to give her four eyedrops. But, they have to be spaced out. So, I sit with her, and then, just to kill time, we ask [the VA] to play a game... And, you know, either you sit there, just staring at the wall, or we play a game [together].

Some families made up their own games to play using VAs. Jen and Daniel's (V) family played the "0/0 Game" in which family members took turns asking the VA to divide zero by zero, and the person who received a specific response won. Hung and his kids played together by asking their VA things like "what does a random, strange animal sound like?" and testing "the breadth of knowledge that [the VA] is capable of—or incapable of—giving responses to."

In addition to playing games together, several families used VAs as in-home intercom systems to speak to each other more easily. Some families used this feature primarily to call children from their rooms for dinner or to leave for school. But, Vince and his son used this feature to tell each other jokes, while on separate floors of their house. In other examples, simply learning how to use VAs was a bonding experience that allowed everyone in the house, regardless of visual ability or age, to participate. For instance, Vince and Paula's (V) family acquired their first VA on Christmas, and Vince recounted how they spent the evening exploring the VA's potential together with extended family:

**V:** We're bored, and there we are sitting around barking orders at [the VA]... sitting around it for, like, four hours or something, all of us and the kids, and they're asking it jokes. It was just funny because every individual in the house [was there, and] it was really different what everyone was asking. You know, you

can ask it to make fart sounds—and it'll do it.

Many interpersonal experiences occurring with and around VAs were positive. But, several families identified ways that integrating VAs into their homes had created interpersonal tensions. For example, Hung and Yvette (V) initially had difficulty agreeing to purchase a VA for their home, because she was concerned digital devices might displace interpersonal connections with their two children:

**Y(V):** When they were younger, I would try not to have my phone open... There was a time, I told [Hung], 'I don't want the computer voice in the living room...' [Because] they weren't old enough to really get, for me, to get boundaries... [Talking about VAs,] I'm kind of wondering right now, 'How did they get in the house?'

Ryan and Cooper (V), frequently struggled to share VAs with their sons, because, as Ryan explained, one of them “uses it for bull\*\*\*\*. He'll ask about new Twitch tournaments and stuff, and I'm like 'Get the hell off! I'm trying to do something.' ” Cooper (V) and the children also used VAs during debates, to fact-check Ryan, who is “gonna sulk about it,” when he is wrong. In a more extreme example, they explained that providing VAs with their credit card information to make household purchases also allowed their adult son to make unsanctioned purchases. Ryan recounted his son's purchase of a new MacBook:

**R:** I had no intention on buying him a new [freaking] MacBook... the next thing I know is—it's comin'. And I'm like, 'Okay, who the [hell] ordered a MacBook?'... That [ticked] me off, because I felt that that was stealing from me...

Despite the anger and trust issues that ensued, Cooper (V) and Ryan decided to keep the credit card connected to the account to support Ryan's access to grocery shopping. This

purchase was perhaps the most extreme example, but most pairs had at least one example of how using VAs caused headaches for other family members. Daniel (V) and his daughter have “freaked Jen out” using VAs as intercoms to communicate, and startling her when she thought she was alone. Similarly, Vince and Paula (V) had unintentionally awoken family members by using VAs as intercoms.

## **Domestic Labor**

Participants often pointed to ways VAs had eased the burden of domestic labor in their homes, when assessing their experience. Setting timers, finding recipes, and helping their children with homework were frequent uses of VAs for domestic labor for our participants. In addition to using timers for tasks like cooking and monitoring laundry cycles, our participants often used timers as part of their parenting. Hung and Yvette (V) used VAs to set timers for their children’s timeouts. Ben and Carrie (V) used VAs’ timers to let their son know when it was time to start homework, or he had reached his daily quota of “screen time.” Conversely, Vince used timers to monitor his own media consumption, to remember to put his kids in bed:

**V:** I play video games, sometimes... [And] the kids used to pull, you know, they’re like, ‘Dad’s going to forget to put me in bed and brush my teeth’... with the timer, it’s totally more structured.

Using VAs to find recipes was also common for our participants, although some, like Hung and Yvette (V) removed their VAs from the kitchen to avoid getting food on them. Fatima frequently used VAs to search for recipes, and noted that other digital recipes have trended further toward prioritizing visual content, in recent years:

**F:** If I’m looking for how to, like, make a cake... I usually just ask [whatever

VA] is in front of me, at that time, and ask for the recipe... Before, [I would] go to my laptop, go to the website, go to Google, type what I'm looking for, 'chocolate cake' or whatever, and then open it up. Nowadays, the annoying thing is everything is on YouTube. So, it is very hard for me to find a text version of a recipe written down... That doesn't help me at all. They're showing more, playing music, and talking very little—I have no clue what they're doing.

Four of our six pairs identified VAs as a central part of helping with their children's homework. The remaining two had children who were either too young (Fatima and Ahmed (V)) or too old (Ryan and Cooper (V)) to seek homework help. Hung and Yvette (V) also used VAs to answer questions that had arisen for their children during the school day and encouraged their children to ask the VA how to spell words, because "there's only so many times that somebody can repeat how to spell a word before it gets frustrating." Carrie (V) used VAs to teach herself Common Core pedagogy, to help with her son's math homework. Vince and Paula (V) used VAs to help with their eldest daughter's homework, which covered unfamiliar topics:

**V:** [The VA] will highlight the basics to really get them started—and us. So, we can better teach our kids. We can, kind of, confirm, because we're a little rusty on some of that stuff.

**P(V):** Before we got the [VA], it was just getting on the computer... For him, it takes him a little bit longer to navigate through certain websites. Me, having vision, I can see search results, right in front of me, and I can click on what is most relevant.

Interestingly, in one case, VAs prompted new domestic contributions by providing access to tasks which were tangential to completing the chore. Before Vince and Paula (V) had VAs,

Paula was responsible for the family's laundry. But, VAs prompted Vince to do laundry, too:

**V:** You know why I actually do laundry? It's because I can stream Twitch with [the VA on my TV]... So, while I'm doing all this folding and hanging, I'm able to turn my TV on in my room. I'm able to alter the volume. I'm able to tell it to go directly to my favorite YouTube channel and play the latest videos, or tell it to play the latest podcasts. So, I think it eases the pain...

**P(V):** That's taken a little [work] off me, for sure.

While VAs assisted in performing domestic labor, many participants also identified new household responsibilities which were involved in owning VAs. Hung and Yvette (V), for example, had concerns about the access to digital content afforded to their children by VAs' non-textual interactions. To ensure that their children did not encounter inappropriate content, Hung felt it was important to be physically present each time they used the VA. They were also concerned about how the feminine representation of many VAs and the ability to make requests of VAs without manners might impact their children's respect for humans:

**H:** The part that's really challenging for our family—and others—is the concept of giving a request to a machine without the whole concept of respect and politeness...

**Y(V):** And they're starting to get to the age where they think it's funny not to be nice... That's a big part of [why I resisted using VAs] when they were younger. I didn't want them to get into a loop of playing with a machine and reflecting back the worst of themselves.

**H:** I think another concern that I've had more recently is that the default voice of [VAs] is female... There's all kinds of submission/submissive issues, all kinds

of stereotypical challenges around the narrative of giving requests to a gendered assistant. I don't necessarily have the language, at the moment, to discuss what it is that I'm trying to get them to understand, other than the fact that it's really important that we give our requests respectfully—to whatever medium.

Similarly, because Vince uses VAs to help his children with their homework, he also had to teach their son about the importance of learning when he asked, “Why do we need to know math, if I can just use [the VA]?” He and Paula (V) ultimately instituted a policy of using VAs only to check answers. Jen and Daniel (V) had instituted a similar policy for limiting their daughter's VA use for schoolwork.

The new responsibilities created by VAs for Ryan and Cooper (V) were quite different from these examples; after their son's purchase of the MacBook, described above, they looked for ways to limit their children's transactions, or to be notified when their children attempted purchases. But, at the time of our interview, they had not found a solution.

Although the added labor of attending to the responsibilities created by VAs was often mitigated by the reduced burden of labor eased by access in other domestic tasks, when examined together, it is difficult to conclude whether VAs decrease or increase domestic labor for families. Notably, the introduction of new domestic labor due to VAs in the home was identified by the majority of households, though my questions did not inquire about burdens of ownership.

## **Physical Safety**

Many participants identified ways that VAs could increase the safety of themselves and their families. Only three pairs owned VA-connected smart-home devices. But they and two pairs without home automation devices each identified their potential to increase household safety

by providing access for blind partners. For example, Hung used his VA to turn the lights on for his family, because “as a blind person, I can’t tell when the lights are on. It’s kind of nice to get some verbal confirmation.” Vince used VAs to turn off his TV, and noted that this was an improvement over “knocking it off the stand, in a hustle to go catch the bus,” which had happened to him in the past. But the risk of injury of stumbling in the dark or falling TV sets may be relatively small, when compared to the benefits of other smart-home technologies. For example, Jen was interested in purchasing a smart doorbell, and explained:

**J:** It would be great if it announced to me, ‘Hey, so-and-so is at the door,’ because I don’t see who’s at the door... My dad is blind, and for him, it would be a safety feature to know who is at the door, because [he] does not open up the door for anybody. [So], we do have a code [ring pattern], so he [knows] it’s family.

Similarly, Fatima explained that being able to use VAs to automate her home would help her to remain safe while cooking. She recounted a time her house nearly caught fire because of her current oven’s inaccessibility:

**F:** I was cooking, and my oven has no Braille, no raised [indicators], no buttons... I probably put it up too high. I don’t know, because I can’t tell—it’s touchscreen. I couldn’t control it, and then it started, like, burning my eyes. I had no idea what was happening... I had to find a neighbor to come help me turn the oven off... When [Ahmed] came home, he saw smoke everywhere.

Though participants frequently identified ways VAs’ accessibility for blind partners could support safety for the whole family, many weighed this against perceived threats of integrating VAs into their home. Most often participants’ fears about using VAs were due to the threat of malicious actors. The potential for strangers to “listen in” on the home through

the VA was discussed by the majority of participants. Though Ryan called him “paranoid,” Cooper (V) viewed privacy infringement as a threat to safety:

**C(V):** Nowadays, the government is getting hacked. So, who’s to say that some, you know, thief or mastermind is not able to access [our] information and see my location or see what I’m doing, so they can rob me or something of that nature? That’s what it comes down to.

**R:** Yeah, but all they’re gonna get is ‘Hey, I want some almond milk.’ (laughs)

Other participants expressed similar concerns about the safety implications of using home automation devices, despite the frequent recognition they would increase accessibility for blind partners and, consequently, the household’s safety. Ben and Carrie (V) did not own home automation technologies, because they worried “some nut-job” might be able to unlock their door, or frighten their children by turning on their lights during the night. Ahmed (V) expressed similar concerns about to potential for malicious actors to tamper with their access to their home. He shared:

**A(V):** I’m not a fan of [smart home automation], because there’s hackers out here... I had a friend of mine—he had everything [connected]. Now, he’s got a million-dollar home [that] he can’t get in.

Though perceived threats were sometimes rooted in hearsay or misinformation, they were often salient enough for participants to alter their use of VAs, or to forgo acquiring VA-connected devices, altogether.



### **3.3.5 Social Considerations of Adopting Voice Assistant for Blind Adults and their Intimate Partners**

Many of the findings shared above regarding VA adoption and use in families where some members are blind and some are sighted describe inherently social considerations of AC system design research. For instance, a prevalent concern about how VA adoption may impact interpersonal relationships with family members. But, returning to these data with an explicitly critical and socially-oriented analytical lens also highlights additional social considerations of adopting VAs for blind adults and their intimate partners. Below, I discuss three ways in which my findings regarding the adoption and use of VAs in homes where some occupants are blind and others are sighted surface larger social considerations in the design of domestic AC systems.

#### **Privilege and Responsibility of Being the Primary User**

Blind participants in my sample were frequently the household's primary VA user. Blind partners demonstrated higher motivation to acquire, use, and learn about VAs than their sighted partners. Negotiations between family members have been identified as an important factor in understanding domestic technology adoption (Hindus, 1999). But, some blind partners in my sample were motivated enough to acquire a VA to sidestep negotiations with their partner entirely, like Ben, who ordered a VA without Carrie's (V) knowledge. After VAs were adopted, blind partners in my sample each reported using VAs as often as, or more often than, their sighted partners. Additionally, blind partners learned to use VAs more proactively than sighted partners, and disseminated their knowledge to their family. Ben sometimes beckoned Carrie (V) to teach her about VA features, calling "Hey, Babe! You got to check this out!" Similarly, despite Yvette's (V) apprehension of VAs, Hung demonstrated their use for her, and encouraged her to use VAs to set timers, instead of

continuing to use methods which are inaccessible to him. I observed many such cases where sighted family members learned how to use VAs primarily from more-knowledgeable blind partners, through direct instruction or mimicry.

Although many blind partners expressed pride in sharing their knowledge of VAs with their families, *being the primary user* of VAs can be a tenuous role in the home. Rode found previously that being the primary user of a technology can be advantageous for demonstrating knowledge to assert equality, but may also require assuming additional domestic labor (Rode, 2010). Through this lens, blind partners' proactivity in adopting and using VAs can be viewed as a domestic contribution and assertion of equality, and also as an added responsibility to maintain their own access amidst their families' activities.

Inaccessibility in the home has been shown to exclude blind partners from contributing to the domestic labor of the household, disproportionately burdening sighted housemates and creating tensions in their interpersonal relationships (Branham and Kane, 2015a). I found many ways that VAs lowered access barriers, and enabled blind partners to participate in household tasks, like grocery shopping, supervising homework, and finding recipes for dinner. Some partners with vision, like Paula (V), noted that reducing inaccessibility in domestic labor for their partner has “taken a little work off” them personally. But, given the responsibility of being the primary VA user, it is uncertain whether adopting VAs into the home eased domestic burdens for blind partners. Perhaps most importantly, because VAs were often identified as the only accessible method for blind partners to accomplish some domestic task, it is not clear that the role—and associated work—of being the primary VA user was entirely *optional* for them.

## Accounting for Nondisabled Family Members' Needs

Given the nonvisual accessibility of VAs for blind users, it was unsurprising that blind participants in my sample were more motivated to adopt and use VAs in their home. At the same time, the increased accessibility of VAs for blind partners was not the sole—or even primary—consideration that partners discussed when describing their adoption experiences. Rather, because VAs were shared devices within the household and across family members, the decision to adopt, and agreements about how to use, VAs were often described in relation to the risks and rewards for the *family*, and not just for the *blind partner*. That is, despite the benefits VAs can provide, the access needs of the blind partner were just one of many factors weighed in the assessment of whether VAs should be adopted and used in homes.

Consider, for instance, Hung and Yvette's (V) repeated concerns about how VAs might provide access to inappropriate content to their children, might affect their children's behavior, and might cause interpersonal disconnection by distracting from family activities. Both partners acknowledged the accessibility benefits that adopting VAs in their home ultimately provided for Hung. Yet, in recounting their decision making process to me during these interviews, Yvette wondered aloud "How did they get in the house?". In this case, accessibility for blind partners can be seen as just one of many considerations of adopting VAs that is weighed during the adoption process and, potentially, lingering through long-term use of the device.

This scenario emphasizes the fact that accessibility, while often a primary concern of AC system designers, and even AC users, is not necessarily the only goal dictating the successful design of domestic AC systems. Rather, accessibility is one of many considerations that are weighed against each other throughout the cycle of adoption and use.

## Negotiations and Imbalanced Risks and Rewards for Blind and Sighted Intimate Partners

Integrating VAs into the home often required partners to reach agreements about acceptable use of the shared device. Because the relative advantage of using VAs was much higher for blind partners, who may have no alternative, the risk/reward tradeoffs of integrating VAs into the home were uneven for partners. So, most often when agreements were reached either 1) blind partners were not able to use VAs for something they desired, because the risk was too great for their sighted partner, or 2) sighted partners used VAs for something they might not otherwise, because the reward was high enough for blind partners. For example, Fatima expressed interest in acquiring VA-connected home automation devices. But, her family did not own any, because Ahmed (V) perceived the risk of malicious actors as too large. Conversely, Ryan and Cooper (V) each made purchases using VAs, though they expressed concerns about having their credit card information stolen, because the advantage for Ryan of avoiding a rideshare was high enough for the pair to take a perceived risk. Integrating novel access technologies into the home often requires cohabitants to reach agreements, like these, because individual access needs can conflict (Branham and Kane, 2015a). Though VAs did not create direct access conflicts, their universal usability for blind and sighted partners did not guarantee equal access for all household members. Rather, the tradeoffs of owning VAs complicated partners' negotiations about use of a shared device, where the uneven benefits of VAs for partners often resulted in limitations placed on the access provided to blind partners. While universal usability is an important goal of designing for settings where disabled and nondisabled people interact, focusing only on a technology's mutual accessibility may obfuscate concerns of owning a device which limit its practicality in context. These findings of the complex social considerations blind partners weighed against access echo previous calls for designers to consider more holistic lived experiences of disabled people ((Branham and Kane, 2015a; Mankoff et al., 2010; Shinohara et al., 2018), for example), and

not only their individual accessibility needs.

## **3.4 Social Considerations of Domesticity Relevant to Accessible Computing Design Research for Blind Adults**

While the particularities of the contexts produced different social considerations relevant to AC design in each of these studies, across both of these studies, I found high-level similarities in the social considerations of domestic relevant to AC design for blind adults, in their roles as parents and as partners. Specifically, I found that, in both their roles as parents and as partners, blind adults described 1) a desire to contribute to their household, 2) a demonstration of care for family members, and 3) a desire to experience feelings of autonomy in their domestic activities. Here, I outline these similarities across studies and unpack the ways in which these social considerations may inform the design of domestic AC systems.

### **3.4.1 Desire to Contribute to the Household**

Across these two studies of blind adults as parents and as partners, I found that a desire to contribute to the family unit and household motivates blind adults to seek domestic technologies which increase their access in domestic spaces and lower the barriers to make those contributions.

In the case of co-reading for blind parents, many, if not most, of the perspectives shared by blind parents evidenced a desire to contribute to the household. That is, many advice-seekers on BPF were seeking advice about co-reading strategies *because* they wanted to be able to read to, and educate, their children. For instance, BP1 mentioned making up stories as a

way to “allow you to teach your child some valuable pre-literacy skills, like learning what books are, how to turn pages, how to read from left to right in a sequence... etc.” Similarly, BP13 expressed skepticism about using audiobooks because of their questionable educational merits, saying, “They could miss out on a lot of fundamental visual learning that way.” In each of these cases, co-reading is not simply a fun or social act, but an educational activity to which blind parents want to contribute.

In the case of VA adoption in homes, I found blind partners leveraged the increased accessibility afforded by VAs to increase their domestic labor contributions to their household. For instance, blind partners mentioned using VAs to turn on the lights for their families, find recipes when cooking dinner, help children with homework, and set timers for cooking or monitoring laundry cycles. Additionally, and similarly to the case of co-reading, I found that blind partners also contributed education to their families, specifically about the use of shared VAs. While these educational responsibilities might have been viewed as burdensome, blind participants in my sample most often expressed pride in being the most knowledgeable VA user, and disseminating their knowledge to their family members.

### **3.4.2 Demonstrating Care for Family Members**

Across these studies of blind adults as parents and as partners, I found that a desire to demonstrate care to other family members impacted the adoption, use, and assessment of AC systems in domestic spaces.

In the case of co-reading for blind parents, the desire to demonstrate care for family members was most visible in the frequent assessment of accessible co-reading strategies in relation to whether that strategy provided an opportunity for interpersonal connection between blind parents and their children. For instance, BP12 acknowledged that audiobooks are accessible and accurate, but noted that they did not feel “appropriate at all” because “It doesn’t give

*that intimate vibe to me*” (emphasis added). Similarly, BP14 suggested parents might not need to worry about the accuracy of the words they vocalized, sharing that it is “the communication between parent and child that matters most. So, go ahead and make up your own words to the book. Your baby will love it!” In each of these cases, the selection and assessment of given accessible co-reading strategies is considered in relation to the interpersonal care and bonding that the strategy can provide the parent/child dyad.

In the case of VA adoption in homes, the desire and need to care for others in the household was most visible in examples blind partners provided about the potential for VAs to impinge upon the safety of others, especially children. For example, Ben and Carrie (V) explained that they did not own any home automation technologies, despite the potential for increasing the accessibility of domestic infrastructures for Ben, because they worried that “some nut-job” might attempt to frighten their children by flickering the lights during the night. Likewise, the majority of participant pairs in this study mentioned the risk of malicious actors gaining hold of smart home automation technologies, or even just “listening in” through the always-on microphones of smart speaker VAs. In these cases, the accounting for, and caring for, the needs of others in the household was a primary concern weighed in the adoption process, often outweighing the access needs of blind partners.

### **3.4.3 Feelings of Autonomy in Domestic Activities**

Across these studies of blind adults as parents and as partners, I found that a desire to experience feelings of autonomy and agency in domestic activities motives blind adults to seek and adopt domestic AC systems which increase their own access in domestic spaces, and reduce barriers to acting autonomously in domestic life.

In the case of co-reading for blind parents, the desire to feel autonomous in domestic activities was most visible in the frequent mentioning of wanting to “do it myself.” While it could

be easiest for blind parents to simply defer co-reading responsibilities to a sighted spouse, friend, or extended family member, deferring co-reading responsibilities was the least discussed method for accessible co-reading described in my sample. Instead, many BPF posts emphasized the direct involvement of the blind parent in the co-reading process. For instance, BP1 elected to listen to audiobooks through a headphone, and repeat the words they heard to their child, because of the importance of allowing “*your* [children to] hear *your* voice and *your* interpretation” (emphasis added). Similarly, BP11 shared, “[my spouse] is sighted and usually will read the books, but it is something that I would like to do, also.”

In the case of VA adoption in homes, the ways in which the increased accessibility provided by VAs facilitated direct participation of blind partners in domestic life were quite diverse. For instance, VAs helped Jen to participated in her family’s “games more now, because you don’t need any cards.” Vince and Paula(V) were both able to participate more directly in their children’s educations, because:

V: [The VA] will highlight the basics to really get them started—and us. So, we can better teach our kids. We can, kind of, confirm, because we’re a little rusty on some of that stuff.

In each of these cases, ability to participate directly and act autonomously in routine domestic activities was identified as a benefit of the increased accessibility afforded by VAs.



## Chapter 4

# Accessible Computing Literature's Perspectives on Social Considerations of Domesticity Relevant to Accessible Computing Design Research

The second contribution of this dissertation is an examination of AC literature's perspectives on social considerations of domesticity relevant to AC design research. To understand these perspectives, I performed discourses analysis on a corpus of systematically collected academic AC articles published by the ACM. The insights shared here are based upon results of an article titled *Deinstitutionalizing Independence: Discourses of Disability and Housing in Accessible Computing*, which was originally published at the ACM SIGACCESS Conference on Accessible Computing (Storer and Branham, 2021).

In the remainder of this chapter, I begin by providing relevant background, research methods used, and findings. I then discuss these findings in relation to discourses of homes in AC,

examining how these discourses frame social considerations of domesticity relevant to AC design research.

## 4.1 Study Background

### 4.1.1 (De)Institutionalization and the Independent Living Movement

The meaning of “homes” is complicated for disabled people because of the historical link between (de)institutionalization, housing, and civil rights. Carceral institutions, sometimes euphemistically referred to as “homes,”<sup>1</sup> have been a primary residence for disabled people throughout modern history.

The practice of institutionalizing disabled people is a Western movement, invented in Western Europe in the 1750s and adopted in English North America a century later (Noll, 2018). In the colonial USA, disabled people typically lived in residential settings, where family and local community members provided any necessary care. At this time, colonists had a predominantly agrarian economy, and more people in the community—regardless of their (dis)abilities—was beneficial for performing agricultural labor. Additionally, in tight-knit rural communities, caring for community members was perceived as a responsibility of being a community, not a responsibility caused by any one individual’s (dis)abilities. So, most colonists in the USA did not see a major need for state intervention in caring for disabled family and community members. This perception changed when three major shifts in economic, scientific, and moralistic cultural attitudes converged between the late-eighteenth and mid-nineteenth centuries.

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<sup>1</sup>Because of this dual meaning of “home,” here I use “institutional” and “community-based” to refer to the level of carcerality of a specific environment. “Housing” (noun) and “domestic” (adjective) refer to a more general concept of living environments.

As the USA's economy shifted during the First American Industrial Revolution, families were drawn away from rural communities which contributed to the care of disabled family members, to urban areas where extrafamilial social connections were looser (Noll, 2018). Simultaneously, where distinguishing between disabled and nondisabled people had been largely irrelevant in agricultural labor, industrialization “re-created the category of worker” (Davis, 1995), such that “disability,” as a descriptor of people, was invented to indicate whether one could operate factory machinery. This change in economic structure labeled disabled people both as defective workers and burdensome on their families and the economy.

During this same period, acceptance of two threads in societal thinking promoted institutionalization as a solution to the growing “problem” of disabled people (Noll, 2018). Firstly, scientific advances of the European Enlightenment gained popularity in North America and cast doubt on previous assumptions that disability was attributable to divine influences. Instead, it was reasoned that disability had natural origins which could be scientifically explained. Secondly, the USA was experiencing the Second Great Awakening—a Protestant Christian revival emphasizing believers' moral duties to improve the lives of those perceived as disadvantaged, like disabled people. This convergence of scientific and religious thought suggested 1) disability could be scientifically “cured” and 2) attempts to do so were morally righteous.

The unity in scientific and moralistic logics driving institutionalization in the USA is evident in the use of “asylum” to describe carceral institutions. But, accounts of unspeakable abuses inflicted upon disabled people in institutional settings rebut notions that institutions served to provide clinical services or that their implementation was ethical (Deutsch, 1948; Johnson, 2003). Horrific portrayals of asylums in popular culture serve as well-known examples of such abuses, which make the institutionalization of cognitively and intellectually disabled people especially visible. But, physically disabled people were also frequently institutionalized in facilities with similarly troublesome histories, despite being euphemistically referred to as

“schools” (Noll, 2018).

Institutionalizing disabled people remained a normalized aspect of life in the USA until the 1950s and 60s, when economic, scientific, and moralistic attitudes shifted again. Following the Great Depression, state-run institutions were lacking in financial resources, raising questions about the merits of public investment in them. Simultaneously, the advent of psychiatric medications in 1954 offered the possibility to provide some clinical services in community-based settings—at a lower cost to the state—prompting healthcare professionals to advocate for deinstitutionalization (Davis et al., 2012). These economic concerns and scientific advances led to increased scrutiny into the activities of institutions. Awareness of their abuse grew throughout the 1960s—against the backdrop of the Civil Rights movement in the USA, which was already prompting conversations about societal treatment of marginalized groups.

The successes of Civil Rights leaders prompted critical reflection by disabled activists, who realized their rights “would come only as [they] fought for them” (National Council on Independent Living, 2012). So, disabled people and their allies united around of the goal of securing disabled people’s right to “participate fully in all areas...of mainstream community living on a par with nondisabled peers” (Barnes, 2014) under the banner of the IL Movement. Disabled leaders within the IL Movement organized remarkably bold protests, including the longest occupation of a federal building to date (National Council on Independent Living, 2012). Their labor and tenacity led to significant legislative reforms in the USA. Notable examples include 1) the *Lake v. Cameron* ruling in 1966 which mandated hospitals treat people in the “least restrictive setting” possible (Davis, 1995), 2) the passage of the *Rehabilitation Act* in 1973 which prohibited discrimination on the basis of disability in programs receiving federal resources (Dejong, 1979), 3) the passage of *the Americans with Disabilities Act (ADA)* in 1990, which broadly mandated accessibility in public spaces and workplaces (noa, a), and 4) the 1999 *Olmstead Decision*, which ruled that requiring disabled people to live in

institutional settings is an unlawful act of discriminatory segregation, and community-based supports must be provided where appropriate and desired (noa, d).

The IL Movement remains a significant political force today (National Council on Independent Living, 2012), in part, because it is not clear the deinstitutionalization of disabled people was fully accomplished. Particularly visible examples of contemporary institutions in the USA are nursing homes and care facilities, in which many disabled people, often older adults, still reside. More subtle examples can be seen in the USA's prison system, in which as many as 40% of incarcerated people are disabled—twice the reported rate of disability in the nonincarcerated population (Learning Disabilities Association of America). This transition from living in clinical institutional settings to criminal institutional settings, and only temporarily in community-based settings, has been termed “transinstitutionalization” (Schildbach and Schildbach, 2018).

Additionally, for brevity, the history provided is partial, focusing on a broad construal of “disability,” the USA, and experiences of White, English colonists. But, institutionalization was, and is, enacted differently across geographies and on the basis of socioeconomic status, disability, race, and gender. For instance, with sufficient economic resources, older adults may be able to reside in assisted living institutions that afford greater autonomy and privacy than those that are available to low- and middle-income older adults Hawes et al. (2003). Today, a disproportionate number of disabled people institutionalized in carceral settings are Black, men, and cognitively disabled (She and Stapleton, 2006). Similarly, I focus this discussion on two types of housing. But, disabled people are also more likely than nondisabled people to be unhoused (Shinn et al., 2007), adding complexity to discussions of housing justice and disability. Here, it is not feasible to unpack particularities of (de)institutionalization across geographies, disabilities, races, and genders, nor to frame this discussion inclusive of incarceration and lack of housing as intersections of disability and housing external to a community-based/institutional dichotomy. But, these topics merit future research and,

though not discussed further, evidence need for additional critical inquiry in domestic AC.

## 4.2 Study Methods

### 4.2.1 Critical Discourse Analysis

To examine the effects of (de)institutionalization on discourses of housing in AC, I performed Critical Discourse Analysis (CDA) on a body of literature from the Association for Computing Machinery (ACM). CDA has an extensive history in humanistic disciplines, by many accounts, originating in the work of Foucault (Foucault, 1970). Recent works in computing have used CDA as an approach to Critical Literature Reviews (CLRs) to examine how specific topics are discussed across a research community (Kannabiran et al., 2011; Spiel et al., 2019). But, CDA remains less established in computing than similar methods, like Thematic Analysis (Braun et al., 2014) and Systematic Literature Reviews (SLRs) (Khan et al., 2003). So, while a comprehensive history of CDA is not possible here, the differences between these approaches merit explication.

CDA is an interdisciplinary “research programme,” (Wodak and Meyer, 2009) encompassing a variety of approaches, perspectives, and methods. At its core, CDA is an abductive approach to “de-mystifying ideologies and power through the...investigation of semiotic data” (Wodak and Meyer, 2009). The use of abduction in logic is attributed to Charles Sanders Peirce, who described abduction as a form of reasoning in which “The surprising fact, C, is observed. But if A were true, C would be a matter of course. Hence, there is reason to suspect that A is true” (Frankfurt, 1958). As such, CDA flows between theory-driven, deductive reasoning and data-driven, inductive reasoning throughout analysis. For this reason, CDA differs from Thematic Analyses (Braun et al., 2014) which typically identify patterns inductively, without a priori frameworks to guide inquiry. These analytical differences also

make the goals of CLRs distinct from those of SLRs (Khan et al., 2003). SLRs often aim to categorize works in a domain to map the landscape of a research area (for example, see (Desjardins et al., 2015) or (DiSalvo et al., 2010)). By contrast, the abductive approach of CLRs using CDA is designed to examine implicit understandings guiding how a topic is discussed. So, although our methods for collecting texts are systematic, as in SLRs (Khan et al., 2003), my goal in analyzing these articles is not to provide an overview of domestic AC research. Rather, I explore how housing is discussed in these works, and examine whether and how (de)institutionalization explains observed patterns in these discussions.

### 4.2.2 Corpus Collection Procedure

I collected 1,037 articles, by searching the ACM Digital Library (DL) for works published by the ACM over the decade from January 2010 to December 2019, containing the keywords {home\*; hous\*; domestic\*} and classified using the 2012 ACM Computing Classification System (CCS) terms {Accessibility; Assistive technologies; People with disabilities; Seniors}. I conducted the final search on March 18th, 2020. These criteria were developed collaboratively by the first and second author of the original work, with the following considerations:

1. I analyzed only ACM articles, for pragmatic reasons. Many disciplines relate, somehow, to housing and AC. So, it was not feasible to examine all related fields. For reference, a Google Scholar query analogous to the final query yielded over one-million results.
2. I analyzed only works published in the decade between January 2010 and December 2019, to attend to changes impacting discourses of AC and domestic technologies. Research in AC dates to at least the 1960s (for example, (Sterling et al., 1964)). But, perceptions of disability have changed significantly over time. Patterns of domestic technology use has also changed, as more people adopt digital technologies in their homes (Pew Research). Analyzing all works across time would likely unearth discourses

which do not represent current interests.

3. I used the search terms {home\*; hous\*; domestic\*}, based on Desjardins et al.'s (Desjardins et al., 2015) review of HCI literature on domestic design outside the context of AC, which additionally included {everyday}. I found, in the context of AC, {everyday} was not closely related to domesticity, typically meaning “mundane.” I considered borrowing keywords from outside resources, like Schlesinger et al. (Schlesinger et al., 2017). But, surveying thesauri for synonyms of “home” and “housing” did not yield viable results.
4. I targeted AC articles by collecting works using the 2012 CCS terms {Accessibility; Assistive technologies; People with disabilities; Seniors}, which is exhaustive of accessibility CCS terms. Some collected literature was published prior to the shift in CCS concepts in 2012. In the 1998 CCS {Assistive Technologies for Persons with Disabilities} was the only accessibility classifier and is no longer indexed on the DL. But, at the time of the final search, I found works originally using this 1998 classifier were indexed under the 2012 terms used. I considered constructing a list of Accessibility keywords, as for housing. But, disability language varies. Selecting terms which I judged as representative would bias corpus collection toward works whose language use matches mine. Conversely, general terms, like “access,” returned many unrelated results.

To reduce the dataset to a size feasible to analyze, I developed four criteria for filtering the 1,037 works collected:

1. Publication Venue. To tailor my findings to the intended audience, I analyzed the five conferences and five journals in which conversations around housing and disability are most frequent, based on the number of articles returned in our search. For communities



which have shifted from conferences to journals, I included conference proceedings affiliated with journals meeting these criteria.

2. Level of Peer-Review. To ensure all reviewed articles were fully peer-reviewed, I manually removed articles with less than three pages of content, or published in lightly-reviewed formats, like extended abstracts.
3. Use of the Housing Keywords. I searched for each occurrence of {home\*; hous\*; domestic\*} and removed works which used these words only in ways not pertaining to housing (for example, “Gross Domestic Product,” “Homepage”).
4. Relatedness to Topic. I read the introduction and abstract of each work remaining after the above filtering to determine relatedness to my topic. To be included, a paper’s abstract or introduction needed to mention some topic related to disability, aging, or chronic illness, and to domestic spaces and/or some activity typical of domestic settings (eating, showering, etc.). When a topical connection was loose, I tended toward inclusion.

Figure 4.1 shows a visualization of steps in the collection, filtering, and analysis process. Table 4.1 shows analyzed venues and counts of results returned and filtered in each round. Journal publications extending works published in conference proceedings were analyzed as unique contributions, as multiple works show these discourses have persisted over time. Notably, neither article collected from ACM Transactions on Applied Perception was related to my topic, leaving nine venues in the final analysis. After filtering, my corpus contained 101 articles. I read each in full to examine discourses of housing discussed below.

| Publication Venue  | Results | Review | Keywords | Topic | Total |
|--|---------|--------|----------|-------|-------|
| SIGACCESS Conference on Computers and Accessibility (ASSETS)   | 197     | 37     | 49       | 73    | 38    |
| SIGCHI Conference on Human Factors in Computing Systems (CHI)  | 91      | 22     | 23       | 29    | 17    |
| Pervasive Technologies Related to Assistive Environments Conference (PETRA)  | 50      | 19     | 6        | 8     | 17    |
| Transactions on Accessible Computing (TACCESS)   | 65      | 1      | 17       | 31    | 16    |
| Proceedings of the ACM on Human-Computer Interaction, Issue CSCW/ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW) | 20      | 4      | 1        | 11    | 4     |
| Transactions on Computer-Human Interaction (TOCHI)   | 9       | 0      | 2        | 4     | 3     |
| European Conference on Cognitive Ergonomics (ECCE)   | 44      | 15     | 2        | 24    | 3     |
| International Web for All Conference (W4A)   | 74      | 17     | 41       | 14    | 2     |
| Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies/ International Conference on Ubiquitous Computing (IMWUT)      | 24      | 14     | 4        | 5     | 1     |
| Transactions on Applied Perception (TAP)   | 2       | 0      | 0        | 2     | 0     |
| Total  | 576     | 129    | 145      | 201   | 101   |

Table 4.1: Analyzed venues, results collected, and total filtered by 1) level of peer-review, 2) use of housing keywords, and 3) topic fit. In total, the 576 works from these venues were reduced to a final corpus of 101.

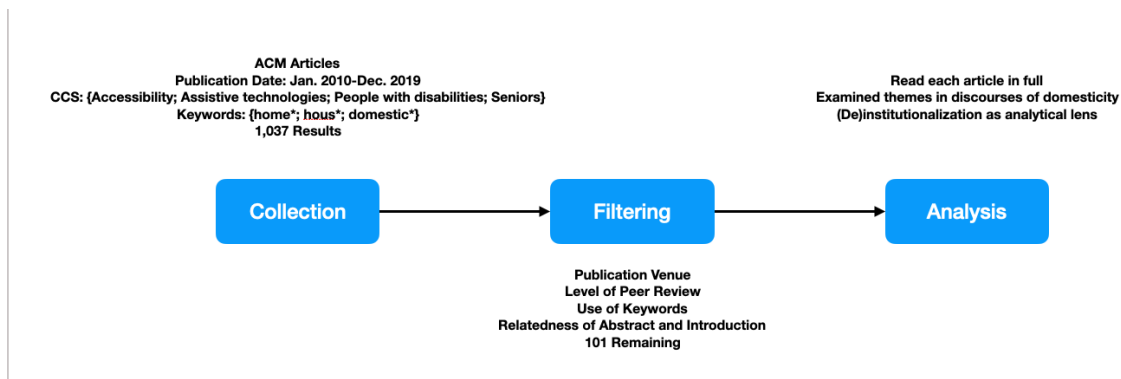


Figure 4.1: Visualization of Collection and Filtering Process

### 4.3 Study Findings

I found the history of (de)institutionalization structures discourses of housing in contemporary AC research. References to institutional and community-based living were common in the corpus. Setting “independence” as a primary goal of AC system design was also common. But, the history of (de)institutionalization was not explicitly addressed in these works. Instead, institutionalization was primarily discussed in relation to contemporary institutions, like nursing homes. Discourses surrounding contemporary institutions normalized their existence using similar economic, scientific, and moralistic frameworks as those which first justified institutionalizing disabled people in the USA. Importantly, because community-based living and its associated value of “independence” were positioned as opposite to institutional living, discussions of community-based living and independence were often subject to these same logics. That is, I found economic, scientific, and moralistic discourses of community-based living and independence which were complementary to, and consistent with, the understanding that contemporary institutions are normal and justifiable for similar reasons as institutions in the nineteenth-century USA. So, collectively, these works evidenced a commitment to setting goals of community-based living and independence. But, they approached these goals from distinctly institutional perspectives, which complicated and undermined their attainment.

### 4.3.1 Economic Views of Housing and Disability

Economic logics in the First American Industrial Revolution, which framed disabled people as burdens on their families and the economy, were a catalyst for institutionalization in the USA. Within the corpus, I found discourses surrounding contemporary forms of institutionalization often adopted similar economic and resource-oriented analytical lenses. These economic discourses were particularly frequent in discussions of disabled people transitioning to and from institutional living.

Discourses surrounding *deinstitutionalizing* disabled people often emphasized the resources expended on transitions to community-based settings. For example, Kosch et al. noted “[p]eople with cognitive impairments currently leverage extensive human resources during their transitions from assisted living to independent living” (Kosch et al., 2018). Some works identified educational labor involved in community-based living, like Sitbon et al., who noted, “a focus in recent years on life skills training and rehabilitation for people with intellectual and learning disabilities. This has come from a move from institutions into homes” (Sitbon et al., 2019). Others pointed to the presence of “facilities [that] have emerged to foster and train independent living skills” (Kosch et al., 2019) and “institution[s] to help people with disabilities to...integrate with the society by organizing various trainings” (Liu et al., 2016). In these examples, community-based living was portrayed as being made possible through the labors of others and society.

In contrast, discussions of *institutionalizing* disabled people often framed transitions to institutional settings as an effortless response to circumstances. For example, van Dijk et al. motivated their research by noting “[t]here are many reasons people may be forced to leave their homes...and start a new lifestyle in a nursing home” (van Dijk et al., 2010). Likewise, Vacher et al. described institutionalization as a “de facto course of action” in certain situations (Vacher et al., 2019). Others indicated circumstances may lead to “having to

send people to care homes” (McGee-Lennon et al., 2011), or to disabled people “having to receive institutionalized care” (Petrie and Darzentas, 2017). Notably, this perception that institutionalization is a direct outcome of circumstances was also shared by some research participants. One interviewee of Birnholtz and Jones-Rounds, indicated an imagined system might be acceptable “if it meant the difference between being able to stay wherever it was I was living or having to move into someplace that’s more structured and regulated” (Birnholtz and Jones-Rounds, 2010), alluding to institutional facilities. The role of others and society in institutionalizing disabled people was notably absent from these discussions. Instead, responsibility for institutionalization was placed on situational factors, not requiring the intervention—or effort—of any individual.

The dichotomy between the above economic discourses of deinstitutionalization and institutionalization portrayed an institutional system in which becoming independent was resource-intensive and required deliberate effort from others, while becoming institutionalized was effortless and a result of circumstance. Importantly, this perception of independence-as-effort was pervasive in the corpus, even outside the context of transitions between institutional and community-based settings. For instance, in the design of domestic AC systems, authors often indicated goals of “enabling” independence (Birnholtz and Jones-Rounds, 2010; Branham and Mukkath Roy, 2019; Kosch et al., 2019, 2018; Petrie and Darzentas, 2017), reflecting the conception independence is created through others’ labor. At a deeper level, ideas of independence-as-effort were also reflected in perceptions of disabled people living independently. Many reviewed works suggested disabled people in community-based settings were, in some way, a resource burden on others (Anderson et al., 2018; Branham and Kane, 2015a; Lopez et al., 2018; McNeill et al., 2017; Mulvenna et al., 2010; Peters et al., 2014; Petrie and Darzentas, 2017; Viswanathan et al., 2011). Skorupska et al. suggested older adults in community-based settings were a burden on the economy and society, more broadly, motivating their crowdworking platform by citing a “shortage of adequate research-informed activities and programs allowing them to contribute to the society” (Skorupska

et al., 2018). In this sense, disabled people becoming and being independent were both portrayed as resource intensive activities.

Within a framework where disabled people's community-based living and independence are the result of the ongoing labor of others, institutionalization is *inevitable*. That is, since independence is created through resources provided by others and society, given enough time, these resources will be depleted, and independence will be rescinded. Accordingly, I found many works in the corpus suggested independence was an inherently temporary state of being. For example, Vacher et al. noted disabled people “want to stay in their residence for as long as possible” (Vacher et al., 2019). McGee-Lennon et al. suggested designed systems might help “people with disabilities...stay active and independent for longer in their own homes” (McGee-Lennon et al., 2011). Other works indicated “seniors wish to remain independent” (Birnholtz and Jones-Rounds, 2010) and disabled people made “some adaptations [to their homes] in order to stay independent” (Vacher et al., 2015), where “remaining” and “staying” allude to the threat to independence caused by time. In this way, because independence was resource-intensive and ultimately unsustainable, institutionalization is portrayed as a force of nature.

Because institutionalization was perceived as inevitable, efforts aimed at constructing independence for disabled people may be viewed only as delaying institutionalization, rather than preventing it. So, when goals of community-based living and independence were set, disabled people's independence was typically discussed as something aimed at rather than attained. For example, independence was often described as something to be “supported” (Boujarwah et al., 2011; Consel et al., 2015; Pradhan et al., 2018; Sharma et al., 2018; Sitbon et al., 2019; Yuan et al., 2017), to be “increased” (Bhattacharjee et al., 2019; Bonani et al., 2018; Jain et al., 2019; Viswanathan et al., 2011), to be “promoted” (Dimitrov et al., 2019), or to be “improved” (van Dijk et al., 2010) by design efforts. Where community-based living was framed as resulting from others' labors, the inevitability of institutionalization suggested

efforts aimed at independence will eventually fail, rendering goals of independence fundamentally out of reach for researchers. Importantly, these boundaries further emphasized the resources involved in independence, by calling into question whether efforts made in pursuit of independence will—or can—ultimately achieve their goals.

As a collective, I found economic logics of institutionalization were mirrored in discourses of community-based living and independence. Where institutionalization was portrayed as reflexive and automatic, independence was portrayed as deliberate and difficult. Where institutionalization was the result of forces beyond the control of other individuals and society, independence was portrayed as possible only because of others and society. Put more simply, disabled people’s institutionalization was nature’s fault, and their independence was society’s achievement. Notably, positioning institutionalization and independence within this framework largely problematized disabled people’s community-based living and independence. Metaphorically speaking, within these works, independence was akin to swimming upstream—a laborious, active resistance against natural forces, which can only be sustained temporarily. Put more directly, disabled people’s independence was a problem which, when eventually too burdensome for others, will be solved by institutionalization.

### **4.3.2 Scientific Views of Housing and Disability**

Scientific advances of the Enlightenment justified institutionalization in the USA, by suggesting disabilities may be clinically treated or “cured.” Within the corpus, I found discourses surrounding contemporary forms of institutionalization often adopted scientific and clinical views of the function of institutions in society.

Specifically, many works within the corpus suggested institutionalization is, in some way, beneficial for disabled people’s health and clinical wellbeing. In fact, discussions of institutions-as-clinically-beneficial were intertwined with the portrayal of institutionalization as a result

of circumstance, discussed above. That is, institutionalization was inevitable because of clinical healthcare becoming increasingly complex over time, due to aging or accidents. For instance, one of the “many reasons people may be forced to leave their homes,” described by van Dijk et al. (van Dijk et al., 2010), is “due to a degrading physical or mental condition.” Likewise, institutionalization was described as the “de facto course of action,” by Vacher et al. (Vacher et al., 2019), “after a fall [because] falls have serious [health] consequences.”

Conversely and accordingly, I found many cases where disabled people’s community-based living and independence were portrayed as being in tension with their health and safety. For instance, in observing disabled people in the kitchen, professional caregivers were noted to “make crucial tradeoffs between safety concerns and independence” (Kosch et al., 2018). Viswanathan et al. noted, because of these tensions, “older adults with cognitive impairments are excluded from powered wheelchair use because of safety concerns. This leads to...higher dependence” (Viswanathan et al., 2011). Likewise, Holbø et al. (Holbø et al., 2013) described “the risk of relying on one’s own abilities” when walking alone. Madjaroff and Mentis found participants in their study also perceived these tensions, such that the “autonomy of the care-recipient would often be compromised due to the need for safety that was expected by the caregiver” (Madjaroff and Mentis, 2017).

Importantly, portraying institutionalization as clinically beneficial and community-based living and independence as threatening to physical well-being, casts both institutional and community-based living within a clinical framework. That is, since institutionalization is necessary in cases of complex clinical healthcare needs, *sustaining independence is a clinical problem*, in which safety and adequate healthcare are the dividing line between institutional and community-based living. In emphasizing clinical aspects of institutional and community-based living, I found discourses of domestic life—even in community-based settings—were often medicalized, in areas which would likely be viewed as nonclinical outside the context of disability.



For instance, domestic labor is routine in the domestic spaces of many people. But, within the context of AC, domestic labor tasks were typically discussed as part of “Activities of Daily Living” or ADLs. For example, Belley et al. (Belley et al., 2013) contributed insights toward smart-home recognition of older adults’ performance of ADLs, like making tea and cooking toast, bacon, and pancakes. Similarly, Mulvenna et al. (Mulvenna et al., 2010) designed the COGKNOW system for people with dementia, to “support daily activities” like controlling domestic infrastructures, preparing and eating meals, and using household appliances. Importantly, the phrase ADL was not simply a way to describe domestic labor. Rather, describing domestic labor as ADLs alluded to the use of domestic labor performance as a clinical measure, which determines whether disabled people will be institutionalized. For instance, Caroux et al. motivated their work, by stating ADLs “are abilities defining the functional status of an individual. Verifying what ADLs are performed by an older adult is a decisive factor to determine...whether aging in place is desirable” (Caroux et al., 2014). Peters et al. noted, “[p]roblems related to this [cognitive] functioning appear in a human’s daily routines where the successful execution of Activities of Daily Living (ADLs) is an integral part of an autonomous and self-determined life” (Peters et al., 2014). Indeed, Bhattacharjee et al. motivated their work by referring to a prior study which found “needing help with one of more ADLs is the most cited reason for moving to assisted or institutionalized living” (Bhattacharjee et al., 2019). So, although examining domestic labor is important in understanding domestic life, in the reviewed works, domestic labor primarily manifested as a clinical measure of ability—more specifically—the ability to remain independent and in community-based living.

Familial relationships are also a particularly important and nuanced aspect of domestic life. But, within the context of AC, familial relationships were also frequently discussed in clinical terms. Specifically, within the corpus, familial relationships were typically defined by caregiving/care-receiving interactions. For example, Madjaroff and Mentis conducted a study with the purpose of understanding “the narratives of people living with a mild cognitive

impairment as well as their partners that live with them and provide care” (Madjaroff and Mentis, 2017). In a separate study, Mentis et al. noted “older adults with MCI often cope with...the help of caregivers, including partners [and] children” (Mentis et al., 2019). Peters et al. noted “informal care-givers such as family members worry about the well-being of care recipients” (Peters et al., 2014). Likewise, Alves et al. designed “a mobile application that allows communication and information sharing between informal caregivers, namely family and friends” (Alves et al., 2019). Several works designed systems specifically to support family members in their role as healthcare providers. For example, Parnandi et al. designed a speech therapy tool “potentially allowing for a higher intensity of practice than is typically possible with parent-directed home practice” (Parnandi et al., 2013). Elor et al. shared a system “for upper limb rehabilitation, which can be set up inside or outside the therapy office by a caregiver or family member” (Elor et al., 2018). For Vacher et al., this emphasis on familial caregiving is directly related to disabled people’s independence and living environment in that, due to the aging population, “it is likely that families will have to provide more support than in the past century given the reduced availability of specialized institutions” (Vacher et al., 2015). In this way, family members are framed as extensions of the institutional system, providing healthcare, rather than supportive social connection. Caregiving could be viewed as a central component of most familial connections—cooking for one’s spouse or children, for example. But, here, the clinical emphasis of caregiving downplayed the inherent intimacy of familial connections, by portraying interactions as medically-oriented and unidirectionally beneficial. That is, family members are shown to care *for*, but not necessarily care *about* or *with* disabled people. Likewise, disabled people are shown to receive care *from*, but not necessarily provide care *to*, their family members.

Similarly, leisure and play are important aspects of domestic life, in that private domestic spaces serve as non-professional settings where occupants can freely engage in nonutilitarian activities. But, within the context of AC, leisure activities were most commonly discussed as vehicles for delivering clinical care, or for deemphasizing the clinical aspects of therapy.

For example, Korn and Tietz outlined recommendations for “gamifying rehabilitation” in order to improve adherence to clinical regimens “at home without regular observation by a therapist” (Korn and Tietz, 2017). Sitbon et al. drew on previous insights into “[i]nteractive, game-like Virtual Environments” when designing immersive videos to train disabled people in common life skills (Sitbon et al., 2019). Parnandi et al. suggested “game-like features and animations would increase the patient’s interest” in therapy tools for apraxia of speech (Parnandi et al., 2013). Gerling et al. designed wheelchair-based games with the goals of “improving [older adults’] cognitive, physical, and emotional well-being” (Gerling et al., 2013). Similarly, Hornof et al. presented a media player designed to motivate a young girl with Rhett Syndrome to begin “interacting with her world as was needed to learn cause and effect” (Hornof et al., 2017). While leisure activities were frequently discussed as an aspect of domestic life, it is unclear leisure was the intent of these designs promising playfulness. Rather, these leisure activities served as metaphorical “spoonfuls of sugar to help the medicine go down,” since their playful aspects were intended to deemphasize, or hide, their purpose as vehicles for delivering clinical care to disabled users.

As a collective, I found discourses which portrayed institutionalization as scientifically and clinically beneficial for disabled people were reflected in conceptions that community-based living and independence are clinically challenging, or even dangerous. Consequently, domestic life—in both institutional and community-based settings—is best understood within clinical frameworks. As such, in the corpus, many nonclinical aspects of domestic life, including domestic labor, familial relationships, and leisure, were discussed primarily in relation to their clinical utility. Indeed, receiving appropriate clinical care within the local community is an important aspect of domestic life for both disabled and nondisabled people, and domestic labor, familial relationships and leisure may have clinical benefits for people regardless of their (dis)abilities. However, the clinical aspects of domestic labor, familial relationships, and leisure are but one of many qualities which define community-based domestic life. Here, the predominance of clinical perspectives left other significant aspects of domestic life, like

distribution of domestic labor, intimate connection, and playfulness, largely unexamined.

### **4.3.3 Moralistic Views of Housing and Disability**

The religious fervor of the Second Great Awakening in the USA justified institutionalization, in that believers felt institutionalizing disabled people was a moral and ethical act of helping disadvantaged members of society. Within the reviewed works, I found discussions of ongoing forms of institutionalization frequently adopted similar moralistic languages, and presented institutionalization as benevolent and helpful for disabled people.

In particular, when contemporary institutions were discussed, they were most often not identified as institutional settings. Rather, these institutions were euphemistically described as “nursing homes” (Alves et al., 2019; van Dijk et al., 2010; Gerling et al., 2013; Korn et al., 2018; Mentis et al., 2019; Neves et al., 2015; Scheffler et al., 2011; Vacher et al., 2019), “sheltered living” (Kosch et al., 2019, 2018), “care facilities” (Becker et al., 2010; Bhattacharjee et al., 2019; Birnholtz and Jones-Rounds, 2010; Neves et al., 2015; Viswanathan et al., 2011), or “care centers” (Alves et al., 2019; Aruanno et al., 2018; Hernandez et al., 2014; Lopez et al., 2018). Notably, these phrases are common in vernacular English. But, it is important to recognize that by sidestepping discussions of institutions as institutions, these optimistic euphemisms both deemphasize institutions’ carceral qualities and emphasize their supposed benevolent qualities—nursing, shelter, and care. The benevolence of institutions was similarly emphasized in discussions of the activities happening within institutional settings. Professional staff working within institutions were frequently described as “care-takers,” “caregivers,” or “assistants” (Alves et al., 2019; van Dijk et al., 2010; Kosch et al., 2019; Scheffler et al., 2011), suggesting caring for or assisting disabled people is a primary responsibility of their job.

At the same time, the specific duties described as being involved in “caring for” disabled

people in institutional settings often had distinctly carceral qualities. For example, one role of the “caretakers” described by Scheffler et al. (Scheffler et al., 2011) was to retrieve “patients [who] walk away from the nursing home,” and return them back to the institution. Similarly, van Dijk et al. indicated “care professionals” in institutions may gatekeep social interactions, in that “[m]ost of the social contacts in rehabilitation centers and nursing homes are based on scheduled visits” (van Dijk et al., 2010). Yet, these activities were typically understood as being clinically justified, as discussed above, and therefore carried out in the care of disabled people. In fact, at a higher level, many works indicated helping disabled people was a primary societal function of institutions. For example, sheltered living facilities “offer people with cognitive impairments assistance with learning,” (Kosch et al., 2018), nursing homes provide “help to get up” (Korn et al., 2018), and halfway houses “help people with disabilities to rehabilitate” (Liu et al., 2016). Together, these discourses framed institutions as benevolent and staffed by people who care for disabled people, working within an institutional system which serves to help. Even when carceral aspects of institutions were identified, they were secondary to institutions’ benevolent qualities, understood as modes of caregiving, and portrayed as ways institutional systems help disabled people.

This understanding of institutions-as-helpful promoted conceptions that *institutional modes of care are ethical* frameworks for guiding the design of domestic AC systems. For instance, Becker et al. motivated their exploration into activity recognition in a smart home environment by noting “[i]t is critical to provide a means to help the individual [with disabilities] in their home as they would be helped should they be in a care facility” (Becker et al., 2010). Others sought design inspiration from institutional settings and institutional caregivers. For instance, Bhattacharjee et al. provided design recommendations for a robot-assisted feeding system based on insights from a study “in an assisted-living community with five potential care recipients and five caregivers...fifteen domain experts including occupational therapists and feeding specialists” (Bhattacharjee et al., 2019). Peters et al. based their design of an assistive toothbrushing system on interviews with caregivers, because “[c]aregivers are

experts in prompting since they provide professional nursing care in the task of brushing teeth as part of their daily routine” (Peters et al., 2014). Likewise, Kosch et al. provided insights for the design of a cooking assistance system, based on a comparative study of “participants in a sheltered living facility that were supported by either caretaker assistance or in-situ assistance” (Kosch et al., 2019). Professional caregivers may be an important source of domain-specific knowledge. But, by guiding design using insights from institutional caregivers, these works could equally be seen as suggesting institutional models of care are desirable standards of care which design should emulate, or by which AC systems’ efficacy should be measured.

One consequence of framing institutional models of care as desirable models to emulate in design was that many AC systems for community-based settings in the corpus were designed to achieve carceral goals. In particular, many systems in the corpus were designed to surveil disabled people. For example, Becker et al. designed an ambient assistive living environment in which various sets of sensors were “deployed to monitor human activity” (Becker et al., 2010). Caroux et al. shared an approach to “verifying the activities of daily living of older adults at their home...supported by a lightweight sensor infrastructure” (Caroux et al., 2014). Meliones et al. presented a domestic “adaptive intelligent video surveillance and motion detection system employing a network of IP cameras for patient monitoring” (Meliones and Kokkovos, 2015). Holbø et al. indicated “[r]emote monitoring, such as electronic tracking, may be perceived as a means of enhancing personal safety” in community-based settings (Holbø et al., 2013). Anderson et al. suggested their MANA gait monitoring system “can be used at home as it is a convenient and invisible wearable system” and “battery life makes long term monitoring using MANA a strong possibility” (Anderson et al., 2018). Ferdous et al. pointed to “recent advances in RFID Technology [like those for] monitoring elderly people at home” (Ferdous et al., 2010) to motivate their techniques for managing data generated by such systems. Systems for surveilling disabled people in community-based settings were prevalent enough that Consel et al. even identified “monitoring of activities of daily living” as

one of the “main domains of assisted living” (Consel et al., 2015). Additionally, several works explored privacy concerns with such systems. Vacher et al. indicated “there is a balance between the benefit of such monitoring (sensors of all kinds) and the intrusion into privacy” (Vacher et al., 2015). Similarly, McNeill et al. expressed a concern “that some developers assume, sometimes without asking, that while older adults desire to live independent, there is a need for some kind of health supervision in order [to] protect them from harm” (McNeill et al., 2017). It is important to recognize these tensions. However, it is unsurprising that privacy may be intruded by these designs, as lack of privacy through surveillance is a mode of institutional “care” emulated by these systems.

Taken together, I found discourses surrounding contemporary institutions portrayed institutionalization as part of a benevolent system which helps disabled people. This conception was reflected in the framing of *institutional approaches to care as desirable* models for design to emulate in community-based settings. Clinical caregivers and institutional practices were important sources of design insights. Consequently, many domestic AC systems replicated the carceral logics applied to “caring for” disabled people in institutional settings. Importantly, here, design goals of independence were not necessarily undermined by carceral design solutions. Rather, surveillance itself was understood as a mode of creating independence for disabled people.

#### **4.4 Institutional Discourses of Housing and their Consequences for Accessible Computing Design Research**

At a high level, I found evidence the history of (de)institutionalization shapes recent domestic AC research approaches and trajectories. The historical connection of housing to disabil-

ity rights manifested most commonly in authors setting goals of “independence” within the reviewed works. But, the ongoing presence of contemporary institutions, and the normalization of them, placed limitations on what could be said about community-based living and independence within these texts. Specifically, I found discourses surrounding contemporary institutions often adopted economic, scientific, and moralistic perspectives which paralleled those used to justify institutionalizing disabled people in the nineteenth-century USA. These logics portrayed institutionalization as an effortless result of circumstance, clinically beneficial, and helpful to disabled people. Correspondingly, I found discourses of community-based living and independence portrayed as a temporary and laboriously constructed state, clinically dangerous, and best supported by institutional models of care.

#### **4.4.1 Dialectical Views of Discourse and Perpetuation of Ableist Views of Housing in Accessible Computing**

How we, as an academic community, write about issues of housing and disability not only has practical implications for AC design research, but also ethical implications for how our collective work contributes to societal understandings that institutionalization is normal and justifiable. A key claim of much CDA is that discourses have a dialectical relationship with societal power structures (Wodak and Meyer, 2015). That is, discourses are shaped by political relations and shape political relations. In accepting the political relations of the institutional system without critique or caveat, the AC community not only implicitly orients our problems to these frameworks, we reinforce the normalcy of the institutional system. This may be an especially critical issue for AC researchers, as our discussions are documented in archival texts, which are peer-reviewed and granted positions of authority. Many of our readers may be nonacademic, turning to us as experts on this topic, while lacking historical context available to seasoned scholars. In this way, our discourses of housing are impacted by wider conceptions of housing and disability, but also may perpetuate problematic societal



thinking, by reinforcing the normalcy of these logics.

#### 4.4.2 Design Problem Setting and Problem Solving

Importantly, the institutional discourses of housing in these works not only shape what can be said, they also impact *how domestic AC design research can be executed*. In his canonical *The Reflective Practitioner*, Donald Schön describes the work of design as a cycle of problem setting and problem solving, in which:

When we set the problem, we select what we will treat as the ‘things’ of the situation, we set the boundaries of our attention to it, and we impose upon it a coherence which allows us to say what is wrong and in what directions the situation needs to be changed (Schön, 2017).

In Schön’s terms, discourses evidence commitments to what is treated as the “things” of the situation, influencing problem setting. Here, the history of (de)institutionalization and the normalization of contemporary institutions present a situation in which the problem set is: disabled people in community-based settings are 1) burdensome, 2) clinically endangered, and 3) would be helped by being institutionalized. By setting the problem in these terms, the boundaries of attention paid to it and the directions in which the situation should change are also defined.

Consider, for example, Elor et al.’s system “for upper limb rehabilitation, which can be set up inside or outside the therapy office by a caregiver or family member” (Elor et al., 2018). The ongoing history of (de)institutionalization suggests “what is wrong” is disabled people in community-based settings are clinically endangered. So, a lack of clinical care available outside the therapy office is an appropriate problem to set. In setting the problem this way, the boundaries of attention to it become limited to clinical concerns. The fungibility

of “caregiver” and “family member” in this sentence suggests the attention paid to family members in this scenario is bounded to their clinical utility. By setting the problem as a clinical problem and limiting the boundaries of design attention to clinical concerns, building a system to provide clinical services outside of clinical settings which employs the aid of pseudo-clinician family members becomes a viable mode of problem solving. But, the viability of solving the problem with clinical design solutions follows the setting of the problem in clinical terms—and the problem is set in clinical terms because of scientific conceptions of disability and housing rooted in the ongoing history of (de)institutionalization. Similar patterns can be found in economic and moralistic discourses of housing, where crowdworking platforms solve the problem of a “shortage of...programs allowing [disabled people] to contribute to the society” (Skorupska et al., 2018), and surveillance systems solve the problem of “help[ing] the individual [with disabilities] in their home as they would be helped should they be in a care facility” (Becker et al., 2010). In this way, the discourses of housing explicated here are not simply words on a page—but dominant logics of society, and of the AC community specifically, which implicitly guide how the “things” of design situations are selected and, consequently, how problems are set and solved.

### **4.4.3 Accessible Computing Research Trajectory Setting**

For fellow academics, it is important novel research engages in conversation with existing work. So, how discourses of housing are constructed in current research directly impacts how future work is approached and produced. Together, failing to address the problematic history of (de)institutionalization in these works perpetuates institutional logics, by omission, and promotes additional research which further perpetuates these logics, by demanding research is relevant to current domains of inquiry in AC, which have been built on institutional logics. The cycle repeats.

At the same time, in critiquing these discourses and explicating their practical and ethical implications for AC research, my goal is not to discredit the reviewed works. Nor do I intend to suggest AC literature is uniquely responsible for dismantling nor upholding the institutional system through their research and design praxis. The dominant economic, scientific, and moralistic ideologies discussed reflect those held, more broadly, by many societies in which AC researchers are situated. So, the presence of institutional discourses in AC literature should not necessarily be interpreted as reflecting AC researchers' individual intentions or thinking. Rather, institutional discourses, and the complexity they add to discussions of community-based living, highlight inherent tensions in challenging institutional systems while working within larger societal structures which shape the problems that might be addressed by technology design. The reviewed works, even where critiqued, accurately depict societal realities and speak to vital issues affecting many disabled people. For instance, many technologies considered here to be “institutional” fill gaps in the availability of community-based services whose public funding, in the USA, varies widely due to regional politics and can be prohibitively expensive to pay out of pocket (Hayes et al., 2017). Currently, this gap is most often filled by women whose labor is unpaid (Family Caregiver Alliance), who may also benefit from the support provided by institutional domestic AC systems. So, my aim is not to argue that tackling institutional design problems is wholly without merit, nor that the discourses critiqued here should, or even could, be completely abandoned in AC research.

However, I believe the centrality of “independence” to the works in our corpus is evidence of communal goals of achieving permanent community-based living for disabled people. Institutional discourses of housing in AC may shape the setting and solving of design problems in ways that are fundamentally antithetical to this goal. This dissonance suggests a need to balance a pragmatic desire to address problems of immediate importance to disabled people with the acknowledgement—and challenging—of social injustices produced by the historical and ongoing practice of institutionalization, which place boundaries around technology's ability to solve those problems. In this way, my exploration of institutional logics embed-

ded in discourses of housing in AC is a call for both 1) alternative perspectives on housing which expose novel modes of problem setting, and 2) more nuanced discussions of disability and housing which engage housing's connection to (de)institutionalization as simultaneously accurate and ableist, prescient and problematic, normalized and contestable.

## Chapter 5

# Comparing Blind Adults' and Accessible Computing Literature's Perspectives on Social Considerations of Domesticity Relevant to Accessible Computing Design Research

The third contribution of this dissertation is a critical analysis of points of alignment and tension between blind adults' and AC literature's perspectives on social considerations of domesticity relevant to AC design research. Here, I synthesize the results of the three studies described in Sections 3 and 4. Across these studies, I found recurring themes of 1) disabled people's resource contributions to the household, 2) care in familial relationships between disabled and nondisabled people, and 3) disabled people's autonomy and agency in domestic life. However, I also found tensions between the ways that AC literature and blind adults described these aspects of domestic life.

## 5.1 Conceptions of Disabled People’s Resource Contributions to the Household

All three studies of social considerations of domesticity relevant to AC design research described in Sections 3 and 4 discussed, in some way, the resource contributions of disabled people to their families and households. However, these discussions took distinctly different tones. In the case of my study on AC literature’s perspectives, discussions of disabled people’s resource contributions to their household typically described disabled people taking resources, or being fundamentally unable to contribute to their families without the aid of some novel AC system. In the case of studies of blind parents’ and partners’ perspectives, the resource contributions described were a net positive for the household, where blind parents and partners did, or desired to, contribute to their families. These tensions in conceptions of disabled people’s resource contributions in domestic settings are particularly visible in the ways that blind adults and AC literature differently imagine the directionality of resource exchanges between disabled people and nondisabled others.

In the case of AC literature, disabled people may take resources from others and society, for example, when they “leverage extensive human resources during their transitions from assisted living to independent living” (Kosch et al., 2018), or by employing the support of “institution[s] to help people with disabilities to...integrate with the society by organizing various trainings” (Liu et al., 2016). Additionally, disabled people may be viewed as fundamentally unable to contribute, at all, without some novel AC system to assist them, for instance, a novel crowdworking platform “allowing them to contribute to the society” (Skorupska et al., 2018).

In contrast, the perspectives that blind adults shared about technology use in their roles as parents and partners described many ways in which they contributed resources to others and to their household, for instance blind parents sharing ways “to teach your child some

valuable pre-literacy skills, like learning what books are, how to turn pages, how to read from left to right in a sequence... etc.” (BP1) and blind partners using VAs to turn on the lights for their families, find recipes when cooking dinner, help children with homework, and set timers for cooking or monitoring laundry cycles.

Here, the perspectives of blind adults and AC literature diverge in their conceptions of whether and how disabled people do or can contribute resources to nondisabled people in domestic settings and to society, more broadly.

## **5.2 Directionality and Reciprocity of Care in Familial Relationships between Disabled and Nondisabled People**

All three studies of social considerations of domesticity relevant to AC design research described in Sections 3 and 4 discussed, in some way, the care relationships between disabled and nondisabled family members in the same household. However, these discussions took distinctly different tones. In the case of my study on AC literature’s perspectives, discussions of caring relationships between disabled and nondisabled family members in the same household almost exclusively imagined disabled people as solely the recipients of care. In the case of studies of blind parents’ and partners’ perspectives, the caring relationships described typically involved blind adults caring for other family members, or caring with other family members in a bidirectional manner.

In examining the perspectives of AC literature, I found that nondisabled family members in the household, when considered at all, were most often described as “caregivers” rather than as “spouses,” “children,” or “parents,” for example. For instance, Peters et al. noted “infor-

mal care-givers such as family members worry about the well-being of care recipients” (Peters et al., 2014). Madjaroff and Mentis conducted a study with the purpose of understanding “the narratives of people living with a mild cognitive impairment as well as their partners that live with them and provide care” (Madjaroff and Mentis, 2017). Elor et al. shared a system “for upper limb rehabilitation, which can be set up inside or outside the therapy office by a caregiver or family member” (Elor et al., 2018). In these cases, the intimate relationships that are described are not only defined in terms of the caregiving responsibilities involved, but also with a unidirectional understanding of care, in which disabled people are solely recipients.

In contrast, the perspectives that blind adults shared in their roles as parents and as partners described many ways in which blind adults demonstrated care for and with nondisabled family members. For instance, blind parents assessed methods for co-reading based upon whether they “give that intimate vibe” (BP12) and argued that “the communication between parent and child that matters most” (BP14). Likewise, blind partners often demonstrated care for their family members to the point of limiting their own access. For example, Ben and Carrie (V) explained that they did not own any home automation technologies, despite the potential for increasing the accessibility of domestic infrastructures for Ben, because they worried that “some nut-job” might attempt to frighten their children by flickering the lights during the night.

Here, AC literature and blind adults both indicate that familial relationships involve caregiving/receiving dynamics. However, there is tension in these discussions about whether disabled people can *provide* care to or only *receive* care from nondisabled others.



### 5.3 Desirability of Disabled People’s Individual Agency and Autonomy in Domestic Spaces

All three studies of social considerations of domesticity relevant to AC design research described in Sections 3 and 4 discussed, in some way, the individual autonomy and agency of disabled people in domestic spaces. However, these discussions took distinctly different tones. In the case of my study on AC literature’s perspectives, disabled people’s individual autonomy was often framed as clinically dangerous and the limitation of disabled people’s autonomy through surveillance and monitoring systems was positioned as being in their best interest. In the case of studies of blind parents’ and partners’ perspectives, autonomy and agency were described as desirable, and increasing blind adults’ individual autonomy was a recurring motivation to adopt AC systems.

In examining the perspectives of AC literature, I found that disabled people’s autonomy and agency were often described as being in direct conflict with their safety. For instance, professional caregivers were noted to “make crucial tradeoffs between safety concerns and independence” (Kosch et al., 2018), and “older adults with cognitive impairments are excluded from powered wheelchair use because of safety concerns. This leads to...higher dependence” (Viswanathan et al., 2011). Likewise, Holbø et al. (Holbø et al., 2013) described “the risk of relying on one’s own abilities.” In this framing, it is then logical and desirable to limit disabled people’s autonomy through surveillance and monitoring systems, which were pervasive in my corpus, or, as an article put it, “to provide a means to help the individual [with disabilities] in their home as they would be helped should they be in a care facility” (Becker et al., 2010).

In contrast to these views that autonomy is potentially dangerous and should be limited, blind parents and partners often described their own agency in domestic spaces as an important value. For instance, in the case of co-reading many blind parents expressed wanting

to “do it myself,” and BPF posts frequently emphasized the direct involvement of the blind parent in the co-reading process, so that “*your* [children] hear *your* voice and *your* interpretation” (BP1)(emphasis added). Similarly, in the case of VA adoption, blind partners often noted that their ability to participate directly in family activities was a key benefit of using VAs. For instance, Jen participated in her family’s “games more now, because you don’t need any cards.” Vince and Paula(V) were both able to participate more directly in their children’s educations, because:

V: [The VA] will highlight the basics to really get them started—and us. So, we can better teach our kids. We can, kind of, confirm, because we’re a little rusty on some of that stuff.

Here, for AC literature, autonomy and agency are potentially dangerous, while, for blind adults, autonomy and agency are essential components of participating in a fulfilling domestic life.

## Chapter 6

# A Deinstitutional Framework for Understanding Social Considerations of Domesticity Relevant to Accessible Computing Design Research

The fourth, and final, contribution of this dissertation is a design research framework for aligning points of tension in conceptions of social aspects of domesticity relevant to AC design research, held by blind adults and AC researchers. In this pursuit, I found that the housing justice advocacy work of disabled activists and their allies, both within and outside of the IL Movement, forms a useful basis for deriving values to uphold in domestic AC design research. It would be difficult and potentially problematic to promote research stances for aligning AC researchers' perspectives of homes with those of disabled people, without incorporating the views of disabled people, themselves. In this case, the housing justice initiatives and resultant legislative and societal achievements of disabled activists and their allies represent decades of work articulating positions that advance equity for

disabled people and, as such, offer direct insight into some values that an anti-ableist research perspective on domesticity might uphold. Because these values are derived from disabled activism centered upon deinstitutionalization and the IL Movement, I refer to the values articulated by this framework as Deinstitutional. While there are likely many Deinstitutional values that can—and should—inform research praxis in the AC community, here, as a first step in this process, I outline three principles which directly address the tensions observed between blind adults’ perspectives and AC researchers’ perspectives on social considerations of domesticity relevant to AC design research, as described in Chapter 5.

## **6.1 Upholding Independence as a Right**

The IL Movement argues that independence for disabled people, as for nondisabled people, is an innate civil and human right. In addition to “being able to exercise the greatest degree of choice about where you live, with whom you live, [and] how you live,” the right to independence means “controlling and directing your own life and taking responsibility for your own actions” (Westchester Independent Living Center, 2021). For design research employing a Deinstitutional framework, upholding independence as a right involves internalizing these ideas and beginning inquiry from the perspective 1) that independence is defined by autonomy and agency and not by one’s living environment or ability to act alone and 2) that independence is a human right inherently guaranteed to all people, not an artificial state produced by technical or social interventions in disabled people’s lives.

### **6.1.1 Upholding Independence as a Right in Accessible Computing Design Research Discourse**

In the works reviewed in Chapter 4, I found when institutionalization was portrayed as effortless and reflexive, independence was described as temporary and laborious. But, a De-institutional perspective of design research suggest that independence should be treated as an innate civil right, not a constructed state. While civil rights are not unalienable without limitation (consider the well-known example of shouting “Fire!” in a crowded theater), understanding independence as a right positions independence as the default state, prioritizes its normalcy over that of institutions, and frames independence as natural, not constructed. From this perspective, institutionalization can be seen as an unnatural infringement upon disabled people’s rights, rather than a reflexive response to “burdensome” independent disabled people.

### **6.1.2 Upholding Independence as a Right for Blind Parents**

In my exploration of blind parents’ strategies for co-reading with their children, as described in Section 3.2., I found that blind parents had a strong desire to “do it themselves.” That is, when faced with inaccessibility in co-reading with their children, many blind parents expressed reluctance about using techniques for increasing accessibility which would have obstructed, or even outright prevented, their own involvement in the co-reading process. For example, deferring co-reading to a sighted partner would have resulted in a co-reading experience of desirable quality for the child and would have required very little, if any, labor for blind parents. However, this method was considered to be unacceptable to a vast majority of parents in my sample. Here, the perceived success of the co-reading experience for blind parents was not based upon whether the essential elements of co-reading were provided to children, nor was success based upon whether co-reading was easy, or low-overhead, for blind

parents. Rather, the success of the co-reading experience was, at least in part, based upon the blind parent’s ability to be directly involved in the process.

For AC design researchers, adopting the stance of upholding independence as a right may be beneficial for attending to blind parents’ desire to be directly involved in the co-reading process. Recent advances in artificial intelligence and text processing enable the potential for a fully automated co-reading experience between a child and a virtual agent. Such a solution would be highly accessible for blind parents, in so far as the inaccessibility encountered in the technology would be little and the ease of using the technology would be high. However, such a solution might also conflict with notions of independence as agency and autonomy, by eliminating the need for blind parents’ participation altogether. By upholding independence as a right, a Deinstitutional framework for design research highlights the need to balance ease of use and disabled people’s right to participate in the activity supported by a given technology.

### **6.1.3 Upholding Independence as a Right for Blind Partners**

In my exploration of blind partners’ experiences of adopting shared smart speaker devices in their homes, as described in Section 3.3., I found that the universal usability of VAs for blind and sighted partners in the same household enabled new opportunities for blind and sighted partners to share domestic labor and leisure activities in a way that is accessible to blind partners. At the same time, whether blind partners could participate in shared activities depended not only on having a mutually-accessible device, but also on sighted partners’ willingness to use VAs. That is, because the domestic labor and leisure activities described were shared activities, it was necessary for sighted partners to coordinate their own domestic labor and leisure around and through the VA in order for blind partners to participate. In this way, disabled people’s being *independent* meant *acting together*.

For AC design researchers, adopting the stance of upholding independence as a right may be beneficial for understanding this need to consider the usability of domestic AC systems within a larger sociotechnical ecosystem of a home and family unit. Traditional approaches to domestic AC system designs largely focus on the technical accessibility of technologies, by evaluating whether a given technology provides a viable method for a disabled user to complete some task. But, understanding independence as autonomy rather than as aloneness complicates such an approach. Consider, for example, the case of shopping for home goods using a shared smart speaker device. The nonvisual accessibility of VA-enabled smart speakers provides a technically accessible method for shopping to blind partners. But, this technical accessibility did not necessarily translate to independence in performing domestic labor within the household, for instance, if sighted partners did not feel comfortable storing their credit card information on the device, or even if sighted partners simply preferred to continue using handwritten shopping lists that are not accessible to their blind partners. In this way, an understanding that independence is an indicator of how many people are involved in a task may obfuscate the reality that the task itself might be inherently collaborative. But, upholding independence as a right to be autonomous and have control over one's own life highlights the potential for other people to be involved in, and even central to, disabled people's independence.

## **6.2 Domestic Research on Par with Nondisabled Peers**

Although living environment is a key area of concern for the IL Movement, the IL Movement's advocacy does not end at ensuring disabled people can live independently, outside of institutional settings. Rather, the IL Movement advocates, more broadly, for disabled people's right to "participate fully in all areas...of mainstream community living on a par with nondisabled peers" (Barnes, 2014). From a research-oriented perspective, ensuring full

participation in all areas of mainstream living on a par with nondisabled peers is predicated upon conducting research into mainstream living that is, itself, on a par with the research that is being, and has been, conducted in domestic settings with nondisabled people. So, for design research employing a Deinstitutional framework, domestic research on a par with nondisabled peers requires design researchers to 1) understand the types of research that is and has been conducted in domestic spaces with nondisabled technology users, and 2) recognize domains explored in nondisabled users' domestic lives which may be underexplored in AC research as valid domains of inquiry meriting research attention.

### **6.2.1 Domestic Research on Par with Nondisabled Peers in Accessible Computing Design Research Discourse**

In the works reviewed in Chapter 4, I found that when institutionalization was framed as clinically beneficial, independence was portrayed as clinically dangerous, and most aspects of domestic life were understood in terms of their clinical utility. However, issues other than clinical care are known to be an important part of full participation in mainstream community living, by HCI researchers (Bell et al., 2005; Bell and Dourish, 2007; Judge et al., 2010; Mazmanian and Lanette, 2017; Rode, 2010; Thayer et al., 2012). But, the academic attention paid to these issues is not on a par with nondisabled peers. This framing highlights opportunities for AC research which aims for community-based living to be equally fulfilling for disabled people as for their nondisabled peers—not just possible in light of the continued threat of institutionalization.



## **6.2.2 Domestic Research on Par with Nondisabled Peers for Blind Parents**

In my exploration of blind parents' strategies for co-reading with their children, as described in Section 3.2., I found very little prior research related to blind parents' strategies for co-reading. In fact, the study that I conducted was the first study, to my knowledge, of blind parents' strategies for co-reading in either HCI or Education literature. This stands in sharp contrast to several works describing co-reading between sighted parents and their children in HCI (Cingel and Piper, 2017; Raffle et al., 2010, 2011) and an extensive body of Education literature in this domain (see (Mol and Bus, 2011) for a metaanalysis of some 99 works in this space). When examined within the context of the scientific discourses of housing in AC, described in Section 4.3.2., it is evident that the overwhelming conception that disabled people are universally and unidirectionally the recipients of caregiving is, at least in part, contributing to the dearth of research in this space. That is, disabled people are not typically conceptualized in research as caregivers, so their roles as parents are underexplored. In this way, a Deinstitutional framework which emphasizes the need for domestic research in AC which is on a par with nondisabled peers is both an ethical stance aligned with the goals of the IL Movement and a pragmatic stance for surfacing the myriad opportunities for additional research in this space.

## **6.2.3 Domestic Research on Par with Nondisabled Peers for Blind Partners**

In my exploration of blind partners' experiences of adopting shared smart speaker devices in their homes, as described in Section 3.3., I found very little HCI or AC research related to blind adults within their role as intimate partners. As above, within the context of the scientific discourses of housing in AC, described in Section 4.3.2., it is evident that framing

disabled people as universally and unidirectionally the recipients of caregiving is, at least in part, also contributes to the dearth of research in this space. Most often within the reviewed works in Section 4.3.2., intimate partners of disabled adults were described as their “informal caregivers.” But, describing intimate partnerships in this way obfuscates the cooperative aspects of being an intimate partner. That is, by describing intimate partners as caregivers rather than as, for example, care-partners, nondisabled partners were elevated and recognized as providing to, and typically not receiving from, their disabled partners. But, the nature of intimate partnerships is, ideally, nonhierarchical, in which both partners contribute equitably and share autonomy and decision making power. So, in works which characterized nondisabled/disabled intimate partnerships by their caregiving potential, there may be little room for explorations of disabled people’s concerns as equals in a partnership. Yet, these concerns are valid domains of AC design research. In this way, to recommend domestic AC research on par with nondisabled peers is, as above in Section 6.2.2., both an ethical and pragmatic matter.

### **6.3 Least Restrictive Design Approaches**

A key legislative achievement of the housing-based advocacy work of disabled activists and their allies was the 1966 *Lake v. Cameron* ruling (Davis et al., 2012). In this case, the United States District Court for the District of Columbia ruled that the state bears the burdens for finding alternatives to institutionalization of disabled people. An important aspect of this ruling is that it established the principle of “Least Restrictive Setting,” which requires that healthcare and clinical supports be provided to disabled people in the least restrictive setting in which those services can reasonably be provided. A Deinstitutional design framework proposes that the principle of Least Restriction is a valuable addition to the design of domestic AC systems. That is, where AC systems are often evaluated by what

they enable or make possible, the ways in which AC systems may restrict or limit possibilities should also be assessed.

### **6.3.1 Least Restrictive Design Approaches in Accessible Computing Design Research Discourse**

In the works reviewed in Chapter 4, I found that when institutionalization was framed as helpful, design approaches replicating institutional models of care in community-based settings were understood as viable methods of supporting independence. On one hand, replicating institutional care in community-based settings can be viewed as a means of providing the community-based supports required by the 1999 *Olmstead Decision* (noa, d). On the other, introducing surveillance technologies into community-based settings 1) risks promoting transinstitutionalization (Schildbach and Schildbach, 2018) by shaping community-based housing into pseudo-institutional spaces, and 2) makes disabled people’s domestic spaces inherently more restrictive than they would otherwise be—potentially undermining the principle of “least restrictive setting” of the *Lake v. Cameron* ruling (Davis et al., 2012). A Deinstitutional design framework argues, even if community-based surveillance is less restrictive than institutional surveillance, the *Lake v. Cameron* ruling suggests designing supports which impose as little restriction as possible may be the more important goal. In this way, this principle challenges the acceptance and replication of institutional models of care in domestic AC systems and research discourses.

### **6.3.2 Least Restrictive Design Approaches for Blind Parents**

In my exploration of blind parents’ strategies for co-reading with their children, as described in Section 3.2., I found that blind parents had a strong desire to “do it themselves.” Not only

is this finding evidence of the need to uphold independence as a human right to agency (as discussed in Section 6.1.2.), it also emphasizes the need for AC design researchers to consider restrictions created by digital technologies in domestic spaces, and not just technologies' ability to enable. Consider, for instance, the use of audiobooks described by blind parents in Section 3.2. Audiobooks provide an accessible format for delivering textual content to children, very much akin to reading a book aloud oneself. But, because these technologies restrict and limit the potential for parents to engage directly in the co-reading process, many parents chose not to use audiobooks in their co-reading activities. Some created clever solutions for modifying their use of audiobooks in their co-reading, like listening to the audiobook in an earphone and repeating the words back to their child. Importantly, in this case, the utility of audiobooks is not strictly measured by their accessibility, nor by the potential activities they enable for blind parents and their children. Rather, the utility of audiobooks is measured, in part, by the possibilities it removes. Upholding the principle of Least Restriction in design, here, emphasizes the need for design researchers to consider both positive and negative aspects of technological intervention in co-reading, and to ensure that the approaches used to provide access to co-reading for blind parents do not unnecessarily limit the options available to them.

### **6.3.3 Least Restrictive Design Approaches for Blind Partners**

In my exploration of blind partners' experiences of adopting shared smart speaker devices in their homes, as described in Section 3.3., I found that formal agreements between blind and sighted intimate partners, about the appropriate ways of using shared smart speaker devices, often determined the upper limit of that device's utility. That is, none of partner pairs that I interviewed used all potential features of their smart speaker devices, even when they were aware of an unused feature, and recognized that using VAs for this purpose would improve blind partners' access to domestic activities. A common example of these agreements

concerned the use of smart speaker devices for online shopping. Using VAs to shop online was recognized as much more accessible for blind partners than browsing e-commerce sites with a screen reader, or using a rideshare service to shop in a physical store. However, in order to make purchases with a smart speaker VA, users must upload their credit card information, thereby exposing all members of the household to financial vulnerability in the event of privacy failures due to technical issues or malicious actors. Accordingly, all partner-pairs described discussing the use of VAs for shopping and reaching a formal agreement about whether they, together, felt comfortable risking their financial information. Because the perceived risk was so high, only one partner-pair used their VA to shop, even though all partner-pairs noted that shopping with their smart speaker device would be more convenient for the blind partner. In this case, a failure of the designers of smart speaker VAs to account for the perceived risks associated with VA shopping directly limited the potential utility of these devices for blind users, despite the fact that VAs are technically accessible solutions for this purpose. This example highlights the benefits assessing the limitations that accessible technologies may impose upon disabled users in domestic spaces for AC design researchers, in a similar fashion as the positive and negative aspects of adoption and use are weighed by users.

## **6.4 Applying Deinstitutional Values in Domestic Accessible Computing Research**

Hofmann et al. argued “that naming ableism is necessary for its revision. Accepting this enables learning and growth to move past debating whether discrete acts are ableist, to revising them” (Hofmann et al., 2020). In this spirit, identifying the ableism inherent to institutional understandings of domesticity and disability is not an accusation levied against the AC community or any critiqued works. Instead, this dissertation aims to name ableism

where it exists and invite conversation about how we may collectively revise these acts.

I believe that critiquing and correcting ableist discourses which impact our collective perspectives of domesticity and disability is a contribution to AC Research, in its own right. Yet, I recognize that some AC research practitioners will not agree. So, it is worth noting that, while the focus of my work is examining institutional logics at play in how we, as AC researchers, discuss and describe domesticity, the implications of these logics—and the implications of the counter-logics of adopting deinstitutional values in AC research—extend beyond shifting the ways in which we describe domesticity and disability in our work.

In this section, above, I have detailed the ways in which applying deinstitutional values to the domestic AC research outlined in this dissertation highlighted aspects of domesticity for blind adults in their roles as parents and as intimate partners that may have otherwise remained unexamined. Additionally, I have described how explicit attention to these often-unexamined aspects of domesticity underscored the social considerations of domesticity identified as relevant to technology use by blind adults in these studies. But, the application of deinstitutional values to domestic AC research in other domains would likely also surface latent aspects of domesticity that often remain under explored in domestic AC research, as outlined in Chapter 4.

Additionally, surfacing often-unexamined aspects of domesticity through the adoption of deinstitutional values in AC design research can have impacts upon, not only *how* we design, but *what* we design. Consider, again, the case of blind parents seeking digital technologies which might make reading with their children more accessible. Artificial intelligence makes possible shared reading experiences between a child and a virtual agent. But, such a solution does little to support blind parents' independence, by undermining their own role. From a stance that does not explicitly consider the deinstitutional values outlined here, artificial intelligence systems may seem an especially appropriate choice. But, this solution would also likely be perceived as inappropriate by the blind parents described in Chapter 3, who

expressed an explicit desire to be involved in shared reading.

In these ways, adopting deinstitutional values in AC design research not only impacts how we collectively discuss and understand domesticity and disability, but highlights new opportunities for research, and facilitates a deeper and more accurate understanding of the appropriateness of our design solutions.

# Chapter 7

## Summary and Conclusion

In this dissertation, I have described three studies which examine social considerations of domesticity relevant to AC design research from two perspectives: 1) those of blind adults, in their roles as parents and intimate partners, and 2) those of AC design researchers conducting work in domestic spaces. I have compared these perspectives to identify ways in which the perspectives of AC design researchers are in tension with the perspectives of blind adults, who often serve as the intended users of AC systems. I have borrowed key concepts from housing-based disability rights advocacy work and legislative victories to construct a Deinstitutional design framework which may better align these perspectives on social considerations of domestic relevant to AC design research.

My own goal to construct a Deinstitutional design framework is very much informed by my personal ethical stances which influence my approach to research, which strives to center the holistic lived experiences of disabled people, of which disability is only one aspect. At the same time, in sharing these three principles of a Deinstitutional design framework, I do not intend to suggest that AC design research which does not adhere to these principles is inherently unethical or unneeded. Likewise, I do not believe that the principles of this Dein-



stitutional design framework are useful only for researchers who share my own philosophical views. Rather, I present the principles of this framework, here, as a foundation for future work which might adopt a Deinstitutional stance, in full or in part, toward constructing a more holistic picture of disabled people’s domestic lives.

As discussed in Chapter 2, social considerations of domesticity are not detached from domestic technology adoption and use—nor are domestic technology adoption and use detached from social considerations of domesticity. For this reason, the principles outlined in the Deinstitutional framework for design which I propose are directed at highlighting the too-often-neglected social considerations of domesticity in disabled people’s lives, which are themselves key to fully understanding the technological aspects of domestic AC design research. So, while ethical considerations motivated by own work, I do not view these principles as solely the domain of ethicists and AC design researchers seeking to engage in explicitly anti-ableist work. Rather, these principles also have deeply pragmatic implications for any AC design researchers conducting work in domestic spaces, by providing a lens through which to understand the nuanced and interconnected social considerations relevant to domestic AC design research which impact the ultimate success of our designed systems.

It is my sincere hope that future research, either my own work or that of others, will engage with the principles outlined in the Deinstitutional design framework proposed in this dissertation, to test the limitations and benefits of adopting these stances in practice. I welcome future work which corroborates, builds upon, refutes, and problematizes the positions advanced by this framework. Through generative discussion about these topics, we can construct a more holistic picture of disabled people’s domestic lives and advance critical and socially-oriented approaches to domestic AC research.

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