Reframing Homes and Families in Accessibility

Kevin M. Storer

University of California, Irvine Irvine, CA, USA storerk@uci.edu

Stacy M. Branham

University of California, Irvine Irvine, CA, USA sbranham@uci.edu

Abstract

Many Assistive Technologies are designed to support disabled people in living independently, outside of institutional settings. But, much HCI scholarship has focused narrowly on goals of supporting living independently, potentially at the expense of tenets of the wider Independent Living Movement, like individual agency and full participation in all aspects of society. We suggest explorations of Assistive Technology in the home often medicalize domestic settings and ignore more nuanced aspects of family life. Here, we briefly overview two research projects in which adopting a critical perspective on disability foregrounded disabled informants' active participation within their families and led to deeper understandings of domestic technology use. We hope these cases will prompt discussion of how homes and families may be reframed in Accessibility Research in the HCI community.

Author Keywords

Disability Studies; Families; Homes; Domesticity

CSS Concepts

Human-centered computing~Accessiblity

Introduction

The "Independent Living Movement" was, and remains, one of the most significant political movements for

securing and protecting the civil rights of disabled people₁ at an international scale. First emerging in the United States in the 1970s, amidst widespread political unrest amongst many marginalized groups, the Independent Living Movement asserts the equal worth of all lives regardless of (dis)ability, the capacity of disabled people to assert agency in choices affecting their own lives, and the rights of disabled people to "participate fully in all areas ... of mainstream community living on a par with nondisabled peers" [3].

While the Independent Living Movement encompasses broad civil rights goals, its namesake emerged in opposition to the historical incarceration of disabled people in state-sanctioned institutional settings, where they were isolated from society and, in many cases, subjected to egregious human rights violations [4]. Accordingly, deinstitutionalization—the relocation of disabled people from institutional settings to community-based living—is an important aspect of the Independent Living Movement. A primary goal of deinstitutionalization is the prevention of inappropriate hospitalization of disabled people through "the provision of community alternatives" to the long-term supports and services which might otherwise be provided in a medical setting [9].

Assistive Technologies (ATs), like those studied and designed by the Human-Computer Interaction (HCI) community, are an important component of the longterm supports which help ensure independent, community-based living for disabled people. For example, voice assistants can support blind and lowvision people in independently controlling inaccessible home appliances, like thermostats [1,14]. Interactive memory aids can remind cognitively-disabled people to carry out daily-living tasks, in lieu of receiving a reminder from a care provider [7].

However, ensuring that home environments are equipped with adequate and appropriate supports to prevent unnecessary hospitalization for disabled people is only one component of the wider philosophy of Independent Living. In fact, we argue, focusing too narrowly on preventing hospitalization through AT design may lead to HCI research which overly medicalizes domestic settings, effectively reinstitutionalizing community living for disabled users. ATs which support *living independently* do not necessarily guarantee the agency and equal participation which is advocated by Independent Living. Within the context of the home, medicalized design inquiry may even limit full and equal participation, especially within the family unit. For example, complicated AT designs have been shown to create stress for disabled users and their families [8].

Despite the recognition that domestic accessibility and AT design impact family life, the literature examining sociotechnical aspects of domestic AT use is limited. By contrast, technology use in families where no members identified as disabled has been the subject of rich theorization in HCI literature, since the significance of studying domestic settings was first identified [10]. In these contexts, HCI literature has examined how domestic technology affects interpersonal relationships [19], individual family roles [12], and the gendered distribution of domestic labor [15]. While some notable exceptions exist [5,8], the majority of literature

¹ Here, we use identity-first language in consistency with the workshop organizers, but recognize preferences differ.

concerning domestic technology use by disabled people approaches them as recipients of in-home care or support provided from some technological intervention.

In this workshop paper, we reflect upon two of our recent research projects in which adopting a critical perspective on disability repositioned our informants from passive care-recipients—as "patients"—to active participants in family life—as parents and as partners. We share how this reframing led to deeper understandings of domestic accessibility and insights into domestic technology use by disabled and nondisabled people alike. We hope these cases will prompt discussion amongst HCI researchers of the ways that critical perspectives on disability might support explorations into AT use in homes and families that attend to *all* philosophical tenets of Independent Living, including individual agency and full participation in domestic life.

Blind Parents

In our work entitled "*That's the Way Sighted People Do It:" What Blind Parents Can Teach Technology Designers about Co-reading with Children* [17], which appeared at DIS '19, we explored the ways that blind parents read with their children through a content analysis of Facebook posts discussing parent/child coreading, in a group dedicated to blind parenting.

From a purely technical view, blind-parent/sighted-child co-reading is not particularly complicated. There are myriad digital and analog tools designed to make text non-visually accessible—screen readers, audiobooks, and Braille each share this goal. However, by adopting an analytical lens which foregrounded blind informants' familial roles as *parents* and highlighted the unique importance of parent/child relationships, we found ways in which the social considerations of co-reading rendered each of these "accessible" methods for coreading impractical, and in many cases, altogether unusable. For instance, for many parents, screen readers and audiobooks were perceived to intrude upon an otherwise-intimate moment shared between parent and child. Other parents were skeptical of whether these text-to-audio tools offered equal literacy benefits for their children. Likewise, many of our informants were not able to read Braille—some 90% of blind adults do not [16]—and those who did faced a selection of children's books which are limited in their offering and prohibitive in their price.

Perhaps most importantly, adopting a lens which foregrounded family relationships, we found that blindparent/sighted-child co-reading often involves highly collaborative sensemaking practices. Because children can see and recognize letters and parents can spell and make sense of letters in sequence, parents and children are often able to read together, even when neither can read alone. Collaborative sensemaking practices, like these, are important for maintain universal access in mixed-ability homes [5].

Without a critical lens of disability to foreground blind parents' role as *caregivers*, in contrast to many works which position disabled people strictly as *care recipients*, we may have offered design suggestions which were impractical in context, or worse, impeded the ability for parent/child dyads to practice the collaborative skills which make their home accessible.

Blind Partners

In our work entitled "All in the Same Boat:" Tradeoffs of Voice Assistant Ownership for Mixed-Visual Ability Families [18], which will appear at CHI '20, we explored the ways that cohabiting blind and sighted romantic partners negotiated the decision to integrate smartspeaker voice assistants into their home, through pair interviews.

From a purely technical view, in-home, smart-speaker voice assistants are particularly accessible for blind users. Because of their native voice-in/audio-out interaction paradigm, their nonvisual accessibility is unique amongst mass-market devices and, as such, they have been the topic of excitement amongst blind advocacy groups [11,13] and HCI researchers, alike [1,2,6,14].

However, by adopting a lens which foregrounded blind informants' roles as *romantic partners*, we found that the *potential* accessibility of voice assistants is often hindered by limits placed on acceptable use, as negotiated between partners. Sighted users have not been shown to have equal enthusiasm for voice assistants, and the benefits of adopting voice assistants are not as large for sighted partners. So, often sighted partners' fears about privacy, security, and the impacts of technology on family relationships limited blind partners' ability to take full advantage of the domestic accessibility voice assistants could provide. For example, using voice assistants for home automation can be highly beneficial for blind people, because many domestic appliances are operated through inaccessible touch interfaces. But, using voice assistants in this way can also leave home infrastructures vulnerable to malicious actors. Consequently, very few of our pairs

owned home automation devices which integrated with their voice assistants.

Without adopting a critical perspective on disability to foreground blind participants' role as both *partners* and *parents*, in contrast to many studies which consider disabled users acting alone, we may have concluded that in-home, smart-speaker voice assistants are fully accessible for blind users. However, by foregrounding familial relationships, we found that many blind informants limited their own access out of respect for their partners' wishes and concern for their family's safety and comfort.

Conclusion

In this workshop paper, we have described two cases where adopting a critical lens of disability helped us to develop richer explorations into domestic technology use. By foregrounding active participation in family life, we sidestepped traditional notions that disabled people are *care recipients* or examine accessibility without respect for disabled users' interpersonal relationships, and developed a more holistic picture of domestic accessibility. While the cases described above are only two examples of how critical lenses of disability can be productively employed toward richer theorization of domestic technology use in HCI, we hope they will serve as the basis for a generative and reflective discussion of how homes and families are conceptualized in HCI literature.

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