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IRVINE

How Parents with Blindness or Low Vision Leverage Technology to Care for Their Children

THESIS

submitted in partial satisfaction of the requirements
for the degree of

MASTER OF SCIENCE

in Informatics

by

Kelly Dickenson

Thesis Committee:
Assistant Professor Stacy Branham, Chair
Professor Melissa Mazmanian
Associate Professor Anne Marie Piper

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ABSTRACT OF THESIS

Parents with Blindness or Low Vision: Embracing Care and Technology's Role

by

Kelly Leona Dickenson

Master of Science in Informatics

University of California, Irvine, 2023

Assistant Professor Stacy Branham, Chair

This research paper investigates the role of technology in the caregiving experiences of Blind or Low Vision (BLV) parents for their child(ren). Initially, the study aimed to explore the assumed use of assistive technologies (ATs) through analysis of YouTube videos, expecting to find a significant reliance on these technologies in BLV parenting. However, the findings reveal a nuanced perspective. Technology is found to play a supplementary rather than central role in BLV parenting. BLV parents exhibit active adaptation and innovation in their caregiving approaches, focusing on developing personalized systems and solutions. Predominantly mainstream technology is creatively repurposed to cater to their specific needs, a practice akin to life hacking. The research emphasizes that BLV parents prioritize their child(ren)'s health, safety, and well-being, fostering a nourishing environment through their resourceful caregiving strategies.

Chapter 1

Introduction

People with disabilities (PWD), specifically people with blindness or low vision (BLV) are routinely denied rights as caregivers, including the right to parent. Until the nineteenth century, PWD were forcibly institutionalized and isolated from society in the United States (Storer & Branham, 2021). For decades throughout the mid-to-late 20th century, PWD were coerced into sterilization, under the belief that a mother with a disability was unfit to raise a child. Pressured both by medical professionals and family members alike, PWD's reproductive rights were highly regulated (Malacrida, 2019). This assumption that a PWD are not capable of giving care continues to be a widely held belief today (Frederick, 2014). Parents with disabilities can be legally denied parental rights in 37 states, simply based on their disability status as opposed to their ability to care (Frederick, 2014). Accordingly, parents with disabilities experience "ominously high" chances of being investigated by social services, and thus, Child Protective Services may remove their child from their care (Frederick, 2014). In addition, few supports exist to reunify parents with disabilities whose parental rights have been terminated (Frederick, 2014).

Presently, there is a dearth of research central to blind parenting. Common discourse involving PWD focuses on how they *receive* care from non-disabled people, as opposed to *providing* care for others. Scholars have even referred to blind parents' children as "young carers," insinuating that the child cares for the parent (Kroger, 2009). This shifts

attention solely to the child's narrative, portraying them as burdened, and further discriminates against disabled parents. Moreover, it hinders parents with disabilities from obtaining the necessary support they need and are entitled to (Kroger, 2009). In Feminist scholarship, parents with disabilities have also been excluded in their role as caregivers. Only as recently as the early 2000s did they acknowledge this exclusion (Kelly, 2013). Where feminist literature interprets care as oppressive and transactional, it overlooks PWD's perspective where care enacts equal rights (Herring, 2014). Disability Studies scholars have just begun to engage feminist scholars in dialogue to identify and address this bias in their work (Beckett, 2007; Kelly, 2013; Malacrida, 2019).

Perhaps relatedly, Accessible Computing (AC) research has not focused on disability and parental caregiving. Out of 115 references in Storer and Branham's paper on Deinstitutionalizing Independence, which conducted a Critical Discourse Analysis on PWD related to domestic AC research, only two papers specifically addressed the technology needs of BLV parents. Both papers highlighted the potential for new AC support systems to be developed for blind parents (Storer and Branham, 2021).

For people with BLV, much of Assistive Technology (AT) design is oriented towards task-based solutions, possibly overlooking the significant care work performed by individuals with BLV (Bennett, Brady, and Branham, 2018) (Bennett, Rosner, and Taylor, 2020). Current Artificial Intelligence (AI) and AT approaches prioritize task completion over expressions of care and unintentionally subvert access to PWD. The interdependent work done by PWD to secure this access has been referred to as "invisible" in AT and feminist-oriented HCI research (Bennett, Brady, and Branham, 2018).

A preliminary search in the ACM Digital Library produced a total of five relevant papers on parents with BLV within the past five years. Parents with BLV were the main subject of two papers (Soto & Barzegar, 2021; Storer & Branham, 2019), while the remaining three only briefly acknowledged people with BLV as parents (D'Ignazio et al., 2020; Storer, Judge, & Branham, 2020; Bandukda et al., 2021). Soto and Barzegar (2021) evaluated existing eye tracking technology for aiding parents with visual impairments in establishing eye gaze interaction. Storer and Branham (2019) investigated how visually impaired parents co-read with their children, revealing a "significant gap" of technological resources for visually impaired parents. The remaining three papers collectively validate the existence of BLV individuals as parents. They account for blind parenting along with acknowledging the need for further dedicated research specific to this subject, one going as far as admitting to being unintentionally "unconsidered" (D'Ignazio et al., 2020). Overall, parents with BLV were frequently discussed as a subject needing more attention and were identified as an underdeveloped area of research.

To begin understanding how BLV parents inhabit their role of care I ask under the framework of technology: ***What role does technology play as BLV parents care for their children?*** In order to answer this question we ran a study consisting of watching and analyzing a carefully filtered collection of 47 videos demonstrating BLV Parenting caring for their child(ren). Reflexive Thematic Analysis was then conducted in order to determine pertinent categories related to my research question involving iterations of code and theme development.

Similar to Liz Jackson's New York Times article "We Are the Original Lifehackers", my study found that BLV parents use life hacks as "creative ways" to "alter things to make them more accessible" (Jackson, 2018) when navigating parenthood and caregiving. BLV parents also develop systems and routines to support their caregiving practices, but advanced technology has a minor role in these systems and routines. As such, we make several contributions:

1. Orient the AC community to caregiving roles of disabled people, particularly BLV parents.

2. Corpus of YouTube videos of blind parents sharing their lived experiences pertaining to caregiving for children.

Chapter 2

Related Works

Care Work and Disability

Our understanding of care is based on the work of Disability Studies scholar Kittay (2011). Kittay defines care as a *labor*, an *attitude*, and a *virtue* (Kittay, 2011). Labor references "the work of maintaining others and ourselves when we are in a condition of need." Attitude references "a positive, affective bond and investment in one's well being." Virtue is the shift from self interest to another's situation. Where caring behavior is the combination of labor and attitude, and virtue being one's disposition "manifested in caring behavior" (Kittay, 2011). Kittay's definition is particularly useful in the context of blind parents caring for children because it emphasizes the reciprocal, empathic nature of care and acknowledges the power differentials that can exist, e.g., between parent and child. This is in contrast to the many definitions which imbue the medical model, which can "downplay the inherent intimacy of familial connections" and cast caregiving as "unidirectionally beneficial" (Storer & Branham, 2021). Further, the use of the term "labor" (instead of, e.g., "work" (Kroger, 2009)), helps us recognize both the unpaid nature of care work as well as the additional invisible work (Branham, 2015) done by people with disabilities to create access. Finally, by separating attitude from virtue, unlike other scholars (e.g., Kroger, 2009), Kittay's definition helps us emphasize the agency of the parent with a disability to be other-focused.

Blind Low Vision Parents

Currently, scholarly documentation into the phenomenon of blind parenting remains scarce. From the Journal of Visual Impairments, four papers[1] spanning between 1991 to 2017 explore *commonalities between visually impaired parents* along with *concerns*, *strategies*, and *advantages* particular to visually impaired parents.

Commonalities between sighted and visually impaired parents
As previously mentioned, an individual's disability oftentimes overshadows their capabilities and can undermine their agency. This notion is consistently addressed within the Journal of Visual Impairments, where papers reveal a significant amount of common ground amongst parents, regardless of visual ability. In examining decision-making between two parents and their child, the earliest of papers found that regardless of a parent's visual impairment, the parents were consistently much more involved than their child (Gill-Williamson, 1991). This rudimentary finding significantly evolves in sophistication where Conley-Jung and Olkin (2001) found concerns expressed by visually impaired mothers common to all parents. Mothers indicated proper guidance/discipline, time management, and maintenance in availability and energy as general concerns. Unsurprisingly, the safety of one's child was another identified concern for parents regardless of their visual impairment (Rosenblum, Hong, & Harris, 2009). These discoveries inform the parental side of BLV parenting (rather than the BLV), as one quite similar to any other parent.

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[1] The following papers interviewed BLV individuals who were parents with at least one young child (Gill-Williamson, 1991; Conley-Jung & Olkin, 2001; Rosenblum, Hong, & Harris, 2009; Moghadam et al., 2017)

That being said, safety becomes a more heightened issue for parents (described later). Past

parental involvement and concerns, parents with BLV described their transition into

parenthood as an enriching, positive experience, more like those of their non-disabled

peers (Conley-Jung & Olkin, 2001). While acknowledging particular challenges exist in

being a blind parent, one parent expressed that overall it's "not about being a blind parent;

it's about being a parent" (Rosenblum, Hong, & Harris, 2009).

Concerns of blind parents
Concerns about their child's safety, transportation, and public reactions were further

heightened in parents with BLV (Conley-Jung & Olkin, 2001; Rosenblum, Hong, & Harris,

2009; Moghadam et al., 2017). Consequently, more time was consumed to account for their

concerns along with a rise in anxiety (Conley-Jung & Olkin, 2001). Non driving parents

required prior planning in transportation for their child. Extra time was consumed in

planning alternative travel methods from public transportation, paratransit, taxis, or

reliance on close family and friends to drive. This furthermore limited their capacity for

flexibility with their children and frequently influenced where the families lived

(Rosenblum, Hong, & Harris 2009).

Strategies of blind parents
One study found that only 33% of mothers perceived equipment for parents with visual

impairments as user-friendly (Conley-Jung & Olkin, 2001). This is further supported by

Moghadam et al. (2017), where one mother preferred using her hands to feed her child

rather than using a spoon, ensuring all the food had been eaten. Through trial and error

(Moghadam et al., 2017; Rosenblum, Hong, & Harris, 2009) along with reliance on

alternative sensory inputs such as tactile touch (Moghadam et al., 2017), visually impaired

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parents adapted their own workarounds/strategies for childcare. Some strategies mentioned include attaching bells to the children's shoes or using a leash on their child to keep them close (Rosenblum, Hong, & Harris, 2009). For dressing their child, mothers developed a labeling system for their child's clothing along with hanging complete outfits rather than storing them in drawers (Conley-Jung & Olkin, 2001).

Technology and Disabled Caregiving

So far, technology designed with BLV parents in mind is limited. Upon examining co-reading practices in parents with visual impairments and their children, Storer and Branham discovered a considerable gap in technological and material resources for parents. Existing materials influenced how a visually-impaired parent co-read to their child. They associated this lack of resources with "the backdrop of a society which often devalues or denies the parenting capabilities of people with disabilities" (Storer and Branham, 2019). The parent with a disability, rather than the child, is seldom studied. For example, accessible book subscription services centered on visually impaired children. Storer and Branham's findings suggested that "parents with disabilities are not only capable, they have valuable insights into parenting which would likely improve the design of technologies and services for all parents and children, regardless of their abilities"(Storer and Branham, 2019).

Soto and Barzegar along with Nicot, et al. focused on technology as a means to enable traditionally visual feedback to blind parents. For pregnant and expectant BLV parents, 3D printing of prenatal ultrasonography was proposed to aid in prenatal attachment. "this tactile experience can enable an emotionally richer aspect to the medical consultation,

offering blind expectant parents an accommodation that allows the first ultrasound appointment to be refocused on the parents' encounter with their unborn child. Blind parents can thereby perform their own mental representation process by extrapolating sensory information obtained from 3D tactile support" (Nicot, et al. 2021). Using existing eye tracking technology, Soto and Barzegar were interested in enabling "visually impaired users to participate in the non-verbal interaction possibilities of eye-gaze with their young infant children." (Soto & Barzegar 2021). A prototype that recognized when infants looked at their parents was used. Key findings included parents not realizing how often their child gazed at them and provided more awareness and confidence. They found it "helpful to be aware by myself when my child asks for attention specifically from me." (Soto & Barzegar, 2021). These technological solutions targeting vision for BLV parents may inadvertently promote or reinforce the belief that vision is desired and a necessary skill for parenting.

Chapter 3

Methods

In my study, I conducted Reflexive Thematic Analysis (TA), as described by Braun and Clarke (2006) and (2019). This approach involves the following: deep immersion in the data, the subjective engagement of the researcher's perspective, a mixture of deductive and inductive analysis, and an iterative theme development.

The six phases of reflexive TA outlined by Maguire and Delahunt (2017) include: 1) Familiarization with the data, 2) Generation of initial codes, 3) Generation of initial themes, 4) Reviewing themes, 5) Defining themes, and 6) Write up. It is important to acknowledge that these steps do not necessarily occur linearly. Additionally, Braun and Clark (2019) describe reflexive TA as "theoretically flexible", where it can be adapted in various ways by a researcher.

With this six-phase framework, my research is outlined within two phases. The first phase uses data collection strategies that closely aligns with that of other recent research in this area, such as Anthony, Kim, and Findlater's (2013) and Abdolrahmani et al. 's (2019), which similarly involve the analysis of extant data collected online. The second phase progresses into coding and theme development informed by Byrne's (2021) work using reflexive TA.

Throughout this MS thesis, I refer to myself and the work I did in close conversation with my thesis advisor, Stacy Branham in the first person. In cases where I worked with student collaborators Ethan Vu and Mayra Cortez, the term "we" is used.
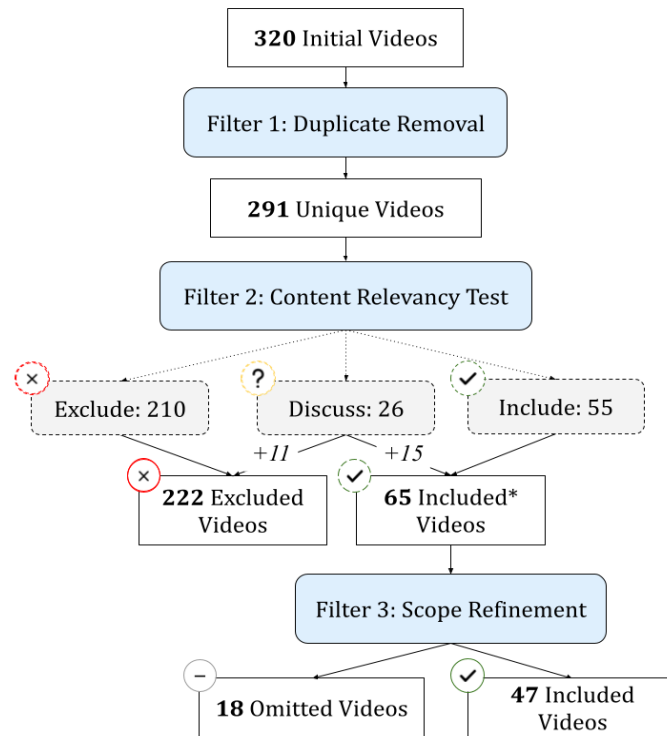
Phase 1: data collection

I first identified relevant search terms. This consisted of two categories: Visual Disability related terms and Parental Role related search terms (Table 1).

Visual Disability	Parental Role
● Blind, ● Low vision, ● Visually impaired	● Parent, ● Mother, ● Mom, ● Father, ● Dad

Table 1. Relevant Search Terms.

We created a script to query YouTube with all unique combinations of search terms in each list. For example, we searched "blind parent", then "blind mother," and so on down the list until the final query, "visually impaired dad" was run. The top 25 search results for each query were stored into a spreadsheet. We collected the following metadata for each result: *Date Collected (Time Acquired), Visual Disability Search Term, Parental Role Search Term, Video Link, Video Title, Date Posted, Channel Title, Channel Link, Tags, Description, Video Length, # Likes, # Views, and # Comments.* This resulted in a total of 320 initial videos collected.

I applied a series of filtering and validation criteria to ensure the resulting videos were

relevant to our research study (Table 2). I began by removing any duplicate results leaving

291 unique videos. Keeping in mind my research question, I developed a series of inclusion

and exclusion criteria. Videos were *excluded* if they showcased one or more of the

following: contained product placement, advocated for making people with BLV see, were

not in English, or identified themselves in a non-USA setting. Videos were *included* if they

featured a person with BLV in the video *and* the person with BLV demonstrated or talked

about a parenting role from their point of view. The remaining videos were then skimmed

through along with using the video's title and description to inform our decision in

categorizing the videos as one of the following: Include, Exclude, or Discuss. Discussed

videos were more carefully watched and discussed in a group, where ultimately they were

relabeled as a Include or Exclude. Application of the inclusion and exclusion criteria

resulted in a total of 222 excluded and 65 included videos, as at the time four videos had

become unavailable on Youtube.

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                   ┌──────────────────────┐
                   │ 320 Initial Videos   │
                   └──────────────────────┘
                   ┌──────────────────────┐
                   │ Filter 1: Duplicate Removal │
                   └──────────────────────┘
                   ┌──────────────────────┐
                   │ 291 Unique Videos    │
                   └──────────────────────┘
                   ┌──────────────────────┐
                   │ Filter 2: Content Relevancy Test │
                   └──────────────────────┘
```

Exclude: 210   Discuss: 26   Include: 55

+11   +15

222 Excluded Videos   65 Included* Videos

Filter 3: Scope Refinement

18 Omitted Videos   47 Included Videos

*Originally 69 Included Videos, four videos are no longer available online

Table 2: Data Filtering and Validation Process

While filtering my video collection, I generated and iteratively refined a list of data I wanted to collect for each remaining video. I sorted these into two divisions (Table 3). "Background Information" includes basic information about the video (e.g., the channel owner and video genre) along with additional information on each BLV Parent (e.g., the BLV Parent(s)'s identified parental role, marital status/other primary caregivers, age, number of children, age of children, visual disabilities/characteristics, and assistive technology used/mentioned). "Categories" includes details about the parenting activities and technology use of BLV Parents (e.g., Parenting Tasks, Technology Used, Technology Challenges) within the contents of a video.

Background Information ***** is used to indicated the BLV Parent(s) of interest that is used to code for	Categories of Video Content
● Channel Owner ● Video Genre(s) ● BLV* Identified Parental Role ● BLV*'s Marital Status/ Other Primary Caregivers ● BLV*'s Age ● Number of Children ● Age of Children ● Visual Disability/Characteristics ● Assistive Technology Used/ Mentioned	● Parenting Tasks ● Parenting Strategies ● Technology Used ● Technology Strategies ● Challenges

Table 3: Data Collection Categories of Passed Videos.

The remaining 65 videos were more carefully observed and watched multiple times for initial coding within the five preliminary themes. 18 of the 65 videos were further omitted after careful discussion. Omitted videos were either too short and lacked depth in content to properly code. For example, one video omitted contained a clip of a BLV mother participating with her son in a "chicken nugget challenge" where a certain amount of nuggets are eaten under a constrained amount of time. This left a total of 47 final passed videos for coding.

Phase 2: reflexive thematic analysis

Through active engagement in reflexive thinking, the remaining 47 videos underwent numerous, iterative cycles of coding and theme development. Simultaneously, my initial research questions repeatedly evolved out of deep reflection during this analytical process.

In essence, my codes, themes, and research question(s) evolved and concurrently impacted one another.

Drawing from my literature review and research question, along with notetaking of passed videos I identified the following five categories to capture relevant content: *Parenting Tasks, Parenting Strategies, Technology[2] Used, Technology Strategies,* and *Challenges.* For each video, data were recorded within these categories using semantic coding and transcription of direct quotes, followed by latent coding (when appropriate). Both semantic and latent codes were refined and tracked during this iterative process. Additionally, certain codes were omitted from the combined set of over 1000 semantic and latent codes to prioritize the focus on answering my research question. From this coding process I constructed a number of sub themes under 10 main themes using a select few in order to answer my research question.

Semantic codes contained low-level, explicit descriptions based on the voices of BLV parents. For example, under the category "Parenting Tasks" I recorded the codes "taking child to park", "keeping track of child", and "feeding baby". Under the same category, some direct quotes I recorded were the phrases "*keep tabs*", "*I'm* [BLV parent] *always checking*", and *"I'm* [BLV parent] *always trying to find different ways of having fun with my sighted children that is accessible for me"*. It was important to me to ensure enough detail was given to be understood without lacking context.

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[2] For this thesis, "Technology" refers to all technologies regardless of the level of sophistication. This includes what I later refer to as no-tech, low-tech, and high-tech.

Latent coding, involving a higher level of interpretation, consisted of examining and collating semantic codes that were arranged in higher level topics. Within the category "Parenting Tasks", the latent code "Providing and Having Fun for Children'' encompasses the semantic codes "*takes kids on walks and supervises*", "*BLV Parent plays softball with kids, roots for children, plays against children, and referees game*", and "*soccer with kids".* Depending on the specific category, the level of detail, analysis, and interpretation varied. Table 4 provides a diverse set of examples from each category.

Categories	Example Latent Codes	Example Semantic Codes
Parenting Tasks	Housekeeping	- vacuum - clean dishes - keeping household clean - laundry - take out trash
Parenting Strategies	Staying Near Child in Distance	- When son was younger, he held BLV parents' hand when they went places. "He wasn't the kind of kid that in the store was going under the clothes racks and running across the mall. He was always with us" (BLV Parents) - closeness with kids, always is close to kids to see features and make them out. even when just having a conversation
Technology Used	Child's Safety Harness Backpack	- kids harness backpack - doggy backpack leash with a bell attached to it - backpack leash, leash that clips onto backpack
Technology Strategies	Transportation	"We go places by ourselves (BLV father with kids, without mother), especially with Uber" - mentions using Uber as a means for transportation, public transportation used during walk, environment shift from wildlife landscapes to more city, - Uber, used for transportation to grocery store when sighted

		husband isn't available
Challenges	Children Attempting to Get Away with Rules	● BLV mothers* note their children would attempt to get away with little things due to them* being visually impaired, but "nothing too bad", "normal kid stuff" (sneaking candy, adding extra food to cart. ● Daughter as a teen would try to "would pull all these stunts", sneaking/military crawling to sneak past BLV Father* so she wouldn't see him* ● BLV Father* lightheartedly mentioned how his kids try to "pull something" over on him.

Table 4: Example Set of Codes

Theme development involved generating an initial set of potential themes through deep interpretation and reflection of the relationships between codes, and then between candidate themes themselves. Codes were collapsed and reorganized into potential themes, which were then further reviewed in terms of their scope and relevance to my research question. These candidate themes were then further organized into main themes or sub-themes. A final review was conducted to reflect on the constructed connections between themes and sub-themes and their overall relationship to my research question. This iterative process allowed me to deeply engage, reflect, and advance my understanding of the collected data to create the finalized set of themes presented in Table 5.

	Main Themes	Sub Theme(s)		
	Adapted Techniques	Tactile	Auditory	Trial and Error
	Educated Themselves	Trial and Error	BLV Community	
Parenting Strategies	Created Systems	Based in Routine	Based in Organization	

Technology Strategies	Used Technology as Designed			
	Used Technology Unconventionally			
Technology Used	Intended User of Technology	General Population	Sighted Parents	BLV People
	Level of Sophistication	No to Low Tech	High Tech	
Challenges	Public Stigma			
	Additional Energy and Efforts	Extra Precautious	Extra Planning	
	Minor Challenges			

Table 5: Finalized Themes and Subthemes

Table 6 below is a summary of the variety of contents collected along with a brief overview of results. The availability of information for each category varied and is based on the date videos were uploaded which ranged from 2014 to 2022.

Background Information	Categories/Labels Given for Background Information * = BLV Parent of Interest	Notes and Overview
Channel Owner	BLV Parent*, BLV Parent, Family Member of BLV Parent*, Third Party Member/Organization	34 of the 47 passed videos were owned by the BLV Parent of interest; 3 were owned by a BLV Person; 1 was a family member of BLV Parent; 9 owned by Third Party Member/Organization
Video Genre(s)	Comedy, Informational (content is intended to educate the audience of how BLV Parents take care of their child and/or advocates for BLV Parents being capable parents. Content goes past simply depicting a BLV parent parenting),	36 Informational; 7 Vlogs; 3 Video Journalism; 1 Comedy

	Interview Q/A, Podcast, Video Journalism, Vlog	
BLV* Identified Parental Role	Mother, Father, Grandmother	All but one identified as a Mother or Father with BLV.
Other Primary Caretakers	None, Partner, Babysitter, Other Family Members	32 mentioned having a partner, 1 mentioned also using a babysitter; 1 mentioned also relying on close family members.
Number of Children	Ranged from 1 to 5	Most had 1 to 2 children.
Age of Children	Infant up to 22 years old	Most were infants/ young children
Age of BLV Parent(s)		Unable to get ages from most videos, one BLV Parent mentioned being 60. Based on the appearance and age of children, most appear to be younger in age.
Visual Disability/Characteristics	Partially Sighted, Legally Blind, Completely Blind, Stargardt disease,retinitis pigmentosa, LHONs	BLV Parents varied in sight from having partial vision to none. Additionally, some were born with their visual impairment while others lost their vision later in life- most having been BLV most of their life.
Assistive Technology Mentioned	white cane, guide dog,	A majority of videos did not contain this information.

Table 6: Overview Background of Relevant Video Demographics and on the depicted BLV parents

Chapter 4

Findings

I determined that technology plays a minor, supplementary role in the overall experience of BLV parents caring for their child(ren). While forming my RQ, I initially believed that YouTube videos would portray BLV parents using multiple assistive technologies (AT) to help care for their child(ren). I anticipated that the answer to my RQ would lie in evaluating ATs based on how well they were designed and functioning to support BLV parenting. However, it was the BLV parents themselves who inhabited the role I expected technology to fulfill. BLV parents actively focus efforts in developing and discovering systems and adaptations for caretaking, while occasionally utilizing technology as a supportive tool in the process. Additionally, BLV parents frequently utilize common, mainstream technology in creative ways, adapting it to their needs instead of relying on items specifically designed for either BLV people or sighted parents (also known as life hacking). They consistently ensure the health, safety, and wellbeing of their child(ren) while providing and maintaining a nourishing environment for them.

BLV parents create systems[3] rooted in organization and routine that incorporate predominantly low tech, everyday items

Parenting with low tech and everyday items
　　"Being a visually impaired parent is the same thing as a sighted parent, you just have

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[3] "Systems" in this paper refers to the constructed arrangements devised by BLV Parents to structure their lives as parents.

to figure out a different way to do things." These are the attitudes expressed by one BLV parent, when describing the journey of parenthood for BLV individuals. BLV parents rely on their tactile and auditory senses and employ trial and error to creatively engage with everyday technology while caring for their child(ren). BLV parents, like any other parent, rely on tactile perception to fulfill common parental tasks such as cooking, cleaning, feeding, dressing, and bathing, but some BLV parents express having a heightened attunement and sensitivity to auditory cues, which enables them to be aware of their surroundings and the needs of their child(ren). As typical of parenting, BLV parenting actively involves trial and error, where BLV learn from and build upon experiences throughout their parenting journey. This can be seen in a statement by another BLV parent who describes being a visually impaired parent as a process of figuring things out, stating "*We're master adapters. We're creative thinkers.*" Another BLV parent expresses similar sentiments saying "*you just sort of make your accommodations along the way and become creative and make it work.*" BLV parents embrace their roles as creative adapters who have figured out alternative ways to parent, which is discussed further in the following section.

		Used Technology: Level of Sophistication	
		No to Low-Tech	**High Tech**
Used Technology: Intended User	**General Population**	Bell, Dark Colored Bowl, Disposable Neat Solutions, Placemat, Fabric Bin Basket, Large Pots, Mail Bin Slot Holder, Mesh Laundry Bag, Mesh Laundry Hamper, Pizza Cutter, Pots with High Walls, Purell Hand Sanitizing Wipes, Safety Pins, Small Plastic Bowl, Spoon, Squeaky Shoes, Storage Plastic Bin Rack, Sunglasses, Take and Toss Cups, Towels,	Alexa, Amazon, Amazon Echo, Audiobook, Beeping Easter Egg, Cab, Facebook, FaceTime, Google Hangouts, iPad, Netflix, Public Transportation, Smartphone, TV, Uber, YouTube

		Triangular Crayons, Whiteboard, Wooden Clothespins, Ziploc bag	
	Parents with Sight	Activity Books for Children, Baby Carrier, Baby Chair, Baby Seat to Stroller, Butt Paste, Carseat, Changing Table, Child's Safety Harness Backpack, Detachable Table Top, Diapers, Highchair, Magnetic Letters, Magnetic Numbers, Multimodal Toys, Pack and Play, Plastic Portable Bathtub, Spiral Flipbook with Large Font, Stroller, Toy Chest, Various Toys with Tactile Components	Apple TV application, "Endless Learning Academy", Interactive Talking Map, Interactive Talking Solar System Chart, LeapFrog Interactive Baby Book
	People with BLV	Braille Book for Kids, CCTV, Digital Talking Thermometer, Magnifier, Monocular	Application Service for BLV, "Aira", Application Service for BLV, "Be My Eyes", Color Identifier Device, Paratransit, Screen Reader

Table 7: Used Technology

While a majority of tech items were found to be creatively integrated into the systems below or found to be used creatively (refer to Table 7), there are a few cases of technology designed and used as intended by BLV individuals in their parenting. For instance, one BLV Parent (V#1) used an electronic thermometer that reads out the temperature when their child felt sick. Two other BLV Parents (V#9, V#47) mentioned using a color identifier device that scanned and read out colors for distinguish between colored and white clothing, while another BLV Parent (V#34) used the device to identify different toys by color. Finally, one BLV Mother (V#5) demonstrated using the Aira App, a

live video support service that connects a BLV individual to a sighted human assistant who

provides visual details through a smartphone. A Child's Safety Harness Backpack was also

found to be used as intended for BLV Parents in three videos (V#6, V#9, V#18), in certain

cases when their child was out in public.

Creating systems rooted in organization
The following systems of organization created by BLV parents involve orderliness and

cleanliness within their household's physical space, enabling them to operate with greater

efficiency in the background to better focus on their child. As BLV parents take care of their

child(ren), many emphasize the need to be organized and maintain order. As put by one

BLV Mother, "*you* [specifically referring to mothers with a disability] *just have to amp that*

game up… get used to being hyper organized…" with kids in the home. Such purposeful

arrangements in place assist BLV Parents in fulfilling their various parenting tasks.

Several BLV parents have created an organizational system for matching

appropriate outfits for their child(ren), ensuring clothes are coordinated and stay together.

One BLV mother devised a "*little system*" utilizing the lowtech ordinary items of wooden

clothespins and a mesh laundry bag (V#7). A matching set of clothes consisting of a top and

bottom are paired together with a wooden clothespin. When clothes are dirty, she places

the matching set straight into a single mesh laundry bag to be laundered and re-clipped

once they are clean again. The clean, pinned outfits are then stored in a designated drawer

in the BLV mother's dresser while the drawer above is specifically used to store more

wooden clothespins for future outfit pinnings. By memorizing the locations of the paired

outfits within her drawer, she simply "*feels*" for the clothespins and selects a desired outfit

to dress her child in. Initially, her sighted husband matches tops with bottoms, so she is

able to then "*keep this system going*" without help. This allows her as a mother to ensure her child is appropriately dressed for *appearance*, but also according to the changing *weather* conditions, due to the streamlined organization provided by her system.

Another BLV couple uses a similar system for matching clothing utilizing only safety pins (V#43). As both identify as being completely blind, they exclusively purchase clothing that has already been paired in stores. "*I don't just buy a shirt… I have to buy the shirt and the pants*". Once purchased, matching sets are safety-pinned together and remain pinned though the course of being cleaned and stored. The safety pin is only removed when it is time to dress their child. The use of everyday low-tech items such as wooden clothespins, mesh laundry bags, and safety pins serve as an integral part of the organizational system created by BLV parents in caring for their child(ren). Although these items may seem simple, BLV parents have found ways to transform them into valuable and reliable tools. In fact, one mother even affectionately refers to her wooden clothespin as her *"trusted clothespin."* Such items serve as reliable tools for BLV parents to maintain organization in this aspect of their parenting lives.

One father with BLV uploaded a video titled "Organization Tips for the Blind Parent | Life After Sight Loss", (V#22), in which he highlights the importance of being organized as a "VIP" (visually impaired parent) to other VIPs. This VIP father demonstrates using multiple organizational systems on a larger scale. Within his household he has created two systems, one involving a fabric basket and one using a mail slot holder in order to stay organized and easily access things within the house.

This VIP father emphasizes the importance of organization for VIPs, especially when dealing with the frequent messes children make. To manage these day-to-day messes, he

strategically places a fabric bin in a readily accessible location within the house, one easily found by both himself and his two children. In his setup, the fabric basket is positioned at the bottom of a staircase that leads up to his children's rooms. This then serves as a centralized designated point where various items brought down by his children throughout the day are stored temporarily. As he explains, *"whatever the case, we can put it all in the basket"*. In the evening, he sends his children upstairs with any remaining items from the basket to be put away in their respective rooms. This organizational system helps this VIP father not only maintain a tidy environment but also avoid searching the entire house for a certain item as he recapitulates "*everything's in the basket*".

This VIP father incorporates a mail slot holder into another system designed to organize the important paperwork of family members within the household, allowing him to stay up to date with his family's affairs. With a total of five individual pull-out slots, each assigned to a specific family member. The top slot is reserved for both him and his wife to store receipts and mail. The second and third slots are assigned to a single child where they place their school related papers (i.e. homework, worksheets, field trip papers, or teacher notes) in their respective slots. The mail slot holder is positioned near the front door of the house where "*they* [his children] *come home, they empty their backpack, boom. All the paperwork goes in there. They don't even have to think about it*." This configuration of the mail slot holder allows him to easily check and stay informed on his children's school activities. By accessing the appropriate slot, he is able to narrow down what the paperwork will be about. As he describes it, "*Whatever you're doing, you got it organized right here in the mailbox.*"

"You can use bins or mail slots or laundry hampers or whatever you want to use … The key is to help your family - you, your spouse, your kids - to stay organized in your house so it runs in the most efficient way possible." This statement expressed from the same VIP father pivots technology's role in a peripheral direction, where its relevance lies not in a certain technology, but in how BLV parents creatively utilize technology to meet their needs. By identifying his primary need for organization as a VIP, he creatively integrated common, everyday low-tech items into his carefully arranged system, showcasing his adaptability and resourcefulness as he cares for his family.

Creating systems rooted in routine[4]
The following routine-based systems created by BLV parents involve a deliberate sequence of actions to ensure the thorough completion of parental tasks. While organizational systems prioritized efficiency, routine systems center on the necessary, meticulous side of parenting. BLV parents in their routines carry out their parenting duties with caution and detail to ensure the wellbeing of their child(ren). In the following examples, technology's role still remains in the background as the BLV parents in my sample focus on specific actions that meet their caregiving needs for their child(ren). While some technologies used by these parents have been selected based on specific design characteristics (i.e., a baby chair found to have auditory feedback via a clicking noise), their routines are shown taking precedence over the technology itself. Furthermore, these established routines exemplify a common sentiment expressed by many BLV parents in my sample: caring for a child(ren) as a BLV parent is no different from caring for a child(ren) as a sighted parent, despite

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[4]Before proceeding, it is important to note that the systems created by BLV Parents naturally incorporate elements of both organization and routine. However, depending on the specific intention of the system, one of these aspects tended to better align with one or the other.

having alternative approaches. In a video of encouragement for parents facing sight loss (V#24), one BLV father stated, *"You just might have to figure out different ways to do things... All those little things that you have to figure out, you will. No worries. You'll figure them out"*. In his assurance to viewers, he reminds them that "*showing them* [one's child] *that you love them unconditionally is really what being a parent is all about*".

One BLV mother details her routine for baby weaning (V#8), where she has begun to introduce solid foods. Feeding is done at the kitchen table with a baby seat positioned on top. She first buckles her baby in the baby seat and sets up the plastic tray attachment onto the baby seat "*all by feel*". In this particular instance, her baby is being fed thin turkey slices that are ripped apart into smaller pieces using her hands. She then places a few pieces on the tray for her baby to grab and feed themselves. Throughout the feeding process, she checks the tray every few seconds to ensure the food is being eaten with her hands. At the same time she monitors her baby and entertains her during feeding times. As solid foods are being introduced for the first time, she is aware of the risk of choking. She notes that this is "*a fear of any mama, whether blind or not*'' where she states she is always near her baby, "*I am so attentive to her. I sit by her every time she eats, and I basically just have my hands near her or I'm always listening.*" This BLV mother demonstrates meticulous care, ripping pieces of meat so small that she admits her baby becomes frustrated at how small the size is, stating she would rather pieces be too small than too big. These extra steps of precaution in feeding her baby have become established steps, demonstrating one form of routine of a BLV parent. This feeding routine is more than just about feeding; it also involves comforting and entertaining her baby, as she pretends to eat alongside her and engages in conversation. Finally, routine is a mechanism by which the BLV mother is able

to *trust* her ability to care for her child effectively, stating "*I'm always right here. So I am not concerned about her choking … I am extra careful.*".

In "How A Blind or Visually Impaired Mother Diapers a Baby" (V#14), a BLV mother explains and demonstrates her process for how she changes her children's diapers from a "*tactile perspective*", ensuring they are completely clean**.** Using a baby doll for the video, she goes over her routine, which largely consists of two main components––diaper removal and wiping––which are further detailed below.

She starts by placing her baby on the ground with a towel underneath, referring to this as the "*floor method*", where the baby is positioned somewhere low and safe. She then holds her baby's feet in her hands, noting *"It gives you confidence in knowing where your child's limbs are, where the diaper is, what you're about to be doing,"* along with soothing the baby, keeping them calm. Next, she uses the baby's feet as a "*marker*", holding them in her hands as a default starting point for orienting herself between actions of diaper changing. Before removing the old diaper, she first gets out a new one, feeling for the sticky tabs, indicating the back of the diaper, and then opens it flat. Lifting the baby by its feet with one hand, she slides the clean, flat diaper underneath with the other hand. She then begins removing the old diaper by going back to her marker position, touching the baby's feet and moving up, feeling for the dirty diaper's tabs and removing them one by one. She follows this by partially folding the dirty diaper upwards, with the clean side exposed. From here, she begins wiping her baby in a "*grid formation*"[5], starting at the belly button and working down, moving gradually from one small section to another. The wiping motion is only done

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[5] "Grid Formation" is explained by this BLV Mother as a commonly taught independent living skill for people with BLV. She learned this skill from her pediatrician, who was also a parent with BLV.

from top to bottom, to avoid any infections. As she wipes, she checks for any diaper rashes by feeling for bumps on her child using her hands. The used wipe is disposed of in the partially open dirty diaper. With one hand, she finishes rolling up the dirty diaper, lifts the baby by its feet with her other hand, and slides out the dirty diaper from underneath. Gently, she places the baby back down onto the clean diaper. Finally, for "*an ounce of prevention"* she applies diaper rash cream using the same formation to ensure thorough application. This routine involves more than just the act of changing a child's diaper; it includes precautionary action to ensure thoroughness. For instance, she mentions starting the wiping process from the belly button, which might be considered high, but it allows her to be certain that any potential messes on her baby are addressed. She candidly states, *"the idea of diapering her* [her baby] *was scary to me, especially because you can't always see the contents of the diaper. It's to make sure that your child is clean."* This quote reflects her proactive approach to diapering, with a routine she can be confident in as a parent for completely fulfilling her task of cleaning her child.

Another BLV mother developed a bathing routine for her baby (V#20), utilizing common, low tech items typical for bathing one's child, including a small plastic bowl for pouring water, a washcloth for scrubbing, and a baby tub to place her baby in. She specifically recommends the 3-in-1 baby tub she uses in her video from other parents with BLV explaining at "*this* [the sling in this specific baby tub] *keeps the baby secure in the bathtub so you can have a free hand*", allowing her to carry out her routine, which requires use of both hands. She places this baby tub on her kitchen counter next to her kitchen sink. Similar to the previous BLV mother's diaper changing routine, this BLV mother also cleans her baby in specific sections, addressing one ear at a time, one leg at a time, and bathing the

front and back sides of the baby in sections. When she needs to reach the baby's back areas, she gently picks up her baby against her chest to clean it. Additionally, she also uses one of her hands to feel the baby and guide herself and ensure her baby is comfortable: "*I am feeling her body. So that way I know where I'm pouring the water, because I don't want to get her face wet yet.*" Throughout her bathing routine, one of her hands is always tending to her baby while the other is involved in cleaning. For instance, when cleaning the more delicate areas around the eyes and ears, one hand protects her baby by covering their eyes or folding their ears. Each section of her baby is cleaned in a general cycle of first rinsing the section of her baby with water using a small bowl, gently scrubbing with a tiny amount of baby soap on a washcloth, and finally carefully rinsing any remaining soap off. Once all areas undergo this cycle, she concludes bathtime with one final rinse using clean water. Once again, this routine exemplifies a different need addressed in caring for children in a spectrum of parental tasks. These BLV parents have taken the necessary and meticulous steps to properly fulfill tasks of care, considering more intricate factors beyond mere efficiency. Here, the focus is on the quality of care provided, emphasizing attention to detail and thoroughness.

BLV parents also develop lifehacks that reframe their engagement with everyday objects in service of efficiency of everyday household activities and safety/wellbeing of their child(ren)

In my video sample, BLV parents have displayed their life hacking skills through uncovering unintentional features of specific technologies that prove to be helpful for them as parents with BLV, as well as ingeniously manipulating technology in entirely unique

ways to meet their needs in caring for their children. I observed numerous instances of life

hacking demonstrated by BLV parents as they fulfilled various aspects of parenting for

their children, such as being food providers, safety monitors, play companions, and more.

Many BLV parents conveyed a similar message to others watching their videos: "*Find what

works for you*." (V#12) As they shared their hacks, tips, and unique methods, they

encouraged fellow BLV parents to discover solutions that suit their individual needs and

preferences. What truly supported BLV parents was not directly the technologies

themselves, but rather how they ingeniously "hacked" and adapted these technologies to

meet their specific parenting needs further described below.

Referring back to Table 7 of Used Technology, my video sample reveals that there is

currently no specific piece of technology used by BLV parents that is designed for BLV

parenting. Instead, many of the technologies used have been creatively hacked. These life

hacks have altered and expanded upon the intended use and understood relationship

between many technologies and their assumed user.

Cooking and Mealtime

One BLV mother shares her hack of creating visual contrast between her cooking

supplies and food ingredients to reduce visual frustration (V#36). While baking, she pours

white flour into a regular bowl of a dark color, reducing her visual strain. This hack

furthermore grants her another opportunity to form precious memories for both her child

and herself as a parent. As she expresses, "*as a visually impaired mom, I do treasure those

activities and recipes that are not visually frustrating for me. And so I can really enjoy

preparing and creating something in the kitchen with my daughter.*" Where she transformed

an originally visually burdening activity into one much less straining on her vision that also lets her engage in all the dimensions of caregiving.

Another BLV father found cooking to be a "*much easier*" and "*more successful*" task by using pots that were large in size with high walls (V#42). He explains that for those with low vision or no vision at all, using such pots reduces the risk of food sloshing out of the sides or in burning oneself. The high walls contain any potential spills, and the size of the pot prevents it from getting too hot. He shares a "*bonus tip*" of placing the cooking utensil being used, such as a spoon or a spatula, in the holes of pot handles. This allows him to conduct other cooking activities with the pot handle securely holding the utensil where furthermore any leftover food "*will drip right back in the pot*" which he finds to be "*brilliant*".

When dining out with her family, another BLV mother carries around a pizza cutter covered in tinfoil in her bag (V#12). She uses the pizza cutter to cut food for her children, affectionately referring to it as one of her "*favorite tools*". From mozzarella sticks, chicken tenders, or a sandwich she is able to whip out her pizza cutter and quickly cut food for her children stating "*it's done in two seconds flat*". Where otherwise, she would be sitting, listening to her children crying while her husband gets impatient. She highly recommends using a pizza cutter for other visually impaired parents stating that "*you will never use a knife again*". For her, the pizza cutter is a reliable tool she found "*works for me* [her]" in feeding her children firmly stating that "*there is nothing like it*".

Monitoring and Safety
Another area of concern for any parent is the safety of their child(ren), ensuring they are constantly monitored and protected from potential hazards. One trick used by

multiple BLV parents is attaching bells to their child to hear their movements and whereabouts. In V#6, a BLV mother attached bells to her child's backpack while in V#31, a BLV father attached bells to his children's shoes in order to keep track of them. The same mother from V#6 also sought out shoes that happened to be squeaky for her child, creating another layer of protection through auditory feedback to "*keep track of my* [her] *running around crazy toddler as a blind mama*".

In her video titled "Tips & Hack for Outside | Blind Mom Hacks …" (V#39), one BLV mother shares her hack of utilizing bright colors on her children to track them more easily during outings. By cleverly dressing her children in a vividly colored hat, they stand out more. This extra visual element "*has made it easier to track them on playgrounds, birthday parties, parks, that kind of thing…*" In settings such as at night or in a crowded environment, this hack becomes particularly helpful for tracking by simply creating a way to make her children stand out. An added benefit she mentions is that this hack can be "*tweaked to assist anyone who is visually impaired in a social group type atmosphere*", where she can easily ask anyone in her group to wear bright colors.

Playtime and Entertainment

Multiple BLV parents mention certain difficulties in playing with their children involving certain toys that are too small in size where they would end up being painfully stepped on, accidentally vacuumed up, and too tiny to distinguish and clean up. (V#40, V#22, V#23). In order to supplement such challenges, BLV parents have found and shared specific toys they prefer to use in providing and having fun with their children. Many of these toys happen to possess tactility and or auditory feedback in its design that are discovered by these BLV parents.

One BLV mother (V#34) uses large magnetic letters and numbers with her children. She finds these toys to be perfect where she can easily pick them up and distinguish the exact number and letter though tracing them with her fingers stating "*they're big, they're very tactile. Like, you can feel every line of the T. You know, that's a T*." She is able to interact with her children and actively engage in play with them making use of the tactility of these specific toys stating "*it's easier for them, it's easier for me*".

A different BLV mother (V#40) shares other toys she prefers to have when playing with her child due to their tactile nature along with auditory feedback. She mentions an electronic interactive LeapFrog baby book that when touched it speaks back, POP Snap Bead Jewelry consisting of beads that loudly snap together, and Fat Brain Squigz Suction toys consisting of a toy collection of various shapes and sizes with suction cups at the end of them. She also likes Magformers Magnetic Toys that can be connected in versatile ways to create different structures. She explains that as a visually impaired parent, "*I have found these to be pretty easy to manipulate. And I don't need any vision at all. I just do it by feel*."

Finally, Triangular Crayons were found to be favored by two BLV mothers (V#40,V#12). One of the mothers mentioned how great triangular crayons were as she no longer had to worry about them rolling around everywhere as opposed to the typical circular crayons where she regularly had to go "*on a scavenger hunt looking for them*". The ridges on the triangular crayons keep them locked in place, saving both mothers the unnecessary frustrations of searching for lost crayons.

Other Hacks and More…
Overall, BLV parents exhibited a variety of hacks with technology encompassing a large range of specific situations they encounter in their daily lives that come with raising

children. Below are additional hacks various BLV parents in my sample demonstrated as they enact their care.

When one BLV couple's child had an ear infection (V#43), they cleverly administered antibiotics by putting a notch in a syringe to indicate the correct dosage. This enabled them to feel for this point and give their child the right amount of antibiotics. They continue to use the same method for any new prescriptions they use, measuring out the appropriate amount of medicine and putting a notch in the plunger "*without having anybody's help*". In the same video, another strategy they shared was in exclusively using white socks to dress their child, this ensures socks are always easily paired together and helps them always have a complete matching outfit assembled.

Another BLV father (V#25) uses his smartphone's camera while helping his children with their homework. With his smartphone, he takes a picture of worksheets and magnifies the text to better read homework. For example, his children are regularly giving spelling homework where they are to learn around 30 words to memorize and spell out. He is able to help his children practice their spelling by taking a picture of the vocabulary list, zooming in on words, and guiding them through each word. This approach is one way he is able to actively be a part of his children's education and stay involved in additional areas of their life. He emphasizes the importance of being actively present as a visually impaired parent, stating "*when you're visually impaired, it's all too easy to just bow out and let your spouse take care of it. ... Help your kids out when you can, where you can and how you can, because, trust me, they will appreciate it so much.*" Where he is able to participate with his children as they grow.

In V#46, a different BLV father also uses his smartphone to assist him in grocery shopping with his seven year old son. This BLV father shows his son pictures of the specific items they need to purchase on his smartphone. Then, his son helps him search and collect the items in the store. While he promotes independence as a visually impaired parent, he also acknowledges the valuable support from his family network when he needs help. "*Without them … I wouldn't be able to do it* [parent] *on my own*". Among the responsibilities of parenting, grocery shopping is one task he seeks help from others, such as his son. While perhaps different, he emphasizes that encountering difficulties is one experienced by all parents, whether sighted or visually impaired.

BLV parents connect with each other with Technology

Two BLV parents also found technology, in the form of online content, to be a valuable source of support in fulfilling their roles of care. They sought out support online in order to learn how other BLV parents took care of their child(ren) along with seeking out a community of other BLV parents for encouragement. One BLV mother specifically went online to look up videos for tips from other BLV parents in cooking and providing meals for her child (V#45). In the same video, she shared the tip she learned of using a large pot for cooking, explaining that it helps her waste less food and create fewer messes while cooking. Furthermore, as a new BLV mother, she used Facebook to connect with other BLV mothers for support and encouragement. She expressed her initial overwhelming doubts questioning herself, "*What kind of mom am I going to be now that I can hardly see anything? How can I help my son with his homework? How can I do that? I had so many questions.*"Being connected to other BLV mothers not only helped in better educating herself but also provided her with a space of mental support, where she felt understood and encouraged by

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others who could emphasize and support her. Likewise, another BLV mother in while interviewed about recommended resources for BLV Parents mentioned Facebook groups of BLV parents and supporters of BLV parents. When the interviewer raised a point that *"it's important for them to know that they're not the first person to do this, they're not on their own. That there are people who have advice and can help them"*, the BLV mother responded strongly with an "*absolutely*". This provides just a glimpse of the larger issue of negative stigma affecting potential and current BLV parents in parenting. Another BLV mother (V#11) candidly shares, "a*s disabled people, we come up against so many microaggressions in a day, and after time, it wears you down. It really does.*"

Moreover, a significant number of the collected online videos reflect the idea of technology being used as a means of connection and education for BLV parents to engage with others. Out of the 47 videos I collected, 36 of them contain content focused on sharing and educating other BLV parents about how they approach parenting as visually impaired individuals.

Chapter 5

Discussion

At the time of this research, this paper is one of few (if any) delving into BLV parenting, situating and contextualizing BLV individuals in their caregiving roles. It not only recognizes and acknowledges their adeptness as proficient caregivers, but it also takes it a step forward in investigating how technology plays a role in this dynamic. Through this exploration, it became evident that technology's contribution in supporting BLV parents' needs in childcare played a more subtle, minor role. In my video sample, I observed BLV parents developing their own adaptations through carefully crafted systems emphasizing routine and organization, along with numerous life hacks. Their ingenuity and efforts stand out, with their resourcefulness driving their caregiving.

BLV parents are not different, they just parent differently

Across my findings, BLV parents strongly and consistently demonstrate, both in their words and actions, that the role of being a parent is universal for all parents, regardless of visual ability. Any challenges encountered while caring for their child(ren) are understood as typical aspects of parenting rather than overwhelming obstacles. They perceive and embrace these obstacles as natural components of the parental journey. They fulfill their responsibilities and care just as any parent, but they do so in different ways. BLV parents embraced the "challenges" and instead see and understand them as just typical bumps in the road that every parent goes through.

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My findings portray life hacks as integral components of the parenting journey. Rather than viewing them as isolated "hacks," they form a woven narrative of parental adaptation and innovation. We can refer back to Kittay's definition of care denoted as "*a labor, an attitude, or a virtue*" (Kittay, 2011), accordingly: the *work* done in maintaining oneself and others, the positive invested affection, or *feeling* for another, and a *shift* of precedence in priority over oneself to another.

Consider the BLV father (V#25) described in my Findings section, who creatively used his smartphone to assist him in helping his children with their homework. In this example, care manifests in the following ways: **labor**, evident in his actions of photographing homework, magnifying the worksheets for reading, and engaging in teaching and spelling quizzes; **attitude,** as he wants his children to be properly educated; and **virtue**, by creatively finding a way to access his children's homework, thereby dedicating additional effort in order to prioritize and support his children's learning. His children take precedence over his own concerns, as he candidly mentions, "*it's all too easy to just bow out and let your spouse take care of it".* Nevertheless, he is wholeheartedly dedicated to actively participating in his children's lives, asserting, "*Help your kids out when you can, where you can and how you can, because, trust me, they will appreciate it so much.*" Rather than seeing his additional efforts as a hindrance or complaining, he expresses feelings of satisfaction as a caring parent.

Research portrayals of BLV parents emphasize needs, not care
Upon reexamining the prior literature, BLV parents were often depicted as struggling and facing challenges. For example, two papers used the word "cope" in describing how BLV

parents managed to care for their child(ren). In Moghadam et al's paper, we see how blind

mothers are "helped" through "coping mechanisms:" "*Turning to alternative senses or*

abilities is an important coping mechanism that helps these mothers in communicating and

bonding with their children (Shackelford, 2004)."

Furthermore, several papers conducted under the premise of understanding the parenting

experiences of BLV individuals (Moghadam et al., 2017)(Rosenblum, Hong, & Harris,

2009)(Conley-Jung & Olkin, 2001) asked questions confined to the parents' visual

impairment, often centered around presumed challenges associated with their disability.

Consequently, this led to conversations centered only on needs rather than providing the

full context of their actual parenting experience. For instance, in Conley-Jung and Olkin's

(2001) paper, strategies used by BLV parents were presented as isolated instances, rooted

in their visual impairment; these presentations lacked depictions of the parental care that

were so pronounced in my findings:

> "The parents who were blind were more apt to keep their children **close**; put bells
>
> on the children's shoes when they were young; …be on the floor with their children,
>
> especially during the infant and toddler years; … they used such strategies as
>
> keeping the children **restrained** (for example, in a stroller or on a leash or
>
> harness)." (emphasis added)

This framing contradicts my findings of how BLV parents perceive themselves as it

emphasizes a disability-based divide between BLV and sighted people, rather than

emphasizing the much more substantial shared experience and capability of parenting.

Relatedly, in the context of BLV populations and the aging demographic, Lazar et al. (2016)

and Das et al. (2019) highlight this tendency where visual or cognitive impairments were perceived as deficits, often emphasizing limitations and what individuals are unable to accomplish. Some researchers proposed that scholars in the health field take an asset-based approach (as opposed to deficit) where an individual's strengths and capacities are explored and built upon (Wong-Villacres et al., 2021)

In the field of Accessible Computing, certain scholars have also highlighted that HCI designers "have more to gain" by recognizing low-vision users as having a distinct and valuable type of skilled vision (Zolyomi et al., 2017). This approach validates the nuanced role of a BLV parent by re-contextualizing their experiences as an added value of their BLV, rather than against.

Research portrayals of BLV parents emphasize disability, not parenting
Another point of divergence, perhaps due to a more disability-focused orientation in prior literature, is ironically in the similarity in findings regarding strategies used by BLV parents. Both the prior literature and my own research mention BLV parents utilizing tactile features of items (Moghadam et al., 2017), implementing an organization system for dressing their children (Conley-Jung & Olkin, 2001), and multiple cases of BLV parents attaching bells to their children to enhance monitoring (Moghadam et al., 2017)(Rosenblum, Hong, & Harris, 2009). The strategies identified in the literature dating back to 2001 continue to be employed in videos as recent as 2022, indicating their enduring reliability. These tried and true methods developed and upheld by BLV parents potentially reduces the need or desire for them to seek out technological solutions.

The contrast between my findings and previous research highlights a significant discrepancy in the way BLV parents and their caregiving roles are perceived. In the portrayal of a "BLV parent," the emphasis on the disability aspect is more prominent in the literature reviews than in my actual research results, where the context of care is included. This incongruity may stem from differences in approach and underlying assumptions. As discussed in my findings, my research question originally stemmed from an assumption that the technology used would be based in AT. However, through watching YouTube videos uploaded by BLV parents (where BLV parents had complete control over their content and expressive freedom), a parenting experience much like that of all parents emerged. This distinction underscores a notable gap in our comprehension of BLV parenting dynamics, and by extension, challenges the potential assumptions made about the role of technology in this context. We need to actively recognize and admit that our perception of a parent with BLV[6] may still carry ableist assumptions. To address this, we should consciously step back and engage in understanding parents with BLV primarily as parents before even considering the role that technology plays in supporting their parenting.

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[6]Moving forward, in the subsequent sections of my thesis, I will adopt person-first language such as "parent(s) with BLV" to align with my findings and the emphasis on the parental aspect of this role.

Chapter 6

Conclusion and Future Work

Limited research currently exists on the intersection of parents with BLV and technology as a whole. In the small amount of prior literature that features parents with BLV as the focal point, the parental role often becomes overshadowed by the focus on BLV as a perceived challenge in parenting. Consequently, the portrayal of parenting with BLV tends to emphasize assumed difficulties, overshadowing the broader parental experience. Through close watching sessions and analysis of online videos showcasing parents with BLV, the role of technology fades into the background. Instead I observed these parents adapting and creating ingenious systems and hacks that are heavily upheld by their own skills. Common mainstream technology takes on a new value on the accord of parents with BLV through their creativity and discovery. In their pursuit of caregiving, parents with BLV carry out all aspects of care for their children. My video sample depicts accomplished parents who are fulfilled in their parenting efforts, rather than constrained or sacrificing themselves due to their BLV in trying to care for their child(ren).

Based on my discussions and findings, future considerations regarding technology's role should shift away from assisting parents with BLV in carrying out parenting tasks, as they have demonstrated competence in this aspect. Instead, greater emphasis could be placed on the parental aspect of individuals with BLV. One interesting approach shown in an asset-based mindset, could open up completely new strategies in collaboration with the unique skills parents with BLV have.

Another possible option is for technology to play a role in promoting social connectivity rather than remaining limited to being solely assistive aids. In shifting away from AT, a potential avenue could be explored in the realm of social technology as a means of support for parents with BLV. In this capacity, future efforts could revolve around improving the space of the online community to facilitate connections and mutual support among parents with BLV. Additionally, technology could play a role in enhancing the visibility and representation of parents with BLV within society. Such initiatives have the potential to counteract persistent ableist stigmas that not only affect societal perceptions but also create genuine challenges for parents with BLV themselves in their right as parents.

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